THE PONTIFICAL
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Edited by **HELEN ALFORD**
FABIO FERRUCCI

DISABILITY AND THE HUMAN CONDITION

Changing the Social Determinants of Disabilities and Building a New Culture of Inclusion

The Proceedings of the 24th Plenary Session
9-11 April 2024

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Some parts of our human family, it appears, can be readily sacrificed for the sake of others considered worthy of a carefree existence. Ultimately, “persons are no longer seen as a paramount value to be cared for and respected, especially when they are poor and disabled, ‘not yet useful’ – like the unborn, or ‘no longer needed’ – like the elderly”.

(*Fratelli tutti*, 18)

I would like to mention some of those “hidden exiles” who are treated as foreign bodies in society. Many persons with disabilities “feel that they exist without belonging and without participating”. Much still prevents them from being fully enfranchised. Our concern should be not only to care for them but to ensure their “active participation in the civil and ecclesial community. That is a demanding and even tiring process, yet one that will gradually contribute to the formation of consciences capable of acknowledging each individual as a unique and unrepeatable person”.

(*Fratelli tutti*, 98)


PIVS · IIII · PONTIFEX · OPTIMVS · MAXIMVS

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ADDRESS OF HIS HOLINESS POPE FRANCIS TO PARTICIPANTS IN THE PLENARY SESSION OF THE PONTIFICAL ACADEMY OF SOCIAL SCIENCES "DISABILITY AND THE HUMAN CONDITION. CHANGING THE SOCIAL DETERMINANTS OF DISABILITIES AND BUILDING A NEW CULTURE OF INCLUSION"

Clementine Hall
Thursday, 11 April 2024

Distinguished Ladies and Gentlemen,

I am pleased to welcome you, the members of the Pontifical Academy of Social Sciences, which was founded thirty years ago. Our thoughts go to the President, who has gone home because her mother is dying; let us say a prayer for her and for her mother. I greet the Chancellor and Vice-Chancellor and their staff, and I thank them for their work.

I appreciate the fact that you have chosen as the theme of this Plenary Assembly the human experience of *disability*, the *social factors* that determine it, and the need to foster a *culture of care and inclusion*. The Academy of Social Sciences is called to face, in accordance with a transdisciplinary model, some of the most urgent challenges of the present time. I am thinking, for example, of technology and its implications for research and for fields such as medicine and ecological transition. I also have in mind communications and the development of artificial intelligence (a great challenge indeed!), as well as the need to devise new economic models.

In recent years, the international community has made significant progress in acknowledging the rights of persons with disabilities. Many countries are moving forward in this direction. Yet in others, this acknowledgment is still partial and uncertain. Nonetheless, where progress has been made, we have seen, between lights and shadows, how individuals can flourish and the seeds can be sown for a more just and solidary society.

By listening to the voices of men and women with disabilities, we have come to realize better how their life is conditioned not only by functional limitations but also by cultural, legal, financial and social factors that stand in the way of their activities and their participation in the life of society.

Naturally, the basis for any discussion of this issue must be the recognition of the dignity of persons with disabilities, with its varied anthropological, philosophical and theological implications. Without this solid foundation, it can happen that, even as we uphold the principle of human dignity, we act concretely in ways contrary to it. The Church's social teaching is very clear in this regard: "Persons with disabilities are fully human subjects, with rights and duties" (*Compendium of the Social Doctrine of the Church*, 148). Every human being has the right to live with dignity and to develop integrally: "Even if they are unproductive, or were born with or develop limitations, this does not detract from their great dignity as human persons, a dignity based not on circumstances but on the intrinsic worth of their being. Unless this basic principle is upheld, there will be no future either for fraternity or for the survival of humanity" (*Fratelli Tutti*, 107).

Vulnerability and frailty are part of the human condition, and not something proper only to persons with disabilities. Some of them reminded us of this in the context of the recent Synod: "Our presence may help to transform the actual situations in which we live, making them more human and more welcoming. Without vulnerability, without limits, without obstacles to overcome, there would be no true humanity" (*The Church is Our Home*, 2).

The Church's care and concern for those with one or more disabilities concretely reflects the many encounters of Jesus with such persons, as described in the Gospels. In these accounts, we can find a number of timely points for our reflection.

First, Jesus *enters into direct contact* with those with disabilities, since, like every form of infirmity, disabilities must not be ignored or denied. Yet Jesus not only relates to disabled persons; he also *changes the meaning* of their experience. In fact, he showed a new approach to the condition of persons with disabilities, both in society and before God. In Jesus' eyes, every human condition, including those marked by grave limitations, is an invitation to a unique relationship with God that enables people to flourish. We can think, for example, of the Gospel account of the blind Bartimaeus (cf. *Mk* 10:46-52).

Sadly, in various parts of the world, many persons and families continue to be isolated and forced to the margins of social life because of disabilities. And this not only in poorer countries, where the majority of disabled persons live and where their condition often condemns them to extreme poverty, but also in situations of greater prosperity, where, at times, handicaps are considered a "personal tragedy" and the disabled "hidden exiles", treated as foreign bodies in society (cf. *Fratelli Tutti*, 98).

The throwaway culture, in effect, *has no borders*. There are those who presume to be able to establish, on the basis of utilitarian and functional criteria, when a life has value and is worth being lived. Such a mentality can lead to grave violations of the rights of the most vulnerable, to serious injustices and situations of inequality, resulting for the most part from the mindset of profit, efficiency and success. Yet there is also present, in today's throwaway culture, a less visible but extremely insidious factor that erodes the value of the disabled in the eyes of society and in their own eyes. It is the tendency to make individuals view their life as a burden both for themselves and for their loved ones. The spread of this mentality turns the throwaway culture into a culture of death. In the end, "persons are no longer seen as a paramount value to be cared for and respected, especially when they are poor and disabled, 'not yet useful' – like the unborn, or 'no longer needed' – like the elderly" (ibid., 18). This is so important: the two extremes of life: the unborn with disabilities are aborted, and the elderly close to the end are administered an "easy death", euthanasia, a euthanasia in disguise, but euthanasia all the same.

Combating the throwaway culture calls for promoting *the culture of inclusion* – the two things go together – by forging and consolidating the bonds of belonging within society. The primary agents of such solidarity are those who, out of a sense of responsibility for the good of each individual, work for greater social justice and for the removal of the barriers that prevent many people from exercising their basic rights and freedoms. The fruits of these activities are mostly visible in economically more developed countries, where persons with disabilities generally enjoy the right to health care and social assistance, and, even if difficulties are not lacking, are included in many spheres of social life, such as education, culture, the workplace and sports. In poorer countries, this remains, for the most part, a goal to be achieved. Governments that are committed in this regard must thus be encouraged and supported by the international community. It is likewise necessary to support the organizations of civil society, since, without their networks of solidarity, in many places people would be left to themselves.

What is needed, then, is the development of a culture of *integral* inclusion. The bonds of belonging become even stronger when persons with disabilities are not simply passive receivers, but take an active part in the life of society as agents of change. Subsidiarity and participation are the two pillars of effective inclusion. In this regard, we can appreciate the importance of associations and movements of disabled persons that work to promote their participation in society.

Dear friends, "recognizing that all people are our brothers and sisters, and seeking forms of social friendship that include everyone, is not merely utopian. It demands a decisive commitment to devising effective means to this end. Any effort along these lines becomes a noble exercise of charity. For whereas individuals can help others in need, when they join together in initiating social processes of fraternity and justice for all, they enter the field of charity at its most vast, namely political charity" (ibid., 180).

Brothers and sisters, I thank you because part of this commitment is your own work of research and discussion within the scientific community, as well as your efforts to raise consciousness in different social and ecclesial circles. In a special way, I am grateful for your concrete concern for our sisters and brothers with disabilities. I cordially bless you and your work, and I ask you, please, to pray for me.

CONCEPT NOTE

There is no exact number of persons with disabilities worldwide. International organisations estimate that 16% of the world's population experience significant disabling conditions. This is approximately 1.3 billion people.[1] However, the social boundaries of what has been called the 'third nation of the world' are far more extensive. The lack of a common language defining disability makes these numbers variable,[2] uncertain, yet very relevant. Disability is a broad concept. Indeed, as established by the World Health Organisation (WHO) and the United Nations, disability is defined by the interaction between a health condition and environmental factors that can be facilitators or barriers. These environmental factors therefore concern families, acquaintances, friends, colleagues and professionals who share many areas of social life with persons with disabilities. Environmental factors also include schools, the world of work, religious, cultural, recreational and sports organisations, social and health services, and policies.

Disability is a growing phenomenon. With the ageing of the world's population and the increase in chronic and disabling diseases, the number of persons with disabilities is set to rise in the future. Alongside this global trend, there are also national traits where a plurality of risk factors combine to differentiate the highly-developed countries from those of medium and low development. Lack of universal health coverage, environmental pollution, impacts of climate change and natural disasters, road and domestic accidents, the spread of certain lifestyles, pandemics or violence can all have disabling effects. Wars fought in various parts of the world, in addition to devastation, death and suffering, increase the number of those who become permanently disabled.

Since time immemorial, illness and impairment have been an integral part of the human condition. But the life experiences of persons with disabilities do not depend on them alone, but on cultural meanings and the judgement of whether or not they conform to a certain ideal type of man.

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[1] Cfr. World Health Organization. (2022). *Global Report on Health Equity for Persons with Disabilities*. World Health Organization. Geneva.

[2] Cfr. Pettinicchio, D. & Maroto, M. (2021). Who counts? Measuring Disability Cross-Nationally in Census Data. *Journal of Survey Statistics and Methodology*, 9 (2), 257-284.

Meanings and ideals are variable in time and space.[3] Societies have not always recognised equal dignity and the same rights for persons with disabilities, who have therefore suffered various forms of social exclusion: from physical elimination to abandonment, from segregation to discrimination.

Knowledge about the living conditions of persons with disabilities is mainly confined to countries with high economic development. We still know little about the 80% of the population with disabilities who live in the rest of the world. The *First World Report on Disability* showed that people with some form of physical, sensory or intellectual impairment experience multiple disadvantages compared to the rest of the population: they report worse health conditions, they experience barriers (physical, economic, social, political) in accessing services, they have lower levels of education, their participation in the productive system is also low, they more frequently experience poverty and they participate less in political, social and cultural life.[4] The cumulative effect of these situations accentuates inequalities and pushes persons with disabilities to the margins of social life, loosening the bonds of belonging to the community. In contemporary societies, despite the progress made, in the words of Pope Francis, many persons with disabilities "feel they exist without belonging and without participating. They are 'hidden exiles', treated as foreign bodies in society" (*Fratelli tutti*, 98).

The world is still largely hostile to disability. A widespread cultural attitude still considers disability to be a 'personal tragedy'. The inadequate support from public policies contributes to ambivalent feelings towards a son or daughter with a disability or an elderly parent with a disability. Many believe that social relations are in themselves oppressive. At the same time, however, it is mainly families who take care of persons with disabilities, accompanying them throughout their growth into adulthood, even in the presence of severe limitations. These families are often supported by other families and family associations with whom they share the difficulties but also the social commitment to promote respect for the rights and participation in social life of their family members with disability. In these circumstances, the solidaristic role of family relationships becomes visible, with a form of solidarity that does not remain confined to the private sphere but takes on a social significance. When these solidaristic and caring relation-

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[3] Cfr. H.J. Stiker (1999). *A History of Disability.* University of Michigan Press. Ann Arbor; C. Gardou (2017), *Le handicap et ses empreintes culturelles*. Édition érès. Toulose.

[4] World Health Organization & World Bank (2011). *World Report on Disability 2011*. World Health Organization. Geneva.

ships wear out or fail, institutionalisation of persons with disabilities often appears as the only viable solution.

Nonetheless, several elements at a global level allow a reading of disability as a changeable phenomenon, thanks to the interventions possible both at the level of the person through rehabilitation, care, therapies, aids, and at the level of the context, i.e. all the environmental and social factors that can be transformed from barriers into facilitators. The main drivers of a global cultural change are the UN Convention on the Rights of Persons with Disabilities (CRPD) and the International Classification of Functioning and Health (ICF) of the World Health Organisation (WHO). They are complemented by the global action agenda outlined in the 2030 Agenda for Sustainable Development, which identifies multiple areas of action in which to promote the equality of persons with disabilities.

The CRPD, adopted by the United Nations General Assembly in December 2006, and the Optional Protocol that entered into force two years later, represent the most advanced instruments by which the international community intends to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity" (Art. 1). The CRPD incorporates a new biopsychosocial understanding of disability, seen as the result of a relationship between persons with impairments and behavioural and environmental barriers that prevent their full and effective participation in society on an equal basis with others. Promoting the dignity of persons with disabilities and respect for their rights requires knowing how to manage this relationship in a way that gives it enabling properties. This is a complex challenge because situations vary greatly in type and in the level of severity. The condition of a paraplegic person is different from that of a person who is deaf or blind, or with psychic problems, or an autistic syndrome.

This new concept is aligned with the biopsychosocial model of disability, developed by the WHO in the ICF Classification whereby each human being can have a level of disability, depending on the barriers or facilitators that determine health and disability. Disability is thus a manifestation of possible variations in human functioning resulting from the interaction with barrier environments, rather than a physical abnormality to be discarded. Therefore, disability poses a decisive challenge: a new global culture of inclusion must be developed by eliminating the barriers that hinder the full citizenship of persons with disabilities and their "unique contribution to the common good through their remarkable life stories" (*Fratelli tutti*, 98).

The development of a new culture of recognition and inclusion appears urgent in today's society, which is increasingly questioning what conditions make life worth living. In public opinion, stereotyped representations of persons with disabilities prevail, which are a priori associated with the idea of vulnerability, dependence and incapacity, thus belittling their human dignity. But vulnerability and frailty are a part of the human condition and not only of persons with limitations. In fact, if the determinants of health and disability that surround them are transformed from barriers into facilitators, empirical evidence shows that persons with disabilities can enjoy a good quality of life and contribute actively to social life.

The Plenary intends to take up the challenge and make its own contribution by identifying what are the specific social determinants that in the cultural, family, educational, political, economic, and employment spheres represent the barriers that increase the disability of a society and prevent persons with disabilities from fully participating in social life by making their original contribution. Considering the different socio-cultural contexts, the Plenary intends to question what changes are needed at the cultural, regulatory and public policy levels to implement and make effective the enjoyment of the rights enshrined in the UN Convention.

The Social Teaching of the Catholic Church proposes a unitary and integral vision of the human being. Its founding principles apply to all human persons without distinction. Anticipating the CRPD, it has affirmed that persons with disabilities are fully human subjects with rights and duties, who, "even with the limitations and sufferings inscribed in their bodies and faculties, place greater emphasis on human dignity and greatness". They must therefore be supported so that they can "participate in family and social life in all dimensions and at all levels accessible to [their] possibilities"5.

In his encyclical *Fratelli Tutti*, Pope Francis reminds us that "Every human being has the right to live with dignity and to develop integrally; this fundamental right cannot be denied by any country. People have this right even if they are unproductive, or were born with or developed limitations. This does not detract from their great dignity as human persons, a dignity based not on circumstances but on the intrinsic worth of their being. Unless this basic principle is upheld, there will be no future either for fraternity or for the survival of humanity" (*Fratelli Tutti*, 107).

[5] Compendium of the Social Doctrine of the Church, n. 148.

The Plenary is also intended to explore from a philosophical and theological perspective the foundations of the inherent dignity of persons with disabilities, which is particularly relevant in the early and late stages of life. Often this dignity is made to coincide with autonomy, with the ability to make choices. Is it sufficient to identify this dignity with the capacity for self-determination if we are to safeguard the full and complete implementation of the human rights enshrined in the CRPD? Why are the principles affirmed in it frequently contradicted by the policies implemented by certain countries?

Considering disability from a biopsychosocial perspective eliminates the distinction between "us" and "them", showing the condition that unites every human being, and making possible what Pope Francis indicated: "Recognizing that all people are our brothers and sisters, and seeking forms of social friendship that include everyone, is not merely utopian. It demands a decisive commitment to devising effective means to this end. Any effort along these lines becomes a noble exercise of charity. For whereas individuals can help others in need, when they join together in initiating social processes of fraternity and justice for all, they enter the 'field of charity at its most vast, namely political charity'" (*Fratelli Tutti*, 180).

Political charity is what the Plenary proposes to analyse by identifying the determinants of disability that, at the global and national level, can be changed. In the course of history – albeit with the limitations inherent in every human endeavour – the Social Teaching of the Catholic Church has reaffirmed the value of persons with disabilities, creating and supporting works and initiatives through which to promote their inviolable dignity, in social contexts pervaded by the "throwaway culture" (*Evangelii Gaudium*, 53).

This commitment was, and is, fuelled by charity. Far from the interpretations of those who would reduce it to a 'subjective sentimentality', thus decreeing its public irrelevance, charity is a force for real change. "Charity, with its impulse to universality, is capable of building a new world. No mere sentiment, it is the best means of discovering effective paths of development for everyone. Social love is a 'force capable of inspiring new ways of approaching the problems of today's world, of profoundly renewing structures, social organizations and legal systems from within'" (*Fratelli Tutti*, 183).

In this perspective, the contribution of persons with disabilities, and the associations and movements to which they have given rise, is of primary importance. The activation of solidaristic and mutual aid networks involving persons with disabilities, their associations and third sector subjects and public institutions, shows the multiple ways in which persons with disabilities contribute to the development of societies, through their own initiative and in an original way.

The Plenary is intended to enhance the specific contribution of the social sciences in opening up new horizons and identifying experiences already underway, so that – by combining subsidiarity and solidarity and in fact applying the principles of political charity – we all become the creators of a new culture of inclusion, replacing the old models of welfare assistance with a renewed vision of the common good, capable of making the existence of every person, with or without disabilities, flourish.

WORD OF WELCOME

SR. HELEN ALFORD, OP
President of the Pontifical Academy of Social Sciences

It is my honor and privilege to be able to welcome you all to the 24th Plenary Session of the Pontifical Academy of Social Sciences. This Plenary is significant for a number of reasons. The first among them is the topic, *Disability and the Human Condition: Changing the Social Determinants of Disabilities and Building a New Culture of Inclusion*, but this is the first time in its history that the Academy has dedicated a Plenary to this topic.

Issues connected to disabilities have been addressed within other meetings. At one of them, Fabio Ferrucci, sitting opposite me, was invited to speak and, I have to say, he impressed the Academicians so much that they decided to vote him in as a member, so perhaps some of the other visiting speakers today may end up in that position. But still, this is the first time that a whole meeting has been dedicated to this topic.

I'm also delighted that the person who was the original source of this idea, Baroness Hollins, sitting over here, is able to be with us today and to open the proceedings with her speech. It was Sheila Hollins who planted the idea of this Plenary in my little mind when I met her at a reception at the British Embassy to the Holy See, when the All-Party Parliamentary Group on the Holy See came to Rome to commemorate its founder, Sir David Amess, who had been tragically killed by an assailant when he was in his home constituency, receiving his constituents.

At that time I was on the Council of the Academy and the previous President, the indomitable Stefano Zamagni – those of you who know him know that's the right adjective to describe him – the indomitable Stefano Zamagni asked me to make a proposal for the topic of the 2024 Plenary, so what Sheila had said to me came back into my mind and the balls started rolling from there.

Following the good example that Pierpaolo Donati had set in the preparation of the last Plenary, the 23rd Plenary, where a webinar between Academicians themselves took place before the main Plenary, we also had a webinar last December to help our Academicians, many of whom were working on disability for the first time, to start developing their ideas.

The next person I should thank for making a crucial and essential contribution to the development of this Plenary, is the aforementioned Fabio

Ferrucci. In a real way the structure, the content, the ideas of this Plenary are his brainchild and I, for sure, am in his debt for the amount of work and effort he has put into developing it.

Another reason why this Plenary is significant is that it has driven a set of reasonable adjustments of the very building in which we are sitting at the moment. This part of the building is about one hundred years old, but the part that we will be going down to later was built in the mid 1500s so the modifications of it are quite important and significant, they have both practical and symbolic value, so I would like to take this opportunity to thank Fabio again, who brought in some very well-qualified technical staff to help evaluate what could be done and then also Monsignor Dario Viganò, the Vice Chancellor, who oversaw the work, and the various skilled artisans and workers who actually produced these adjustments. Thanks to your precious work we have been able to make a concrete step forward in creating a culture of inclusion for persons with disabilities on a practical level.

Lastly, this Plenary takes place in the 30th year of the existence of this Academy, representing a milestone in its history. Later in the proceedings we should take some time to reflect on these first thirty years, since our future depends in no small degree on our past.

For me personally, this is the first Plenary at which I was due to participate as President and I would like to take this opportunity to thank the previous President, Stefano Zamagni, and the Chancellor, Cardinal Turkson, for all their help and support in the handover process, as well as the members of the PASS Council sitting by my side, who are a constant source of support and good ideas. Stefano is a very hard act to follow, as most of you will already know. Those of you who don't know him will learn why I say this when we have the brief ceremony later today to install him and Joseph Stiglitz, also sitting behind me, as Honorary Academicians.

I said a moment ago I was *due* to participate as President. This is because I'm sorry to have to tell you all, but I received news yesterday evening that my mother is dying and thus I have to go to London this evening to be with her in her last hours, and my family, so, once again, I thank the former President, Stefano Zamagni, who has very kindly agreed to take over from me when I need to leave to go to the airport later today, in the afternoon, and the dear Cardinal who has assured me of his prayers so many times since I told him yesterday evening about this, and to all of you who will stay here and make this Plenary really worthy of the 30th anniversary of the foundation of this Academy.

I ask the Academicians in particular, but I would be equally happy to ask all of you here, to take this opportunity to think about where we could take our Academy in the next thirty years, what work do we need to prioritize and how should we do it.

I hope to be able to join you on Zoom at least some of the time and especially for the session where we will look back over the first thirty years, and also for the Closed Session at the end for the Academicians so, in both moments, I'm looking forward to sharing with you my ideas about where I think we could go and to hearing your responses and counter proposals.

In conclusion, I would like to thank all of you, Academicians, external experts, accompanying persons, people who are following us online who weren't able to come in person, all of you who have come to participate in this Plenary, as well as to thank the Chancellor, Cardinal Turkson the Vice Chancellor, Monsignor Viganò, the seven staff members who work here, to all of you for your stalward efforts on the practical and logistical levels to make this meeting possible, so thank you for your attention and now I hand over to the Cardinal.

INTRODUCTION

CARDINAL PETER K.A. TURKSON
Chancellor of the Pontifical Academy of Sciences

Thank you, Sr. Helen, and good morning to all of you. I just want to tag on to the sentiments expressed in detail by Sr. Helen and immediately also express the condolences of this Academy, on behalf of all members present and not present, to her and her family in this tough situation. If events like these preannounced themselves I think Sr. Helen would probably have asked us to postpone the Plenary Session, but it wasn't possible, so we are very understanding and we sympathize with you, and also express our condolences to you.

Dear colleagues, professors and all members of the Academy and invited guests, I think Sr. Helen said it all about why the theme for this Plenary assembly is on disability. She has explained it fully to all of us and justified its choice to us. I simply want to support all of that, and add the observation that it was actually Pope Francis who also invites us to consider the theme of this assembly, so disabled people as not simply people who need care, but to go on to consider how they can be considered citizens fully integrated in social-cultural life and everything of society, so not limit ourselves to caregiving for such people, but actually how to fully hasten or fashion their full integration in society, in our culture and in all forms of existence.

This essentially means that it's a way of recognizing what we all are as human beings, essentially personal beings and relational beings, that's what we are. We are personal beings because of dignity, because of the dignities everybody has, and dignities which may not, in any way, be diminished by appearance or looks or any physical or corporal appearance of any sort. We need to uphold the basic dignity that all human beings have, and also recognize the fact that we are all relational beings, we develop and live in our relationship, and anything that diminishes or, again, begins to obstacle that are things that we need to address. These two factors, being persons and being relational beings, are two things that are easily and readily affected by people in such conditions, and that's also why we want to look at it.

All of this, then, leads us to consider the fact that this meeting is not just to amass information or to satisfy our curiosity about any state or condition of life but rather, borrowing the words of Pope Francis in *Laudato si'*, it is to make us all painfully aware and to dare to turn what is happening to a big section of our human community, the experience of disability, into our own personal experiences and suffering and, so doing, to discover and to put ourselves a question about how we can help deal with that, solve that and make all with such conditions fully integrated in our social conditions.

On this note then we invite all of you to this assembly to share a lot of information, but not to limit ourselves to sharing information, but to feel ourselves invited to feel, and to make the experience of such people our own experiences, and see how we can, therefore, commit to making their own experiences as last as possible and in a way that does not, in any way, diminish their own lives. So we want to welcome you all to this event. Our program, as Sr. Helen has mentioned, will be slightly modified on account of the present experience that she has, but everything will still take place to full satisfaction of all gathered here. Thank you again for coming, and have a nice Plenary assembly.

Programme

TUESDAY APRIL 9, 2024

8:00 Holy Mass for Deceased Academicians – Altar of St. Joseph, St. Peter's Basilica

SESSION 1 | LIVES WORTH LIVING: OPERATIONALIZING THE RIGHTS OF PERSONS WITH DISABILITIES
Chair: **Ana Marta González**

9:00 Word of Welcome
Sr. Helen Alford PASS President
H.Em. Cardinal Peter Kodwo Appiah Turkson PASS Chancellor

9:15 Opening Speech
An Ordinary Life: Imagining a World in which Disability is a Normal Part of Life
Sheila Hollins

9:40 *Disability: An Anthropological and Theological Challenge*
H.E. Msgr. Roland Minnerath

10:05 Discussion

10:15 *ICF: The Universalizing Conception of Disability and Functioning*
Matilde Leonardi

10:40 Discussion

10:50 **Coffee Break**

11:20 *Disability and Persons with Disability* (by Zoom)
Jerome Bickenbach

11:45 Discussion

11:55 *Disabilities, Rights and Relations*
Marta Cartabia

12:20 Discussion

12:30 General Discussion

13:00 **Lunch at the Casina Pio IV**

SESSION 2 | DISABILITY, POVERTY AND INEQUALITIES: WHAT NEW POLICIES FOR ECONOMIC INCLUSION?
Chair: **Gustavo Osvaldo Beliz**

15:00 *Multidimensional Poverty in Developing Countries, Disaggregated by Persons Living with Disabilities and their Households*
Sabina Alkire and Monica Pinilla Roncancio

15:25 Discussion

15:35 *Economic Inclusion of Persons with Disabilities: Imperatives, Impediments and Remedies*
Fr. Albino F. Barrera

16:00 Discussion

16:10 *On the Inclusion of Disabled Persons in the Labor Market: Lessons from the Disability Employment Gap*
Jutta Allmendinger

16:35 Discussion

16:45 **Coffee Break**

17:15 *Mental Disabilities. Why Are They Increasing and What Should Be Done to Reverse Such a Perverse Trend*
Stefano Zamagni

17:40 Discussion

17:50 *Employing Persons with Disabilities: Insights from Catholic Social Thought and Social Enterprise*
Sr. Helen Alford

18:15 Discussion

18:25 General Discussion

19:00 **Appointment of Honorary Academicians, followed by Dinner at the Casina Pio IV**

WEDNESDAY APRIL 10, 2024

8:00 Holy Mass – Chapel of the Choir, St. Peter's Basilica

SESSION 3 | PHILOSOPHICAL, ETHICAL AND THEOLOGICAL PERSPECTIVES ON DISABILITY AND THE HUMAN CONDITION

Chair: **Vittorio Hösle**

9:00 *Physical and Moral Disabilities: Plato and Confucius on the Life Worth Living*
Tongdong Bai

9:25 Discussion

9:35 *Human Beings Above and Beyond Functional Categorizations: Taking Stock From Philosophy of Disability*
Ana Marta González

10:00 Discussion

10:10 *The Roots of the Intrinsic Dignity of Persons with Disabilities*
Rodrigo Guerra López

10:35 Discussion

10:45 **Coffee Break**

11:15 *One Like Us: Disability and the Incarnate Word*
Fr. Justin Glyn

11:40 Discussion

11:50 *The* Culture of Exclusion *in the Time of Civilizational Crisis*
Krzysztof Wielecki

12:15 Discussion

12:25 General Discussion

13:00 **Lunch at the Casina Pio IV**

SESSION 4 | CULTURE, EDUCATION AND COMMUNITIES AS FACILITATORS OF THE FLOURISHING OF PERSONS WITH DISABILITIES

Chair: **Marta Cartabia**

15:00 *Media Representation of Disabled Identity in Contemporary Society*
Msgr. Dario Edoardo Viganò

15:25 Discussion

15:35 *Raising Children according to their Needs and Nurturing their Gift: The Story of "Mele"*
Chiara Paolini

16:00 Discussion

16:10 *Education for All: Children, Disabilities, and the Global Compact for Education*
Marcelo M. Suárez-Orozco

16:35 Discussion

16:45 **Coffee Break**

17:15 *Interacting with the Disabled: Experimental Evidence on Helping, and on Deciding on Behalf of Others*
Christoph Engel

17:40 Discussion

17:50 *The Care of Disabled and Fragile People through the Creation of Relational Goods*
Pierpaolo Donati

18:15 Discussion

18:20 General Discussion

19:00 **Dinner at the Casina Pio IV**

THURSDAY APRIL 11, 2024

8:00 PAPAL AUDIENCE

9:30 **Coffee Break**

SPECIAL SESSION | CELEBRATION OF THE 30TH ANNIVERSARY OF THE PASS

10:00 Data Presentation **Sr. Helen Alford**
Comments **H.E. Msgr. Roland Minnerath, Pierpaolo Donati**
General Discussion

SESSION 5 | CHALLENGES AND OPPORTUNITIES FOR INCLUSIVE SOCIETIES: EMERGING ISSUES

Chair: **Justin Farrell**

10:45 *Being Human: The Challenge of Impairment and Disability*
Tom Shakespeare

11:10 Discussion

11:20 *Research and Innovation for the Inclusion of Persons with Disabilities: A Science Policy Survey*
Riccardo Pozzo

11:45 Discussion

11:55 *Towards a New Welfare of Rights. People with Disabilities and their Families as Protagonists of Change*
Vincenzo Falabella

12:20 Discussion

12.30 General Discussion

13:00 **Lunch at the Casina Pio IV**

SESSION 6 | PROMOTING SOCIAL JUSTICE IN PARTICIPATORY SOCIETIES: A GLOBAL PERSPECTIVE

Chair: **Sabina Alkire**

Please note the earlier start time of the afternoon session compared to the first two days of the plenary

14:30 *Disabilities and Forest Peoples: Challenges to Building a Culture of Inclusion*
Virgilio Viana

14:55 Discussion

15:05 *The Vulnerabilities of Persons Living with Disabilities in Nigeria*
Kokunre K. Agbontaen-Eghafona

15:30 Discussion

15:40 *The Invisible Wealth of Nations: Care Economy and Disability: a Community-Based Approach to Public Policies from the Peripheries*
Gustavo Osvaldo Beliz

16:05 Discussion

16:15 **Coffee Break**

16:45 *Living with Disabilities in Developed Countries: The Consequences of Welfare Reforms in the UK*
John Francis McEldowney

17:10 Discussion

17.20 General Discussion

17:50 End of the Plenary

18:00 Closed Session for Academicians

19:30 **Dinner at the Casina Pio IV**

List of Participants

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Tongdong BAI
PASS Academician
Dongfang Chair Professor of Philosophy at Fudan University, Global
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Gustavo Osvaldo BELIZ
PASS Academician
Former Secretary of Strategic Affairs,
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Jerome BICKENBACH (by Zoom)
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Emilce CUDA
PASS Academician
Secretary, Pontifical Commission for Latin America, Vatican City

Pierpaolo DONATI
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Emeritus Professor of Sociology, University of Bologna, Italy

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PASS Academician
Former Prime Minister of Italy

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Vittorio HÖSLE
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University of Notre Dame, USA

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PASS Academician
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Matilde LEONARDI
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Roland MINNERATH
PASS Academician
Archevêché
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Chiara PAOLINI
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SESSION 1. LIVES WORTH LIVING: OPERATIONALIZING THE RIGHTS OF PERSONS WITH DISABILITIES

AN ORDINARY LIFE: IMAGINING A WORLD IN WHICH DISABILITY IS A NORMAL PART OF LIFE

SHEILA HOLLINS

Professor Sheila the Baroness HOLLINS, FRCPsych, FRCP hon, FCMSA, FHEA, FIPD, Hon DD London, Hon MD Sheffield; Hon DLL Durham, Hon DLitt Bath, Hon DSc Worcester, DUniv ACU. Crossbench Life Peer, House of Lords; Emeritus Professor Psychiatry, St. George's University of London

Introduction

What can we learn from deep reflection on personal and group experience that would strengthen the Church (in its broadest sense) as an agency of social inclusion in the spirit of Christ?

This paper was presented at the 10th Plenary Assembly of the Pontifical Academy of Social Sciences and draws on personal family experience, further enriched by the voices of disabled colleagues and friends, by my work as a psychiatrist and psychotherapist, and parliamentary work in the House of Lords. I have included some personal and family experience to illuminate the wider forces at work in shaping the lives of people with disabilities. My intention is to complement hypotheses drawn from experience with insights and conclusions from larger-scale studies.

Potentially modifiable determinants of disability are inspired by these stories, and I invite readers to consider implications for the global and local Church.

I have three broad aims:

1. To provide a philosophical and conceptual basis for understanding 'disability' as part of ordinary life.
2. To use my family and professional experience to illuminate what this means in practice.
3. To draw implications, at different levels of abstraction, for Catholic Social Teaching and Practice.

These stories are about people living good lives, sometimes having faced extraordinary challenges. People who have been loved and supported by their families and communities and helped by health and care professionals. People who have thrived when their own gifts have been recognised, but who have at times been let down by a lack of political focus when the design and delivery of public services fall short (Marmot et al., 2005, 2009; House of

Lords, 2022). And stories about people with intellectual and developmental disabilities (IDD) that challenge our preconceptions and unconscious bias.

The evidence is unequivocal that health and disability are most strongly influenced by social determinants, such as the circumstances in which people are born, grow, live, work, and age (The Commission on Social Determinants of Health, 2005).

Local and regional inequalities in the context of global threats to our security

Speaking to the UN Security Council in 2021, naturalist David Attenborough called climate change "the biggest threat to security that modern humans have ever faced" – that "exacerbates the risks of conflict". He challenged the international community to finally create a stable, healthy world where resources are equally shared and where – for the first time in history – people "come to know what it feels like to be secure". Climate security and national security are of course linked.

Is enough attention being paid to the impact on people's lives, of the physical and psychological harms caused by climate migration or displacement because of conflict or indeed by the threats of misinformation and manipulation by social media (Hollins et al., 2022, 2023). Disability cannot be adequately considered without understanding these global challenges.

In remembering the victims of war, the focus is often on those who died; but those who are abandoned or who live with life-changing injuries and psychological scars, shape the behaviour of future generations, sometimes building peace but often sowing the seeds of further division and disharmony. My own family experience of my father, as a traumatised D-day war veteran, has helped me to understand the role of trauma in the development of mental health problems.

The UN CRPD: A Global Framework for Positive Change

The UN's Convention on the Rights of Persons with Disabilities (CRPD, 2006) provides a detailed normative framework, based on a human rights perspective, for what persons with disabilities have the right to expect from public policy and daily experience. This Convention is a powerful and comprehensive normative statement, ratified now by the great majority of state parties.

But the Convention was (and is) needed precisely because most people's experience lags way behind these expectations. The history here is complex but looking back over the last century and more, two social trends are most evident: both discriminatory. The first is the tendency to understand disability, following a medical approach, as problems located within the person – and often interpreted as 'deficits' to be 'fixed' if possible. The second is the social exclusion of people so labelled – most clearly through sending them to live in institutions and be 'cared for', separately from the rest of society.

In living memory, both these trends have been effectively challenged in ways that point to a different future. People with disabilities have themselves articulated an alternative to the 'medical model': the social model recognises individual impairments but sees 'disability' as arising from the interaction between these impairments and the physical and social barriers imposed by the current organisation of society. The action imperative focuses then on removing barriers (Oliver, 2013; Shakespeare et al., 1997).

Similarly, and reinforcing the first point, exclusion has been seen as a denial of full citizenship and led instead to a focus on promoting everyone's inclusion in all aspects of life: precisely the agenda of the UN CRPD.

In the British context (although there have been similar movements in many other countries) this kind of transformative change is well demonstrated in the 'An Ordinary Life' movement, that, in the last decades of the 20th century, sought the closure of all institutions for people with intellectual disabilities and their return to living like other people, in local communities (Towell, 2022). Transformative change requires a different way of thinking, in this example captured in the simple idea that everyone needs the opportunities and support to live an ordinary life. But of course, visions have to be 'carried' by people, networks and organisations; so, the story of this change is essentially about creating and sustaining a social movement that would support a wide range of people in different places and roles in taking actions, small and large, designed to advance this philosophy.

Learning from the past

Sometimes transformation fails to plant the seeds of more transformational change and lessons from the past are forgotten.

Within this change process, a particular challenge is related to the role of Psychiatry. There were many good psychiatrists who both led and supported this transformation but institutionally, psychiatrists were also the gatekeepers and often the managers of the services that needed to be transformed. People with a serious mental illness are living with a disability too and the points in this paper about listening to each person and their particular needs are deeply relevant to them.

My own work in the 1980s included clinical work in a long-stay hospital for people with IDD, complemented by work in the community developing the psychosocial support that we hoped would enable the hospital to close. With social anthropologist Dr Jane Hubert, ethnographic research in a locked ward uncovered the extent of dehumanisation caused by typical institutional practices. Long-stay hospital stays in the UK began to decline in the early part of this century with an initially successful hospital closure programme (Hubert et al., 2006, 2008, 2010). Sustaining these programmes has been challenging with unconscious bias still commonplace and a continuing failure to see each person first and foremost as a human being.

A former colleague had been sure that one very distressed man (let's call him John) would not be able to be discharged when we closed the hospital. He has now been living contentedly in the local town for many years. When she asked him why he had behaved in such a challenging way in the hospital, he replied that he didn't like being locked up. His story was of being bullied and abused at school. His distressed behaviour after his father's death had led to his exclusion from school. Hospital admission was offered to give his mother a rest, but he never went home. This had been a typical scenario until community-based services in the 1980s and 1990s began to be developed as alternatives. Over time, gaps in this provision have created a space for hospitals to again offer admission at times of crisis. Less than adequate community services allow what begins with one loss, one abusive event, one exclusion and then another, to lead to an admission for 'assessment', and then permanent or long-term exclusion from society.

Highlighting the harms of exclusion

Research into the impact of adverse childhood experiences on any child, including disabled children, shows how cumulative events have long-lasting effects on both physical and mental health and life expectancy (Silverman 1996). Trauma-informed services will recognise many protective factors. But the things that tip the balance towards resiliency are in short supply for far too many people (The Belong Manifesto, 2018). What needs to change? We must learn to understand each 'patient', each person, first and foremost as an individual with a story, a family history, a son, brother, uncle – not first as a diagnosis. As a human being who needs friends, who just wants to belong (Emerson et al., 2011). My eldest daughter is a psychiatrist like me. She understands about the discovery of IDD in a family, the resulting confusion and the learning that needs to take place. She consults for local authority, third sector and health services, to build their confidence in understanding and responding to the needs of young families and the importance of building emotional resilience and avoiding exclusion from infancy onwards.

Author Alexis Quinn eloquently describes her own lived experience in her autobiography *Unbroken* (2018), including her escape from detention in enforced social isolation (called Long-Term Segregation in England and Wales) in a psychiatric hospital in the UK, long after such practices were thought to have been ended. Her admission to hospital followed her being overwhelmed by two traumatic events in quick succession. Alexis' experience confirms other accounts of the enduring relational harms caused by confinement which have been called a 'social death'[1] (Guenther, 2013; Borgstrom 2016). Many people subject to isolation develop an inability to feel deep positive emotion for people and a sense of who they once were. Alexis now uses her own experience to manage the Restraint Reduction Network in England.[2]

As an expert by experience, Alexis Quinn joined my government-appointed independent panel in 2020, to oversee an intervention intended to reduce the use of Long-Term Segregation, such as she had herself experienced, in mental health settings. The panel's report, '*My heart breaks – solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people*' (Hollins, 2023), was published simultaneously with the government's response (DHSC 2023). The Oversight Panel had considered the findings from 191 independently chaired, multidisciplinary reviews of children, young people and adults with IDD who had been detained in Long-Term Segregation. The essence of the report was that the life stories and needs of autistic people, and of people with intellectual disabilities, detained in mental health settings, were poorly understood; that hospital admissions compounded previous trauma histories; and that lengths of stay were inordinately long. Average in-patient lengths of stays vastly exceeded those for people with mental illness. Admissions to mental health settings for autistic people and/or people with IDD are typically described as a last resort when other interventions have failed or been lacking. Sadly, social and systemic interventions are rarely a priority for people with IDD.

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[1] https://www.upress.umn.edu/9780816679591/solitary-confinement/

[2] https://restraintreductionnetwork.org

The numbers of people with disabilities being detained, and their length of stay, are beginning to reduce with the help of culture change and community development programmes such as H(O)PES (2022), although admissions continue. In other countries including the USA and Italy, community development programmes based in meaningful relationships have had considerable success in reducing school exclusions and hospitalisations.

Co-production – doing things together

My autistic son has an intellectual disability. The list of things he can't do is long. We prefer to talk about what he can do, but the truth is that his cognitive and executive functioning difficulties get in the way of him living an ordinary life without the right support, the right 'scaffolding'. Perhaps, if he hadn't had a family who tried to include him in everything, if he hadn't had speech therapy every school day for several years as a child, he might be a non-speaking adult in a long-stay hospital ward – like the one that John lived in, and where I worked as a consultant psychiatrist in the 1980s.

He won a leadership award in 2022, for years of work teaching family members, carers and professional supporters how to use a communication tool originally designed to build people's emotional resilience through honest storytelling. With my son's help interpreting stories created together with artists and other experts by experience, word-free books have been published to explain both difficult life events and the everyday challenges and opportunities that we all experience.

Today there are around 80 stories told in pictures without any words and it's no longer a university pilot but an established charitable social enterprise.[3] Because they are word-free, and because human emotions are universal, our stories are used around the world, depending on the cultural context. And these word-free stories are read in book clubs in libraries and in community centres.[4] They also provide a space to meet people and make friends. During the pandemic, the book clubs went online, and the technical and moral support for my son's first Zoom book club was provided by one of his sisters.[5] Many of the book clubs now meet both in person and online.

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[3] www.booksbeyondwords.co.uk

[4] https://booksbeyondwords.co.uk/book-club-in-a-box

[5] https://booksbeyondwords.co.uk/book-clubs

Inclusive education

UNESCO's Global Education Monitoring Report (2020) addresses the challenges of delivering inclusive education – that is, creating a system of education in which all students are able to participate and learn in regular schools but with educational experiences tailored to their individual requirements.

We can start to understand what is involved in this transformation with two examples from Latin America: the first demonstrating innovation; the second illustrating how such innovation can be delivered at the 'whole system' level.

In Bogotá, Colombia, there is an excellent private school, Liceo VAL, that precisely seeks to welcome a wide variety of students and address classroom effort to ensure that they are all making progress in relation to their individual educational plans (Porter et al., 2017).

In one of the provinces of Argentina, La Pampa, the education system is 10 years into a radical change process, that has already closed all the special schools and is working to ensure every regular school is able to welcome all students (Van Rompaey et al., 2024, in press).

One of my daughters worked in an all-age school in Zambia with children with 'special educational needs and disabilities'. There had been no disabled children in the school until shortly before her arrival. Enquiries in the town hadn't located any. A religious sister in a leadership position in the school initiated a case-finding inquiry during school assembly and identified about 120 previously unknown disabled brothers and sisters. Soon 70 of them were being brought into school to learn life and occupational skills. The remainder received home visits from a teacher once a week. A few years later the home visit programme had been extended to 1000 children, children who were no longer out of sight and out of mind, no longer hidden out of shame (Dawson et al., 2003).

Lessons for Catholic philanthropy

Child abandonment of children with disabilities is more likely in poorer communities. The Zambian children described above were sufficiently valued as human beings to have a teacher visit them at home. Their parents or other caregivers learnt useful skills and were less likely to abandon their children.

Of the 8 million children living in orphanages worldwide, a large minority have disabilities – but *not* orphaned. During periods of conflict or natural disaster, family members with disabilities are at even greater risk of abandonment. The charity Hope and Homes for Children (2022) works internationally to develop family support to enable all children to grow up in a family. This was also one of the ten recommendations in my report to the European region of WHO, adopted by all 52 Ministers of Health in Azerbaijan in 2012, called *Better Health, Better Lives: children with intellectual disabilities and their families* (WHO EURO 2010).

Hope and Homes for Children work with international companies to encourage them to use their charitable funds to provide family-based support for the children currently living in orphanages, rather than providing financial support to the orphanages. As a result, more than a million children have moved into family-based care. There may be lessons here for Catholic philanthropy. A lot of 'orphanages' around the world are provided through religious orders. Is there more that could be done through these efforts to invest in family-based support, especially for children with disabilities and to end 'special' segregated provision?

Supporting Church leaders to be more inclusive

People with disabilities should be visible and participating in church communities, requiring careful attention to the conditions required for inclusion; for example, not just separate spaces at the front or back of the church but a choice of accessible spaces on either side of each aisle enabling a disabled wheelchair user – or anybody who needs more physical space – to be able to sit with their family or friends or other churchgoers, just like everyone else. Lay and clerical roles within the church community could be fulfilled by people with disabilities in similar proportions to their presence in wider society, even if their contributions are unconventional (e.g. in their own expression of being human, such as in their communication, appearance, spontaneity). Even though the Church has moved away from the biblical requirements for priests to be without physical disabilities (Leviticus 21:18-20), this attitude remains (Eiesland, 2005), meaning it's very rare to see anyone with a disability serving on the altar.

It is time to educate our priests, deacons and catechists about the importance of inclusion, but not only as an academic module. For example, joining a pilgrimage to Lourdes (the pilgrimage town in France), *not* as a chaplain, but as a helper with Assisted Pilgrims, could embed some authentic learning through extraordinary moments of grace in the genuine giving and receiving of friendship and help (also see Reinders 2008). At the French pilgrimage site in Lourdes, seminarians and clergy might experience first-hand more equal and inclusive practices in worship, such as the practice adopted by the English Diocese of Arundel and Brighton of remaining seated or kneeling at all times during Mass – an eminently transferable practice that could encourage many more people with disabilities come to Mass.

Another of my daughters focussed her Theology MA dissertation on better inclusion for disabled children and adults in Church services, using multi-sensory initiatives such as Messy Church.[6] She questioned why there are so few people with disabilities present, let alone fully participant, in our churches, and proposed adjustments to Church environments to make the sensory experience more accessible. She discovered that sensory items (e.g. candles, scented oils, and images), movement, and hands-on activities, particularly help autistic people, and people with learning disabilities, to more fully participate in prayer and worship (Hollins 2021, Margaret Beaufort Institute, Cambridge Theological Federation, unpublished). Some of her suggestions about the inclusiveness or otherwise of the standard organisation and procedure for services offer profound insights into the extent of the transformation that is needed. She was partly drawn to this research because of what she had learnt from her brother, but also from her own personal experience as an autistic woman, and from running retreat weekends for people of all ages and abilities. She also had the experience, with the rest of the family, of sharing holidays and worship with other families with children with disabilities, an opportunity that could be open to everyone. The key point here is that people with lived experience gain invaluable insights which could have huge impact if shared.

Supporting family members and people with disabilities to be community leaders

Effective co-production is achieved by doing things together. As a young woman with Down Syndrome said in a powerful short YouTube film, if you assume that she can't then she won't, but if you assume that she can, then her achievements and experiences may astound us (Walmsley, 2017; Coor Down, 2024).

In 2022, I sponsored the Down Syndrome Act during its passage through the House of Lords. Some Members of Parliament argued that no child should be born with Down Syndrome (DS), and that we should aim to elim-

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[6] https://www.messychurch.brf.org.uk

inate DS before birth, as has reportedly been done in Iceland. Some people with DS listening to these suggestions are angry that people want to eliminate them. Others with DS feel guilty, believing that they are a burden. My chapter, *Remorse for Being,* explores the experience of realising, as a person with IDD, that others wished you were dead (Hollins, 1998; DS Act, 2022).

The Down Syndrome Act 2022 recognises people with DS as a specific minority group and legislates for their social care needs to be met. It is the first such legislation in the world. The supporting guidance was drafted with the guidance of people with DS and their families and advocates and is now under public consultation.

Discussion

There are traditions which are difficult to change and the way we use language provides powerful examples. I struggle with some of the language used in the following passage which sustains a discourse of us and them, in part by talking about 'the sick' rather than people who are sick. In 1982 during the Papal Visit of Pope John Paul II to Southwark Cathedral, the Holy Father said:

> "*Today I make an urgent plea to this nation. Do not neglect your sick and elderly. Do not turn away from the handicapped and the dying. Do not push them to the margins of society. For, if you do, you will fail to understand that they represent an important truth. The sick, the elderly, the handicapped and the dying teach us that weakness is a creative part of human living, and that suffering can be embraced with no loss of dignity. Without the presence of these people in your midst you might be tempted to think of health, strength and power as the only important values to be pursued in life. Let us keep the sick and the handicapped at the centre of our lives. Let us treasure them and recognize much*".

Life only becomes disabling when we – each in our own way – reject people who are differently abled to ourselves. When we allow some people to become hidden exiles for our convenience. When we see some as inherently vulnerable, rather than understanding instead that our policies and practices can place people in vulnerable psychosocial situations where they are at risk of neglect, abuse and exploitation. When we are afraid. When we listen to other people's fears and assumptions.

We can do something about this – we can make inclusion part of every person's life from the beginning. And this should not be condition specific. But it does require that we ask each person about their own needs and make every effort to respond. And the changes that are made for one person, whether that is a ramp to the altar or an accessible toilet, may benefit many other people. The mother of a teenage boy with a neuromuscular disability wrote:

> *'All of us should feel able to join in without making a big issue of being there. Any events within the church should automatically include all – this should be the norm and expectation – in churches, schools, monasteries, retreat centres. As a family, we don't want to be separated due to disability, but enabled to fully join in with both physical and human support'.*

She goes on to say:

> *Really see a person. Look for that spark of God, that unique giftedness in each person.*
>
> *Listen to each person. Listen to those who support them. Don't assume you know or understand their situation or feelings. Place yourself in their situation – as the person, their mother, father, brother, sister, friend – not just for a moment but throughout the day, a week – live it all – the practical, the emotional, the medical, the educational' (Hartley, personal communication).*

Before my son was born and diagnosed, I knew nothing about IDD. As a doctor I had learnt about genetic syndromes, and the 'tragedy' model of brain injury caused by accident or disease. Not what it is like for an individual to be born with, or to acquire physical or cognitive or emotional 'impairments'; and who, in addition to their own struggles to make sense of our world, have to face additional environmental barriers which further exclude and disable them. I didn't find the various models of disability helpful in making sense of my family experience (Shakespeare, 2014). And I didn't learn about the impact of trauma, or adverse childhood experiences, in medical school. That came from my personal experiences. I didn't understand the drivers of exclusion until I experienced them in my own family.

And then in 2005, my youngest daughter survived a criminal assault, with a permanent, high-level spinal injury. The national media treated her story as tragic, as did some of her social circle, which is an indication of public attitudes to disability. For us, she was still the same person. She was alive. Onlookers were puzzled by our acceptance of her new condition and saw her as a saint (Hollins, 2005). My daughter says of herself that her condition has brought unimaginable gifts. But she also recognises that, having been brought up with a disabled brother, and having spent time with other disabled people, gave her a huge advantage. She *could* imagine her life as a disabled woman.

And there are many conditions that can lead to older people becoming disabled in their later years. In Europe 52% of all people with disabilities are over the age of 65 (European Council, 2022).

One of my own contributions to the global work of the Church has focused on abuse, including as a Founder member of the Pontifical Commission for the Protection of Minors. Safeguarding offices do not yet prioritise the safety of disabled children and adults. Before I worked with disabled victim/survivors of abuse as a psychiatrist, I didn't know that the prevalence of abuse of disabled children and adults is much higher than for other people (Groce 2005, Jones 2012).

The hypothesis is that they are relatively invisible, and experience power imbalances in nearly all of their relationships (Hollins et al., 2012). Could the Pontifical Commission for the Protection of Minors review its guidelines[7] to ensure that they do prioritise safeguarding and safe environments for disabled children and adults? Recommending adequate adaptations to safeguarding processes and healing services is a priority.

Conclusion

The breadth and fundamental importance of this agenda requires all of us to draw out implications for our own lives, roles and areas of influence. Both the causes and the responses are multi-level and multi-faceted. Cross-government and international approaches are needed. This includes recognising the differential impact of climate change and other 'natural' disasters. And facing up to the global threats posed by social media.

The lack of familiarity within Church communities of people who are different points to some of the most modifiable environmental barriers, the most modifiable determinants of disability that lead to exclusion. We could make church processes more inclusive; develop the orientation and skills of the clergy as inclusion facilitators; and ensure measures to prevent/ameliorate abuse (including in/by the church) by prioritising (potential) victims with impairments. Church leaders could support families to ensure children are not taken into care or 'orphanised'.

Transformative change will only succeed if we learn from those with first-hand experience. Some with the power to implement change will have natural empathy, others will have the logistic skills and others the political authority to 're-pattern' language, thought and action into a new synthesis (Sharpe, 2013). As Pope Francis said on World Communication Day 2016:

"Listening means paying attention, wanting to understand, to value, to respect and to ponder what the other person says. ... Knowing how to lis-

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[7] https://www.tutelaminorum.org/universal-guidelines-framework/

ten is an immense grace, it is a gift which we need to ask for and then make every effort to practice".

So, let's listen to each other, ensure our visibility and amplify our voices. Let's welcome all of us into our communities and offer us valued roles. Let's support all of us to have an ordinary life. Let's end an attitude of 'them and us' and show the way.

Epilogue

I will end with a poem by my daughter, Abigail Witchalls, who acquired a high-level spinal injury following a criminal assault.

Discussing this paper with her, as I prepared for the 2024 PASS Plenary, Abigail wrote the following poem, in part inspired by the writings of Edith Stein:

Mere Difference?
Let's see differences for what they are
Not unbridgeable gulfs or forbidding brick walls
Nor irrelevant varieties or mere diversities
We're all unrepeatable so one size won't fit all
We all have our beauties and broken bits
We're each a unique mix of gifts and gaps
We each show a different divine dimension
And new ways of shining His light through the cracks

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DISABILITY AS AN ANTHROPOLOGICAL AND THEOLOGICAL CHALLENGE

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We have learnt from interacting with persons with disabilities that they change our own perception of disability. Not that the phenomenon was unknown, but that it cannot be reduced to a one-way relationship. Persons with disabilities reveal to the healthy their own fragility. Beyond disability is a world of spiritual strength and dignity.

1. Our societies have changed their look on disabilities and are making efforts to overcome attitudes of marginalisation or exclusions of persons with disabilities. The 2006 UN *Convention on the Rights of Persons with Disabilities* is a remarkable achievement in international law. National legislation very often gives guidelines protecting affected people in the fields of education, employment, access to public places and transportation. Certainly, much has still to be done. The *International Day of Persons with Disabilitie*s is celebrated every year. The point is that there is a promising ongoing change of mentality.

This change of mentality is also clear in the teaching of the Church. No longer should we consider pastoral care for – but with – disabled persons. We receive from them as much as we may give, when interacting with them.

When we speak of disabilities, we include those originated by physical, psychological, and mental limitations. Sometimes we forget the spiritual dimension of the human being. Yet, this spiritual dimension is addressed precisely because the physical or mental dimensions suffer limitation.

Brain injuries may affect the mind and mental operations. But they do not annihilate the sphere of the spirit. The spirit is able to inspire resilience to a person with physical or mental illness. The spirit is a provider of sense and values. So the dialogue with persons with disabilities often shifts to the spiritual level, where the identity of the human person dwells. Behind the limitations linked with our carnal condition appears the spirit. Spiritual strength is exactly the opposite of mechanical superiority. God, says the Prophet, "gives power to the faint and strengthens the powerless" (Is 40, 29). Ep 3,16 states that the Spirit strengthens "the inner man".

Our brothers and sisters who suffer disabilities and limitations in their body and even in their brain, are not deprived of the enjoyment of their spirit. The strength of the spirit always operates within the limits of our human condition, often in a situation of weakness. Persons with disabilities may be able to manifest wonder in front of the beauty of creation and compassion with those in need, and experience selfless love.

The Apostolic Exhortation *Evangelii Gaudium* (2013) says "the worst form of discrimination is the lack of spiritual care". Pope Francis stressed: "We are called to recognize in every person with disabilities, even complex and serious disabilities, a unique contribution to the common good through their original life stories" (Intern. Day Disabilities 2019).

The image of the strong, healthy, powerful and generous actor offering support and help to the passive disabled persons in order to give them access to the world of full humanity has been replaced by the rediscovering of our common frailty. A handicap is the hollow image of health. It powerfully reminds the healthy ones of their own fragilities.

2. The message of the Gospel is directed to the weak, the ill, those possessed, all people who call for help. Jesus heals as a sign of the efficiency and proximity of God's Reign. God wants his creatures healthy and happy. Jesus restores the wounded human condition. He offers to all fullness of life through a process of conversion.

St. Paul, writing to the Corinthians, does not argue of this superiority as an apostle. He knows that sharing the Gospel is not a one-way operation. It questions the transmitter as well as the receiver. Paul is fully aware of his own limits and fragility. Indeed, it is from his weakness that he exercises his mission as an apostle. He does not pretend to seduce his listeners through rhetoric or illusive promises, so as to manifest the power of the Gospel. We find often in Paul a contraposition of weakness and power: *asthenia* and *dynamis*. *Asthenia* is what characterises the natural individual, the flesh (2 Co 11,30-12,13). Paul puts his pride in his weakness. "When I am weak then I am strong". He recognizes that he had "a thorn in his flesh" (2 Co 12, 7), which could be a permanent physical disease. Elsewhere, Paul states that he holds the treasure entrusted to him in "earthen vessels" (2 Co 4, 7).

3. These remarks of Paul may suggest more than a confession of his own weakness. They give insight into the limited condition of all human beings. The present condition of human life in flesh is weakness opposed

to the future condition of redeemed life in glory. In our world "the Spirit comes to the aid of our weakness" (Rm 8, 26). In Christ, God has revealed himself voluntarily Weak. Christ, who "was in the form of God … emptied himself, taking the form of a slave" (Ph 2, 6-7). Paradoxically, the cross of Christ shows how "the weakness of God is stronger than human strength" (1 Co 1, 26). Moreover "God chose the weak of the world to shame the strong" (1 Co 1, 27). Promethean pretention to be all powerful and to dispose of unlimited power and strength is a permanent temptation of humanity. But it is an illusion. The Encyclical *Laudato si'* (2015) 117 states: "Once the human being declares independence from reality and behaves with absolute dominion, the very foundations of our life begin to crumble".

The challenge of disability opens us to the question of our limits. Limits are not limitations. Limitations are imposed from outside and can be avoided. Limits are inherent to a being or a system and must be respected. Transhumanist thinking promises to explode biological and mental limits. The idea of "enhanced man" suggests a rebellion against our real human condition. It is not a humanist reaction of healing or repairing damaged health or brain conditions but of creating something else, a hybrid entity connected to big data. We would lose what makes us human: our spirit and our capacity to make free choices. Our inner personality would be absorbed in electronic synapses.

Society puts limitations to our freedom as we have to respect the freedom of others. But our freedom meets its inherent limit in truth. Truth is the objective hindrance and the guide to an arbitrary use of our freedom of judgment. The ancient ecumenical councils shared by Catholics and Orthodox used to adopt a *horos* and canons: a definition and rules. The "de-finition" precisely puts the limit beyond which you are no longer in the truth.

Recognizing the fundamental weakness inherent to our common human condition opens a new understanding of disability and interaction with the world of disability. Human disability indeed sheds light on anthropology as well as on theology. By sharing our common wounded humanity, we may engage into communion, giving and receiving from each other, in an exchange located on the level of the spirit.

Our society relies on the increasing power of high performing technologies. This may be good, but says little about the condition of disability. Society has put forth that what is more desirable is a partnership with the disabled persons on a basis of human equality.

St. Paul witnesses that preaching the Gospel in his own weakness brings more fruit than talking from learned to ignorant, from mighty to weak.

Only God knows and is mighty. And he humbled himself to our condition. The apostle who teaches is himself permanently taught by the Lord. So should be our relationship with the world of disability.

Persons with disability help us stay on the ground of our own weakness in a shared human fraternity.

ICF: THE UNIVERSALIZING CONCEPT OF DISABILITY AND FUNCTIONING

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The WHO International Classification of Functioning, Disability and Health (ICF)

The functioning of an individual in a specific domain reflects an interaction between the health condition and the contextual environmental and personal factors. There is a complex, dynamic and often unpredictable relationship among these entities and understanding this interaction is crucial to understand what disability is and how the concepts of functioning and disability can be defined and operationalized.

The WHO International Classification of Functioning, Disability and Health (ICF) is a framework for organising and documenting information on functioning and disability (WHO 2001). The ICF was approved for use by the World Health Assembly in 2001, after extensive testing across the world involving people with disabilities and people from a range of relevant disciplines. A companion classification for children and youth (ICF-CY) was published in 2007. The ICF integrates the major models of disability. It recognises the role of environmental factors in the creation of disability, as well as the relevance of associated health conditions and their effects. It conceptualises functioning as a “dynamic interaction between a person’s health condition, environmental factors and personal factors”.

ICF provides a standard language and conceptual basis for the definition and measurement of disability, and it provides classifications and codes. It integrates the major models of disability – the medical model and the social model – as a “bio-psycho-social synthesis”. It recognises the role of environmental factors in the creation of disability, as well as the role of health conditions. Functioning and disability are understood as umbrella terms denoting the positive and negative aspects of functioning from a biological, individual and social perspective. The ICF conceptualises a person’s level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. It is a biopsychosocial model of disability, based on an integration of the social and medical models of disability. The ICF therefore provides a multi-perspective, biopsychosocial approach which is reflected in the multidimensional model of health.

Health has been defined in the WHO Constitution as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (Constitution of the World Health Organization, WHO 1948). The ICF provides a scientific, operational basis for describing, understanding and studying health and health-related states, outcomes and determinants. The ICF is recognised as a reference member of the WHO Family of International Classifications (WHOFIC), and complementary to the International Statistical Classification of Diseases and Related Health Problems (ICD). Health conditions are classified using the ICD (most current version is ICD-11), which provides codes for diseases, disorders, injuries or other health problems thus an aetiological framework. The health and health-related states associated with any health condition can be described using ICF. The ICF and ICD are two complementary WHO reference classifications; both members of the WHOFIC. ICF is not associated with specific health problems or diseases; it describes the associated functioning dimensions in multiple perspectives at body, person and social levels. From WHO’s perspective, ICF is most relevant to the health information component of health systems, complementing its two other data classifications, ICD and the International Classification of Health Interventions (ICHI), which together allow for the routine collection of data concerning all three indicators of health status – mortality, morbidity, and functioning.

Definition of disability and the biopsychosocial model

The ICF provides a framework for the description of human functioning, on a continuum. It is important to remember that it classifies functioning, not people. Because the development and testing of the ICF involved people from a broad range of backgrounds and disciplines, including people with disability, the ICF has a wide range of potential applications. People use the ICF across broad sectors including health, disability, rehabilitation, community care, insurance, social security, employment, education, economics, social policy, legislation and environmental design and modification.

The ICF conceptualises functioning and disability in the context of health, and therefore does not cover circumstances that are brought about solely by socioeconomic or cultural factors. Nevertheless, if poverty results in a health condition such as malnutrition, related functioning difficulties can be described using the ICF.

The ICF has been accepted as one of the United Nations social classifications and provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation. Hence, the ICF provides a valuable framework for monitoring aspects of the UN Convention on the Rights of Persons with Disabilities (UN 2006), as well as for national and international policy formulation.

In 2006 the WHO Family of International Classifications (WHO-FIC) Network established the Functioning and Disability Reference Group (FDRG) to advise on functioning, disability and health classification and coding issues. The FDRG, with members from more that 30 WHO collaborating centres around the world, has developed a work program to enable it to provide well researched advice. Topics include coding guidelines, ICF updates, ICF-ICD joint use, ICF-ICHI, use of WHO DAS 2.0, education, ethical use of ICF, measurement and environmental factors. The FDRG works collaboratively with other committees and reference groups in the WHO-FIC Network to address these issues and to create a common language for health, disability and functioning.

Definitions and categories in the ICF are worded in neutral language, wherever possible, so that the classification can be used to record both the positive and negative aspects of functioning. In classifying functioning and disability, there is not an explicit or implicit distinction between different health conditions.

Disability is not differentiated by aetiology. ICF clarifies that we cannot, for instance, infer participation in everyday life from medical diagnosis alone. In this sense ICF is aetiology-neutral: if a person cannot walk or go to work it may be related to any one of a number of different health conditions. By shifting the focus from health condition to functioning, the ICF places all health conditions on an equal footing, allowing them to be compared, in terms of their related functioning, via a common framework. In developing collections of information on functioning and disability it is important to consider all components of the ICF.

A common definition of disability is crucial to understanding and improving outcomes for people with disabilities as well as for increasing the power of information through the ability to relate data from different sources, such as in service settings and at the population level. When consistent language and concepts are used, they facilitate comparisons, complementary information and knowledge building.

Functioning, disability and the components of the ICF have precise definitions that have been so far translated in more than 65 languages. Body functions are the physiological functions of body systems (including psychological functions). Body structures are the anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function and structure such as significant deviation or loss. Activity is the execution of a task or action by an individual. Participation is the involvement in a life situation. Activity limitations are the difficulties an individual may have in executing activities. Participation restrictions are problems an individual may experience in involvement in life situations. Environmental factors are the physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning. (WHO ICF 2001).

Human Functioning: to reconceptualize health

Functioning is an umbrella term for body function, body structures, activities and participation. It denotes the positive or neutral aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors). Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors).

Two constructs, 'performance' and 'capacity', can be used in operationalising the qualifier scale for the activities and participation domains. These constructs provide a way of indicating how the environment (in which measurement has taken place) impacts on a person's activities and participation, and how environmental change may improve a person's functioning. 'Capacity' relates to what an individual can do in a 'standardised' environment. 'Performance' relates to what the person actually does in his or her 'current' (usual) environment. The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance (WHO ICF 2001).

From a public health perspective, functioning augments the biomedical view of health measured in terms of the indicators of mortality and morbidity. Functioning constitutes WHO's third health indicator of health. Avoiding premature mortality and controlling morbidity are obviously important to us, as individuals and as society at large, but only to the extent to which they are conducive to enhanced functioning and so better health. Population aging, adding more years to our lives, underscores the equal importance of adding more life to our years. The increased prevalence of non-communicable diseases and chronic health conditions – the so-called compression of morbidity which lead to a decline in functioning – is concerning, and from the perspective of society they warrant increased investment in prevention and cure. But the impact of these trends also points to the need to prepare our healthcare systems to focus on optimizing functioning.

Moreover, operationalizing health as human functioning completes the picture of health envisaged by SDG3 by explaining why health is a driver of individual well-being and, in turn, why population health contributes to societal welfare.

Human functioning as the third indicator of health (complementing mortality and morbidity) provides a basis for reconceptualizing multidisciplinary health sciences; a new interdisciplinary science field – human functioning sciences – itself holds promise to integrate diverse research inputs and methods to provide a fuller understanding of human health. Implementing functioning as defined and conceptualized in the International Classification of Functioning, Disability and Health could profoundly benefit practices, research, education, and policy across health systems and health strategies and help integrate health and social systems. It also offers a foundation for reconceptualizing multidisciplinary health sciences and for augmenting epidemiology with information derived from peoples' lived experiences of health.

Conclusions

As this Plenary of the PASS shows, it is necessary today for "Changing the Social Determinants of Disabilities and Building a New Culture of Inclusion" to identify what are the specific determinants that in the cultural, family, educational, political, economic, and employment spheres represent the barriers that increase the disability of a society and prevent persons with disabilities from fully participating in social life by making their original contribution. This is what matters to people, and the COVID-19 pandemic showed to everybody that health is a key component for each individual and the environment plays a crucial role in determining functioning.

During their life all people experience decline in body functioning as well as any health condition that can cause pain, anxiety, fatigue and other sensory, mobility, and cognitive impairments. What people can do in their daily life is what matters to people DESPITE the presence of a health condition, this is the lived experience of health and functioning. This essential component of lived health complementing the traditional biomedical understanding of health, creates a more meaningful operationalization of what health means to us.

Human functioning is the bridge that links health to individual well-being and societal welfare. Functioning incorporates biological health (the physiological and psychological functions and anatomical structures of the body that constitute the intrinsic health capacity of a person to perform human activities) and lived health (the individual's actual performance of activities in interaction with their actual physical, built, and social environments) (Bickenbach J et al. 2023).

Disability is thus a manifestation of possible variations in human functioning resulting from the interaction with environments that are barriers, rather than a mental or physical impairment to be discarded.

As Pope Francis affirms, "we need the courage to give voice to all those that suffer discrimination because of their disability as unfortunately in some Countries, still today, it is difficult to recognize equal dignity to all". Therefore, disability poses a decisive challenge: a new global culture of inclusion must be developed by eliminating the barriers that hinder the full citizenship of persons with disabilities and their "unique contribution to the common good through their remarkable life stories" (*Fratelli tutti*, 98).

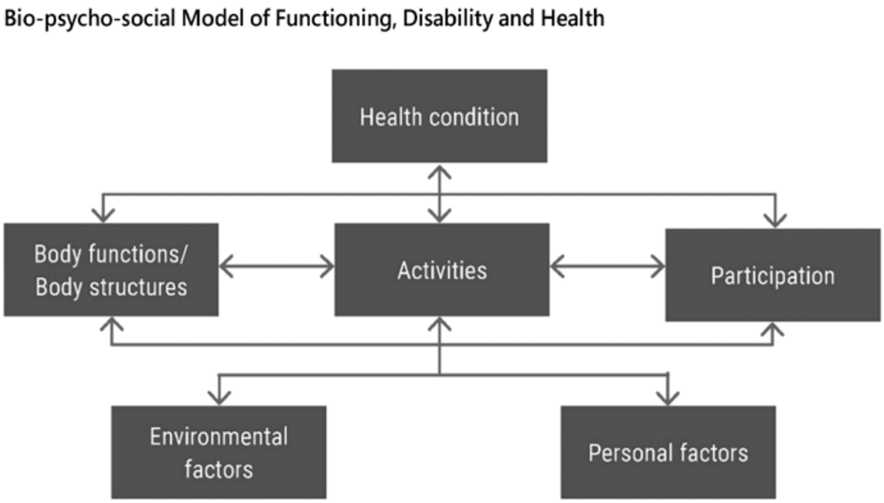

Figure 1. Bio-psycho-social model of the International Classification of Functioning, Disability and Health (ICF).

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DISABILITY AND PERSONS WITH DISABILITY

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In social policy research a distinction is made between universal and targeted programmes. Universal programmes provide benefits and services to every individual in a population, while targeted programmes select candidates for support based on eligibility screening on demographic, behavioural or other characteristics. Each approach has advantages and disadvantages: universal programmes are available to everyone and so avoid the cost and inconvenience of administration qualification or eligibility procedures, but will inevitably provide benefits or services to those who are do not need them or easily afford them. By contrast, targeted programmes directly benefit people who actually need them, but require costly, if not invidious, administration eligibility procedures. A universal child benefits policy, for example, exemplifies the principle of equality of treatment while potentially ignoring specific vulnerabilities; while a targeted child benefit policy focusing on those children truly in need requires costly procedures to identify this cohort diffusing the overall impact of the policy. To preserve what is beneficial while avoiding the downside costs, researchers have proposed, somewhat contrived, modifications such as 'targeted universalism' or 'proportionate universalism'.

I bring up this universal/targeted dilemma in social policy because disability is one human phenomenon in which the tension between universal and target societal responses is particularly relevant, and the source of both conceptual confusion and practical dilemmas. This has significant impact on policies that operationalize the rights endorsed by the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).

On the one hand, the primary determinant of the disability experience – impairments of body function and structure, linked to underlying diseases, injuries and other health decrements – are basic human phenomenon, unavoidable and universally experienced across the lifespan. Decrements in health that play out in people's lives as limitations in functioning are, across the lifespan, an essential component of the embodied human condition. Everyone experiences ill-health, decreased functioning, ageing and death. This makes us human. On the other hand, as disability exists in the actual social context of a person's lived experience, and that context is highly variable, the experience of disability lies on a spectrum of severity from none or negligible to highly severe, and that spectrum generates qualitative differences that create very different levels of vulnerability and need. This means that a 'one size fits all' societal response to operationalizing human rights is inadequate whereas, in principle, a nuanced and targeted response makes more sense.

The same underlying conceptual point can be expressed in the language of political and moral equality: Our equal vulnerability as embodied human beings entails an equal need for support from others; but that equal need is not equally distributed across the population, so, inevitably the basic human right of equal concern and respect demands a recognition of differences in need, and so targeted, that is unequal, policies and treatment. In 1990, legal theorist Martha Minow call this the 'dilemma of difference', namely the apparent political tension between legally recognizing the equal rights for all, while at the same time treating people differently in order to compensate for the adverse consequences of their differences. Yet the dilemma, or even paradox, that equality requires unequal treatment, conceptually dissolves in light of the practical realization that people deserve equal respect and that entails recognition that they differently situated and their vulnerabilities needs are differentiated by circumstance.

Some years ago myself and some colleagues tried to flesh out in more sociological and political detail the apparent tension in the realm of disability between the universal human condition of vulnerability and the practical societal requirement that operationalizing human rights must respond to situational differences.

We based our work on what I still believe to be a broad consensus about the conceptualization of disability: For nearly fifty years, and across disciplines from the health sciences, sociology, politics and law, disability has been generally understood to be rooted in physiological and psychological functioning (that is, states of health), but experienced in terms of activities, relationships and social roles that are created, or strongly shaped, by the physical, human-built, attitudinal and social environment in which people actually live out their lives. We argued that political debates about "models of disability" that occupied past decades have more or less resolved into this broad consensus. The resulting "interactional model" of disability has been most fully developed in the World Health Organization's *International Classification of Functioning, Disability and Health* and is reflected in the characterization of disability in the CRPD, namely "... disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

What we suggested in the paper was that there is an important conceptual distinction: 'a person with disabilities' and 'a person experiencing disability'. What might on first hearing appear to be a linguistic variation, is not only deeply theoretical but has historical roots and far-reaching social consequences. In effect, these two phrases generate different connotations of the word "disability", one linking it to a socially-constructed disadvantage or devalued social status, the other to the outcome of sub-optimal health states interacting with the physical and social environment. And it is this distinction which, I want to argue here, complicates the operationalization of rights for persons with disabilities in social policy.

Disability as Social Identify: Persons with Disabilities

What is often termed "minority group analysis" of disability was an outgrowth of the scholarship and political activism in the 1960s and 1970s in North America and Europe, and eventually came to be called the "social model of disability". Advocates in the United States used the civil rights movement as their model, while in the UK the basis was the Marxist analysis of social oppression. Both groups relied on earlier medical sociological accounts of the "sick role" in the context of rehabilitation as well as deviance theory and the dynamics of social marginalization. Some theorists directly blamed health and human service professionals, especially rehabilitation therapists, for devaluing people with disabilities and, in effect, creating the disvalued social role of "the disabled".

Although this analysis of disability was closely linked to "identity politics", which emphasized the rigid social dichotomy between those with and those without disability, it was political scientist Harlan Hahn, in a series of influential articles in the 1980s, who consciously aligned disability with the social dynamics of racial activism, underscoring the crucial role of political advocacy to secure equal rights. In the United States, it was this analysis that paved the way to the passage of *The Americans with Disabilities Act*, 1991, the preamble of which directly borrows from *The Civil Rights Act*, 1960: "Individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment and relegated to a position of political powerlessness in our society...".

Like all rights-based political movements, the minority group or social identity analysis of persons with disabilities put full participation and social inclusion at the top of its advocacy agenda. As a political strategy and social movement attacking systemic discrimination, it was highly successful. Indeed, this perspective of disability can be credited with nearly every change in attitude and treatment of people with disabilities in the past 40 years, leading to the passage of the CRPD itself. Along the way, scholars such as Tom Shakespeare began to overlay the psychological dimension of disability self-identity that addressed the stigma of biological inferiority by valorizing the identity, and further underscoring the separateness of persons with disabilities.

Being modelled on the American civil rights experience, it was essential that people with disabilities be a "discrete and insular minority", which in effect meant that, sociologically, disability needed to be a dichotomous notion: one is either a person with disabilities or not. To make sense of this, only those with long-term, serious and severe impairments could be said to be "disabled". As the lives of people with severe impairments were more profoundly impacted by personal and social environments, it was plausible to argue for entrenched socially disadvantage, and indeed for self-identity. Indeed, some disability advocates strongly objected to people with temporary health problems, however incapacitated (or discriminated against), or those whose impairments were seen as self-created (obese people or substance abusers) to be viewed as persons with disabilities.

The minority status of persons with disabilities was consequence of the fact that this status was "socially constructed" by social and economic forces that under-valued the persons with disabilities identity. This was manifested in discrimination, prejudice, lack of equal opportunity and other social disadvantages. These disadvantages, moreover, were neither accidental nor contingent, but intrinsic to the very ontological status of being (viewed as) persons with disabilities. Since these social disadvantages were based on persistent attitudes and misperceptions, the only effective remedy was to address the social structures that reinforced these attitudes and misperceptions. And the most effective political and legal basis for the social remedies needed was legally enforced human rights, which, once again, provided the intellectual and political motivation for the CRPD.

Disability as Universal Human Experience: Experiencing Disability

The other perspective on the experience of disability follows from the (universal) fact that people are biological entities that experience diseases and injuries that affect their biological functioning. These assaults on health, in turn, impact on the things people can do in their lives, from reading a book, to going to school, doing a job, and being a parent, neighbour, community member or citizen. Human beings break down, fall apart and eventually die. This is not social construction; impairments are simple universal and unavoidable facts of human life. But significantly, impairments are also variable in severity: the basic body function of visual acuity ranges from some statistically determined level of normality to a mild and moderate impairment, to a serious degree of limitation to, finally, blindness or a total loss of visual acuity. All body functions (and structures) follow this pattern; they are experienced, and assessed, on a continuum. We can prevent some health problems that lead to impairments, and slow the progress of decline, but in the end, impairments of some level of severity, like death itself, are simply unavoidable.

This perspective on disability has always been (and associated with) what is commonly called the medical understanding of disability. Yet this basic view is not monopolized by health professionals. For example, American sociologist Irving Zola in important 1989 paper "Toward the necessary universalizing of a disability policy", argued that the minority approach to disability, although a productive short-term political strategy, could not be sustainable for the long term. It is a mistake, he argued, to think that disability is a dichotomous notion, applicable only to those with permanent and severe impairments. Disability is a near-universal phenomenon, part of the human condition. For this reason, in the long term, social policy must be universal, applicable to everyone experiencing or at risk of experiencing disability of any level of severity. A universal policy would match the level of resource, service, or support to the level of need, recognizing that impairments, though dynamic over the life course tend, given ageing, to be increasing in both number and severity.

The Two Perspectives on Disability and Operationalizing Human Rights

Zola's views might have been radical to sociologists and disability advocates, but it was the unspoken consensus amongst health professional, in particular rehabilitation professionals for whom disability was an infinitely various, yet universal feature of humanity. In rehabilitation especially, it was understood that the experience of disabilities was the product of two sets of determinants, impairments and health conditions on one side, and physical, human-built, attitudinal and social environmental factors on the other. Since no one could claim to possess a complete repertoire of capacities, suitable for all permutations of the physical and social environment, both epidemiologically and clinically people exhibit a spectrum of abilities, changeable over time, changing as the environmental context changes. As Zola himself later stated, "having a disability was not a fixed status, but rather a continually changing, evolving and interactive process".

But here the underlying tension between the two perspectives on disability has taken its toll. One of the persistent themes of the persons with disabilities perspective has been the distrust of health professionals in general and rehabilitation professionals in particular. The unstated assumption seems to be that rehabilitation professionals seek to mould the person to an environment that is a given and cannot be changed, and, when this is impossible, to relegate the individual to the social sidelines. Although frequently hinted at in the disability studies literature, this assumption profoundly misunderstands the objective of rehabilitation and the self-perception of rehabilitation professionals themselves. Ironically, this criticism is most more appropriated directly to traditional social policy, that tends to rely on targeted disability policies – pensions, income replacement, sick leave and other compensation schemes – in which eligibility is determined by so-called 'baremic' tables that directly link impairments to 'disability percentages' utterly ignoring the impact of the physical and social environment on the experience of disability.

At the same time, the persons with disabilities perspective has itself relied on targeted approaches to policy – from anti-discrimination laws to the CRPD itself – in which eligibility is not based on impairments but on perceived social disadvantage caused by social arrangements (created and kept in place either through ignorance, benign neglect or design and overt discrimination). Because of this, the appropriate social response must be to ensure social inclusion at the individual level by means of political advocacy towards legal and policy change. The focus of this legal and policy change must be both negative (to prevent and compensate for discrimination and prejudice) and positive (to provide the accommodations and supports needed for enhanced participation).

In the case of the CRPD itself, the persons with disabilities perspective has created a troubling dilemma of its own: The CRPD is undeniably a human rights document. But human rights are exactly those rights that are not targeted to some specific minority or of humans but are precisely those rights the only eligibility criterion for which is being human. During the development of the CRPD there was some debate whether this human rights document – unlike the *Universal Declaration of Human Rights*, for example – that created 'special' rights for a specific minority, namely persons with disabilities. Recognizing the incongruity of *human rights* that only a sub-population of human enjoyed (non-universal human rights in other words), the United Nations official position was that the CRPD did not created special rights, but rather was operationally a document that persons with disabilities could rely on to ensure that they had human rights – in a phrase repeated throughout the CRPD – "on an equal basis with others".

If we shift to the other perspective on disability, it is very clear that it is universal in form and function. The experiencing disability perspective embodies the view that the social disadvantages an individual experiences are jointly determined by underlying health conditions, and resulting impairments, as well as by environmental barriers (or the absence of environmental facilitators). As all human experience across the lifespan, both health conditions and live in environments that can limit full inclusion, the social response must apply universally to everyone. Moreover, as both the health and the environmental determinants of the experience of disability exist on a spectrum of severity from negligible or mild to severe or very severe, the social response, although universal available to all, must be nuanced to the actual severity of the experienced disability. For some underlying health conditions, interventions can effectively optimize capacity so that the disability is reduced to negligible. For other, more severe impairments, improving capacity may not be enough (or may not be possible), in which case some form of environmental adjustment or modification will be required. This can take the form of the provision of appropriate assistive devices (eye glasses, hearing aids, wheelchairs, and communication devices), personal assistance, or the removal of unnecessary environmental obstacles (providing ramps or widening doors for persons in wheelchairs) or both. As these services and supports are socially-provided, it is inevitable that facilitating laws and policies, available and applied to everyone, will be required.

The differences are subtle, but have an impact on how social policy is designed. The persons with disabilities perspective insists that the appropriate social response to the injustice experienced by persons with disabilities is essentially targeted compensatory or remedial, given that most environmental barriers (or failures to provide facilitators) are a feature of social design and thus are changeable. To make this case, however, advocates tend to downplay the essential need for health interventions to enhance intrinsic capacity (medical, pharmaceutical and rehabilitative), turning their attention to the goal of inclusion and emphasizing the unfairness of forcing people with "physical differences" to make their way in a human-built environment designed for people without impairments.

As the basis for social policy – operationalizing human rights – the persons with disability perspective makes more sense for those experiencing severe, chronic underlying health conditions for which improvements in health capacity are not available, and the primary determinant of disability is environmental. For these individuals targeted policies make sense. For the other perspective, universal policies that response to differences in several and cause of disability – whether health-based or environmental – are more effective and cost-effective.

The two perspectives on disability have different lineages and strategically impact social policy in different ways. Each has strengths and weaknesses: although, epidemiologically, limitations in functioning are a universal human experience, it is obvious that more severe impairments impact individuals more profoundly than milder ones and those impairments have very different impacts on the lived experience in different social environments. These realities could justify highlighting, however artificially, the needs of a minority group of persons with disabilities for advocacy purposes.

At the same time, given the ageing population and increasing prevalence of chronic, non-communicable diseases, it is essential that society prepares itself to respond, not only to the obvious needs created by severe impairments, but also to the needs created by mild and moderately severe impairments. For these impairments are experienced by a much larger population for whom prevention and rehabilitation efforts can have the greatest benefit.

Conclusion

To be clear, disability advocates are undoubtedly correct that persons with disabilities have historically been, and continue to be, denied basic human rights, which limits their opportunities to participate fully in society. At the same time the persons with disabilities perspective is limited to those with severe impairments that are chronic and unalterable, in physical and social environments that are unaccommodating or even discriminatory. While the strength of this perspective has been its capacity for political advocacy, it has achieved this in part as a function of artificially restricting its constituency to a minority of people.

Whatever the exact size of this sub-population may be, and it has been notoriously difficult to precisely quantify it, as a general portrait of the disability experience, it may increasingly become unrepresentative: The ever-increasing prevalence of non-communicable disease and population ageing (where more people are living longer but experience more disability) means that we are entering a future in which a greater and greater portion of the world will experience mild and moderate disability. In order to meet the challenges of demographic and epidemiological trends, the growing population of persons experiencing mild or moderate levels of impairment must also have a call on our social resources, for they too have human rights. The interests of what in the next fifty years may become the majority of the world's population who experience mild or moderate disability should not be ignored.

But ultimately, both because of demographic and epidemiological trends and because of the increasing inefficiency of targeted social programming for minority groups, societies will move, as Zola predicted, to an universal approach to operationalizing human rights. The strength of the experiencing disability perspective is that it emphasizes the universality, and therefore the utter human normality, of disability and the need to effectively address it through basic social and health policies and practices that respond to the human condition as actual exists, in both its universality and its differences.

Resources

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DISABILITIES, RIGHTS AND RELATIONS

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1. Preliminary remarks: a new approach to disability

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is universally recognized as a turning point in the social and legal thinking about disability.[2] Centered on the full and unconditional respect of the *inherent human dignity* of each and every member of the human family, the Convention develops a new definition of disability, promotes and defends the rights of people with disabilities and fosters a culture more respectful of all human persons, regardless of their condition. It engages all social and institutional actors in advancing inclusivity and reducing discrimination, prejudice, and stigma.[3] From the legal perspective, this new understanding of disability has brought about important changes that are unprecedented.

In fact, not only did the UN Convention put disability in the framework of the human rights discourse,[4] but it also provided for a new understanding

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[2] It has been argued, especially with reference to the direct EU accession to this Convention, that it represents one of the most visible examples of cooperation between states for human rights protection. See G. De Burca and C. Kilpatrick, *Resisting External Accountability: The European Union and Human Rights*, K.A. Armstrong, J. Scott and A. Thies (eds), *EU External Relations and the Power of Law: Essays in Honour of Marise Cremona*, Hart, Oxford, 2024, p. 9.

[3] E. Celik, Exploring the use of the concept human dignity in disability human rights law: from UNCRPD to ECtHR*, The Age of Human Rights Journal* (17) 2021, p. 28 ff.

[4] V. Della Fina, R. Cera and G. Palmisano, *The United Nations Convention on the Rights of Persons with Disabilities, A Commentary*, Springer International Publishing, Cham, 2017, p. 2: "The first phase, dating from 1945 to 1970, marks a time when disabled persons were invisible in United Nations policy. This changed in the second phase, from 1970 to 1980, when disabled persons became recognised as subjects of rehabilitation. The third

of disability as such, that has slowly been integrated in the legal systems, starting from the European one.

The new understanding of disability enshrined in the Convention since its Preamble, and repeated in its first article, states: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory *impairments* which in interaction with various *barriers* may hinder their full and *effective participation in society* on an equal basis with others".

Disability is not a physical, mental or sensorial impairment as such. An impairment, a weakness or a disfunction becomes an issue of disability in the interaction with the surrounding context, where barriers and obstacles become an impediment to social participation.[5] Therefore, disability cannot be treated only as a pure medical problem and does not define the person;[6] it is also a social problem that calls for medical as well as social answers. Disability is neither an exclusive medical nor social issue, it is rather a relational problem, one that arises from the interaction between a medical and a social condition.

This new social, or rather bio-social, understanding of disability has struggled to gain acceptance in legal practice.[7] Yet the evolution is clear and evident, especially in Europe, where a dramatic change has been brought about by the Court of Justice of the EU,[8] since the Union itself became part of the UN Convention.

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phase comprised the two decades from 1980 to 2000, and during this time persons with disabilities became objects of human rights. Only in the new millennium, during the fourth phase, disabled persons became subjects of human rights".

[5] T. Degener, M. Gómez-Carrillo De Castro, *Disability Law and Human Rights*, F. Felder, L. Davy, R. Kayess (eds.), *Palgrave Studies in Disability and International Development,* Palgrave Macmillan, Cham, 2022, p. 32.

[6] M. Leonardi, J.L. Ayuso-Mateos, J. Hollenweger, A. Pessina, J.E. Bickenbach, *Multidisciplinary Research and Training Network on Health and Disability in Europe: The MURINET Project*, American Journal of Physical Medicine & Rehabilitation 91(13) 2012, pp. S1-S4. In fact, the Convention has also changed the language, and the preferred expression is person with disabilities rather than disabled person.

[7] The comments on this new understanding of disability are uncountable. Out of many, see E. Colombetti, *La dipendenza condivisa*, MEDIC – Metodologia didattica e innovazione clinica, (21) 2013, p. 24, stressing that both the biophysical and the social conditions are to be considered in their reciprocal relations.

[8] The notion of disability has been enriched since the first decision of the CJEU, Grand Chamber, 11 July 2006, case C-13/05, Chacón Navas v. Eurest Colectividades SA. A broader approach to disability was taken by the Court of Justice of the EU, Second Chamber, decision 11 April 2013, Joined Cases C-335/11 and C-337/11 HK v. Danmark: "Following the ratification by the European Union of the United Nations

On the one hand, the UNCRPD has broadened the notion of disability, the borders of which are yet to be defined (see par. 2); on the other hand, the new understanding of disability imposes new positive obligations to remove or reduce barriers to give value to all the residual resources and capabilities of the persons with disabilities in order to support their full participation and inclusion in social life. This evolution generated a development of new legal instruments, the most relevant of which is the *reasonable accommodation* and policies of *support*, which will be explored in the following pages. All in all, the new understanding of disability has, over time, revealed that a comprehensive approach to disability entails not only a number of individual rights, but also a good set of human and social relations.

2. On the borders of disability: infertility, obesity, drug and alcohol addiction

Notwithstanding the general consensus reached on the notion of disability as defined by the UN Convention, the external borders of the new understanding of disability are not always clear and some disputed areas are emerging, among which: infertility, obesity and – most relevant – drug and alcohol addiction.

On *infertility*, the Court of Justice of the EU excluded the applicability of the labor law legislation on disability rights in the Irish case *Z v. A Government department* (2014).[9] The case concerned a woman who was without uterus and who wanted to have a baby through a surrogacy arrangement.

Convention on the Rights of Persons with Disabilities [...] the Court held that the concept of 'disability' must be understood as referring to a limitation which results in particular from long-term physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers. [...] That concept of 'disability' must be understood as referring not only to the impossibility of exercising a professional activity, but also to a hindrance to the exercise of such an activity. Any other interpretation would be incompatible with the objective of that directive, which aims in particular to enable a person with a disability to have access to or participate in employment". This definition has been followed by the Court of Justice ever since. See, for example, decision 4 July 2013, case C-312/11, European Commission v. Italian Republic; 22 May 2014, case C-356/12, Wolfgang Glatzel v. Freistaat Bayern; decision 1 December 2016, C-395/15, Mohamed Daouidi v. Bootes Plus SL and Others; 9 March 2017, case C-406/15, Petya Milkova v. Izpalnitelen direktor na Agentsiata za privatizatsia i sledprivatizatsionen control, among many others.

[9] CJEU, 18 March 2014, case C-363/12, Z v. A Government department, The Board of management of a community school (Grand Chamber).

She applied for leave equivalent to maternity or adoption leave. The Irish Government department and the Board of management of a community school refused to grant Ms. Z. paid leave equivalent to maternity leave or adoptive leave following the birth of that child. The Court noted that her inability to have a child by conventional means did not prevent her from having access to, participating in, or advancing in employment. Consequently, it held that her condition did not constitute a disability within the meaning of the EU legislation and concluded that "the refusal to provide paid leave equivalent to maternity leave or adoptive leave to a female worker who is unable to bear a child and who has availed of a surrogacy arrangement does not constitute discrimination on the ground of disability".

Less sharp was the position of the Court concerning *obesity*. In fact, in *Kaltoft v. Kommunernes Landsforening (KL)* (2014)[10] the Court considered that, whereas obesity as such cannot be considered as a form of disability, yet, under certain conditions – such as when obesity results in reduced mobility or medical conditions that hinder a person's ability to work or cause discomfort during professional activities – it can be recognized as a form of disability.

It is worth noting that this case gave the opportunity to the Advocate General to express his opinion about the possibility to extend the definition of disability also to cases of alcohol or drugs assumption, about which he concluded that "in medical terms, alcoholism and addiction to psychotropic substances are diseases. This does not, however, mean that an employer would be required to tolerate an employee's breach of his contractual obligations by reference to these diseases".[11]

Around drug addiction as a form of disability, the debate is open and it involves scholars and Courts, with different, and even opposite conclusions.[12]

For example, Canada has been one of the first countries to explicitly include drugs and alcohol addiction into the definition of disability contained in the section 25 of the Canadian Human Rights Act (1985).[13] Similarly, in

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[10] CJEU, Case C-354/13, Kaltoft V Municipality of Billund, Judgement of the Court (Grand Chamber), 16 December 2014. See CJEU, Case C-354/13, FOA v. Kommunernes Landsforening, 18 December 2014, in particular para. 53-64.

[11] Case C-354/13, Kaltoft, cit., Opinion of the Advocate General, para. 59-60.

[12] R. Lines, J. Hannah, G. Girelli, '*Treatment in Liberty*' *Human Rights and Compulsory Detention for Drug Use*, Human Rights Law Review, Vol. 22, Iss. 1, March 2022, p. 12. Particularly relevant are also the reflections presented by S. Flacks, *Deviant Disabilities: The Exclusion of Drug and Alcohol Addiction from the Equality Act 2010*, Social & Legal Studies, 21(3), 2012, pp. 395-412.

[13] Section 25 of Canadian Human Rights Act "disability means any previous or ex-

Australia some labor judgements considered that the condition of a former heroin addict, who has been on methadone since many years falls under the definition of disability.[14]

On the opposite, the UK does not include drug and alcohol addiction within the definition of disability with the consequence that, in case of disclosure of an addiction in the hiring process, potential employees have no protection under the UK Equality Act (2010).[15]

The notion of disability has been stretched and has reached some very sensitive limits, where the consensus among the different jurisdictions is yet to be found. All these problems under discussion are indeed very relevant from the social point of view. The problem with obesity, drugs, alcohol, gambling and other forms of addictions is where to draw a distinction between cases where medical evidence proves that the mentioned conditions are beyond the individual control, from cases that results from voluntary behavior and are due to lifestyle choice. In some countries,[16] this distinction is relevant to decide whether the case is covered by the disability legislation.

3. Reasonable accommodation and policies of support

The UN Convention's perspective on disability has fueled a new search for more appropriate legal instruments, capable of respecting and promoting a culture of human dignity of people with disabilities. Indeed, law alone cannot do all that is necessary to create empathic and supportive living conditions for persons with disabilities. Social norms and widespread cultural attitudes are crucial for their effective respect and care. Yet, law can influence the broader context, and an inadequate legal approach can do wrong and perpetuate a biased and hostile society to disability. So, without over-emphasizing the role of law in addressing issues related to disability, it is relevant to discuss the suitability of the available legal instruments.

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isting mental or physical disability and includes disfigurement and previous or existing dependence on alcohol or a drug".

[14] Federal Court of Australia Case, Marsden v HREOC & Coffs Harbour & District Ex-Servicemen & Women's Memorial Club Ltd, 2000, 1619.

[15] This topic is debated for example in S. Flacks, *Deviant Disabilities: The Exclusion of Drug and Alcohol Addiction from the Equality Act 2010*, cit., p. 399.

[16] See for example BCCA Case, Ontario (Human Rights Comm.) v. Vogue Shoes, 1991 CanLII 13168 (ON HRT), available at https://canlii.ca/t/gdb89, and BCCA Case Kemess Mines Ltd. v. International Union of Operating Engineers, Local 115, 2006, 58 (CanLII), available at https://canlii.ca/t/1mkk1

One of the most innovative tools introduced by the UN Convention is *reasonable accommodation*, which over time has become a cornerstone in legislation pertaining to individuals with disabilities. This instrument has proved to be one of the most effective as well as one of the most flexible and suitable to improve the inclusion and full participation of persons with disabilities in social life. In fact, the UN Convention requires much more than refraining from open, direct discrimination against people with disabilities. Nor are the traditional economic benefits, social services or medical treatment usually provided by the legislation on this matter sufficient. The effort required by the Convention is *to remove* as much as possible *the factual barriers* that in the "standard" daily life in fact hinder the participation of the person with disability in social life. Accommodating the conditions of life in order to remove or to reduce impediments for people with disabilities is at the heart of this innovative legal instrument.

Reasonable accommodation has been successfully experimented in cases of physical disability, but the same rationale can lead to similar approaches for accommodating the needs of mentally disabled people.

The reasonable accommodation method echoes one of the most important provisions of the Italian Constitution (1948). In fact, art. 3, second paragraph, reads: "It is the duty of the Republic *to remove those obstacles* of an economic or social nature which constrain the freedom and equality of citizens, thereby impeding the full development of the human person and [her] *effective participation* [...] in the political, economic and social life". Indeed, this provision was written long before the UN Convention, and it is not specifically targeted towards persons with disabilities. Rather it has a broader and more general scope. Its rationale is to address all conditions of social and economic disadvantage suffered by any vulnerable group or individual, in a very concrete and proactive manner. It is worth underscoring that this provision calls for a collective effort, engaging the entirety of the Republic in its multiple articulations, including institutions and civil society, to take responsibility to support disadvantaged persons in order to enhance the quality of social life for all. The Italian Constitution does not explicitly employ the term *reasonable accommodation*, but it does lay the groundwork for extensive utilization of positive measures to achieve substantive equality. In essence, reasonable accommodation finds its roots in a substantive interpretation of the principle of equality, requiring not only to refrain from direct or indirect discrimination, but also to take positive action to level the ground for people with any kind of impairment.

From a historical point of view, as previously mentioned, reasonable accommodation originated in Canadian antidiscrimination law. It requires employers, landlords, public and private service providers to accommodate the needs of individuals, in order to ensure that they can enjoy equal opportunities in social life. This could mean, for example, permitting an employee not to work on a religious holiday or creating an appropriate workplace for a person with a physical disability. In Canada, reasonable accommodation applies to all forms of discriminations, such as those based on sex, gender, ethnic origin, color, age religion, etc., and, indeed, disability. It is widely applied in labor law, but has a lager scope of application.

The leading cases in the Supreme Court jurisprudence are *Meiorin*[17] and *Grismer*.[18] In the first case, the Supreme Court ruled that the physical fitness standards imposed in British Columbia for some jobs were discriminatory against individuals with disabilities, as they were not reasonably necessary for the job in question and did not accommodate the needs of employees with disabilities. In Grismer, the compliant had suffered a stroke and was in a condition that impaired his peripherical vision. His driver's license was cancelled because he was no longer meeting the prescribed minimum field of vision of 120 degrees. The Canadian Supreme Court ruled that the 120-degree vision standard was not reasonably necessary in all situations and prescribed that an accommodation was to be found.

According to this jurisprudence, in Canada employers are required to make every reasonable effort to accommodate an employee with disabilities. This responsibility to "accommodate" requires the employer to look at all other reasonable alternatives. The employer must try to accommodate up to the point of "undue hardship". To prove that his or her accommodation efforts were serious and conscientious, an employer is required to engage in a four-step process: "(i) Determine if the employee can perform his or her existing job as it is. (ii) If the employee cannot, then determine if he or she can perform his or her existing job in a modified or 're-bundled' form. (iii) If the employee cannot, then determine if he or she can perform another job in its existing form. (iv) If the employee cannot, then determine if he or she can perform another job in a modified or 're-bundled' form.

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[17] SCC Case, British Columbia (Public Service Employee Relations Commission) v. BCGSEU, 1999 CanLII 652, [1999], 3 S.C.R. 3, available at https://canlii.ca/t/1fqk1

[18] SCC Case British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights), 1999 CanLII 646, [1999], 3 S.C.R. 868, available at https://canlii.ca/t/1fql1

The limit is a disproportionate or undue burden implying excessive economic or organizational or safety costs. If the accommodation requires an overburden on one part, it cannot be requested".[19]

Eventually, reasonable accommodation became very influential in American law with the American with Disabilities Act (ADA) of 1990. Not surprisingly, then, at the time of the negotiations of the UNCPRD, reasonable accommodation was at the center of the legal framework. According to the definitions provided by the UN Convention, art. 2: "'Reasonable accommodation' means necessary and appropriate modification and adjustments [of the environment] not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

A similar definition is provided by EU Directive 78/2000/CE, art. 5 *Reasonable accommodation for disabled persons*: "In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned".

4. Elements for a theory of *reasonable accommodation*

There are some features of the model of reasonable accommodation that are worth underscoring.

First, the duty to accommodate is an obligation for *public as well as private actors*: reasonable accommodation is widely applied in labor law, so that the duty to accommodate falls, first of all, on employers; yet the same duty obligates local and national institutions, schools and other educational facilities, sport facilities, movie theaters, commercial activities, music institutions, prisons and any other social infrastructure. Removing barriers is a collective community effort, involving public institutions as well as private

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[19] For a clear and comprehensive overview of the Canadian system see M. Lynk, *Disability and Work: The Transformation of the Legal Status of Employees with Disabilities in Canada* (December 2007). Available at SSRN: https://ssrn.com/abstract=1068403 or http://dx.doi.org/10.2139/ssrn.1068403

economic and social actors. For example, in the *Cam v. Turkey* case (2016),[20] the European Court of Human Rights (ECtHR) addressed the refusal to enroll the applicant as a student at the Turkish *National Music Academy* because she was blind. The applicant was completely qualified for admission to the academy, and the refusal had been based solely on her disability. Therefore, the Court considered that the failure to provide reasonable accommodation to facilitate access for persons with disabilities to education constitutes a form of discrimination on grounds of disability.[21]

Many cases decided by the ECtHR concern people with disabilities *in prison*. Just to provide one example out of many, consider the case of *Grimailovs v. Latvia* (2013)[22] where the Court found that the absence of independent access to prison facilities for the *paraplegic prisoner*, along with the lack of organized assistance regarding his mobility and daily routine, amounted to degrading treatment. The reasoning of the Court relied on the duty to find a *reasonable accommodation,* as required by the UNCRPD, and considered that the failure of looking for a reasonable accommodation amounted to a violation of the European Convention. Incidentally, we can note that the imprisonment of persons with disabilities is increasingly contentious, raising the question of whether it is at all possible to accommodate the needs of people with disabilities, especially mental disabilities, in a jail setting.[23]

These are just a couple of examples, among many, to have a sense of the broad scope of reasonable accommodation and the number of subjects addressed by the duty to accommodate.

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[20] ECtHR Case Cam v. Turkey, application no. 51500/08, 23 February 2016.

[21] The case-law of European court of human rights considers that the violation of the duty to accommodate amount to a discrimination on the grounds of disability. See for another example ECtHR Case Horovath and Kiss v. Hungary, application no. 11146/11, 29 January 2013.

[22] ECtHR Case of Grimailovs v. Latvia (Application no. 6087/03), 25 June 2013. Similar cases are the ECtHR Case Asalya v. Turkey (Application no. 43875/09), 15 April 2014; ECtHR Case Butrin v. Russia (Application no. 16179/14), 22 March 2016.

[23] With the growing number of cases brought in front of the European Court of Human Rights, claiming multiple violations of the European Convention, the question arises regarding the compatibility of the practice of sentencing people with physical or mental disability to imprisonment in jail. See for example ECtHR, First Section, Sy v. Italy (application 11791/20), 24 January 2022, finding a violation of art. 3 of the Convention (Prohibition of inhuman and degrading treatment) for the imprisonment in jail of a person with bipolar syndrome, without appropriate medical treatment.

Second, as illustrated by the cases mentioned above, the unjustified refusal to provide accommodation is considered a form of discrimination or even a more severe violation of human rights. The UN Convention expressly provides in this sense (see art. 2 and art. 5) and the jurisprudence of the European courts consistently applies this principle.

A good example is the case of the CJEU, *European Commission v. Italian Republic*.[24] The Commission considered that the Italian system of promoting the employment integration of disabled people was essentially based on a set of incentives, facilitations and initiatives by the public authorities. This was not enough because the Italian legislation does not require the employers to look for reasonable accommodations for people with disabilities: "By failing to require all employers to provide, in accordance with the needs of the specific situations, reasonable accommodation applicable to all disabled persons, the Italian Republic has failed to fulfil its obligation to transpose correctly and completely Article 5 of Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation".

In the same vein, the ECtHR considers that the failure to require reasonable accommodation amounts to a violation of the principle of non-discrimination and other human rights.

Just to add an example, in *Guberina v. Croatia* (2016),[25] the applicant had requested a tax exemption on the purchase of a new property adapted to the needs of his severely disabled child. The authorities did not take into consideration his son's particular needs and found that the applicant was not entitled to the tax exemption because they already had a suitable place to live. The ECtHR stressed that principles of reasonable accommodation, accessibility and non-discrimination against persons with disabilities required to consider the specific needs of the applicant's family related to his child's disability. Ignoring these specific needs amounted to a violation of human rights and non-discrimination.

Third, one of the distinctive features of reasonable accommodation is that it *triggers a process* of dialogue between the parties involved, rather than prescribing an outcome predetermined by the law. The results of the process can vary case by case: sometimes it can achieve the expected results, in other cases the request proves to be impossible or overburdening. The result

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[24] CJEU Case C-312/11, European Commission v. Italian Republic, 4 July 2013.

[25] ECtHR, Case Guberina v. Croatia (application 23682/13), 22 March 2016.

of a reasonable accommodation cannot be pre-established by law. The law is prescriptive in that it mandates to start a process and sets some essential rules of the game: but the solution is to be found in dialogue with all the parties involved. What is relevant is that "it calls upon the parties involved to be creative and sincere in negotiating and finding solutions".[26] In a word, the obligation does not entail to reach a specific result, but it does entail to make a genuine effort.[27] This is an interesting aspect of this legal instrument, *because reasonable accommodation urges the parties to engage in a relationship*: the duty holder and the individual seeking an accommodation are expected to work together, to develop a mutual understanding of the reciprocal needs and constraints and to get to a solution that can be reasonable for all the parties. When an accommodation is offered and it is reasonable, the individual cannot reject that offer in search of a better solution. The duty to accommodate is not about finding the best possible accommodation, but about finding an accommodation, reasonable for all the parties involved. The reasonable accommodation reflects an idea of legislation that not only provides rules, rights, obligations and sanctions but takes care of personal *relations* and put them at the center. It is based on a paradigm of *trust*[28] in social relations, rather than distrust and coercion.

Fourth, the goal of providing accommodation is usually achieved through practical adjustments to material conditions, such as removing architectural barriers and reducing workload or working hours. Yet, in some cases, providing accommodation requires implementing a *policy of support*, especially for individuals with mental disability. Paradoxically, the individual autonomy and independence of persons with disabilities, which is one of the main goals of the UNCRPD (see for example art. 3, 12 and 19) often requires personal support. Make no mistake: a *policy of support* should not be confused with the old-fashioned, paternalistic approach based on a paradigm of *substitution*. Support does not mean substitution: "the support paradigm is a system in which people work together to understand an individual's desires and choices and then provide the means for that person to exercise legal

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[26] R. Mason, J. Nicol, J. Walker, *An Examination of the Duty to Accommodate in the Canadian Human Rights Context*, Library of the Parliament, 2012-01-E, 1 December 2020, p. 3.

[27] Italian Civil Law provides for this purpose a useful distinction between *obbligazioni di mezzo* and *obbligazioni di risultato*.

[28] T. Greco, *La legge della fiducia. Alle radici del diritto*, Laterza, Roma, 2021.

capacity and live life the way they choose as opposed to a way imposed by someone else's decision".[29]

A couple of examples taken from the Italian legal system may serve as a good exemplification of this understanding of *autonomy with support,* but similar approaches are developing everywhere under the influence of the UNCRPD.

In Italian schools, students with disabilities or other specific needs are indeed located in schools with all the other students, but they are supported by a tutor, called "insegnante di sostegno", a support teacher whose mission is to assist these students in participating in classes alongside their peers. Out of a total number of 950,000 teachers in Italy, 200,000 serve as support teachers, catering to around 300,000 students with disabilities.[30] A good idea would be to replicate this in the field of employment: some persons with disabilities might need a tutor in order to discharge their duties at work.

This support-based model is mirrored in law n. 6 of 2004, which introduces an "amministratore di sostegno", typically a family member, or a friend, designated by the interested person, tasked with the responsibility of acting as a caregiver, or support administrator, for the elderly and the disabled.[31] These support figures can also be appointed to assist for temporary difficulties. Their role and competence are defined on a case-by-case basis, under the supervision of a judge. This institution is tailored on the specif-

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[29] A. Arstein-Kerslake, *Legal Capacity and Gender*, Springer Switzerland AG, Cham, 2021, pp. 17-18.

[30] A. Gavosto, *La scuola bloccata,* Laterza, Roma, 2022, p. 9.

[31] This model is also consistent with the Art. 12 of the UNCRPD interpretation proposed by the UNCRPD Committee. Indeed, it has been observed by S.J. Hoffman, L. Sritharan and A. Tejpar, *Is the UN Convention on the Rights of Persons with Disabilities Impacting Mental Health Laws and Policies in High-Income Countries? A Case Study of Implementation in Canada*, BMC International Health and Human Rights, Nov 11;16(1):28, 2016, p. 8, that the CRPD Committee "takes the position that this Article on legal capacity allows only supported decision-making for persons with disabilities. The Committee explains that guardianship and all other substitute decision-making regimes are inconsistent with the CRPD's goal of achieving autonomy and equality for persons with disabilities. Substitute decision-making, which is the prevalent regime worldwide, is a process by which a guardian or representative makes decisions for persons with disabilities deemed to lack capacity, often without a requirement to obtain their consent. In contrast, supported decision-making uses a persons' network of 'friends, family, or other allies' to help the affected person make decisions by assuming capacity and assessing their communications. If this communication is inconclusive, the regime relies on the persons' 'previously expressed wishes, abiding values, and experience in similar situations' to help make decisions".

ic situation:[32] their presence alongside the person in need preserves their remaining capacity to make their own choices, empowering the disabled person to be the protagonist of their own life.[33]

These examples serve as compelling illustrations of a pragmatic approach to respect the independence and autonomy of people with disabilities: autonomy is not equated to complete self-sufficiency; it often necessitates support or stewardship without crossing the line into substitution. The support paradigm fosters social solidarity without sacrificing the recognition of the dignity and the capacities. It removes the illusion of self-sufficiency and opens the door for a societal dialogue about the inter-independence of all persons.

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[32] This Italian and, generally, some European systems, have been endorsed by many international scholars such as M. Nussbaum and C. Faralli, *On the New Frontiers of Justice. A Dialogue*, Ratio Juris, Vol. 20, no. 2 June 2007, p. 159, who observed that "Europe, similarly, has made progress (...) and I argue that some of the European approaches to the crucial issue of legal guardianship are superior to U.S.A. approaches, because we need flexible and multi-valent types of guardianship, not an all-or-nothing declaration of competency or noncompetency".

[33] On the rationale of the "amministratore di sostegno" see the Italian Constitutional Court, Judgement n. 114/2019, 7 March 2019, concerning the case of an elderly woman whose desire was to donate 10,000 euros to one of her children. The Civil Code prevented the incapacitated person from making donations. It was indeed an old rule on incapacity, with the *ratio* of protecting vulnerable persons against frauds. The Court decided that, with the help of this "amministratore di sostegno", the elderly woman should be allowed to make the donation to her child, affirming that "by introducing the support administration, the legislature has endowed the legal system with a measure that can be shaped by the tutelary judge in relation to the personal status and life circumstances of each beneficiary and in view of the concrete and maximum development of his or her actual abilities. Thus, the legal system today shows greater sensitivity to the condition of persons with disabilities, is more attentive to their needs and at the same time more respectful of their autonomy and dignity than in the past, when the civil code limited itself to establishing a clear distinction between capable and incapacitated persons, linking rigid predetermined consequences to one or the other qualification. The new rules are fully in line with the most recent instruments developed in the European and international legal order: with the United Nations Convention on the Rights of Persons with Disabilities (...) and with the Charter of Rights of Persons with Disabilities, done in New York on 13 December 2006 (...), and with the Charter of Fundamental Rights of the European Union, proclaimed in Nice on 7 December 2000 and adapted in Strasbourg on 12 December 2007, Article 26 of which protects 'the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community'" (para. 4 of the "considerato in diritto").

Fifth, reasonable accommodation does not overlook the costs – of whatever nature – imposed on the duty holder. In fact, it imposes an obligation to accommodate, short of *undue hardship*. The accommodation required by the legislation is qualified as *reasonable,* because it takes into account the context and the constraints deriving from economic issues and social relations. Indeed, there is no standard definition of what amount is required to undue hardship, yet the case law – especially in Canada – has set out a number of factors that must be considered. They include the *financial costs* to an organization or to an individual, provided they reach a substantial amount; the *risks for health and safety* of the disabled person, of other fellow employees and the general public; and indeed, any other *conflicting right*. In this respect the keyword as in any other case of clashes of rights is proportionality.[34]

An example is provided by an Icelandic case decided by the ECtHR[35] concerning a person paralyzed from the chest down and who uses a wheelchair for mobility. The applicant complained about a lack of wheelchair access in two buildings housing arts and cultural centers run by his municipality. In this case, the Court was persuaded that the lack of access to the buildings in question did not amount to a discriminatory failure to accommodate the needs of the appellant. The Court notes, in this regard, that considerable efforts have been made by the municipality to improve accessibility to public buildings and buildings with public functions, *within the confines of the available budget and having regard to the cultural heritage protection of the buildings in question*. Therefore, the Court concludes that the applicant was not discriminated against.

The *sixth* feature of reasonable accommodation is that it always requires case-by-case solutions rather than general rules and general standards. Disabilities can hardly be approached with one size fits all measures. Persons with disabilities need tailored suits.

The reason is simple and yet often overlooked. In her eye-opening work, Matilde Leonardi says that disability is *a continuum*.[36] And in fact, the border between functionality and disability is blurred. All people can be located

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[34] The scholarship on proportionality as the common currency in human rights litigation is very broad. One book though towers over many others: A. Barak, *Proportionality: Constitutional Rights and their limitations*, CUP, Cambridge, 2012.

[35] ECtHR, Case Arnar Helgi Lárusson v. Iceland, application n. 23077/19, 31 May 2022.

[36] M. Leonardi, J.L. Ayuso-Mateos, J. Hollenweger, A. Pessina, J.E. Bickenbach, *Multidisciplinary Research and Training Network on Health and Disability in Europe: The MURINET Project*, cit.

along this *continuum* between very low and very severe disability, and this becomes all the more evident in the context of an aging population.[37] Furthermore, no single person with disability is similar to the next. Nor are the social conditions where she lives. That is why it has been said convincingly that "disability is not a social category: there are no such things as disabled people [...]. Rather, there are people with disabilities, i.e. children, men, women who, starting from a health problem and in relation to the environment have different degrees of functioning. In other words, disability is one of the possibilities of the human condition and not a characteristic of a few particular individuals recognizable, therefore, as a group".[38] Each person with a disability is unique, differing from the others, and has special needs as well as special capabilities. This is also the position of the Italian Constitutional Court in decision n. 80 of 2010: "People with disabilities do not constitute a homogeneous group. [...] For each of them, it is necessary to identify mechanisms for removing obstacles that take into account the specific type of impairment that a person is affected by in concrete terms".

This diversity poses a challenge for lawmakers, who are requested to craft appropriate legal measures for people with disabilities and to accommodate the requirements of persons with disabilities. In fact, law typically provides rules for a specific category of people, applying regulations to distinct groups such as "disabled" or "severely disabled" individuals, in contrast to those considered "functional". Yet, when we deal with people with disabilities there are no clear borders between different groups of people, and consequently rules are difficult to design and to apply.

Disability calls for a new approach to legislation. Flexibility is a crucial attribute of rules aimed at addressing disability issues effectively. This entails crafting regulations that are flexible enough to accommodate the unique circumstances of each individual case. Without such flexibility and adaptability regulation, instead of supporting social transformation, becomes a bureaucratic cage.

In recent legislation and case law of different jurisdictions a number of examples can be found in support of this legislative approach that gives room to individual and tailored answers in contrast with standard solutions. For example, in the case law of the European Court of Human Rights this approach is commonly referred to as "gradation of state measures for disa-

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[37] See chapter written by Ana Marta González in this volume, p. 208.

[38] E. Colombetti, *La dipendenza condivisa,* cit., pp. 25, 27.

bled people". Take the case *Alajos Kiss v. Hungary* (2010),[39] where the ECtHR clearly affirmed that a State that takes away the right to vote of any person with disability under partial guardianship, irrespective of his or her actual faculties, is in violation of the European Convention of Human Rights. The applicant was a Hungarian national with a psychiatric condition, who was placed under partial guardianship. As a consequence, he had been omitted from the electoral register. The Court considered that treating persons with mental abilities as a single group was a questionable classification. And concluded that the European Court could "not accept an absolute bar on voting rights applied to any person under partial guardianship irrespective of his or her actual faculties".[40]

This personal or case by case approach is necessary if we want to give value to all the residual capabilities of the person with disability. It requires to shift the focus from the weaknesses to the capabilities, the skills, the talents of the person with disability.

5. Conclusion: for a relational approach to disability

The previous overview on the law on disability shows that relations are relevant for an effective approach to disability. Current sociological research focuses on the contextual and relational dimension of the experience of disability: on the one hand, recent studies demonstrate that "we cannot fully understand disability without knowing about the context that is disabling" and consequently advocate the necessity to address the relational and structural context – starting from the family – in order to mitigate the

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[39] ECtHR, Case Alajos Kiss v. Hungary (application no. 38832/06), 20 May 2010. On this judgement see L. Peroni and A. Timmer, *Vulnerable groups: The Promise of an Emerging Concept in European Human Rights Convention Law*, International Journal of Constitutional Law, Vol. 11, Iss. 4 October 2013, pp. 1066-1067, who observed that the ECHR was taking "the first steps towards embracing a 'social model' of disability: this way of framing disability recognizes the built environment and society's negative attitude towards people with impairment as the main factors disabling and excluding people. Contrary to the 'medical model' of disability, the hallmark of a social approach to disability emphasizes social prejudices and stereotypes, rather than individual impairments". Similarly, in ECtHR, Fourth Section, Case Anatoly Marinov v. Bulgaria (application no. 26081/17), 15 February 2022, the European Court of Human Rights considered that the indiscriminate removal of voting rights without an individualized judicial evaluation, solely on the grounds of mental disability necessitating partial guardianship, could not be considered to be proportionate to the legitimate aim for restricting the right to vote.

[40] ECtHR, Case Alajos Kiss v. Hungary (application no. 38832/06), 20 May 2010*, quoted,* para. 42.

disadvantage associated with disability and to support any special need connected with disability.[41] On the other hand, they draw attention to the fact that "disability not only impacts the lives of those who are directly affected, but it also has important spillover effects on family members".[42] This is evident in children with disabilities, but also at any other stage of life, with a growing number of elderly individuals with disabilities.

To elaborate deeper in the relational dimension of disability, four different aspects can be unpacked.

Firstly, disability impacts not only the lives of the individuals but also those of the people surrounding them: parents, siblings, schoolmates, and fellow workers. That is why, for example, labor law provides special benefits for parents of children with disabilities and, in general, the law provides benefits for the caregivers of persons with disabilities. To this purpose it is worth mentioning the *Coleman* decision of the Court of Justice of the EU (2008),[43] where the Court applied the labor legislation concerning the rights of disabled people to the mother of a disabled child.

Secondly, in most cases, families are the main caregivers of persons with disabilities, even when public institutions provide the necessary medical and social services to support their social life. This is reflected, for example, in the pragmatic approach taken by the Italian Constitutional Court in decision n. 203 of 2013, concerning the benefit of paid leave from work accorded to the caregivers: "the governing principle is that care for the disabled person within the family is preferable [...] and, more importantly, is most compliant with principles of constitutional law, irrespective of the age of the assisted person and whether or not he or she is a child". After all, the roles of families "remain fundamental in the provision of care and

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[41] M. Maroto and D. Pettinicchio, *Relational Inequality and the Structure that Disadvantage*, in *The Oxford Handbook of the Sociology of Disability*, R. Lewis Brown, M. Maroto and D. Pettinicchio (eds), OUP, Oxford, 2022, pp. 389-413.

[42] N. Balbo and D. Bolano, *Child disability as a family issue: a study on mothers' and fathers' health in Italy*, European Journal of Public Health, 2023, pp. 1-6.

[43] In this case, by way of example, examined by the Grand Chamber of the Court of Justice of the EU, it was clearly stated that "Where an employer treats an employee who is not himself disabled less favorably than another employee is, has been or would be treated in a comparable situation, and it is established that the less favorable treatment of that employee is based on the disability of his child, whose care is provided primarily by that employee, such treatment is contrary to the prohibition of direct discrimination laid down by Article 2(2)(a) [of the Council Directive 2000/78/]". CJEU, Grand Chamber, Case C-303/06, S. Coleman v Attridge Law and Steve Law (Grand Chamber), 17 July 2008.

assistance to the disabled". For similar reasons, the same Court a few years later (decision n. 18 of 2020) extended the possibility of serving a sentence of detention at home rather than in jail for mothers of children with disabilities, regardless of the age of the child.

Thirdly, the aim of the most recent legislation – beginning with the UN Convention – is to advance toward the *full and effective participation and inclusion* of persons with disabilities in every aspect of social life, i.e. *improving their relational life*: from education and sports to employment and cultural activities. The quality of the relations that a person with disabilities is able to cultivate can make the difference, as the same person may have entirely different experiences in varying relational contexts. To put it bluntly: inclusion and participation is a matter of relations.

Fourthly, the cornerstone of disability legislation, as we have seen, is *reasonable accommodation*, which implies a relational approach, rather than a rules-based one. When the law requires the duty-bearer to provide a reasonable accommodation, it is not imposing a specific rule or solution: it rather calls for starting a dialogical process between the duty-bearer and the person with disabilities, a process that involves all interested parties, with the aim of finding a solution that is sustainable and acceptable to everyone. In many cases, a reasonable accommodation can be attained through a *policy of support*. All in all, reasonable accommodation is based on a *duty of solidarity* or on a *shared responsibility* of all social actors. Again, it is a matter of relations. It has a horizontal dimension as well as a vertical one. The genuine inclusion of persons with disabilities is the result of a collective effort. It is not merely a matter of welfare benefits delivered by states and other public institutions, but the result of a shared responsibility among all social and economic actors, including individuals and social groups, and companies. This common effort also includes the persons concerned, who should not be considered merely as recipients or beneficiaries of paternalistic measures but full protagonists of the decisions to be taken.

The experience of life of people with disabilities calls for a relational approach[44] in which, indeed, nothing should be done for them without them – as the UN Convention requires – while also avoiding the mistake of confusing dignity, autonomy and independence with solitude or abandonment.

"Relationships are central to people's lives – to who we are, to the capacities we are able to develop, to what we value, what we suffer, and what

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[44] See chapter written by Pierpaolo Donati in this volume, p. 315.

we enjoy": these are the opening words of the seminal and visionary book by Jennifer Nedelsky, *Law's Relations*,[45] where she outlines *a relational theory of self, autonomy and law,* as the subtitle of the book explains. She advocates for a paradigm shift in the common understanding of social life and in the legal infrastructures, aiming to move "relationship from the periphery to the center of legal and political thought and practice".[46]

Personal and institutional relations have been underestimated in the legal theory and practice on many respects.[47] Our legal culture would gain a lot from a reasoning that put relations at the center. Prioritizing relationships would be beneficial in many domains; yet, if there is an area where the focus on relations is urgent and imperative, this is the field of disability.

Here is a cultural challenge for the years to come.

The individualistic culture based on individual rights has made an invaluable contribution and is to be cherished for unveiling the humiliating effect of adopting a paternalistic attitude towards persons with disabilities, treating them as an object of pity or, at the very best, of care. The human dignity of every human being is to be firmly maintained at the center.

Yet, in some legal discourse, human dignity has been reduced to concepts such as independence, self-determination, freedom of choice. The condition of disability reveals that the two sets of concepts do not overlap.

Consider the growing number of cases decided by the ECtHR concerning persons with mental disabilities that committed suicide under custodial conditions. In these cases, the Court was asked to strike a balance between the respect of the autonomy of the patient, with the duty to protect the patient and the community.[48] This difficult balance between competing val-

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[45] J. Nedelsky, *Law's Relations: A relational theory of Self, Autonomy and Law*, OUP, Oxford, 2012, p. 3.

[46] *Ibidem*. Nedelsky is not alone: her aspiration is also the aspiration of many critics of the American liberalism, of some of the feminist scholarship, and of the egalitarian liberals. She builds her powerful thinking on the work of Alasdair McIntyre, Feder Kittay, Martha Nussbaum and many others. Interestingly enough the relational dimension is also at the center of the most recent book by B. Ackerman, *The Postmodern Predicament,* Yale University Press, New Haven, 2024, where he considers the conflicts between sphere-mates as a part of the contemporary condition, that shapes our personal lives and also impacts on the political dimension.

[47] Also, in institutional design. On this point see A. Kavenagh, *The Collaborative Constitution*, Cambridge University Press, Cambridge, 2023.

[48] Some scholars have raised radical concerns about the culture of individual rights and some conditions of mental disability. See, among others, M.C. Freeman, K. Kolappa, J.M.

ues is well represented in an important and recent case of the ECtHR, *Fernandes de Oliveira v Portugal* (2019).[49] In this case, the applicant complained under Article 2 of the Convention that her son had been able to commit suicide as a result of the negligence of the psychiatric hospital where he had been hospitalized on a voluntary basis. It particularly concerned the State's obligations in terms of protecting the lives of people in psychiatric institutions. By a majority, the Grand Chamber found no violation of the State's obligation to protect the life of the patient. The Court did not find the violation because, according to the judges, today's paradigm in mental health care is to give persons with mental disabilities the greatest possible personal freedom in order to facilitate their re-integration into society. The Court considered that it is not only permissible but also desirable to grant hospitalised persons the maximum freedom of movement, in order to preserve as much as possible their dignity and their right to self-determination and individual autonomy. Yet, some of the judges expressed their (partial) dissent from the reasoning of the majority of the Court targeting the fact that emphasizing the liberty and autonomy of persons without addressing their extreme vulnerability may result in the person's death and even in the reoccurrence of similar events.[50] In a similar precedent case, *Hiller v. Austria* case,[51] Judge Andras Sajo – one of the most respected voices of the liberal culture of individual rights – dissented and he clearly wrote, in his concurring opinion: "I beg to differ: precaution is not paternalism".

De Almeida, A. Kleinman, N. Makhashvili, S. Phakathi, B. Saraceno, G. Thornicroft*, Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities*, Lancet Psychiatry, 2015, p. 845 who affirmed that "A universal presumption of legal capacity and the primacy of supported decision-making therefore cannot be absolute and exceptions have to be considered. This must apply to both physical and mental health. In our view, excluding any exemption to the presumption of legal capacity due to mental impairment, and as a result not allowing a person with severe mental illness or other impairment to have their circumstance treated as exceptional, might in fact violate his or her rights, and in some circumstances could result in harm to self or to others"; S. Wildeman, Protecting Rights and Building Capacities: Challenges to Global Mental Health Policy in Light of the Convention on the Rights of Persons with Disabilities, *J Law Med Ethics*, 41:1, 2013, pp. 48-73.

[49] ECtHR, Case Fernandes de Oliveira v. Portugal (Application no. 78103/14), 31 January 2019.

[50] E. Celik, *Exploring the use of the concept of human dignity in disability Human Rights law: from the CRPD to ECtHR*, cit., p. 47.

[51] ECtHR, Case Hiller v. Austria (Application n. 1967/14), 22 November 2016.

There is a lesson to be learned from these tragic cases, and in general from the living experience of people with disabilities. The focus on the individual rights and the autonomy of people with disabilities should not come at the price of overlooking the concrete conditions of the person with disabilities. It is a matter of realism: *living independently* for people with disabilities cannot be interpreted as living on their own.[52] In reality, no one in contemporary society is completely independent: as a matter of fact, we all live in a state of mutual interdependence.[53]

A *realistic* and *experiential* understanding of the human condition – with or without disability – is effectively captured by the idea of *inter-independence*, rather than independence, recently elaborated by Chiara Giaccardi and Mauro Magatti,[54] whose thinking does not artificially separate the claim for autonomy and freedom from the craving for connections and relationships that are interwoven into the fabric of every human experience. This correction of some hyperbolic versions of the hyper-individualistic culture, based on an abstract claim of self-determination and free choice, is relevant not only for persons with disabilities, but for all. When Jennifer Nedelsky, along with many others,[55] elaborates a critique of the American liberal version of individual rights, she provides an invaluable contribution not only for a better legislation on disability, but more generally for a more comprehensive understanding of the *Rights Talk* – to recall the title of an evergreen book by Mary Ann Glendon.[56]

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[52] G. Palmisano, *Comment to Article 19 [Living independently and Being Included in the Community]*, in V. Della Fina et al. (eds), *The United Nations Convention of the Rights of Persons with Disabilities*, cit. p. 359.

[53] M. Oliver, *Disability and dependency: a creation of industrial societies*, in: Barton L. (ed), *Disability and dependency*, Routledge, London, 2005, pp. 6-22.

[54] C. Giaccardi, M. Magatti, *Supersocietà. Ha ancora senso scommettere sulla libertà?*, Il Mulino, Bologna 2023, Iid., *Generare libertà. Accrescere la vita senza distruggere il mondo*, Il Mulino, Bologna 2024.

[55] One voice, out of many: M. Sandel, *Liberalism and its critics*, New York University Press, New York, 1984.

[56] M.A. Glendon, *Rights Talk: The Impoverishment of Political Discourse*, Free Press, New York, 1991. In a more recent work M.A. Glendon writes: "Despite our attachment to the ideal of the free, self-determining individual, we humans are dependent social beings. We still begin our lives in the longest period of dependency of any mammal. Almost all of us spend much of our lives either as dependents, or caring for dependents, or financially responsible for dependents. [...] We should start from acceptance of this profound and unchangeable fact of life". Ead., *Discovering our dependence*, First Things, 2004, available at the following link: https://www.firstthings.com/article/2004/10/discovering-our-dependence

She moves from a double critique to both the liberal individualism and the communitarian thinking: "The problem with 'self-determination' (and many conceptions of autonomy that deny or ignore its relational nature) is that it presumes or implies that the nature of the 'selves' is entirely a matter of our choice. And, conversely, a common objection to 'communitarian' thought is that it overstates the constitutive nature of human embeddedness in community".[57] In her understanding of the human experience "the capacity for autonomy can only develop and thrive when fostered by constructive relationships, such as those with partners, teachers, friends, and agents of the State".[58]

This is a paradox of human experience: that autonomy requires good relations. Not only in the early stages of children's development, but in all ages and conditions of life.[59]

A more comprehensive and realistic approach to human experience – one that combines the self with the we – can help craft more appropriate legal instruments capable of preserving and giving value to all the capabilities of the human person, without overlooking or downplaying their fragilities and vulnerabilities.

I believe there is a valuable lesson to be learned from people with disabilities: as paradoxical as it may sound, to achieve autonomy, we must rely on others.

Persons with disabilities open the eyes of our culture that has insisted too much on one side of the human experience focusing only on independence and autonomy: as a matter of fact, *we are all dependent to a certain degree*. We all want autonomy, but this is not in contrast with our dependency from others: "the alternative in the relationship between the self and society is not the dualistic dependency/independence [...] Rather, human life is char-

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[57] J. Nedelsky, *Law's Relations,* cit., p. 167.

[58] *Ibidem*.

[59] Needless to say, Pope Francis, in his Message for the International Day of Persons with Disabilities of 2022, insists on this point: "How much would a better awareness of our need for one another help us to have less hostile relationships with those around us! And how much would the realization that entire peoples cannot save themselves prompt us to seek solutions to the senseless conflicts we are experiencing! (...) This magisterium of fragility is a charism by which you – dear sisters and brothers with disabilities – can enrich the Church. Your presence 'may help transform the actual situations in which we live, making them more human and more welcoming. Without vulnerability, without limits, without obstacles to overcome, there would be no true humanity'". Message of the Holy Father Francis for the International Day of Persons with Disabilities, 3 December 2022.

acterized by '*inter-independence*' [...]. In the framework of inter-independence – which is itself a paradoxical condition – being free does not mean having no ties. And freeing oneself does not mean dissolving the structural bond that ties us to what and who surrounds us: it means recognizing it and, if necessary, rearticulating it [...] Freedom – as an essential expression of human life – exists only as an open relation".[60]

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[60] C. Giaccardi, M. Magatti, *Supersocietà. Ha ancora senso scommettere sulla libertà*, cit., p. 174.

SESSION 2. DISABILITY, POVERTY AND INEQUALITIES: WHAT NEW POLICIES FOR ECONOMIC INCLUSION?

MULTIDIMENSIONAL POVERTY AND DISABILITY: ANALYSIS OF 52 COUNTRIES USING THE GLOBAL MPI

MONICA PINILLA-RONCANCIO[1], SABINA ALKIRE[2], GUSTAVO CEDEÑO-OCAMPO[3]

1. Introduction

People with disabilities account for 16 per cent of the global population (World Health Organization (WHO), 2022); it is expected that the prevalence of disability will increase over time, given the demographic changes that most countries are facing, and the prevalence is expected to be higher in Low and Middle-Income Countries (LMICs) where conflict, lack of access to health services and the limited provision of social protection and support services create that persons with health conditions face higher barriers to access health services, as well as education and employment (World Health Organization and The World Bank, 2011).

Although the number of studies analysing the levels of poverty and deprivation of persons with disabilities has increased in the last decade (Banks et al., 2017), there is limited evidence at the global level of the levels of monetary or multidimensional poverty among persons with disabilities.

The number of studies analysing multidimensional poverty for persons with disabilities in low-middle-income counties (LMICs) has increased in the last decade (Pinilla-Roncancio and Alkire, 2021; Pinilla-Roncancio et al., 2020a; Banks et al., 2017), especially after the Convention on the Rights of Persons with Disabilities (CRPDs) and the Agenda 2030. The foundational documents of both CRPDs and the Agenda 2030 mention the importance of having disaggregated data on disability, and flag the need to measure the levels of poverty of persons with disabilities. The CRPDs call for inclusion and guaranteeing the rights of persons with different disabilities in all areas of human life (United Nations, 2007). The Sustainable Development Goals Agenda (Agenda 2030) calls for recognising that groups in society are usually excluded and left behind (United Nations, 2015). There-

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fore, it becomes fundamental to design and implement actions to deliberately include vulnerable groups, including persons with disabilities. To do so, it is necessary to know not only whether persons with disabilities are poorer than others but also which deprivations they experience, indicator by indicator.

1.1 Why are persons with disabilities poor?

Persons with disabilities and their families face social and economic barriers to participating in society (World Health Organization and The World Bank, 2011; Mitra and Yap, 2021). In general, persons with disabilities around the globe have lower levels of education and lower participation in the labour market. They demand more health services but face higher costs and barriers to accessing healthcare when needed, and they usually present lower levels of social and political participation. In most LMICs, persons with disabilities are relatively invisible. A large number of countries do not mention persons with disabilities in their national policies aiming to guarantee access to basic services, or persons with disabilities who do have access face barriers that limit their enjoyment of services and the fulfilment of their capabilities.

From a capability approach, persons with disabilities face an earning and a conversion handicap. Indeed, persons with disabilities are more likely to earn less income (earning handicap) as a result of their lower levels of education and the social exclusion they face. In addition, persons with disabilities need to consume disability-specific items; thus, their consumption of other items which might increase their well-being is limited (conversion handicap) (Sen, 2009). Both types of handicaps are related to the extra costs associated with living with a disability. On the one hand, persons with disabilities face higher barriers to participate in the labour market. Therefore, the average household income is expected to be lower than that of households without members with disabilities of similar characteristics. On the other hand, persons with disabilities and their households need to cover the extra costs associated with disabilities, which directly affect their consumption and generate a reduction in the consumption of non-disability-related items to compensate for the acquisition of disability-related items such as a wheelchair and rehabilitation, among others.

Persons with disabilities and their families also face indirect costs and opportunity costs, which are associated with the reduction in the number of household members working and the need to provide care and support to the person with disability. All these individual and household characteristics create that persons with disabilities are considered one of the poorest groups (Mont et al., 2022).

The evidence regarding the levels of poverty of persons with disabilities has shown that, in most cases, no significant differences are found between the levels of income poverty of persons with and without disabilities (Banks et al., 2017). This is given because, in most cases, income or consumption measures do not capture how persons with disabilities and their families compensate to cover their basic needs and the costs of disability-related items. This creates a reduction in the well-being and living standard of the household and individual, but that is not observed in the reduction of food consumption.

In the case of multidimensional poverty measures, the evidence has shown that persons with disabilities present higher levels of poverty and deprivation in aspects related to education, health and employment (Pinilla-Roncancio and Alkire, 2021; Mitra and Yap, 2021). However, there are no significant differences in access to basic services such as water, sanitation or electricity, in part because those services mostly cover households with and without members with disabilities. Nevertheless, it is not well known whether having access to a clean water source or an improved sanitation service guarantees that persons with disabilities use these services, given that, in most cases, aspects regarding accessibility are not considered (Pinilla-Roncancio et al., 2020b).

Multidimensional poverty measures computed at the individual level have shown that persons with disabilities present important disadvantages and, therefore, higher levels of deprivation and poverty than persons without disabilities, even in the same household (Pinilla-Roncancio et al., 2020b; Banks et al., 2021). Indeed, persons with disabilities present higher deprivations in education, employment and participation. If aspects regarding accessibility are included in the measure, the deprivation that persons with disabilities face is higher than for persons without disabilities in the same household.

In addition, persons with severe disabilities face higher levels of multidimensional poverty and deprivation. According to Mitra and Yap (2021) the levels of poverty of persons with severe disability (using the Washington Group Short Set of questions) are higher than for persons with moderate disabilities, and the ones of this last group are higher than for persons with mild disabilities. The magnitude of the difference varies per country, but the results are consistent across levels of economic development. Thus, persons with higher levels of severity of their disability are more likely to be poor and face higher levels of deprivation.

Finally, the evidence reveals that persons with disabilities living in countries with higher levels of development show higher levels of multidimensional poverty than families in which no one experiences a disability (Groce and Kett, 2013). In most cases, this is because of the lack of access to education, health and employment as well as the lack of protection and guarantee of the right to social and economic participation and the higher levels of social and economic discrimination that persons with disabilities face.

At the global level, earlier, some of us disaggregated the global multidimensional poverty index (global MPI) by disability status (Pinilla-Roncancio and Alkire, 2021). This study could not use a comparable measure of disability, given data limitations. Still, it revealed that households with members with disabilities face a higher incidence of multidimensional poverty in five of the 11 countries. A critical finding of this study was that in countries with higher levels of multidimensional poverty (e.g., Uganda), persons with disabilities and their families were not significantly poorer than persons without disabilities and their families. However, in countries where levels of poverty were lower than 5 per cent, persons with disabilities and their families were significantly poorer than other households, revealing the existence of a disability poverty gap.

2. Methodology

This study uses data from 52 countries with information on disability and computes the levels of multidimensional poverty of households with and without members with disabilities. We used the global MPI as the main indicator of poverty measured (see Table 1). The global MPI uses ten indicators and three dimensions (health, education, and living standards). It applies nested weights and uses a poverty line of 33.33 per cent. Thus, a person is considered poor if s/he lives in a household deprived in one or more dimensions of poverty or in weighted indicators the sum of which is one-third or more.

Table 1. Dimensions, Variables, Indicators, Cutoffs and Weights of the MPI.

Dimensions of Disadvantage	Indicator	Deprived if...	Weight
Health	Child Mortality	Any person under 70 years of age for whom there is nutritional information is undernourished.[1]	1/6
	Nutrition	A child under 18 has died in the household in the five-year period preceding the survey.[2]	1/6
Education	Years of Schooling	No eligible household member has completed six years of schooling.[3]	1/6
	School Attendance	Any school-aged child is not attending school up to the age at which he/she would complete class 8.[4]	1/6
Living Standards	Cooking Fuel	A household cooks using solid fuel, such as dung, agricultural crop, shrubs, wood, charcoal, or coal.[5]	1/18
	Sanitation	The household has unimproved or no sanitation facility or it is improved but shared with other households.[6]	1/18
	Drinking Water	The household's source of drinking water is not safe or safe drinking water is a 30-minute or longer walk from home, roundtrip.[7]	1/18
	Electricity	The household has no electricity.[8]	1/18
	Housing	The household has inadequate housing materials in any of the three components: floor, roof, or walls.[9]	1/18
	Assets	The household does not own more than one of these assets: radio, TV, telephone, computer, animal cart, bicycle, motorbike, or refrigerator, and does not own a car or truck.	1/18

Source: Based on (Alkire et al., 2023).[1] Children under 5 years (60 months and younger) are considered undernourished if their z-score of either height-for-age (stunting) or weight-for-age (underweight) is below minus two standard deviations from the median of the reference population. Children 5-19 years (61-228 months) are identified as deprived if their age-specific BMI cutoff is below minus two standard deviations. Adults aged 20 to 70 years (229-840 months) are considered undernourished if their Body Mass Index (BMI) is below 18.5 m/kg^2.[2] The child mortality indicator of the global MPI is based on birth history data provided by mothers aged 15 to 49. In most surveys, men have provided information on child mortality as well, but this lacks the date of birth and death of the child. Hence, the indicator is constructed solely from mothers. However, if the data from the mother are missing, and if the male in the household reported no child mortality, then we identify no child mortality in the household.[3] If all individuals in the household are in an age group where they should have formally completed 6 or more years of schooling, but none have this achievement, then the household is deprived. However, if any individuals aged 10 years and older reported 6 years or more of schooling, the household is not deprived.[4] Data source for the age children start compulsory primary school: DHS or MICS survey reports; and http://data.uis.unesco.org/[5] If the survey report uses other definitions of solid fuel, we follow the survey report.[6] A household is considered non-deprived in sanitation if it has some type of flush toilet or latrine, or ventilated improved pit or composting toilet, provided that they are not shared. If the survey report uses other definitions of improved sanitation, we follow the survey report.[7] A household is considered non-deprived in drinking water if the water source is any of the following types: piped water, public tap, borehole or pump, protected well, protected spring, or rainwater. It must also be within a 30-minute walk, round trip. If the survey report uses other definitions of improved drinking water, we follow the survey report.[8] A small number of countries do not collect data on electricity because of 100% coverage. In such cases, we identify all households in the country as non-deprived in electricity.[9] Deprived if floor is made of natural materials or if dwelling has no roof or walls or if either the roof or walls are constructed using natural or rudimentary materials. The definition of natural and rudimentary materials follows the classification used in country specific DHS or MICS questionnaires.

Of the 52 countries, 39 estimations were based on the Multiple Indicator Cluster Survey (MICS), which used the child functioning disability module for children 2 to 17 years older, developed by the Washington Group and validated in different contexts. In 15 countries, MICS also included information on disability for women and men of reproductive age. In addition, 12 Demographic and Health Surveys (DHS) included the Washington Group Short Set of questions for all household members. In these cases, we compute disability following the suggestions made by the WG, where a person with disabilities is identified as someone who reported facing severe difficulty or cannot do at least one of the six domains. We computed, in this case, disability for persons five years or older (Table 2). Finally, we aggregated the information on disability at the household level and identified households with and without members with disabilities. When we had information for children and adults, the information was not combined. Instead, the households were analysed independently in each group (households with children with disabilities and households with adults with disabilities).

Using the global MPI, we disaggregated the measure by disability status at the household level. We analysed and compared the incidence, intensity, MPI, censored headcount ratios and percentage contributions between households with and without members with disabilities.

Table 2. Number of countries and their survey types per region.

Survey	Region	Number
MICS	E. Europe & C. Asia	6
MICS	East & South Asia	4
DHS	East & South Asia	4
MICS	Latin American and the Caribbean	7
DHS	Latin American and the Caribbean	2
MICS	Middle East and Northern Africa	4
MICS	Oceania	5
MICS	Sub-Saharan Africa	14
DHS	Sub-Saharan Africa	6
	Grand Total	52

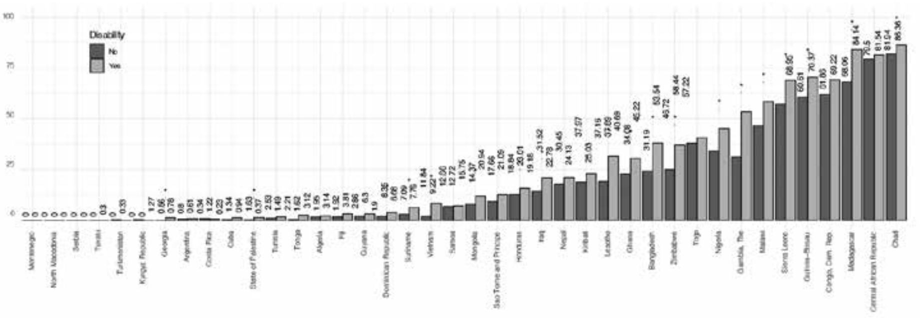
3. Results and Discussion

The results of the analysis show that households with members with disabilities (adults or children) face significantly higher levels of multidimensional poverty in 21 of the 52 countries. In total, 15 countries have households with children with disabilities where the levels of multidimensional poverty are higher compared to households without children with disabilities, and six countries have households with adults with disabilities with higher levels of multidimensional poverty compared to households without adults with disabilities. The intensity of poverty was significantly higher in ten countries (Figure 1).

When we analysed the censored headcount ratios of households with adult members with disabilities, we found that depending on the country, households with members with disabilities face higher levels of deprivation in years of schooling and are multidimensionally poor compared to households without members with disabilities. In countries such as Haiti, households with adults with disabilities face significantly higher levels of deprivation in all indicators included in the MPI (Figure 2a).

When we grouped countries by region, we identified that countries in Africa face the largest differences between households with and without children with disabilities. The indicator with the largest contribution to the MPI in most of the countries was nutrition, revealing that the censored headcount ratio (percentage of people deprived of nutrition and multidimensionally poor) in nutrition was higher for households with children with disabilities compared to households without children with disabilities (Figure 2b).

(a) Incidence of Multidimensional Poverty for Children with or without disabilities



(b) Incidence of Multidimensional Poverty for Adults with or without disabilities

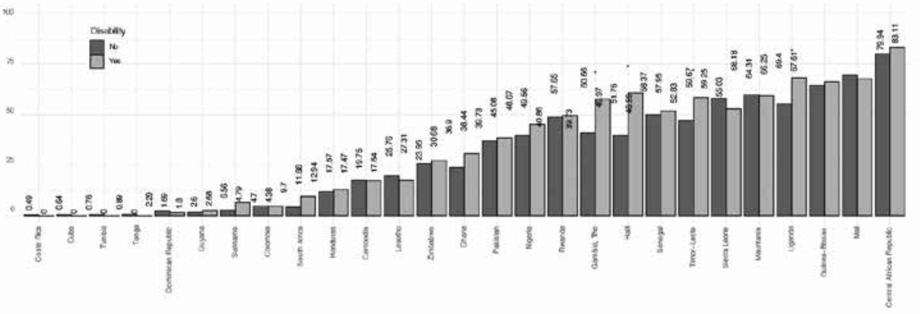
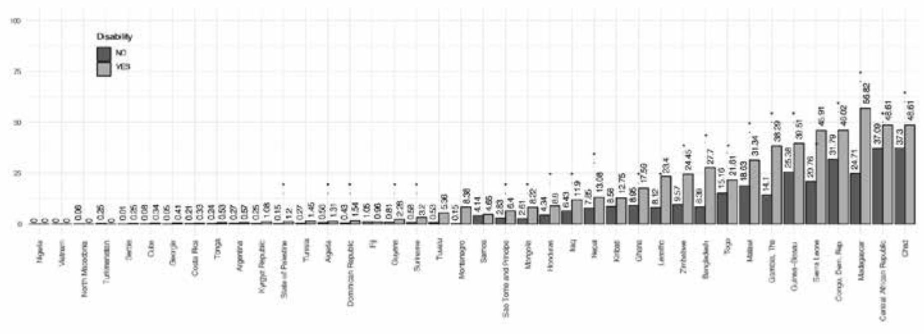


Figure 1. Incidence of Multidimensional Poverty for Households with Adults or Children with and without disabilities.

Notes: * significant differences between the incidence of multidimensional poverty for households with or without members with disabilities using a significance level equal to 5 per cent. Countries with significant differences in the incidence of multidimensional poverty for households with adults with and without disabilities: Uganda, Timor-Leste, The Gambia, Haiti, and South Africa. Countries with significant differences in the incidence of multidimensional poverty for households with and without children with disabilities: Bangladesh, Chad, Dominican Republic, The Gambia, Georgia, Ghana, Guinea-Bissau, Honduras, Iraq, Lesotho, Madagascar, Malawi, Mongolia, Nigeria, Sierra Leone, State of Palestine, Suriname, Vietnam, and Zimbabwe.

(a) Percentage of households with and without adults with disabilities deprived of years of schooling and multidimensionally poor



(b) Percentage of households with and without children with disabilities deprived of nutrition and multidimensionally poor

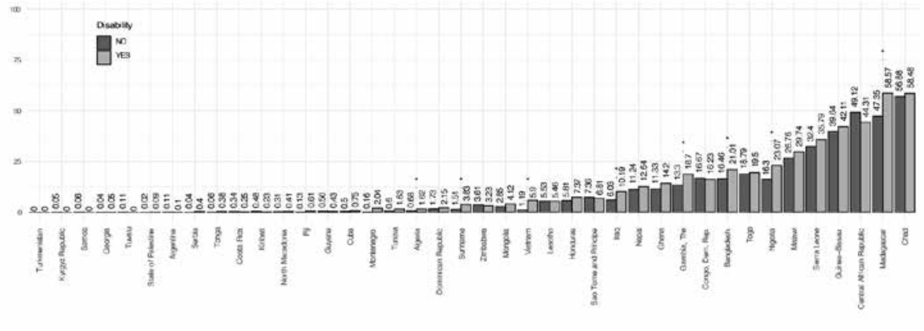


Figure 2. Censored Headcount Ratios for Years of Schooling and Nutrition.

Notes: * significant differences between the censored headcount ratios of indicators using a significance level equal to 5 per cent. Countries with significant differences in the censored headcount ratio of years of schooling: Madagascar, Nigeria, Bangladesh, The Gambia, Iraq, Algeria, Suriname, and Vietnam. Countries with significant differences in the censored headcount ratio in nutrition: Madagascar, Chad, Guinea-Bissau, The Gambia, Central African Republic, Congo, Dem. Rep., Malawi, Bangladesh, Zimbabwe, Togo, Sierra Leone, Nepal, Ghana, Honduras, Lesotho, Iraq, Sao Tome and Principe, Mongolia, Guyana, Algeria, State of Palestine, Suriname, and Dominican Republic.

4. Discussion and conclusions

Persons with disabilities and their families face high levels of deprivation and multidimensional poverty around the world. The global MPI covers over 100 countries and 6.1 million people in developing regions. Of those, we found that 1.3 billion correspond to people living in households with persons with disabilities. Persons with disabilities and their families are more likely to be multidimensionally poor in all regions of the world. In addition, households with children with disabilities face higher levels of poverty and deprivation in 15 countries. They are more likely to be multidimensionally poor and deprived of nutrition indicators. In the case of households with adults with disabilities, depending on the country, households with members with disabilities are more likely to face higher deprivations in school attendance and other indicators in the health, education and living standard dimensions.

Although global levels of multidimensional poverty have reduced over time, the findings of this research show that persons with disabilities have been left behind in development. Indeed, in most countries, this group presents higher levels of multidimensional poverty and deprivation, and even in counties with high levels of poverty, persons with disabilities are part of the poorest groups. This is a common finding across the distribution of levels of poverty and development, revealing that policies implemented to reduce deprivation have not reached persons with disabilities.

Children with disabilities and their families face higher levels of deprivation in nutrition. According to Rotenberg et al. (2024), children with disabilities face higher levels of undernutrition and are more likely to be stunted compared to children without disabilities. Therefore, it is important to analyse if children with disabilities are the ones creating the deprivation and in which cases children with disabilities are deprived of nutrition and also live in households where other children are not deprived in this indicator.

This is the first study that computes the levels of multidimensional poverty of households with children and adults with disabilities around the globe. In the last decade, the number of household surveys, including comparable questions on disability, has increased (Mitra and Yap, 2021). This increase has been mainly due to including the child functioning module for children 2 to 17 in MICSs. In addition, DHS has included the WG-SSQ as one of the optional modules, which has also contributed to the increase of sources of information, including questions on disability in LMICs. However, there are still important data concerns and limitations regarding how to measure disability. Indeed, of the 110 countries included in the global MPI, only 52 have included questions on disabilities. While numerous, these countries only cover 1.3 billion persons, corresponding to 21 per cent of the total population covered by the global MPI. It is essential to highlight that multidimensional poverty better captures the deprivations faced by persons with disabilities and their families and should complement monetary poverty measures. According to Pinilla-Roncancio (forthcoming), multidimensional poverty measures better capture the deprivations of persons with disabilities, and it is a better option for this group's measurement of poverty. It is important to continue disaggregating multidimensional poverty measures, such as the global MPI by disability status, and to tailor multidimensional poverty measures by disability.

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ECONOMIC INCLUSION OF PERSONS WITH DISABILITIES: IMPERATIVES, IMPEDIMENTS, AND REMEDIES

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Abstract

There are strong economic, theological, and philosophical imperatives for economic inclusion for persons with disabilities (PWD). Nevertheless, the impediments PWDs encounter in the marketplace are significant. Even by the standards of neoclassical economics, the economic exclusion of PWD is a market failure because allocative efficiency is not attained. This is so because the private benefits of PWD economic inclusion are less than its social benefits. Thus, the marketplace, left on its own, will not demand the appropriate level of PWD inclusion for allocative efficiency. The gap between private and social benefit increases even further in the globalized knowledge economy. Extra-market remedies are needed to correct this. One could treat PWD socioeconomic inclusion as a merit good with the government providing subsidies to rectify PWD economic exclusion as a market failure. Other remedies include the use of fair trade, social enterprises, subminimum wages, and educational initiatives within civil society. PWD economic inclusion is an important and achievable goal, but it will require commitment and careful thought.

1. Imperatives

The economic inclusion[1] of persons with disabilities (PWDs)[2] can be made based on economic, legal, ethical, and theological arguments. In what follows, I briefly outline these except for legal arguments that are examined by other papers.

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[1] Economic inclusion entails participation in both input and output markets. For this paper, I concentrate on employment inclusion as this is the constraint that most PWDs encounter.

[2] For this paper, I focus our attention on the person(s) with disabilities. Nevertheless, it is important to remember that disability also adversely affects the caregiver(s) and the family of the disabled person who consequently may also suffer varying degrees of economic exclusion.

1.1 Economic arguments

It is in the self-interest of any community to ensure the socio-economic participation of PWDs. Empirical studies suggest that many nations are well within their production possibilities frontier because of the untapped contributions of large numbers of PWDs. The World Health Organization estimates that there are around 1.3 billion disabled people worldwide, or 16% of the global population, that is, one of every six people.[3] This is particularly disturbing in the case of developing countries which need all the help they can get to lift themselves out of poverty. Low-income countries lose anywhere from $135 billion to as much as $192 billion a year due simply to the economic exclusion of PWDs (Metts 2000). In a study in Sri Lanka in 2001, 90% of disabled people were unemployed (Fritz, et al., 2009, 677).

The economic case for the inclusion of PWDs becomes even stronger once we talk of contemporary globalization and the Microelectronics Revolution. First, we have become a knowledge economy. The bulk of value creation for the global economy has come from those related to microelectronics. The Dow of the pre-1980s was heavily industrial in its composition. Today, information-related firms dominate the Dow Jones. The five biggest companies by capitalization are technology stocks. The last half century has witnessed a radical transformation in how we live, work, travel, and interact with each other. The gig-economy, ridesharing, autonomous driving, social-media connectivity, and telecommuting are just a sampling of the radical transformation of the Industrial Economy into what may be called the knowledge economy. And even now, we are on the cusp of another revolution that many believe will dwarf even the changes effected by the Microelectronics Revolution. This is the major technological breakout inaugurated by Artificial Intelligence.

Development economics captures the shift in value creation well. In the pre-1980s, the ladder of comparative advantage was based on resource endowments. Nations' comparative advantage vis-à-vis other nations was a function of their relative abundance in natural resources, labor, or capital. Resource-rich nations relied on commodity exports, those with large populations specialized in labor-intensive manufactures such as apparel, while capital-rich countries parlayed their capital in services or in high-end capi-

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[3] This the latest data as of March 7, 2023. https://www.who.int/news-room/fact-sheets/detail/disability-and-health#:~:text=An%20estimated%201.3%20billion%20people%20%E2%80%93%20or%2016%25%20of%20the%20global,diseases%20and%20people%20living%20longer. Last accessed November 4, 2023.

tal-intensive manufactures. Scholars refer to this pattern as natural comparative advantage – based on their natural endowments.

The knowledge economy has transformed this ladder of comparative advantage from natural comparative advantage to "created comparative advantage." Nations create their own comparative advantage. The prime example of this phenomenon is Bangalore, India. From sub-contracting Y2K work prior to the turn of the millennium, Bangalore has been the incubator for global tech champions that have gone up the value chain in software innovation. Bangalore created its own comparative advantage. The Microelectronics Revolution has allowed India to leapfrog many middle-income countries in the ladder of comparative advantage to carve out a niche for itself as a software powerhouse.

This shift from natural comparative advantage to created comparative advantage underscores the even more vital role of human capital in the contemporary marketplace – a post-Industrial, knowledge economy. Thus, it makes no sense to exclude potential "value creators" from the marketplace just because of their disability. Human ingenuity has always been the source of wealth creation. It has now become even more so in the knowledge economy. If we are truly intent on maximizing and optimizing value creation as prescribed by mainstream economic analysis and thinking, then every person counts. It would be a self-inflicted wound to take disabled people offline just because of the extra impediments they face.

The tandem of globalization and the knowledge economy presents a second argument for the economic inclusion of PWDs. A globalized knowledge economy has drastically reduced the cost of accommodation and creates more workarounds for PWDs that easily enable them to participate in the marketplace. A wide range of new assistive technologies from the simplest (e.g., motorized wheelchairs) to the most advanced (artificial intelligence-enabled autonomous driving) have opened new or expanded existing opportunities for PWDs in terms of greater mobility or seamless participation in the marketplace such as telecommuting. These advances have been so rapid, so much so that even severely wounded soldiers who have lost limbs have been able to go back into the service and even serve on the battlefield again, courtesy of advanced prosthetics. Empirical studies done in the wake of the Americans with Disabilities Act suggest that technology and innovation have been pivotal in making workplaces PWD-friendly through the flexibility and access that they provide (Basas 2013, 79).

Consider too how the Microelectronics Revolution has drastically lowered the barrier to entry in global marketing. The Internet has enabled even the smallest business enterprise to market its wares or services to the entire world (e.g., outsourced copy-editing, typesetting, computer-assisted design, accounting, etc.). This has been a boon for billions worldwide, but especially for the self-employed, entrepreneurial PWDs. Furthermore, social media and crowdfunding open the door to financing, marketing, networking for employment, and other collaborative work much easier for PWDs. In sum, new assistive technologies that compensate for disabilities and thereby lower the cost of accommodation make the economic and moral obligation to include PWDs in the marketplace even more imperative.[4]

A third argument for the economic inclusion of PWDs is its efficacy in breaking the poverty cycle. Empirical evidence from Ireland clearly shows that the onset and persistence of disability lead to a significant decline in employment. Moreover, among the people most prone to being disabled are the elderly. Furthermore, people from low-income households are also more likely to see the onset of disability (Brenda and Nolan 2007). This link between poverty and disability is cause for concern because they can mutually reinforce each other and generate a poverty trap. In OECD countries in 2010, the income of PWDs was 15% lower than those without a disability, and 22% of households with a disabled member were below the poverty line compared to only 14% for other households (Walsham 2019, 98). The mitigating consideration here is that developed countries generally provide a social safety net to ensure that there is a moral floor beneath which the poor or elderly disabled are not allowed to sink.[5]

Unfortunately, such a social safety net is not available in many poor developing countries where the link between poverty and disability is even stronger and much more severe. The difficulties are magnified even further in poor developing countries where PWDs are among the poorest, the ultra-poor (Ahmed, et al., 2007). Moreover, households with disabled members are also most likely to be poor (World Bank 2007; Morris, et al., 2022, 965-966, Mitra, et al., 2013). This should not come as a surprise because the need to care for the disabled makes it much more difficult for both PWDs and their families to break out of the poverty trap. For example, caregivers of PWDs and the disabled themselves are unable to participate fully in the marketplace given the severe constraints on their time (Emmett and Allant

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[4] See Morris, et al. (2022, 979, Table 6) for a list of several types of assistive technologies and other remedies for employment inclusion and retention.

[5] See Jastner, et al. (2020) for a recent empirical study of the role of government transfer programs in mitigating the economic exclusion of PWDs in the United States.

2006). The foregone income is substantial. Moreover, households with a disabled member incur additional healthcare expenses that drain what is a small and irregular family income to begin with (Fritz, et al. 2009, 676-677; Sen 1999). Besides these special requirements, the inability of PWDs and/or members of their family to gain a foothold in the formal market often leaves them to work in the informal sector. In Kenya, PWDs are more likely to be self-employed compared to non-PWDs (Morris et al., 2022, 967). Such work is less productive, uncertain, demands longer hours, and pays poorly. With such low and unsteady streams of income, PWDs and their families cannot address the disability.

The link between poverty and disability in low- and middle-income countries is so strong that it is an empirical regularity. In a systematic review of 150 studies, 122 (81%) showed a positive and statistically significant correlation between these two phenomena. The results were robust as various measures were used to measure poverty, such as asset ownership, income, expenditures, and socioeconomic standing. Moreover, the strong correlation held across various age groups, locations, and disability types. Variations in study design produced the same correlation. These studies also identified the specific venues by which PWDs descended into poverty: higher unemployment, lower educational attainment, lower enrollment, less remunerative and unstable jobs, higher morbidity, higher healthcare expenses, and greater expenditures for assistive devices and transportation. M. Walsham, et al., (2019, 98) conclude that this pattern across numerous studies suggests that there is "poverty-disability" cycle whereby disability is both a cause and an effect of poverty. Disability and poverty mutually reinforce each other to trigger a descent into a poverty trap.

Economic inclusion breaks a vicious cycle of decline whereby the lack of gainful employment leads to insufficient basic-needs satisfaction and in many cases homelessness, which in turn harms the mental and physical well-being of PWDs and their families, and which in turn makes getting a job even more difficult. This is a spiral of decline. A steady and gainful stream of income is a necessary condition for breaking PWDs and their families out of this poverty cycle. Thus, the economic inclusion of PWDs is a necessary component of poverty reduction strategies. PWD economic inclusion breaks the poverty cycle.

Finally, PWD economic inclusion is in the self-interest of employers. Thomas Aichner (2021, 2) surveys a variety of empirical studies of PWD employment and finds that PWDs are excellent hires because of their high work motivation, their work ethic, their company loyalty, their friendlier interaction with customers, their higher job satisfaction, and their consistency in job performance. Furthermore, having risen from and being used to dealing with their disability, PWDs turn out to be better problem solvers, are more creative in their solutions, and are much more open to innovating and experimenting with solutions to problems. They are much better at "thinking outside the box." Consequently, their employers reap benefits that include lower absenteeism, lower worker turnover, better returns for training and development, a much more pleasant and less stressful workplace, and better innovation. All these generate improved shareholder value. This survey of empirical studies belies the stereotypical characteristics commonly attributed to PWDs as we will see in our list of impediments. Anecdotal accounts in the wake of the PWDs surge in employment due to remote work during the pandemic affirm that PWDs are so appreciative of their being employed, so much so that they turn out to be more loyal, work harder, and are more committed to their work. They are more reliable, especially during a worker shortage, because they will not simply quit on the employer, unlike non-PWDs who were more prone to moving from employer to employer during the "Great Resignation" (Gittleman 2022). A wide variety of employers, from hotel chains, manufacturers, pharmaceutical firms, hospitals, and even military bases were successful in hiring PWDs and expressed satisfaction with the results (Torry 2023).

1.2 Social Philosophy

The economic inclusion of PWDs can be argued as both a personal and a communal moral obligation based on Cicero's notion of justice as a cardinal virtue, Kant's categorical imperative and universalizability rule, David Hume's duty of humanity, Peter Singer's duty of easy rescues, the ethics of care, and moral cosmopolitanism.

For Cicero (1913), justice as a cardinal virtue is comprised of *iustitia* (justice proper) and *beneficentia* (duty of beneficence). *Beneficentia* underscores people's mutual obligation to care for one another. This is reiterated as well in *iustitia* itself and its call for the duty to prevent harm. Economic exclusion is clearly a harm that must be redressed. Thus, Cicero's justice as a cardinal virtue presents arguments for the economic inclusion of PWDs.

Immanuel Kant's (1993) universalizability rule and the categorical imperative have much to provide in arguing for PWDs economic inclusion. If I expect others to come to my assistance in my moment of need, then I should in my own turn extend assistance in their own moment of need (universalizability rule). The categorical imperative notes that we should act in such a way that the principle of our action can be generalized for everyone else without exception. It is akin to the Golden Rule. If I do not deem it to be my moral duty to do anything to prevent the economic exclusion of PWDs, then, I cannot and should not expect others to come and help, as a moral obligation, in preventing my economic exclusion. Along these lines, we have John Rawls' (1971) leximin rule whereby we allow inequalities within our community but only if they are for the benefit of the most disadvantaged in our community. In other words, PWDs, as among the most disadvantaged, ought to be among the first in line to benefit from the community's joint efforts and resources.

Peter Singer (1972) argues that there is a duty of easy rescues. We have a moral obligation to prevent harm if it will not cost or require us to give up something of comparable moral value. The example he gives is that of rescuing a child drowning in a shallow pool of water at a personal cost to us of only a ruined pair of shoes and pants and delay in getting to where we are supposed to be. Our own moral sensibilities will condemn us if we do not save the drowning child. This is self-evident for reasonable people. Similarly, we could argue that as individuals and as a community, we have a moral obligation to prevent harm from befalling PWDs in their economic exclusion if this is something that we could accomplish without incurring a significant loss on our part.

Moral cosmopolitanism calls for treating every person with the dignity that is intrinsic to personhood. We do not engage in ethical particularism whereby we treat people differently based on our bonds, ties, proximity, or any other criteria. We simply treat everyone equally. Clearly, the economic exclusion of PWDs, or of anyone else, is unacceptable under moral cosmopolitanism.

The ethics of care underscores our strong moral obligation to come to each other's assistance based on our three shared characteristics as part of what it is to be human, namely:

- We are vulnerable to the chance and contingencies of life.
- We need others to get over these unexpected events in our lives.
- We are unable to provide for all our needs and require the assistance of others.

In other words, we owe each other a strong moral obligation of mutual assistance because of our mutual vulnerability, interdependence, and needy nature (Miller 2011).

The character of a community is revealed in how well it takes care of the most vulnerable and the weakest members in its ranks. This is the measure of a community's strength and virtue.

1.3 Theology

Christian theology also presents arguments on the imperative of PWDs economic inclusion. In the first place, *Laborem Exercens* (1981, §38-45) argues that work is a necessary venue for self-realization and perfection because through labor, people (1) secure the goods of the earth for themselves and their dependents, (2) exercise the obligations of stewardship over their personal gifts and that of creation, (3) act as co-creators in sharing in the creative activity of God, (4) share in the sufferings of Christ through the toil and hardships of human labor, (5) contribute to the common good and participate in the social order, and (6) express themselves and their creativity (Barrera 2001, 265-267).

St. Paul underscores the moral obligation to provide for oneself and not be dependent on the community, to the extent possible. Despite his firm belief in an imminent Parousia and his sense of urgency in getting people to prepare themselves for this event, St. Paul is nevertheless adamant that people must necessarily still work. He instructs the Thessalonians not to feed those who refuse to work (2 Thess 3:10-12). Moreover, with such work, the indolent will be able to provide alms to those who truly need such assistance. St. Paul himself exemplifies the importance of working for one's own keep and not be dependent on others. As the Apostle to the Gentiles, St. Paul had the right to ask for and receive material support from the churches to whom he was preaching. Nevertheless, he did not exercise this right but worked instead as a tentmaker in order not to be a burden on the people whom he served (1 Thess 2:9). Indeed, work is a constitutive element of integral human development.

Given such vital importance, *Laborem Exercens* argues that there at least two critical communal obligations: (1) a shared societal obligation to provide meaningful and gainful work opportunities for all and (2) humane working conditions, including a living wage. A "meaningful" job is one that truly gives people the chance to develop fully and put their gifts and training to full use and contribute to the common good. It is not merely tedious or mindless work, just for the sake of getting an income, but one that puts a person's education, skills, and training to proper use. Moreover, meaningful work pushes people to grow further in their skills – to be stretched to their full potential. This is a challenging task to fulfill and requires extensive cooperation and a long lead time. Consequently, note that the moral obligation to provide meaningful and gainful employment opportunities is a communal responsibility. Like everybody else, PWDs have a right to benefit from this societal moral obligation.

We can extend *Laborem Exercens*' insights by noting that there is an economic dimension to human flourishing and existence. In addition to work, PWDs also need to actively participate in the socioeconomic life, such as access to credit, goods, services, and labor markets. This includes being independent, drawing benefits from the community, and contributing toward the upkeep of society. All these are essential for the self-respect of PWDs in being able to satisfy the economic dimension of integral human development.

A second theological argument is the nature of the common good. The common good is difficult if not impossible to define completely, given the complexity of social life and its fluidity. Nevertheless, a second-best solution is to identify the minimum conditions that must be satisfied in any reasonable account for the common good. One of these minimum conditions is that of due order in the constitutive relationships that comprise the common good. Three of these key relationships[6] are (1) interpersonal relationships between persons, (2) the relationship of the community vis-à-vis individuals within its membership, and (3) individual and the community's relationship vis-à-vis those at the margins. All three relationships are essential for PWDs.

Relationship #1: Interpersonal relationships between persons in a truly functional common good require that people accord one another mutual respect. It is to treat each other as equals. Clearly, PWDs must be accorded the same respect as one extends to everybody else. PWDs must be treated as equals. This is a major shortcoming in practice because discrimination against PWDs and their treatment as inferior is a common observation and complaint in many settings, not only from the PWDs themselves but even from the public.

Relationship #2: The community-individual relationship is marked by a two-way exchange of benefits and contributions. The community has a

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[6] The other relationships are (a) between the person and God, (b) between the current and future generations, and (c) between the community and the earth.

moral obligation to provide every individual within its membership with the necessary conditions for human flourishing, including the necessary safety nets to deal with life's chances and contingencies. The individual, for its part, has the moral obligation to contribute to the community in the measure he/she can. Clearly, this is central to the concerns of PWDs. PWDs are a prime example of people who have fallen prey to the chance and contingencies of life. Clearly, the community is there to provide the necessary assistance for PWDs to be able to participate in community life, pursue their lifegoals, and thrive even with the disabilities they must bear.

Relationship #3: Individuals and the community have moral obligations toward those who are at the margins of the common life. PWDs are often numbered among these for manifold reasons – neglect, discrimination, voicelessness, destitution, severe disability, among many others. It is incumbent upon the community and individuals to reach out to those at the margins and bring them into the community.

This is not the place to develop fully the requirements of the common good. It suffices for our purposes to note that attaining the common good requires outreach and care for PWDs. This includes economic inclusion, especially since economic exclusion is a major reason for their chronic poverty and their marginalization.

A third theological argument that calls for the economic inclusion of PWDs is the all-important principle of subsidiarity. There are two parts to this principle. The first part of the principle forbids higher bodies from arrogating for themselves functions that lower bodies or individuals can perform by themselves. In other words, people ought to be able to do things for themselves. Decision-making and action should be left at the lowest possible level. Nevertheless, part 2 of the principle cautions that once the individual or the lower bodies are no longer able to function on behalf of the common good, then it becomes a moral obligation (not merely an option or a right) on the part of the higher body or other individuals with the necessary resources to intervene and provide the necessary assistance for the sake of the common good. This principle is central to the issue of PWDs' economic inclusion. Given the disability that PWDs are unable to surmount on their own, it becomes the moral obligation of the community (the higher body) or other individuals to provide the necessary assistance to PWDs. The principle of subsidiarity provides a second important insight. The goal for such assistance is to enable PWDs to be able to function on their own and not to breed dependency. This is part 1 of the principle of subsidiarity. In sum, the principle of subsidiarity has a dual function of (1) aiding and (2) empowering and enabling the PWD to be independent. Clearly, the principle of subsidiarity has a built-in safeguard to ensure that it does not harm PWDs by engendering dependency. Economic inclusion is a major part of the principle of subsidiarity's dual task vis-à-vis PWD.

Many other theological arguments can be presented. *Populorum Progressio*'s integral human development is a journey that is taken jointly with one's neighbor, and it can be completed only together. Clearly, the economic exclusion of PWDs is incompatible with this principle. Another relevant principle is the universal destination of the goods of the earth whereby all are supposed to be able to satisfy their basic needs. The principles of solidarity and participation also warrant the economic inclusion of PWDs. Not included in this section's theological imperatives for lack of space are the biblical norms relevant for this issue.

2. Impediments

2.1 Nature of actual (not theoretical) markets

PWDs will find it difficult to participate in the marketplace for several reasons. First, their disability often adversely affects their productivity and is much lower compared to those who do not suffer from such disability. Productivity differentials have been cited as a key factor that impedes labor market participation by PWDs (WHO and World Bank 2011, 233-257). This difference in productivity may be directly due to the disability itself (e.g., limitations in motor skills), to higher morbidity rates (e.g., more sick days), or the need to seek medical care with a consequent loss of working days or hours. Such a productivity differential puts them at a significant disadvantage because of the resulting higher production cost. Moreover, employers will find it risky to hire PWDs in an extremely competitive marketplace characterized by tight delivery schedules, requisite short turnaround times, small profit margins, just-in-time inventory, expensive employee training cost, and ease of entry or exit. Traditional business management is averse to uncertainty and avoidable risk. PWDs may not merely be much more expensive to hire relative to those without a disability because of the productivity differential, but they might also be deemed to be much riskier hires, given their perceived greater likelihood of calling out sick.

Nevertheless, it is important to recall the earlier observation on Aichner's (2021, 2) survey of studies that find PWDs to be more productive because of their work commitment and loyalty. The difference in the findings of

Aichner (2021) and WHO and World Bank (2011) may be due to the great heterogeneity of disability that allows PWD to excel in various activities, while struggling in other forms of employment. Moreover, empirical evidence showing PWDs to be more productive may be due to their greater loyalty, better motivation, and lower turnover compensating for their disability.

A second practical impediment to PWD economic inclusion is also related to cost. PWDs would most likely require special accommodation at their workplaces. Take the case of those who are wheelchair-bound. Most public workspaces are not wheelchair friendly. For example, doors and bathroom stalls are not wide enough for wheelchairs, there are no alternatives to walking up steps, and bathroom sinks or breakroom counters are too high. Some of the required fixes are easy and cheap. Others, however, require major renovations and are expensive, as in the case of putting wheelchair ramps as an alternative to stairs, or even installing chairlifts or elevators. Unless mandated by law (such as the *Americans with Disabilities Act of 1990*), most employers will not incur these additional expenses on their own. This is particularly so in poor developing countries where businesses are already stretched in their funding needs. Thus, even in those cases where there is no productivity differential between PWDs and those who are disabled, employers may still balk at hiring PWDs because of expensive retrofitting fixes in the workplace that they might require.

The expense incurred in accommodating PWDs is relevant for the earlier arguments we have seen from social philosophy on the need for PWD economic inclusion. Cicero's duty of beneficence and duty to prevent harm as part of justice as a cardinal virtue are premised on their not costing too much. In fact, Cicero (1913 [I, vxi, 51]) follows Ennuis' principle in which beneficence is mandatory only to the degree that it costs the giver nothing. Along the same lines, Peter Singer's duty of easy rescues is also premised on such assistance not being too costly. This is not the place to debate the threshold of what is too costly for PWD economic inclusion. It is sufficient for us to note that even within social philosophy, the duty to rescue or prevent harm is not carte blanche but is also conditioned on the expense incurred. Cost is a legitimate consideration. This is particularly true if such costs put the entire business at risk by pricing itself out of the market.

A third practical impediment to PWD economic inclusion is the difficulty of getting to the workplace. Once again, let us take the case of the wheelchair bound. Public transportation (buses, trains, subways, etc.) are often inaccessible by wheelchair. Sidewalk curbs at street crossings are rarely designed for wheelchair use. These limitations are prevalent even in the major metropolitan areas of the most developed nations of North America and Europe (Ergon Associates 2020). If this is the case, even for the wealthiest countries, it is even worse for middle- and low-income countries that would be even more hard-pressed to come up with public funds to make these necessary accommodations. This severely limits the type or location of employment or business opportunities available to PWDs. Workarounds may be expensive, as in the case of the wheelchair-bound having to take a taxi instead of the public bus.

A fourth impediment to PWD economic inclusion is the array of many other and even more urgent socioeconomic problems that need to be addressed. Poor developing countries are overwhelmed as it is with many other troubles that threaten their stability and even existence. In particular, generating sufficient income and creating jobs for a young and growing population are perennial concerns. This poses even greater hurdles to PWD economic inclusion because there is already a problem with providing employment to non-PWDs to begin with. Governments in poor nations will most likely not take PWD economic inclusion as a priority, especially if the requisite expenditures are substantial. Much needed health, education, and social services for an impoverished population will compete for the scarce government funding that PWDs themselves will need. PWDs will most likely be bumped further back to the rear of the queue. PWD-friendly legislation such as the *Americans with Disabilities Act of 1990*, the *European Accessibility Act*, the *UK's Disability Discrimination Act*, and Canada's *Accessible Canada Act*, are a luxury that many developing nations cannot afford, besieged as they are with even more urgent spending and legislative priorities.[7]

A fifth impediment to PWD economic inclusion is the discrimination to which they are subjected. Employers, co-workers, and many in the public stereotype people with disabilities as somehow deficient, less productive, unreliable, sickly, needy, and vulnerable, among others. In empirical studies done in Kenya, Uganda, Nigeria, and Bangladesh, PWDs and their families cite stigma and discrimination as major hurdles. They are perceived by their employers and fellow workers as low-value, and there is often pressure

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[7] It is a similar dynamic on the issue of special education. Special education is a luxury that many nations cannot afford. This is particularly so in developing nations whose budgets for education are already so woefully insufficient to begin with. Special education is not a priority for them since providing a basic, primary education for their population is already a problem in the first place.

for them to find a livelihood in self-employment. They are denied even reasonable accommodations and face obstacles to access in education.[8] The bias is even worse for women who are disabled. They carry the double hurdle of gender-bias on top of PWD-bias (Emmet and Alant 2006). There is also danger of abuse, especially for those who are intellectually disabled (Bialik and Mhiri 2022). Such discrimination and stereotyping are also prevalent even in advanced countries and in the more innovative sectors of the economy. For example, entrepreneurs with disabilities are often deemed to be high-risk borrowers without any evidence to back up this view (Ergon Associates 2020, 3). Discrimination and stereotyping also impede PWDs' access to continuing education and training to upgrade skills. Both are essential in generating employment or entrepreneurial activities for PWDs.

Sixth, the heterogeneity of disability makes it much more challenging to come up with policies and practices since these must consider the type, severity, and duration of disability, not to mention the age of the person (Emmet and Alant 2006). PWD economic inclusion requires a wide variety of measures that address the issues specific to the type of disability encountered. This aggravates the earlier impediment on the cost of workplace accommodation. Employers will have to accommodate different disabilities, each with its respective unique requirements for mitigation (e.g., physical, emotional, social, intellectual, etc.). It is not as if we could have a one-size-fits-all solution, which would have been ideal because we can avail ourselves of the resulting economies of scale in our mitigation efforts. Instead, we require different ameliorative measures, and this increases the cost compared to having a standard solution. The wide range of disabilities means that it may be difficult and expensive for the employer to accommodate many PWDs.

Finally, there is a perverse complementarity among the aforesaid impediments that raises ever higher hurdles for PWDs' economic inclusion. Impediments mutually reinforce each other. PWDs experience multiple disadvantages simultaneously in being excluded from social programs, education, employment, transportation, and social life. They are most likely to be in poor households (Lockwood and Tardi 2014: 433-434). The link between disability, health, and poverty in low- and middle-income countries has been repeatedly established in multiple empirical studies (Morris et al., 2022, 965). The lack of reasonable accommodations in public transpor-

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[8] In an empirical study of eleven low- and middle-income countries, children with disabilities were found to be less likely to be in school (Fritz, et al., 2009, 677).

tation and public spaces makes it much more difficult for PWDs to access education and training. Discrimination and stereotyping not only worsen their employment prospects but make it even more likely for employers to refuse even the most reasonable accommodations. Ableism is a bias in organizations that stereotype PWDs as deficient or less productive (Kwon 2016, 181-182). The World Health Organization and the World Bank (2011, 233-257) report on disability identify discrimination and prejudice as significant hurdles to PWDs' employment.

The resulting lack of work experience locks them out even further from the labor market and makes them even more unlikely to be hired. PWDs' perceived or assumed lower productivity only strengthens even further the view that they are high-cost hires. Problems encountered in one type of disability are attributed to all PWDs, with employers or the public not making a distinction between disabilities and their heterogeneity. These mutually reinforcing impediments make PWDs' economic inclusion much more difficult and expensive to achieve.

2.2 Globalization and the knowledge economy

As mentioned earlier, the tandem of globalization and the knowledge economy has opened new avenues for PWDs' economic inclusion. For example, the Internet and new assistive technologies have mitigated or altogether rendered disability irrelevant for PWDs' prospects of marketplace participation, as in the case of back-office work, sub-contracting, or marketing via telecommuting from home. Nevertheless, globalization and the knowledge economy have also raised even more hurdles for PWDs.

First, the globalized knowledge economy has accelerated the pace of economic life. In addition, higher skills or constant learning and training may now be the norm, as in the case of e-related work. Those with learning disabilities will find it much more difficult to secure the much more remunerative types of employment and will be left even farther behind because of this requisite need for upskilling. This is not even to mention the higher cost in terms of time, travel, and effort that may be required to secure such training. Recall that PWDs and their families are often in the lower wealth-income quintiles to begin with. Moreover, as mentioned earlier, they face discrimination or hurdles in educational access. Keeping up with the knowledge economy may be a challenge for some PWDs.

Second, globalized markets have intensified competition even further in the labor markets. For example, telecommuting and online back-office operations expand employment opportunities for physically disabled persons. However, offshore outsourcing as part of globalization widened the pool of workers overnight. Domestic PWDs now face stiff competition from workers worldwide, and they run the risk of getting crowded out further back in the queue. Nevertheless, the same offshore outsourcing creates the opposite effect by expanding the employment prospects of PWDs in other countries, especially those in poor countries, such as India and the Philippines.

Third, globalization has intensified the competition for a wide variety of goods and services that can now be imported at a much lower price and perhaps of even better quality. Profit margins are under pressure, and firms will be even more cost-conscious. Such greater sensitivity to production cost will dent the employment prospects of PWDs even further. As we have seen earlier, disability often raises production costs either due to lower productivity or the higher cost of workplace accommodations for disabled people. Such additional costs will be a tempting target for hard-pressed managers looking for requisite cuts to stay competitive in global markets.

Fourth, globalization has spared those parts of the services sector that require the actual physical presence of workers from stiff competition (e.g., construction, food service, agriculture, etc.). As we have seen in the post-pandemic era, such workers are in short supply, and competition for them has been severe thereby resulting in higher wages. The impact on PWDs is mixed depending on the type of disability. Those who are physically disabled would most likely be unable to do such service jobs.

3. Remedies

3.1 Extra-market interventions

Social philosophy, theology, and even economics itself present compelling arguments for PWDs' economic inclusion as an imperative. Nevertheless, we have also seen that actual market conditions present significant hurdles to such inclusion. We can work around these impediments through a variety of extra-market interventions.

3.1.1 PWDs' economic inclusion as a merit good

First, PWDs' economic inclusion should be treated as a merit good. Using neoclassical economics, we can describe PWDs' economic exclusion as a market failure. As we have seen from economic history and from empirical evidence, human capital is the driver behind value creation across all eras, from the ancient to the modern industrial economy. As mentioned earlier, human capital has become even more important in the knowledge economy with the shift from natural comparative advantage based on natural resources to created comparative advantage. Allocative efficiency requires putting scarce resources to their best use. Clearly, by the standards of neoclassical economics, PWDs' economic exclusion leaves us well within our production possibilities frontier, well within the optimum welfare that we could attain jointly with the maximized use of the resources available to us.

Take the case of PWDs' exclusion in labor markets. Market failure arises because employers are not able to internalize the social benefits of PWDs putting their human capital to work and contributing to the overall welfare of the entire economy. Human capital, by its nature, spawns positive externalities for the whole community. It is a similar phenomenon to that of education. A more educated population produces many more benefits at the community level, well above those reaped at a personal level. For example, at a personal level, people procure a college education because it eventually leads to better jobs and better incomes. However, there are many more benefits to education beyond this increase in personal productivity, such as greater civility in community disagreements and even more important, the creation of new knowledge as people interact with each other. Silicon Valley is a prime example of this phenomenon. Such positive externality to a more educated population does not enter the person's calculation of how much education to pursue. Left on their own, people will not procure for themselves the right level of education for the long-term benefit of the entire community. Note how most governments treat education as a merit good and provide free 12 years of education and subsidize post-high school education. In many cases, 12 years of education is also mandatory, and in some jurisdictions, parents can be held to account for their children's truancy.

Employers are concerned only with the costs they incur vis-à-vis the revenues they generate in hiring PWDs. However, such private benefits at the level of the employer do not capture the many other benefits, the positive societal externalities, of employing PWDs. This includes the maximization of community resources (the PWDs), imparting skills and further honing the human capital of the PWDs hired and the future contributions that may emerge from such improved human capital, averted unemployment insurance that would have otherwise been paid, and greater spending by the hired PWDs, among many other benefits not seen nor considered by the employer. And this is not even to talk about the non-economic benefits that PWDs can bring about, such as the impact of such inclusivity on the public ethos and civil society. In other words, private benefits are less than the social benefits, and this leads to the underemployment of PWDs.

Governments are best poised to address PWDs' exclusion as a market failure for several reasons. In the first place, it has the power of fiat. The *Americans with Disabilities Act* of 1990, the *European Accessibility Act*, the UK's *Disability Discrimination Act*, and Canada's *Accessible Canada Act* are proven examples of how legislation can pave the way not only for PWDs' economic inclusion but also facilitate their participation across the various realms of social life. Such legislation requires action beyond mere mandatory accommodations in public services, such as affirmative action in employment, contracts, and public offices, among others. Disability is also sometimes included as a measure of workplace diversity.

Governments can also provide subsidies. Unlike education in which government steps in as a provider of last resort, the economic inclusion of PWDs is a much more difficult merit good to deliver. It is unlikely that the government can take upon itself the role of being the PWD employer of last resort. The more feasible solution is to rely on the marketplace itself. This could be achieved with the use of subsidies. For example, a solution for such market failure is to subsidize employers with the goal of closing the gap between the community's social benefits and the employer's private benefits in hiring PWDs. Tax credits are a ready solution.[9]

Nevertheless, there are limits to government action as a remedy for PWDs' economic exclusion. In the first place, there is the danger of regulatory creep or, worse, regulatory overload, such as affirmative action or mandatory hiring quotas. In fact, overly protective labor legislation and improperly designed regulations can backfire and discourage the employment of PWDs (Ergon Associates 2020, 3). Regulations can assist or impede the economy's efforts to approximate its point of allocative efficiency. Great caution is required. Improperly designed disability benefits may in fact create disincentives to PWDs' economic inclusion (WHO and World Bank 2011, 233-257). Moreover, there is the perennial problem of how to fund

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[9] One can model this formally by using the Edgeworth Box diagram in production with PWDs' employment as a non-economic objective. The deviation from the core that makes for allocative efficiency can be achieved by changing the factor prices in the marketplace in such a manner as to lower the cost of PWDs' employment. This can be achieved through tax-subsidy schemes on factor employment. Employing PWD workers, for example, could bring government subsidies, tax credits, or exemption from different employment-related taxes.

subsidies. This is not even to mention the contentious debates on doing a triage of the nation's needs and priorities. PWDs' economic inclusion as a goal does not stand by itself. It is only one of many issues competing for national attention and resources. This is particularly true for poor developing countries which are pressed by many other spending priorities.

Considering these limitations to government action, the most sustainable remedies are those that ensure a strong and smoothly functioning labor market as this provides the best chance of sustainable employment for PWDs (Agovino and Rapposelli 2016, 646). This is particularly important in poor developing countries where PWDs' social inclusion as a goal will be relegated to the bottom of the list because the more pressing concern is not having enough gainful, formal-sector jobs for the labor force to begin with. Providing support services to PWDs in terms of counseling services, training, and continuing education is also essential. Empirical evidence suggests that these measures are positively correlated in matching PWDs with jobs in the marketplace (Agovino and Rapposelli 2016). Nevertheless, there are significant hurdles to incorporating PWDs into the workplace, and much has yet to be learned.[10]

3.1.2 Targeted poverty alleviation programs

The economic inclusion of PWDs also requires measures that help their caregivers. Mothers who tend to disabled children bear heavy burdens in addition to their already significant household responsibilities (Emmett and Alant 2006). Furthermore, such caregivers are often unable to secure remunerative employment, and the household is often in poverty. The problem becomes even more severe for women-headed households. Poverty itself not only compounds the original disability, but it might also create secondary disabilities from malnutrition, chronic morbidity, and social isolation.

In such cases, economic inclusion should consider not only the needs of disabled people but also of their caregivers. Both require assistance and accommodation for them to participate meaningfully and gainfully in the economy. For example, flexible hours of work will be of immense value to mothers or other caregivers of disabled relatives. Given the multiple disadvantages experienced by PWDs, their caregivers, and their families, the economic inclusion of PWDs must be embedded within a communi-

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[10] See Shaw, et al. (2022) for anecdotal accounts of the various challenges faced by PWDs in their job search or in their places of employment.

ty's overall development strategy instead of being addressed as an ad hoc issue (Emmett and Alant 2006). The argument for inclusion in a larger development plan becomes even more compelling considering the empirical evidence showing that disabled people are among the ultra-poor (Ahmed, et al., 2007). Furthermore, empirical evidence suggests that despite their much greater need for social protection, PWDs have far lower enrollment rates than non-PWD in these programs. This suggests the need to take extra measures to target PWDs specifically (Kuper et al., 2016).

3.2 Market-based Remedies

3.2.1 Fair Trade & Social Enterprises as Venues for PWD Economic Inclusion

Government fiat may be the most effective remedy at this time, but it is not the ideal. The best remedy is the marketplace itself, that is, for market participants themselves to include PWDs in their market transactions.

Left on its own, the marketplace operates based on allocative efficiency. To date, there is no other social institution that can orchestrate the exchange of the unimaginable volume of goods and services currently traded among disparate economic actors spread across a wide geographic area in a timely fashion, 24/7/365. A key mechanism that allows the marketplace to accomplish this feat is its price mechanism which alerts market participants as to when, how, and to what degree they ought to alter their choices regarding consumption, savings, the disposition of their resources, and all other economic decisions. Thus, markets are instrumental in actualizing the claim that economics is about putting resources to their most valued uses. This is allocative efficiency.

"Most valued use" by the standards of allocative efficiency is ultimately founded on consumers preferences. Resources are valued based not on their intrinsic worth but on how much value they command in the marketplace. Take the case of factor markets. Market wages are based on the value of the marginal productivity of labor. Producers employ workers who produce sufficient goods or services that payoff the wages they receive.[11] This leaves PWDs excluded because the marketplace deems them to be high-cost "factors of production."[12] Such high factor cost means that they will be replaced

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[11] Wages = Price x Marginal Product of Labor

[12] In this paper, I use the term "factor of production" only because it is the language used in the disciplines of economics and business. Labor is not a factor of production but is properly the subject of work. See *Laborem Exercens*' distinction between the subjective and the objective dimensions of work.

by other factors of production in the production isoquant. In other words, PWDs will most likely find it extremely difficult to compete with non-PWDs for jobs in the marketplace.[13]

The ideal solution is for market participants to price goods and services based on their intrinsic worth. For example, consumers might be willing to forego a much cheaper non-PWD-made apparel for a much more expensive one manufactured with PWDs' labor. These consumers willingly pay the much higher non-market price because of the intrinsic worth they ascribe to PWDs and their economic inclusion. Such valuation based on intrinsic worth rather than market price has already been tried and tested in the fair trade of a wide range of goods and services, from coffee, chocolate, apparel, and many others. Fair trade in these goods is geared toward ensuring that the workers and, not the intermediaries, are properly and justly compensated. The same principle and mechanism can be applied to achieve PWDs' economic inclusion.

Social enterprises are another way of getting around the market's failure to price goods and services based on intrinsic worth. Unlike non-profits, these are business enterprises that appreciate the importance of market discipline and the imperative of making profits to keep their operations viable and sustainable in the long term. However, unlike for-profit firms, these social enterprises do not make profit-maximization their overriding goal. Equally important, these profits are used to promote social causes. In other words, they are guided by a stakeholder, rather than a shareholder, model of corporate governance.

Examples of fair trade and social enterprises geared toward PWDs' inclusion abound worldwide from PWD-sewn bags and leather craft in the Philippines,[14] to ice cream franchises in North America that deliberately

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[13] The appendix accounts for how such exclusion comes about. We can model disabilities and the higher cost they impose using the household production model (Becker 1965). Disabilities lead to a greater use of requisite inputs, such as time and material goods, in going about the person's daily life. The resulting output will be more time- and resource-intensive compared to non-PWD output (appendix). The consequence of such lower PWD productivity is their inability to compete with non-PWDs when it comes to jobs. This theoretical account must, however, be juxtaposed against empirical evidence that find PWDs to have a much higher productivity than non-PWDs. Recall Thomas Aichner's (2021) survey of studies on this issue.

[14] World Intellectual Property Organization. "Handy in the Philippines: Leather Crafting Brand Helps People with Disabilities," https://www.wipo.int/pressroom/en/stories/harls_2021.html Last accessed November 4, 2023. Kitty, Elicay. 2019.

employ mostly disabled workers,[15] to prosthetics manufacturers.[16] People are willing to pay a premium over and above market prices because they want to enable PWDs' participation in the marketplace.

Unfortunately, fair trade and social enterprises are limited in effecting PWDs' economic inclusion because it is difficult to scale up these operations. Moreover, they are completely dependent on the goodwill of consumers who willingly seek out and pay more to help PWDs. Not too many people have the motivation and the time to do this.

Nevertheless, such willingness to pay based on need and intrinsic worth is not too far-fetched because it is already customary practice in the marketplace. Compensation according to need is already a mainstream market practice. Consider the following examples. Workers with families have the option of getting family health insurance with their employment. This means that they are getting more benefits compared to single workers without dependents. Similarly, paternity and maternity leaves favor workers with children versus single workers who do not have children. Tuition remission for the children of university staff and professors is a boon for these workers especially in the U.S., where college tuition is prohibitive. Clearly, university staff and professors who avail themselves of such tuition remission for their children are paid more compared to the other university workers who are childless. In all these cases, people are in effect paid according to their needs and not according to their work. This is an instance in which the common standard of fairness of equal work for equal pay does not apply. Related to this is the provision of special education for children with special needs. Clearly, special education is much more expensive. Yet, most people would not begrudge children with special needs using much more of the community's educational resources compared to other children who do not need to avail themselves of these extra services. Again, note how the community allocates its resources based on need, even if it may lead to inequalities.

"Thinking of Gifts For Christmas? These Tote Bags Are Made with Love by PWDs." https://www.smartparenting.com.ph/parenting/kids-with-special-needs/pwd-tote-bags-a00228-20191016 Last accessed November 4, 2023.

[15] Howdy Homemade Ice Cream https://howdyhomemade.com/franchise/ Last accessed November 4, 2023.

[16] Medpage. 2017. "Disabled Workers Make Prosthetics for the Poor (Reuters)" https://www.medpagetoday.com/primarycare/generalprimarycare/67205 Last accessed November 4, 2023.

3.2.2 Educating the Public

Discrimination is an impediment to PWDs' economic inclusion. Civil society plays a key role in this regard by educating the public. Well-crafted extra-market interventions can prepare the groundwork for market-based solutions to work on their own. This is particularly so for educational programs. Consider the following examples.

Autism Speaks[17] is an advocacy group that works toward the inclusion of people with autism across their lifespan. One of its initiatives is a nationally aired TV ad campaign that shows people with autism in various professions. TV viewers come away with the message that people with autism easily fit into the labor force and can perform as well as everybody else.

Mattel produced a Barbie doll with Down syndrome with the goal of promoting the inclusion of people with this condition. It is an effort to let children with this condition see themselves like any other kid, and for other children to see the world around them much more realistically than the idealized earlier versions of the Barbie dolls.[18] The educational value of this effort cannot be overemphasized especially in teaching inclusion and acceptance of diversity at an early age. *British Vogue*, for its part, put a model with Down syndrome on its cover page.[19]

These educational initiatives go a long way toward disabusing people of their stereotypes of PWDs. They lay the groundwork for the other earlier remedies we had seen such as fair trade and social enterprises whereby market price is based on the intrinsic worth and not on exchange value. Educating the public, including employers and workers, on PWDs paves the way for the latter's easier and successful labor market participation.

Governments also turn out to play a significant role in changing attitudes toward PWDs. Experience from the two decades since the *Americans with Disabilities Act* show that PWDs have a preference to work for the public sector because of its benefits, stability, and its perceived responsiveness to

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[17] https://www.autismspeaks.org/ last accessed October 31, 2023.

[18] Diaz, Jaclyn. 2023. "Mattel unveils a Barbie with Down syndrome," National Public Radio. (April 25). https://www.npr.org/2023/04/25/1172017348/barbie-doll-down-syndrome-mattel last accessed October 31, 2023. See also the Mattel website on this initiative. https://corporate.mattel.com/news/barbie-introduces-its-first-doll-with-down-syndrome-further-increasing-representation-in-the-toy-aisle last accessed October 31, 2023.

[19] Morgan, Ellie. 2023. "Ellie Goldstein Shares an Empowering Message About the First Barbie Doll With Down's Syndrome," https://www.vogue.co.uk/article/barbie-down-syndrome-ellie-goldstein last accessed October 31, 2023.

PWDs' issues. It turns out that the public sector has set an example for how to treat PWDs' economic inclusion as a civil rights issue (Basas 2016, 79). That PWDs gravitate toward public sector jobs is a testament to government responsiveness. This is a case whereby the government is leading the rest of the nation by example. Unfortunately, this phenomenon may not be replicable in many other settings, especially in developing nations in which there is stiff competition for public sector jobs. These are often created to solve chronic unemployment among favored political constituents.

Project Search[20] began as an effort by staff members in 1996 at Cincinnati's Children's Hospital to add training for eventual job-placements for the young people with developmental disabilities with whom they had been working. Today, this initiative has become an international effort that provides a one-year transition-to-work program for developmentally disabled youths. This includes a business-led effort to train intellectually disabled young people to take on even nontraditional complex jobs. The goals are to enhance these young people's employability in the marketplace by providing them with the requisite skills, training, and experience, in addition to coaching on life skills. *Project Search* is about helping young PWDs transition into adult life with regular jobs.

3.3.3 Subminimum wages

Economic theory suggests that employers generally set wages according to the value of what workers can produce. In other words,

Wage (W) = Price of the good produced (P) x Marginal productivity of labor (MPL)

After all, employers need to recoup their wage bill and still have some leftover to cover their overhead, their other factor inputs, and their profits.

Unfortunately, market wages need not necessarily be above what people need to satisfy their family's basic needs. In fact, often they are not. Consequently, legislated minimum wages are the norm in most countries. It turns out that this is yet another means to facilitating PWDs' economic inclusion via their employment.

As mentioned earlier, disabilities can impair PWDs' productivity. This is an impediment to their getting hired because they are unable to produce enough to make up for the wages that are paid to them (Recall W = P x

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[20] https://www.projectsearch.us/core-model-fidelity/ Last accessed November 7, 2023.

MPL). In the U.S., one solution to closing this productivity-pay gap is to grant an exemption to the minimum wage law for PWD hires.[21] In other words, the law provides a leniency to employers who are willing to hire PWDs by exempting them from having to pay the minimum wage. Many find this remedy to be attractive because it is market-based and does not cost taxpayers. It is also deemed to be a win-win proposition in that both the hired PWDs and firms benefit. Subminimum wages leniencies can be viewed as minimizing distortions to make markets function much more smoothly in approximating allocative efficiency.

Nevertheless, this subminimum wage provision for PWD is deeply controversial, largely on ethical concerns.[22] It is a trade-off between creating more PWD job opportunities, on the one hand, and paying a wage that can fill basic needs, on the other hand. Opponents to this leniency decry succumbing to economism – that at the end of the day, economic factors are decisive and carry the day. In this case, the leniency yields to the practice of Wage = P x MPL. Since PWD MPL is lower, so should their wages be to get them hired. Severe space constraint does not permit me to weigh the economics, ethics, and theology of this leniency in this paper. Suffice it to say that it is one of the remedies that is currently in use.

3.4.4 Remote work

The Covid pandemic inadvertently uncovered what seems to be one of the most effective market-based paths to PWDs' economic inclusion, to wit: remote work. Empirical evidence from the United States reveals just how important this change in the workplace makes for PWDs' employment. Since the pandemic, 1.8 million PWDs joined the labor force. This additional labor is a huge jump of 28% compared to just 1% growth for the total workforce. By August 2022, the U.S. Labor Department reports

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[21] See https://www.dol.gov/agencies/whd/special-employment last accessed November 4, 2023. Such subminimum wage arrangements require permission from the Wage and Hour Division of the U.S. Department of Labor.

[22] Various states have challenged and banned such subminimum wages for the disabled in their jurisdiction: Vermont, Alaska, Maine, Maryland, New Hampshire, Oregon, Washington, Hawaii, Colorado, California, Delaware, Tennessee, South Carolina, and Rhode Island. Advocacy groups for people with disabilities have also challenged in court the provision in Federal Law that permits this arrangement. See https://apse.org/state-legislation/#:~:text=14(c)%2Fsubminimum%20wage%20legislation&text=Note%3A%20Prior%20to%202023%2C%20the,%2C%20South%20Carolina%20%26%20Rhode%20Island. Last accessed November 4, 2023.

that 25% of PWDs were part of the labor force, with 21% of PWD being employed. These are the highest ever recorded numbers for these statistics (Gonzales 2023; Tory 2023). The shortage of workers in the post-Covid era partly accounts for this sudden jump in PWDs' employment statistics. However, anecdotal accounts suggest that it is remote work that opened a whole new opportunity never seen before by PWDs. Many have long been asking if they could work remotely even before the pandemic because of the obstacles to commuting and navigating workplaces. In addition, flex time can easily be incorporated into remote work, thereby making the combination even much more attractive and PWD-friendly. These requests for pre-Covid remote work had been rebuffed, until the pandemic upended it and turned such remote work into the norm.

4. Summary and Conclusions

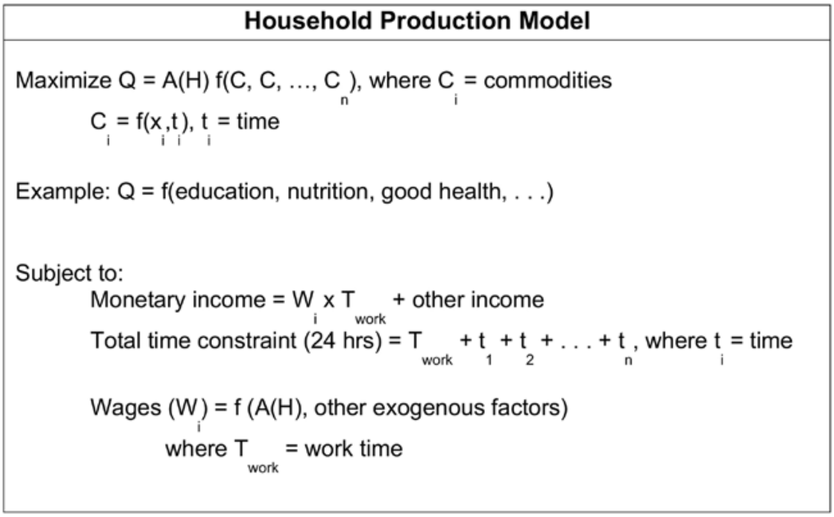
Economics, social philosophy, and theological ethics converge in their conclusion that the socioeconomic inclusion of persons with disabilities (PWDs) is an imperative. This is consistent with human dignity and our self-understanding that we are a human community. From a strictly economic viewpoint, PWDs' exclusion is self-defeating because of their untapped contributions that could have boosted the whole community's well-being. This is particularly so in the new knowledge economy.

Nevertheless, there are significant hurdles to PWDs' socioeconomic inclusion. This is largely because of the added cost of accommodating their needs in the workplace and public spaces. In addition, some forms of disabilities may lead lower productivity compared to non-disabled people. Given the unforgiving nature of markets, especially in the wake of even stiffer competition due to globalization, firms are cost-conscious and always on the lookout for ever greater efficiencies and savings. This may discourage PWDs' employment. It should perhaps not be surprising that in the two decades since the *American Disabilities Act*, PWDs have gravitated to public-sector employment. After all, government is not subjected to market discipline, while private firms are. In addition to these, PWDs face discrimination. The public often perpetuates many misconceptions about PWDs' economic capabilities and needs.

Remedies are available to get around impediments to PWDs' inclusion. Among these are government subsidies, fair trade, social enterprises, and disabusing the public of common stereotypes of PWDs as deficient or inefficient. Developing countries face even greater hurdles to rectifying PWDs' economic exclusion given the expense involved and their many other pressing needs. This is one area of possible foreign assistance from the Global North to the Global South.

Appendix

PWDs and the Household Production Model



Household Production Model

Maximize $Q = A(H)\ f(C, C, \ldots, C_n)$, where C_i = commodities

$C_i = f(x_i, t_i)$, t_i = time

Example: Q = f(education, nutrition, good health, . . .)

Subject to:

Monetary income = $W_i \times T_{work}$ + other income

Total time constraint (24 hrs) = $T_{work} + t_1 + t_2 + \ldots + t_n$, where t_i = time

Wages (W_i) = f (A(H), other exogenous factors)

where T_{work} = work time

Gary Becker's (1965) model of time allocation lends itself well to modelling disability using the household production model. Disability can be incorporated in the household production function in the A(H) variable that impedes or advances the production of Q. In addition, disability can also be incorporated in the increased usage of time and goods inputs by PWD due to the need to compensate for the impediments they face. Disability can be modelled for specific commodities. Thus, PWDs' total output Q would be much lower compared to non-PWDs' Q thereby showing a much lower productivity. Thomas Aichner's (2021) finding of higher PWD productivity can be incorporated into the same variables above, although showing a positive rather than a negative impact. PWDs' work ethic, greater loyalty, attention to details, and resiliency may compensate for their disability and thereby give A(H) a positive impact.

The consequences of lower (or higher) PWD impact on PWDs and non-PWDs' competition for jobs can also be modelled using the specific factors model with PWDs' labor and non-PWDs' labor as the specific factors. The x-axis would be the available jobs for which PWDs and non-PWDs are competing. The y-axis is the remuneration from these jobs.

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ON THE INCLUSION OF DISABLED PERSONS IN THE LABOR MARKET: LESSONS FROM THE DISABILITY EMPLOYMENT GAP

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Albino Barrera's paper (PASS 2024) provides an impressive list of ethical, moral, and economic reasons comprehensively including persons with disabilities (PWDs) in the labor market. At the same time, it convincingly shows that there are many factors preventing the integration of PWDs. For one thing, PWDs are thought to have lower productivity, they may find it difficult to commute to the workplace, and they are stereotyped by the population. What's more, disabilities are highly heterogeneous in their form and extent, they intersect strongly with socio-economic characteristics (low household income, housing problems, health problems), and companies incur high costs for universal accessibility. All of these factors are closely interwoven and are intensified by the speed of transformations in the labor market, increased competition, and globalization.

In this paper, we turn to the statistics. In the first section, we compare countries based on new OECD publications (OECD 2022) and answer four questions: (1) How many people are classified as disabled, and how is disability linked to age and education? (2) How do PWDs transition into the labor market and what proportion of PWDs are especially vulnerable because they are not in education, employment, or training (NEET)? (3) How well do PWDs participate in the labor market? (4) What are PWDs' income situations? How do they fare in the interplay between the market, the state, and the family?

The second section deals with the more conceptual question of whether the proportion of PWDs in education or work is a good indicator for the integration of people with disabilities. It looks at what is lurking behind the aggregated country figures. Using Germany as an example, we show that figures that suggest a high level of inclusion may hide extensive exclusion of PWDs in education and work. This clearly contradicts the guidelines of the UN Convention on Human Rights.

The third section addresses another conceptual issue: whenever we talk about the inclusion of PWDs in the workplace, we very narrowly think about gainful employment, that is, market-based employment. We omit the nonmarket work that is just as necessary for society, such as raising children, caring for the elderly, or volunteering. In doing so, we apply an all-too-narrow and unsuitable concept of work to PWDs. Even work that serves the common good rather than the market can also be productive.

We close with a short summary of lessons learned.

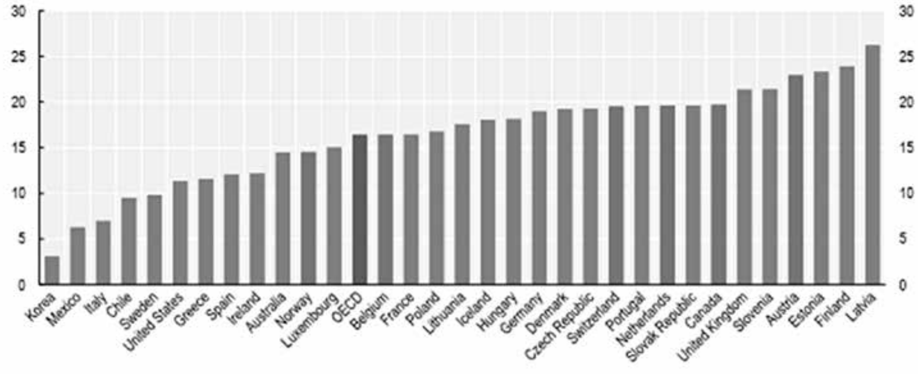
1. Proportion of PWDs, transition to the labor market, employment, and household income in selected OECD countries

1.1 Persons with disabilities

For anyone wishing to compare the proportion of PWDs in selected OECD countries, the first issue to address is the selectivity of the sample. For instance, samples do not include persons under the age of 15 and older than 69 or PWDs living in care homes. This results in an underestimation of PWDs.

As Figure 1 shows, the cross-country average of PWDs is 18 percent across all 32 OECD countries surveyed. However, the range is huge, going from 3 percent in Korea to 27 percent in Latvia. This is extremely unlikely to be due to state-specific PWD rates, as the different levels would be difficult to explain. In this instance, statistical artifacts may be to blame. The country data is based on different definitions of what constitutes a disability. European countries define people as disabled if they state that they (a) suffer from any chronic illness or condition with (b) moderate to severe activity limitations due to health problems. In Australia, PWDs are people with “restrictive long-term health conditions, impairments or disability.” In Canada, the definition lists nine specific impairments (such as seeing, hearing, moving, thinking, etc.) along with other long-term illnesses. The USA, Mexico, and Chile take a similar approach, referring to six specific disabilities (see Fig. 1, legend). The application of different definitions may result in different levels of PWDs.

Moreover, we face different national cultures in the self-assessment of disability. This is best seen when we compare nations with similar definitions of disability, such as Korea (with a 3% PWD rate) and Canada (with a 19% PWD rate), or by comparing European countries following the same definitions of PWDs, such as Italy (where PWDs make up 7% of the population) and Latvia (with a 27% PWD rate). Quite obviously, people with similar symptoms do not consider themselves disabled in one culture but do so in another. Another possibility is that people differ in their willingness to define themselves as PWDs according to how problematic they find it.



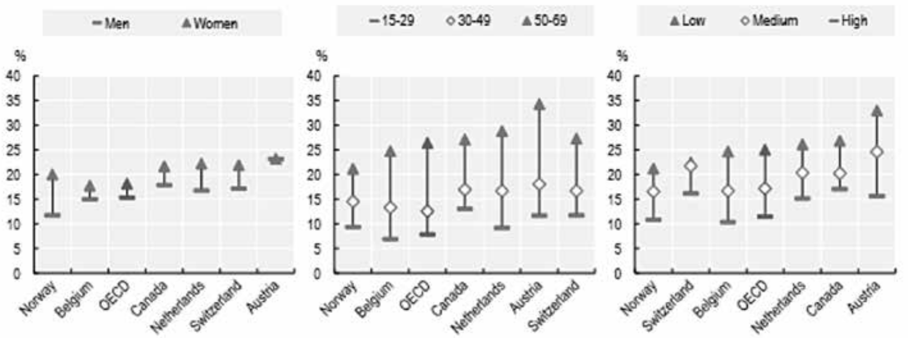
Note: OECD is the unweighted average of the 32 countries shown. Based on different sources for European and non-EU countries, data are not fully comparable. European countries define people with disability as those who 1) declared to suffer from any chronic illness or condition and 2) with moderate to severe activity limitation due to health problems. For Australia, persons who declared having a long-term health condition, impairment or disability that restricts them in their everyday activities, lasting for six months or more. For Canada, persons who report a limitation in their day-to-day activities due to difficulty in 1) seeing, hearing, mobility, flexibility, dexterity, pain-related, learning, developmental, mental health-related or memory issues, or 2) because of any other long-term health condition. For Chile, Mexico and the United States persons who reported having difficulty in: 1) Walking, moving around, going up or down stairs; 2) Vision, even when wearing glasses; 3) Talking, communicate or exchange (and difficulty doing errands alone, United States); 4) Hearing, even with a hearing aid; 5) Dressing, bathe or eat; or 6) Concentrating or learn simple things. For Korea, persons who declared having any persistent physical limitations or disability: 1) Visual, auditory problems or speech impediment, 2) Difficulties in physical activities, 3) Difficulties in learning; 4) Difficulties in indoor activities; 5) Difficulties in outdoor activities; 6) Difficulties in working. Levels of education defined according to the International Standard Classification of Education (ISCED). *Low* refers to below upper-secondary, *Medium* to upper secondary and *High* to tertiary education. Data refer to 2016 (Mexico), 2017 (Canada), 2016-17 (Chile) and 2016-18 (Belgium, Iceland, Ireland, Italy, Korea, United Kingdom, United States) and 2018 (Australia).

Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC) for European countries; Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2018 (Table 3.1); the Canadian Survey on Disability (CSD, 2017) provided by Employment and Social Development Canada; Chile's Encuesta de Caracterizacion Socio-economica Nacional (CASEN, 2016-17). Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH 2016); the Korean Labour & Income Panel Study (KLIPS, 2016-18) and the American Community Survey (ACS, 2016-18).

Figure 1. People with disabilities as a share of the population aged 15-69, selected OECD Countries, average over 2016-19. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 33*

This is interesting in itself, as it indicates the extent to which the respondents' self-classifications are a result of their social environment. For meaningful international comparisons, however, it is crucial to have a common definition of PWDs and to have data based on medical diagnoses rather than self-assessments. At present, not much can be learned from country percentages.

Much more can be learned when we consider differences by gender, age group, and educational level *within* the countries. Figure 2, Panels A, B, and C, show very uniform trends. Women consider themselves to be disabled slightly more often than men, but the differences are modest. Age makes a greater impact: There is a lower proportion of PWDs in the youngest



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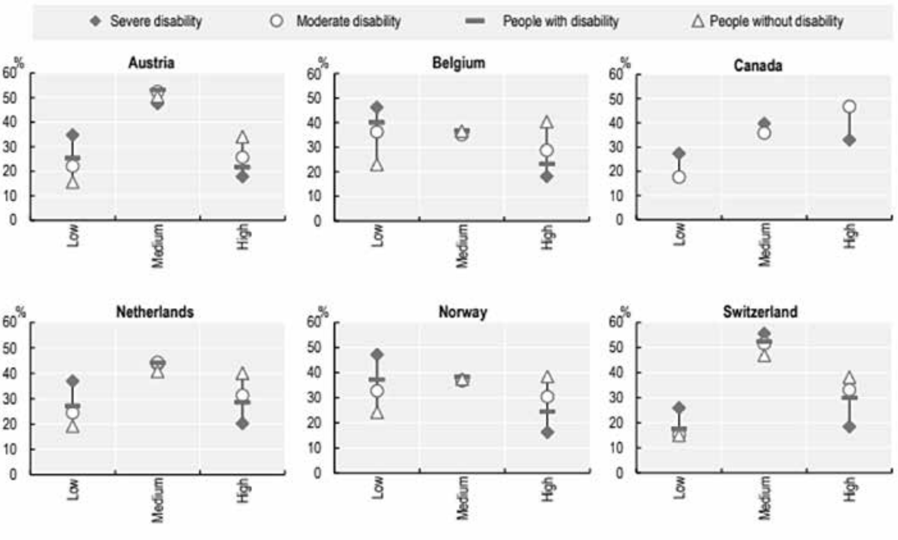
Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC) for European countries; Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2018 (Table 3.1); the Canadian Survey on Disability (CSD, 2017) provided by Employment and Social Development Canada; Chile's Encuesta de Caracterizacion Socio-economica Nacional (CASEN, 2016-17). Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH 2016); the Korean Labour & Income Panel Study (KLIPS, 2016-18) and the American Community Survey (ACS, 2016-18).

Figure 2. Panels A-C: Disability prevalence by gender, age, and level of education, 2019. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 33.*

age group (15-29 years) than in the middle age group (30-49 years), and there are especially clear differences with the oldest age group (50-69 years). Note, however, that the surveys are selective, as they often do not reach people with severe disabilities at all. Since the oldest age group (69 and older), which has the highest disability rates, is not included in the data, we could assume that most disabilities are due to employment, accidents, or military service and less so to increased life expectancy. In turn, many disabilities may be avoided with preventive health policies.

Differences by educational attainment are equally clear, albeit difficult to interpret. The data say nothing about causality: Are PWDs less likely to achieve a good education or does a good education protect them from disability? Life-course data would be required to answer this question; however, they are not available in most countries. Not surprisingly, people with a high level of education are less likely to report a disability than people with a medium level of education, and they are much less likely to report disability than those with a low level of education (Fig. 2, Panel C). These differences are not inevitable. In Switzerland, for example, differences in disability by level of education are much lower than the OECD average or in neighboring Austria. The reason for this is that, in Switzerland, people with disabilities find it easier to access a good education, so level of education is less likely to determine disability.

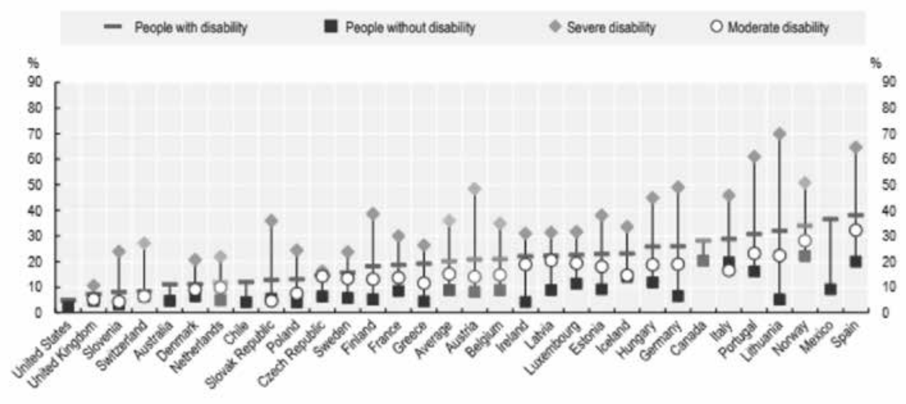
Figure 3 provides more detail and contrasts different levels of disability. In the six countries examined, people with a severe disability are most likely have a poor education and least likely to attain a high level of education. There are striking differences between countries. In Belgium, 50 percent of people with severe disabilities have the lowest level of education; in Switzerland and Canada, the figure is under 30 percent. In Canada, more than



Note: Data cover persons aged 15-69. Levels of education defined according to the International Standard Classification of Education (ISCED). *Low* refers to below upper-secondary, *Medium* to upper secondary and *High* to tertiary education. Data refer to the average over 2016-18 for Belgium and to 2017 for Canada; for exceptions and for country definitions of people with disability, see Figure 2.1.

Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC 2005-19) for European countries and data provided by Employment and Social Development Canada based on the Canadian Survey on Disability (CSD, 2017).

Figure 3. Share of the working age population by highest level attained and disability status, average over 2016-2019. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 36.*



Note: Data for Canada refer to 2017. No data available in 2019 (Belgium, Iceland, Ireland, Italy, United Kingdom) and in 2018 (Estonia). The purple markers are an unweighted average of the 32 countries shown. Early school leavers are defined as persons aged 15-29 who are not in education and do not have an upper secondary school diploma.

Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2016-19) for European countries. Household, Income and Labour Dynamics in Australia Survey (HILDA, from 2016-17), the Canadian Survey on Disability (CSD, 2017) provided by Employment and Social Development Canada, Chile's Encuesta de Caracterizacion Socio-economica Nacional (CASEN, 2017), Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016), the Korean Labor & Income Panel (KLIP) and the American Community Survey (ACS).

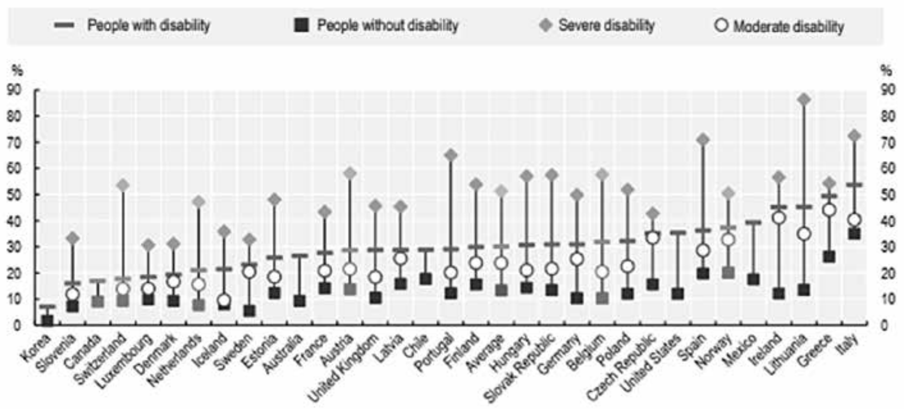
Figure 4. Share of early school leavers by disability status, average over 2016-19. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 37.*

30 percent of people with severe disabilities have a high school diploma, compared to just 18 percent in the Netherlands. In addition to the level of education achieved, the gap between people with and without disabilities is also interesting. In Switzerland, there is merely a 10-percentage-point gap between people without and with severe disabilities in the low education sector; in Belgium, by contrast, it is almost 30 percentage points. The Swiss school system and/or Swiss disability policies seem to be more inclusive.

Let us now turn to educational poverty, defined as the proportion of people without any school diploma. Research shows that educational poverty often impedes labor market access. However, educational poverty has even more far-reaching consequences: The people affected often lack social contacts, self-efficacy, and the knowledge that they are wanted, valued, and needed. Country comparisons show (Fig. 4) that differences in educational poverty among people without disabilities are quite low – with the exception of Italy, Spain and Portugal. Country differences increase as disabilities become more severe. In Switzerland, 25 percent of people with severe disabilities are educationally poor, in Germany, the figure is 50 percent, and in Portugal, Spain, and Lithuania, it is over 60 percent.

1.2 Disability and transition to employment

The transition between education, training, and employment is important for everyone, but PWDs find it more difficult than almost any other group. This is demonstrated by the very high proportion of NEETS – people not in education, employment, or vocational training – between the ages of 15 and 29. As a basis for comparison, consider that, among people without a disability (PWODs), the proportion of NEETs is generally around 10 percent; in Italy, Greece, Spain, and Mexico, it is around 30 percent (Fig. 5). Yet, for PWDs, especially those with severe disabilities, rates are much higher. In most of the OECD countries presented here, the proportion of NEETs is over 50 percent; in Italy, Spain, Portugal, and Greece, it is even over 70 percent. Diplomas seemingly make little difference. For example, few PWDs leave the Dutch education system without credentials but the proportion of NEETs is 50 percent. This suggests some reluctance and stereotyping on the part of employers – for reasons mentioned at the beginning and described so aptly in the paper by Albino Barrera (PASS



Note: Data for Canada refer to 2017. No data available in 2019 (Belgium, Iceland, Ireland, Italy, United Kingdom) and in 2018 (Estonia). The purple markers are an unweighted average of the 32 countries shown. NEETs are defined as persons aged 15-29 who are not in education, employment or training. NEETs rates based on other data sources seem to suggest that the data in the figure overestimate the NEET levels in some countries, especially Norway and Italy. Disability gaps are likely less affected by the choice of the data source.

Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2016-19) for European countries. Household, Income and Labour Dynamics in Australia Survey (HILDA, from 2016-17), the Canadian Survey on Disability (CSD, 2017) provided by Employment and Social Development Canada, Chile's Encuesta de Caracterizacion Socio-economica Nacional (CASEN, 2017), Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016), the Korean Labor & Income Panel (KLIP) and the American Community Survey (ACS).

Figure 5. Transition from school to work: Share of NEETs (aged 15-29) by disability status, average 2016-2019. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 37.*

2024). At this sensitive juncture between the state and the market, large numbers of people with (severe) disabilities are being lost.

1.3 Disability and labor market participation

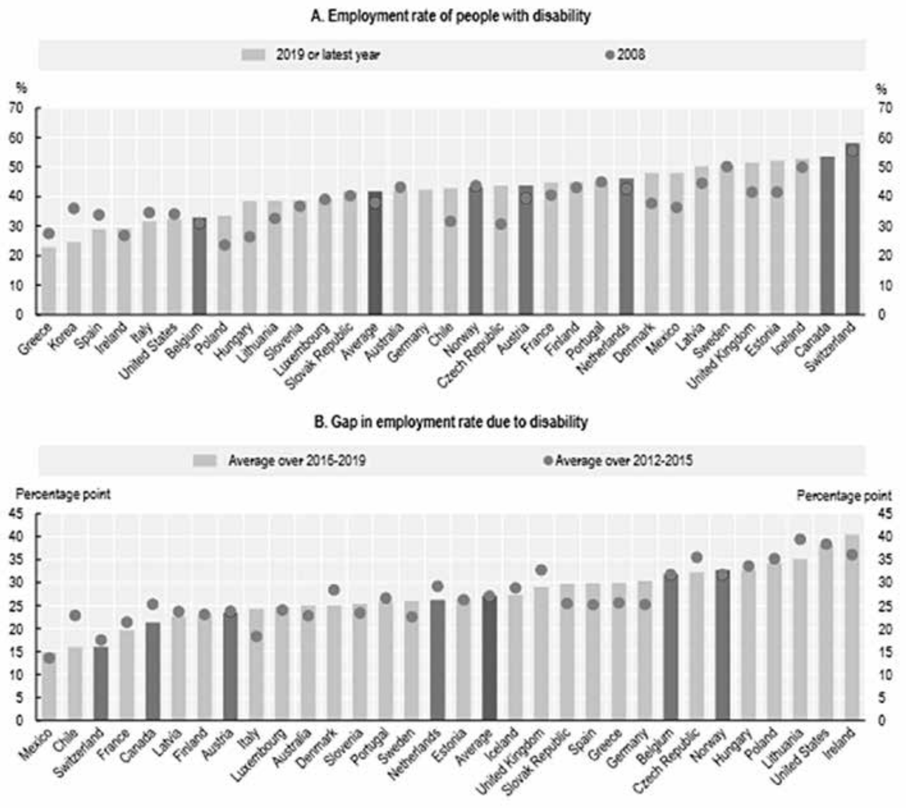
Panel A of Figure 6 shows the employment rates of people with disabilities, while Panel B depicts the differences between the employment rates of people with and without disabilities. Again, there are significant differences between the countries, which cannot be explained by educational certificates. For example, in the US, PWDs' educational poverty is quite low while the percentage of NEETs is high and the employment gap between PWDs and PWODs is almost 40 percent.

People with severe disabilities find it particularly difficult to get a job, and it is more difficult for women than for men (Figure 7, Panels A and B). PWDs' employment rates also vary by age. The younger (15-29) and older (50-69) age groups have a lower labor force participation than PWDs aged 30 to 49. The same applies to PWDs with low and medium education levels compared to those with high education levels (Figure 7, Panels C and D), although differences here are smaller than expected.

Once PWDs have found a job, further inequalities emerge. In all countries, PWDs have a significantly lower average income than PWODs. As Figure 8 shows, these differences are particularly high in Korea, Lithuania, Sweden, and Mexico, where PWDs' annual income is between 65 and 75 percent of the income of PWODs; in Italy and Greece, the differences are significantly lower (Figure 8).

Many PWDs receive transfer payments due to illness, disability, unemployment, retirement, or social assistance (see Figure 9) that either replace or supplement their market income. Among people with severe disabilities, between 60 and 100 percent of people receive these payments. Transfers are particularly high in the 50 and 69 age group and among PWDs with a low level of education. For many, state transfers are higher than market income.

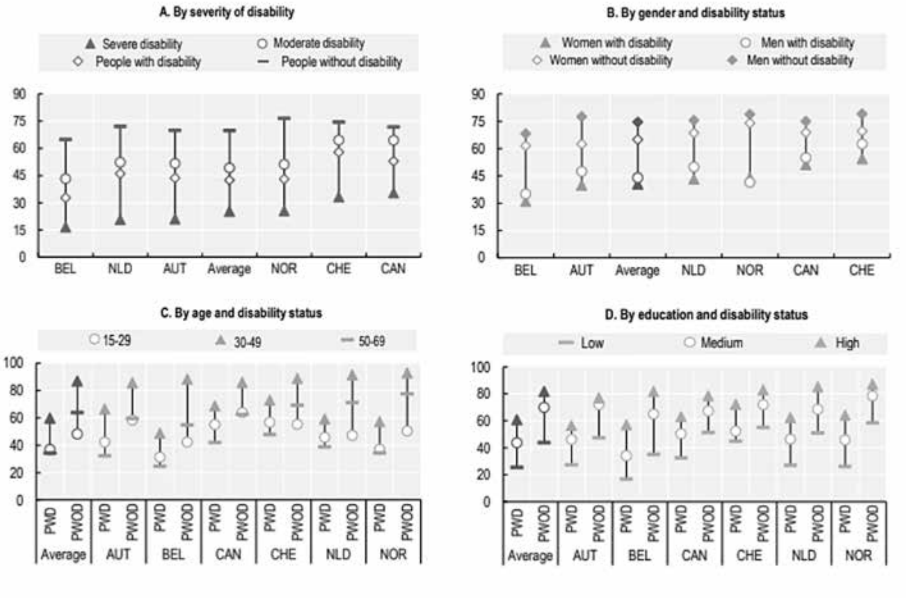
Despite transfer payments, PWDs' disposable household income is still significantly lower than that of PWODs. This is shown in Figure 10. The differences are again stark in the US, where PWDs receive only 65 percent of the disposable household income of PWODs; they are considerably lower in Slovakia and Italy. It is thus not surprising that a high proportion of PWDs live in poverty and that they have a significantly higher risk of living below the poverty line than PWODs (Fig. 11).



Note: Data cover persons aged 15-69. For country definitions of people with disability, see Figure 2.1. Exceptions Panel A: Year 2019 refers to 2014 (Korea), 2016 (Mexico), 2017 (Australia, Chile) and 2018 (Belgium, Iceland, Ireland, Italy, United Kingdom, United States). Exceptions Panel B: Periods refer to 2013-16 and 2017-19 for Canada, 2016-18 (Belgium, Iceland, Ireland, Italy, United Kingdom) and no data in 2018 (Estonia). The purple bars represent the unweighted average of the 26 countries shown (excluding Korea). For Australia, data presented are based on the Household, Income and Labour Dynamics in Australia Survey (HILDA). When using data from the Australian Bureau of Statistics' *Survey of Disability, Ageing and Carers (SDAC)*, the employment rate of persons with disabilities in 2018 is slightly higher at 48%, and the gap in employment due to disability is also higher at 32 percentage points.

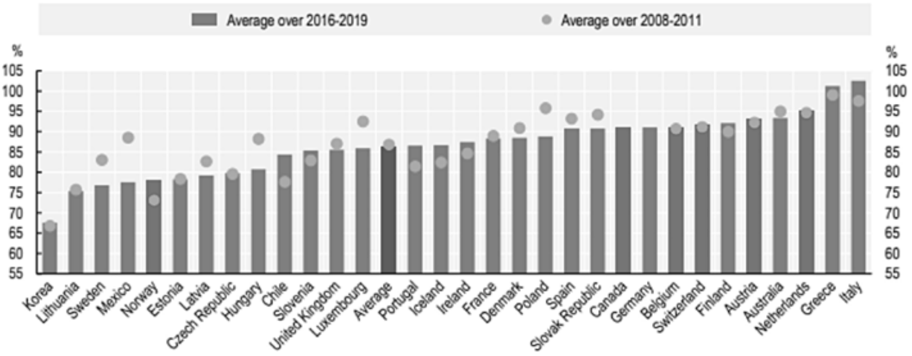
Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2005-19) for European countries; the Household, Income and Labour Dynamics in Australia Survey (HILDA, 2005-17); Chile's Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2006-17); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2010-16); the Korean Labour & Income Panel Study (KLIPS, 2008-18) and the American Community Survey (ACS, 2008-18). Data for Canada provided by Employment and Social Development Canada based on the Canadian Income Survey, 2013-19.

Figure 6. Employment rate for PWDs and gap in the employment rate, calculated as the percentage point difference of rates of employment of PWODs and PWDs. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 39.*



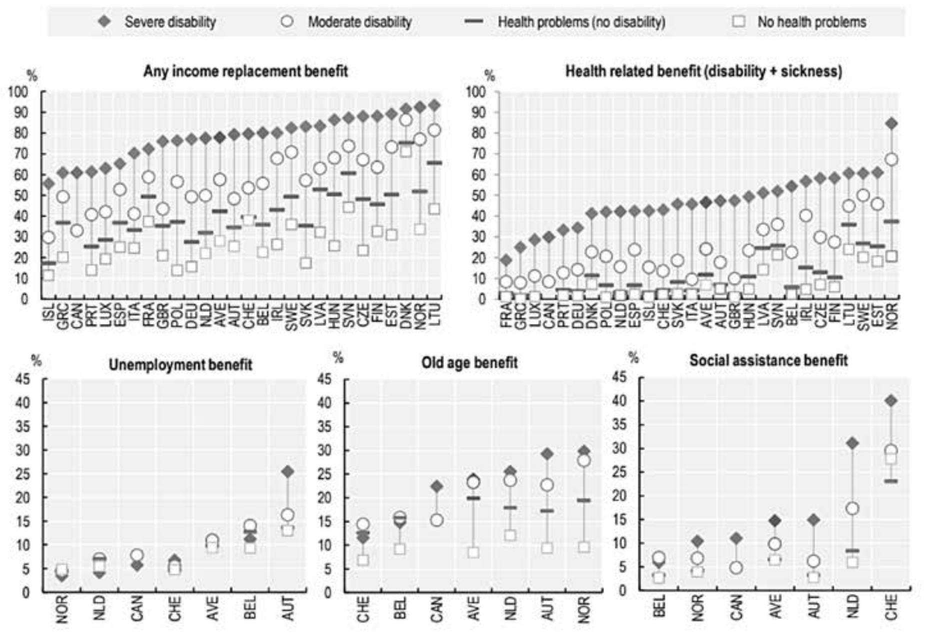
Note: PWD: People with disability; PWOD: People without disability. The purple markers represent the unweighted average of 26 European OECD member countries and Canada. Data refer to 2017 (Canada, Panels A and B) and 2018 (Belgium).
Source: OECD calculations based on the European Union Statistics on Income and Living Conditions, 2019. Data provided by Employment and Social Development Canada based on the Canadian Survey on Disability, 2017 (Panels A and B); Canadian Income Survey, 2019 (C and D).

Figure 7. Employment rate by severity of disability, gender, age, and level of education. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 42.*



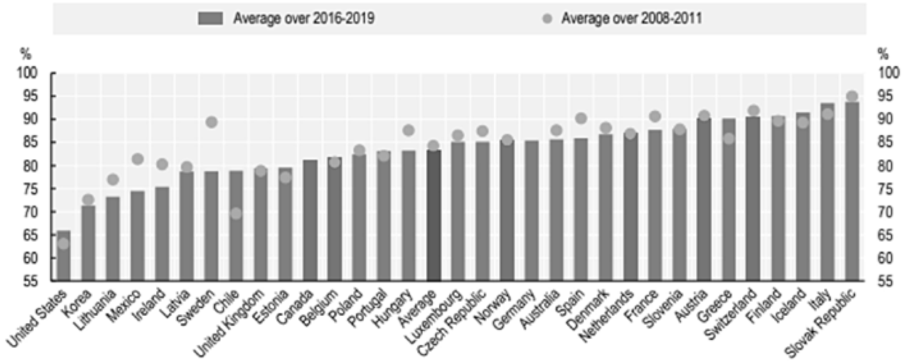
Note: Data refer to annual employee wages employee cash or near cash income for employees and cash profits or losses from self-employment for persons self-employed (European countries); main labour income in cash (Chile); financial year gross wages and salary (Australia); average hourly wage excluding self-employed and the Canadian Armed Forces (Canada); total after-tax yearly earned income (Korea); main wage in main work, piece rates, commissions, payment for extra hours in main work, incentive pay, bonus, holiday pay and cash income second job (Mexico) and total wage and salary earnings (United States). Period 2016-19 refers to 2012-15 (Korea). The purple bar is the unweighted average of the countries shown excluding Canada and Germany which do not have data for the earlier period. For country definitions of people with disability, see Figure 2.1; Panel B: Data represent the unweighted average of 21 European countries: Austria, Belgium, the Czech Republic, Denmark, Estonia, Germany, Finland, France, Ireland, Latvia, Lithuania, Luxembourg, the Netherlands, Norway, the Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Türkiye and the United Kingdom). Shift: working in shifts. Night, Saturday, Sunday, More than 10 hours a day relates to normally working at least once a month this type of unsocial working hours.
Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2008-19) for European countries. Exceptions: 2016-18 (Belgium, Iceland, Ireland, Italy, United Kingdom). The Household, Income and Labour Dynamics in Australia Survey (HILDA, 2008-17); the Canadian Income Survey (CIS, 2016-19) provided by Employment and Social Development Canada; Chile's Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2010-17); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016).; the Korean Labour & Income Panel Study (KLIPS, 2008-18) and the United States Current Population Survey (CPS, 2008-18).

Figure 8. Average annual full-time wage of PWDs over PWODs, average for 2016-19 and for 2008-2011. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 45.*



Note: Data refer to 2017 for Canada. For country definitions of people with disability, see Figure 2.1. The purple markers (AVE) represent the unweighted average of the countries shown in the top panels.
Source: The Canadian Survey on Disability, (CSD, 2017) provided by Employment and Social Development Canada and OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2016-19).

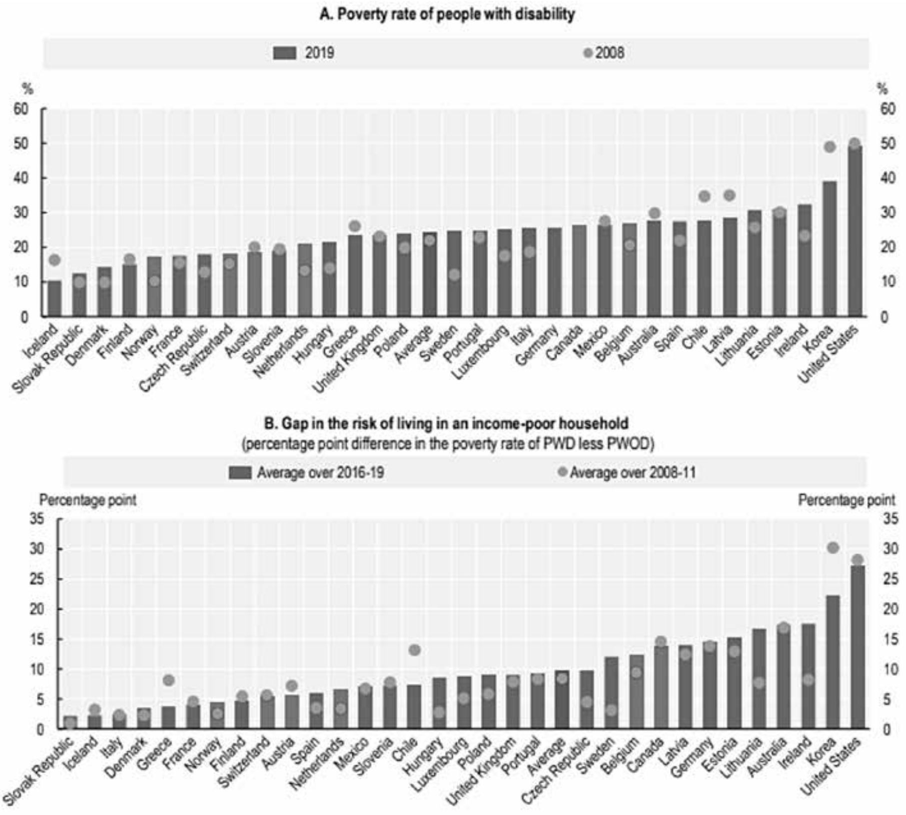
Figure 9. Share of persons (aged 15-69) receiving income replacement benefits by type of benefit and disability status. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 49.*



Note: Data cover persons aged 15-69. Panel shows the average equivalised disposable household income ratio between households with and without people with disability. Household income was equivalised dividing by the square root of the size of the household. The purple bar represents the unweighted average of the countries shown for both time periods (excludes Canada and Germany).

Source: OECD calculations based on European Union Statistics on Income and Living Conditions (EU-SILC, 2008-19) for European countries. Data not available in 2019 (Belgium, Iceland, Ireland, Italy, United Kingdom) and 2018 (Estonia). The Household, Income and Labour Dynamics in Australia Survey (HILDA, 2008-17); the Canadian Income Survey (CIS, 2016-19) provided by Employment and Social Development Canada; Chile's: Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2016-17); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016); the Korean Labour & Income Panel Study (KLIPS, 2008-18) and the United States Current Population Survey (CPS, 2008-18).

Figure 10. Ratio of disposable household income, PWDs to PWODs, 2016-19. *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 54.*



PWD: People with disability, PWOD: People without disability.
Note: The data in Panel A show relative income poverty, i.e. the share of people living in a household with an income below 60% of the median income. Household income is equivalised for household composition by dividing by the square root of the size of the household. The data in Panel B show the percentage point difference between households with and without people with disability in the risk to live in a low-income household. The data for 2008-11 refers to: 2013-16 (Canada); 2012-15 (Germany) and 2010 (Mexico). Data for 2016-19 refers to 2016-17 (Australia); 2017-19 (Canada); 2017 (Chile); 2016-18 (Belgium, Iceland, Ireland, Italy, United Kingdom, United States); 2016-17, 2019 (Estonia); 2018-19 (Korea); 2016 (Mexico). The purple bars represent the unweighted average of the countries shown in each panel.
Source: OECD calculations based on the European Union Statistics on Income and Living Conditions (EU-SILC, 2008-19) for European countries. The Household, Income and Labour Dynamics in Australia Survey (HILDA, 2008-17); the Canadian Income Survey (CIS, 2013-19) provided by Employment and Social Development Canada; Chile's: Encuesta de Caracterizacion Socioeconomica Nacional (CASEN, 2016-17); Mexico's Encuesta Nacional de Ingresos y Gastos de los Hogares (ENIGH, 2016); the Korean Labour & Income Panel Study (KLIPS, 2008-18) and the United States Current Population Survey (CPS, 2008-18).

Figure 11. Poverty rate of PWDs and gap in the risk of living in an income poor household (difference between PWDs and PWODs). *Source/Copyright: OECD (2022). Disability, Work and Inclusion: Mainstreaming in All Policies and Practices, p. 55.*

2. Participation in the education and employment system as a measure of social integration? The case of Germany

At first glance, Germany appears rather unremarkable in an international comparison of PWDs. On most of the indicators used so far to measure participation by PWDs, Germany ranks in the middle of the table. We could therefore reasonably assume that the inclusion of PWDs in Germany is not good but not much worse than in other countries.

This is not the case. In Germany, institutions such as special schools and workshops for the disabled (*Behindertenwerkstätten*) constitute parallel structures in the education and employment system. They separate PWDs and PWODs into two institutional realms. Aggregate figures mask this institutional divide.

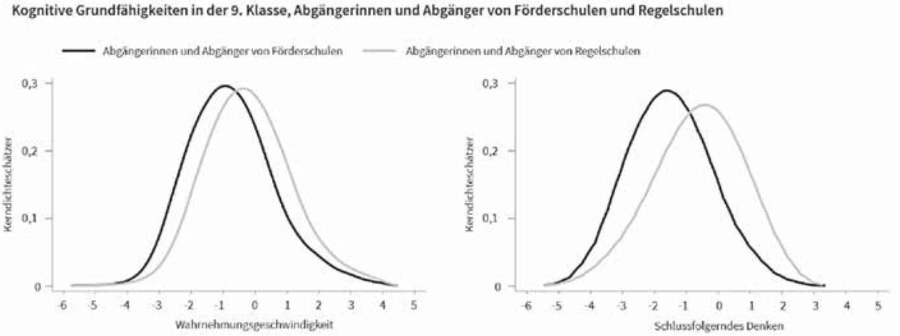
The UN Convention on the Rights of Persons with Disabilities (Art. 24, United Nations 2006) came into force in Germany in 2009. It demands that PWDs' needs be considered in all areas and requires inclusive schooling – meaning that children with and without disabilities learn together – as well as an integrated education and employment system. The reality in Germany is different.

In Germany, pupils with special educational needs are often taught at separate schools. In 2018, 320,922 pupils attended separate special schools. This represents more than half of all school-age children with special educational needs (KMK 2020). By contrast, in the USA and Italy, for example, almost all children – including those with learning difficulties and disabilities – are taught at mainstream schools (Powell 2016).

In special schools, children with disabilities are taught separately from other children in all areas. In 2020/21, 313,857 of the 567,908 pupils with special educational needs were in special schools, meaning that the inclusion rate was 44.7 percent. This is significant progress compared to 2008/09, when the inclusion rate was only 9 percent (Klemm 2022). However, the overall proportion of children at special schools in relation to all pupils in a birth cohort (exclusion rate) has only fallen from 4.8 percent to 4.3 percent, which corresponds to a decrease of around 37,000 pupils (Menze et al. 2021; Klemm, 2022). This can be explained by the fact that children are increasingly being diagnosed with special educational needs and that this group has grown significantly in terms of numbers.

Differences between the federal states are striking. In Bremen, almost all special schools have been abolished since 2008/9 and children with special educational needs have been integrated into normal school life. The exclusion rate in that state is 0.7, while it is much higher in Saxony-Anhalt (6.5), Saxony (5.5), Mecklenburg-Western Pomerania (5.3), and Baden-Württemberg (5.0) (Klemm 2022). The opportunities for children with disabilities therefore differ almost as much within Germany as they do internationally.

The retention of special schools cannot be justified on educational or social grounds. On the contrary, studies suggest that children in special schools are in many respects worse off than children in Germany's lowest mainstream educational track, the *Hauptschule*. This is also the conclusion of a study by Laura Menze and others (2021) that examined transition processes between school and work using data from the National Educational Panel Study. Laura Menze et al. noted that the basic cognitive abilities (perceptual speed and deductive learning) of school leavers from special schools and mainstream schools clearly overlapped (Figure 12). Allocations to one or the other type of school therefore appeared arbitrary. Yet, the consequences of this allocation are severe. The majority of school leavers from special schools do not attain the lowest school diploma, the *Hauptschulabschluss* (73 percent) while the vast majority of school leavers from mainstream schools do so, with only 10 percent leaving school without this diploma. Furthermore, young people from mainstream schools enter vocational training



Kognitive Grundfähigkeiten in der 9. Klasse, Abgängerinnen und Abgänger von Förderschulen und Regelschulen

Anmerkung: Die kognitiven Grundfähigkeiten wurden über die gesamte NEPS-Startkohorte 4 hinweg z-standardisiert. Dies resultiert für die Gesamtkohorte in einem Mittelwert von 0 und einer Standardabweichung von 1. Fehlende Werte wurden mittels Imputationen (basierend auf multiple imputations by chained equations / MICE) ersetzt. Es wurden 25 Datensätze imputiert; in der Abbildung ist jeweils die erste Imputation dargestellt.

Lesebeispiel: Die höchsten Punkte der Verteilungen zeigen die Bereiche der Fähigkeiten, die bei den den Jugendlichen am häufigsten vorkommen. Bei einer Verteilung, die weiter rechts liegt, zeigen die Jugendlichen bessere Fähigkeiten.

Quelle: doi:10.5157/NEPS:SC4:10.0.0; eigene Berechnungen (N = 991, davon 287 Förderschulabgängerinnen und -abgänger und 704 Regelschulabgängerinnen und -abgänger). © IAB

Figure 12. Basic cognitive skills in the 9th grade, graduates of special schools (*Förderschule*) and standard high schools (*Regelschule*) (in Germany). *Source/Copyright: Menze, L., Sandner, M., Anger, S., Pollak, R., & Solga, H. (2021). Young people from special schools with a focus on "learning": Difficult transition to training and the labor market (IAB-Kurzbericht 22). IAB, p. 6.*

more frequently than pupils from special schools (87 percent vs. 77 percent) and complete it more often (30 percent vs. 13 percent).

Special schools achieve the opposite of what they are supposed to achieve. They educate pupils less well than mainstream schools. They make the transition into the employment system more difficult. And they lead to a vicious circle of stereotyping and feed PWDs' sense of not belonging.

After special schooling, few PWDs start vocational training. Instead, most transition from special school into special employment programs, appropriately called rehabilitation programs. These are paid for by the Federal Employment Agency and rarely lead to permanent integration into the labor market. Here, too, PWDs remain among themselves.

This also explains the substantial difference in the proportion of NEETs between people with severe disabilities (50 percent) and people without disabilities (8 percent). The majority of people with severe disabilities are assigned to special schools, cannot switch to another school type, and leave school without a diploma, which is the worst possible starting point for a successful transition into training and later into employment.

Exclusion also continues in working life. Workshops for people with disabilities are facilities that isolate rather than integrate PWDs. In 2023, around 270,000 people, mostly people with cognitive and multiple impairments, were employed in workshops for people with disabilities (Bellan 2023). Their salary is 226 euros per month, which corresponds to an hourly wage of just over one euro. As most of these people receive basic income support, the income they earn is also offset against their basic income support (Schütz and Eibelshäuser 2023).

Many people who work in these workshops do not do so of their own free will. Typically, they express a desire to work in the primary labor market. When asked why they have not been able to enter it, they cite a lack of information, a lack of support, problems in commuting to work, or the lack of barrier-free working environments. Moreover, some lack the confidence to work in the primary labor market or are worried about losing their friends in the workshop (ibid.).

The magnitude of the difficulties faced by people with disabilities in Germany is demonstrated by the companies that do not employ PWDs despite an obligation to do so and instead pay the resulting fines. Companies are obliged to employ people with disabilities if they have 20 or more employees; they must fill at least 5 percent of these positions with people with severe disabilities. Statistics show that in 2020, of around 160,000 private-sector employers with 20 or more employees, a good 100,000 had to pay a penalty. More than 43,000 of them did not employ any people with a severe disability at all. In the public sector, the picture is more mixed: 7,100 of 11,700 employers met their obligations and were thus not liable to pay the levy but almost 1,200 did not employ any persons with severe disabilities. The federal government has since reacted: In order to increase pressure on companies, the rates rose on January 1, 2024. Since then, large companies that do not employ any people with severe disabilities have had to pay 720 euros/month for every job that, according to the law, should be filled by a person with a severe disability.

Nevertheless, given the highly segregated structures in education, training, and employment, it is not surprising that the UN clearly criticizes Germany in its latest state report on the realization of the rights of people with disabilities (United Nations 2023), focusing in particular on special schools: "The chain of exclusion from special schools to special workshops and residential homes for people with disabilities must finally be broken in Germany too by inclusive services for a life in the middle of society."

3. From a society of gainful employment to a society of activity

In the previous sections, we have tacitly equated integration with integration into the labor market and gainful employment – that is, we have regarded work as purely market-related work through which services and goods are produced to generate income, be it dependent or independent employment or one of the many forms in between. We propose a shift in emphasis from a "work-oriented society" to an "activity-oriented society" as was envisioned by Ralf Dahrendorf (1983) and has been repeatedly emphasized in feminist, ecological, and Catholic discourses (National Academy of Sciences/Union of German Academies of Sciences and Humanities 2024). This means that work should no longer be considered synonymous with paid work. Instead, the concept of work should be understood more broadly and include non-market-related activities, such as citizen work, care work, education, family, and household work.

There would be several implications of such a shift. First, it would create a more complex understanding of the work-oriented society and explore potential dimensions of the *purpose of work* far beyond its market value and its results. An extended understanding of work could account for the practical and intellectual developments of a time in which the concept of work was not yet subsumed or limited by industrial capitalism. It would address work as an irreplaceable medium of individual fulfilment and self-realization, community building via cooperation and mutual recognition, and the – indirect – participation in a larger whole. It would understand work as part of creating the common good beyond one's individual benefit and ultimately also beyond service to the individual. To speak of an "activity-oriented society" rather than a "work-oriented society" is more than a language policy or symbolic demand; language not only reflects societal reality but also shapes it. When non-market-related work is identified and dealt with as such, these activities – which are a necessary precondition for and addition to paid work – will become visible. At the same time, currently existing tensions between paid work and other activities will become apparent, as will the regulations and social safety nets associated with the different forms of activities.

Second, the concept of an activity-oriented society also entails culturally enhancing non-market-related activities. It should therefore be reflected in the cartographies of society and politics and be included in key economic metrics. This would be a welcome contribution to gender equality, since non-market-related activities are predominantly still performed by women. In the long term, this could lead to a further alignment of male and female activity profiles. Moreover, it would make a more flexible distribution of work between people of different ages, with different health conditions, and in different phases of life easier, as well as improving the inclusion of PWDs. The concept of unemployment, which so far is exclusively defined by the lack of paid work, would likely also undergo change.

At the same time, and third, a broader concept of work could shift attention to the opportunities and limitations of individual self-realization in view of the challenges that have to be overcome together.

This shift toward the concept of an activity-oriented society would not lead to a devaluation of market-related paid work. It would remain a central and necessary element in order to ensure societal prosperity and enable people to engage in unpaid activities. This shift would, however, mean assessing the opportunities that lie in an activity-oriented society. This includes the opportunity for people to participate in flexibly shaping their work biographies and carrying out other activities without ending up in financial dead ends. For this purpose, a certain degree of federal regulation, welfare-oriented social security, and public good provision (education and continuing education, health, and constructed environment) would be necessary. If such changes occurred, they would bring the achievements that an activity-oriented society provides to the fore and enable the promotion of the common good.

The likely potentials for development concern the societal organization of work on all levels: individuals and their immediate environment, the relationship between free enterprise and responsibility, and the design of appropriate political frameworks. At its core, it is about a new balance between cooperation and competition, creation and appreciation of value.

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MENTAL DISABILITIES. WHY ARE THEY INCREASING AND WHAT SHOULD BE DONE TO REVERSE SUCH A PERVERSE TREND

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Abstract

After a synthetic characterization of mental disabilities and of the socio-economic determinants of their growing, the paper focuses on two major issues. On one hand, which policies can be envisioned to cope with the inhumane disability employment gap, especially as far as the neuro-divergent people are concerned. On the other hand, how to accelerate the transition from the by now obsolete model of welfare state to the community welfare model in order to implement practically the subsidiarity principle. A final section suggests that if the ultimate goal is to arrive at a substantial social inclusion of all disabled people it is necessary to introduce into the institutional design the *agape* principle.

1. Introduction

October 10, 2023 marked World Mental Health Day, established in 1992 by the World Health Organization, with the aim of increasing the perception of the urgency of combating the stigma still persisting on the issue. The term “mental health” is not limited to the mere absence of mental pathology or existential distress, but refers to the state of inner balance that enables a person to use all the emotional, cognitive, social and physical resources available to him or her. Today, medicine clarifies how there is no separation between body and mind. Therefore, mental health does not end with psychological well-being alone, but involves a more global dimension of the person.

Mental suffering has always been accompanied by fear and shame, and while it is true that today mental pathology is viewed differently than in the past, partly because there are effective therapies for it, it is equally true that social prejudice and the stigma of incurability are still so deeply rooted. People with mental disorders are often viewed as dangerous by society, and mistrust of doctors who deal with these conditions is one of the biggest barriers to accessing treatment. Talking about mental health and realizing that the mental dimension deserves at least equal, if not greater, attention than that given to the physical component in order to experience complete well-being is something that can and should be done.

If the terms are the analysers of the times – the *signa temporum* – vulnerability fits right into their ranks. Etymologically, vulnerability evokes the concept of wounding (*vulnus*), whether physical or psychological. Different is the concept of fragility. Vulnerable is one who *can* be wounded, so it is a person who is not necessarily weak. Fragile, on the other hand, is one who can easily break, because his nature is unstable (Achilles was not fragile, but vulnerable!).

Vulnerability is a common connotation of the human condition and has a complex and paradoxical character. Complexity consists in its being universal (all humans are vulnerable) and individual at the same time (it does not affect all people equally). Paradoxicality, on the other hand, consists in the fact that vulnerability is relational and contextual (we are vulnerable in a given context). Moreover, it is society that makes individuals vulnerable, not the other way around; but it is also society that makes it reversible – if it wants to – by appropriate measures that affect the context and its causal factors (social inequality; access to knowledge; territorial disparities, etc.). With greater intensity following the effects produced by the COVID-19 pandemic, mental disabilities, which have always been the last in the economic investment of the health care systems, require to be no longer so marginal in national investment programs.

One relevant point deserves specific consideration. When it comes to people with mental disabilities, a legal-only reading of rights risks being reductive if the expectations, feelings, and desires of such people are not also taken into account. After a long season of policies marked by the protection of people with mental disabilities, we are now at a turning point where a real paradigm shift is required if the goal pursued is that of inclusion. The complex system of responses to the social needs of which the mentally ill people – think, for example, of people with Down syndrome – are bearers must be characterized by marked flexibility and personalization, so as to unhinge standard service models, now obsolete.

Generalizing somewhat, disability is a condition that is much more widespread than people think. According to the latest WHO estimates, people with disabilities are the largest minority in the world: more than 1 billion people, 15 percent of the global population. But what does it mean to have a disability? Over the past 40 years, we have slowly moved away from the idea that disability is a state of illness or a-normality, due to the presence of a physical, intellectual, or sensory dysfunction, and have increasingly embraced the concept of disability as the interaction between the presence of a dysfunction and the barriers posed by the social environment in which the person with that dysfunction lives. This latter definition tells us two important and symmetrical things: the first is that a person's disabling condition depends on all of us, as part of the social environment, and that we can therefore help reduce or eliminate existing barriers. The second is that the consequences of this interaction, positive or negative, inevitably touch the whole population. That is why ultimately disability affects us all (see the contribution to this Volume by C. Engel).

2. Health of person includes physical, mental and spiritual well-being

The etymology of the English word "health" is derived from Old English wholeness. In other languages, this relation of health to wholeness or soundness is likewise present. But how is wholeness itself to be understood? To be whole is to be intact, to have all of the parts together, to be functioning as a thing ought, to not be missing something essential. If something has a purpose, then wholeness entails that thing is well-functioning, but wholeness extends beyond being well-functioning; it also includes the notion of being intact. To what extent can the idea of wholeness be used to understand mental health?

As suggested by Vanderweele (2022), many of the disputes around health can be resolved by simply acknowledging that the word "health" is used in two related, but distinct, senses. There is a narrower conception of health that is focused on the health, or wholeness, of the body. However, there is also a broader conception of health that we might refer to as the health of the person, or the wholeness of the person. These two concepts of health are, of course, inter-related. As will be developed further below, the health of the person is in part constituted by the health of the body. Moreover, numerous aspects of the health of the person, such as psychological well-being, do often have effects on the health the body. (For recent reviews of the empirical evidence of effects of psychological well-being on physical health see: Hernandez et al. 2018; Steptoe, 2019). The relations between health of the body and health of the person are perhaps especially complicated when it comes to questions of mental health. The relations and distinctions are also important when it comes to trying to understand the scope and limits of medicine.

In any case, neither of these approaches to defining health is adequate without an account of what the human body or the human person is meant to be, i.e., without some conception of its nature. Some of the disputes around the definition of health thus likely also pertain to competing accounts of human nature (T. Vanderweele, 2024; Messer, 2013). That is why it is proper to take action in order that the "Resolution concerning decent work and the social and solidarity economy" taken by ILO on June 12, 2022 should include explicitly the term "disability". If such a proposal would be accepted, point 1 in the Conclusions of the Resolution would read as follows: "Guided by the Declaration of Philadelphia in the Constitution of the International Labor Office (ILO), which affirms that all human beings, irrespective of race, *disability*, creed or sex have the right to pursue both their material well-being and their spiritual development in conditions of freedom and dignity, of economic security and equal opportunity; and that the attainment of the conditions in which this shall be possible must constitute the central aim of national and international policy" (Italics added).

Development is not a single linear and progressive (or retrograde) process, but an extremely complex interaction of several global and local processes. Population growth, urbanization, rising literacy and schooling levels, economic restructuring, changes in production technologies, the "information revolution", the distribution of military resources, the weakening of the state, fundamentalist religious movements, the dissolution of family structures, and a long series of changes in local cultures and customs are inseparable from development processes. Each of these aspects has implications for overall mental health, some positive, some negative, and the result is a complex social distribution of social and psychological pathology. Simple models that attribute social diseases to either underdevelopment or rapid development do not lead to any breakthrough in their understanding.

Although research does not indicate a simple, direct relationship between economic development and mental health, poverty and deep-seated inequalities are clearly decisive risk factors for almost all forms of psychiatric and social morbidity. Poverty exacerbates existing problems and leaves individuals and communities with few resources to cope with, especially in parts of Africa, Latin America, the Caribbean and Asia. Unfortunately, rapid economic development is not a sure remedy. Development often creates poverty alongside well-being, laying the groundwork for the social origins of suffering for many people on the one hand improving living conditions for some on the other. New forms of poverty, along with the social ills they produce, are challenges to social justice and human rights. Only when economic development is combined with a general concern for justice and human rights can it eliminate a major source of new morbidity. Although no single model or general theory can explain all social, behavioural and mental health problems, researchers have identified a number of causal pathways that may be useful in developing intervention strategies.

3. The case of mentally disabled people

Since the Ottawa Charter in the 1980s, the World Health Organization (WHO) has proposed a model of health "that values social and individual resources", describing the conditions necessary for effective health promotion; the development of appropriate public policy, the creation of supportive care environments, the reinforcement of community action, and a reorganization of health services that, in addition to the provision of care, includes education regarding protective and predisposing factors for well-being. In line with this approach and following alarming reports on the psychological, emotional, and economic burden of disabilities on families, communities, and health care systems, WHO and the European Union (EU) have long placed mental health among their priorities. With greater intensity as a result of the effects produced by the COVID-19 pandemic, mental illness, which has always been last in the economic investments of health care systems in all Western countries, demands that it no longer be marginal in national investment programs. There is an absolute need to strengthen integrated public policy planning in the knowledge that, even if mental illnesses are not the most prevalent, they certainly entail a very high care burden, on sick people and also on the community that cares for them. Consider the paradox: the huge savings generated by the closure of the costly network of psychiatric hospitals led to the idea that savings could be made on mental health. This is the great betrayal that has taken place in recent decades. For example, the European Union sets 10% of the National Health Fund as the minimum level of spending that each country should devote to mental health. (In Italy, it barely reaches 3% and in no European country is that target met). Recall that care is about social inclusion, rehabilitation and prevention and not simply about a chronicizing medicalization of mental disorder.

The World Health Report (WHO, 1997) listed the ten leading causes of morbidity and the ten leading causes of disability. No psychiatric disorders appear in the mortality table or even in the morbidity table. Yet, in terms of chronic disability, mental disorders constitute the most important single cause. A recent survey by the Harvard Centre for Population and Development Studies indicates that depression is the fourth leading cause of Disability Adjusted Life Years (DALYs) lost in 2000 worldwide. Essentially, a quarter of the total DALYs lost were attributable to mental and behavioural disorders. By 2025, depression will be second only to ischemic heart disease as a cause of the global burden of disease. Despite all this, mental health does not appear on international health agendas. Although the burden of disease resulting from psychiatric and behavioural disorders is enormous, it is severely underestimated by conventional public health statistics because they aim to focus on mortality and not also morbidity or dysfunction. Deaths are traditionally attributed to their immediate causes, rather than to the underlying behaviours or disease conditions that lead to the ultimate crisis. Thus, for example, even when suicide is due to depression or schizophrenia it is classified simply as suicide.

Let me pause a moment to suggest that the Disability Adjusted Life Years (DALYs) criterion that has emerged in the international health policy lexicon as a new measure of the "burden of disease" poses some delicate problems. Developed as a tool for policy-making to measure the impact of disease and to establish the success or failure of policy interventions. (Murray, 1997). DALYs combine time lived with a disability and the time lost due to premature mortality. Years lost from premature mortality are estimated with respect to a standard expectation of life at each stage. Years lived with disability are translated into an equivalent time loss by using a set of weights which reflect reduction in functional capacity, with higher weights corresponding to a greater reduction. In both cases time spent in the lived is adjusted using a set of value choices which weight time lived at different ages and at different time periods differently. Because DALYs are defined in terms of time lost, they are "a bad" which should be prevented and minimized. Yet, more than a life-year (even adjusted) should be regarded as a "good" which should be maximized and not minimized. This is the main reason why the conceptual basis for DALYs is flawed and morally dangerous.

Development policies must protect and promote mental health. This includes: assisting governments in formulating national mental health programs; improving the representation and protection of basic human rights for patients with mental disorders; taking into account the views of users and their families when making decisions about mental health. It should be remembered that the number of people with major mental disorders will increase in the coming decades, and this is for two main reasons. The first is that the number of people living in the age at risk for this illness is increasing. The second reason is that rates of depression have risen in recent decades and will continue to rise as a result of the pattern of economic growth that has been emerging as a result of globalization and the digital revolution. Today we are able to document that the endemic increase in social inequality; the scarcity of relational goods; and the cultural spread of the competitive principle to the detriment of the cooperative principle are among the major causal factors in the spread of mental disabilities.

A short paper published in *The Lancet* (2023) explores work-related causes of mental health conditions and has some striking findings. For example, the job strain model (a combination of high job demand and low job control) is the model most robustly associated with the onset of depressive disorders. Among the specific working conditions assessed, exposure to workplace bullying is associated with the greatest risk of depressive disorders. Macintyre (2001) has written that humans are “dependent relational animals”. To what extent is our society able to understand and protect this dependence? To what extent are we able to translate a biological fact into a cultural model that implies a definitive ethical framework? Clearly, this is not just about economic dependence, but more importantly existential dependence. Dependency, from an ontological dimension that is the foundation of morality, has become a kind of stigma that fuels social exclusion. It is not only old people, but also the disabled and the mentally ill. Each with their own place of exile: the hospice, the hospital, the asylum. How not to perceive in the ideology of compassion, which lies behind the many forms of care, a not too veiled form of contempt? (Relevant, in this regard, is the notion of aporophobia, in Adela Cortina’s sense).

Remarkable is the reference contained in the encyclical letter *Fratelli Tutti*, in the paragraph devoted to “Social Discard”, where we read that the principle is being affirmed that certain parts of humanity are expendable when “not yet needed” (this is the case of the unborn), or “no longer needed”, as is the case with the mentally ill and the elderly. The culture of discard stems from a paradox: technical progress has made it possible to improve the quality of life, and increase life prospects, but it burdens society with problems it is unable to deal with. A new form of vulnerability emerges that is based on the “sickness of wellbeing”. If getting sick is a guilt, continuing to live can also become a guilt. Hence the impulse to suicide. It is a “modernized poverty”, as Ivan Illich wrote, that is the result not of scarcity but of the excess of resources from which descends the singular phenomenon of “counter-productivity”: the corruption of the best begets the worst. The marked improvement in health care provision, and food availability has resulted in abandonment, impatience with new burdens, and concern about rising costs.

This gives us an account of a novelty in recent technological development. Robot companions, family robots, personal assistants, care-robots, socially assistive robots are taking the place of humans in caring for the mentally disabled and other categories of disabled people. Now, while the benefits of these “caring machines” must be recognized, some perverse effects, such as the risk of increasing the isolation of those who are already alone, cannot be overlooked. Meanwhile, social and neuropsychiatric problems do not appear in the official agendas of many international agencies and ministries of health. International agencies and national ministries have shown relative indifference to mental health issues. Until recently, international health experts excluded much of this field from standard assessments of overall health. As a result, allocations in national health budgets to prevent and treat these problems are disproportionately low in relation to the human health risks they pose.

4. On the disability employment gap

The most recent data (Atanasova, 2023) on the disability employment gap show that persons with disabilities are persistently disadvantaged in the labour market compared with persons without disabilities. Between 2014 and 2022 in the EU27 this gap ranged from 22.7 to 21.4 percentage points. And in spite of the fact that quality employment for people with disabilities has been on the EU agenda for more than decades (reasonable accommodation for people with disabilities in the employment market was introduced by the Equality Framework Directive 2000/78 in 2000), the United Nations Committee on the Rights of Persons with Disabilities (UN CRPD) has recurrently raised concerns about high unemployment among persons with disabilities in the EU (UN 2015), as well as about the labour market conditions for persons with disabilities working in segregated sectors (Priestley 2021). A recent special report of the European Court of Auditors on the impact of EU action in supporting people with disabilities also concluded that “no significant improvement in recent years” is seen with regard to the disability employment gap.

As Atasanova (2023) courageously points out, despite enlargement of the legislative framework at EU and national level aimed at protecting people with disabilities from discrimination in employment, and at providing reasonable accommodation when such is required, the disability employment gap has not shrunk significantly. A dedicated flagship initiative, the ‘Disability Employment Package’, incorporating a list of set actions, is included in the new EU Strategy for the Rights of Persons with Disabilities 2021-2030 (EDRS), which is one of the EU’s continuing efforts in this direction (see also, in this regard, the specific considerations advanced by A. Barrera in his contribution to the present volume, “Economic inclusion of person with disabilities: Imperatives, Impediments and Remedies”).

The above applies to disabled people in general. But what can be specifically said for the mentally disabled? In February 2022, Sam Altman invested significant sums in *Mentra*, a startup created by three autistic people, with the aim of using AI to help large information technology companies hire workers with dyslexia, attention deficit hyperactivity disorders, or Asperger’s syndrome. Altman, the father of ChatGPT, knows well both the potential of AI and the troubling lack of talent needed to work with it. Manpower informs us that the world today lacks 78% of the tech talent that AI needs. It begs the question: why look for these personnel among those who are neuro-divergent? The social enterprise Auticon – whose president is Alberto Balestrazzi – answers that people with neuro-diversity have characteristics-attention to detail, high concentration even on repetitive tasks, and precision in problem solving – that prove very useful for information technology projects. Auticon, founded in Berlin in 2011, now operates in 14 countries selling neuro inclusion services to large companies. The more than 400 neuro divergent workers occupied in Auticon, have above-average logical intelligence that enables them to develop information technology projects more efficiently than neurally normal people. They are also incapable of lying, a quality that makes them well suited to work on sensitive data in sensitive areas such as cybersecurity.

In March 2022, the world’s largest professional platform, LinkedIn, listed dyslexic thinking with distinctive qualities. Credit for this breakthrough that shatters many stereotypes about people with diversity goes to Kate Griggs, founder of the nonprofit organization “Made by dyslexia”. In her view, dyslexics are born explorers and thus well suited to stimulate AI to grasp the crux of a question and respond with the most useful information. For example, in pattern recognition, neurodivergents have above-average abilities. In March 2022, the report “AI and the Rights of Persons with Disabilities” was presented to the UN Human Rights Council. The special rapporteur, Gerard Quinn, denounced the fact that people with disabilities are at risk of being rejected for a particular job without even considering their merits or without considering that with a simple aid they would be able to do the required work. Hence the suggestion to hire AI developers who have experienced or are experiencing disabilities. And this is in accordance with the motto of the United Nations, "nothing about us without us". That is to say that people with diversity should not simply be listened to in order to take into account their perspectives, they must also be involved in their development. And this is so in order not to transfer onto machines the implicit prejudices related to emotions, prior experience, and external conditioning.

Enthusiasm for the possibility that AI opens wide and for the role as protagonists and not just passive beneficiaries that people with diversity can play is spreading, especially among those working in neuromuscular and neurodegenerative diseases. People are beginning to talk about disability as an empowering element of technology research. In short, a major shift is taking place: diversity is proving to be a key competency in the current technology transition. Manpower (*The Talent Shortage Report*, 2023) suggests that people with disabilities have an expertise to spend on the human-machine relationship front. Indeed, those who live first-hand with an aid have an embodied experience of it, which they can describe much better than those who have not gone through a similar process, because they know what it is like to live with a machine. This is why people with disabilities must be included in the construction of *social robots*, capable of artificial empathy (see Bennett, Gibb, 2022, where the Authors defend the thesis of diversity as a value).

In a very recent and authoritative piece of work, Abramson et al. (2024) develop an economic theory of mental health. Based on classic and modern psychiatric theories, they model mental illness as a state of negative thinking and rumination which are reinforced through behaviour. Agents who experience mental illness have pessimistic expectations of future productivity, risky returns, evolution of mental health and loose time due to rumination. As a result, they work less, consume less, invest less in risky assets, and forego treatment. Which, in turn, reinforces their mental illness. The Authors use their model to evaluate the welfare costs of mental illness and the effect of mental health policies. They conclude that expanding the availability of mental health services substantially improves mental health services and welfare. In contrast, reducing the out-of-pocket cost of mental health services has minimal impact. A similar approach has been followed by a team of researchers (Lund et al. 2024) who empirically find that treating mental health conditions substantially improves recipients' capacity to work in an effective way.

5. Ways ahead. Mental health in the perspective of community welfare

The social transformation of the past three decades intersects with the profound crisis of the welfare model that still prevails today. What emerges from the *res novae of* the present era is the need for a comprehensive readjustment of welfare systems capable of overcoming outdated protection schemes and at the same time being financially sustainable. The new proposals of social investment call for abandoning a centralized model of public intervention (welfare state) in order to experiment with different forms of community welfare in which the univocal relationship between the public system and the welfare state is overcome. Basically, the community welfare is a relational service model (see Donati in this volume). In addition to the public, private agents (individuals, families, Third Sector organizations) are also called upon to play a relevant role at the allocative and redistributive level, in homage to the principle of subsidiarity.

The initial response to the crisis of the welfare state in the 1990s was a neoliberal model known as the welfare mix, in which public agencies retain the monopoly of commissioning but give up, in whole or in part, the direct provision of services in favour of their provision by private producers through increasing outsourcing. In the last 15 years, however, dissatisfaction with the results generated by the welfare mix has led toward the construction of a plural welfare model, known as community welfare, in which civil society actors are also given the power to participate in the process of planning interventions and not only in the process of designing them. From the point of view of the services offered, community welfare differs from welfare state and welfare mix because, unlike the former, it does not offer standardized services and, unlike the latter, it does not offer services that tend to favor the privatization of the service, resulting in fragmentation and isolation. (See Ugolini, 2023).

A few examples to clarify the differences between these models. While the response of the welfare state to the need for assisted living of the mentally ill has been predominantly the admission to nursing homes, creating socially isolationist situations of institutionalization, the response of the welfare mix, on the other hand, has been the provision of home-based services, which has caused isolation and the spread of the phenomenon of *assistential-*

ism. In contrast, the community welfare response is a different idea of housing, which includes multiple forms of co-housing (such as family-homes) and social street experiences. Over the past two decades, mental health services have built pathways for taking care of mental patients that involve clinical, rehabilitation and social inclusion aspects, with an approach to long-term care typical of the chronic dimension that mental health problems often entail. Another important example is that concerning health budgets, a social-health integration tool to support the Individual Therapeutic Rehabilitation Project of people with severe mental disorders, consisting of individual, family, social and health resources networked in order to improve the person's inclusion and active participation in the community.

In essence, it must be acknowledged that the care of the mentally disabled cannot take place in a disjointed manner from the care of the bodies of those same individuals. Unlike physical disability, which requires the already difficult definition of pathways of integration between health and the social dimension, mental disability, influenced by genetic predisposition, socioeconomic background, negative experiences during childhood, alcohol and drugs, requires to systematize not only health and social policies but all policies for the definition of a comprehensive approach that cannot absolutely disregard the involvement of the community in which the mental distress manifests itself.

One point on which there seems to be a consensus is that neuropsychiatric disorders are biosocial – that is, that both biological and social factors are involved. Mental disorders are not simply symptoms of broad social conditions. They also reflect an inherited vulnerability and are mediated by neurophysiological processes. However, the quality of a person's social environment is closely related to the risk of suffering from a mental illness, whether an episode of illness is triggered, and the likelihood of that illness becoming chronic. For example, a deficiency of essential trace elements in childhood associated with malnutrition, poverty and uprooting leads to neurological deficits and brain dysfunction. Schizophrenia is not a "social disease"; however, social and cultural factors strongly influence the course of the disease and the likelihood of recovery. Epilepsy is a consequence of brain pathology; why 90% of epilepsy patients in several Asian and African societies do not receive any proven biomedical treatment is a social problem. Although neurotransmitters are implicated in major depression, trauma in childhood, such as the loss of a parent, increases lifelong vulnerability to depression; significant loss, violence, and trauma play an important role in triggering specific depressive episodes, especially when experienced by relatively helpless people with few personal and social resources.

What to do to meet the challenge? One thing is clear. For the many and varied proposals to be taken seriously and implemented, there must be an international movement that prioritizes mental health. There is no doubt that a worldwide consensus such as that organized on democratization will determine substantial pressure to get all societies to rethink priorities and practices. It is essential that similar international attention be given to mental health issues by international agencies such as the United Nations, the World Bank, the World Health Organization and regional organizations such as ASEAN, the Organization of African Unity and the Organization of American States. It is essential, in short, to raise the international level of awareness that will condition the priorities that policymakers and those who develop them in countries around the world assign to mental health. Such a global campaign for mental health should involve the media, businesses, educational institutions and networks of those who design health and social policies (on the topic above, see the classic work by Desjarlais et al., 1995).

6. A concluding remark

The distress that comes from many tragic events and cases of destitution leads us to consider careful the notion of "social inclusion" and to identify in with the litmus test of the seriousness of our declarations. To include means sharing, participating, moving from being a stranger and misfit to being an integrated and active person, from a subject to a sovereign citizen. Above all, inclusion means, today, to consider that in the last decades there has been a sharp growth in the number of people that have been warehoused, displaced, trafficked, reduced to mere labouring bodies and body-organs. The Princeton economist Anne Case and Angus Deaton (2020) suggest that recent patterns of mortality and morbidity go hand to hand with exclusion from marriage, children, religious congregations and political society.

Social inclusion can take place only on the grounds of the formal recognition of equal opportunities to participate in the strategic decisional and operative moments that make a social aggregate an active civil society, polyarchic and solidaristic. It should never be forgotten that the principle of inclusion does not originate in satisfying debts by exchange or distribution. Distribution operates within an already given social inclusion. One does not become a member of society by the fact of being given something. Already pope Leo XIII worried that all of the so-called "necessary societies," would be gradually reduced "to the genus of commercial contracts, which can rightly be revoked by the will of those who made them" (*Humanum Genus*, April 20, 1884, no. 21).

It is noteworthy that the distinguished demographer N.N. Eberstadt has coined the expression "our miserable 21st century" to indicate that miseries arise not so much from plagues and natural disasters as from exclusion from the basic social forms of living-together. ("Our Miserable 21st Century", *Comm.,* Feb.15, 2017). Needless to say, the spread of such a mentality is the result of the disappearance of the principle of fraternity from our cultural horizon. It was the Franciscan school of thought that gave the fraternity principle the meaning it has kept over time: that of complementing and at the same time transcending the principle of solidarity. In fact, where solidarity is the social organizing principle that enables unequals to become equals, fraternity is the social organizing principle that enables equals to be diverse. Fraternity enables people who are equals in dignity and with the same fundamental rights to freely express their life plan or their charisma. The past centuries, the 19th and especially the 20th, were characterized by major cultural and political battles in the name of solidarity, and this was certainly a good thing; think of the history of trade unions and of the civil rights movements. The point is that a good society cannot content itself with the horizon of solidarity, because while a fraternal society is also one of solidarity, the opposite does not necessarily hold true.

Having forgotten that no human society is sustainable where the sense of fraternity is extinguished and where everything is reduced, on the one hand, to improving transactions based on the exchange of equivalents principle and, on the other, to increasing transfers by public welfare institutes explains why, in spite of the quality of the intellectual resources deployed we have not yet come to a credible solution of the great trade-off between efficiency and equity and that between negative and positive liberty. The society in which the principle of fraternity is dissolved is not capable of a future; in other words, a society where there exists only "giving in order to get" or "giving out of duty" cannot progress. Gift-giving as gratuitousness, i.e. fraternity, is the experience of a non-functional, non-mechanical reality in a world that tries to exclude, to eliminate, all that is non-functional, all that is gratuitous. This is why neither the individualist vision of the world, where everything (or nearly everything) is trade, nor the Hobbesian vision of society, where everything (or almost everything) is duty is a safe guide to lead us out of the shallows in which our societies are grounded today.

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EMPLOYING PERSONS WITH DISABILITIES: INSIGHTS FROM CATHOLIC SOCIAL THOUGHT AND SOCIAL ENTERPRISE

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The reflection in this paper is different from what we might normally find in other intellectual academies. In the Pontifical Academy of Social Sciences, we can combine two elements: firstly, a vision of where we could go – a shared goal that we can hope to try to achieve in the long term (a horizon), which we can draw from the millennial traditions of the wisdom of the world, and specifically from Christianity, and, secondly, a serious consideration of the technical problems that need to be faced and proposals for possible steps forward, give where we are now, or a "pathway" towards where we could like to go.

The part of the paper regarding Catholic Social Teaching (CST) will provide the main source for thinking about where we could go, while the part regarding social enterprise will be the source for thinking about concrete steps forward from where we are now, in both cases focusing the discussion on the question of employing persons with disability.

We may begin the elaboration of the vision with a quote from *Gaudium et spes*, the Pastoral Constitution from the Second Vatican Council on the Church in the Modern World. This text is taken from the third chapter of part one, entitled "Human Activity Throughout the World":

> "Just as [human activity] proceeds from the human person, so it is ordered towards him or her. For when a person works they not only alter things and society, they develop themselves as well. They learn much, they cultivate their resources, they go outside of themselves and beyond themselves. Rightly understood, this kind of growth is of greater value than any external riches which can be garnered" (*Gaudium et spes*, n. 35).

We see here the core idea coming from the Christian social tradition as regards human activity in general, and work in particular. Such activity is for the human person; it is about human development, with the philosophical idea behind this that we are beings with potential that we realise (turn into reality) through activity. We learn, we cultivate our talents and resources, we go beyond ourselves (we become "more human" as the same document will also say in n. 38). This is the central issue about human activity, even if "altering things" is also important. It is what John Paul II will later call "the subjective dimension of work" in his encyclical on work, *Laborem Exercens* n. 6, contrasting it to the "objective" dimension, the products and services we produce. Every work process has both objective and subjective dimensions. We are used to recognizing the first – the production system, including its machinery and work procedures, as well as the product or service produced by a work process – but we often miss the second. This dimension gives work its meaning and sense, since we develop into the people we could truly be through work (indeed, only human beings work – machines function or operate, but they do not work, since the subjective dimension is constitutive of work and only human beings have it). Every work process, therefore, has two outputs: an objective and a subjective one. Our quote above indicates that a proper recognition of the subjective dimension of work, which is important for all human beings, will be a crucial part in making the breakthrough needed to involve persons with disabilities fully in the workplace. We might say that while barriers on the objective level of work can create extra problems for persons with disabilities, on the subjective level there is both less difference between those with and without disabilities, and the common challenge of finding ways to recognise the subjective dimension of work for us all.

John Paul II will also apply this distinction to the situation of work in the capitalist system by talking about the priority of labour over capital. Labour, he will say, always remains the "active" or "efficient" cause of work, while capital (machines and money) are only "material" causes. Furthermore, much of what constitutes the capital resources at our disposal are the results of human labour, so in this sense too, labour is prior to capital (the rest of our capital resources are a gift to us from the Creator – the natural resources at our disposal). In a later encyclical, *Centesimus annus*, John Paul II will add to this discussion, in n. 32, that a key capital resource for today's economy is constituted by the knowledge and skills that workers themselves have developed, what is often now called "human capital", linking labour and capital in an even more direct way. If labour does have priority over capital, this implies many things on a practical level. For instance, it implies that costs that protect workers from injury will be sustained, or that we should be developing technology to enhance human skill, not using human beings to support machines. Going further, we can recognise that it implies that costs to protect the employment of women (i.e. of human beings who have babies) should be sustained, and, finally, of human beings who have disabilities should also be sustained. Normal human beings have babies and have disabilities, just as they all need safe workplaces. If we are going to put the human being at the centre, then recognising that having children and having disabilities is part of the picture of being human, rather than as something strange or odd, is part of doing this.

We could not finish this section without mentioning solidarity, a key principle of CST. Through sharing our difficulties and working together to resolve them, that is, exercising solidarity, we can achieve goals that would otherwise be impossible for us. It was through their solidarity, for instance, that the trades union movement achieved the recognition of so many rights for working people. We might say that solidarity is the virtue, or social principle, behind the phrase so often mentioned by persons with disabilities: "nothing for us without us".

Compared to the way we usually think about work in our current economic system, where the crucial consideration is what we produce and decisions are mostly driven by a search for financial return and the reduction of costs, this is a kind of "upside down" way of looking at things. For the "normal" way of thinking prioritises what we just called the objective dimension of work, which fits into the search for profit and the reduction of costs. And yet, when we look at things like this, the "normal" starts to become "strange", and this "upside down" way of looking at things begins to ring true and actually seem quite realistic. We know that we do not work just to create profit. Pope John Paul II talked about work as a "key" for understanding our social problems in general: "human work is *a key*, probably *the essential key*, to the whole social question, if we try to see that question really from the point of view of man's good. And if the solution – or rather the gradual solution – of the social question, which keeps coming up and becomes ever more complex, must be sought in the direction of 'making life more human', then the key, namely human work, acquires fundamental and decisive importance" (*Laborem Exercen*s, n. 3). If this statement is really true, then "solving" the problems to do with work and employment regarding persons with disabilities could be the "key" to solving many other aspects of the problems regarding their full inclusion in society. We might also note that article 27 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), covering the right to work, deals in depth with this issue. It is one of the most detailed articles of the Convention.[1]

In some ways, the realism of thinking like this might seem to present dangers to our current economic order. For example, one of the "problems" we face today is that young people are not as driven by the goal of achieving economic gain as they were in the past. Many of them want to work part-time, in order to realise their other goals in life, causing a real shortfall in labour market supply in some parts of the world (Furnham, 2024). At the same time, in relation to our topic, this "realism" of young people may actually be exactly what we need, since, along with the ageing of societies, this development could lead businesses to take more seriously the opportunities provided by employing persons with disabilities, creating improved job prospects for them.[2]

We may summarise what we have said so far by saying that if putting human development at the centre of our thinking about work might seem utopian from an economic point of view, it does inspire us and the tension it sets up in our minds and hearts can create openings for improvement that we may not have thought achievable without the motivation that such tension can give us. We have already made comparisons between "persons who have babies" and "persons with disabilities", and the story of the struggle of the first for greater recognition of their dignity and equality shows how this tension between the where we could be and where we are now can give us

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[1] https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf (last accessed 28.03.25)

[2] Data from many sources shows the disadvantages that persons with disabilities face in the labour market. The disability employment gap in the EU-27, for instance, was 24.4 percentage points in 2020, with only 50.7% of persons with disabilities aged 20-64 employed compared to 75.1% of their non-disabled peers (Grammenos 2022, 10). Pay gaps are also noticeable: "The age-adjusted disability pay gap in the EU 27 was 9.6% in 2019, for which we have data for all Member States. This figure covers all employees aged 15-74 working in firms with 10 or more employees, without restrictions for hours worked (public administration excluded). A higher gap can be found among managers, with the lowest gap among elementary occupations. A significant difference may be observed between men and women with disabilities" (Grammenos 2022, 7). Disability and economic insecurity are deeply intertwined, with disability both a cause and consequence of poverty. Structural barriers, economic instability, and lack of access to healthcare perpetuate this cycle, underscoring the urgent need for economic justice as integral to disability justice (Vallas et al. 2022, 1)

the strength and energy to bring about change for the better.[3] Things that seem impossible can become normal if they have a basis in reality.

In the light of what we have said more generally about work so far, here is the most specific statement in CST that applies this general idea of work to the situation of persons with disabilities:

> "… it is to be hoped that *a correct concept of labour in the subjective sense* will produce a situation which will make it possible for disabled people to feel that they are not cut off from the working world or dependent upon society, but that they are full-scale subjects of work, useful, respected for their human dignity and called to contribute to the progress and welfare of their families and of the community according to their particular capacities", *Laborem Exercens*, n. 22, italics original.

We see here the central importance given to persons with disabilities as "subjects of work", reinforcing what we have said so far about the subjective dimension of work. Pope Francis speaks in a similar way about recognising persons with disabilities as active members of society:

"Many persons with disabilities 'feel that they exist without belonging and without participating'. Much still prevents them from being fully enfranchised. Our concern should be not only to care for them but to ensure their 'active participation in the civil and ecclesial community. That is a demanding and even tiring process, yet one that will gradually contribute to the formation of consciences capable of acknowledging each individual as a unique and unrepeatable person'", *Fratelli tutti*, n. 98.

So, where do we arrive with this? What is the vision that we can get from CST that we can then try to realise gradually, using examples from social enterprise to give us some idea of the next steps forward?

In one sentence, we may put it like this: the labour market, and the economic system more generally, needs to be focused on the human person. We need to change what we see as "normal", so that the human person (and life as a whole) is put at the centre of our economic system. As we mentioned above, this may seem utopian or impossible to attain, but we also know that our current system has been at the root of many of the problems we face today, such as the climate crisis, causing us to adopt systems of work and

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[3] See, for instance, the work of the Nobel Prize winner, Claudia Goldin, such as her 2021 book *Career and Family: Women's Century-Long Journey Toward Equity*, Princeton University Press, Princeton and Oxford.

wealth creation that are not focused on life or the human person. Many of us knew that these problems were emerging, but we did not know what else to do; the alternative seemed utopian and impossible to achieve.

The interrelated crises that we now face, as well as the vision we are talking about here, push us towards moving out of our current system and into a new one where the human person, as a part of an integrated life-support system, is at the centre, where human freedom, drawing on the quote we just saw from *Gaudium et spes*, is about human development, and so focussed more on "freedom for" than "freedom from", and we can bring shared goals back into our way of life together. We are already doing this on a practical level with the SDGs.

This will also mean that our economic and work systems will need to take on meaning and purpose; we will be managing the subjective dimension of work as much as the objective. We will move away from the "technocracy" which Pope Francis ably denounced in his document, *Laudate Deum* (nn. 20-33).

In this context, it is no surprise that a recent OECD report on disability and work has said: "A real change will require shaking up the existing system".[4]

This is a pretty tall order, and we are not going to get there quickly. So now we will turn to the situation of social enterprise, a form of business activity that is already trying to bring respect for the subjective dimension of work and social goals into its way of working by creating economic and social value in an integrated way; some of these are "faith-based organisations" (FBOs), which gives them the resources of religious faith to draw on as well.[5]

According Martin and Osberg (2007), the "social entrepreneur should be understood as someone who targets an unfortunate but stable equilibrium that causes the neglect, marginalization, or suffering of a segment of humanity; who brings to bear on this situation his or her inspiration, direct

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[4] OECD (2022), *Disability, Work and Inclusion: Mainstreaming in All Policies and Practices*, OECD Publishing, Paris, https://doi.org/10.1787/1eaa5e9c-en.

[5] FBOs tend to adopt a holistic approach, often aiming for long-term, transformative outcomes within the communities they serve. "Christian organizations, moreover, emphasize relationships arising from a business encounter in a special way because of the belief that they are responding to the most basic of Christian calls: to love one another and to be a gift to each other" (Racelis 2017, 123). See, for instance, https://www.vaticannews.va/it/chiesa/news/2023-09/storia-laudato-si-chiesa-ucraina-disabilita.html See also Roundy and Evans (2016).

action, creativity, courage, and fortitude; and who aims for and ultimately affects the establishment of a new stable equilibrium that secures permanent benefit for the targeted group and society at large." Data from the report "The State of Social Enterprise 2024" by the Global Alliance for Social Entrepreneurship shows that, globally, there are around 10 million social enterprises.[6] They are creating $2 Trillion in annual revenue, plus the social value they create.[7] They have created 200 million jobs, while 50% of them are led by women. Furthermore, data from the US and the EU shows that the proportion of people who are self-employed, which could reveal an openness to entrepreneurship, is higher among persons with disabilities than among others.[8] Jacocks and Bell, using US data, highlight that, while almost all indicators point to lower levels of participation in work by persons with disabilities, "people with disabilities are twice as likely to be self-employed or launch their own businesses as the general population" (Jacocks and Bell, 2020, 117). We may also note that principle 17 of the EU Pillar on Social Rights explicitly "provides further impetus to the active social and labour market inclusion of persons with disabilities" (Lecerf 2020, 4), and that the EU's strategy document "Union of Equality" sees social enterprise, understood as part of the broader "social economy", as particularly important in achieving this goal.[9]

A useful way to frame how social enterprise could help us on the question of employing more persons with disabilities is to look at a couple of evaluations of the key problems that need to be addressed if we are going to make a breakthrough in this area.

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[6] https://www3.weforum.org/docs/WEF_The_State_of_Social_Enterprise_2024.pdf (last accessed 09.03.25).

[7] In comparison, the same report notes that the size of the global apparel industry in the same year was $1.57 trillion, and the global advertising industry was $875 billion (https://www3.weforum.org/docs/WEF_The_State_of_Social_Enterprise_2024.pdf)

[8] "Data from Europe and the US suggests that self-employment rates are higher among disabled people than those without … A study of 13 of the then 15 EU member states using European Community Household Panel data for the period 1995-2001 found that self-employment rates among disabled people are higher than among people without disabilities … Countries with a higher disabled/nondisabled differential, with the partial exception of Austria, are all countries with high rates of self-employment overall. This suggests that countries with high self-employment rates might be better placed to increase self-employment among disabled people." (Kitching, 2014, 5)

[9] The EU Strategy emphasizes the role of social enterprises in bridging persons with disabilities to the labour market, offering targeted support and inclusive opportunities, particularly through EU-funded programmes (European Commission 2021, 12).

Two interesting sources on this point are the website of the ILO Global Business Disability Network (GBDN) and the OECD report *Disability, Work and Inclusion: Mainstreaming in All Policies and Practices* (OECD, 2022).[10]

The first source, a network of about 30 multinational corporations, gives the following 4 points as key issues that need to be addressed:[11]

1. "Invalid opinions", which create attitudinal barriers against the inclusion of persons with disabilities, including stigma, misconceptions, and stereotypes. Attitudinal barriers are particularly important to confront because they contribute to other kinds of environmental and institutional barrier.
2. Workplace adjustments
3. Digital accessibility
4. Neurodiversity

As regards the contribution that social enterprises can make in confronting these problems, we will focus on invalid opinions, given their importance, and also on creating workplaces that welcome neurodiversity, where it emerges that the question of recruitment is particularly important. On this point, the OECD report shows that persons without disability are 2.5 times more likely to be hired than someone with a disability, but then continues: "Once employed, however, the likelihood of a job-to-job change is relatively similar for people with disability and people without disability …" (p. 18), indicating that the critical and difficult moment is the initial recruitment into a workplace.

The OECD text, produced by an organisation of states and focused on mainstreaming the question of disability across policy areas, is more elaborate than the GBDN. It points out that there have been serious attempts to improve the participation of persons with disabilities in the labour market for at least 20 years with little or no success, and argues that two key factors are crucial in addressing this:

- mainstreaming and individualised targeting must go hand in hand
- Supply-side elements need more attention:

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[10] https://www.businessanddisability.org/ (last accessed 08.03.25); OECD (2022), *Disability, Work and Inclusion: Mainstreaming in All Policies and Practices*, OECD Publishing, Paris, https://doi.org/10.1787/1eaa5e9c-en.

[11] https://www.businessanddisability.org/at-a-glance (last accessed 08.03.25).

- young people have received too little attention
- persistent skill gaps need to be addressed
- earlier and faster interventions (see footnote 3, p. 16)

On this last point, the OECD report points out that when people experience some disabling event in their life, they usually first enter a situation of sick pay before transitioning to disability benefits. In these cases, "policy efforts must be reoriented to prevent people from getting to a stage from which there is no sustainable return to work." (p. 23), because "[s]kills depreciate very fast and evidence shows that it is much easier for people to remain in employment building on the existing employer-employee relationship, than to find new employment" (p. 21).

In what follows, we will focus on four key issues raised here that can be addressed by social enterprises in a particularly effective way: invalid opinions, the inclusion of neurally-diverse people, confronting the situation of people who have not received early and fast interventions, and entrepreneurs with disabilities.[12] How can social enterprise help us deal with these issues? Here are some illustrative examples.

We know that the arts are a central way of communicating profound ideas and building a shared culture, so it is interesting to see that there are quite a number of social enterprises that focus on the sphere of the arts, not only generating employment for persons with disabilities but also acting to change those invalid opinions we have mentioned.[13] Some, like the Heart to Heart orchestra based in Seoul, Korea, are using a classical orchestral format and recruiting young people with disabilities, during which they continue training, have masterclasses and develop also in smaller ensembles. It is interesting that each of the young people involved is presented in a personal way on the orchestra's website. They pride themselves on having played in

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[12] There are also "Work Integration Social Enterprises" (WISEs) that have evolved from sheltered workshops, moving towards community-integrated employment by offering valued goods and services. This transition supports both market competitiveness and positive public perceptions of workers with disabilities (Lysaght et al. 2018, 21; Gallo & Melé, 2024).

[13] "The Commission calls on Member States to promote and encourage arts of persons with disabilities and raise awareness making them visible through exhibitions and performances; and make more art collections and museums accessible to persons with disabilities." (European Commission 2021, 18).

some of the leading concert halls of the world, and on being as financially solvent as possible.[14]

Others, like Able orchestra, are more experimental. Able emerged out of a project to use iPads in creating music with school pupils in North Nottinghamshire, UK; gradually, a network of performers, experts in musical technology and the Hallé orchestra got involved in the project.[15]

BSO resound is a small disabled-led ensemble that developed out of a "changemakers" programme created by the Bournemouth Symphony Orchestra. All of the musicians involved are adults; the conductor has cerebral palsy and conducts with a baton attached to his glasses. They have performed world premieres of pieces written for them by composers with disabilities.[16]

The main goal in all these cases is to show that persons with disabilities can be creative performers and to inspire others with the same idea, so dealing directly with the problem of invalid opinions.

Another type of performing arts social enterprise is "Epic Arts", founded between the UK and Cambodia, using dance as its main art form. They have developed a suite of activities between which persons with disabilities can move: a café, community outreach, education, and the performing arts group. We can see here a kind of ecosystem approach, one that is dealing with both supply and demand sides of employment, with a special focus on young people.[17] Other social enterprises contribute to creating a supportive ecosystem by offering consultancy services to other businesses on workplace adjustments and inclusive hiring practices (Crosta & Sanders 2021, 10).

Art Enables is an example of a collective creating a space for the production of visual arts which can be sold by the artists.[18] The focus on this place of work is to help those who have been struggling for some time to find work, as well as a place to express themselves. Artists gain income from selling their work, although it does not usually provide a full income for

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[14] https://orchestra.heart-heart.org/en/main/orchestra/introduce (last accessed 08.03.25). Like all orchestras, they do need some government or private funding, but they are no more dependent on this support than any other orchestra of a similar size with a similar programme of activities.

[15] https://www.inspireculture.org.uk/arts-culture/children-young-people/able-orchestra/ (last accessed 08.03.25).

[16] https://bsolive.com/events/bso-resound/ (last accessed 08.03.25).

[17] https://epicarts.org.uk/ (last accessed 08.03.25).

[18] https://art-enables.org/ (last accessed 08.03.25).

them. However, the main issue is the way in which the people involved in the collective can grow and develop themselves, regaining confidence such that transitioning back into work becomes more possible.

In all these cases, persons with disabilities are creative performers and artists, paid for their work. In the first two cases there is a supply-side element, connected with the training of young people to develop the kinds of skills of which orchestras like these are in need. In the third case, we see a social enterprise that is creating pathways back into work for those who have dropped out of the labour market, which is, as the OECD report indicates, one of the most difficult groups to try to get back into work.

Turning to digital accessibility and the inclusion of neurally-diverse workers, tech-based social enterprises like the Ghanaian-based Tech Era aim to train disabled people in digital skills, sometimes providing them with assistive technology in order to do so.[19] Tech Era funds itself by teaching robotics in private schools and selling school management software. Forming an alliance with a Canadian social enterprise, another tech company, Dextra, and a lab at Ashesi university, it is encouraging others to produce assistive technologies by launching a makerspace in Ghana.

Flow, based in Taiwan, was started by a group that wanted to create a business with purpose and, after many iterations, decided to focus on two businesses that create jobs for two groups of persons with disabilities, one with less capacity for movement than the other.[20]

The AI Data Service Division, part of the AI department, develops a data processing platform for computer vision and trains people with disabilities at home to become AI data annotators. By providing a full range of integrated AI data processing services, with the labelers integrated into the system rather than being self-employed part-timers as often occurs, Flow can offer benefits to its customers, such as data insights alongside lower costs, that other providers would find difficult.

The Building Information Modeling (BIM) division offers full-time jobs for disabled people who are capable of more physical movement (i.e. who are able to walk or need less supporting equipment). About half of this division is disabled and primarily works as modeling engineers. As in the AI division, Flow can offer competitive advantages that stem from its organi-

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[19] https://ashesiventureincubator.medium.com/meet-derick-omari-founder-of-tech-era-8bdd31791d63 (last accessed 08.03.25).

[20] https://hr.asia/awards/2021-event/taiwan2021/flow-inc-tw-2021/ (last accessed 09.03.25).

sation and experience. Overall, Flow has a low turnover rate, with around 200 of its 400 trained people on long-term contracts. Although training costs are high, these are compensated for by the savings made on recruitment expenses because of the low turnover rate.

Auticon, a social enterprise set-up between Germany and Canada, offers IT consulting services at competitive prices while employing neurally-diverse people.[21] The key idea for this company is that workers on the autistic spectrum can be extremely productive if they are in the right role, that is, if the "fit" between work and the kinds of things they are good at, such as precise attention to detail, ability to focus and drive to complete tasks, is there. Out of its 290 employees, Auticon has 210 who are neurally-diverse.

The management teams of Auticon have realised that knowing how to interview a person with this kind of disability is key.[22] According to Auticon's founder, "the hiring process in general is quite broken. If you're able to sell yourself, you can get a job, but it doesn't mean you can do that job." He notes that the average length of unemployment for persons with autism before being hired by Auticon is 22 months. A question like: "why should we employ you rather than any of the other candidates?" will floor a person with autism, because he or she does not know the other candidates and so cannot answer the question. Rephrasing the question to something like: "why do you think we should employ you?" produces an interesting answer. Furthermore, Auticon's interview process includes the chance for the person to show how he or she actually performs, which is assessed over a period ranging from between six hours to two weeks, depending on the seniority of the candidate. Auticon's founder maintains that if mainstream businesses started to hire in this way, they would not only make it more possible for neurally-diverse people to get into the labour market, but they would also make fewer mistakes in general when they hire people.

Among the social enterprises that we can mention here, perhaps the most interesting category of all are those where the founding entrepreneur is a person with a disability, not least because of the specific ways in which this allows them to work, as well as their special sensitivity to the needs of others: "Entrepreneurship offers people with disabilities attempting to overcome barriers and stereotypes the ability to self-define their role ... Be-

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[21] https://auticon.com/ (last accessed 09.03.25).

[22] https://www.pioneerspost.com/business-school/20210917/advantage-autism-the-social-business-champions-neurodiversity-work (last accessed 09.03.25).

cause of the challenges they have personally faced, people with disabilities may be uniquely equipped to address social needs in communities and society by creating innovative solutions to overcome disadvantages facing other people with similar disabilities" (Jacocks and Bell, 117-118). As employers, entrepreneurs with disabilities are more willing to accommodate other persons with disabilities because they "can recognize the potential of such people and also understand barriers first hand ... entrepreneurs with a disability also aspire to empower other disabled individuals" (ibid., 120). Young persons with disabilities may be especially willing to consider this option.[23] The fact that not much research exists on this phenomenon limits what we can say about it, but research is developing.[24] Data published in 2019 by the Observatorio Estatal de la Discapacidad (2019) of the Spanish government indicate that: "a large part of the entrepreneurial activity carried out by persons with disabilities is focused on activities related to the third sector ... 10,500 organizations, of which 73.3% are more than 20 years old and represent 36% of the social action third sector, in which – according to estimates made in 2013 – 5,181 million euros were earned and 4,894 million euros were spent alone in that year, 52% of the entities recorded a positive balance sheet, 28% recorded a compensated one, and, last but not least, 92% generated the funds for their own self-financing, [revealing] excellent economic management in the sector" (Ortiz García & Olaz Capitán 2021, 2).

Problems faced by persons with disabilities both stimulate them to become entrepreneurs and can provide obstacles in their way to doing so. In resolving the obstacles, research shows that friends and family can be especially important, as these entrepreneurs often lack access to other networks of support. It is also striking that government support for entrepreneurs with disabilities tends to be lower than for other special categories, as the table from the OECD report "The Missing Entrepreneurs" shows. This may

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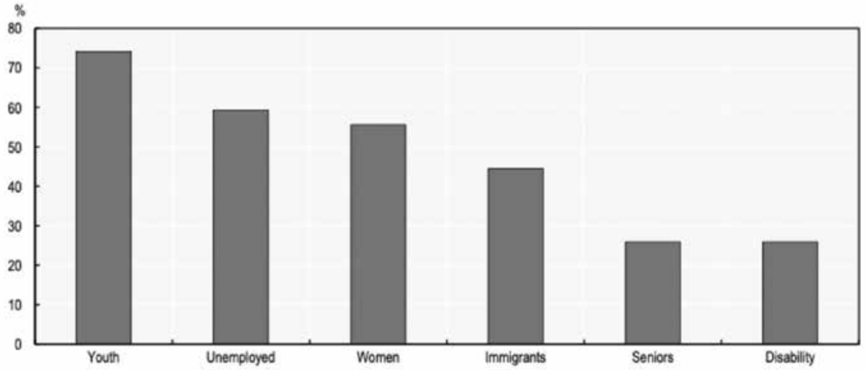
[23] A notable trend in the ASEAN region is the rise of young leaders with disabilities as social entrepreneurs. Driven by a deep personal understanding of disability rights, these youth-led initiatives are pushing for greater inclusivity and workplace reform, positioning young entrepreneurs at the forefront of social change. "Most of these social enterprises are led by young social entrepreneurs, many of whom are persons with disabilities themselves. Trends in social entrepreneurship worldwide have shown the growing emergence of young leaders. Numerous studies show that young people today are highly motivated to generate positive social change and interested in developing innovative solutions through social entrepreneurship (UN DESA, 2020)" (Crosta & Sanders 2021, 13).

[24] Most of the research cited by Jacocks and Bell, for instance, dates from the last ten years.

also be because, as Jacocks and Bell suggest, "government services may place greater emphasis on helping disabled individuals secure stable employment, [with] entrepreneurship as more of a secondary option for disabled individuals" (p. 120).[25]

Proportion of EU Member States with a group-specific entrepreneurship strategy, 2022



Note: Strategies could be stand-alone dedicated entrepreneurship strategies or embedded within another strategy, e.g. employment strategy, active ageing strategy.
Source: (OECD, 2023[15])

Many of these examples show some potential for steps towards involving persons with disabilities in employment or for tackling the attitudinal barriers that exaggerate the real barriers they face. Aiming interventions at young people, keeping persons experiencing difficulties connected to the workplace or providing them with pathways back into work, creating a supportive ecosystem around the transfer from school into work, often by involving and mobilising family members in a way that respects subsidiarity – all of these strengths show that social enterprises can provide effective solutions to the frontier problems that the ILO GBDN and the OECD identify as blocking improvement on the question of employment for persons with disabilities. Gallo and Melé (2024) even present a social enterprise, La Fageda, employing over 250 persons with disabilities, that use a "Doble Mirada" or "two ways of looking" at work that corresponds

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[25] The OECD recommends flexible benefit systems that allow disabled entrepreneurs to re-enter support systems if their ventures fail, which could reduce perceived financial risks associated with leaving secure benefits (OECD 2014, p. 12).

very closely to the subjective and objective dimensions discussed at the beginning of this text.

However, this discussion would not be complete without a brief discussion of some of the problems with this group of actors.

The one that is always mentioned is the lack of scalability of the business models of social enterprises.[26] Nevertheless, we should not over emphasise this problem. Firstly, we know that the vast majority of all businesses are small; in this sense, social enterprises are part of the norm. Secondly, it is a relatively new business form that is still finding its way and for which governments and other institutions are still finding the best way to support and regulate; compared to "standard" businesses, the ecosystem to support social enterprises is still underdeveloped. In the past, it was said that cooperatives suffered from similar limitations, but large clusters of cooperatives, such as the Mondragon system, exist and flourish. Thirdly, it is interesting that at least one of the cases we have looked at (Flow) have set themselves the task of producing a replicable and scalable model that can be applied elsewhere.

More important is the critique made by Mauksch and Dey (2023) in their article "Treating Disability as an Asset (Not a Limitation)" of the idea of "disability as an asset". Here they focus on the kind of business that "treat[s] disabilities not as negative deviances from an able-bodied norm (read: limitation) but as conditions associated with "hidden talents" that can be unlocked through productive activities in the mainstream market" (p. 3). They refer to the case of a social enterprise founded by a UK couple to provide massage services in Nepal which recruits "blind masseurs" who are promoted to potential clients as having a special sense of touch, and therefore the capacity to provide a massage that is better than a person with sight. They market this capacity as the "magic fingers" of the enterprise's name.

Mauksch and Dey show how Magic Fingers create a kind of hierarchy among disabled people and give preference to some. Although disabled

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[26] Added to this, the lack of a clear legal basis can be problematic. For instance, a lack of clear legal definitions for social enterprises in ASEAN countries, aside from exceptions like Vietnam, limits their growth, creating regulatory challenges for income-generating and social service activities. Legal clarity in defining SEs could significantly enhance the sector's impact and sustainability. "Yet, there is still a lack of legal incorporation status for organisations that simultaneously pursue a social mission while carrying out profit-generating business activities, with the notable exception of Viet Nam which officially recognised SEs under its Enterprise Law in 2014 (British Council et al., 2018). Thailand also has a legal definition for SEs, but qualifying as a SE in Thailand has been described as a prohibitively difficult process." (Crosta & Sanders 2021, 9).

people are employed by this business, it is therefore at the cost of creating a different kind of exclusion, that is, of certain levels or combinations of disability. Their research shows that "disability as an asset" is ambiguous; it develops a kind of meritocratic scheme between people with disabilities, excluding as much as including. This case is interesting to compare with Auticon, or Tech Era: in these latter cases, the difficulties that persons with disabilities are experiencing are part of the story – they are not "only" being "sold" as having a skill, or something "better", than persons without disabilities, even if the "autism advantage" might come close to that.

In conclusion, it is clear that we need more data.[27] At present it is hard to give more than an impressionistic idea of the contribution that social enterprise is already offering, and could offer in the future, to the question of employing persons with disability. The particularly intriguing question of persons with disabilities as social entrepreneurs also needs further illumination. Without that, we are rather in the dark regarding the real potential for social enterprise to provide employment for persons with disabilities or pathways forward towards the horizon we mentioned at the beginning of the paper.

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[27] A key barrier to effective inclusion is the lack of high-quality, disability-related labour market data, as identified by the ILO's field offices. Addressing this gap is essential for shaping inclusive employment policies and programmes (ILO 2015).

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SESSION 3. PHILOSOPHICAL, ETHICAL AND THEOLOGICAL PERSPECTIVES ON DISABILITY AND THE HUMAN CONDITION

PHYSICAL AND MORAL DISABILITIES: PLATO AND CONFUCIUS ON THE LIFE WORTH LIVING

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Abstract

The mainstream discourse of treating the disabled with care is based on equal dignity of all human beings, but both the *Republic* and early Confucian texts seem to reject this idea. As a result, the *Republic* proposes eugenics and euthanasia, even killing the physically and mentally disabled. Despite the problematic account, it does raise the issue of what makes a life worth living, which may serve as medicine to the sickness of many humans today, who indulge themselves in radical and self-absorbed individualism. Early Confucians, however, have a broader sense of 'worth', and believe that many of the physically, mentally, and even morally disabled people are always able to earn the worth of life through their effort. Moreover, compassion is a central virtue for Confucians, and to be a human means to care for the disabled, even for those who cannot earn the worth of life. Not to do so suggests our own moral disabilities, even our not being human. This shows that we do not have to assume equal dignity to have a theory of treating the disabled well. This broadens our discourse on how to treat the disabled and sheds some new light on this issue.

1. Introduction: alternatives to the equality- and dignity-based approach to disabilities?

Sanctity and dignity of life, and equality among all human beings, seem to be the mainstream – if not universal – values today. The Church and the secular world, for example, may differ on when life begins (and thus on the issue of abortion), and yet both sides would agree on the idea that a disabled person who is already born should enjoy the sanctity and dignity of life *just as* a physically-abled person does.[1] Let's call this the equal dig-

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[1] There can be relatively rare exceptions on the secular side. For example, Peter Singer has gained notoriety by justifying the (conditional) killing of a seriously disabled infant. It should be noted that his argument is partly based on the typical secular and liberal endorsement of abortion, thus challenging the consistency of the position that

nity approach to disabilities (EDAD). Within EDAD, however, there can be a lot of disagreements. For example, the distinction between the abled and the disabled may not be as clear as it first appears, and can be socially and politically dependent.[2] Moreover, the aforementioned "just as" can be another source of disagreements. That is, equality in equal treatments of the abled and the disabled, as equality in any situations, is always a controversial issue.[3] Beyond this approach, we can also ask whether there can be a theory of treating the disabled with care that does not presuppose equal dignity among all. Universal as they appear to be, equality and dignity are not really universal values. To offer a path for those who reject these values to embrace some form of care for the disabled, then, may have both theoretical and practical significance.[4] After all, we live in a pluralistic world. If we don't wish to impose one set of values on all, but still wish as many of us to embrace some form of common decency as possible, we would better "conceptually engineer" paths such as the aforementioned one.

In this paper, then, I will look into two sets of theories that do not embrace equal dignity. First, I will look into what Plato's *Republic* would have to say about the treatments of the disabled. We will see, as expected, that this text seems to reject our idea of decent treatments of the disabled. Though disturbing, ideas from this text may also have some merits. To see these merits and to address them may help us to develop a more adequate theory of care for the disabled. Second, I will look into how two early Confucian thinkers, Confucius and Mencius, would deal with the disabled. Although both seem to reject today's conception of equal dignity and resonate, to some extent, the values in the *Republic*, they could nevertheless strongly defend care for the physically and mentally disabled. Indeed, not to care for the physically and mentally disabled would reveal our moral disability, a much more serious disability to early Confucians. From their account, then, we can discover an alternative approach to disabilities.

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both supports abortion and rejects the unequal treatment of disabled people. See Singer 2011, 160-67.

[2] See, for example, the contribution to this Volume by M. Leonardi, p. 59.

[3] For example, is it adequate to give the same resources to both an able-bodied person and a disabled person? Amartya Sen says no and introduces what is known as the capabilities approach (1979).

[4] Presentations from other participants in the December 2023 PASS webinar in preparation for the 2024 PASS Plenary on *Disability and the human condition* and Sr. Helen Alford's comments on my presentation helped me to develop this formulation of the significance of my paper. I thank them for the inspirations.

2. Life worth living in the *Republic*

2.1 Eugenics and euthanasia in Sparta and the Republic

Plato's *Republic* is a founding text in Western political philosophy, and a core issue in this text is how the ideal *polis* (city-state) should look like.[5] After rejecting the first proposal by Socrates as a "city of sows" (372d), from Book II to Book IV, another ideal city is constructed, which is shown to be a virtuous city (372e-434d). It is actually a slightly idealized and improved version of Sparta, as many commentators have observed.[6] It is well known that ancient Sparta employed many means to produce the most fierce and fearless soldiers, including the elimination of all the physically and intelligently disabled on every stage, which starts from infanticide. In Book III of the *Republic*, Socrates discussed such eliminations.[7] In Book V, he went one step further by proposing a radical reform of the family structure. Together, we see a very early account of eugenics and euthanasia, some of which would be considered murders even by those who defend euthanasia today.

In Book III, Socrates praises Asclepius the medical doctor, saying that he revealed an art of medicine for those whose bodies are by nature and regimen in a healthy condition but have some distinct and definite disease in them ... But with bodies diseased through and through, he made no attempt by regimens ... to make a lengthy and bad life for a human being and have him produce offspring likely to be such as he; ... on the grounds that he's of no profit to himself or to the city (407c-e).

That is, medicine should only be applied to those who have easily curable diseases, and not to those who have diseases that cannot be easily cured, including, apparently, people with many forms of disabilities. The latter people cannot even be allowed to have children, because the children may carry the same kind of diseases.

More generally, Socrates argues that in the ideal city, killing by medicine and by court is sanctioned. Those who have terminal sickness in the body should be left untreated and let die, and the city should actively kill those

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[5] Throughout this paper, I will rely on Bloom 1991 for the English translation of the *Republic*.

[6] See, for example, Bloom 1991, 380.

[7] We do not really know whether the Socrates in this dialogue represents the historical Socrates in any way, and Plato himself is completely missing in this dialogue (and most other Platonic dialogues). In this paper, I will avoid using "Plato" when discussing ideas in the *Republic*, and use "Socrates" instead. This "Socrates" is the one in the dialogue, not necessarily the historical one.

who have incurable sickness in the soul (409e-410a). In the ideal city, a law for both the arts of medicine and judging should be set down,

> "which will care for those of your citizens who have good natures in body and soul; while as for those who haven't, they'll let die the ones whose bodies are such, and the ones whose souls have bad natures and are incurable, they themselves will kill" (409e-410a).

In Book V, Socrates proposes "we'll make … the most beneficial marriage … sacred" (458e). The best men should have intercourse as often as possible with the best women, and reverse for the ordinary men and women. Only the offspring of the former will be reared (459c-460a). One main purpose for all these arrangements is to produce the best children, and thus this is a theory of eugenics. According to this theory, the mediocre, let alone the physically and mentally disabled, are prevented from being born, and if born, should be let die or even killed.

Later in Book V, talking about war, Socrates says that warriors who are captured alive should be given as a gift to the enemies (468a). The reason seems to be that warriors are supposed to be brave and fight to death. Being captured is a sign of cowardice and does not deserve to be respected, and such a life should not be saved. This resonates with the legendary words of a Spartan mother to her son: "either [come back with] this or upon this" when presenting the shield to him before he goes to war (Plutarch, *Moralia* 241f).[8]

In sum, according to Socrates in the *Republic*, pregnancy with fetus that is not likely to be of the physically and mentally best should be prevented. Infants with clear disabilities should be killed. Adults with not easily curable diseases and lacking certain virtues should be let die or even be actively killed.

2.2 The idea of life worth living and its worth evaluated

The aforementioned picture from the *Republic* is deeply disturbing, to say the least. What is the justification of it? In Book III, Socrates explains his hostility toward medicine. According to him, the greatest sign of a bad and base education in a city is that it needs eminent doctors and judges even for those reared in free fashion (405a). For illness is often the result of being idle (404e), that is, needing medicine "not because one has met with wounds or some of the seasonal maladies, but as a result of idleness and a way of life" (405d).

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[8] For the English translation, see Babbitt 1931, 465.

An extreme example Socrates offers is that of Herodicus: "Attending the mortal disease, he wasn't able to cure it ..., and spent his whole life treating it with no leisure for anything else, mightily distressed if he departed a bit from his accustomed regimen" (406a-b). Apparently, Herodicus's disease is not said to be the result of idleness, but he has no leisure for anything else and is thus "idle" with regard to all other things. Even worse, in contrast to the good doctor Asclepius, Herodicus invented medicines that could preserve the life of other people like him: so busy with saving one's own life as to be completely "idle" and useless to the city.

In contrast, someone who is not idle, such as a craftsman, "had a definite job, and if he couldn't do it, it would be of no profit to go on living" (407a). Generally speaking, "for all men obedient to good laws a certain job has been assigned to each in the city at which he is compelled to work, and no one has the leisure to be sick throughout life and treat himself" (407c).

It should now become clear that, according to Socrates, one has to have some "profit to himself or to the city" (407e) in order for his or her life to be worth living and the sickness worth curing. If a person's disabilities prevent him or her from physical and "musical" (intellectual) education, education that is profitable to himself, herself, or to the city, this person's life is not worth living anymore.

Politically incorrect as this theory sounds, it does pose a challenge to us. Equal dignity and equal rights sound correct and even wonderful, but what if one used dignity and right to defend an undignified life full of wrongs? If one's leg is cut off due to sicknesses caused by chain smoking or knowingly indulging oneself in an eating habit full of fat and sugar, should this person be treated the same as someone who is born with a deformed leg? In a highly individualistic culture where one is obsessed with preserving one's own health, isn't it good to ask questions such as whether we are creating new diseases and disabilities through our obsession with medicine, exacerbated by the capitalistic greed;[9] whether a life of health is worth living if there is no happiness or higher purpose in it;[10] and whether one earns the right to

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[9] An example is to have a medicine to cure dwarfism where dwarfism is defined as the shortest 5% of the population. The recently discovered miracle drug for weight loss, Ozempic, may pose a similar challenge: what weight would be a "normal" weight? How much society should and can pay for it?

[10] A good example of this kind of absurdity of modern life is given by Woody Allen. In his movie "Annie Hall" he said, "There's an old joke – um... two elderly women are at a Catskill Mountain resort, and one of 'em says, 'Boy, the food at this place is really terri-

live a healthy and happy life by contributing to the society?[11] The theory in the *Republic*, then, may offer a cure to the sicknesses and disabilities of contemporary societies.

Therefore, there could be some merits of a theory that rejects equal dignity and rights in general and EDAD in particular. But there are some obvious problems with the theory in the *Republic*. For one, "use" or "profit" is hard to define. In the case of disabilities, function and the lack of it are a matter of degree.[12] To be near-sighted is a disability, but with corrected and even contact lenses, the issue of how to treat the near-sighted would not be considered a serious issue. But in ancient Sparta, a deeply near-sighted person may be considered seriously disabled, and perhaps no use to the city, although even in contemporary Athens where one's military abilities are not the only use valued by Athenian citizens, this person could be of some use to himself and to the city.

This complexity with regard to function and use is actually present in the *Republic*. In the earlier books, the military function of the rulers (the "guardians") is emphasized, but in the later books, it turns out that ideal rulers should be philosophers and thus intellectual capacities are more important than physical ones. If we do not think Plato is a muddle-headed thinker and a lousy writer, perhaps there is an internal dialectic movement within the dialogue. However, there is another serious problem with the *Republic* that prevents it from developing a more sympathetic account toward the disabled: sympathy or compassion is never considered a virtue! On this issue, let me turn to the early Confucians.

3. Life worth living in the Analects and Mencius

3.1 Life's worth is earned

Confucius, the alleged founder of the Confucian school, lived around the same time as Plato. He and early Confucians (for example, Mencius)

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ble.' The other one says, 'Yeah, I know; and such small portions.' Well, that's essentially how I feel about life – full of loneliness, and misery, and suffering, and unhappiness, and it's all over much too quickly."

[11] Many years after Socrates and Plato, Kant insisted that "an impartial rational spectator" (a Kantian God?) would not be delighted to see the happiness of "a being who is not graced by any touch of a pure and good will" (4:393; for an English translation, see Kant 1993, 7).

[12] On this point, I benefitted from Matilde Leonardi's presentation "ICF: the universalizing conception of disability and functioning" in PASS's webinar in December 2023. See Leonardi (manuscript).

were known to defend some form of hierarchy, and dignity and rights are apparently not in their vocabularies. In a conversation, Confucius also raised the issue of life worth living. According to the *Analects*, a collection of conversations often between Confucius and someone else, Yuan Rang, an old friend of Confucius, sat casually, with his legs sprawled out, waiting for Confucius. The Master said,

> "when young, you had no humility and respect for your elders; when growing up, you made nothing worthy to pass on; when growing older but not dying, you are a thief [of resources or of the long life you don't deserve]." He then rapped him on the shin with his staff [admonishing him for his impolite way of sitting when seeing a friend]. (*Analects* 14.43)[13]

Though jokingly, Confucius also suggested that not every life is worth living. Life's worth consists in acquiring certain virtues, including ritual propriety, which would make a person a good member of a community, and in making contributions to society by having something worthy to pass on, such as being a good moral exemplar, preserving traditions, teaching pupils, and so on – all embodied by Confucius as presented in the *Analects*.

Despite apparent similarities, the worth of one's life, for Confucius, lies in one's *moral* capabilities, not in one's physical or even intellectual capabilities. Those who are physically and intellectually disabled can prove their life's worth by cultivating their morality. With regard to moral cultivation, another early Confucian Mencius explicitly stated that everyone can become the ideal moral sage if s/he tries (for example, *Mencius* 6B2). As was indicated earlier, there is an implicit movement from the emphasis on both physical and intellectual capabilities to the emphasis on the latter alone, culminating in the idea of the philosopher-king (473c-474c). This leaves a little more room for the physically disabled – but not the intellectually disabled – to have a life worth living in the ideal city of the *Republic*. More importantly, Socrates in the *Republic* also insists on educating everyone, including even women, a very unconventional, if not scandalous, idea of his times. But he also claims that this education is not open-ended, and those who fail to pass certain tests at a certain point will be excluded from education and the possibility of becoming ruling elites (414b-415d). For early Confucians, although they, too, believe that in reality, people differ and

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[13] The translations of passages from the *Analects* and the *Mencius* are all mine. For different translations, see Lau 2000 and 2003.

there are those who rule and those who are ruled (see, for example, *Mencius* 3A4), for Mencius, upward mobility is always available.

In short, by focusing on morality and acknowledging equal moral potentials, early Confucians do not have harsh attitude toward the physically disabled. Even for the mentally disabled, clearly, people with, for example, Down Syndrome can still be virtuous and thus have life worth living. They should not be "let die," as suggested in the *Republic*. Even for someone with a bad "soul" such as Yuan Rang, we should keep trying to improve his morality. For in contrast to the *Republic*, there is no cut-off line for moral cultivation, and thus the life of an "idle" person should not be "cut off" or actively terminated. But what about those who are "diseased through and through" to such an extent that any meaningful moral cultivation becomes impossible? Lacking an account of inherent dignity of human life, Confucians seem to have to deny the worth of these people's lives. Is this really the case? Moreover, not letting die or killing is one thing, but why should we help those with a bad soul or a "bad" (disabled) body? I will answer these questions in the following.

3.2 Centrality of compassion as a virtue

It is well known that a key Confucian virtue is *ren* 仁, which is translated as "benevolence" or "humaneness." Although apparently a conservative, Confucius wished to restore the old regime that is represented by rituals and music, he claimed, "a man who is not humane – what has he to do with ritual? A man who is not humane – what has he to do with music?" (*Analects* 3.3)

Mencius further elaborated on this virtue of humaneness. In a famous passage, he claimed that every human being has "a heart that cannot bear [to see the suffering of] others," and he offered a "thought-experiment" to demonstrate this.

> "If anyone suddenly sees a child about to fall into a well, he or she will have a feeling of alarm and distress, not to gain friendship with the child's parents, nor to seek the praise of their neighbors and friends, nor because they dislike the cry of the child. From this we see that whoever is devoid of the heart of compassion is not human; whoever is devoid of the heart of shame is not human; whoever is devoid of the heart of courtesy and modesty is not human; whoever is devoid of the heart of right and wrong is not human. The heart of compassion is the germ of humanity (ren); the heart of shame is the germ of righteousness (yi); the heart of courtesy and modesty is the germ of

> the observance of rituals (li); the heart of right and wrong is the germ of wisdom. A human being has these four germs, as he or she has four limbs. Possessing these four germs but claiming one's incapability [of developing them into four virtues] is to cripple oneself … If a human being who possesses these four germs knows to develop them, it will be like a fire starting up or a spring coming out. If one can develop it, one can tend to what is within the Four Seas [i.e., the world]; if one can't develop it, one can't even serve one's parents". (*Mencius* 2A6)

This is a key passage in the *Mencius*, and there are many important issues involved. For example, there is a political dimension of 2A6, but many of the relevant lines are not included in the above quotation because they are not directly related to the topic of this paper. On what I have actually quoted from 2A6, why the thought-experiment is persuasive and how persuasive it is are also important issues. Let us assume it is very convincing. That is, "the heart that cannot bear to see the suffering of others" or what we would simply call compassion is indeed universal. Still, why should this emotion be considered to be a *moral sentiment*? Even if it is a moral sentiment and should be the "germ" or the basis of a virtue (humaneness), where do the three other germs come from? These are controversial issues, but what is clear in this quotation is the following. In the analogy between the four cardinal virtues and four bodily limbs, we can literally say that those who fail to develop these virtues are disabled, for their moral limbs are disfigured. Among the four virtues, compassion is (the seed of) a virtue, the virtue of humaneness, and humaneness is the virtue of all virtues because Mencius seems to focus on elaborating on this virtue alone. To be compassionate is what makes us human.

In contrast, as mentioned, compassion or anything similar is nowhere to be found in the *Republic*. With this "tool," Confucians can offer an additional account of treating the disabled well. Although the physically and intellectually disabled could have a life worth living by developing their potentials as human beings, it cannot be denied that it is not easy for them to do so. Compassion then requires us to help them out. As Confucius said, "a humane person is someone who, desiring to take his or her stand, helps others to take their stand; and who, desiring to realize himself or herself, helps others to realize themselves" (*Analects* 6.30). For morally disabled people such as Yuan Rang in the *Analects* or the "idlers" in the *Republic*, we should try to change their ways through admonishments and other means, as Confucius did to Yuan Rang. After all, Confucius only said that Yuan Rang's life is not worth living, and did not really suggest to have him killed, as Socrates suggested with regard to the idlers in the *Republic*. By reminding Yuan Rang of what makes a life worth living, Confucius wished to set him straight or to show others the importance of living a worthy life. For those who are born to have some seriously disabling conditions and who are so sick as not to be able to take up even the minimal moral cultivation, we as *human* should be compassionate about their tragic fate and help them out as much as possible. That is, even if their life is not worth living in a Confucian sense and this cannot be changed, to help them out from *our* humaneness is making *our own life* worth living. Not to help the physically, mentally, and even morally disabled reveals our own moral, humane, and human disabilities.

Before I conclude, let me quote in full a very famous passage, the "Western Inscription," from a later Confucian thinker by Zhang Zai 张载 (1020-1077).

> "Heaven [*qian* 乾] is called my father and Earth [*kun* 坤] is called my mother. And I, this tiny thing, find an intimate place in their midst. Hence, what fills Heaven and Earth is my body, and what directs Heaven and Earth is my nature. All people are my siblings, and all things are my companions. The great ruler is the eldest son of my parents, and his ministers are his retainers. To respect those great in years is the way to treat the elderly as elderly should be treated. To be loving to the orphaned and the weak is the way to treat the young as young should be treated.[14] … All in the world who are tired, infirm, crippled, or sick; brotherless, childless, widows or widowers – they are all my siblings who are helpless and have no one else to appeal to. …
> Riches, honor, good fortune, and abundance shall enrich my life, while poverty, humble station, care, and sorrow shall discipline me to fulfillment. In life I follow and serve [Heaven and Earth], and in death I shall be at peace".[15]

Let me conclude with a summary of the main points of this paper, which may be unnecessary and even annoying after quoting this beautiful passage. Not having an account of dignity and equality, Plato's *Republic* does con-

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[14] For "the way to treat the elderly/young as elderly should be treated" (所以长/幼其长/幼), see: "treat the elderly of my own family [as they should be], and extend this treatment to the elderly of other families; treat the young of my own family [as they should be], and extend this to the young of other families" (*Mencius* 1A7).

[15] For other English translations, see Chan 1969, 497-498 and Bryan Van Norden's translation which is available on line http://faculty.vassar.edu/brvannor/Phil210/Translations/Western%20Inscription.pdf, accessed on 08/20/2011).

firm our intuition that such a theory wouldn't have an account of treating the disabled well. Indeed, it argues for actively killing the disabled. But early Confucian texts show otherwise. Such a theory can have an account of treating the disabled humanely by having a more diverse understanding of life's worth, and by having compassion as a cardinal virtue. The above discussion, then, shows that we do not have to have dignity and equality to have an account of treating the disabled well, thus broadening the discourse. Indeed, the disabled, by definition, are those who lack certain abilities to do things. Therefore, by putting the moral burden on the abled, that is, those who are able or at least more able to take actions, the Confucian account may be more effective than an account that is based on equality and dignity.

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HUMAN BEINGS ABOVE AND BEYOND FUNCTIONAL CATEGORIZATIONS: TAKING STOCK FROM THE PHILOSOPHY OF DISABILITY

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Abstract

In this essay I refer to the way disability is currently approached in legal and policy texts, and then turn to the underlying philosophical controversies. Drawing on Eva Kittay's pioneering work on the philosophy of disability I resume a classical perspective that sheds light not just on the blurring frontiers of functional approaches to disability, but on the general human condition. In this context, I contend that reflection on human aging constitutes an occasion to highlight other, specifically human abilities that often get lost when we are too focused on sheer functionality.

Social systems depend on abstract categorizations. Refining and enriching those categories can help us dealing with a variety of situations real people face, even if, in absence of a broader cultural framework, using those categories can eventually reinforce cultural prejudice and damage your self-conception.

Indeed: although words are useful, they also can be two-edged swords. If you fall under the category "unemployed", you can have access to certain benefits. Yet, being categorized as unemployed is not considered something desirable; in a productive society it carries a certain stigma. But of course, you are never only "an unemployed person", because your life is never exhausted in that or any other aspect of your social identity.

Individual people always exceed or transcend social categorizations. Hence, in order to create more inclusive societies, we should not merely aim at refining those categories. Rather, we need to enlarge our cultural vision of the human being, move beyond the categories entrenched in the social system and make room in society for the variegated contribution of people with unique life trajectories, subject to all sorts of contingencies.

1. Current policy and legal approaches to disability

During the last few decades we have witnessed important changes in the way legislation approaches disability. The Optional Protocol to the Convention on the Rights of Persons with Disabilities, issued in 24 January 2007, explicitly states that "disability is an evolving concept"; it further notes that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".[1]

Thus, instead of approaching disability in medical terms, as it was common in the past, current legal texts have adopted a mixed approach, which conceptualizes disability in terms of interaction between persons with impairments and their social environment. Accordingly, overcoming disabilities is not just a matter of medical interventions, but also a matter of social interventions.

The mixed model of disability advanced in those legislative texts tries to mediate between the medical and the social model. In Kittay's words,

> "Proponents of what has become known as the social model of disability claim that the difference that exists in the body or mind of a disabled person is disadvantageous only when there is a lack of fit between the body and the environment. They claim that disability, as opposed to the impairment in the body, is a social factor often caused by built physical environments that can, if the political will is there, be built differently. Sometimes 'the environment' needs to be understood more broadly. The obstacles that disable people face may be social: discrimination, neglect of needs and important services, social stigma and an intentional exclusion from participation in normal life. These result from social technologies that fail to accommodate disabled people" (Kittay, 2020b: 294-5).

While the social model certainly captures an important aspect that affects the lives of many disabled people, one could discuss whether everything in the experience of disability can be captured merely in social terms. In this presentation I will address this concern.

In the meantime, however, it is the mixed model what has gained its place in legislation and policy. It was used in the World Report on Disabil-

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[1] United Nations, General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106 (24 January 2007), available from http://www.un.org/esa/socdev/enable/rights/convtexte.htm

ity (2011)[2] and represented the basis for both the World Health Assembly resolution WHA66 on "Disability" (2013)[3] and WHA74.8 on "The highest attainable standard of health for persons with disabilities" (2021),[4] which also considered the Disability and Development Report issued in 2018.[5] In an article entitled "Rethinking disability" (2018), some contributors to the 2018 Report stated that

> "The important lesson learned from WHO's activities conceptualizing and measuring disability is that disability is a universal human experience, in the sense that everyone can be placed on a *continuum of functioning* and either currently experiences or is vulnerable to experiencing disability over the course of their lives. This understanding of disability is the key to mainstreaming disability within the public discourse. Truly, disability is about all of us, and as disability advocates rightly say, disability must be mainstreamed in society and throughout health and social policy such that it indeed becomes everyone's business" (Cieza & Sabariego & Bickenbach, 2018).

By placing disability in a continuum of functioning, the concept has certainly been expanded and virtually made universal, so that almost everybody can recall an experience that gives a personal insight in its meaning, even if not everybody can identify himself or herself as disabled. For the latter, malfunctioning must be permanent. Interestingly, that malfunctioning needs not to be placed on the individual alone, but in the interaction between the individual and his or her environment.

Thus, the Spanish law directly approaches disability as a *situation* resulting from interaction of people with foreseeably *permanent* deficiencies, physical, mental, intellectual or sensory, and certain barriers that hinder their participation in society in equal conditions to others.[6] Accordingly, the situation of disability could disappear if those barriers were removed, even if the permanent deficiencies on the side of the individual were not. This obviously makes room for treating disability as a social problem to be tackled with appropriate social policies.

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[2] https://www.refworld.org/pdfid/50854a322.pdf

[3] https://iris.who.int/bitstream/handle/10665/150160/A66_R9-en.pdf?sequence=1&isAllowed=y

[4] https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

[5] https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf

[6] https://www.boe.es/boe/dias/2013/12/03/pdfs/BOE-A-2013-12632.pdf

2. The cultural challenge

Yet, precisely because of its socially relative dimension, the universal scope of WHO's resolutions on disability remains open to cultural interpretation, in ways that can hinder the implementation of certain social policies. Thus, in a webpage devoted to the topic of disability, the German Federal Ministry for economy and development explicitly states that "There is no universal, legally binding definition of disability. Social and cultural norms have a significant impact on what is considered a disability in a society".[7] The explanation provided in the same webpage is enlightened:

> "Official statistics from developing countries often underestimate the number of people with disabilities. On the one hand, because there is often a lack of funds for scientifically correct surveys, but on the other hand, because people with disabilities remain virtually invisible due to stigmatization and exclusion in their societies.
>
> In international politics – and thus also in development cooperation – a 'social' definition of disability is increasingly becoming established. Accordingly, disability is characterized less by individual characteristics such as physical impairments, but rather by barriers in the environment and negative attitudes among other people. These prevent people with disabilities from being able to participate equally in social life".[8]

In other words: while the social approach to disability is gaining ground in the realm of public policies, we still need to consider that there is not a simple way of counting disabled people, not just for economic or technical reasons, but also for cultural ones. This means that the determination to extend universal human rights to all people, including all disabled persons, and thus walking towards more inclusive societies cannot materialize itself unless we consider specific cultural contexts. As Faye Ginsburg and Rayna Rapp (2013) note,

> "In the Global South, where an estimated 80% of people with disabilities reside, cross-cultural work in anthropology and disability studies shows that what counts as a disability in different cultural settings cannot be taken for granted (Devlieger et al. 2003, Addlakha et al. 2009). Ingstad & Whyte's landmark coedited volume, *Disability and*

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[7] https://www.bmz.de/de/themen/rechte-menschen-mit-behinderungen/definition-behinderung-20364

[8] https://www.bmz.de/de/themen/rechte-menschen-mit-behinderungen/definition-behinderung-20364

> *Culture*, early on highlighted non-Western social circumstances to understand how people with impairments survive and are integrated into or segregated from local social worlds. As Africanists, Ingstad & Whyte point out the complexity of the very category of disability when working in cross-cultural settings: "In many cultures, one cannot be 'disabled' for the simple reason that 'disability' as a recognized category does not exist. There are blind people, lame people, and 'slow' people, but 'the disabled' as a general term does not translate easily into many languages" (Ingstad & Whyte 1995, p. 7).

In this process, we should be careful not to approach cultural differences simply in terms of "barriers". For, very often, those differences are embedded in culturally meaningful lifestyles. This makes cultural anthropologists' approach to disability all the more relevant. In their introduction to *Disability and culture*,

> "[Ingstand & Whyte] point out the danger of imposing a Western individualizing model onto the heterogeneity of cultural worlds. At the same time, they caution against cultural essentialism: While they characterize societies as on a *continuum* that ranges from individualistic to sociocentric, they are quick to point out that either framework might be called into play as individuals negotiate kinship and opportunity structures (pp. 11, 36)" (Ginsburg & Rapp, 2013).

I take the reference to negotiation as a relevant indication of how to proceed in practice. While humanity is embodied differently in different traditions and cultures, the human inclination for what is good and true remains a practical way to articulate universal moral requirements within particular cultures, if only we take the time necessary to reflect on all the aspects involved in the human experience of disability.

3. Recent contributions to the philosophy of disability

In *The Minority Body* (2016), Elisabeth Barnes tried to develop a metaphysical approach that "does not build normative assumptions into the definition of disability", i.e. that treats disability as just one difference and not necessarily a bad difference. She "proposes that disabled bodies are minority bodies of a certain sort, the sort for which the disability movement strives to achieve justice" (Kittay, 2020a: 226). In this way, she tries to overcome the incoherence incurred by this movement, insofar as it embraces a celebratory attitude of disability while aspiring to get rid of "ableism". Accordingly, she insists that disability is "neutral with respect to a person's well-being", even if, when combined with other factors can be experienced negatively, just like "lacking an ability or enduring a hardship is not always a disadvantage, even if it is a disadvantage for certain purposes and for some people" (Kittay, 2020a: 229).

Despite being voiced by a disabled person, which in this way tries to create a "hermeneutical space" for naming certain experiences that lack appropriate designation (Kittay, 2020a: 225), Barnes' approach has proved a controversial one. In a recent article that "reports the results of a philosophically-informed literature review of the relevant empirical research concerning the relationship between disability and wellbeing", Avram Hiller has summarized his critique to Barnes in the following terms:

> "(1) on average, those with disabilities have a significantly lower level of wellbeing than those without disabilities; (2) this lowered level of wellbeing endures across time; (3) this lowered level of wellbeing is probably not *fully* due to ableism or to society's lack of accommodation of disabled people; (4) disabled people in wealthy countries nevertheless typically do lead *good* lives; and (5) individuals with some *congenital* disabilities do *not* experience as much of a lower level of wellbeing than those without disabilities" (Hiller, 2023).

Interestingly, however, Hiller shares the view that "the lives of disabled people are typically good lives, and there should be more of a focus on the *positive* aspects of being disabled, which in some cases are not possessed by those who are non-disabled" (Hiller, 2023). Yet, how can this possibly become a general outlook in absence of adequate social policies, or in cultural context that values achievement and productivity above everything else?

Eva Kittay's pioneering philosophical work on disability was inspired by her experience as a mother of Sesha, born with a severe cognitive disability. While praising Barnes' contribution to the field, she objects that her focus on physical disabilities assumes "an unwarranted dualistic conception" (Kittay, 2020a, 228), which results in a marginalization of other forms of disability. In an interesting interview, following the publication of her book *Learning from my daughter* (2019), Kittay reflected on how little conventional philosophical approaches had helped her to confront this situation:

> "If I were to approach Sesha from a philosophical standpoint, a traditional philosophical standpoint – she wrote – I'd have to approach her as a kind of non-person and that would be exactly the opposite of how any decent mother would relate to her child. I wouldn't say that

> my theoretical and philosophical life had influence on my approach to Sesha as a mother. But, rather, my life with Sesha has had a profound influence on my philosophical and theoretical work" (Gesser & Fietz & Kittay, 2021: 2).

Kittay's philosophical reflection on disability was prompted by her experience as a mother of a disabled child, and her own sense of what a decent mother would do. At first, her philosophical training was even experienced as problematic in this regard:

> "For me philosophy occupied that space where I was nobody's mother for a long time. But even from the start it was clear that Sesha's life with intellectual disabilities was a challenge to me as someone who invested so much importance to a life of the mind, to thinking, to rational discourse... but I didn't take up that challenge for quite a while... There was really no acceptable place in philosophy to write about these matters. There was no field of Philosophy of Disability when I started out" (Gesser & Fietz & Kittay, 2021: 2).

In that context, feminist philosophy, "and the ways in which being a woman impacted on both the subject matter of philosophy and the way one did philosophy", opened an epistemological space for her to deal philosophically with the issue of disability. Specifically, she recalls the challenge she experienced as she was invited to participate in a conference on prenatal diagnosis and selective abortion:

> "Thinking about the issue from that vantage point was something I didn't relish. Nonetheless, these were the two instances where I first started to think about my life with Sesha and how Sesha poses a challenge to conceptions of the primacy of rationality, the role language plays in how we think about being human, the notions of what justice involves, and so forth. If you start thinking about these questions from the perspective of disability and especially cognitive disability (because you could work people with physical disabilities into the theories more easily than you could include people with mental disabilities), you have to question prominent theories" (Gesser & Fietz & Kittay, 2021: 2).

Thus, confronted with Singer's reduction of personhood to a set of properties, she argued that a human being cannot be captured in a set of properties (Kittay, 2019b), for it simply consists in being born to human parents (Kittay, 2021). "By a living human being – she writes – I mean all those born humans who are in a condition that is compatible with life". This she takes to represent a “sufficiency condition” to be accorded full moral status,[9] against MacMahan and Singer’s criticisms, which consider that principle as the reason why we would have neglected our moral obligations towards the non-human world. As she writes,

> “Philosophers may be the only people who think that being human isn’t sufficient for being morally significant or morally equal. But I do believe that being human is sufficient for being a moral equal. And in fact, when you are mistreated in certain important ways, what do you say? You say “how can you treat me this way. I’m a human being”. Not I’m a person. You can say that but most of the time what we say is “I’m a human being” (Gesser & Fietz & Kittay, 2021: 6).

While Eva Kittay has developed her philosophy of disability in connection with the ethics of care (Kittay, 2020b: 293), she acknowledges that many theorists of disability are hostile to this approach (Gesser & Fietz & Kittay, 2021: 4); they think that it diminishes the autonomy of disabled people, and thus their equal moral standing with other citizens, for it somehow sanctions their dependence on interpersonal relationships. Yet, in Kittay’s view, dependence is a feature of every human life, this being a reason for care to go beyond interpersonal relationships and inform a theory of justice. A defining feature of such theory would be the balance between the idea of rights and that of responsibilities toward dependents, given that dependence is often an unavoidable situation.

Accordingly, she proposes to place the idea of dependence, rather than that of independence, at the center of our institutions and public policy. To those critics that claim that the notion of “dependency is construed” she has a powerful argument on the contrary:

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[9] Controversially, she holds that this condition leaves the moral status of the fetus undecided: “The fetus is not yet a human being in this sense. It exists, even in later stages, because another human being houses it and makes its existence possible. This intricate relationship complicates determining its moral status relative to the human being to whom it is tethered. But we need not resolve the vexing question of the moral status of the fetus, nor need we reject or accept abortion rights, to accept the sufficiency condition”. (Kittay, 2021: 80) By contrast, “Individuals who enter end-stage Alzheimers or other forms of fatal dementia are still in a condition that is compatible with life – though barely so. At the very end of end-stage Alzheimer’s, for example, once the brain is so damaged that the condition ceases to be compatible with life, the individual dies” (Kittay, 2021: 81). In my view, Kittay’s own insistence on “dependency” as a feature of all human beings does not fit well with the restriction she places on the moral status of the fetus because of its being dependent on its mother.

> "No, the dependency of my daughter is not constructed. She would perish if there was not someone there tending to her needs. And there's nothing constructed about that. But independency is constructed." It's a construct that is an abstraction from all the various dependencies that we decide to make invisible. Like other constructs, it has its use. And certainly, there are many times when we say things like, "don't help me, I want to do it myself". Fine. I think of this impulse less in terms of independency, and more as an expression of a desire to be efficacious, to make an imprint on the world. We all want that to some extent or another" (Gesser & Fietz & Kittay, 2021: 7).

Of course, this is not to deny the existence of pernicious dependencies that are socially constructed. Distinguishing between genuine, normal dependencies and pernicious ones requires some conceptual work.

It should be clear that some sort of dependency belongs to the human condition: we all depend on one another, and there is nothing humiliating in this; we all accept the other's help in many occasions and contexts, simply to save efforts for other purposes. For this reason, rather than resorting to the notion of "independence", which emphasizes "self-determination" (autonomy) and "self-reliance", Kittay signifies the human condition through the notion of "managed dependency" to signify the general human condition.

For similar reasons, rather than speaking of autonomy, Kittay draws on the feminist notion of "relational autonomy" to say that "who we have become as individuals has always been influenced by the relationships we've been in and is always affected by the relationships we currently have. That is, who we are is both a consequence of, and is constituted by, those with whom we have been and are in relationship" (Gesser & Fietz & Kittay, 2021: 8).

The point of drawing those distinctions is that some human beings lack the kind of "self-determination" and "self-reliance" that make up the usual notion of "independence", even if they retain a clear sense of themselves that makes them able to lead good lives in their situation. The fact that their lives are affected by a special precariousness is, again, an accentuation of something that is proper to every human life: nobody has a good life fully secured. In Kittay's view, such precariousness "need not affect our quality of life – again, as long as we have reason to feel relatively secure that we can get what we need. *Precariousness reduces well-being when that precariousness is not countered with a security that we can either procure or receive from another what we need*" (Kittay, 2020b: 296).

The latter, however, requires entrenching the idea of dependency in our social system: "Until we have a system of justice that is designed to take dependency seriously", she writes, "the already precarious well-being of disabled people will be made that much more precarious by the precarity that caregivers face" (Kittay, 2020b: 293)

This explains her ambivalent position towards the disability rights movement: while she supports their fight against pernicious dependencies, deriving from lack of societal resources to remove constraints that hinder quality of life of disabled people, she does not share the focus of disability rights movement on autonomy. For sure,

> "When people are made dependent by built environments that are not suitable to them, when people are made dependent because they're not given the kinds of services or equipment they need, when they are left to sit in their house and be dependent on whomsoever happens to come in to give them an assist, these are awful constraints that impede having a flourishing life. The removal of those kinds of constraints are certainly worth fighting for" (Gesser & Fietz & Kittay, 2021: 8).

Yet, in her view, fighting for those causes is different to put the concept of autonomy at the center of the movement. Indeed: although "self-governance" certainly represents a good, not every human being has the rational capacities required to act in that way; not everybody can even aspire to be independent and productive (Kittay, 2020b); surely, not people in the situation of her daughter, who nevertheless retains a sense of her agency, for which she demands respect: "I do think that I have to respect her sense of agency, and I do think I have to respect her sense of what feels right and doesn't feel right" (Gesser & Fietz & Kittay, 2021: 8). Hence, a valid way to argue for the rights and well-being of disabled people, would be to stress the need of removing constraints, but also exploring "ways that disabled people can be empowered by the appropriate assistance", for "dependencies can at times be a good thing, something that can make life rich" (Gesser & Fietz & Kittay, 2021: 9).

Kittay is well aware that the concepts and approaches to disability that she has developed within the framework of an ethics of care are difficult to transfer to the institutional level, for the institutional level focuses on the generalized other,[10] while care for care is primarily focused on the particular

[10] "Rawls' [Theory of Justice] is based on the Kantian Ethics. The point of the state is to allow people to develop self- respect, which from a Kantian point of view is the most essential thing: to be able to act as a self-respecting person, acting out of goodwill. In a Kantian ethics, right action, which leads to self-respect, takes priority over happiness.

other. In addition, the concept of autonomy is so embedded in the legislation that "where people don't see any manifest autonomy, they assume a lack of agency and competency, which in turn, gives them license to ignore what that person may want" (Gesser & Fietz & Kittay, 2021: 10). This, however, would be a sad mistake, and actually an injustice. For those people do have a sense of their agency that need to be respected, even if that agency does not achieve the level of full autonomy.

From this perspective, Kittay is even ready to take part of Barnes' argument. For, as she rightly notes, "Much of Barnes's discussion is directed to showing us how the difficulties and disadvantages of a life with disability has analogies in most of human life". Along these lines, but moving beyond Barnes' focus on physical disabilities, Kittay adds that "the precariousness of a good life lived by a person with mental disabilities directs us to see the analogous precariousness in all of our lives". This she takes to be "one of the most urgent reasons for bringing awareness of disability into philosophical thought", namely, "to provide a fuller understanding of the human condition" (Kittay, 2020a: 231).

This is what I would like to consider more closely in the following section.

4. The human condition reconsidered

Even if language can often be vehicle of cultural prejudice, it is also a repository of basic understandings that might be helpful to make sense of human experience. All we need is a philosophical critique of language. Thus, while the very word "disability" directs our attention to the thought of one or some abilities that are defective or lacking, nothing is initially said as to the place where those disabilities are to be placed, whether in individual bodies or in their environment. Furthermore, one could argue that, insofar as we are social animals, there exists a certain continuum between the two, especially when we adopt a practical approach, i.e. if we focus on the ability

What does a theory of justice look like if you take an ethics of care as the central ethical perspective? Rights that we can claim for ourselves or that others insist upon would not have quite the importance that they have in the theory of justice. Instead, the importance of acting in accordance with our own or another's rights needs to be reconciled with the need to honor our responsibilities – especially responsibilities that we have toward dependents. Such a theory of justice would need to take dependence rather than (or along with) independence as central to our thinking about the sorts of social institutions we want to have". (Gesser & Fietz & Kittay, 2021: 5).

to perform "the basic activities of life", as suggested in the definition above.

Indeed, from a philosophical point of view the basic problem to arrive at an operational definition of disability seems to be the loose meaning of the "basic activities of life" as well as the kind of assistance we might need to carry them out. For, while the basic activities of life are fundamentally similar across societies, the assistance required to perform them in a functional way may vary from some societies to others, depending on the kind of social relationships or the technological means one has access to on an ordinary basis. As Aristotle puts it,

> "If people meet with an impossibility, they give up... But if it seems possible they will try to do it. *What is possible is what can be accomplished by our own efforts; what can be brought about through our friends is in a sense accomplished by our own efforts, in that the first principle is in us.* The question is sometimes what tools to use, sometimes what use to make of them. The same goes for other cases: sometimes the question is the means, sometimes how they are to be used or the means to that use". (NE, III, 3, 1112b 25-32)

These words could provide some ground to the view that aims to overcome decontextualized approaches to disability, insofar as, assuming that each human being is principle of his or her own actions, directs our attention to the available tools and the use he or she can make of them, which depends on a variety of factors. Interestingly, however, Aristotle establishes a significant difference between what we can attain through our own efforts, and what can be attained only through other means; and, even more interestingly, he expands the meaning of our own efforts to include our friends, arguing that, in this case, the first principle is still in us. The argument is intriguing, because, at first sight, one could object that in all cases the action's principle is in us, and all the more so in case we use technical means, which, unlike friends, will not present any opposition to our own will. Yet, Aristotle takes friends to be closer to the action's principle than whatever technical means, perhaps because we invest more efforts in identifying with our friends than in using external tools.

Considering what could count as "socially normal" in a given society, both in terms of relationships and available technological means, Aristotle's words could partially support the invitation to frame disability in social terms. Thus, to the extent that having a cell phone has become a must in our societies, lacking this device already represents a clear impairment to perform many routine activities.

Certainly, we would not say that someone lacking a cell phone suffers a disability, for we still make a meaningful distinction between bodily based disabilities and externally based disabilities, between our organism, as a natural part of our own selves, and external instruments that we use to pursue our ends. I think this distinction cannot be dispensed with, not just for ontological reasons but for pragmatic ones, to differentiate enabling technologies, which restore organic functionality to normal parameters, and enhancing technologies, which go beyond what is normal organic functionality, exponentially increasing differences among humans depending on their different access to those technologies, ultimately depending on their wealth.

I am fully aware that speaking both of what counts as "socially normal" and of "normal parameters" is likely to arise objections, to the extent that it can easily acquire normative connotations that bypass individual circumstances and features. In this context, I cannot but recall my mother's anguish as the pediatrician told her that my brother's weight and stature was "below the canon". Yet, speaking of the "socially normal" and "normal parameters" represents a guidance both for social policies and medical diagnosis, which does not replace judgment on the particular relevant circumstances. If the purpose of social policies is to help people to make the most of their lives in an equitable way, we cannot dispense with that reflection.

Of course, at this point we should be discussing what we mean by "making the most of our lives". Current discussions rarely consider the difference between good life, wellbeing and quality of life. When they do, they often consider Aristotle's approach to happiness in terms of virtuous actions and works. Yet, in normal circumstances, virtuous actions not only require good *prohairesis* but also organic functionality and some external tool. The fact that human affairs are subject to many contingencies and misfortunes only speaks of the fragility of this sort of happiness.[11] Aquinas also seems to subscribe this view,[12] even if, as a Christian, he is more prepared than

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[11] Aristotle, NE, I, 10, 1100 b 23 ff.

[12] In fact, although in his discussion of the means required for happiness Aquinas clearly distinguishes between the good disposition of the body and the external goods, he also notes that both are necessary for the soul to exercise itself in perfect works: "If we speak of that happiness which man can acquire in this life, it is evident that a well-disposed body is of necessity required for it. For this happiness consists, according to the Philosopher (Ethic. i, 13) in "an operation according to perfect virtue"; and it is clear that man can be hindered, by indisposition of the body, from every operation of

Aristotle to deal with misfortune and anticipate another kind of happiness, which he calls perfect happiness, thus nourishing a principle of hope.

Interestingly, it is only when Aquinas discusses the requirements for that perfect happiness, which he places in seeing God, when the basic distinction between a functional body and external instruments emerges. In that context, he asserts that the perfection of the body will be part of perfect happiness, for "it is natural to the soul to be united to the body" (Sth. I-II, q. 4, a. 6); external goods, by contrast, "are not necessary for perfect Happiness". Indeed, external goods are only requisite "for the support of the animal body; or for certain operations which belong to human life, which we perform by means of the animal body: whereas that perfect Happiness which consists in seeing God, will be either in the soul separated from the body, or in the soul united to the body then no longer animal but spiritual" (Sth. I-II, q. 4, a 7).

The talk of "animal body" in this fragment is a way of referring to our present body, in contrast with the "spiritual body" that, according to St. Paul, the blessed would have after the resurrection. The important point, for our purposes here, is that *in this world* there is a practical equation between having a functional body and having access to the external goods necessary for sustaining it and operating through it.

This practical approach, then, would support a relative blurring of the frontiers between disability and social context. Only relative, because, as stated above, there is still a difference between the ways we relate to our body and to external instruments. Indeed, our body is not only meant to be a silent instrument of our soul, but also a natural expression of ourselves, which, in principle, only calls attention upon itself when it fails in its normal operations. When we speak of remedying disability, we refer primarily to remedying that kind of failing. In practice, however, the remedies can involve both medical and social interventions. Thus, current research in the US has shown that the situation of disabled people in rural areas in significantly worse than in urban ones (Zhao & Okoro & Hsia & Garvin &Town, 2019), which should have consequences at the level of public health inter-

virtue…" (Sth. I-II, q. 4, a. 6). "For imperfect happiness, such as can be had in this life, external goods are necessary, not as belonging to the essence of happiness, but by serving as instruments to happiness, which consists in an operation of virtue, as stated in Ethic. i, 13. For man needs in this life, the necessaries of the body, both for the operation of contemplative virtue, and for the operation of active virtue, for which latter he needs also many other things by means of which to perform its operations…" (Sth. I-II, q. 4, a. 7).

vention. More generally, as Kittay has emphasized, the precarity suffered by many caregivers has an impact on the precariousness suffered by many disabled people (Kittay, 2020b).

Indeed, as soon as we consider the social context in which we carry on our ordinary lives, the concept of disability becomes blurred with that of poverty and social inequality. After all, two people with similar physical and psychological conditions can be impaired or not to carry on their ordinary lives depending on their different access to health care and other kinds of medical services that are common in that society, such as a wearing a pair of glasses. Presently, "to be considered legally blind, a person must have visual acuity ten times less than normal even when wearing glasses or contact lenses. On the other hand, a person who does not have a visual field greater than 10 degrees is also considered legally blind". Yet, what if you don't have access to those glasses in the first place?

Another option, of course, is that you have someone to read to you aloud, as Jorge Luis Borges had Alberto Manguel. As Aristotle noted, "what can be brought about through our friends is in a sense accomplished by our own efforts, in that the first principle is in us". More generally, friends can certainly compensate some deficiencies and be useful for many purposes, even if they are never mere instrument. Thus, following Aristotle, Aquinas says that the good man needs friends,

> "Not, indeed, to make use of them, since he suffices himself; nor to delight in them, since he possesses perfect delight in the operation of virtue; but for the purpose of a good operation, viz. that he may do good to them; that he may delight in seeing them do good; and again, that he may be helped by them in his good work. For in order that man may do well, whether in the works of the active life, or in those of the contemplative life, he needs the fellowship of friends" (Sth. I-II, q. 4, a. 8)

And, in meaningful contrast with other kinds of "external goods", which are required in this world for functional reasons, but are not necessary for the vision of God, Aquinas quotes Augustine to say that the presence of friends does contribute even to that perfect happiness, in that "they see one another and rejoice in God at their fellowship" (Sth I-II, q. 4, a. 8).

As a matter of fact, already in this world, friendly and trusting relationships provide the context for human development in fundamental ways, which are also relevant for adequately addressing and remedying certain disabilities. Thus, a distinctive basic human response to the disabilities affecting people is care. This is perhaps particularly obvious in the case of families who take care of a disabled relative, but also in many other human communities. As cultural anthropologists Ginsburg and Rapp (2013) note, “Discoveries of burials of individuals who survived for years with disabilities have opened up work on the ‘bioarchaeology of care’, showing the relevance of this category across time”. This is not to say that human beings have always responded to disability with care; other times they have responded with eugenic and dehumanizing policies. The way disability is approached in a given society, as well as the readiness to accept the label of “disabled” upon oneself certainly varies (Ginsburg & Rapp, 2013: 59) across societies, depending on the relative value that this society ascribes not only to independence or solidarity, but more generally to the very fact of being human, independently of whether one is functional or not in certain situations are contexts. As we have seen, in the last decades, the efforts to change cultural perceptions on disability have been prominent. Only lately a similar effort is being made with aging.[13]

5. Disability and aging

It is noteworthy that, despite of the increasing view of disability as a “universal human experience”, we still tend to view it as an alien phenomenon, as something that happens to others, not to ourselves. As we daily engage in different activities, we easily give physical and psychical functionality for granted. To the extent we feel our strength we tend to forget our own fragility and vulnerability. This obliviousness, however, has consequences in the way we relate to others who suffer from any impairment; specifically, it makes difficult for us *to imagine* how it feels like to live with disabilities, and hence needing an extra help to perform routine activities.

From this perspective, being reminded our own fragility can also have a positive impact on the way we relate to others. Interestingly, we need not going very far to experience that fragility, for we carry a living reminder within ourselves. As a matter of fact, disability represents a possibility embedded in our very human nature, lurking silently within us, not merely

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[13] “Iwakuma and Breitenbach demonstrate that people with lifelong disabilities often transition with relative ease to the changed pacing of old age when compared with their typical peers (Breitenbach 2001, Iwakuma 2001) … Similarly, Cohen’s (1998) book, *No Aging in India*, situates and contrasts South Asian and American assumptions about cultural understandings of senility, as does the edited collection *Thinking About Dementia* (Leibing & Cohen 2006)” (Ginsburg & Rapp, 2013: 61).

as the collateral effect of unfortunate accidents, or unexpected diseases, but rather as something implicit in the uneventful and ordinary passing of time that brings the gradual decline of certain abilities, physical as well as mental. As Ginsburg and Rapp note

> "Unlike the categories of race and gender from which one can only enter or exit very rarely and with enormous and conscious effort – 'passing' or 'transgendering', for example – disability has a distinctive quality: It is a category anyone might enter through aging or in a heartbeat, challenging lifelong presumptions of stable identities and normativity. Of course, some will be more vulnerable than others owing to poverty, war, disaster, and the vagaries of health and health care, but no social category is exempt from disabling experiences, however they are defined" (Block et al. 2001, Boyce & Weera 2001, Fjord & Manderson 2009, Eide & Ingstad 2011, MacMakin 2011) (Ginsburg & Rapp, 2013: 55).

Aging can certainly be experienced as a slow evolving, diachronic disability, as a disability in progress. Why should be like this? Isn't it funny that we spend half of our life trying to acquire the skills necessary to perform certain activities, and then spend the second half losing part of those hard-earned skills? Yet, does this observation do full justice to the phenomenon of human aging? Definitely not. Things are not so simple. Considering human aging merely from the perspective of disability represents a limited and partial view of it, for the passing of time also unveils for us new dimensions of experience which enrich human life both at the individual and the societal level.

At the individual level, nobody conveyed this experience in a more passionate way as St. Paul in one of his letters to the Corinthians: "Indeed, though this outer human nature of ours may be falling into decay at the same time our inner human nature is renewed day by day" (2 Co, 4, 16).

These words by St. Paul show that human aging cannot simply be equated to natural decay. There are other, spiritual dimensions that need to be considered in order to give full account of human experience of aging. In human beings, natural decay can actually be accompanied by spiritual growth – a spiritual growth that, beyond any phenomenology of human experience, for Paul could even remain hidden to our own conscience.

From a philosophical perspective, we probably cannot go that far. However, we can retain the fact that human aging is not a one-sided phenomenon. Only a callous naturalism, blind to the richness of human experience, would allow aging to be valued only through individual physical or intellectual performance, deprived of any social context. For human aging, too, is not just a matter of being physically and psychically functional but also a matter of social context and cultural perceptions: very often, the problem is not be so much aging *per se* as rather the way in which aging is perceived in a given society, because of the sort of abilities that are deemed necessary to be entirely functional in that society (Edgerton, 1967). Accordingly, if what a society values most is sheer productivity, it will tend to cast a negative light upon those who are less productive, leaving them at the margins. In the meantime, however, society runs the risk of losing sight of other kinds of values that enrich social life and lend meaning to productivity itself.

While there is an increasing conscience that disabled persons should be given the opportunity to contribute with their specific talents, no less than any other person, a similar conscience is still in the making in the case of aged people: it is only in recent times that the term "ageism" is gaining traction, to signal a specific form of discrimination that systematically ignores the specific contributions that aged people could make to society. In part, this movement is caused by reflecting on how demographic transition to older populations is going to change our societies. Thus, drawing on the World Report on aging and health of 2015,[14] which explored the different ways in which the demographic shift is going to impact on our lives, and health care systems, the 69th World Health Assembly, held in 2016, clearly stated that

> "Longer lives are an incredibly valuable resource, both for each of us as individuals and for society more broadly. Older people participate in, and contribute to, society in many ways, including as mentors, caregivers, artists, consumers, innovators, entrepreneurs and members of the workforce. This social engagement may in turn reinforce the health and well-being of older people themselves".[15]

It further noted that most of the health problems of older age are linked to chronic conditions, and "can be prevented or delayed by healthy behaviors and by the environments that support them", so that "for people with significant declines in capacity, supportive environments can promote dignity, autonomy, functioning and continued personal growth", even if "the world is very far from this ideal, particularly for poor older people and those from

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[14] https://iris.who.int/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=3A09FA98F1D41A0EDE0080AEB8370408?sequence=1

[15] https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_17-en.pdf, n. 10.

disadvantaged social groups".[16] Indeed, while, "ageing societies are a triumph of economic growth, health care, public health and social policy (...) population ageing is still viewed as creating an unsustainable fiscal burden, particularly due to increased demand for social security and health care provision" (2023: 1). Viewing them as a burden, however, does not constitute any supportive environment. Yet, as Sarah Harper notes,

> "it is not the changing demographics per se which are the challenge, rather the policies and institutions which frame the outcomes. Nearly 25 years after the Millennium many of our institutions are still defined by 20th century structures which are no longer effective for 21st century Dynamics. And these institutions and public perceptions influence the behaviour of individuals within ageing societies" (Harper 2023: 2).

Thus, considering the French opposition to enlarge the age of retirement, and based on her own previous research in the UK, Harper further suggested that "growing awareness of age discriminatory practices by employers and fellow employees over a 20-year period was one of the main drivers of men moving out of full-time employment from age 50 onwards, while lack of training and development opportunities also figured highly as a driver of early retirement. Similarly, French research has suggested that older people's working conditions have deteriorated over recent decades" (Harper, 2023: 2) as it is "the importance of older adults being able to give un-paid care and support to family members through elder care and grand-parenting" (Harper, 2023: 3), thus contributing both to economic support and family well-being.

From this perspective, walking towards more inclusive societies involves paying attention to all people in all moments of their life trajectories, including the late phase of their lives, and make room to the unique contribution that each person can make to social life, not just in terms of productive goods, but also, as Donati would put it, in terms of "relational goods". Importantly, while in some ways those relational goods can be measured in monetary terms – at least in the sense that they provide un-paid care and support family members in their professional careers – their specific contribution to human flourishing cannot be measured in those terms.

Accordingly, while we certainly need structural changes to tackle the societal challenges derived from demographic change, we also need to pay

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[16] https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_17-en.pdf, n. 13.

attention to the “relational goods” involved in intergenerational relationships. From this perspective, besides considering the societal resources needed to sustain the demographic change, we also need to spark cultural change regarding the value of later life, especially in those cases in which all productivity fades, a change that can aptly be described in terms of “humanization”.

This is particularly to be seen especially in the case of people affected by severe disabilities or senility. Precisely in those cases, when all functional values have disappeared, and there is only room for recognizing and asserting the *presence* of the other, we are confronted with our bare humanity. This is clearly the experience Kittay describes in her last book, *Learning from My Daughter* (2019), as she speaks of “the ability to just being able to be. Just being able to appreciate the gifts of being”, and “coming up with this as one component of a good life”. Far from being a philosopher’s privilege, this is a current human experience, which invites reflection on both our consideration of disability and aging. To this effect, she refers an anecdote:

> “Recently I met an advocate for disabled and abused children who works in a hospital. She told me of a woman who would come in frequently because the child she had adopted had very significant disabilities and many serious medical conditions that needed constant monitoring. The mother, she said, was not an educated woman, but she was someone who acted as a foster mother for many and had adopted several of the children who had disabilities. The child in question was the most seriously affected of her children. The adoptive mother took beautiful care of him. In speaking to the advocate, she said: “People always ask me, ‘What he do?’ Why people always ask me ‘What he do?’ He be! He be!” She understood what I take to be an extremely profound point about the value of another human being: It’s not what he does. He just is. He’s just here. And in his case, that is sufficient” (Gesser & Fietz & Kittay, 2021: 9).

No doubt, it is.

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THE ROOTS OF THE INTRINSIC DIGNITY OF PERSONS WITH DISABILITIES

RODRIGO GUERRA LÓPEZ[1]

Introduction

The contemporary literature on the nature of the dignity of the person is very extensive.[2] Likewise, studies addressing the relationship between dignity and people with disabilities have begun to appear in recent times.[3]

As in many other issues in which the recognition of the human person as a person is at stake, the controversy over dignity and disability explicitly or at least implicitly involves topics as varied as the notion of "health", the role of context, capabilities, functional diversity, common human nature, the idea of justice, the scope of practical reason and the problem of the very notion of personhood. This is not surprising. The United Nations *Convention on the Rights of Persons with Disabilities*, in its "Preamble", has risked a sort

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[2] See: M. Rosen, *Dignity its History and Meanings*, Harvard University Press, Cambridge 2012; G. Kateb, *Human Dignity*, The Belknap Press, Cambridge, 2011; C. McCrudden, *Understanding Human Dignity*, Oxford University Press, Oxford 2013; L.L. Sardiñas Iglesias, *Dignidad humana. Concepto y fundamentación en clave teológica latinoamericana,* USTA, Bogotá 20218; C. Trueba – S Pérez (Eds.), *Dignidad. Perspectivas y aportaciones de la filosofía moral y la filosofía política*, Anthropos – UAM, Barcelona – Mexico 2018; R. Guerra López, *Afirmar a la persona por sí misma. La dignidad como fundamento de los derechos de la persona,* Comisión Nacional de los Derechos Humanos, Mexico 2003.

[3] M. Melgar Alvarez – A. Mota Rodríguez, *Humanity and disability: a hermeneutic-analogical reading of the Rights of persons with disabilities in Mexico*, CNDH, Mexico 2016; M. Atienza, "Dignidad Humana y Derechos de las Personas con Discapacidad", **in** *Revista Ius et Veritas*, n. 53, December 2016, pp. 262-266; T. Amezcua, M. Garcia, V. Fuentes Gutiérrez, "Dignity as a fundamental principle of the citizenship status of persons with intellectual disabilities", in *Revista Electrónica de Investigación y Docencia (REID),* Monograph 3, March 2018, pp. 97-113; S. Graumann, "Human dignity and people with disabilities", in M. Düwell, J. Braarvig, R. Brownsword, & D. Mieth (eds.), *The Cambridge Handbook of Human Dignity: Interdisciplinary Perspectives,* Cambridge University Press, Cambridge 2014, pp. 484-491.

of definition of disability that immediately appeals to a set of issues that are not easy to clarify:

> Disability is an evolving concept resulting from the interaction between people with impairments and attitudinal and environmental barriers that prevent their full and effective participation in society on an equal basis with others.[4]

And further on, in its first article, it states:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.[5]

In a recent document of the Pontifical Academy for Life (PAV), this general approach is also assumed, and the elements offered in the World Health Organization's *International Classification of Functioning, Disability and Health (ICF)* are cited as inspiration:

> Disability refers to any physical and mental health impairment or condition that, when interacting with environmental and social factors, limits a person's functioning and participation in society. Examples of disability include limited mobility, impaired vision or hearing, genetic and neurodevelopmental conditions such as Down syndrome or autism spectrum disorder, acquired brain injuries, dementia, and certain mental health conditions.[6]

The ICF provides a conceptual basis for defining and measuring health and disability. Thus, it is possible for the PAV document to state that "one in six people in the world, or more than one billion, live with some level of disability".[7]

In the following, we will limit ourselves to point out some of the main elements that allow us to overcome the easy invisibilization of the dignity of persons with disabilities. We will insist mainly on the value of the personalist norm of action – *Persona est affirmanda propter seipsam!* – and on the

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[4] United Nations, *Convention on the Rights of Persons with Disabilities,* December 13, 2006, Preamble.

[5] Ibidem, art. 1.

[6] Pontifical Academy for Life, *Friendship with persons with disabilities: the beginning of a new world,* June 14, 2021.

[7] Cf. World Health Organization, *World Report on Disability,* Geneva 2011: *https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability*

need to distinguish between the ultimate metaphysical foundation of the person as a subject with dignity and the ultimate normative foundation in order to actively recognize the person as a non-instrumentalizable subject.

1. The obscuring of dignity: the problem of the "throwaway culture"

Contemporary society is complex. Social phenomena are often multi-causal and cannot be defined by a single aspect. However, one of the axes around which an important part of culture seems to revolve is precisely the identification of the rational as a primarily instrumental phenomenon.

Indeed, not only Max Horkheimer identified that purely pragmatic reason becomes a maddening machine that ends up sacrificing its own creators, but Josef Ratzinger himself in *Introduction to Christianity* emphasizes that something proper to our times is that truth ceased to be seen as a property of being (*verum quia ens*) to be affirmed, first, as a property of human facts realized in the past (*verum quia factum*), and finally, as a property of human action projected into the future (*verum quia faciendum*). This means that reason has undergone a profound mutation: it is no longer the capacity to understand reality in its ultimate and definitive meaning, but has become the capacity to exercise dominion and utilitarian transformation of the world and, in particular, of people, especially the most vulnerable.[8] Pope Francis synthetically calls this phenomenon the "throwaway culture".[9]

The pragmatic and utilitarian drift of reason is no accident. When the truth is not dense, but by various means affirms that its consistency is tenuous, reason is subjected to the pure will to power, which no longer finds reasons to define limits. The important thing is to interpret life as a pure game of power and seek to affirm one's own self through the submission and sacrifice of the other. This mentality is painfully visible not only in the games of the self-referential market but also in the uncomfortable coexistence with the functionally diverse, fragile and vulnerable human being. In other words, the "throwaway culture" shows its absurdity when it despotically sacrifices disabled people through oblivion, isolation, lack of inclusion, and lack of due care, which sometimes reaches subtle or not so subtle forms of humiliating mistreatment.

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[8] Cf. M. Horkheimer, *Crítica de la razón instrumental*, Trotta, Madrid 2010; J. Ratzinger, *Introducción al cristianismo*, Sígueme, Salamanca 1968, p. 43 et seq.

[9] Among many other places: Pope Francis, *Evangelii Gaudium,* n. 53.

Dietrich von Hildebrand offers us a hypothesis that can illuminate this question. This important philosopher, a disciple of Husserl, devoted much of his life to exploring the structure of moral life. In his analyses he recovers many ideas from classical thought. However, he also explores new territories such as the so-called "value blindness".[10] What does this expression mean? It means that there are people - and eventually peoples – who in certain periods, sometimes very long periods, suffer from a lack of awareness of the existence and obligatory nature of some value. "Value blindness" is not an error in moral judgment or a certain ignorance due to lack of study. It is rather a true eclipse in the capacity to appreciate some valuable realities. Nor is "value blindness" a compulsive unwillingness to look or a state of distraction. There are people with great intelligence and capacity to be attentive, who, nevertheless, do not appreciate, do not esteem, do not manage to receive the provocation of a certain type of values, for example, the provocation of the dignity of the functionally diverse other.

Some people when thinking about this phenomenon consider that a "value blindness", such as the one we are describing, exempts the subject who suffers from it from responsibility. This may be true with respect to a certain specific act, but it is not true with respect to the general moral state of the subject suffering from the "blindness". Blindness usually arises from a culpable lack of education in the gaze and in the affective life.

There are various types of "value blindness". The one that interests us with respect to the subject that concerns us is the so-called "moral blindness of subsumption". This is the type of blindness that occurs in the person when individual interest or a passion habitually settles in the conscience and obscures the values that demand attention. It is not that the person does not understand theoretically the nature of his neighbor, it is not that the person does not perceive a certain conduct as wrong. In subsumption blindness the issue is that in one's own life the value in question is not perceived and more or less immediately the reason invents subterfuges to justify the immoral conduct carried out in the name that "in this precise case the situation is different".

The lack of real and concrete appreciation for the dignity of the disabled person in many of us is due to the fact that rationality, driven by the will to power, clouds the conscience and orients the heart in a habitual way towards a utilitarian goal that sacrifices dignity or identifies it with a stan-

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[10] Cf. D. Von Hildebrand, *Moralidad y conocimiento ético de los valores*, Cristiandad, Madrid 2006, p. 43 et seq.

dard of functional efficiency. To sum up: when we spoke of pragmatic or instrumental rationality, we did not mean to point to an abstract question, but rather to a concrete phenomenon of subsumption blindness that significantly determines individual and sometimes collective consciousness.

2. The human person is a unique, unrepeatable, irreplaceable subject

If we look closely at the most elementary human experience, we can discover that this experience is not solitary, individual or isolated. On the contrary, the experience of the self, with all its richness and inner tensions, has always been accompanied by the experience of a "you". In fact, in the first awakening of consciousness, when the central nervous system acquires a certain constitutional sufficiency, the self perceives "being" as an abode that welcomes it, as an embrace that shelters it, as a love that sustains it. To put it briefly: each of us discovers the meaning of "being" by discovering ourselves in original relationship with the others who have engendered me, and eventually, with the Other who has created me. At the beginning of consciousness, although the "I" does not yet perceive analytically the being of each of its parents, much less the divine being, they are already there as a presence, as a good mystery that insinuates that one's being is not rooted in oneself but in a complex of interpersonal relationships.[11]

In this way, the "other" does not only indicate a certain distant similarity with respect to oneself, but the "other" participates with me in the fundamental human experience, enriching and illuminating it continuously. The "other" is not a more or less arbitrary projection of my own "I", but the "other" contributes data that only a subjectivity full of value can offer. The "I" is not a subjectivity that after existing, then alters and becomes a "being-along-with-others". The "I" lives its own experience of being not only "being-along-with-others" but "being-thanks-to-others".

The experience of the "I", although it refers to the non-transferable and transcendent self that I am, cannot be explained except with the "others" with whom I "co-exist" and for whom I am responsible. This is why Karol Wojtyla used to say: "Another human being is a neighbor not only on the basis of his generic feeling of humanity, but primarily on the basis of his being another-self".[12]

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[11] H.U. von Balthasar, *Gloria*, trd. cast. V. Martín-F. Hernández, Encuentro, Madrid 1988, T. V (*Metaphysics. Modern Age),* p. 565 et seq.

[12] K. Wojtyla, "Participation or Alienation?", in *El hombre y su destino*, Palabra, Madrid 1998, p. 117.

Why remember this? Mainly to discover that the experience of my own irreplaceable being is constituted in an original way together with the equally irreplaceable experience of my neighbor. This is more foundational than the experience of participating in a "common humanity". In other words, *our common belonging to the species is not the deepest reason for the peculiar bond that each person has with each of his brothers and sisters*. The basic reason why, in order to affirm myself, I need to accept the practical challenge of the presence of the "other" is that the "other" is as much a person as I am.

Indeed, the other does not only occur as part of my most elementary experience in the theoretical order, but it occurs mainly as an experience in the practical order, that is, as a concrete imperative that demands a response. If I am a unique, unrepeatable and irreplaceable case, and my neighbor is also unique, then a primary moral norm emerges that I cannot leave aside: *Persona est affirmanda propter seipsam, we must love the person by his own sake!* The value of my neighbor is not that of an interchangeable or substitutable being! His value is the highest because he is a being of whom there can be no "copy" whatsoever!

This discovery makes it possible to make the most important universalization in practical life: every human person has the very high value of a true end and not a mere means!

This right is maximally normative and true, especially in cases where a purely efficiency-based approach blurs the perception of the inalienable dignity of the human person. In other words, the encounter with the "other" is a primarily ethical experience that constantly invites us to rediscover the non-instantializable character of people, especially those whose functional diversity segregates them and displaces them from the gaze, culture, public policies, etc.

3. The sources or roots of the dignity of disabled persons

The sources of the dignity of the disabled person cannot be different from those of the "functional" person.[13] For dignity does not come from the fulfillment of some functional standard but from the way being has been given to us, making us incomparably unique, making us truly ends.

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[13] For the various roots or sources of dignity we are partially inspired by J. Seifert, "Dignidad Humana: Dimensiones y fuentes de la persona humana", in *Actas del III Simposio Internacional fe cristiana y cultura contemporánea "Idea cristiana del hombre",* Eunsa, Pamplona 2002, pp. 17-37. However, in some arguments we differ from the author.

"Dignity" is the value possessed by a being whose being is given in a loving act of benevolence (loving the other for the sake of the other). Therefore, to discover one's own dignity, to a large extent, is to discover that we are what we are because we are loved in a special way, in a very particular way, "by our own sake". Or as Carlos Diaz often says, *amor ergo sum,* "I am loved, therefore I am".[14]

This is the origin or root of the *ontological dignity of the human person as a person*. And this dignity gives rise to fundamental rights such as the right to life, to physical integrity, to the right to freedom of conscience of the person, etc.

When ontological dignity is made to rest on the conscious state of the person, on a certain standard of neurological efficiency, on the activation of mental processes, or on something else similar, we immediately enter a scenario marked by absurdity: the fundamental dignity of the person would be subject to different degrees and levels, placing those who did not reach a certain "level" in the status of a "thing". People would not possess dignity because of their being but because of their conscious-doing, and with this, there would be inequality of fundamental rights.

This is relevant for cases of persons with mental disabilities. The fact that there are certain deficits in mental processes, either temporarily or permanently, does not mean that the person ceases to be a person and/or loses his or her dignity. The profound reason for this is the following: *the being of the person does not presuppose consciousness, but rather it is consciousness that presupposes being*. If there is no being prior to consciousness, there is no place to return to through conscious processes. Consciousness is always consciousness-of-being. All the consciential maturation that genetic psychology usually studies is possible thanks to the fact that the being of the "I" is always greater and more original than what we consciously consider of it. Being and "conscious-being" are not correlative. The first founds the second. Not vice versa.[15]

Now, having said this, the ontological dignity of the person can *manifest itself through* conscious acts. This is the root of the right to freedom of expression, education, political participation, etc.

Likewise, the ontological dignity of the person can be exhibited through free acts when they are performed in accordance with the demands of their

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[14] C. Díaz, *La persona como don,* DDB, Bilbao 2001, p. 145.

[15] Cf. R. Guerra López, *Volver a la persona,* Caparrós, Madrid 2002.

highest value. This is where the "moral dignity" of the person is displayed. This dignity, obviously, admits degrees and levels depending on the moral quality of the actions. On this level is based, for example, the right to a person's good reputation and the right to reply to an unjust accusation.

Finally, there is a "dignity granted" by the community to persons who enjoy certain special qualities, such as their intelligence, their goodness, their role of authority or their singular social significance because of a limitation. For example, here rests the dignity of magistrates or judges, but in general, also of all persons who deserve being recognized positively for a quality or for physical or psychological limitations.

In other words, in a certain sense, living with a disability should be cause for special consideration, special respect and care on the part of society. We are not talking here about moral dignity because of a virtuous life. Rather, we are talking about the dignity that is socially attributed to a special way of living the human condition under certain psychophysical and, in many cases, social limitations. In other words, the situation of vulnerability associated with disability, rather than inviting to "discard" should motivate to a special respect because of the same vulnerability.

I have the impression that in the recent *Declaration "Dignitas infinita"*, published by the Dicastery for the Doctrine of the Faith,[16] this is perceived in theological see when it is stated:

> By proclaiming that the Kingdom of God belongs to the poor, the humble, the despised, and those who suffer in body and spirit; by healing all sorts of illnesses and infirmities, even the most dramatic ones, such as leprosy; by affirming that whatever is done to these individuals is also done to him because he is present in them: in all these ways, Jesus brought the great novelty of recognizing the dignity of every person, especially those who were considered 'unworthy.' This new principle in human history – *which emphasizes that individuals are even more 'worthy' of our respect and love when they are weak, scorned, or suffering, even to the point of losing the human 'figure'* – has changed the face of the world.[17]

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[16] Published on April 8, 2024. Signed on April 2, 2024.

[17] Dicastery for the Doctrine of the Faith, *Declaration "Dignitas infinita",* April 2, 2024, n. 19, italics added.

4. The normative ultimate foundation is different from the metaphysical ultimate foundation

With what has been said above, it is possible to say with certainty that the ontological dignity of the person must be recognized beyond *any circumstance, beyond any context, beyond the particularities of this or that culture*.[18]

In order to be able to have an eventual "situated" thought, to be able to denounce eventual "colonizations" in societies, to be able to adequately value cultures, it is necessary to recognize *the dignity of every person as a meta-contextual principle*.[19] When the dignity of the person and his fundamental moral imperative are thus recognized, a light is found that allows the development of a critical theory based on a robust, ontologically founded anthropology. When the recognition of *meta-contextual principles*, such as the one mentioned here, is explicitly or implicitly renounced, thought easily collapses into an endless relativism, that is, into an immanentism that closes off the possibility of truly affirming that reality has primacy over our modest interpretations.

However, we still need to clarify a delicate question: dignity is the value that, when discovered by the practical reason of the person, allows us to formulate a primary moral precept: *the personalistic norm of action*. Where does the binding force of this norm come from? Why does the response to the value that we call "dignity" have a "moral necessity" for the conscience and for the free will?

In some iusnaturalist authors it was common to maintain that the obligatory force of any imperative is due to the "*lex aeterna*" of God that participates in the creature. Since God exists, and since there are precepts promulgated by him, the obligation to comply with them proceeds from their divine origin.[20]

In our opinion, a metaphysical explanation of the natural law, in effect, demands that it be recognized as a participation of the eternal law in the

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[18] Pope Francis, *Encyclical "Fratelli tutti"*, n. 107: "Every human being has the right to live with dignity and to develop integrally, and this basic right cannot be denied by any country. He has it even if he is inefficient, even if he is born or grows up with limitations. Because that does not undermine his immense dignity as a human person, which is not based on circumstances but on the value of his being. When this elementary principle is not safeguarded, there is no future either for fraternity or for the survival of humanity."

[19] R. Guerra López, *Afirmar a la persona por sí misma. La dignidad como fundamento de los derechos de la persona*, CNDH, Mexico 2003.

[20] Among others, see: O.N. Derisi, *Los fundamentos metafísicos del orden moral*, CSIC – Instituto Luis Vives de Filosofía, Madrid 1951, Ch. VIII.

rational creature.[21] However, we have wanted to insist that *the practical obligatoriness of the personalistic norm of action comes from human dignity*. Therefore, the fact that this dignity is a perfection that the human being possesses by the fact of having an "act of being" (*actus essendi*) that constitutes him as an entity *per se* willed *per se* does not mean that only by accepting the existence of God as the ontological foundation of the person is the absolute respect due to each person obligatory. In the practical order, that is, from the point of view of the way in which the experience of action is constituted, *the encounter with the person is sufficient for the absolute imperative that derives from his dignity to be unconditionally binding*.[22]

This is important because it focuses attention on the dignity of the person and does not displace it to the always complex issue of the existence of God and his arguments. Dignity, then, is a constitutive dimension of the person that is the source of the binding nature of the personalist norm of action. The personalist norm is a moral principle that should deactivate the valuation of persons by their efficiency and that rather obliges us all to look at the functional diversity of persons from a supra-utilitarian criterion. Only with this criterion is it possible to make a more inclusive culture, and therefore, a slightly more humane society.

5. In conclusion

People with disabilities are a borderline issue that tests the moral sentiments of contemporary culture. We are currently in a "resurgence of morality". Social media is awash with uplifting moral phrases and value-driven living. However, if we look more closely, this new moment is not entirely

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[21] Cf. St. Thomas Aquinas, *Sum. Theol.* I-II, q. 91, a. 2, c.

[22] Karol Wojtyla, in a little studied text, stated: "*Getting to the bottom of* morality by explaining it on the basis of the ultimate end has given way to explaining and justifying morality on the basis of values and norms. We are concerned today not so much with determining the ultimate end of moral conduct as with giving ultimate justification to the norms of morality. Credit for bringing about this change in how the central problem of ethics is posed and formulated undeniably goes to Kant. But to accept Kant's starting point in ethics – that is, to consider the problem of the justification of norms as the main ethical problem – is not necessarily to accept his solution. Indeed, a search for the ultimate justification of moral norms can lead us directly to the ultimate end. But this is not presupposed in advance at the starting point. One thing, however, is presupposed right from the start: in the whole way ethics is treated, normative rather than teleological tendencies will prevail, even in the case of *teleological* conclusions." K. Wojtyla, "Etyka a teologia moralna", in *Znak,* Vol. XIX, 1967, pp. 1077-1082.

clear. For Gilles Lipovetsky, we find ourselves in "the emergence of an ethical regulation of an unprecedented kind. Through the charitable and humanitarian effervescence, what is at work once again is the eclipse of duty; under the old habits of morality, the post-moralist functioning of our societies is actually organized. What is very loosely called the *return of morality* merely precipitates the exit of the moralistic epoch from the democracies by instituting a *morality without obligation or sanction* in keeping with the mass aspirations of individualistic-hedonistic democracies".[23]

At no other time has there been so much talk about people with disabilities and their rights. However, new forms of marginalization and stigmatization are appearing on the scene. Therefore, perhaps it is time for a more profound review based on the recognition that *every human being has disabilities to some degree and that, eventually, they may be further amplified by age, illness, mishap, etc. Perhaps it is time to relearn to see that the encounter with value generates a duty without which value itself is silenced in its call, in its vocation, in its profound nature.* Perhaps it is time to affirm that every person, especially the disabled, deserves our welcome, our inclusion and our commitment, because this is the measure of the degree of humanity of our societies. Everything is put to the test when a person is partially or totally excluded from the path of development that we all deserve because of our dignity.[24]

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[23] G. Lipovetsky, *El eclipse del deber. La ética indolora de los nuevos tiempos democráticos,* Anagrama, Barcelona 2002, pp. 128-129.

[24] In this regard, see the following text: "One criterion for verifying whether real attention is given to the dignity of every individual in society is the help given to the most disadvantaged. Regrettably, our time is not known for such care; rather, a 'throw-away culture' is increasingly imposing itself.[97] To counter this trend, the condition of those experiencing physical or mental limitations warrants special attention and concern. Such conditions of acute vulnerability[98] – which feature prominently in the Gospels – prompt universal questions about what it means to be a human person, especially starting from the condition of impairment or disability. The question of human imperfection also carries clear socio-cultural implications since some cultures tend to marginalize or even oppress individuals with disabilities, treating them as 'rejects.' However, the truth is that each human being, regardless of their vulnerabilities, receives his or her dignity from the sole fact of being willed and loved by God. Thus, every effort should be made to encourage the inclusion and active participation of those who are affected by frailty or disability in the life of society and of the Church". (Dicastery for the Doctrine of the Faith, *Declaration "Dignitas infinita"*, n. 53. Available online https://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_ddf_doc_20240402_dignitas-infinita_en.html

ONE LIKE US: DISABILITY AND THE INCARNATE WORD

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Time and habit have sometimes dulled our awareness of the uniqueness of the claim of the Incarnation – that in becoming "one like us in all things but sin", Christ has irrevocably entered into the lives of all of us.[1] We do not hold that the incidents which Christ assumed were restricted to those of his time, place, gender or ethnicity. Christ is not only the saviour of 33-year-old, first century, male Jewish craftsmen! Indeed, theologians have long been comfortable with the understanding that, while Christ had to be contingent and limited (even unto death) to become incarnate, the act of salvation was not bound by those limits but extends to all.[2]

It is therefore perhaps surprising that we have been much slower to accept that among the many-splendoured attributes of the human person included in the Incarnation are the many manifestations of impairment and disability and the incidents which attend it. Instead, we have tended to put disability into the category of theodicy – how can a good God allow suffering and evil in a good world? This, despite the fact that much disability is innate – a part of the human design (the spectrum of fleshliness, if you will) – and causes no pain beyond that inflicted by a discriminatory society. Instead, the understanding has been that disability is a problem of "them", not "us" – a marring or diminishment of the image of God, rather than its embodiment.[3]

As I have commented elsewhere, this theological understanding of disability, closely parallels what is sometimes called the "medical model" of disability: the idea that disability is a flaw in the individual and demands

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[1] *Catechism of the Catholic Church* 467, cf. Heb 4:15.

[2] Karl Rahner, *Grundkurs des Glaubens: Einführung in den Begriff des Christentums* (Munich: Verlag Herder, 1984), 217-222; Gerald O'Collins, *Incarnation* (New York: Continuum, 2002), 63.

[3] Justin Glyn, 'Pied Beauty: The Theological Anthropology of Impairment and Disability in Recent Catholic Theology in the Light of Vatican II', *Heythrop Journal* 60 (2019), 571-584; Catechism of the Catholic Church, 2276.

nothing of the society at large.[4] Most of us who do experience disability would subscribe rather to a "social model" – an understanding that impairment is something much more variable and an intrinsic part of the human condition but that disability reflects the way that people are excluded from society because of it.

Consider, for example, that prior to the COVID-19 pandemic, people who wished to work or study from home by remote means, or asked for groceries to be delivered to their homes because of their lack of mobility, were often refused these concessions on the grounds of expense or inconvenience. When lock-downs came, of course, these measures became standard for everyone. When it was decided that (despite a rapidly mutating virus) society should be opened up again, these "concessions" once again became impossibly expensive or inconvenient. Society made clear who was included and who was not. It was left to disabled people ourselves to form mutual aid networks to assist each other where we could.

The truth (which many have found unpalatable), of course, is that impairment (innate or acquired) and lack of function of body or mind in general, is a part of every human's condition. We were all born without the ability to speak, to see clearly, to reason or to control our most basic bodily functions. Those who live long enough are likely to die that way as well.

All of this is true of Jesus, too. Indeed, it is exactly what we would expect, given our long-held belief that, as it was put by Gregory of Nazianzus, "that which he has not assumed, he has not healed; but that which is united to his God-head is also saved".[5] We devoutly picture the newborn Jesus lying in a manger, wrapped in swaddling bands (Lk 2:12) without considering the very *lack* of physical capacity that such a picture implies. Jesus, like any other human baby, was loved into existence and cared for through all his childhood, bearing all the incapacities that come with human birth and maturation.

One area of Jesus' incarnate life which receives much attention, especially from those who would equate disability with sin, is his ministry of healing. Matthew 8:16-17 (quoting Is. 53:4) describes Jesus' healings as follows:

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[4] See Justin Glyn, "'Et homo factus est:' Incarnation, disability and interdependence". *International Journal for the Study of the Christian Church, 22*(1), 47-57, which explores some of these themes in more detail.

[5] Gregory of Nazianzus, 'Epistle 51, to Cledonius (First Epistle Against Apollinarius)' in *The Nicene and Post-Nicene Fathers, vol. 5,* Philip Schaff ed. (originally published 1893, republished New York: Cosimo, 2007), 440.

> "(16) That evening they brought to him many who were possessed with demons; and he cast out the spirits with a word, and cured all who were sick. (17) This was to fulfill what had been spoken through the prophet Isaiah, 'He took our infirmities and bore our diseases'".

As Thomas Weinandy points out, this strongly suggests that Jesus entered into so great a solidarity with those he healed that he actually *assumed* their ailments.[6] In other words, the healing miracles were acts of profound accompaniment – entry into their world, impairments and all – as much as they were acts of healing. If this is correct, it represents something much more akin to the profound solidarity of the Cross than it does the action of a story-book wizard curing ills with the wave of a hand.

Indeed, it is at the Cross and Resurrection where Jesus' assumption of human disability has long been most obvious. As Nancy Eiesland famously pointed out, he not only suffered the incapacities that go with being scourged and tortured to death under one of the Roman Empire's most horrific punishments – but also proudly retained and showed those wounds as token of his Resurrection.[7]

This is, of course, dangerous talk. As the Concept Paper to this Conference noted: "vulnerability and frailty are a part of the human condition and not only of persons with limitations".

Indeed, even the limits imposed by disability and impairment are more apparent in some areas than others. When I am ministering as a priest or a lawyer, for example, it is I who am the person in the relationship who is able to render assistance to supplement the limits of the other. By contrast, when I am being picked up off the floor after an epileptic seizure or reliant on someone else to transport me because I cannot drive, then I am most definitely the one in need of help. As noted above, much of the work of disabled communities of solidarity during the pandemic has involved communities of love supplying each other's weaknesses. As Ignatius famously puts it in his Contemplation to Attain the Love of God:[8]

> "... love consists in mutual communication. That is to say, the lover gives and communicates to the loved on what they have, or something of what they have, or are able to give; and in turn the one loved does the same for the lover".

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[6] Thomas G. Weinandy, *In the Likeness of Sinful Flesh: An Essay on the Humanity of Christ* (London: T&T Clark, 1993), 103-104.

[7] Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability*, (Nashville: Abingdon Press, 1994).

[8] Ignatius of Loyola, *Spiritual Exercises*, 231.

While Ignatius is clear that this is describes the relationship between God and the individual, he is equally adamant that we are called to image this in our own interrelationship also.

If this could be internalised in our theology, in our teaching and in our pastoral praxis, then we would not indeed *need* a theology of disability at all. If all humans are limited in various ways, if the Incarnation entails a radical acceptance by Christ of all human limitations (including disability) and if Church and society were prepared to live that vision, helping each other in the love of Christ and bearing one another's burdens and so fulfilling the law of Christ (Gal. 6:2), then the question of how to protect or include disabled people as an "other" would not arise. Unfortunately, while the journey has indeed begun (as evidenced by this very conference) we are some way off that yet.

THE *CULTURES OF EXCLUSION* IN TIMES OF CIVILIZATIONAL CRISIS

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Abstract

The starting point is the assumption of the civilizational crisis of our times. Here I consider its main causes and the results that are already visible, as well as expected. Against this background, I briefly characterize the concept of culture and mass culture in order to show the historical and cultural significance of the contemporary culture of exclusion. In particular, I am concerned here with the sociological and psychological dimensions of this phenomenon, which – as I claim – is the result of several basic so-called long-lasting processes, but produces very specific mental and social results. They foster a culture of exclusion and hinder the progress of an inclusive culture.

Key concepts: civilization, civilizational crisis, culture, mass culture, culture of exclusion, culture of inclusiveness

The civilizational and cultural context of modern times

I have italicized the title concept of the "culture of exclusion", as well as the "culture of inclusion" mentioned later, because I do not believe that we need another linguistic cancer. Such a term suggests that there are some entities that are separate in the sense of social ontology and that can be defined in this way. I am rather of the opinion that we can talk about certain cultural dimensions of the contemporary civilization crisis, which has its extremely important causes and sometimes causes even dramatically important effects in the sphere of both culture and the mentality of individual people. This is the context of human, collective and individual indifference to ourselves, nature, the world of values, etc. This indifference sometimes takes the form of callousness and even hostility. In such a world, as Zygmunt Bauman wrote, we are all strangers and excluded. People who are disabled in any sense or are considered different, alien or inferior for any other reason, are excluded even more. I also believe that in our times each of us is disabled, inferior and alien in many ways. In times of the modern civilizational crisis of post-industrialism, the fate of people in a worse situation than average is much, much more difficult.

On the other hand, it should be noted that in the past, the fate of people with disabilities was not enviable either. It seems that it was often much worse than today. It seems that in addition to the spreading social insensitivity, or to some extent against it, especially among the younger generation, in wealthier societies, we are observing a significant increase in sensitivity, not only ecologically, but also towards other people, their harm, shortcomings, including disabilities and alienation. Many countries, especially the more prosperous ones, enjoy the dynamic development of volunteering, i.e. interest in social issues (including the problems of disabled and excluded people, etc.). So what is it like in reality?

But let's start from the beginning. I attach so much importance to the concept of civilization because I believe that, without it, we will not understand the full depth, complexity and chaos of our times. Especially since all this is the result of processes covering almost the entire globe and lasting for at least several decades. We have fallen into this fascinating and difficult fate of witnesses of the breakthrough of civilization.

Trying to define the concept of civilization is as pleasant as a toothache. Fernand Braudel wrote:

> "It would be nice to define the word 'civilization' clearly and simply, if possible, just as we define a straight line, a triangle, a chemical body…
>
> Unfortunately, the dictionary of the humanities does not allow for any clear definitions. With everything uncertain or in the works, most of the dates that have not yet been settled once and for all vary from author to author and continue to evolve before our eyes" (Braudel, 1993:41).

In order to move more quickly to the main topic of this speech, I will skip the long and difficult suffering associated with defining this concept and assume that it is a certain social form, common to many countries (macro communities), over a long period of time. These macro-societies, today organized primarily in the institutional forms of states, last as long as they retain at least the basics of integration, which I would describe as social order. For me, social order is: a constantly created, recreated, and therefore variable result of an internally heterogeneous, as well as complex and dynamic structuring process. It is a process of crystallization, reproduction, disintegration and transformation of relatively permanent and relatively continuous foundations for organizing the social practice of life within a relatively separate large community (today, still most often a nation or a union of nations and ethnic groups) and organized (at least in our times) in the institutional form of the state. The social order understood in this way determines a more or less permanent framework for the common practice of life.

Civilization, therefore, is a certain state of culture, the result of long-lasting historical processes (Braudel, 1958:725-753), produced by societies, exceeding the lifespan of several generations. Civilization creates a framework in which, to a considerable extent under its influence, people construct social order, create social groups and institutions, culture and their identities. Civilization therefore structures the life of many societies over a long period of time, but it is also a product of these societies and the individuals who constitute them. Margaret S. Archer would write here about the generative mechanisms of morphogenesis and morphostasis (Archer, 1989).

Civilization – when analysed from a different perspective – is the totality of social products that arise in response to the civilization crisis. By civilization crisis I mean situations in which civilization challenges make it impossible for society to exist without significant changes. The factors of such a crisis may be great historical events (wars, revolutions, etc.), natural phenomena (floods, earthquakes, etc.), or breakthrough scientific and technical discoveries, or new religions, ideas or great rationalizations, imaginations, myths. Such factors often pose a challenge not only to some isolated community, but also have a more universal significance. Tradition, therefore, associates the concept of civilization with a wider space. Civilizations take a long time to emerge and develop slowly. It is usually a process that takes place over many generations.

Today, I would argue, we are dealing with a rather dramatic process of civilizational structuring. The advanced decomposition of industrial civilization is progressing. Some people believe that some other, new, informational – as some say, post-modern, post-industrial – civilization emerges; the multitude of names seems to indicate great confusion. The civilization crisis is often associated with achievements in the field of scientific and technical discoveries, which have resulted in such revolutionary technical changes that not only are there changes in production technologies unprecedented in history, but all dimensions of human life and societies are in a state of profound transformation. Hence, we commonly talk about all kinds of crises: values, climate, economic, culture, mental health, church, etc. In fact, it seems to me, we are dealing with one great crisis of the breakthrough of civilization, which manifests itself in all dimensions of human life.

The effects of these changes have been known for over a hundred years. That is, since the times of the previous industrial civilization crisis. Today, only the degree of their advancement is incomparably greater. Even in Alexis de Tocqueville we read about various types of freedom and individualism, including a serious threat to democracy, which is the concept of equality leading to the spread of egocentric individualism. And from the work on the French Revolution we learn about despotism that:

> "When men are no longer bound together by caste, class, corporate or family ties, they are only too prone to give their whole thoughts to their private interest, and wrap themselves up in a narrow individuality in which public virtue is stifled. Despotism does not combat this tendency; on the contrary, it renders it irresistible, for it deprives citizens of all common passions, mutual necessities, need of a common understanding, opportunity for combined action: it ripens them, so to speak, in private life. They had a tendency to hold themselves aloof from each other: it isolates them. They looked coldly on each other: it freezes their souls" (Tocqueville, 1856:IX).

And already in the twentieth century, Jürgen Habermas wrote about the same thing, i.e. civic privatism and family-professional privatism, which is another side of civic privatism. It is intended to focus on consumption and career, and divert attention from claims to emancipation [Habermas 1962:136-144].

Émile Durkheim wrote about the same thing almost a century earlier:

> "nations [...] have the single or chief purpose of achieving industrial prosperity [...], industry, instead of being still regarded as a means to an end transcending itself, has become the supreme end of individuals and societies alike. Thereupon the appetites thus excited have become freed of any limiting authority. By sanctifying them, so to speak, this apotheosis of well-being has placed them above all human law. Their restraint seems like a sort of sacrilege" (Durkheim 2002:216).

And this leads to further consequences, uncontrolled development of desires. The clientelism associated with economic and market development and the corresponding mental facts make people even more reluctant to restrain their expectations. Therefore, the real world will necessarily always offer less than people would demand, that's why it seems that:

> "the state of crisis and anomy is constant and, so to speak, normal. From top to bottom of the ladder, greed is aroused without knowing where to find ultimate foothold. Nothing can calm it, since its goal is far beyond all it can attain. Reality seems valueless by comparison with the dreams of fevered imaginations; reality is therefore abandoned,

> but so too is possibility abandoned when it in turn becomes reality. A thirst arises for novelties, unfamiliar pleasures, nameless sensations, all losing their savor once known. Henceforth one has no strength to endure the least reverse. The whole fever subsides and the sterility of all the tumult is apparent, and it is seen that all these new sensations in their infinite quantity cannot form a solid foundation of happiness to support one during days of trial" (Durkheim 2002:216-217).

Therefore, a hundred years ago, as today, what Durkheim wrote is true:

> "The doctrine of the most ruthless and swift progress has become an article of faith. But other theories appear parallel with those praising the advantages of instability, which, generalizing the situation that gives them birth, declare life evil, claim that it is richer in grief than in pleasure and that it attracts men only by false claims. Since this disorder is greatest in the economic world, it has most victims there" (Durkheim 2002:218).

Durkheim painted a picture of an anomie-stricken, rather narcissistic industrial society. But in our times of post-industrial crisis, the French sociologist's diagnosis not only remains relevant, but also seems particularly accurate. Contemporary narcissistic culture would manifest itself in the domination of entertainment over other forms of communication and in the disappearance of real cultural content in private and local relationships in favor of mass communication. The media dictates the most important values, goals and lifestyles. In such a culture, the most important would be idols, celebrities whose significant contributions are unclear or non-existent. In such a culture, they are rewarded with fame, prestige, money and power, while those on whom important human affairs depend (e.g. doctors, teachers, volunteers, artists, social activists, scientists) are not appreciated. Narcissism is largely a manifestation of what de Tocqueville called egoism. It also seems to be the result of individualism, especially in its egocentric form. Individualism associated with democracy, and especially equality, means – according to de Tocqueville – that a person has no authority beyond himself and is not interested in anyone but himself. In this way, social bonds loosen. Society is replaced by a quasi-society, something like a social mass. All the more so because modern civilization processes weaken social divisions, loosen the social structure and free the individual (for better or worse) from dependence on others. If there is anything else that arouses the interest of narcissistic individuals beyond themselves, it is their immediate family circle. We remember that family, apart from the desire for a career, became the subject of Habermas's sharp criticism. For some reason known to him, he treats families as closed circles of obstructive self-centeredness. Although such things happen, it is not their defining feature. The clinical case is a post-industrial society in which mass culture creates every individual (no longer an abstract individual) regardless of their education, merits or advantages, as the center of the axiological order of modern times. If others were such prestige stars for us, it would be great. But it's the opposite. Mass culture convinces each of us individually that he is the idol of the world, unlike everyone else. This is where the concept of the 'other', the 'stranger' comes into play, to which, for example, Zygmunt Bauman paid so much attention. In the name of everyone's uniqueness, which is to be particularly protected (we know the slogan: 'be yourself') and become a unique object of expression ('express yourself'). At the same time, mass culture appeals to the client, the public, the electorate, and as a result, it equalizes and makes all individuals similar to each other, making each of them, in the end, an insignificant object, an easily replaceable element of mass society.

This weakens the motivation of individuals to self-development, improvement, change themselves and the world, and imitate those who are better educated, more cultured, and more moral. It also deprives us, to some extent, of the sense of meaning in our own lives and the meaningfulness of the world. Forcing a narcissistic and hedonistic understanding of happiness, which allows, among others, being uncritically dazzled by mass culture, fixates on the current level of mental development, on felt needs and drives, makes one incapable of altruism, and also – in the pursuit of unattainable happiness resulting from the complete satisfaction of drives and the ecstasy of pleasure – makes one incapable of development and also feeling real happiness and contentment, such as is available to a person who is able to take up the challenge of humanity and fate.

The social mass is not only the negation of society, but also one of the most degenerate forms of the implementation of collectivism, just as a narcissistic, self-centered individual, accepting himself unconditionally and deprived of a sense of responsibility for himself and others, is one of the most degenerate forms of the implementation of extreme individualism. But it is indeed impossible not to notice this very common concern of modern man to be authentic, that is, to be himself, as if there was a possibility of being someone else. We are authentic and ourselves even in the face of the greatest doubts on this matter. We are then someone who has these kinds of problems, and we will be completely inauthentic if we want to be someone who does not have such problems. It's fashionable to be assertive today. It probably strengthens people who allow themselves to be exploited. But the slogan of assertiveness promoted by mass culture often hides regular rudeness, extreme egoism, callousness and lack of empathy. The idea of assertiveness is, to a large extent, part of the ideology of egoism and narcissism, so eagerly propagated by mass culture. Meanwhile, if someone is particularly sensitive to the good of others, it is a beautiful quality, and above all, it is authentic for that person. Of course, we understand that in the case of people who are very unsure of themselves, who are excessively submissive to others, to the point of crossing real human, social and cultural boundaries, some level of assertiveness is needed. But this only applies to some people.

Over a hundred years ago, Durkheim wrote that this process has been going on "for a hundred years" (i.e., as you can easily guess, since the beginnings of industrial civilization). According to him, the reason was progress, especially related to the industrial economy. But the next hundred years did not liberate us from this poverty. On the contrary, as Charles Taylor, a philosopher of our times, says:

> "... the culture of self-fulfilment has led many people to lose sight of concerns that transcend them. And it seems obvious that it has taken trivialized and self-indulgent forms. This can even result in a sort of absurdity, as new modes of conformity arise among people who are striving to be themselves, and beyond this, new forms of dependence, as people insecure in their identities turn to all sorts of self-appointed experts and guides, shrouded with the prestige of science or some exotic spirituality" (Taylor 2003:15).

Strangers and the problem of a society of inclusion and exclusion

I mentioned the category of the stranger, which, understandably in the context presented earlier, is becoming one of the most central in contemporary sociology and social philosophy. Globalization has become a result of the progress mentioned several times in this text. I don't want to go into details here. This issue has been the subject of considerable and well-known literature (Bauman, 1993). Let us pay attention to the mobility of modern man. The development of means of communication, especially electronic means, means that people who lived within their own cultures several decades ago now move around looking for work, a place for investment, better living conditions, a safe territory, entertainment or relaxation. This clearly violates the hermetic nature of the cultures of their birth. Whether we like it or not, most of us encounter strangers every day and we are constantly, often or sometimes, strangers to many people. The global economy requires the abolition of borders. But while it is easier to abolish administrative boundaries, the ones that people set for themselves individually and collectively, in the form of cultural boundaries and distances that we protect from strangers we recognize, are no longer so fluid and flexible. It can be said that the problem of the stranger and inclusion or exclusion is becoming one of the most difficult, painful and dramatic problems of our times. By excluding, we defend not only our material goods, work, living space, but also culture. And, with it, our identities, about which Bauman wrote how impossible it has become to protect them today.

In ambiguous modernity and modern ambiguity, all reality becomes fluid, including identity. Bauman says we have to come to terms with it. In fact, we should be happy about the freedom we have gained in this way. It is no longer the hard circumstances of our social situation and the iron directives of our culture that determine who we are – said the Polish philosopher and sociologist – but ourselves, our aspirations, dreams and will (Bauman, 1993). Bauman understood that it was difficult, but – as he believed – freedom was worth taking responsibility for one's identity. If this scholar was more of a psychologist than a sociologist, he would have known that perhaps he demands from his contemporaries what is beyond the capabilities of man – at least most of them. The process of identity formation, as we know from outstanding psychologists such as Karen Horney, Erik Erikson or Abraham Maslow, is extremely difficult, subtle, and dependent on many factors. It is the result of parallel psychological, social and cultural processes, lasts a long time and often involves many problems. This was the case when the world was not as fluid as it is today. We also know from psychological literature that identity disorders or, simply put, immaturity have serious consequences for personality, mental health, psychological maturity and a happy life.

In times of globalization, this is becoming a permanent state of affairs for the absolute majority of people. The culture of inclusiveness seems to be a sine qua non condition for the continued existence of the world and the human species. However, it encounters significant barriers. And it's not just about legal, economic and organizational boundaries and obstacles. Who knows, maybe the more serious obstacles are people's mentality. But, contrary to what we like to think about it, it is not subject to instruction, persuasion, training, propaganda or orders. This type of obstacle is not just a result of misunderstanding. Then, it would be enough for the good of inclusiveness to become the subject of education and appeals. It is not just that the old are exclusive and the young are open. We are observing the growth of opposing social movements of young people with completely different attitudes towards others. They can clash so sharply that we see that both sides are probably inclusive to their own and completely exclusive to others, who indisputably become strangers to them.

If I wrote so much about the civilizational changes of our times and the situation of individual people, their groups, nations and cultures, my intention was to show that the mentioned civilizational crisis is largely the result of globalization. As a result, it confronts us with the need to build a culture of inclusiveness, but at the same time it makes the processes of building individual and collective identity so difficult that it deprives many, many people of the opportunity for this inclusiveness.

Conclusions

Perhaps a noteworthy conclusion will be that no one can stop globalization, and therefore human mobility in the form of migration between continents, countries, communities and their cultures, which, as a result, become more exclusionary than inclusive. Solving the process of the lack of a culture of inclusiveness requires many patient steps, a long time, but also understanding all determinants and barriers, including cultural and mental ones. We also need to understand how difficult it is for millions of people around the world to crystallize their identity in the face of all these civilization processes, that is, to obtain the basis for mental health, which is a condition for the development of humanity in a person, including openness to others. Therefore, in-depth research on this topic and discussion on policies that take into account even the most profound and seemingly invisible problems and barriers are necessary. As Alain Touraine wrote:

> “for we must guard against over-reliance on progress, rationalization and efficiency, creating a ‘secular’ quasi-religion that leads to the erasure of the past. We recognize the need to find the unity of the subject in all its imaginations, each of which was and remains hidden in the instruments of social domination” (Touraine 2011:177).

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SESSION 4. CULTURE, EDUCATION AND COMMUNITIES AS FACILITATORS OF THE FLOURISHING OF PERSONS WITH DISABILITIES

MEDIA REPRESENTATIONS OF THE DISABLED IDENTITY IN CONTEMPORARY SOCIETY

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An introduction to cultural imagination

This essay, which in no way claims to be exhaustive, moves from cultural representations of disability, studies that represent "The way in which scholars in the social and cultural sciences became interested in language in the 1970s and in speech in the 1980s"[1] and which, within the framework of semiotic studies, continue to understand how cinema, literature, and advertising contribute to defining cultural imagination. This is an imagination that is inevitably underlying the canons and attitudes that societies, in their acceptation of systems composed of social actors in relation to one another,[2] convey with respect to disability, understood as a "social problem".[3] From a sociological point of view, in fact, the issue of disability as a social problem has alternated between multiple approaches,[4] which at times have considered it as a form of involuntary deviance,[5] and at others as a true form of social stigma,[6] to finally establish it as a true social model.[7] This differentiation

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[1] T. Shakespeare, *Disabilità e società* [*Disability Right and Wrong Revisited*. Second Edition, Routledge, Abingdon 2014], Erickson, Trento 2017, p. 76 in Italian [Free translation].

[2] P. Ammassari, I fondamentali problemi di metodologia della ricerca sociale, in *Studi di Sociologia*, n. 2-3, 1985, pp. 176-193.

[3] W. Griswold, *Sociologia della cultura* [*Cultures and Societies in a Changing World*, Sage, Thousand Oaks 2004], Il Mulino, Bologna 2005.

[4] For a sociological reconstruction of such paradigms, see F. Ferrucci, *La disabilità come relazione sociale. Gli approcci sociologici tra natura e cultura*, Rubbettino, Soveria Mannelli 2004.

[5] For structural-functionalism, illness – in this case understood as disability – is regarded as a form of institutionalized deviance, according to which the condition of "[being] sick" is considered legitimate only if the individual conforms to the social expectations associated with his or her role as an involuntary deviant. Cf. T. Parsons, *Il sistema sociale*, Edizioni di Comunità, Milan 1996.

[6] For interactionism, society provides a label for disability, understanding it as a stigmatized social identity. In this sense, the stigmatized (disabled) individual is he or she who fits into social relations with other individuals carrying an aura of diversity. Cf. E. Goffman, *Stigma. L'identità negata*, Giuffrè, Milano 1983.

[7] Cf. C. Barnes, G. Mercer, T. Shakespeare, *Exploring disability. A sociological introduction*, Polity Press, Cambridge 1999.

is useful because it allows me to dwell upon cinema by trying to identify different genres, eras and forms of disability to offer at least a perspective of the presence of audiovisual narratives on disability.

Stories about disability in the audiovisual scenario have most often been relegated to a rigid genre: drama. The condition of people with disabilities has been depicted in the logic of dis-empowerment, of deficiency. Such descriptions seem to refer back to the so-called "medical model of disability", which "is based on a naturalistic conception of disability as being dependent upon impairments at the biological level of the organism".[8] However, this trend is probably influenced by a cultural approach related to the idea of a high-performing society and an unbalanced view of economics in the logic of profit, without any attention towards the individual, the community. The focus on performance and profit, on the other hand, are phenomena that characterize contemporary society, defined by Zygmunt Bauman as liquid modernity[9] to emphasize its highly tricky, individualized, uncertain, vulnerable and contradictory structure. So, "by closely observing our contemporary societies – says Pope Francis – we see numerous contradictions that lead us to wonder whether the equal dignity of all human beings […] is truly recognized, respected, protected and promoted in every situation. In today's world, many forms of injustice persist, fed by reductive anthropological visions and by a profit-based economic model that does not hesitate to exploit, discard and even kill human beings".[10]

The beginning of the new Millennium brings with it some novelties. In fact, both cinema and TV have begun to tell the story of people with disabilities and of the various forms of disability, by resorting primarily to genres other than drama, staging stories bearing the characteristics of thriller, fantasy, action, or cartoon films.

The approach towards audiovisual forms of language reminds us how cinema has a dual function: one of *representation* and the other of *regulation*.[11] That is, not only does it reflect society, but in some way it also restores us with the keys to interpret the same elements put into the picture. In other words, cinema helps us to look at the dimension of reality, moving our

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[8] F. Ferrucci, *La disabilità come relazione sociale. Gli approcci sociologici tra natura e cultura*, Rubbettino, Soveria Mannelli 2004, p. 16. [Free translation]

[9] Cf. Z. Bauman, *Modernità liquida*, Laterza, Rome-Bari 2011.

[10] Pope Francis, Encyclical Letter *Fratelli Tutti*, 2020, n. 22.

[11] Cf. F. Casetti, *L'occhio del Novecento. Cinema, esperienza, modernità*, Bompiani, Milan 2005, p. 15.

vision even in unthinkable directions, and on the other hand, in doing so, it inevitably ends up conditioning our outlook by suggesting what to observe, and "arbitrarily" deciding what is destined to remain out of the picture. This is sort of what has happened in terms of the meanings that different societies have attributed to disability, reflecting in them the multiple configurations of social control, the varied forms of conditioning that social structures have often imposed on individuals, oppressing and discriminating them against their ability to have meaningful social relationships.

Of course, this approach prompts a matter that cannot be ruled out – that is, the effects of cultural representations on society. As a matter of fact, today, in light of studies about the theory of social effects of mass media, no one could imagine the relationship between stories and society according to a behaviorist paradigm. Therefore, "representations in general have a kind of indirect effect on the fate of disabled people".[12]

Disability in films that break with tradition

A film that marked a distinct change regarding storytelling on the condition of disability is the comedy film *Intouchables*, 2012, directed by French directors Olivier Nakache and Éric Toledano. *Intouchables* takes its moves from a real story as told in the book *The Guardian Devil* by Philippe Pozzo di Borgo.

Directors Nakache and Toledano primarily outline a collective story, depicted with brilliant humor, about two people living on the edge of life. Two kinds of loneliness. Two individuals worn out by the events and closed up. However, their encounter marks the beginning of a change: together they pick up the pieces of their fragile and unhappy lives trying to put themselves back in the game, discovering the many possibilities still open for the future.

In the film, Driss is a young man of African descent in his 30s, who lives like so many fellow countrymen in today's France, seeking his fortune. Driss' expectations are tiresome from the beginning; he no longer believes there are opportunities for redemption. He drags himself along a faded path without a glimmer of optimism, taking what he can get. His meeting with Philippe throws him off balance: for the first time, a person wants to hire

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[12] T. Shakespeare, *Disabilità e società*, Erickson, Trento 2017, p. 78. [Free translation] On the issues of media representations and audiences see also F. Ferrucci, *La disabilità come relazione sociale. Gli approcci sociologici tra natura e cultura*, Rubbettino, Soveria Mannelli, 2004, pp. 158-168.

him, because he sees abilities, talents in him. Philippe places continuous cultural stimuli before him, inviting him to want and demand more of himself, to strive to be happy. Alongside Philippe, Driss discovers the meaning of kindness, of closeness, as well as the beauty of art, culture, and the importance of education.

On the other hand, there is Philippe, who initially looks to Driss as being a powerful diversion, a breath of fresh air compared to days spent in resignation. Philippe is a wealthy, educated, and accomplished man. He no longer feels capable of leading a full life; he can no longer hope and struggle. He surrenders to the repetition of the days, using money to soothe his anxieties. He approaches Driss with great curiosity and a desire to revolutionize the course of his days. What he does not expect, however, is that this immigrant from the suburbs would turn his life upside down, forcing him to learn about himself, to face his unresolved problems head-on and to come to terms with his condition. Driss helps him to see disability not as a limitation and to renew his outlook on it. Indeed, thanks to him, Philippe understands that despite his quadriplegia, he is still a man, he still has opportunities, starting with love. What Driss and Philippe have is a friendship that heals wounds and reconciles, a friendship that restores by opening to change.

Directors Nakache and Toledano are good at keeping the story balanced between drama and comedy, without the film slipping too far to one side or the other; they allow the spectator to approach a story full of pain without ever losing a glimpse of hope.

An equally significant resonance can be found for the comedy-drama film *Coda* (2021) by Sian Heder, a Hollywood film that began as a successful remake of the popular French comedy, *La Famille Bélier* (2015) by Éric Lartigau. The film centers around the hearing disability condition of a family. *Coda* started out on the U.S. distribution market as an independent film; being highly acclaimed and through word-of-mouth, it was then endorsed by the giant streaming company Apple TV+, which took it all the way to the “night of the stars”: in 2022 it won three important awards at the 94th Academy Awards, winning in the categories of best picture, Troy Kotsur as supporting actor, and non-original screenplay by director Heder.

Here is the story. United States, present-day Massachusetts, in a small coastal town not too far from Boston there lives the Rossi family: father Frank, mother Jackie, and their two children, 20-year-old Leo and high school student Ruby. Everyone in the family has been deaf since birth except Ruby, who is effectively the Rossi’s link to the local community. The family runs a fishing business and is part of a consortium. Enrolling in the school choir, directed by Prof. Bernardo Villalobos, Ruby realizes that she has a distinct gift for singing, and so she cultivates her dream of auditioning at the prestigious Berklee College of Music. When at home the family discovers the girl's intentions, the Rossi's come to a standstill, between the fear of Ruby's possible move to Boston and the bewilderment of no longer having her as a support in community relations.

Throughout the story's structure, in particular, the feelings of (mutual) fear and prejudice between the Rossi's and the local community are emphasized. Frank and Jackie look at others with suspicion, because they fear that they will not be understood and welcomed, precisely because of their being deaf; Jackie relates with insecurity to the other women in the consortium, convinced that they judge her, that they intentionally marginalize her. There are unfounded impressions that generate the family's (self-)isolation.

Other outstanding elements of the Hollywood version of *La Famille Bélier* include the relationship between the two siblings, Leo and Ruby, which is decidedly more articulate and multi-faceted, such as the one with the music teacher, Prof. Villalobos, or with the friend – who is in love – Miles. It is worth noting that in the U.S. film for the role of Ruby's family members, all genuinely hearing-impaired actors were involved, particularly Troy Kotsur and Marlee Matlin, the latter the Academy Award winner in 1987 for *Children of a Lesser God*.

On the topic of hearing impairment, another film to emphasize is the intense *Sound of Metal* (2020), the first feature film by screenwriter Darius Marder. Despite its troubled distribution process, complicated by the Covid-19 pandemic, *Sound of Metal* gained high visibility on the Prime Video platform. What turned the spotlight on this work, however, were the Academy Awards in 2021: the film was in the running for 6 Oscars, won in the editing and sound categories. And it was precisely the sound editing that was the most beautiful feature of the work, yes because *Sound of Metal* is a rough and evocative journey into the existence of a musician, a hard rock drummer, who all of a sudden is overcome by deafness. He finds himself enveloped in silence and must relearn the grammar of communication.

This is the story of Ruben and Lou, a rock music duo that performs across the country, moving from one venue to another; he plays drums, she is the lead vocalist. During a concert Ruben is affected by an increasing buzzing sound. He goes to the pharmacy and has a specialist prescribe an examination, and the diagnosis is without appeal: irreversible hearing loss.

Ruben plunges into silence and despair. Spurred to react by his companion, the young man goes to a shelter run by former veteran, Joe. The young man desperately pursues the possibility of surgery, capable of partially restoring his hearing; Joe shakes him and urges him not to see himself as a defective or broken human being. Finally, Joe leads Ruben, who is definitely an atheist, to discover the dimension of silence, to inhabit it with a renewed gaze: a space where sound is missing but God's voice and His presence can be clearly perceived. In the end, we do not know whether Ruben will decide to listen to that Voice, but he will certainly no longer be able to ignore its presence. The young man will thus learn to no longer be afraid of silence, discovering unprecedented perspectives towards life as well.

Hollywood recently came up with another remake: we are talking about Bobby Farrelly's *Champions* (2023), an adaptation of the Spanish comedy *Campeones* (2018) by Javier Fesser, Goya Award for Best Picture. A story that focuses on sports and disability, through the filter of social comedy with a brilliant edge that aims at eradicating prejudices and clichés about people with Down syndrome.

Marcus is a minor league basketball coach looking for a gateway to the NBA championship. His temper and outbursts of anger, however, do not help him. He loses his job and, while drunk-driving, he crashes into a police patrol car: so he is sentenced to serve 90 days of community service coaching a team of young people with intellectual disabilities, the Friends. Reluctantly Marcus shows up at the new gym, thinking about how to get out of that dead end, but meeting the Friends will make him reconsider, sparking in him a slow and irreversible journey of change, of redemption...

Champions moves along the plot-connection between sports and people with disabilities from an educational perspective (similar to Volfango De Biasi's *Crazy for Football* of 2021), with the goal of original storytelling about disability. Indeed, the comedy, between crackling jokes and enthralling scenes, emphasizes how children with Down syndrome have the right to have a job, economic and housing independence, including the possibility to experience romantic relationships and express their sexuality. In short, they are people who claim the right to a full life, without compromises.

It's a portrait of society that plays out between realism and dreams of inclusion beyond the barriers of prejudice. Along with the effective lead actor Woody Harrelson, the true stars of *Champions* are the young people who play the Friends. Like them, the Italian dubbers all have Down syndrome.

Italian storytelling between innovation and kind humor

There is no shortage of examples of disability storytelling in Italy. First of all, one of the starring series of the Rai 2023-24 season, is *Blanca* (2021, 2023), a Lux Vide and Rai Fiction production, directed by Jan Maria Michelini and Michele Soavi. The story in short: present-day Genoa, Blanca Ferrando (Maria Chiara Giannetta) is a young woman in her 30s, who works at the San Teodoro police station. She has an extraordinary talent for analyzing details at the crime scene, skills looked upon with suspicion by her colleagues: many doubt her because she has a visual disability. Inspector Michele Liguori (Giuseppe Zeno) supports her, while Commissioner Mauro Bacigalupo (Enzo Paci) openly disapproves of her.

Blanca is a young woman with a visual disability, who moves through her private life and work with great confidence, determination, and also constant (self)irony. She does not hide behind her disability, and on the contrary she jokes about it making sure that she is never treated differently. Alongside her is her loyal dog Linnaeus, an American bulldog, as well as Inspector Liguori.

In the series, the various vertical and horizontal threads work, following both the crime-mystery genre and at the same time with shades of comedy and sentiment. What also particularly works well in *Blanca* is the dynamics of storytelling, the direction, which is indeed lively and fresh, even innovative, convincingly looking to Anglo-American narrative models. Directors Jan Maria Michelini and Michele Soavi govern the structure of the story with originality and control, pushing above all on some fortunate visual choices: they manage to give voice, substance, to Blanca's thoughts, to her feelings as a blind person. There are moments when the protagonist is abstract, somewhere between the real and the dream-like world, scenes that veer towards black, reflecting the woman's inner world, her moment of deduction.

A film that certainly left its mark is Gabriele Salvatores' *Volare* [*Tutto il mio folle amore*] (2019), a comedy with dramatic overtones that veers, however, towards the direction of a fairy tale, tackling the themes of family, parent-child relationships and the autism spectrum disorder. Presented out of competition at the 76th Venice Biennale Film Festival, the film starring Claudio Santamaria, Valeria Golino, Diego Abatantuono and Giulio Pranno takes its cue from Fulvio Ervas' novel *Se ti abbraccio non avere paura [Don't be afraid if I hug you]*, from the true story of Andrea and Franco Antonello.

In short: Northern Italy, Vincent is a 16-year-old boy with autism spectrum disorder; his name comes from the song *Vincent* by Don McLean dedicated to the painter Van Gogh, a song that links him to his father Willy, a singer he has never met and who tours giving concerts around Italy and the Balkan area. Vincent grew up with his mother Elena and adoptive father Mario; he is loved, supported and motivated. However, his father's absence is upsetting. One day, finding himself in the area, Willy decides to visit Elena and discovers Vincent; he discovers he has a now 16-year-old son with disabilities. At first he is surprised, disoriented. Reluctant to accept responsibility, Willy decides to go back on the road to continue his quiet life between dance halls; however, it is Vincent who turns the tables, sneaking into his father's car and setting off with him on an adventure between Croatia and Slovenia. It is an opportunity for the two to get to know each other, slowly reknitting the frayed threads of that never-to-be-forgotten bond...

Sixteen-year-old Vincent's disability in the film is not the problem; the true problem is parental responsibility, the need to re-center oneself in the educational role, re-establishing the bond with one's child. The one experiencing a condition of "disability" in the story is primarily the father Willy, who has always been reluctant to take responsibility. Willy is an aimless 40-year-old, a music wanderer, who in a moment of hesitation retraces the steps of his own existence. He discovers that he is a father, a role that can no longer be silenced, marginalized: the time has come for Willy to look inside himself and discover that he is no longer alone, or a free spirit, instead, he has someone he needs to take care of, his son, who needs his words and presence. As a father, Willy must learn to know Vincent, to understand different ways and dynamics of communication, dictated by his disability, but also by his character.

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A director, who has long been in the forefront of telling stories about disability using a different approach, far from easy pietism, is Silvio Soldini. First of all, we remember his two documentaries: in 2013, *Per altri occhi. Avventure quotidiane di un manipolo di ciechi [For Other Eyes – the Everyday Adventures of a Handful of Blind People]*, followed the year afterwards by *Un albero indiano [An Indian Tree],* about a trip to India with his friend, the blind sculptor Felice Tagliaferri. In 2017 he directed the film *Il colore nascosto delle cose [The hidden color of things],* starring Valeria Golino and Adriano Giannini, which was presented out of competition at the 74th Venice Biennale Film

Festival. It is a successful portrait of a free and resolute woman, on a professional and relational-existential level, beyond her visual disability.

A brief synopsis: Milan, Emma is a 40-year-old blind woman who lost her sight during adolescence. However, she still leads a full and purposeful life, with professional gratifications, as an osteopath, and solid emotional ties. One day in her studio she meets Teo, a 40-year-old publicist with an uncertain and unruly life, who with his partner Greta is living a flat relationship that is dangling from a thread. Teo undergoes a series of medical sessions with Emma, and these encounters become opportunities to get to know each other better. He is surprised by the woman's confidence, so serene and free, despite her disability. A tender and strong bond is born between them, destined to complicate both their lives. Or perhaps to improve them...

This is how Soldini remarked, "It was a world that I was not aware of and that amazed me; I discovered people full of life and irony, who despite their handicap work, play sports, travel... I then realized that I had never seen any of this in cinema, that blind people were often portrayed dramatically, predictably, or with almost super-powers. So I decided to film a love story with a blind woman as occurs in real life. I wanted to tell about the meeting between two very distant worlds, about a man making a change, about the courage to face life, lightly and deeply. And to tell the story about Emma and Teo as if they were two of us, two of our friends".

From this brief overview, clear signals emerge from the world of cinema, of culture, regarding a change of approach toward disability. A suggestion, an invitation, that needs to be discerned more and more in everyday life. As Pope Francis reminds us: "Disability, in any form, represents a challenge and an opportunity to build together a more inclusive and civil society [...]. For this reason, it is necessary to continue to raise awareness of various aspects of the disability, dismantling prejudices and promoting a culture of inclusion and belonging, based on the dignity of the person. It is the dignity of all the most fragile and vulnerable men and women, too often marginalized as they are labelled as different or even useless, whereas in reality they are a great wealth for society".[13]

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[13] Pope Francis, Address to members of the Italian Autism Foundation, April 1, 2022.

RAISING CHILDREN ACCORDING TO THEIR NEEDS AND NURTURING THEIR GIFTS: THE STORY OF "MELE"

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1. Introduction

I am the mother of three children and a primary school teacher. I would like to highlight, through the story of my family and in particular of my second son Mele, who is affected by a mitochondrial disease, what have been the main difficulties we have faced as a family and the main positive contributions that have helped our family grow together, making everyone's gifts flourish.

Emanuele (Mele) was born on 22 April 2008, the second of our three children. Our family was similar to many others, but in July of that same year Mele became ill and was hospitalized for months in a specialized children's hospital. From this moment on I have only "sleeping baby" pictures of him in my computer. In August doctors told us there was not much more they could do for him, so we got him confirmed with the rite for children in danger of death. He did not die and we came back home.

What had happened? Did something break? Did we have a broken baby to be fixed or changed?

2. Raising Mele: the impossible becomes possible

In fact, I can assure you that the expectations, the desires all parents have for their children were still there and they had not changed. We still wanted every one of our children to grow up, communicate, play, study, get a job, form a family for themselves, etc. Our expectations had not changed in substance, but in manner they were now very different.

Moaning is useless: you must "make dinner with what is in the fridge". Sometimes, when an unexpected guest arrives, you think: "Oh my God, I have nothing to serve", but a Mum, checking her pantry, can actually always make a delicious meal with what is already there. What if there is nothing to eat? Well, all you can make is 'Stone Soup'. This is a very famous fifteenth/sixteenth century European folk story. In a village there is a great famine and no one has enough to eat. A woman fills a pot with water, drops a stone in it and places it over a fire in the middle of the village square. One of the villagers becomes curious and asks her what she is doing. She answers she is making 'Stone Soup', which tastes wonderful and which she would be delighted to share with the villager, although it still needs a little bit of garnishing – which she doesn't have – to improve the flavour. The villager does not mind parting with a few carrots, so these are added to the soup. Another villager walks by, inquires about the pot and the story of the stone soup, which has not yet reached its full potential, is repeated. More villagers walk by adding new ingredients to the pot. Finally, the inedible stone is removed and a delicious and nourishing pot of soup is enjoyed by the woman and villagers alike. What wasn't there becomes present. Sharing what everyone has, even if it's not enough by itself, leads to successfully transforming emptiness into a tasty meal that feeds everyone, including the donors. The impossible becomes possible with a minimum effort of sharing.

The ingredients of our 'Stone Soup' were donated by individual people who helped us, believing in the possibility of learning to lead a fulfilling life:

- returning home, thanks to the support and formation from a hospital service which trains parents of children in paediatric palliative care;
- receiving a home nursing service with a nurse who cared for Mele for eight years and who allowed the family to "breathe";
- starting kindergarten with a teacher who stimulated Mele to express himself through painting;
- the enthusiasm of a few art critics and the support of UCAI (Unione Cattolica Artisti Italiani), which led to public exhibitions of a three-year-old artist's paintings;
- the birth of Mele's little sister Maria, who brought a note of joy and confidence;
- attending the local scout group and participating in scout camps;
- the adventure of school, where courageous teachers, consultants, and principals worked and fought for the attendance and inclusion of Mele at school;
- several victories in court, achieved thanks to the pro bono commitment of sympathetic lawyers;
- the arrival of farm animals and the creation of a small rural reality around Mele.

History is made by good, courageous, frequently unknown people, who dare, who lead the others into hope. These people become contagious with hope, simply by concentrating on ordinary problems, because although bad things and habits are certainly contagious, fortunately also good habits, behaviours and feelings are, too. I am not talking only about government leaders, judges, economists, kings: they have a major role and they are important; the bigger the role, the greater the responsibility. Making good laws is important, applying them and making sure they are respected is even more important; creating functional economies is good, but the best thing is throwing seeds of good around. A small flame can light a great fire and you do not need to wait to be elected president or to marry the queen to do this. You can do it here and now. If you are good with little things, you will be good in bigger things. Seeds of hope are the most important things you can spread around, even in your own little situation. Then you can spread seeds of truth, beginning from yourself, seeds of life, seeds of respect, seeds of love. Love is a very inflated thing. Love is not a feeling, or not just a feeling alone; it is a behaviour, it is the will to do positive good.

So how can we make the good seeds in each of our children flourish, considering the very different needs of every one of them? Speaking personally, we as a family simply had to learn how to do exactly the same things, but in a different way.

3. Family learning: all relationships become more challenging

We learned how to feed a child who cannot eat, how to make a child with bone pain sleep comfortably, how to help him sit even though he doesn't have the muscle strength to do so, how to allow him to 'stand up', how to communicate without speaking with his voice, how to breath without his lungs being able to do so, how to teach and how to learn, how to attend school in regular classes. As you know, in Italy we do not have special schools or classes for students with disabilities, we just have classes which all people can attend and you should have all the support you need to achieve formative and educational success.

Disability never ends. Disability is a chronic condition that is different from an intercurrent illness or an occasional emergency. It puts everyone under stress, meaning that everyone is focused on guaranteeing the survival, the wellness, and the quality of life of the child. People relate differently to a child with disability or to a family who has a child with disability: they are all more stressed! I realized, for example, that the nurses in the paediatric ward of our local hospital were really nice when I went there with my eldest son, because they were all relaxed and confident and they were kind to me and to my child; however, they were all very tense, worried and in a defensive attitude when I had previously been there (many times) with Mele.

Disability disturbs, disability scares. Why? Because it reveals our shortcomings, our own fragility, it evokes our deepest fears: could it happen to my son? Could it happen to me? It puts us all in a state of challenge: I am a teacher, can I teach him/her? I am a mother, can I raise all my kids? It puts our system under pressure to achieve better standards: hospitals, schools, the government etc. All relationships become more challenging.

What are the most difficult things we experienced? Facing bureaucracy and having a correct relationship with public systems to get the support needed for a dignified life: first of all, getting needs identified and addressed properly without getting involved in a common public system conflict of interests. The services needed are in fact prescribed by the same entity that pays for them. Very often, the goal of public services is not to help people, but to spend less money to the detriment of the weakest. It is sad when people with disabilities are considered either a resource to be exploited or an opprobrium to be removed.

It is painful for a family to be forced to resort to the courts in order to have common human rights guaranteed, and to receive proper care. Public services can fight strenuously against a family that dares to appeal in a court for their child's rights. They often do so with the specific aim of using the family as a deterrent to discourage future requests from others.

Time is important, especially when you are a child and you have a progressive illness. Court cases, even when they end up by obtaining obvious rights, can still be unjust if they are endless or too long. You can certainly obtain a support teacher if you have a disability and the school hasn't assigned you one, but you will probably get this professional help at the end of the school year, when it has become practically useless.

Recently we were forced to move our son to a new school, because his former teachers gave up teaching him. He himself described the situation with these words: "They are not teaching me because they assume I cannot learn, so I'm not learning". Prejudice is a self-fulfilling prophecy!

To preserve the family's well-being, capacity for work, social life and relationships you must address not just the person with disabilities but the entire family and mainly caregivers (in Italy the figure of the caregiver is not legally recognized). I realized this because there is a situation in which disability of children is caused on purpose: when you want to win a war. Bombs resembling toys are fabricated not to kill children, but to mutilate them so the parents will turn all their energies inside their family to help their children, thus draining resources from the war effort. If we want to win our war against discrimination and segregation a good thing to do is to support families and caregivers in their efforts to raise their children and keep their outside life: working, studying, having a social life, getting proper medical care for themselves and even sometimes enough rest or sleep.

Is it difficult? Yes, it is; but "the greater the struggle the more glorious the triumph".[1]

When I'm tired, I remember this speech from Antonino Caponnetto:

> Refuse all kinds of compromises. Be intransigent about values. When people have got things wrong, convince them that is so. [...] Never ask for favours or to be favoured. The Constitution and the law give you rights, and you must insist that they be upheld. Ask for your rights, firmly and with dignity require them to be given without having to bow down to those who are in power or to the politician of the moment. You need to demand them! This is an imperative action underlining the whole of your life. Always show respect for your own dignity and defend it at all times.[2]

4. What are the things that really helped us?

- Respect for life: No one ever suggested that our son should be killed, neither in utero (but his illness had not yet been diagnosed) nor after. Killing someone thinking you are doing a good thing is only possible if you dehumanize the other person; dehumanization did not start with the Nazi holocaust and, of course, it is not over yet. No one is safe from it. No one proposed the deception of killing him to help our family and society with the surreal excuse of the "best interest", even of the person who is killed. Death is never in the best interests of any living creature; death is not good and it is certainly not in anyone's best interests. It is beyond evil to think of eliminating a person just to eliminate his or her pain. It reminds me of when, as a child, I scratched my knee. I would go crying to my Grandma and she would always say: "No problem, let's cut your

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[1] "The Butterfly Circus", film by Joshua and Rebekah Weigel, 2009.

[2] Speech by Magistrate Antonino Caponnetto (from 1984 to 1990 head of the 'Rocco Chinnici' Anti-Mafia pool) – the man who asked for Falcone and Borsellino's participation.

leg off so it won't hurt any more". It was so obvious to 4-year-old me that this was the most idiotic solution that I simply laughed and was very satisfied with a plaster or even just a kiss. Killing someone is never an act of compassion; anyone who makes you believe this or says this is a liar.

- Knowing our rights: sometimes, in fact, we put ourselves in the position of not considering that we have the perfect right to be "like everyone else". We don't dare to ask or join in any activities or even try to, because we are not aware that we can, simply because the laws guarantee these things to us.
- A network of help, from other parents of children with disabilities who have already walked along this same path.
- Being up to date and competent in doing everything to make sure our child will survive.
- When we actually received appropriate help from services. For example, when we had nursing assistance with substitution of the caregiver and flexibility, and we were able to keep our jobs, to care better for all our children, or just to sleep when we were tired.
- Having dedicated professionals who really took care of us and of our children: doctors, hospitals, nurses, directors, lawyers, judges, principals of schools etc., who actually took personal responsibility, and, for example, signed the documents that were needed (because vital figures in such positions frequently refused to do so), giving the much-needed seal of authority, highlighting not only our exigencies but our rights as well.

After this extenuating, strength-consuming process, what can you do when all the things strictly regarding survival have been done? Well, you can finally start doing what children do – you start playing!

5. Mele's art

My son's active practising of art started by chance, as a family game. My eldest son was just 5 years old and one day I decided to let him paint in his underwear. It was really funny, but he destroyed the piece of paper because of the amount of paint he put on it. I then decided to get a canvas so I would be able to keep his work. When I was at the shop, I remembered an episode of my life. I had been invited to my parents' house because of my younger sister's graduation. When I arrived, my father came to meet me at the gate with a bouquet of flowers. I said to him: “Dad, you’ve got the wrong daughter, it’s not me, it’s my sister who has graduated”. He answered: “I’m not wrong: I have two daughters so I went out and got two bouquets of flowers!” Remembering that I thought: “I have two sons, I’ll buy two canvases”. When Mele tried we started praising him at the beginning saying: “You are great, you are sooo gifted”, but the thing is that in the end his painting really was extraordinary. I decided to have it framed, thinking he would never make another one. When I went to the shop the man said to me: “It’s a really long time since I saw such a beautiful abstract painting! But you didn’t sign it...”. “I didn’t make it”. “The person who made it didn’t sign it…”. “The person who made it cannot sign it”. “Who made it?” “My son”. “How old is he?” “3”. The fact of his age was in itself so special that I didn’t have time to say anything about his disability, in that the man had already given me another blank canvas, saying: “Now let him try again! We must know if this is just a coincidence or an extraordinary gift”. Mele has made hundreds of paintings with his hands since then, and he has received prizes, had national exhibitions and so on.

Very often people attempt to ‘re-qualify’ persons with disabilities by demonstrating what they are capable of doing. But in fact, people are important not because of what they can do, but simply because they exist. You need to give a person the value he has, then the person can show you who he is. Some people say that this is a miracle. But honestly, we don’t need miracles, we need eyes to see them.

6. Conclusions

I want to conclude by reading a poem:

I asked for strength,
and God gave me difficulties to make me strong.
I asked for wisdom,
and God gave me problems to learn to solve.
I asked for prosperity,
and God gave me a brain and brawn to work.
I asked for courage,
and God gave me dangers to overcome.
I asked for love,
and God gave me people to help.
I asked for favors,

and God gave me opportunities.
I received nothing I wanted.
I received everything I needed.[3]

Only you know what that is.

I would like to thank Professor Fabio Ferrucci, Professor Massimo Giulio Campostrini and Professor Sinclair de Courcy Williams for critical reading of this manuscript.

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[3] Sufi poem, attributed to Hazrat Inayat Khan, quoted in *The Soul of Money* by Lynne Twist, 2003.

EDUCATION FOR ALL: CHILDREN, DISABILITIES, AND THE GLOBAL COMPACT FOR EDUCATION

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> *A school's mission is to develop the sense of the true, the sense of the good and the sense of the beautiful. And this happens through a rich journey made up of many "ingredients". That is why there are so many subjects! Because development is the result of various elements which interact and stimulate the mind, the conscience, the affections, the body, etc. For example, if I study this Square, St. Peter's Square, I learn something about architecture, history, religion, even astronomy – the obelisk recalls the sun, you see few people know that this square is also a large sundial.*
>
> *Thus we cultivate within ourselves the true, the good and the beautiful; and we learn that these three dimensions are never separated but rather are interwoven. If something is true, it is good and it is beautiful; if something is beautiful, it is good and it is true; if it is good, it is true and it is beautiful. And together these elements make us grow and help us to love life, even when we are unwell, even amid difficulties. True education makes us love life, and it opens us to the fullness of life!*
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> Address of the Holy Father Pope Francis, May 10, 2014

The mission of education is to cultivate healthy, flourishing, and engaged children. In the Platonic tradition, education endeavors to nurture that which is true (logic and science), that which is ethical and just (goodness), and that which is beautiful (aesthetics). In the face of war and terror, planetary climate crises, global pandemics, and growing inequities, creating a more inclusive and sustainable world is education's urgent challenge. In the words of Pope Francis, a "summons to solidarity" with the next generation, with each other, and with our ever more fragile planet is the ethical imperative of our times.

Including neuro-atypical and children with disabilities, perhaps better referred to as "complex learners," is not an addendum but a critical aspect of addressing the challenge of educating all children and fostering their eudemonic development. The mission to educate all children is built on the imperative to extend solidarity, support, and learning opportunities to every member of our society, particularly those facing additional barriers to accessing opportunities to learn and quality education.

In this chapter, I first delve into the state of education[1] for all children, then evaluate the impacts of the COVID-19 pandemic on children and youth in terms of education (Suárez-Orozco, 2023). Finally, I provide a framework for best practices for children with disabilities, focusing on neuro-atypical children and complex learners.

The Education Global Compact

Basic primary education in schools has become a normative ideal the world over. In the last five decades, schooling has emerged globally as the most critical societal institution for the next generation's education. There is much good news: "Enrolment of children in primary education is nearly universal. The gender gap has narrowed, and in some regions, girls tend to perform better in school than boys."[2] Progress in children's participation in schools is a laudable achievement. However, the work ahead is significant: "Enrollment does not translate directly into education, and education does not translate directly into good education, which is often the real catalyst for engaged citizenship, emotional awareness, human sensitivity, and a tolerance of the other, along with the enhanced potential for working collaboratively, productively, and innovatively" (Bloom & Ferranna, in Suárez-Orozco & Suárez-Orozco, 2022). Education is freedom and is "far and away the single most empowering investment for individuals. It is for that reason that the world has long regarded education as a basic human need and as a basic human right. However, we have not achieved universal education" (Sachs, 2022). Millions remain out of school, and illiteracy remains rampant: 781 million adults over the age of 15 remain illiterate – and women make up well over half of those who are illiterate.[3]

While much remains to be done, education is widely viewed as the *Camino Real* for sustainable development and a driver of wellness (Bloom & Ferranna, in Suárez-Orozco & Suárez-Orozco, 2022). "Seen as part of the global commons, knowledge, learning, and education represent *humanity's greatest renewable resource* for responding to challenges and inventing alter-

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[1] In this Chapter we approach education as formal schooling but also as the entire range of opportunities to learn that include early childhood education settings (Rinaldi; Udwin, in Suárez-Orozco & Suárez-Orozco, 2022), as well as informal and out-of-school educational opportunities in informal settings.

[2] See The World's Women 2015: Trends and Statistics by United Nations Statistics Division https://unstats.un.org/unsd/gender/chapter3/chapter3.html

[3] *Ibid.*

natives" (Giannini, in Suárez-Orozco & Suárez-Orozco, 2022). Ample evidence suggests that education – almost any form that nurtures and supports basic literacy – generates powerful virtuous cycles.[4] As UNICEF researchers have concluded: "An education is perhaps a child's strongest barrier against poverty, especially for girls. Educated girls are likely to marry later and have healthier children. They are more productive at home and better paid in the workplace, better able to protect themselves against HIV/AIDS, and more able to participate in decision-making at all levels. Additionally, this ... furthers [the sustainable development goals of] universal primary education and gender equality" (UNICEF, 2004).[5]

The values and virtues flowing from quality education have been named and memorialized in multiple covenants and declarations by some of the world's most august bodies. The worthy ideals embodied in Article 26 of the Universal Declaration of Human Rights (1948), the right to universal, free, and compulsory education, come to mind: Education shall be "directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace" (Universal Declaration of Human Rights, 1948).

However, as various scholars have noted, the world has failed for over seven decades "to realize that right, and other rights in the Universal Declaration. There has been progress, but we should be more interested in the shortfall than the achievement, as children are losing their future prospects at our hands. The failures point us to the urgent work we have yet to do" (Sachs, 2022). The global data on educational disparities and their corollaries with health, wellness, wages, and the transition to the world of work points to a powerful truth: inequities in learning opportunities and educational outcomes generate bifurcated pathways. Today *qua* education, the rich are getting richer, and poor are getting poorer. In low-income countries, the elephant in the classroom is the disparity in financial resources.

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[4] LeVine, R.A., LeVine, S., Schnell-Anzola, B., Rowe, M.L., & Dexter, E. (2012). *Literacy and mothering: How women's schooling changes the lives of the world's children*. Oxford University Press.

[5] UNICEF. (2004). The state of the world's children 2004: Girls, education and development. United Nations Children's Fund. https://www.unicef.org/reports/state-worlds-children-2004

Investments in quality education are at once ethical (see Hösle, in Suárez-Orozco & Suárez-Orozco, 2022) and intelligent policy. The returns to investments in education are measurable, profound, and multidirectional: "Education investments can promote health and longevity; reduce fertility and population growth rates; improve living standards; and, ultimately, enhance well-being at multiple levels, ranging from individuals to countries. The causal links are bidirectional: health investments and fertility reductions contribute to increasing the returns to education, and, as a result, induce more investment in education. This complexity implies that educational development is probably best approached multisectorally, through an integrated blend of health, population, and education policies" (Bloom & Ferranna, in Suárez-Orozco & Suárez-Orozco, 2022).[6]

Education is a moral, ethical, and civic endeavor. Since Plato and Aristotle, philosophers have pondered education and its purpose for the eudemonic flourishing of human beings. As the idea of educating all children in formal school settings took shape in the modern era, philosophers entered the conversation. In Kant's moral philosophy, we become persons only in and with education. Indeed, education constitutes our humanity (see Hösle, in Suárez-Orozco & Suárez-Orozco, 2022). Over a century ago, Émile Durkheim began lecturing would-be teachers on moral values and

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[6] Education is linked to the fortunes of both nations and individuals. Quality education is literally life-enhancing and is connected to health and wellness outcomes. Darwin briefly noted the nexus between education – especially the education of women, and human improvement. He wrote in the margins of the evolution notebooks, "Educate all classes. Improve the women (double influence) and mankind must improve." Double the influence surely relates to the fact that educated mothers improve the life changes of their children thus commencing self-propelling virtuous cycle. Two centuries later Robert Levine and his colleagues at Harvard studied young mothers and their children's health in four countries and found that girls' schooling was good for children's health. See, LeVine, R.A., LeVine, S., Schnell-Anzola, B., Rowe, M. L., & Dexter, E. (2012). *Literacy and mothering: How women's schooling changes the lives of the world's children.* Oxford University Press. Subsequent empirical studies have confirmed the Levine findings. A large-scale Lancet study of educational attainment and its effect on child mortality in 175 countries shows that education saves lives, "Of 8.2 million fewer deaths in children younger than 5 years between 1970 and 2009, we estimated that 4.2 million (51.2%) could be attributed to increased educational attainment in women of reproductive age." See Gakidou, E., Cowling, K., Lozano, R., & Murray, C.J.L. (2010). Increased educational attainment and its effect on child mortality in 175 countries between 1970 and 2009: A systematic analysis. *The Lancet, 376*(9745), 959-974. https://doi.org/10.1016/S0140-6736(10)61257-3

collective consciousness, first articulating his enduring conceptual contribution to the social sciences: the moral nature of the relationships between the individual and society.

John Dewey is philosophy's most influential voice in education. Dewey's rich conceptual work evolved as the idea of universal, free, compulsory, non-denominational public education was becoming firmly rooted first in the United States and then elsewhere (see Rogers, in Suárez-Orozco & Suárez-Orozco, 2022). In Dewey's early writings, education is constitutive of democratic citizenship. In a passage echoing Durkheim's sentiments, Dewey wrote, "I believe that the school is primarily a social institution. Education being a social process, the school is simply that form of community life in which all those agencies are concentrated that will be most effective in bringing the child to share in the inherited resources of the race and to use his own powers for social ends. I believe that education, therefore, is a process of living and not a preparation for future living."[7] The rise of fascism, nazism, and the diffusion of authoritarian, anti-democratic ethos, redoubled Dewey's focus on education and democracy. The social process in school, Dewey argued, must engage all children as active, hands-on, and involved citizen-learners, laying in place the pathway for renewal of the democratic ethos and eidos of each generation (see also Rogers, in Suárez-Orozco & Suárez-Orozco, 2022).[8] Perhaps more than any other philosopher, Dewey set a tone during the formative years of education as a democratic practice and field of inquiry (see Rogers, in Suárez-Orozco & Suárez-Orozco, 2022).[9] Horace Mann was a leading voice trumpeting

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[7] Dewey, J. (1897). My pedagogic creed. *The School Journal, 54*(3), 77-80. In a note sympatico to Durkheim's views on education and society, Dewey writes, "education is a regulation of the process of coming to share in the social consciousness; and that the adjustment of individual activity on the basis of this social consciousness is the only sure method of social reconstruction" (Ibid.)

[8] William James working in the Anglo-Saxon pragmatist tradition thought deeply about education, teachers, and pupils. He conducted field research on memory and learning and investigated consciousness. Considered the father of American psychology, James' empirical work led him to privilege the child's own incipient capabilities and resources as a point of entry into all authentic teaching and learning in that sense alininging his thinking to the Dewey's learning by doing approach to education. James famously noted, "We are like islands in the sea, separate on the surface but connected in the deep." See, James, W. (1907). *Pragmatism: A new name for some old ways of thinking*. Longmans, Green, and Co. p. 27. Education is surely what deeply connects us all.

[9] Dewey's "learning by doing," became rooted as experimental schools strived to become hand-on, project based, democratic learning communities. Corinne Seeds, build-

the importance of public education for democracy. He argued that civic education "instruction respecting the nature and functions of the government" must be provided in "common schools" open to all.[10] Such schools not only would present civic knowledge but afford opportunities for social interaction and shared deliberation through which all "parties can become intelligible to each other."[11]

However, even as Mann envisioned public schools as sites for preparing citizens to participate in political life, he worried that a fractious partisanship might undermine the democratic project of common schooling. "If the tempest of political strife were to be let loose upon our Common Schools, they would be overwhelmed with sudden ruin. Let it be once understood, that the schoolroom is a legitimate theatre for party politics, and with what violence will hostile partisans struggle to gain possession of the stage, and to play their parts upon it!"[12]

While Jerome Brunner and his students at Harvard, such as Howard Gardner, Patricia Greenfield, and other leading psychologists, became increasingly influential in education and educational psychology by focusing on cognition and socioemotional learning, with the ascendancy of neoliberal economics, education inched away from its foundations in ethics, morals, civics, and psychology.[13] Indeed, throughout the last generation, education scholarship has become increasingly a province of economic em-

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ing on her mentor's teachings, was instrumental in turning the UCLA Lab School into an iconic constructivist, research-based experimental school where children-as-citizens took active roles in the course of their own learning. In Europe, Loris Malaguzzi (see Rinaldi, in Suárez-Orozco & Suárez-Orozco, 2022) built a series of early childhood education programs in Northern Italy inspired in part by Dewey's ideas. The Reggio Emilia pre-schools, in turn, came to deeply influence the thinking of the eminent American cognitive and educational psychologist, Jerome Brunner, and many of his students.

[10] Mann, *Twelfth annual report,* 84. Mann speaks of universal public education in which people across lines of class attend school together. Yet, he remained largely silent about the racial segregation of public schools. See: P., "Horace Mann and Colored Schools," *The Liberator,* December 24, 1847. It should be noted that Mann was not oblivious to issues of race and discrimination. He advocated for the abolition of the slave trade while Secretary of the Board of Education in Massachusetts and later, while a member of the U.S. Congress, spoke out against slavery more generally. See for example, Horace Mann's February 23, 1849 speech, "Slavery and the Slave Trade" in Horace Mann, *Slavery: Letters and Speeches* (Boston: BB Mussey & Company, 1853).

[11] Mann, *Twelfth annual report,* 86.

[12] Mann, *Twelfth annual report,* 86.

[13] See, Lagemann, Ellen, https://bit.ly/3snnDUx

pirical research and conceptual modeling, with economic development a sharp focus of concern.[14] But as Stefania Giannini has cautioned, "Development cannot be simply framed in terms of economic growth – human flourishing and the accessibility of lives of meaning and dignity must be primary concerns" (Giannini, in Suárez-Orozco & Suárez-Orozco, 2022).

Vittorio Hösle has articulated a plea for the re-coupling of education and ethics. His reflections cover the ethical claims for the right to an education and the disparate claim for re-engaging with ethics in education; he examines, *seriatim,* Who has a right to be educated? Who has a duty to educate? What should be taught in the curriculum? What are the challenges and opportunities in the teaching of ethics? Hösle argues that intrinsic to the moral evolution of our species "is the recognition that we share a common responsibility to educate all human beings, not only in order to help them maintain themselves as part of the global society but also to comprehend the complex nature of our world and to attain a greater depth by grasping moral values irreducible to self-interest as well as their ultimate source" (Hösle, in Suárez-Orozco & Suárez-Orozco, 2022).

A sense of purpose is a uniquely human achievement closely connected to the flourishing of potential and well-lived, directed life. When aligned with moral character, purpose generates a cascade of virtuous cycles – health and wellness, motivation, resilience, and other virtuous outcomes have been empirically linked to the sense of purpose. William Damon and Anne Colby have worked on the problem of purpose in education, its development in youth and throughout the life course, and what schools worldwide are doing to foster a sense of purpose in today's students. They define purpose as "an active commitment to accomplish aims that are both meaningful to the self and of consequence to the world beyond the self."

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[14] Increasingly education research turned to efficiencies, returns to investments, and theories of forever growth. Algorithmic metrics delineated pathways from teacher "inputs" to student "outcomes." In a particularly vulgar reductive move, economists constructed complex research experiments such as paying poor children to do their homework to calculate precisely how extrinsic motivational variables (cash for homework) lead to different learning outcomes. The first principle that "every dollar invested in education" shall deliver results in the currency of better skills, better jobs, and better income became an agreed upon shared cognitive schema globally. Arguably no other idea has traveled as well, even across fiercely contested cultural and epistemic boundaries: from pre-school to college, the new *mentalité* announced that education was an investment paying in little and big ways.

They argue,

> "Purpose has long been identified in philosophy and theology as an essential component of a well-directed life. In recent years, support for this longstanding theoretical intuition has come from studies in psychological science and medicine that have documented important life benefits associated with purpose. Such benefits include: energy and motivation; resilience under pressure; a positive personal identity; emotional stability; academic and vocational achievement; faith and trust in the affirmative value of life; and a sense of direction that can withstand episodic periods of uncertainty and confusion.[15] … [and] contribute to energy and health throughout the lifespan"[16] (Damon and Colby, in Suárez-Orozco, 2022).

As Pope Francis and ample research suggest, it is by nurturing socio-emotional learning –including patient listening[17] constructive dialogue and

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[15] See https://coa.stanford.edu/publications for an extensive list of scientific studies that have established empirical associations between such psychological benefits and purpose in life.

[16] See, for example, Atul Gawande: *Being Mortal: Medicine and What Matters in the End* (New York: Henry Holt & Co., 2014).

[17] Listening is at the heart of all teaching and learning. The Reggio Emilia Approach in early childhood education perhaps best captures the richness of listening in education: "The term "listening" is to be interpreted according to a plurality of meanings.

Listening as a metaphor for openness to listen and be listened to, with all the senses, sight, touch, smell, taste, orientation, not only with hearing.

Listening to the hundred, thousand languages and codes used by life to express itself and to communicate.

Listening to the connections that hold us together as living beings; being intimately convinced that we belong to a plural dimension.

Listening that requires a time of its own, of pauses, of silence, an inner time, and therefore listening to ourselves as regeneration, as care towards new questions about us and the others.

Listening as interest, as curiosity, as emotion.

Listening as an openness to the others, welcoming differences, the value of the point of view that is foreign to me.

Listening as an active verb, which interprets, welcomes, gives value and meaning.

Listening that doesn't make answers but builds questions. Listening that is generated by doubt as awareness of the limit and suspension of judgment and prejudice.

Listening that asks for willingness to change, that gives value to the unknown, to the not yet known, to emptiness as an opportunity.

Listening that gives meaning and legitimacy to the person listened to" (Rinaldi, this volume).

better mutual understanding,"[18] the values and virtues of engaged citizenship, and by imparting the new skills to prepare youth for the ever-evolving world of work, that schools become meaningful vehicles for collective empowerment and positive social action. "In order to educate, one has to be able to combine the language of the head with the language of the heart and the language of the hands. In this way, the student can think what he or she feels and does, can feel what he or she thinks and does, and can do what he or she feels and thinks" (Pope Francis, in Suárez-Orozco, 2022). Education must endeavor to inculcate in children and youth humane sensibilities, empathy and perspective taking, communication and collaboration skills, higher-order cognitive skills for critical thinking, and metacognitive abilities to become lifelong learners and civic agents. Today, paraphrasing the words of Damon and Colby (in Suárez-Orozco & Suárez-Orozco, 2022), fostering a sense of purpose in young people must be a vital part of the educational mission. A humanistic ethic of care (Giannini, this volume) – and not simply a reductive utilitarian logic of market efficiencies – must animate the work of education in troubled times.

Twenty-first-century economies and societies are predicated on increasing complexity and diversity – the twin corollaries of an ever-more-globally interconnected, miniaturized, and fragile world. We must mind the gap between what education *is* and what it *needs to* be to build a more humane, equitable, and sustainable future for all.

What are the most critical challenges to schools today?

First, quality education for all – from early childhood (Rinaldi; Udwin, in Suárez-Orozco & Suárez-Orozco, 2022) onwards remains an elusive mirage for millions of children, above all complex learners and children with disabilities. It is a scandal that before the COVID-19 pandemic, over 260 million children and youth were not enrolled in primary and secondary schools – the equivalent of Indonesia's population, the world's fourth most populous country. For those enrolled, the little education provided – especially in literacy (Katzir, 2022), will be vital but perhaps not enough to thrive to their full potential.[19] Too many children in low and lower-middle-income countries are falling further behind their peers in the wealthy nations. Special attention must be paid to the role of literacy (Wolf, in Suárez-Orozco & Suárez-Orozco, 2022) and the opportunities and limitations of new technologies (Barron,

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[18] https://www.educationglobalcompact.org/en/the-invite-of-pope-francis/

[19] https://ourworldindata.org/literacy

in Suárez-Orozco & Suárez-Orozco, 2022) to reach children who otherwise have little opportunities for formal learning.

The second challenge facing schools is unfolding at the vital link between the wealthy countries in the Northern Hemisphere and the metaphorical global South. Schools are struggling to properly educate and ease the transition and integration of large and growing numbers of immigrant and refugee youth (Yoshikawa et al.; Crul, in Suárez-Orozco & Suárez-Orozco, 2022) arriving in Europe, North America, Asia, Australia, and elsewhere; many immigrant and refugee youngsters are marginalized as racially, ethnically, religiously, and linguistically-marked minority groups. The learning complexities of immigrant and refugee children with disabilities are often overlooked and confounded with language and other cultural issues.

The third challenge schools face is educating students to address our ever-more fragile planet (Ramanathan et al.; Iyengar et al., in Suárez-Orozco & Suárez-Orozco, 2022). Unsustainable development is a global threat. The admirable Sustainable Development Goal (SDG 4.7) to provide "education for sustainable development and sustainable lifestyles" remains elusive for most students.

At a time when education must communicate values, virtues, and purpose, we find ourselves reticent and unsure of how to proceed. However, when it comes to values and purpose (Damon & Colby, in Suárez-Orozco & Suárez-Orozco, 2022), children and youth are clamoring for an integral education outlined by Pope Francis (in Suárez-Orozco & Suárez-Orozco, 2022). We are proceeding with too much caution when education needs "a bold, humanistic vision, based on human rights, social justice, dignity, cultural and social diversity, and intellectual solidarity. This vision reaffirms universal ethical principles and the need to strengthen moral values in education and society. It starts with people of all ages and the analysis of development contexts. It is inclusive, equitable, and informed by interdisciplinary research across the sciences, arts, and humanities. Finally, it is participatory and international in scope" (Giannini, in Suárez-Orozco & Suárez-Orozco, 2022).

The world is facing multiple crises – war and terror, climate change, pandemics, racism and xenophobia, growing inequality, and extreme poverty. Stefania Giannini (in Suárez-Orozco & Suárez-Orozco, 2022) argues that "an education crisis mirrors a wider global crisis, one that is social, moral and environmental." Tired-old claims, silver bullets, and magical thinking will no longer do. Nor will averting our gaze to growing inequities in education. Schools, the world over, must endeavor to educate the whole child for the whole world. "Through a humanistic and holistic vision of education and development, which cannot simply be framed in terms of economic growth, learners need the knowledge and the values to live meaningful and purposeful lives in harmony with others and the planet" (Ibid.) Schools need to be laboratories reclaiming the shared ethical principles of reciprocity, solidarity, equity, and inclusion and fighting all forms of discrimination, above all against students with disabilities and complex learners. However, children with disabilities, neuro-atypical children, and complex learners often face a significant undertow as they endeavor to learn.

The COVID-19 Effect

Millions of children and youth experienced COVID-19 damage and dislocations likely to mark their developmental pathways for years (Bloom and Yousafzai, in Suárez-Orozco, 2023). COVID-19 can be described as a long-lasting catastrophic shock removing them from the proscribed pathways that enable children and youth the world over to reach and master culturally determined milestones – in the maturational, socio-emotional, cognitive, and moral realms. Millions of youths are mourning and facing losses that are at once immediate and ambiguous. For millions of children, the pandemic represents a long-lasting "catastrophic education emergency," robbing them of the daily attending school rituals with all that entails: learning opportunities, socializing with other children, seeking support from teachers, physical education, accessing health care and nutrition, and the various other scaffolds needed for developmentally appropriate socio-emotional, cognitive, and meta-cognitive growth. The pandemic stunned education systems with geologic force: by the decade's start, approximately 1.5 billion students were no longer attending in-person school as school closings became mandatory in 160 countries (see Giannini, in Suárez-Orozco, 2023). Moreover, as millions of children would eventually continue their learning remotely, UNICEF data suggest that "for at least 463 million children whose schools closed due to COVID-19, there was no such thing as 'remote learning.'"[20] (Ibid.) Millions lacking electricity, technology, and internet access could not engage in online learning.

Indeed, during the COVID pandemic, it is estimated that over 830 million students did "not have access to a computer at home." As Bridgit Barron

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[20] https://www.unicef.org/press-releases/unicef-executive-director-henrietta-fore-remarks-press-conference-new-updated

notes, "Although unequal access to information technologies had been documented well before the COVID-19 pandemic, dramatic school closures have brought a significant digital divide into sharp relief and exposed the ongoing cost of inequities, as teachers across the world scrambled to continue the education of millions of children. Radio, television, and the internet were deployed in an attempt to connect schools and homes. Learners in rural areas, citizens from less affluent countries, families who have less wealth, and female students were the least likely to have access to any of these forms of remote learning" (Barron, in Suárez-Orozco & Suárez-Orozco, 2022).

UN data suggest that COVID-19 wiped out twenty years of gains as "100 million more children fail basic reading skills because of COVID-19."[21] Two-thirds of those countries are in Latin America and the Caribbean. In addition, school closures disrupted immunization and other health services often provided at school and prevented many children from accessing the only nutritious meal of the day.

Researchers found that neuroatypical and complex learners experienced significant adverse COVID-related mental health, socio-emotional, and physical outcomes "(including [less] sleep, [poor] diets, [less] exercise, [more] use of electronic media; and increased symptoms of child neurodevelopmental disability [NDD] and comorbidities)."[22] As the world of education endeavors to move into a phase of recovery, the most vulnerable children, including complex learners and children with disabilities, face significant losses: Since its outbreak two years ago, the COVID-19 pandemic has disrupted education systems globally; affecting the most vulnerable learners the hardest. [T]he costs stand to be tremendous in terms of learning losses, health and well-being, and drop-out. Prioritizing education as a public good is crucial to avoid a generational catastrophe and drive a sustainable recovery. To be more resilient, equitable, and inclusive, education systems must transform, leveraging technology to benefit all learners and building on the innovations and partnerships catalyzed throughout this crisis. UNESCO, 2022.[23]

Bloom and Ferranna summarize COVID's impact on education, "School closures and difficulties in implementing effective remote learning generally reduce the pleasure of learning, hinder children's socialization opportunities, degrade the emotional and mental health of students, and increase

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[21] https://news.un.org/en/story/2021/03/1088392

[22] https://pubmed.ncbi.nlm.nih.gov/33426739/

[23] https://www.unesco.org/en/covid-19/education-response

the risk of domestic violence and abuse In addition, school closures disrupt immunization and other health services that are often provided at school and prevent many children from accessing the only nutritious meal of their day. School closures also exert considerable pressures on parents, who have to balance childcare, homeschooling, and work duties" (Bloom & Ferranna, in Suárez-Orozco & Suárez-Orozco, 2022).

The COVID-19 pandemic laid bare for the world the deepening inequalities of opportunities to learn that flow from disabilities, country-of-origin, race, ethnicity, and immigration background. COVID sent another 100 million human beings into deep poverty – brutally intensifying extreme poverty and reversing years of progress.[24]

Indeed, poverty is the other pandemic taking a heavy toll on children and youth across the world. The consequences on children are chilling, "different poverty indicators are associated with lower cognitive and academic performance during several stages of development. Psychological and neural evidence generated in recent years suggests the need to review the interpretations of these associations in the sense of deficit and to consider the occurrence of adaptive processes instead" (Lipina, in Suárez-Orozco & Suárez-Orozco, 2022). Poverty, war and terror, structural racism, unchecked climate change,[25] the "globalization of indifference," an extreme form of which is modern child slavery, thwart the opportunities for healthy development and wilt the flourishing of millions of children. Indeed, they represent the most significant undertow towards meeting the UN millennial development goals of reaching universal primary education.[26]

Students with Disabilities and Complex Learners

Students with disabilities and complex learners are not from the other side of the moon. They partake in the joy of learning, discovery, and reflecting on themselves and the world. Their disparate abilities, gifts, and

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[24] World Bank estimates that "Global extreme poverty is expected to rise in 2020 for the first time in over 20 years as the disruption of the COVID-19 pandemic compounds the forces of conflict and climate change, which were already slowing poverty reduction progress...The COVID-19 pandemic is estimated to push an additional 88 million to 115 million people into extreme poverty this year, with the total rising to as many as 150 million by 2021, depending on the severity of the economic contraction. See "COVID-19 to Add as Many as 150 Million Extreme Poor by 2021" https://bit.ly/2Q30uZY

[25] http://www.fao.org/state-of-food-security-nutrition/en/

[26] https://www.un.org/millenniumgoals/education.shtml

the unique challenges they face must be understood and incorporated into the global education compact. They, too, must be given all the relevant opportunities to learn. The education of children with disabilities, therefore, is not a separate agenda but a central part of the overarching goal to educate the whole child for the whole world, reclaiming the shared ethical principles of reciprocity, solidarity, equity, and inclusion, and fighting all forms of discrimination. This is the path towards building societies where everyone can flourish and contribute to the common good regardless of their abilities.

Integrating complex learners and students with disabilities into educational systems requires a multifaceted approach, focusing on accessibility to opportunities to learn, tailored learning strategies, supportive technologies, and data-informed continuous improvement (Gomez et al., in Suárez-Orozco & Suárez-Orozco, 2022). It involves reimagining and reengineering educational environments and pedagogies to accommodate diverse learning needs and abilities, ensuring every child can engage and benefit from educational opportunities. This approach is grounded in the global compact's understanding that education is a fundamental human right and a key to unlocking the potential of every individual, contributing to their ability to lead fulfilling lives and participate meaningfully in society.

Educational institutions, educators, and policymakers must commit to continuously improving inclusive education practices. This requires investing in teacher training on inclusive pedagogies, enhancing the physical accessibility of schools, and providing appropriate learning materials and assistive technologies. Collaboration with families, communities, and organizations specializing in disability advocacy and support is essential to create an enabling environment that fosters the holistic development of complex learners and children with disabilities.

Educating students with learning differences, such as dyslexia, dysgraphia, dyscalculia, children on the spectrum, and students with autism, represents a vital aspect of achieving a genuinely inclusive educational landscape. This commitment to inclusivity and equity demands an approach tailored to meet these students' unique learning needs and strengths, ensuring that the education system supports all learners in realizing their full potential.

Addressing the Needs of Students with Physical Disabilities

Educating students with physical disabilities necessitates a comprehensive, accessible, and inclusive approach, underscoring the broader commitment to equity and inclusivity in the educational landscape. Physical disabilities can range from serving students who are blind/visually impaired, students who are deaf or hard of hearing, as well as mobility impairments, such as those requiring the use of a wheelchair, students facing fine motor skills challenges, affecting a student's ability to write or manipulate small objects. Addressing these needs effectively involves creating an environment that is not only physically accessible but also accommodating to the diverse learning needs of these students. Key strategies include:

1. **Accessible Infrastructure**: Ensuring that school buildings, classrooms, and facilities are fully accessible for students with physical disabilities. This may include ramps, elevators, accessible restrooms, and classroom layouts that accommodate mobility aids and assistive devices.[27]
2. **Assistive Technology and Devices**: Leveraging technology to facilitate learning and communication. Assistive devices can range from specialized computers and software that aid communication to tools that assist with writing, reading, and other educational tasks.[28]
3. **Adapted Curriculum Materials**: Providing educational materials in formats accessible to students with physical disabilities. This may include textbooks in audio format, digital resources that can be navigated through assistive technology, or materials adapted for ease of use.[29]
4. **Physical and Occupational Therapy**: Integrating physical and occupational therapy services within the educational setting can support students' physical well-being and enhance their ability to participate fully in academic and extracurricular activities.[30]
5. **Inclusive Teaching Strategies**: Employing teaching strategies that consider the physical and learning needs of students with disabilities. This involves flexible teaching methods, collaborative learning, and adapting

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[27] See, Sarrasin, J., Gagnon, S., Poliquin, J.-F., & Bélanger, C. (2022). Accessibility and universal design in schools: A scoping review. *Disability and Rehabilitation: Assistive Technology,* 18(1), 1-15.

[28] See, Al-Mouh, N.A., Al-Khalifa, H.S., & Al-Khalifa, H.S. (2023). Impact of assistive technology on students with disabilities in educational settings: A systematic review. *Assistive Technology,* 35(2), 96-108.

[29] See, Hall, T., Vue, G., Koga, N., & Silva, S. (2024). *Adapting curriculum for special education students*. UW-Superior Online.

[30] See, Special issue on occupational therapy with neurodivergent people. *The American Journal of Occupational Therapy, 78*(1), 1-12. https://doi.org/10.5014/ajot.2024.781001

assessment methods to ensure all students can effectively demonstrate their understanding and skills.[31]

6. **Training for Educators and Staff**: Providing ongoing professional development for educators, administrators, and support staff on the needs of students with physical disabilities and creating an inclusive and supportive learning environment.[32]
7. **Collaboration with Families and Caregivers**: Working closely with the families and caregivers of students with physical disabilities to understand their specific needs and strengths. This collaboration ensures that educational strategies align with the student's support and care plan.[33]
8. **Promoting Social Inclusion**: Facilitating social inclusion within the school community through peer support programs, inclusive extracurricular activities, and awareness campaigns that promote understanding and respect for diversity.[34]
9. **Personalized Learning Plans**: Developing individualized learning plans that cater to the specific educational, physical, and health needs of students with physical disabilities. These plans[35] should be flexible and adaptive, allowing adjustments as students' needs evolve.

By addressing the needs of students with physical disabilities through these strategies, educational institutions can ensure that all students can learn, participate, and thrive in a supportive and accessible learning environment. This commitment to inclusivity benefits students with physical

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[31] See, Brownell, M.T., Smith, S.J., Crockett, J.B., & Griffin, C.C. (2012). *Inclusive instruction: Evidence-based practices for teaching students with disabilities*. Guilford Press.

[32] See, Murphy, H., & Cole, S. (2024). Inclusion improves academic outcomes for students with disabilities. *Association of American Universities*. Retrieved from https://www.aau.edu/research-scholarship/featured-research-topics/inclusion-improves-academic-outcomes-students

[33] See, IRIS Center. (2024). *Family engagement: Collaborating with families of students with disabilities*. Vanderbilt University. https://iris.peabody.vanderbilt.edu/module/fam/

[34] Veldman, J., & Kelly, B. (2023). Promoting social inclusion in educational settings: Challenges and strategies for diverse learners. *Educational Psychology Review, 35*(2), 203-228. https://doi.org/10.1007/s10648-022-09634-1

[35] National Center for Learning Disabilities. (2023). Personalized learning: Meeting the needs of students with disabilities. *Center for Parent Information and Resources*. Retrieved from https://www.parentcenterhub.org

disabilities but enriches the educational experience for the entire school community, fostering a culture of respect, empathy, and collaboration.

Addressing the Needs of Students with Autism Spectrum Disorder

Incorporating education for neuroatypical learners into the broader educational mission enriches the learning environment for all students. It underscores the importance of diversity, compassion, and adaptability in education – essential for fostering a more humane, equitable, and sustainable future. Through these inclusive practices, education can embody its role as a transformative force, empowering every student to navigate the world's complexities with confidence, compassion, and competence.

Teaching children with autism spectrum disorder (ASD) effectively requires a nuanced understanding of the condition and its impact on learning and development. Cognitive neuroscience research has shed light on various strategies that can significantly enhance the educational experience for autistic children. These strategies are rooted in understanding the unique neurological profile of individuals with ASD, including differences in brain structure and function that affect processing, attention, and social interaction. Here are key insights and recommendations for teaching autistic children based on cognitive neuroscience research:

1. Structured and Predictable Learning Environments

Children with ASD often thrive in structured environments where routines are predictable. Research in cognition and emotion supports the creation of learning spaces that minimize sensory overload and provide precise, consistent schedules and expectations. This predictability can reduce anxiety and help children with ASD focus better on learning tasks.[36]

2. Visual Support and Schedules

Visual supports, such as picture schedules, visual task analyses, and organizational aids, are particularly beneficial for children with autism. Research indicates that many individuals with ASD are visual learners, and

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[36] Cachia, R.L., Anderson, A., & Moore, D.W. (2016). Mindfulness in individuals with autism spectrum disorder: A systematic review and narrative analysis. *Review Journal of Autism and Developmental Disorders, 3*(2), 165-178. https://doi.org/10.1007/s40489-016-0074-0

visual supports can help them understand and process information, transition between activities, and develop independence in completing tasks.[37]

3. Individualized Instruction Tailored to the Child's Strengths and Needs

Research highlights the importance of personalized instruction, capitalizing on the child's strengths while addressing specific learning needs. Autistic and children with ASD often have uneven skill development, with particular strengths in areas such as detail-focused processing. Educators should use these strengths as a foundation for learning while providing targeted support in areas of difficulty.[38]

4. Social Skills Training

Social communication challenges are a core aspect of ASD. Neuroscience research suggests incorporating social skills training into the curriculum to help autistic children develop essential social and communication skills. This can include explicit teaching of social norms, practice understanding emotions and facial expressions, and opportunities for social interaction in structured settings.[39]

5. Use of Technology and Assistive Devices

Technology can play a crucial role in supporting the education of autistic children. Cognitive neuroscience research supports using computer-based and other technological interventions to enhance learning, communication, and social skills. For example, tablet applications for social storytelling or emotion recognition can be practical tools.[40]

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[37] Knight, V., Sartini, E., & Spriggs, A.D. (2015). Evaluating visual activity schedules as evidence-based practice for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45*(1), 157-178. https://doi.org/10.1007/s10803-014-2201-z

[38] Kasari, C., & Smith, T. (2013). Interventions in schools for children with autism spectrum disorder: Methods and recommendations. *Autism, 17*(3), 254-267. https://doi.org/10.1177/1362361312470496

[39] Wing, L. (1979). Understanding and addressing social communication difficulties in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 9*(1), 11-29. SpringerLink. See also, Sasson, N.J., Morrison, K.E., Faso, D.J., Ackerman, R.A., DeBrabander, K.M., & Jones, D.R. (2020). Outcomes of real-world social interaction for autistic adults paired with autistic compared to typically developing partners. *Journal of Autism and Developmental Disorders*. Neuroscience News.

[40] Boucenna, S., Gaussier, P., Hafemeister, L., & Andry, P. (2014). Interactive technologies for autistic children: A review. *Cognitive Computation*, 6(1), 12-23. https://link.springer.

6. Sensory Integration Activities

Many children with ASD have sensory processing differences, which can impact their learning and attention. Incorporating sensory integration activities into the teaching plan can help manage sensory sensitivities. This might include activities that address specific sensory preferences or aversions, reducing sensory-related distractions and discomfort.[41]

7. Positive Reinforcement and Behavioral Supports

Positive reinforcement techniques effectively promote desired behaviors and learning outcomes in children with ASD. Cognitive neuroscience research supports using specific, positive feedback and rewards to encourage progress and engagement. Behavioral supports, including clear expectations and consequences, can also help manage challenging behaviors constructively.[42]

8. Collaborative Team Approach

A collaborative approach involving teachers, parents, therapists, and children is crucial for effective education. Cognitive neuroscience underscores the importance of a multidisciplinary team in developing and implementing educational plans that address the holistic needs of autistic children.[43]

9. Engaging Families

Engaging families in the educational process is also critical. Parents and caregivers of students with learning differences should be viewed as educa-

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com/article/10.1007/s12559-013-9245-9 See also, Tanner, K., Dixon, R., & Verenikina, I. (2010). Using modern technology to enhance learning of students with Autism Spectrum Disorders. *ADECT 2019 Proceedings*, 3(2), 45-67. https://open.library.okstate.edu

[41] Mallory, C., & Keehn, B. (2021). Implications of sensory processing and attentional differences associated with autism in academic settings: An integrative review. *Frontiers in Psychiatry, 12*, Article 695825. https://doi.org/10.3389/fpsyt.2021.695825. See also, Weitlauf, A.S., Sathe, N., McPheeters, M.L., & Warren, Z.E. (2017). Interventions targeting sensory challenges in autism spectrum disorder: A systematic review. *Pediatrics, 139*(6), e20170347. https://doi.org/10.1542/peds.2017-0347

[42] Baltruschat, L., Hasselhorn, M., Tarbox, J., Dixon, D.R., Najdowski, A.C., Mullins, R.D., & Gould, E.R. (2011). Further analysis of the effects of positive reinforcement on working memory in children with autism. *Research in Autism Spectrum Disorders, 5*(2), 855-863. https://doi.org/10.1016/j.rasd.2010.09.015

[43] Dillenburger, K., & McKerr, L. (2014). Multidisciplinary teamwork in autism: Can one size fit all? *The Australian Educational and Developmental Psychologist*, 30(1), 1-16. https://doi.org/10.1017/edp.2014.13

tional partners, contributing valuable insights into their child's needs and strengths. Effective communication between home and school can facilitate consistency in approaches and strategies, further supporting the student's learning and development.

Research provides a wealth of insights into the effective education of children with ASD. Structured environments, visual supports, individualized instruction, social skills training, technology use, sensory integration activities, positive reinforcement, and a collaborative team approach are all evidence-based strategies that can enhance learning and development for autistic children. By understanding and applying these strategies, educators can create supportive, practical educational experiences that cater to the unique needs of complex learners and children with ASD.[44]

Addressing the Needs of Students with Dyslexia

Reading is foundational in education. As the eminent Harvard scholar Jeanne Chall once noted, children first learn to read and then read to learn the rest of their lives.[45] A uniquely human capability, there is no gene for reading. Literacy is an epigenetic achievement of the human brain. As a species, we began reading some 3,500 years ago – first, a few members of the human family could read – usually individuals with specialized roles in economic, ritual, and religious functions. Today, literacy is a normative ideal all over the world. Reading changes the brain and the world.[46]

Students with dyslexia face unique challenges in reading. Effectively educating dyslexic students requires understanding their unique learning needs and challenges. Maryanne Wolf (2022) has examined the neurological underpinnings of reading, language, and related phenomena in Mind, Brain, and Education, focusing on the challenges and opportunities of teaching dyslexic students.

Emerging cognitive neuroscience research provides valuable insights into the best practices for teaching dyslexic children. These practices focus on structured literacy programs, multisensory learning, early intervention, and individualized instruction strategies. Here is a summary of the significant findings and recommendations from the relevant research:

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[44] Garbacz, S.A., McIntyre, L.L., & Santiago, R.T. (2016). Family engagement and parent-teacher relationships for students with autism spectrum disorders. *School Psychology Quarterly, 31*(4), 478-490. https://doi.org/10.1037/spq0000172

[45] Chall, J.S. (1967). *Learning to read: The great debate*. New York: McGraw-Hill.

[46] Wolf, M. (2022). *Reader, come home: The reading brain in a digital world*. HarperCollins.

1. Structured Literacy Programs

Implementing evidence-based reading programs emphasizing phonemic awareness, phonics, fluency, vocabulary, and comprehension strategies is a point of departure. These programs are most effective when structured, sequential, and multisensory, allowing students to engage with learning material through visual, auditory, and kinesthetic modalities. Research suggests that structured literacy programs can be highly beneficial for dyslexic students. These programs are explicit, systematic, and sequential in teaching phonics, spelling, and reading skills. They focus on language components, including phonology, morphology, syntax, semantics, and structure. Cognitive neuroscience is increasingly focusing on programs to improve the reading skills of dyslexic students by engaging specific brain areas involved in reading.[47]

2. Early Intervention

Research emphasizes the importance of early intervention for children with dyslexia. Early identification and support can significantly improve reading and language skills. Neuroplasticity during the early years is an optimal time for intervention to remediate dyslexia. Early screening and assessment followed by targeted intervention can help mitigate the challenges associated with dyslexia.[48]

3. Multisensory Learning

Multisensory learning approaches, which involve teaching using visual, auditory, kinesthetic, and tactile methods simultaneously, are efficient for dyslexic learners. This approach helps create more neural connections related to language and reading in the brain, enhancing memory and learning processes. Students can better understand and retain the material taught by engaging multiple senses.[49]

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[47] Spear-Swerling, L. (2018). Structured literacy and typical literacy practices: Understanding differences to create instructional opportunities. *Teaching Exceptional Children, 50*(3), 201-211. See also Kilpatrick, D.A. (2015). *Essentials of assessing, preventing, and overcoming reading difficulties*. John Wiley & Sons.

[48] Davis, N. & Norbury, C.F. (2021). Understanding the role of neuroplasticity in dyslexia: Early identification and intervention. *Journal of Child Psychology and Psychiatry, 62*(5), 563-576. https://doi.org/10.1111/jcpp.13328. See also Gabrieli, J.D.E. (2009). Dyslexia: A new synergy between education and cognitive neuroscience. *Science, 325*(5938), 280-283. https://doi.org/10.1126/science.1171999

[49] Eroğlu, G., Teber, S., Ertürk, K., Kırmızı, M., Ekici, B., Arman, F., Balcisoy, S., Özcan, Y.Z., & Çetin, M. (2022). A mobile app that uses neurofeedback and multi-sen-

4. Individualized Instruction Strategies

Given the variability in the severity and nature of dyslexia among individuals, personalized instruction strategies are crucial. Research suggests tailoring educational approaches to fit the specific needs of each dyslexic student. This may include adjusting the pace of instruction, providing additional practice and support for developing phonemic awareness, and using technology and tools to aid dyslexic learners.[50]

5. Continuous Feedback and Support

Providing continuous feedback and support is essential for the learning and confidence of dyslexic students. Positive reinforcement helps in motivating students and in reinforcing their learning progress. Research findings suggest feedback loops enhance learning by actively engaging the brain's reward system, thus improving motivation and engagement.[51]

6. Professional Development for Educators

Educators should receive ongoing training on the latest research and best practices for teaching dyslexic students. Understanding the neurological underpinnings of dyslexia can equip teachers with the knowledge and skills to implement effective teaching strategies tailored to the needs of dyslexic learners. Additionally, accommodations such as extended time on tests, the use of text-to-speech technology, and the provision of written materials in alternative formats can significantly enhance the learning experience and academic success of dyslexic students.[52]

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sory learning methods improves reading abilities in dyslexia: A pilot study. *Applied Neuropsychology: Child, 11*(3), 518-528. https://doi.org/10.1080/21622965.2021.1908897

[50] Snowling, M.J., & Hulme, C. (2012). Interventions for children's language and literacy difficulties. *International Journal of Language & Communication Disorders,* 47(1), 27-34. https://doi.org/10.1111/j.1460-6984.2011.00081.x

[51] Shaywitz, S.E., & Shaywitz, B.A. (2005). Dyslexia (Specific Reading Disability). *Biological Psychiatry, 57*(11), 1301-1309. https://doi.org/10.1016/j.biopsych.2005.01.043. See also, Swanson, H.L., & Hoskyn, M. (1998). Experimental Intervention Research on Students with Learning Disabilities: A Meta-Analysis of Treatment Outcomes. *Review of Educational Research, 68*(3), 277-321. https://doi.org/10.3102/00346543068003277

[52] Moats, L.C. (2009). Knowledge foundations for teaching reading and spelling. *Reading and Writing, 22*(4), 379-399. https://doi.org/10.1007/s11145-009-9162-1. See also, Washburn, E.K., Binks-Cantrell, E.S., & Joshi, R.M. (2014). What do preservice teachers from the USA and the UK know about dyslexia? *Dyslexia, 20*(1), 1-18. https://doi.org/10.1002/dys.1459

Concluding Thoughts

The world faces multiple threats – pandemics, environmental cataclysms, and forced migrations. In the words of Stefania Giannini, "We have an education crisis that mirrors a wider global crisis, one that is social, moral, and environmental" (Giannini in Suárez-Orozco & Suárez-Orozco, 2022). Schools worldwide face the challenge of teaching and learning an ethic of care for a planet facing unprecedented challenges.

Schools worldwide must be at the forefront of preparing the next generation to engage in problematic times and catastrophic contexts. The COVID-19 pandemic was a canary in the coal mine, illustrating our profound global interdependence and exposing the disproportionate vulnerabilities of poor and marginalized people everywhere. This crisis has also exposed the susceptibility of reliable science information to political manipulation, the fragility of public commitment to collective goods, and the role that education must play in cultivating informed publics worldwide, committed to tackling growing inequities in learning opportunities.

People of good faith worldwide share in the ethos and eidos, animating Pope Francis' global compact for education. Indeed, broad sectors of society hold deeply aspirational notions of schooling with access and quality for all children and youth to flourish. However, that aspiration remains an elusive mirage for millions, above all, students with physical disabilities and complete neuroatypical learners.

The preponderance of the scholarly evidence suggests that while progress in education has been laudable and teachers and parents are in many cases making extraordinary efforts to innovate in engaging all students, and new technologies open up significant new avenues for teaching and learning, current education systems are inadequate to meet the defining social, moral and environmental crises of the day.

In short, following Pope Francis's call for a radical new global education compact, we must re-double our efforts to build new levers to improve access to quality education and scale up innovative teaching and learning solutions for all students, above all, the most vulnerable, including children with physical disabilities and complex learners. The education global compact is built on virtues, ethics, morals, civics, a sense of purpose (see Suárez-Orozco & Suárez-Orozco, 2022), and bold humanistic ideals (Giannini in Suárez-Orozco & Suárez-Orozco, 2022). We must ground it on the lessons extrapolated from innovative early childhood education programs worldwide (Rinaldi in Suárez-Orozco & Suárez-Orozco, 2022; Udwin in Suárez-Orozco &

Suárez-Orozco, 2022). We must focus on purposive programs in education for the era of climate change (Ramanathan et al., 2022; Iyengar et al., 2022). We must mind the tools from the new science of Mind, Brain, and Education (Lipina, Katzir; Wolf; all 2020) and the promise and challenges new technologies afford to reach and engage children who currently have little or no opportunities to learn. In conclusion, we turn to the wise and loving world of the Holy Father, Pope Francis, in his call for a global compact on education:

> We commit ourselves personally and in common:
>
> - First, to make human persons in their value and dignity the centre of every educational programme, both formal and informal, in order to foster their distinctiveness, beauty and uniqueness, and their capacity for relationship with others and with the world around them, while at the same time teaching them to reject lifestyles that encourage the spread of the throwaway culture.
> - Second, to listen to the voices of children and young people to whom we pass on values and knowledge, in order to build together a future of justice, peace and a dignified life for every person.
> - Third, to encourage the full participation of girls and young women in education.
> - Fourth, to see in the family the first and essential place of education.
> - Fifth, to educate and be educated on the need for acceptance and in particular openness to the most vulnerable and marginalized.
> - Sixth, to be committed to finding new ways of understanding the economy, politics, growth and progress that can truly stand at the service of the human person and the entire human family, within the context of an integral ecology.
> - Seventh, to safeguard and cultivate our common home, protecting it from the exploitation of its resources, and to adopt a more sober lifestyle marked by the use of renewable energy sources and respect for the natural and human environment, in accordance with the principles of subsidiarity, solidarity and a circular economy.

Finally, dear brothers and sisters, we want to commit ourselves courageously to developing an educational plan within our respective countries, investing our best energies and introducing creative and transformative processes in cooperation with civil society. In this, our point of reference should be the social doctrine that, inspired by the revealed word of God and Christian humanism, provides a solid basis and a vital resource for discerning the paths to follow in the present emergency.

The goal of this educational investment, grounded in a network of humane and open relationships, is to ensure that everyone has access to a quality education consonant with the dignity of the human person and our common vocation to fraternity. It is time to look to the future with courage and hope. May we be sustained by the conviction that education bears within itself a seed of hope: the hope of peace and justice; the hope of beauty and goodness; the hope of social harmony.

Let us not forget, brothers and sisters, that great changes are not produced from behind desks or in offices. No. There is an "architecture" of peace to which various institutions and individuals in society all contribute, each according to its own area of expertise, without excluding anyone (cf. *Fratelli Tutti*, 231). In this way, we must move forward, all of us together, each as we are, but always looking ahead to the building of a civilization of harmony and unity, in which there will be no room for the terrible pandemic of the throw-away culture.

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INTERACTING WITH THE DISABLED EXPERIMENTAL EVIDENCE ON HELPING, AND ON DECIDING ON BEHALF OF OTHERS

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1. Pope Francis on the Disabled

The attitude of humankind towards the disabled takes a central place in the thinking of Pope Francis. In his encyclical *Fratelli Tutti*[1] two commands coexist: inclusion and solidarity.

The Pope calls for "open societies that integrate everyone" (97). He deplores "hidden exiles" [...]. Many persons with disabilities feel that they exist without belonging and without participating. Our concern should be not only to care for them but to ensure their active participation in the civil and ecclesial community, [...] acknowledging each individual as a unique and unrepeatable person" (98). "Every human being has the right to live with dignity and to develop integrally [...] even if they [...] were born with or developed limitations" (107). This is a strong call for recognition.

Yet the Pope also notes: "Some people are born into economically stable families, receive a fine education, grow up well nourished, or naturally possess great talent. They will certainly not need a proactive state; they need only claim their freedom. Yet the same rule clearly does not apply to a disabled person" (109). "Solidarity finds concrete expression in service [... a]nd service in great part means caring [...] for the vulnerable members of our families, our society, our people" (115). This is an equally strong call for assistance.

Actually, these two views should not be seen in opposition with each other. In conclusion, the Pope draws the picture of a world governed by "charity, [... which] is the best means of discovering effective paths of development for everyone" (183). "Charity is always a preferential love shown to those in greatest need; it undergirds everything we do on their behalf. [...] Only a gaze transformed by charity can enable the dignity of others

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[1] https://www.vatican.va/content/francesco/en/encyclicals/documents/papa-francesco_20201003_enciclica-fratelli-tutti.html

to be recognized and, as a consequence, the poor to be acknowledged and valued in their dignity" (187).

Or in short: recognition engenders assistance, and assistance enables the disabled to be recognized.

In this contribution, I draw on experimental evidence to cast light on the willingness of others to assist those in need. I have no direct evidence on recognition. It would be a worthwhile exercise to develop experimental designs that identify recognition. It would be even more important to test in which ways, and to which degree, assistance follows from recognition, and recognition follows from assistance.[2]

Very often, the disabled are needy. They need help from the abled, or from the healthy members of society. Some disabilities are so severe that the disabled person needs a special form of help: someone else must decide on her behalf. I report experimental evidence on both: charitable action, and decision making on behalf of another person. I am using the experimental evidence to gain a sense of the likelihood that persons with a disability receive the help they need, to lead a meaningful life.

2. Why Experiments?

A person suffers from a severe physical or mental handicap: does this person receive the help she needs to lead a tolerable life? A student comes to the lab. He wants to earn a bit of pocket money. The experimenter gives him some extra money, and observes how he spends it: does he share some of the money with another, undisclosed participant in the same lab who has not received such an extra endowment? There is an obvious and wide gap between the aspect of the world this Plenary wants to understand (the situation of the disabled) and the phenomenon I have studied (allocation choices of experimental participants). Is there anything one can learn from the experiment for the real-world situation this Plenary wants to understand?

In the literature, this gap is discussed under the heading of external validity (Bracht and Glass 1968, Calder, Phillips et al. 1982, Lucas 2003, Mitchell 2012). Essentially, no experiment is fully externally valid. Learning from experimental evidence always requires a leap of faith. The phenomenon that one studies is only analogous to the phenomenon one wants to understand. Why would any researcher do that? There are alternative empirical methods.

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[2] As a very weak substitute, I show that decision-making on behalf of others is influenced by knowledge about their autonomous wishes.

The most straightforward does always have appeal. One directly observes what one wants to understand. Yet, normally a researcher is not content with making a statement about one person with disability and one other person on whom she depends. The researcher turns to empirical work because she wants to generalize: under which conditions are persons with disabilities more likely to receive the help they deserve? Observing a single interaction does obviously not suffice to answer this question. Observing many instances of interaction is better. But one can never rule out that help for the needy results from a very positive selection from the population of potential help givers, or from the fact that the person with disability is particularly nice, to mention only two of a myriad of possibilities (more from Angrist and Pischke 2008). Generalisations require causal claims, and isolating causality with observational data is a very challenging enterprise.

These concerns matter for the topic of the Plenary. There are plenty of worthy topics for empirical investigation: the impact of disability legislation; the rate of donations for disability; career choices in families with a disabled member. But all of them are fraught with confounds. Disability legislation is not a one-to-one mapping of the attitudes in the population towards the persons with disabilities. Of course, in a democracy one hopes to find a relation between the desires of the people and the laws that are passed on their behalf. But there are many filters between the former and the latter. Not everything people say translates into what people do. In order for legislation to be adopted in Parliament, the ruling party (or the coalition) must find the issue sufficiently important to prioritize it. It must keep in mind what are likely reactions on the next election day. The donation rate likely differs by income and wealth. People do not only give for the disabled. If they have already donated for other worthy causes, the disabled are likely to get less money (for background see Ploner and Regner 2013). How donations are treated by the tax authorities is also likely to affect donation choices. Career decisions depend on many more things than having a disabled child or sibling. The rest of the family may just need the money. The potential caregiver may have a very attractive career opportunity that she does not want to let go. A tolerable professional care institution may be available, so that the potential caregiver from the family experiences less pressure.

This is where the experiment shines. The very fact that raises the external validity concern actually is its definitional strength. Precisely because the experiment is radically artificial, one may be sure that observed effects have a causal interpretation. If the experiment is properly designed, baseline and treatment differ in a single respect. A sufficiently large number of participants is randomly selected from the population of interest. Half of them are randomly assigned to the baseline, and half of them to the treatment. If the treatment group behaves in ways that systematically differ from the behaviour of participants in the baseline, one may confidently infer that the manipulation has caused the difference in behaviour.

Of course, the external validity gap persists. It depends on the research question whether it is acceptable. In this paper, I argue that the experimental findings are sufficiently related to the topic of the Plenary to make them useful. It certainly will not be possible to conclude from the experimental findings the exact degree of help that the disabled may hope to get. But with the help of the experiments, one learns about elements of human nature that a disabled person may hope to trigger.

3. Charitable Action

Economics is an individualistic discipline. It is interested in the choices of isolated individuals, in the interaction of such individuals, and in societal effects resulting from the decisions of individuals. In the economic textbook, it is assumed that an individual maximizes utility, assuming that everyone with whom the individual interacts does the same, and expecting the first individual to do so as well.[3] Outside economics, these assumptions are often misunderstood. They are conceptual building blocks, not normative commands. And utility need not be confined to income. This last qualification has spawned an entire subdiscipline. Behavioural economics theorizes, tests and catalogues behavioural regularities that induce decision makers to deviate from profit maximization (for a summary account see Dhami 2016). Many of these regularities are cognitive: individuals interpret the available information in a distorted way. In the present context, motivational effects are more important. Under which circumstances do some, many, or nearly all individuals refrain from being selfish?

As I have explained, the very reason for going to the lab is identification. One pays the price of artificiality since one wants to isolate cause and effect. This explains why (economic) experiments are usually radically simple. One such simple design is called the dictator game (the game has been invented

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[3] In the jargon of the discipline, one assumes "common knowledge of rationality"; a classic is Aumann, Robert J (1995). "Backward Induction and Common Knowledge of Rationality". *Games and Economic Behavior* 8(1): 6-19..

by Kahneman, Knetsch et al. 1986, S290 f.). Two participants are randomly matched. One of them receives an endowment. The literature calls this person the dictator. The dictator is free to keep the endowment for himself, or to share any fraction with the other participant with whom she has been matched, and whom she knows has not received an endowment. This experiment has been repeated hundreds of times. There is always a fraction of participants who simply keep the money for themselves. But typically, the majority shares some of the money with the passive counterpart.

I have done a meta study of the dictator games published until 2009.[4] As the left panel of Figure 1 shows, which is taken from this meta study, if the recipient is just another participant of the same experiment, the most frequent individual decision is to keep the complete endowment. The second most frequent decision is the equal split: the dictator keeps 50% of the endowment, and gives the other half to the passive counterpart. It is very rare that a participant gives away more than half of the endowment. Given the design of the experiment, this distribution of choices makes intuitive sense. Yet as the right-hand side of the panel shows, the distribution of choices looks considerably different if the recipient is deserving. Now it not only becomes more frequent that the dictator gives away more than half of the endowment. Actually, giving everything even becomes the most frequent decision. This decision is even more prevalent than keeping the complete endowment. Also the average amount that dictators give away is considerably (and significantly) higher (Engel 2011, 594, Umer, Kurosaki et al. 2022).[5]

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[4] In the meantime, a number of meta analyses of dictator games have been published: Larney, Andrea, Amanda Rotella and Pat Barclay (2019). "Stake Size Effects in Ultimatum Game and Dictator Game Offers: A Meta-Analysis" *Organizational Behavior and Human Decision Processes* 151: 61-72, Cochard, Francois, Julie Le Gallo, Nikolaos Georgantzis and Jean-Christian Tisserand (2021). "Social Preferences across Different Populations. Meta-Analyses on the Ultimatum Game and Dictator Game". *Journal of Behavioral and Experimental Economics* 90: 101613, Doñate-Buendía, Anabel, Aurora García-Gallego and Marko Petrović (2022). "Gender and Other Moderators of Giving in the Dictator Game: A Meta-Analysis". *Journal of Economic Behavior & Organization* 198: 280-301, Umer, Hamza, Takashi Kurosaki and Ichiro Iwasaki (2022). "Unearned Endowment and Charity Recipient Lead to Higher Donations. A Meta-Analysis of the Dictator Game Lab Experiments". *Journal of Behavioral and Experimental Economics* 97: 101827.. But they are all confined to single design features, and do not give an overview over the entire literature.

[5] Meta-regression, dependent variable: fraction of endowment given, cons .261***, deserving recipient .115***, N = 445, adj.R2 .075.

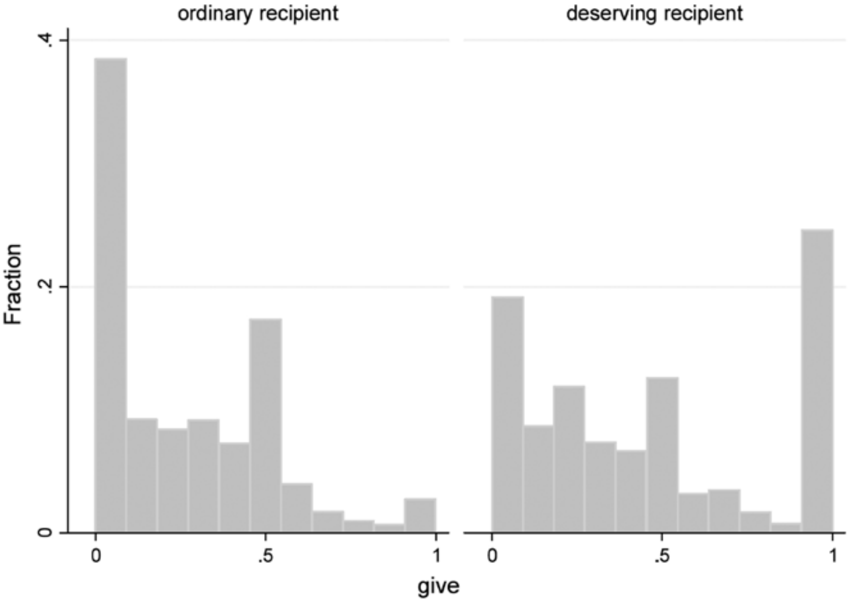

Figure 1. Donation Rates in Dictator Games.

Actually, the available information is even more fine-grained. Some experiments have manipulated the upfront endowment for the recipient. While in the standard design it is zero, in these experiments recipients have received a positive amount. This design feature can be interpreted as a manipulation of the deservingness. As Figure 2 shows, this has a clear effect. The higher the upfront endowment of the recipient, the less she receives. Actually the relationship is almost perfectly linear (Engel 2011, 595).[6]

We had the opportunity to test prison inmates on the dictator game (Chmura, Engel et al. 2017). As Figure 3 shows, they were fairly generous when being in the role of dictator.[7] In the experiment, we have had each prisoner decide twice: once if the recipient is another inmate of the same

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[6] Meta-regression, dependent variable: fraction of endowment given, cons .291***, recipient endowment (as a fraction of the dictator's endowment) −.213***, N = 445, adj.R2 .052.

[7] Actually, the amount prisoner dictators share is not significantly different from the amount that students give.

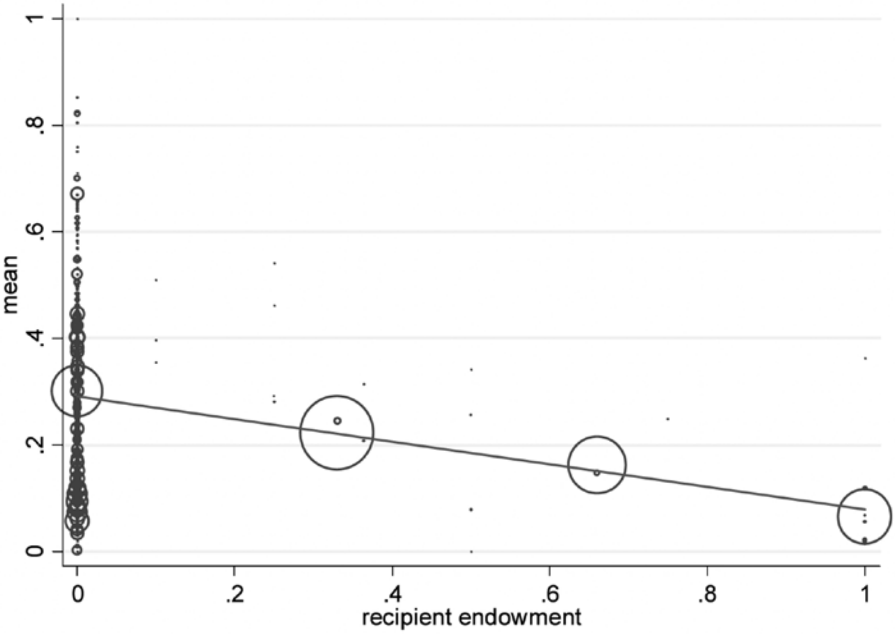

Figure 2. Donations Conditional on the Deservigness of the Recipient.

prison, and once if the recipient is the well-known charity *Brot für die Welt*. Bubbles above the 45° line stand for prisoners who give more to charity than they give to another inmate. Most of them do.[8] Hence even those whom one might have thought to be least likely to do so are sensitive to the needs of those in dire circumstances.

How much another person is in need of help is often not clearly defined. If a person has the ability to help, she quite often faces uncertainty. One might have thought that potential helpers use the uncertainty as an excuse. In other contexts, it has been shown that many individuals exploit the opportunity to hide behind uncertainty. They use “moral wiggle room” to get them both: they are selfish and avoid having bad conscience (Dana, Weber et al. 2007). Yet in a dictator game in which we manipulate the information about the recipient’s endowment, we find the opposite (Figure

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[8] Linear mixed effects regression, dependent variable: fraction of endowment given, cons .265***, recipient charity .110*, N = 124, p model .0308.

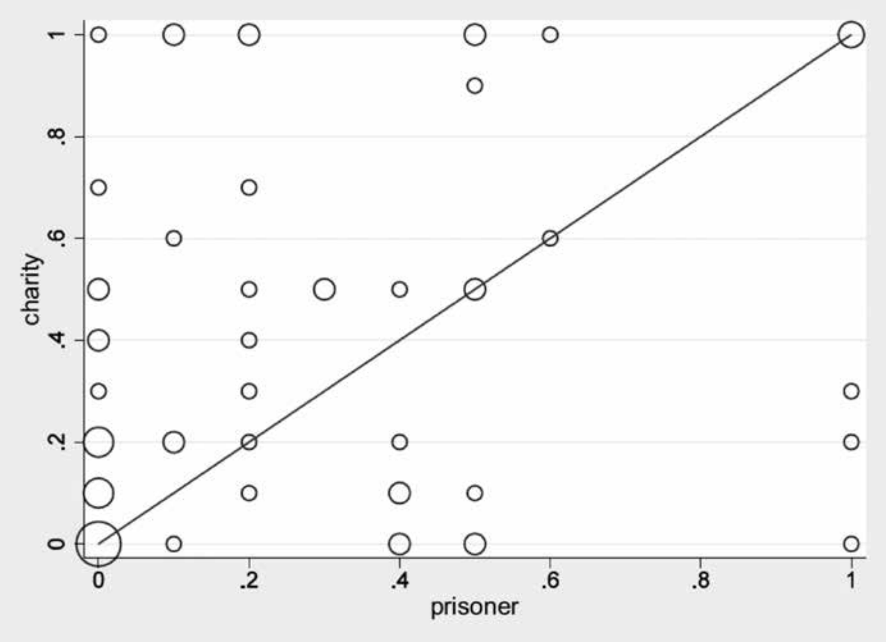

Figure 3. Prisoners Giving to Each Other and to Charity.

4). With an increasing degree of uncertainty, dictators give more, not less. They give most if any information about the recipient's endowment is ostensibly withheld (Engel and Goerg 2018) .

Much of charitable giving is indirect. The donor does not directly interact with the intended recipients. Rather she donates some money, or physical goods for that matter, to an organization that promises to use the donation to the benefit of the intended recipients. Such indirect generosity is inherently risky. The donor must trust the direct recipient that she will use the gift in the intended way. The risks are manifold: the direct recipient may simply embezzle money; she may be ineffective, so that money gets unnecessarily lost; she may not be careful enough in selecting the final recipients. In another experiment, we have addressed this concern, and have given donors[9] the possibility to invest an extra amount of money to insure their donation against such risks (Buijze, Engel et al. 2017). As we wanted

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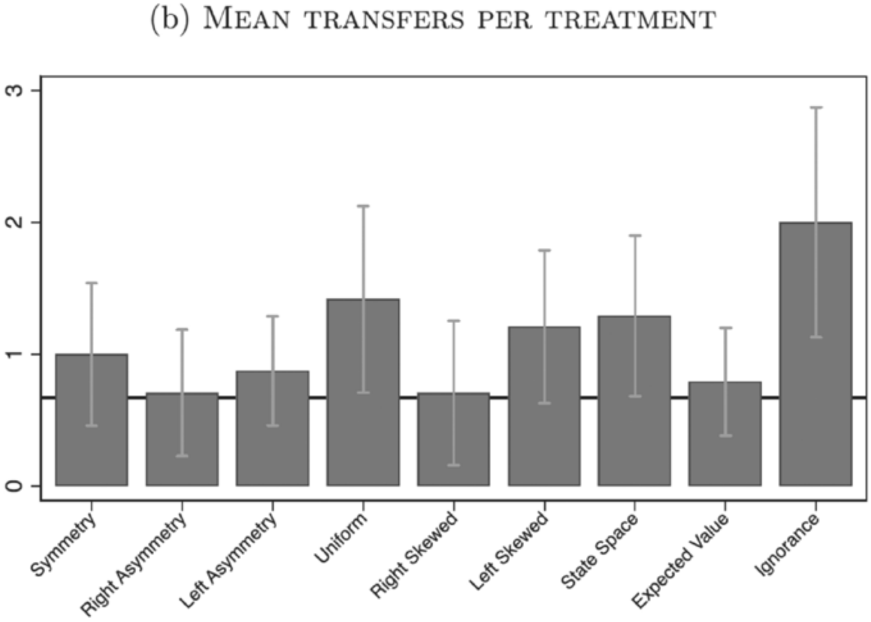
[9] To the charity "Unite for Basic Needs", which serves orphans.



(b) Mean transfers per treatment

Figure 4. Dictator Giving if the Recipient's Endowment is Uncertain.

to be able to isolate the motive, we have had three treatments. In the first treatment, there was a risk that the donation would not be effective. In the second treatment, the risk was exclusively affecting the donor herself: she could not be sure that she would receive a 50% refund from the tax authority. In the third treatment, we have combined both risks. As Figure 5 shows, participants are willing to insure themselves against either risk. We do not find any significant difference between treatments in this respect.

Yet, as Figure 6 shows, we do find clear treatment differences of the availability of insurance on the donation rate.[10] In the baseline, neither risk was present. In the treatments, there either was the risk of the donation not reaching its intended recipients, the tax refund not being granted, or either risk with 50% probability. The dark grey bars demonstrate that, in the absence of the insurance option, the risk that the donation is subverted

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[10] Participants had the choice between keeping the complete endowment and donating 50% to Unite for Basic Needs.

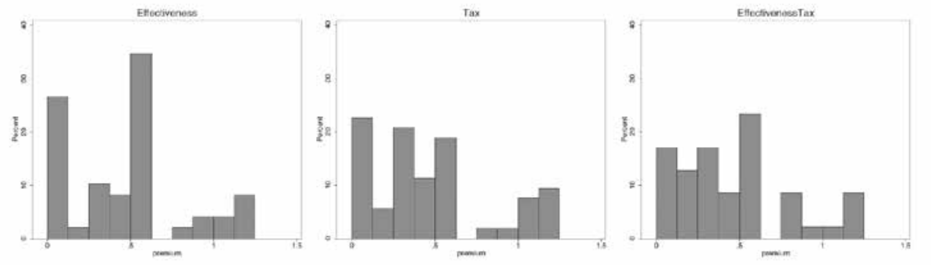

Figure 5. Willingness to Pay for Insuring a Donation.

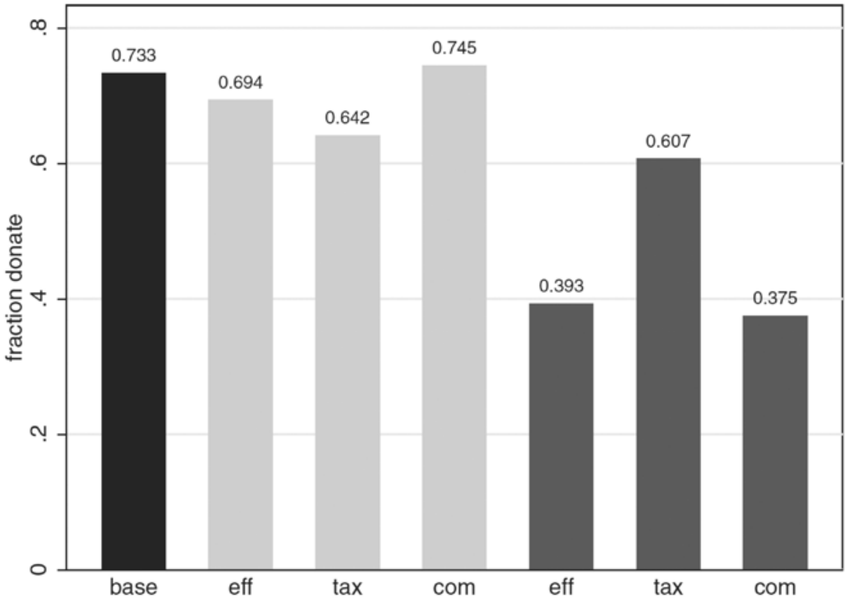

Figure 6. Effect of the Availability of Insurance on the Donation Rate.

has a dramatic effect on the willingness to donate, while the risk that, after the fact, the donation turns out more expensive only has a small effect. Yet once the insurance option is available, the donation rate jumps back to its original degree.[11] This is a remarkable finding. It shows that donors are not

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[11] In a linear probability model, we explain the decision to donate 50% of the endowment (cons .607***) with the risk that the donation is subverted (-.223+), the availability

deterred by either risk as long as they can use extra money to make sure the risk is not materializing.

4. Acting on Behalf of Others

The disabled rightly care about their autonomy. They want to be treated with respect. They want to decide themselves about the kind of life they are living. But unfortunately, some forms of disability make it difficult, if not impossible, for the disabled person to choose herself. Someone else must step in and decide on her behalf. There is growing interest in behavioural economics in the determinants of decision-making on behalf of third parties (Frey, Herzog et al. 2018, Montinari and Rancan 2018, Eriksen, Kvaløy et al. 2020), including decision-making on behalf of incapacitated patients (Elliott, Gessert et al. 2007, Pope 2011). In the typical experimental implementation, the third party is another anonymous participant (see e.g. Cerrone and Engel 2019). This design is appropriate if one wants to understand the general effect of taking responsibility for other people's lives. Yet for the present context, it is more important how natural representatives decide on behalf of a person with disability. The most natural representative is a family member.

This is what Alexandra Fedorets, Olga Gorelkina and myself have studied in an experiment (Engel, Fedorets et al. 2023). We had the good fortune to run our experiment on the complete intervention sample of the German Socio-Economic Panel SOEP (Goebel, Grabka et al. 2019). In 494 households, interviewers randomly selected 2 household members. Theoretically this could have been one of the parents and one of the children. But effectively we have only very few (48) parent-child pairs, but 177 parent-parent pairs, and 269 child-child pairs. Due to concerns about prior consent, we only tested children who are 18 years old or older (but still live in the household of their parents).

Participants had to choose one of 11 lotteries. Each lottery has a high and a low outcome. Both outcomes are equally probable. The first lottery is actually a safe choice, as both outcomes are the same. Participants gain 10€ with certainty. All other lotteries expose participants to true risk. But there is a catch. Risk-taking is profitable. The good outcome increases twice as

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of insurance (.034) and the interaction of both explanatory variables (.300*), N = 229. Hence the net effect of the risk that the donation is subverted plus the interaction effect is even positive, and not significantly different from zero. Hence the availability of insurance neutralizes the detrimental effect of the risk.

fast as the bad outcome deteriorates. Hence in the second lottery, the good outcome is 12, while the bad outcome is 9. The gap between the good and bad outcome increases in steps of 2 for the good and in steps of 1 for the bad outcome. In the final lottery, the good outcome is 30, while the bad outcome is 0. Hence the more a participant is averse to risk the smaller the spread between the good and the bad outcome.

In the present context, the condition is most important in which one family member is randomly given the active role, while the other is passive. The participant in the active role chooses a lottery on behalf of the passive participant. This decision has no material consequences for the decision maker. All effects are on the passive family member. Figure 7 summarizes the main result. It compares the decision made by the active family member with the decision that the passive family member had made in an earlier part of the experiment, when deciding on behalf of herself. The graph peaks at zero: by far the most frequent choice of the active family member is the choice that the passive family member had made herself before. There

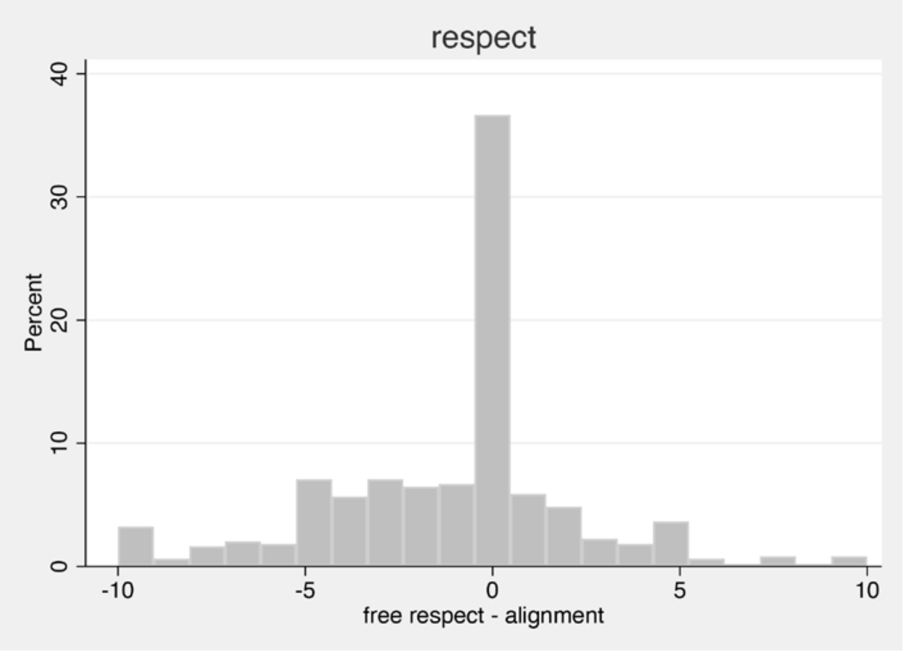

Figure 7. Making a Risky Investment on Behalf of Another Family Member.

are deviations, but they are not symmetric. If the active member deviates from what she knows the passive member to wish, she is much more likely to deviate to a more cautious choice. This suggests that the active family member did not simply want to impose her own preferences or convictions; otherwise, deviations would have to be symmetric. Rather, if she deviates from the discernible will of the passive family member, the active member imposes a more cautious approach. This pattern is consistent with a responsibility effect: most people react much more negatively if they incur a loss, compared with foregoing a gain (cf. Branas-Garza, Durán et al. 2009, Pahlke, Strasser et al. 2015). It is a different matter whether a person freely decides to incur a risk, or whether the same risk is imposed on her by someone else, how benevolent this other person might be.

5. Tentative Implications for Living with the Disabled

At the beginning of this essay, I have stressed the wide gap between the experimental findings I report on and the way society, and its individual members, treat persons with disabilities. Any conclusions must be very tentative. But arguably, the disabled receive respect and help. Being respectful and helping is a human trait that transcends the attitude towards disability. Arguably, if we treat the disabled in the way they deserve, society must capitalize on behavioural traits of considerably broader scope. It is in this spirit that I have reported evidence from dictator games (about the willingness to help those in need) and about decision-making on behalf of third parties (about a respectful way of deciding about other people's lives if they cannot do so themselves).

None of the reported effects is universal. But happily for the present policy problem, this is not a major concern. It certainly would be desirable that everybody comes to the rescue of a person who cannot help herself since she has been hit by a disability. But if the fraction of individuals who are willing to do so is sufficiently large, this already goes a long way towards alleviating the burden on the shoulders of a person with a disability. In that spirit I conclude on an optimistic tone: *Misericordia* is real.

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THE CARE OF PEOPLE WITH DISABILITIES AND FRAGILITIES THROUGH THE CREATION OF RELATIONAL GOODS

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Abstract

The essence of caring for those in need of help consists in a certain relationality, in giving and receiving a certain relationship. The relationship as such is the protagonist of the care. It is a lifeworld relationship. What is lacking in today's society is not so much material and technological resources, but rather the relational skills of welcoming, supporting and socially integrating people in difficulty. The care of the Other is increasingly entrusted to new technologies and impersonal welfare mechanisms, while interpersonal social relationships become increasingly weak, liquid and unavailable. The consequences are evident in the loss of social solidarity and in the degradation of the human condition. We need a social and cultural change which brings out, rather than concealing, the relational character of human needs and, correlatively, of the necessary response, which is realized only in the gift between caregivers and care receivers, that is, in the creation of a relational good between them. We still have a long way to go to understand what it means to say that caring for the Other lies in the qualities and causal properties of human and social relationships, and why it is necessary to make care services relational.

1. The topic and the approach: understanding the relational meaning of care

Caring for others, whether individuals or social groups, consists in a certain relationality, in giving and receiving a certain social relationship. The material help that is given to those in need is certainly important and often decisive for the fate of people, but taking care of the Other consists in the specific qualities and causal properties of the relationship established with the person.

It is the relationship that gives meaning and quality to care, because all requests in conditions of need are requests for embodied relationships. In the relationship, all human dimensions are present, the physical, psychological and spiritual.

Caring for the person implies giving meaning to the interpersonal relationship with the Other in order to respond to the ultimate value of life,[1] and yet this sense is formed and regenerated through the bodily relationship between people in a precise sociocultural context. C. Mora and J. Rivera, for example, presented the results of a study on how mothers with children suffering from degenerative pathologies develop a sense of care in their own bodies and through their own bodily relationship with their child, within a specific cultural context.[2]

I propose to explore this perspective, which I call relational as it is based on a social ontology, an epistemology and practical intervention methodologies that have their fulcrum in the understanding and management of interhuman and social relationality. Its fundamental assumption is that being a person is possible only in the relationship with the Other, as that which goes beyond the individual being and makes it possible.

The word 'relationship' is on everyone's lips, scholars and ordinary people alike. However, ways of understanding what relationship really is differ greatly. There are those who treat the relationship as a variable factor derived from subjective states of mind, without understanding the reality and internal dynamics of relationality. There are those who try to 'fix' objective typologies and taxonomies of relationships that run the risk of reifying relationships. Moreover, in the last decades theories have emerged that conceive relationships as mere events, pure interactions, structureless transactions, which I call *relationalist* theories.

Unlike all these approaches, I propose a generalized theory of the relationship which, unlike positivists, seeks to understand the relationship in its own *sui generis* reality, by entering into the relationship and showing its

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[1] Frankl, Viktor. 2009. *El hombre en busca de sentido último*. Ciudad de México: Paidós.

[2] "It is not enough to take alternatives from what Berger and Luckman called 'repositories of meaning' contained in the social structure. As for the embodiment, it is understood the way of experiencing the body, whether it is one's own or another's, and through it make the meanings created from reality corporeal"; "It is observed that the sense is rebuilt through sociocultural discourses that could be related to religious beliefs; motherhood and care are processes within women's bodies" (Mora, Carolina, and Jesús, Rivera. 2019. *La reconstrucción del sentido en madres de niños con una enfermedad degenerativa. Estudios sociológicos* 35(111): 757-783).

internal dynamism, so as to be able to identify the peculiarities of every relationship, particularly in the case of new forms of disability.

The perspective I am speaking of is justified by the fact that it is social relations that 'constitute' the human person in her identity. In fact, people are subjects who generate relationships, but at the same time they are generated by relationships with others. Care is a relationship in this sense. We need to understand the specific qualities of the relationship between the caregiver (formal or informal) and the care receiver[3] at the same time. Here it is important to distinguish what I call "the order of relationships"[4] with respect to the order of interactions mentioned by Erving Goffman.[5] Social relations are a reality that arises from interactions (contingent events), but they have their own consistency and dynamic structure that defines the identity of the subjects in relation.

The ontological basis of this distinction lies in the fact that there are three orders of reality: the order according to substance (the substance of human persons), the order according to accident (the contingency of interaction), the order of relations (the structure of their exchanges).[6] Each of these orders of reality has its autonomy.

The originality of the relational perspective consists in the fact that it considers care not only as an expression of the commitment of individuals as such (the caregiver and the care receiver, considered for their individual qualities), nor as the result of an efficient organization of services, but above all as a way of living interpersonal relationships in situational contexts in which Ego meets an Alter in need of help. it is necessary for the fragile or disabled person to be supported by a network of people in her lifeworld.

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[3] The terms caregiver and care receiver are generally used to refer to people who care for the elderly and disabled, or in any case individuals in precarious health conditions, in particular their family members. This is how the WHO defines them and also many resolutions of the European Union and of various countries. However, I will use these terms in a more general sense, including people who help strangers, whether the help is given on a voluntary and spontaneous basis or within professional organisations. It is interesting to note that we do not have a specific term to indicate these figures in general, whatever the context of daily life, and not just for social and health problems. Generally, we speak of the 'good Samaritan' or 'volunteer'.

[4] Donati, Pierpaolo. 2011. *Relational Sociology. A New Paradigm for the Social Sciences*. London: Routledge.

[5] Goffman, Erving. 1967. *Interaction Ritual*, Garden City: Doubleday.

[6] Donati, Pierpaolo. 2023. *Alterità. Sul confine fra l'Io e l'Altro*. Rome: Città Nuova.

Personal commitment of Ego and efficient organization of services are necessary but not sufficient requisites to carry out a care for the Other that qualifies as a good practice. In order for it to be such, the relationship between caregiver and cared for must have a *sui generis* form and content.[7]

At the basis of this perspective there is a fundamental ontological and epistemological assumption, according to which it is the relationship with the context that expresses, and at the same time constitutes, the person together with her needs. We must be able to see this when we observe the interaction between the person who is in need and the one who is called to help her. Each person defines and enters the relationship in a certain way, with a certain identity, and leaves it with another identity. Care is a relationship that changes the people involved.

For example, in the story of the good Samaritan (*Lk* 10, 25-37), the three protagonists (priest, Levite, Samaritan) enter the scene with their own identity, and leave with another. The priest represents the Law and therefore should identify himself with the Torah, but his identity comes out defeated and without dignity, because the priest avoids the person massacred by the thieves ("when he saw him, he crossed over to the other side"). The Levite represents the prophets, and therefore should be the bearer of a prophetic identity, but this identity disappears, because the Levite escapes the prophecy ("he saw the man beaten by brigands and passed on"). The Samaritan, on the other hand, enters with the identity of a common person and leaves as a saviour.

The encounter with the person in need, willy-nilly, never leaves one indifferent, due to the fact that the relational context of the meeting has an emerging effect on whoever is involved. The effect can be positive or negative. Since the relational context of need demands a response, it always tests the person's ability to respond in a more or less virtuous way.

When we meet the person asking for help, we cannot remain morally immune from the experience of this relationship. The encounter with the Other in need of help is an opportunity to realize our humanity or it results in a loss of humanity. In any case, after having met the needy, the awareness emerges in ourselves that we have seized, or instead of having missed, the opportunity to generate a relational good with the Other.

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[7] Ferrucci, Fabio. 2004. *La disabilità come relazione sociale. Gli approcci sociologici tra natura e cultura*. Soveria Mannelli: Rubbettino.

2. The relationship is the foundation of care

Taking care of the Other, in the broadest sense of the term, i.e. understood not only as *cure* (that is, the provision of a technically qualified service), but above all as *care*, i.e. taking charge of the person as such, and not just of a particular need, is a relationship. Saying relationship means seeing care as the product of the reciprocal action of the caregiver and the care receiver.

Indeed, one cannot take *care of the other* if, first, one does not take *care of the relationship with the other*, and of the relationships that the other has with the world. The COVID-19 pandemic has revealed just this to us: before dealing with the disease caused by the virus with healthcare services, we had to take care of relationships as such, maintain the 'right distance' with others. Relationships can cause disease, as well as remedying it.

Generalizing, we can say that it is in the relationality between people in a given social context that a condition of need is generated, and it is in that context, or by changing the relational context, that the right way of solving the problem must be sought. This is valid for all conditions of need, for the poor, the sick, the lonely person, the disabled.

Focusing on the relationship as the foundation of care does not mean diminishing the importance of people's subjective factors, i.e. their good intentions, wills and feelings. It means understanding that these aspects are true and authentic if and to the extent that they materialize in the relationship. It means adopting a relational anthropology, passing from an individualistic personalist vision to a personalism centred on the relationship, because the person does not transcend herself in her single act (the performance), but in the relationship. In fact, in the single act the person remains herself, even if she tries to surpass herself in order to seek greater perfection. It is only in the relationship that she becomes a good Samaritan, without this meaning diminishing the importance of generosity and personal dedication.

If it is true that the relationship is the foundation of care, the problem that arises is that of situations in which relationships are problematic, have a deficit or are even rejected or distorted. How to relate to the sick person who does not want to be treated? How to relate to those who want to sleep on the street and refuse the offer of shelter?

In these cases great competence is required in knowing how to manage relationships with the person in whom we see a need while she refuses help because she identifies with her condition and does not want to change it. We should learn the '*art of relationality*'.

This art was asked of us during the Covid-19 pandemic, when interpersonal relationships were reduced or banned due to lockdowns. In these situations, unlike the previous ones, people wanted relationships, but relationships were forbidden or minimized. How do you organize a care service, which requires human relationships at all levels (micro, meso, macro), if caregivers are deprived of human interaction? And what about when the patient is entrusted to a machine?

Whatever the need and the help requested, we see that the problem of care coincides with the problem of human relationships. A *surplus of relational competence* is required: these are the *caring relational skills*. These skills can only be nurtured with more personal and relational reflexivity. To humanize the care of the Other it is necessary to know how to read relationships and know how to deal with them even 'acting at a distance' or by means of technologies. As far as the latter are concerned, they must be evaluated according to the relationships they favour or inhibit

3. What the COVID-19 pandemic has taught us

The pandemic has taught us many things about caring for the Other, but I will mention just a few:

(i) it showed that social relations are not accidental elements of little importance, but are entities endowed with their own and sui generis reality; this reality is demonstrated by the fact that they have a profound effect on our lives; relationships have specific causal properties;

(ii) it redefined the meaning of the disease, of care and of the modalities of care as relational problems;

(iii) it showed that if caring relationships are reduced to role relationships, this generates a dehumanization of people;

(iv) and it also made us understand that the 'right distance' between people is not a physical quantity, but a relational quality.

I would like to say something more about these teachings.

(i) The pandemic has been an epiphany of relationships. It revealed to us the importance of social relationships. Before the pandemic, we gave little importance to relationships, in the sense that we took them for granted. With the pandemic we have learned that relationships have their own reality, somewhat independent of the intentions of individuals, and we can no longer consider them as a reality available to us.[8] The dynamics of infections

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[8] Donati, Pierpaolo. 2022. The pandemic: An epiphany of relations and opportunities for transcendence. *Church, Communication and Culture* 7(1): 23-57.

taught us that health and disease depend on our relationships. We may have good intentions in acting in a certain way, but the relationship that comes out of our actions can have different effects than we expected.

Saying that the relationship exists (in the Latin language ‘ex-sistere’ means ‘standing out’, having one’s own autonomy with respect to the terms of the relationship, therefore standing out from the people who generate the relationship) involves acknowledging that the relationship has its own order of reality, that is, its consistency. The relationship is generated by people, who are indispensable, but it doesn’t consist of people. It consists of symbolic references that become a link between people, i.e. between the caregiver, formal or informal, and the person in need. The caregiver must be able to recognize this reality, that is, he must be able to see the Other in the relationship, with the relationship, through the relationship.

(ii) The pandemic has shown us that our Western systems of organizing care are generally oriented towards individuals rather than their relationships. Our entire welfare system is geared towards people as if they were individuals, while we need social and health care services that are not geared towards the individual as such but towards the social networks (family, relatives and networks of friends) in which he lives. Social needs, from various forms of poverty to multiple dependencies, are generated by social networks that generate pathological social relations and, therefore, to respond to social problems, care services must modify the social structures from which the problematic nature of social relations derives.

(iii) The pandemic has taught us that limiting or even eliminating physical interpersonal relationships, to leave care to the formal role relationships of health care systems, produces a profound sense of dehumanization. Care implies a balance between role relationships (formal) and intersubjective relationships (informal). In any case, care requires intersubjectivity, even if not necessarily a physical attachment in the strict sense, given that it is rather a question of how to manage the care relationship even at a distance, with gestures and communications of help.

(iv) The pandemic has taught us that in an adequate culture of relationships the notion of the ‘right distance’ between people is important. This notion was understood as physical distance, which meant isolating grandparents, locking the elderly in protected social and health care structures, with disastrous consequences on generational relationships and a certain dehumanization of care. The fact is that physical distance must be distinguished from social distance. Often people do not perceive the difference. Physical distance is quantitative (N meters), while social distance is qualitative and relational. It is possible to have caring relationships on the level of social relationality without necessarily being physically in contact. Even if the imperative is to keep physical distance from others to avoid evil, it must be understood that *physical distance depends on social distance, and not vice versa*. If Ego is aware of the relationship and acts in the relationship, then he can take the right physical distance, otherwise the physical distance will be out of control.

4. Care is a gift to the Other and the gift is in the relationship

4.1. Be to care

The expression "*be to care*" refers to a conception of the nature of the human person as a relational being. Being the subject and recipient of care reveals the quality of human essence that is unique among living beings. Non-human animals also take care of their young, but they don't do it 'relationally' as humans can.

We can all agree with Martin Heidegger when he states that our existence (our *Dasein*) is preconstituted by the fact of existing with others, that is, by coexistence (*Mitdasein*). His fundamental thesis is that being-with determines being-there, always and necessarily, even in the case in which the other is, in fact, neither present nor known. Feeling of *being-alone*, wanting to be alone or posing to be alone, is a *defective* way of being-with in the world.

Unfortunately, however, in Heidegger's philosophy, the *Mitdasein*, as an *a priori* ontological structure of human existence, is somewhat formal, and anthropologically translates into indifference towards the Other.[9] It follows that the human person is described as a subject who lives a 'loneliness without relationship' and a 'monological existence', therefore incapable of a true interpersonal relationship with the Other, with a You. For Heidegger the relationship is only a vehicle of thought, nothing more.[10]

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[9] Cicchese, Gennaro. 1999. *I percorsi dell'altro. Antropologia e storia*. Rome: Città Nuova, pp. 171-173.

[10] "Thinking accomplishes the relation of Being to the essence of man. It does not make or cause the relation. Thinking brings this relation to Being solely as something handed over to it from Being" (Heidegger, Martin. 1977. Letter on humanism. In *Basic Writings*, ed. David Farrell Krell. New York: Harper & Row, p. 193).

I quote Heidegger for the enormous influence he had on the entire culture of the 20th century. In fact, this vision still persists, aggravated by the use of new technologies.

On the contrary, the Christian vision indicates in coexistence, in *being-with-and-for-the-other*, the reality of a relationship – original and generative – between human beings which is 'given', that is, has a giving character. Life is received as a gift and must be reciprocated as a gift. Reciprocity is the essence of human relationality. This reality, seen in the light of the Trinitarian conception of being as intrinsically relational, has enormous consequences on the level of secular daily life. It implies that people cannot live without interdependence and mutual exchange. However, relationships that implement interdependence and exchange can have very different qualities.

Care is the relationship that most corresponds to the original and generative sense of being together in the world, since the exchange that takes place between the caregiver and the assisted has its essential and specific quality in the fact that the relationship is given and received regardless of any other consideration and motivation other than meeting the Other and being with him. Such is the gift, an expression of pure original reciprocity as a symbolic exchange between human beings who recognize themselves as such.

What is care? It is an opening to the Other as the bearer of a need that first of all asks for acceptance, recognition, involvement.

Certainly, as Heidegger says, "caring is a way of being with the other that does not respond to the logic of duty but finds a generative reason in feeling needed by the other; a need is felt in the other who calls us into the field in the first person".[11] For him, however, care has its being in the inclinations, projects, illusions of individuals, and therefore has neither a relational meaning nor a relational structure. The relationship is supposed to exist because of temporality.[12]

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[11] Heidegger, *Letter on Humanism*, p. 193.

[12] In a commentary footnote to the text of M. Heidegger (*Letter on humanism*, cit., pp. 199-200), the editor writes: "In the final chapter of division one of *Being and Time*, Heidegger defines 'care' as the Being of Dasein. It is a name for the structural whole of existence in all its modes and for the broadest and most basic possibilities of discovery and disclosure of self and world. Most poignantly experienced in the phenomenon of anxiety – which is not fear of anything at hand but awareness of my being-in-the-world as such – 'care' describes the sundry ways I get involved in the issue of my birth, life, and death, whether by my projects, inclinations, insights, or illusions. 'Care' is the all-inclusive name for my concern for other people, preoccupations with things, and awareness of my proper Being. It expresses the movement of my life out of a past, into a future,

In the Christian vision, instead, the response to the need of the Other is human to the extent that it reflects the structure of a social relationship which, by nature, binds, connects, the co-existing. It is activated in need and is mobilized by subjective moral sentiments, but it has its own reality because it consists in the common origin and destiny of the fraternity. The ontological relationship of fraternity goes far beyond the fact that, faced with the needy, the person feels the moral need for a response, as Heidegger says. Fraternity is what substantiates and articulates moral responsibility by attributing to it a non-subjective meaning (contrary to the idea, supported by Emmanuel Lévinas, that personal ethics of duties towards the Other comes first and replaces the ontological reality of fraternity as a relation).

4.2. Care must overcome the fear of otherness

At the core of what makes humans, and their behaviour, social, is the interplay between self and other. Who is the Other we are talking about in terms of care? I use the word 'Other' to indicate someone who presents himself to us in a condition of weakness, disadvantage, fragility, poverty, marginalization and therefore puts us in front of an otherness – that is, a difference/diversity – which can raise feelings of anxiety, sometimes even fear, and which nevertheless asks for recognition, acceptance and taking charge. In the interaction between the Self and the Other, the identity of both and their inner conversation are brought into play.

Taking care of the Other therefore means facing an otherness in a double sense: first, because it is a question of overcoming the border, sometimes the wall, which divides us, and the fear that the Other can arouse; and then it is a question of validating and also thanking the Other for an identity different from ours.

Lack of recognition can lead to serious repercussions and consequences, which translate, on an individual level, into a reduced way of being, into feelings of exclusion, and, on a social and political level, into tensions and conflicts. For this reason, the care relationship refers, willingly or unwillingly, to power relationships.[13]

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through the present. In section 65 the ontological meaning of the Being of care proves to be *temporality*".

[13] Amer, Amena, and Sandra, Obradovic. 2022. Recognising recognition: Self-other dynamics in everyday encounters and experiences. *Journal for the Theory of Social Behaviour* 52(4): 550-562.

If I maintain that giving the relationship is the first act of recognition of the Other, I am stating that taking care of the Other implies on the part of the caregiver the renunciation of the exercise of a power that is necessarily assigned to him by the asymmetrical position and dependency in which the latter is found. While care implies the adoption of a relationship of subsidiarity towards the Other.

What is at stake is *the real presence* of the Other. It is not the presence of someone who plays a social role, but that of an Other person who is unique, who is here, *hic et nunc*, with his history and his needs and desires, and cannot be 'labelled', it cannot be traced back to some conceptual or spiritual category, nor can it be stigmatized. It must be seen with/through/for the relationship, i.e. with a relational gaze.

The reconstruction of the identity of the suffering person, in need of help, ill, or simply in difficulty, is true if it is also the reconstruction of the identity of the carer. This happens because, if otherness is experienced as an encounter, if it is a true relationship (i.e. reciprocal action), it always involves a certain reciprocity, even if it is asymmetrical. In relating to Alter, Ego experiences Alter's action on himself, and this forces Ego to relate to himself again in his inner conversation. He must re-act on himself in order to be in relationship – i.e. reciprocate – with Alter.

Even before the relationship brings something with it, in terms of performance, it is the spirit of the gift that animates the relationship. Spirit is signified in how one relates to another. It has rightly been said that taking care of the Other means "enlarging the heart". How does the heart expand? It is not an operation that the person can do by herself staying in her own intimacy, because the heart expands with relationships, that is, by opening up to the relationship with the Other. This openness feeds on subjective feelings, but becomes a real relational reality only when it translates into living a *we-relationship* between caregiver and care receiver that involves their life contexts.

5. Understanding relationships and knowing how to manage them

5.1. Three ways to read relationships

If the world of social relationships, as the pandemic has taught us, has its own existence, i.e. it 'exists outside' of the people who generate them, then we ask ourselves: what are social relationships? How can we understand and manage them? And what is the relationality that characterizes taking care of those in difficulty?

When we speak of a social relationship, we must think of it neither as a projection of the ego nor as the product of social structures. I propose to read it according to three semantic modalities (*refero*, *religo*, emergent effect).[14]

(i) The relationship is above all a *symbolic reference*. This meaning of relationship comes from the Latin *refero*, which means to refer something (a need) to someone (the person in difficulty). Relating to an Other means taking the Other as a symbolic reference that identifies him in a certain way, for his specific need. In one respect, the image of the Other is a cultural construction. The caring relationship is a particular form of otherness in which the Other is symbolized for the need it presents. If he is a poor man, what poverty does he suffer from? It takes expertise to answer this question.

(ii) Beyond the psychological-symbolic aspect, the relationship presents itself as a *social bond*. In referring to each other, the one who gives help and the one who receives it interact and thus generate a connection that, in some way, binds them (*religo*). This bond is partly due to the roles they occupy (for example doctor-patient), which depend on the context of the social structure in which they find themselves, and partly it is their creation as a stabilization of mutual expectations. For example, the relationship of helping the blind person who has to cross the street creates a bond that is different from offering accommodation to a homeless person within a voluntary organization for some time. In the first case, the bond is contingent and tenuous, while in the second case the bond is stronger because it is formed within an organized structure.

(iii) The relational paradigm, however, goes further. It indicates an aspect that is difficult to grasp, but is the most decisive for managing the effects of the helping relationship on the people involved and their surroundings. In short, it is the fact that the reciprocal reference and the bond, combined together and repeated for a certain period of time, generate an *emergent effect* with its own reality and causal powers with respect to those of the caregiver and the care receiver. These causal powers influence both the giver and the receiver of help, as well as the people close to them. For example, a relationship of trust is created which has different effects depending on whether the needy person perceives it as conditioned or unconditional, regardless of the

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[14] On the terms 'refero' and 'religo' and their way of working which creates the actual relationship, see: Donati, Pierpaolo. 2013. *Sociologia della relazione*. Bologna: il Mulino.

caregiver's intentions. The emerging effect can have a more ephemeral impact or a stronger and more stable one, depending on the number of interactions and on the characteristics of the context. In any case, the emergent relationship has externalities, which can be positive or negative.

To understand what an emergent effect is, an example may be useful. One often wonders why a couple of good parents, who individually are excellent people, can have problematic and deviant children, for example drug addicts, bullies, or with some mental pathology. The reason is that children don't learn so much from the caring relationship that the father and mother give them individually, even if they are good people; they learn from their relationship as a couple. If the children are problematic, most likely the cause must be sought in the parents' couple relationship, which was not working well, was not very mature or lacking as a relationship. This is why I tell parents: if you want to understand your children, look at your relationship! The relationship is an emergent effect that arises from you, but goes beyond you.

Two things should never be forgotten. The first is that the child's personal identity resides in the relationship between those who generated it. What generates are not two individuals as such, but their relationship. This is the point to understand: what qualifies the generation of a child as human is the male-female structure and the intersubjective quality of this relationship.[15] The second thing is that, as the saying goes, "there are loves that kill". The teaching is clear: it is not enough to love; we need to see what relationship results from our feelings.

5.2. Managing relationships

On the basis of the previous considerations, we can say that good management of the helping relationship involves: (i) seeing it as the product of reciprocal actions between Ego and Alter; (ii) avoiding labelling or stigmatizing the person in difficulty; (iii) accepting a bond that can only continue on the basis of mutual trust and recognition; (iv) reflecting on the emerging effect, to evaluate and modify it from time to time.

Each action has its own goals, its own means to achieve the goals, its regulatory rules and its own basic value attributed to the action itself.[16] The

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[15] Donati, Pierpaolo. 2021. *Engendrar un Hijo.¿Qué hace humana la generatividad?* Madrid: Didaskalos.

[16] I am referring to the AGIL relational scheme that I have elaborated and applied in empirical research: see Donati, Pierpaolo. 2021. *Transcending Modernity with Relational Thinking*. London: Routledge.

social relationship is also made up of these elements which, however, are not supplied by one or the other subject, but rather result from a particular relational combination of the elements sustained by individual actions. The relationship between Ego and Alter intertwines in a complex (*cum plexus*) the ends, the means, the norms, the values of both according to different relational modalities that must be understood on a case-by-case, situation-by-situation basis.[17]

In the example of two good parents with problematic children, they should ask themselves how their goals-means-rules-values combine in configuring their couple relationship, which is both conjugal and parental. Likewise, the caregiver should ask himself how his goals-means-rules-values combine with those of the care receiver if the two are to achieve a good helping relationship.

Based on these considerations, taking care of the Other is certainly not just making a benevolently symbolic gesture or giving alms to someone, but it involves knowing how to read and manage a social context in which relationships are the protagonists. Even when the help consists in advice, the advice should be the result of a relational analysis of the problem.

6. Care is a relational service that creates relational goods

6.1. Care as a relational service

The aid given to people in difficulty can be divided into relational and non-relational services. The former require a relational commitment between people, such as, for example, the education of children, support for a disabled person, assistance to non-self-sufficient elderly people, the rehabilitation of drug addicted and deviant children and young people in general, the help to the homeless person on the street, or to the immigrant in difficulty. Non-relational services, on the other hand, are those given without the need for a relational involvement with the recipient on the part of the provider of the benefit (for example, bonuses and economic benefits given administratively by public or private bodies, or help entrusted to a machine, such as a robot).

Humanizing care means giving priority to relational services over non-relational ones, because authentic and solid social inclusion requires

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[17] This is the relationship as a result of interactions between ‘fractals’, a topic explained in Donati, Pierpaolo. 2021. *Lo sguardo relazionale. Saggio sul punto cieco delle scienze sociali*. Milano: Meltemi, pp. 149-165.

not only material benefits, but above all the construction of a social fabric. As Stefano Cobello[18] writes, "inclusion is a right, is a must of being part of any culturally evolute society and it mainly means to pay attention to everyone in every context of the life in the same way. But more than that, inclusion cannot exist without everyone's awareness of all the human life phases and the capability to look deeply into the human needs of relationship and the common need to be accepted and beloved".

Well, care in the proper sense is a relational service which maximizes its purpose when it manages to create relational goods between the caregiver and the care receiver.

What are relational goods? They are goods that consist in those relationships that make it possible to meet people's needs that cannot be satisfied in another way, i.e. with other types of relationships.[19] Caring for the Other, from a social point of view, consists precisely in creating a relational good between caregiver and care receiver.

For example, the need for companionship that a lonely person has can only be satisfied by creating a relational network with her. The relational good is not a sort of material service given by other subjects to the person alone, but can only consist in a certain relationship created and enjoyed together with her.

In fact, relational goods come into existence only if they are produced and enjoyed together by two or more people, for example by giving and receiving trust, cooperation, and reciprocity, which feed sharing and a sense of communion. Let's think about health. The pandemic has taught us that health is the product of good relationships. People are healthy to the extent that they can enjoy the good relationships (relational goods) that they themselves generate and enjoy with other people who are significant to them. This applies to all forms of care.

Strictly speaking, relational goods have an immaterial character (they are intangible goods) and emerge from subjects reflexively oriented towards producing and enjoying together a good that they could not obtain otherwise. Relational goods are therefore goods common to a network of people who produce them, and therefore are neither public goods nor private goods, but goods shared by the people who form the network. These goods

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[18] Cobello, Stefano. 2023. *Inclusive education for children with disabilities in the relational perspective*. Verona: Delmiglio editore.

[19] Donati, Pierpaolo. 2019. Discovering the Relational Goods: Their Nature, Genesis and Effects. *International Review of Sociology* 29(2): 238-259.

are regenerated the more they are used, and can have positive externalities on the surrounding community, as they create a cohesive and supportive social fabric.

6.2. When does care create relational goods?

Care creates relational goods when those who take care of the Other learn to be 'relational subjects',[20] that is, they operate with a 'relational gaze', they know how to see others through relationships, they look at others with relationships and in relationships.

This means that, in the care relationship, while the caregiver pursues the good of the Other, at the same time he pursues the good for himself. Indeed, the reconstruction of the identity of the needy or ill person is also the reconstruction of the identity of the caregiver. This happens because *in every relationship there is always a reciprocal effect on the inner reflexivity of the people:* in relating to Alter, Ego experiences Alter's action on himself, and this forces Ego to relate again with himself (he must re-act on himself to be in relation – i.e. reciprocate – with Alter).

Care that is oriented towards generating relational goods has an educational and creative value. In the helping relationship there is a pedagogical dimension because the request for help, if experienced as a relationship, teaches us to help others but also ourselves. Caring for others also means caring for yourself. When the caregiver wants to reconstitute the identity of the person to be assisted, at the same time, if he does it well, he also reconstructs his own identity and this happens because in every relationship there is reciprocity between the operator and the person in need. In *Learning from My Daughter*, Eva Feder Kittay[21] claims that living with a daughter who has multiple and significant disabilities, including cognitive disabilities, has been utterly transformative for thinking about her training, career and research as a philosopher.

In encounters with Others it is necessary to be ethically generous, and to know how to be surprised by them. We must be prepared for the challenge of our preconceived ideas about them – those that fix, categorize and constrain their identity. Such encounters are self-transformative because being surprised allows us to rethink and question our taken-for-granted worldview.

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[20] Donati, Pierpaolo, and Margaret Archer, 2015. *The Relational Subject*, Cambridge: CUP.

[21] Kittay, Eva Feder (2019). *In Learning from My Daughter: The Value and Care of Disabled Minds*. Oxford: Oxford University Press.

How does caring for others come about and take place? First of all, it consists in giving attention to the Other. Because of its tension towards the other, attention is the first form of care, an ethical gesture.

Here it is necessary to understand that there are two ways of approaching another person: (i) thinking of her *in front of me*: in this case, the Other speaks to me about herself, and nothing more; (ii) thinking of her *in relation to me*: in this case, the Other tells me something more, she also talks about me, and points to a third reality, that is, the relationship between us as a third party included, in which lies the reality of caring.

To enter this second order of approaching the Other, it is necessary to implement various attitudes. First of all, *receptivity*, that is, letting the other question me, making room for the other, also accepting a certain form of active passivity; it is a question of adopting a non-intrusive, discreet presence that knows how to wait, of one who offers himself rather than wanting to force the Other

Then, a *listening attitude* aimed at understanding the experience that the Other activates to place himself in the world. Here an attitude of *reflexivity*, of *sensitivity*, is appropriate, because taking care is always emotionally connoted.

This way of relating manifests itself as *responsiveness*, that is, knowing how to respond adequately to the calls that come from the other, being prompt. Then, a *cognitive and emotional availability* is appropriate, i.e. placing one's understanding and processing skills at the disposal of the Other, as well as one's ability to express emotions in the relationship with him.

In this way the caregiver realizes an emotionally dense thinking or, in other words, an intelligent feeling, i.e. creates the conditions for the emergence of empathy which, as Edith Stein[22] says, overcomes the split between rationality and emotion.

It is important to distinguish between care as an object of *personal reflexivity* and care as an object of *relational reflexivity*.[23] Both forms of reflexivity are important, and must be present together, but they must be distinguished in order to take the right distance in being next to the Other.

Personal reflexivity is what every agent has within himself, in his own inner conversation, for example, when he thinks: "What should I do?" "How

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[22] Masera, Giuliana. 2007. L'empatia in Edith Stein: la giusta distanza per essere accanto all'altro. *I luoghi della cura* 5(3): 27-29.

[23] Donati, Pierpaolo. 2011. *Sociologia della riflessività*. Bologna: Il Mulino.

can I make the most of this performance?" *Relational* reflexivity is the one directed towards the outside, it is the reflexivity operated *on the relationship*, when the caregiver asks himself: "Is this relationship suitable for the Other?", "What does the Other expect from me?" Personal reflexivity follows ethics in the first person; relational reflexivity follows ethics in the second person.

It is necessary to transform emotions (passions, states of mind) into reflexive feelings, that is, aware, mature dispositions.[24] To carry out this transformation it is necessary to realize that *taking care of the Other and taking care of the relationship with the Other are not the same thing*. For instance, if Albert is married to Lucy, it is one thing for him to take care of Lucy's person and another thing for him to take care of their marriage, even more so if there are children (and the same is true for Lucy toward Albert). In the case of a disabled person, taking care of her body and/or her psyche, as the medical model does, does not necessarily imply that the helping relationship is appropriate. The disabled person needs a human relationship as much as she needs physical care.

The 'care relationship' should not be considered as a sequence of individual acts, but as taking care of the relationship, because it is in the relationship that we find health or illness, and well-being in general.[25]

6.3. The structure of action oriented towards the care of the Other

We can outline in a synthetic way the structure of the action oriented towards the care of the Other as in Figure 1.

Taking care of the Other begins with an unconditional motivation of benevolence, i.e. the gift of the relationship, which presupposes overcoming *aporophobia* (aversion and negative judgment on the needy)[26] and recognizing the relationship existing between the Self and the Other as constitutive of the Self and the Other.

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[24] Masini, Vincenzo. 2009. *Dalle emozioni ai sentimenti. Manuale di artigianato educativo e di counselling relazionale*. Lucca: Edizioni Prepos.

[25] White, Sarah. 2017. Relational wellbeing: re-centring the politics of happiness, policy and the self. *Policy & Politics* 45(2): 121-136.

[26] The word "aporophobia" is a neologism coined by the philosopher Adela Cortina in 1995 to refer to the "rejection, aversion, fear and contempt towards the poor, the indigent who, at least in appearance, cannot give anything in return" (the term aporophobia is formed from the Greek word á-*poros*, 'without resources or poor', and *fobos*, 'fear or apprehension': cf. Cortina, Adela. 2017. *Aporofobia, el rechazo al pobre. Un desafío para la democracia*. Barcelona: Paidós Ibérica).

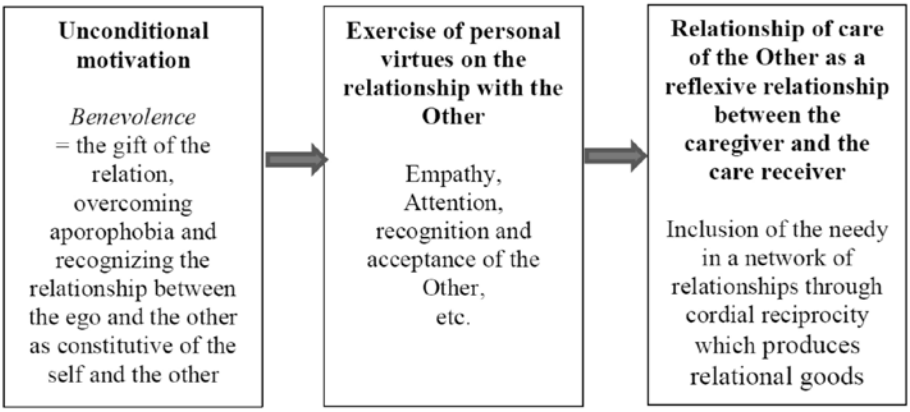

Figure 1. The structure and dynamics of the care relationship.

It continues with the exercise of personal virtues, such as empathy, attention, recognition and acceptance of the Other, implemented by reflecting on the relationship with the Other.

It generates a relationship of care for the Other as a reflexive relationship between the caregiver and the care receiver that includes the needy person in a network of relationships through *cordial reciprocity*[27] that produces relational goods rather than relational evils.

7. The case of health and socio-medical services

The idea that the health of a person or a social group like a family consists in having healthy social relationships is often cited, but poorly understood and practiced. Affirming that the achievement and maintenance of a state of health requires good social relationality is very important to indicate the limits of the definition of health that has been proposed by the WHO, which reads as follows: “health is a complete sense of individual psycho-physical well-being”. This definition forgets the relational dimensions of health and its care.[28]

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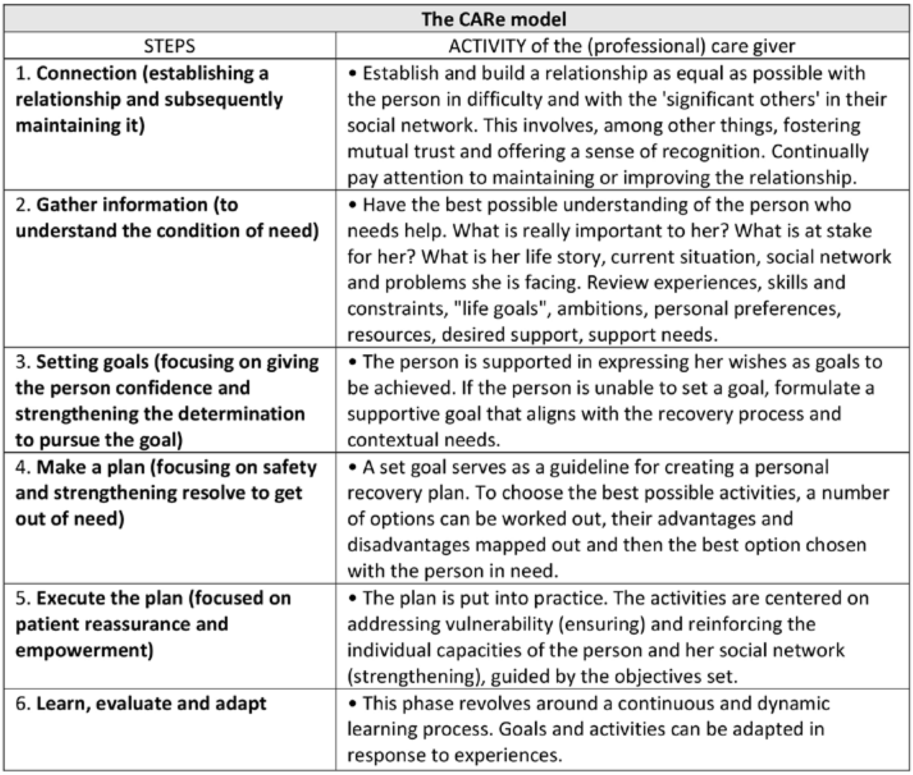
[27] Calvo, Patrici. 2022. Reciprocidad en Adam Smith: la cordialidad como mecanismo de inclusión económica. *Revista de filosofía* (Chile) 79: 25-37.

[28] Donati, Pierpaolo (ed.). 1983. *La sociologia sanitaria. Dalla sociologia della medicina alla sociologia della salute*. Milano: FrancoAngeli.

On the other hand, we can cite two models that help us understand the meaning of the perspective I am proposing.

(I) *The CARe model*[29] bases the care relationship on four principles: *connecting, understanding, ensuring, strengthening the relationship* between caregiver and care receiver. The core of this model lies in understanding care as a dialogue that gives space to the subjectivity of the person in difficulty, reassuring her about the situation and promoting the continuity of the relationship that gives trust with a plan centred on enhancing the abilities of



The CARe model	
STEPS	ACTIVITY of the (professional) care giver
1. **Connection (establishing a relationship and subsequently maintaining it)**	• Establish and build a relationship as equal as possible with the person in difficulty and with the 'significant others' in their social network. This involves, among other things, fostering mutual trust and offering a sense of recognition. Continually pay attention to maintaining or improving the relationship.
2. **Gather information (to understand the condition of need)**	• Have the best possible understanding of the person who needs help. What is really important to her? What is at stake for her? What is her life story, current situation, social network and problems she is facing. Review experiences, skills and constraints, "life goals", ambitions, personal preferences, resources, desired support, support needs.
3. **Setting goals (focusing on giving the person confidence and strengthening the determination to pursue the goal)**	• The person is supported in expressing her wishes as goals to be achieved. If the person is unable to set a goal, formulate a supportive goal that aligns with the recovery process and contextual needs.
4. **Make a plan (focusing on safety and strengthening resolve to get out of need)**	• A set goal serves as a guideline for creating a personal recovery plan. To choose the best possible activities, a number of options can be worked out, their advantages and disadvantages mapped out and then the best option chosen with the person in need.
5. **Execute the plan (focused on patient reassurance and empowerment)**	• The plan is put into practice. The activities are centered on addressing vulnerability (ensuring) and reinforcing the individual capacities of the person and her social network (strengthening), guided by the objectives set.
6. **Learn, evaluate and adapt**	• This phase revolves around a continuous and dynamic learning process. Goals and activities can be adapted in response to experiences.

Table 1. The CARe model: the interpersonal relationship at the heart of care (simplified revision of table 1 in J.P. Wilken, *The CARe model*, *cit.*, p. 41).

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[29] Wilken, Jean Pierre. 2021.The CARe model. The relationship as the heart of good care. *Relational Social Work* 5(1): 34-47.

the sick or otherwise needy person. In order not to lengthen this text, I summarize it in Table 1. The reference is to the professional caregiver, but in many respects it also applies to the informal one.

(II) *The 'relational care' services model* defines disability or frailty as a relational fact generated by relationships and which must be addressed with services based on relationships.[30] The relationality of the service is a quality necessary to maintain the perspective of the whole, in the sense that care is understood here as taking charge of the person in the complex of her human condition, and therefore in the complex of the relationships she has in her lifeworld (*Lebenswelt*). I summarize this model in Table 2.

The 'relational care' service is characterized by practicing care as a lifeworld relationship that goes beyond institutionalized and formal social roles. Compared to traditional medicine, this model introduces subjectivity (both of the doctor and of the patient, the caregiver and the care receiver) in the definition of the disability or disease and of the cure/care as determining factors for carrying out the healing/caring relationship. Health is pursued through healthy and meaningful relationships with others and with the world. The characteristics of the person in need are not considered deviations, but differential qualities that require a specific thematization. *Pathologies or disabilities should be thought of as an existential experience*.

In this model, medicine is considered as an instrumental subsystem in relation to the more general system of care which aims at the social integration of those suffering from the most varied pathologies. In this more general system, medicine has the role of resource and means that must operate alongside and together with the social context of relational aid to the patient. From a cultural point of view, the health service refers to the ethics of care, which legitimizes the concrete objective of the practices that must be pursued in order to achieve a state of health.

The relational approach does not ask the doctor to be an expert in social relationships. It only asks him to take into account, collaborating with other services (hospital, territorial, home, pharmaceutical or other), the fact that his action is part of a system of relationships of which he must be aware.

The relational care service model opts for the integration of technical medicine, health ethics and good practices to help the sufferer to achieve the

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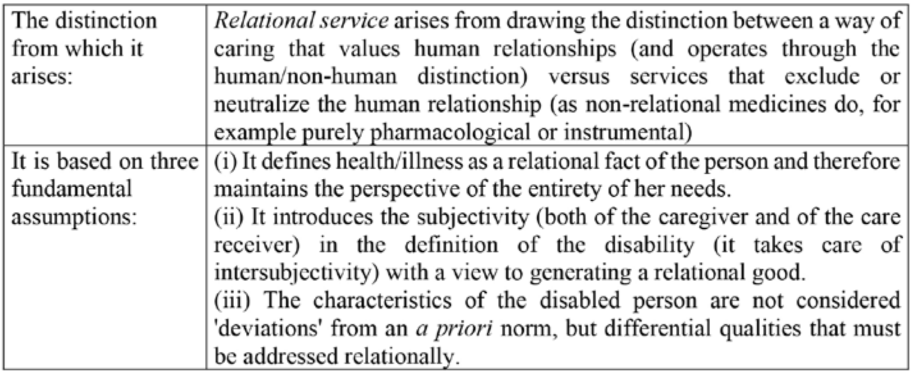
[30] Donati, Pierpaolo (ed.). 1994. *Manual de sociologia de la salud*. Madrid: Ediciones Diaz de Santos.



The distinction from which it arises:	*Relational service* arises from drawing the distinction between a way of caring that values human relationships (and operates through the human/non-human distinction) versus services that exclude or neutralize the human relationship (as non-relational medicines do, for example purely pharmacological or instrumental)
It is based on three fundamental assumptions:	(i) It defines health/illness as a relational fact of the person and therefore maintains the perspective of the entirety of her needs. (ii) It introduces the subjectivity (both of the caregiver and of the care receiver) in the definition of the disability (it takes care of intersubjectivity) with a view to generating a relational good. (iii) The characteristics of the disabled person are not considered 'deviations' from an *a priori* norm, but differential qualities that must be addressed relationally.

Table 2. The model of 'relational care' services.

objective of a health condition which is obviously procedural, dynamic and multidimensional (physical-organic, psychological, social, spiritual).

The two models just mentioned (I, II) have received confirmation of their validity in many field investigations. In particular, I would like to recall the research by Gavin, Evans and McAlister[31] on the importance of considering the healing context, its relational constitution and the ways of providing services in an environment oriented towards a holistic, i.e. comprehensive, medicine. The survey highlighted the importance of the environment in which the treatment takes place, as the elements that compose it (human beings, objects, ideas) create environmental 'vibrations' (vibes) which make it possible to search for new care relationships. A place of care, with its 'relational vibrations', can offer better health opportunities than other environments.

8. Help through technology: the case of the use of robots

We are all fascinated by the use of robots in caring for people, starting with supporting children in difficulty, the disabled, and the elderly who are not self-sufficient. The robot replaces the human body of the caregiver, and more and more tasks of various kinds are entrusted to it, from social to healthcare. One wonders then: is the robot always useful for taking care of people?

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[31] Gavin, Andrews, Joshua Evans, and Seraphina McAlister. 2013. Creating the right therapy vibe: Relational performances in holistic medicine. *Social Science & Medicine* 83: 99-109.

The research conducted so far gives a fairly clear answer. The robot is a machine which, as such, can provide important assistance in terms of functional performance, but has the limitation of not being able to replace the human relationship, which once again reveals itself as a reality in itself.

Let us take the case of caring for the non-self-sufficient elderly. Empirical research confronts us with the fact that the elderly have an ambivalent relationship with the robot.[32] On the one hand, the non-self-sufficient elderly says: "yes, the robot helps me a lot, it reminds me when I have to take my medicine, it helps me make coffee, it helps me get up, go to rest and so on". On the other hand, she says: "but I don't feel treated like a human person". The fact is that the elderly entrusted to the robot feel diminished in their dignity, because the robot does not give them that relationship which is human and only human. The human is in relationality. And such must be the care, of the elderly in particular.

The robot seems to be a friend of the person, but it is not a friend, it is still a machine.[33] We must avoid the mistake of thinking that the relationship between humans and robots is not fundamentally different from the relationship between humans. Many do not understand this difference. The perception that social relationships are all the same indicates that our culture of relationships is highly incomplete. The relationships between humans are different from those between robots and humans, simply because the robot follows the instructions of the algorithms, those that are given to it and those that it can build itself, but it cannot relate as humans do. Those who use the robot to take care of people must be able to distinguish what these different relationships can produce. The diversity of relationships lies in their quality and the effects they generate. We have to pay attention to these different realities.

I think it is possible to generalize these considerations to all technologies, from ICT to AI, which are only an instrumental mediation, however useful. Their problem is that they cannot replace human relationality.

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[32] Sharkey, Amanda. 2014. Robots and human dignity: A consideration of the effects of robot care on the dignity of older people. *Ethics and Information Technology* 16(1): 63-75.

[33] Sharkey, Amanda. 2020. Can we program or train robots to be good? *Ethics and Information Technology* 22: 283-295.

9. How to rethink the formal-informal organization of care

9.1. Three ways of observing caring relationships

In current practices, care relationships are observed according to different methodological approaches that we can summarize as follows:

(i) *approaches centred on the individual* (methodological individualism): caring relationships are seen as an expression of the inner feelings and motivations of individuals (psychology of compassion, psychological flexibility, acceptance of the other, commitment to the other, etc.); relationships are seen as individual decisions that arise from individuals' inner conversation; but one individual's compassion for another, however important, does not make a true relationship;[34]

(ii) *approaches centred on the social system* (methodological holism): care relationships are explained starting from the social structure in which people live; it is thought that there is a system, social or cultural or economic, in any case of power, which conditions possible relationships, even those of service to others;

(iii) *approaches centred on relationships as such* (relational methodology): although care relationships depend on individual agents and are conditioned by social and cultural structures, they must be considered in themselves, as a good that goes beyond the intentions of individuals and organizational constraints; we can only manage them if we see them with the 'relational gaze', that is, focusing on the relationships themselves to understand their causal qualities and properties, modifying them so as to prevent them from generating pathologies and instead favour a healthy and just social relationality.

Examples are multiplying that confirm the validity of the relational perspective. Take, for example, the issue of medical care for patients who have a different cultural and ethnic background. Several researchers[35] have found that strategies that manage cultural differences by focusing on individual

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[34] This is my critical observation to those who simply treat disability with compassion. The disabled person needs a relationship of empowerment and not just good feelings. However, it is true that compassion can enhance the intimacy and emotionality of the disabled individual, filling the void that approaches excessively centred on the macrosociological causes of disability leave uncovered (cf. Clément, Michèle. 2018. Sociologie, souffrance et compassion. *Cahiers de recherche sociologique* 65: 47-69).

[35] Broom, Alex, Rhiannon Parker, and Stephanie Raymond. 2020. The (Co)Production of Difference in the Care of Patients with Cancer from Migrant Backgrounds. *Qualitative Health Research* 30(11): 1619-1631.

patient characteristics are much less effective than those that focus on patient-caregiver relationships. It is highlighted that a large part of the quality of cancer care depends on the ability to activate relationships that do not offend the dignity of the culturally 'foreign' patient, that do not eliminate their cultural differences and that, however, at the same time are not indifferent to cultural differences.

Intervention according to a relational methodology has better healing effects than the others because it combines formal and informal help. This is true not only at an interpersonal level, but also and above all at the level of service systems. For this reason, the methodology that works by enhancing the networks of relationships capable of generating relational well-being is called community welfare. Its guiding principles are as follows:

- community welfare is achieved by a plurality of actors through *social governance*, which is a form of coordination that enhances horizontal networks, minimizing political *government* (use of vertical power);
- caregivers are trained in relational social work,[36] which adopts a methodology based on network analysis;
- welfare is designed and evaluated together by those who offer and those who receive help, i.e. it is co-designed and implemented together by all the actors in the community;
- the well-being of the community is pursued by creating and regenerating social capital, i.e. relationships of trust, cooperation and reciprocity, starting from the primary networks and enhancing the processes of co-production of services.

Co-producing services means that the offer and choice of the service is made jointly by the caregiver and the beneficiary. Both share decisions about how the service should be done. Co-production makes people participate in the process.[37]

9.2. Care as an action of organizational systems

To humanize care, from a social point of view, in a relational key, my proposal is to define care and care services as an ODG (relational observation-diagnosis-guidance) system, that is, as a system that organizes inter-

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[36] Folgheraiter, Fabio, and Maria Luisa Raineri. 2017. The principles and key ideas of Relational Social Work. *Relational Social Work* 1(1): 12-18.

[37] Pestoff, Victor. 2018. *Co-production and Public Service Management. Citizenship, Governance and Public Service Management*. London: Routledge.

ventions to create community welfare on the basis of three steps: relational observation, relational diagnosis and relational guidance. What does ODG mean? Briefly, it means the following.

(O) The observation of the need to be addressed must be relational, which implies that the problem we are facing must be defined as a problem of relationships. Poverty, social exclusion of persons with disabilities, multiple forms of malaise and existential crises, and even illnesses, are consequences of a particular social network that generates the problem as a relational configuration characterized by deficits, structural holes, inability to see and manage good and just relationships.

(D) The diagnosis must be relational, that is, it consists in knowing how to distinguish the relationships that lead to health and well-being from those that do not.

(G) The guide for solving the problem must be relational, in the sense that the practical intervention consists in modifying the relational network so that people are capable of generating relational goods rather than relational evils. The basic idea is that, if the need is generated by defective relationships, the solution lies in evaluating these relationships and changing the network of relationships that produces the need.

Through the methodology of the ODG system, we can create wellbeing of a community nature.[38] It is important that the actors, both social and health, see in the community the privileged environment for creating a humanizing welfare. Community welfare is the set of policy actions and network interventions that are capable of bringing together public institutions, businesses, organized civil society and families who create a 'network welfare' to the extent that they produce a social fabric that is communal because, belonging to the network, it is a source of well-being shared among all participants.

Thus, a community is created which is a *We-relationality*, that is, "a relationality of us". The community is a We which does not mean having the same ideas or the same tastes and preferences, but it means sharing a relationship in which each person is herself, together with the others.

10. In order to humanise care, a relational bioethics is required

Taking care of the Other always implies an ethical dimension. Bioethics, born between the 1960s and 1970s in the Anglo-Saxon context, remains a mixture of biology and individual-oriented ethics. Current bioethics is

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[38] Folgheraiter, Fabio, and Pierpaolo Donati. 1991. *Community care. Teoria e pratica del lavoro sociale di rete*. Trento: Edizioni Centro Studi Erickson.

called to become relational because human life is relationality, and therefore bioethics training consists in thinking and acting on human life as a social relationship. When we talk about care, the reference model is often the purely medical-healthcare one, centred on the individual, while what we need is a relational model of integral ecology.

Assistance to people with disabilities is a paradigmatic field of the need for an ethically sensitive relational approach, because the problem of the autonomy of the disabled person cannot be solved by focusing directly on her individual abilities, but by creating an appropriate relational context that supports her abilities.[39]

The ethics of care (or care ethics), as a cluster of normative ethical theories that were developed by some feminist and environmentalist currents of thought since the 1980s, can and should be conjugated with virtue ethics. It is necessary that bioethical training and the ethics of care become training in thinking and acting according to virtuous relationships, since, in taking care of the Other, it is life itself as a virtuous relationship with others and with the world that is called into request. Only such a "relational view" can guarantee an ethics of care that is human rather than dehumanizing.

In short, the ethics of care cannot ignore that life is human insofar as it is a reciprocal action – endowed with meaning – of subject-persons, and it is not a laboratory alchemy.

Otherwise, bioethics becomes just a set of procedural and functional rules which, devoid of motivation and profound intentional meaning, end up fuelling the business of a market whose commodifying effects we already know. Effects that are still relatively contained compared to the devastating effects and the risks of alienation of the human being that appear as possible on the horizon of the future.

A model of care service provision as a pure performance (merchandise, commodity) is inadequate in the face of moral dilemmas and the need to be able to build and rebuild human lives and valid relationships in the context of the pain we feel towards the fragile and in distress, of the sorrow towards the sufferer, and of the unpredictability of life's events.

What today's society lacks are not so much material and technological resources, but rather the relational skills of welcoming, supporting and socially integrating people in difficulty.

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[39] Ho, Anita. 2008. The Individualist Model of Autonomy and the Challenge of Disability. *Bioethical Inquiry* 5: 193-207.

The care of the Other is increasingly entrusted to new technologies and impersonal welfare mechanisms, while interpersonal social relationships become increasingly weak, liquid and unavailable. People are unable to care for others. Human relationships are replaced by technological means. The consequences are evident in the loss of social solidarity and in human deterioration. Situations of need due to the marginalization of disabled and frail people are spreading. Disabilities in the strict sense represent 16 percent of the world population, but the fragilities that are due to some deficit or pathology, in particular psychological ones, are at least three times as much.

We need a social change, first of all cultural, which brings out, rather than concealing, the relational character of human need and, correlatively, of the necessary response, which is realized only in the gift between the giver and the receiver, that is, in the creation of a relational good.

In an intrinsically risky society, the Other to take care of concerns increasingly large portions of the population, because everyone is potentially subject to falling into conditions of need. For this reason, it is necessary to spread a culture that recognizes and encourages caring relationships as an ultimate concern and a merit good of society as a whole, and not just of specific *ad hoc* organizations, if it wants to be a society with a human dimension. In fact, it is essentially in caring for the Other that the human is expressed, implemented and shared.

11. Conclusions

I have tried to explain why care is not only, after all, a question of good feelings and intentions on the part of individuals, or a question of technical efficiency in the ability of service systems to function well, but it is a social issue of relational responsibility, which must be evaluated and examined for its humanizing qualities. The relationship as such is the protagonist of care.

It is social relationships that make people and what they do human. Relationships are a reality in themselves and it is necessary to know how to deal with them (even remotely) to enhance people and generate relational goods. The good will of people and institutions is necessary, but not sufficient, because it is necessary to grow in the ability to read and manage relationships, their quality, and their effects, in order to take care of the Other in a truly human way.

We still have a long way to go to understand what it means to say that caring for the Other lies in the qualities and causal properties of human and social relationships, and why it is necessary to make all the components of caring relational, i.e. people's actions, the organization of services and the social context that can favour or inhibit care as a relational good.

It is not a question of appealing to an abstract concept of '*universal brotherhood*', but to a *fraternity*[40] experienced as a vital relationship in the world of daily life. Brotherhood is a universalistic concept that indicates the sharing of symbols referring to equality and solidarity among human beings. Most of the time it is expressed in a vague adherence to abstract values, such as perpetual peace or the total abolition of social differences, which are, of course, important objectives but which often turn out to be only illusory dreams. In order for fraternity to become an operational reality, it must go beyond a generic symbolic inspiration. It implies a concrete relationship of mutual care between people, starting with the closest to the most distant, even strangers. It is in concrete fraternity that care generates relational goods. This is the message. However, let us remember that there is something more important than fraternity, which is friendship as God understands it.

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[40] While "universal brotherhood" (in Italian 'fratellanza') is an immanent concept that affirms that people belong to the same species or a certain community of destiny, fraternity (in Italian 'fraternità') is a transcendent concept that is based on the recognition of the common fatherhood of God.

SESSION 5. CHALLENGES AND OPPORTUNITIES FOR INCLUSIVE SOCIETIES: EMERGING ISSUES

LIVING A LIFE LIKE YOURS

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The quest for people with disabilities is to live an ordinary life, like that of everyone else. To be valued. To be included. To have a meaningful occupation. To live and die and form partnerships and to have access to everything everyone else has.

I do not think people with disabilities cannot live a good life. While disability is bad, and to be avoided wherever possible (through diet and road safety and immunisation and similar public health measures), life with disability can be good. People's lives go well when they are included and valued. Those people with disabilities who lead a good life, despite disability, are people who can use the loo, and get on the bus or train, and go to work. In other words, they live and travel and work in accessible environments. They can achieve reasonable accommodation – in other words, they have flexible working and barrier removal. They can get the assistive technologies they need, whether those be wheelchairs, crutches or other aids. In other words, people with disabilities often have fewer choices, but where those choices are met, they can have good lives.

Fifty years ago, Normalization in the Nordic countries took off at the same time as the disability rights movement in Britain and America, which started with the Union of the Physically Impaired Against Segregation in UK, and the Independent Living Movement in the US. All of these ideas were against segregation and in favour of inclusion of people living ordinary lives next to each other, in barrier-free societies, where disabled people were not devalued, remembering that at this time, people with disabilities, particularly many people with intellectual disabilities, lived in big institutions, often far away from their family, let alone population centres, where they lived and died without any meaningful work or activity.

The Nordic countries were dominated by the concept of Normalization, which, in the words of Bengt Nirje called for "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society".

In UK and US, the focus of de-segregation was people with very significant physical impairments, and the key to achieving independent living was personal assistants, where people could employ staff to break the link between physical dependency and social dependency: you could be very physically dependent yet be completely socially independent. Large-scale de-institutionalization of people with mental illness and intellectual disabilities has taken place, powered by outrage at abuse scandals in institutions.

Of course, twenty years ago Norway was the first place in the world to close all its institutions. And I note how in everyday life in the Nordic countries, people with disabilities are included in the mainstream, on the bus and in popular media. They are not separated. And I note how three quarters of families are enthusiastic advocates of deinstitutionalization, whereas in many countries, families are pushing for relatives with disabilities to be kept safe and looked after in institutional settings. All this is good. But, as I read in the analysis by Jan Tossebro, expectations about employment, social networks and social integration never materialized.

In the UK, you have the dominance of what my friend Harry calls 'special world'. Her son Charlie, who has Down syndrome, lives in his own house with personal assistants. However, his friends with intellectual disabilities live in group homes with staff. And if you live in a group home, it is very difficult to make your own choices. Whenever he wants to go swimming, Charlie goes with his support worker independently and does his swim.

Charlie has a friend he used to go swimming with, when he lived with his family at home. But now he lives in a group home, Charlie can never go swimming with his friend, because his friend cannot do his own thing. If the residents in the group home want to go swimming, they all have to go swimming. There are not enough staff for some to go swimming, and some to stay home.

In Norway, it worries me that we are now in an era where the number of people living together is creeping back up. In 1994, people lived in settings of an average of four people together. In 2010, that average had crept up again to eight people. 40% of people lived in a group home of seven people or more. This is obviously to save money. I don't think a group home of eight people is an institution, and I know these flats are in ordinary streets, not separated far away. So it's much better. But it's not normal.

Connected to this, I note how rates of personal assistance are very low in Norway. I think you have about 3,000 people in receipt of personal assistance, for a population of 5 million. In England, we have about 70,000 disabled people, including people with ID, employing their own staff, for a population of 50 million. If I'm right, we have more than twice as many people having personal assistants. And if, like Charlie, you have personal assistants, you can live an independent life: you can make your own choices, you can potentially go to work, or go swimming, and you can live a much more normal life, whether you work or not.

But I don't want to overstate normalization in the UK. How many personal assistants are there? 150,000. And how many people work in social care? Well, just in intellectual disability and autism there are 660,000. Only 31% of people employ their own staff – in other words, have a chance of independent living. More than two-thirds buy in homecare staff from agencies.

And despite independent living, the disability employment gap, which is the ratio between employment of disabled people and non-disabled people, is very stubborn. 81.1% of nondisabled people are employed, and 52.3% of disabled people are employed. Historically, you are approximately twice as likely to be unemployed if you are disabled. The disability employment gap has reduced in recent years, but a lot of that is because adults have retrospectively been diagnosed as having autism, ADHD or dyslexia. In other words, the acceptability of neurodiversity has meant that it looks as if more people with disabilities are employed. However, people with complex disabilities remain under-employed. Only 7% of people with intellectual disabilities have jobs.

So just to recap: the Nordic countries closed institutions to achieve a normal life, and there are many improvements, but they have not quite achieved normality. And in UK, we went for independent living to achieve a normal life, and there are many improvements, but we have not quite achieved normality.

Global advances

On June 10th 2011, nearly fifteen years ago, a team of us from WHO and the World Bank launched the *World Report on Disability* at the United Nations in New York. I remember well the months of writing, preparation and checking. I also remember the films we made with women with disabilities, and the launch film I made with Professor Stephen Hawking. The actual day was a flurry of organisation, to the extent that I remember assistants' feet were bleeding with all the running around in smart shoes.

The *World Report on Disability* was the first of its kind, and was based on the United Nations Convention on the Rights of Persons with Disabilities; it was welcomed and supported by the disabled people's movement. The most notable intellectual contribution was probably the new prevalence data on disability: 15% of the world's population amounting, at that time, to one billion people. These sorts of reports get front page coverage because of new data, and sure enough, I did interviews with CNN, *Al Jazeera* and *The Guardian*.

Any *World Report* is only worthwhile if it's used. The 15% prevalence estimate has been used by organisations of persons with disabilities, UN Agencies and countries, and by many, many researchers. The Report also was pioneering in laying out the major areas of concern: health, rehabilitation, enabling environments, assistance and support, education and employment. If we were doing the Report again today, we would have to include social protection, which was not a big issue in 2011.

I want to say one thing about research. I said the *World Report* was evidence based. We looked for data everywhere: for national statistics, RCTs and systematic reviews. But to my shame, as a disability studies researcher, we did not find many of our answers within the disability studies literature. I think the Nordic literature is more helpful. But a lot of the research in our field is not useful, does not have impact, and cannot be used to improve the lives of disabled people. I think that's a real indictment. Most of us are publicly funded. We research the right to ask questions which are more abstract and general, but I think we should also try and answer questions which matter to the lives of disabled people, from Trømso to Timbuktu.

However, the "million dollar question" is whether the lives of persons with disabilities are distinctly better, as a result of the impact of the *World Report on Disability*. We could ask a very similar question of the impact of the Convention on the Rights of Persons with Disabilities. I think that lives are generally better, thinking worldwide, and the *World Report* and the Convention have helped in that trend. Putting disability inclusion on the policy agenda, highlighting how mainstreaming is the way forward, and how barriers in society represent the biggest problems for most disabled people, has been very helpful.

But the Convention on the Rights of Persons with Disabilities (CRPD), in particular, was revolutionary. It is 15 years since that was adopted by the UN in December 2006. It was not intended to initiate a trend towards improvement. It was meant to be a complete step change in provision. And that has not happened.

In writing the *World Report*, the CRPD was our moral compass. The CRPD talks about "nothing about us without us", it talks about equality and non-discrimination, and inclusion. It is a vital document. But it is also, because it is a human rights document, very individualistic. It is about the rights that persons with disabilities can demand from society. It is about rights not charity.

The CRPD does not mention the community. It barely mentions the family or non-disabled people, even though most of us spend all our time with non-disabled people and much of it in families. It certainly does not mention charity. Individuals with disabilities have the right to make choices and speak for themselves. Individuals with disabilities have to claim their rights. In fact, I think the human rights agenda represented by the *World Report on Disability* and CRPD, and the whole UN system, have not just failed to liberate disabled people. They have done worse than that. They have created inequality between disabled people.

Some people, like myself for example, have done very well out of a human rights agenda. Disabled people who have had a university education, who can flourish in a knowledge economy, have done brilliantly. If you have a physical impairment, or you have a visual or hearing impairment, you have the potential to do really well.

We live in an era, at least in high-income countries, where medicine can remedy many ills, and where technology can compensate for many disadvantages. I wrote this talk at my desk in my home on my computer. If I needed the latest social care statistics, I just googled them. My son is a senior civil servant, working on the digital economy: he works from home. My daughter works in social work, but for a third sector disability organisation: she works from home. Even if you are not in high powered jobs, you can do clerical work on a computer, in an office, if you are physically disabled. You can teach. You can do marketing or business or many, many roles. It's harder to be a fire fighter or a soldier or a farmer, but many jobs are newly accessible to disabled people.

The Covid era, and the way everything has been done remotely, is actually liberating for many educated disabled people who flourish in the knowledge economy. Access barriers and communication barriers and fatigue aren't such a factor any more. We are equal at last.

But this is not all disabled people, by any means. We tend to think about disabled people as a homogenous group. The CRPD encourages this agenda. The *World Report* encouraged this way of thinking, because WHO said 15% of the population were disabled, amounting to one billion people. It suited the authors of the *World Report*, and it suited the disability movement, to see us as one vast undifferentiated constituency.

But we are very, very heterogeneous. Half of us are older people, for a start. And older people have not been well represented in this revolution. Social inequality is a big issue. Sexual and racial inequality is another big issue. And above all, different impairments are a big issue. I think we need to think about the differences between disabled people, differences that can fuel inequality.

- To start with, those people with disabilities where reasonable adjustment and barrier removal means they can fully participate in almost all areas of life. This is the group like me and my children, or all those others who have flourished in the modern high-income-country knowledge economy. If we have a truly level playing field, if we remove unnecessary barriers, if we promote equality and mainstreaming, then this group will, by definition, flourish.
- People with disabilities where they require further support, but can then participate in most areas of life. I am thinking of those people with mild to moderate learning difficulties or autism who could have a job, or else who could benefit from theatre groups or all the other social and cultural activities that have flourished. This group will not benefit as much from mainstreaming, because they require additional targeted interventions to flourish. We will have to spend more, and do extra to give them a chance of living a normal life.
- Then finally, people with more profound disabilities where, even with support, they cannot fully participate. I am also thinking of our friend, the philosopher Eva Feder Kittay, who writes about her daughter Sesha in her book *Learning from my daughter*. I am thinking of many frail older people too. I do not think that choices and rights make a huge different to them. I am not sure it makes much difference if they are in residential settings or in the community. In fact, they might be more lonely and isolated in the community if we are not very careful. They need to be free of violence and abuse. They need to lead good lives. But this is going to depend on the specific interventions and services which we can develop, and the imagination with which we develop them.

Because the first group have advanced and become more integrated, thanks to normalization, many of the second group lead much more included lives. But the third group are still segregated: they may live in the community, but they are not of the community. Those who have access to personal assistants, like Charlie, can lead fairly normal lives, but most people do not have that. To recap, we can think of three routes to living a normal life:

- The normalization and shutting institutions that went on in the Nordic countries;
- The Independent Living and personal assistance that went on in the Anglo-Saxon countries;
- The Convention on the Rights of Persons with Disabilities that went on worldwide.

I would argue that none of these three options has fully liberated disabled people. You could say it is still early days, but I think 15 years, in the case of the CRPD, and 20 years, in the case of closing institutions, should be enough to see a wider transformation of society. And where these options may actually have increased polarisation between different groups of disabled people, I think we have a problem.

To be fully included and respected, in the Western liberal world "the moral status and value of persons is contingent on their capacity to take part in a number of mutual reciprocal ethical obligations, which has profound and negative implications on people with disabilities, particularly people with cognitive and severe physical disabilities" (Onazi, 2020, 2).

In mentioning Eva Feder Kittay's work, I feel that we need to move away from Independence and Individualism. The Independence of Independent Living has risks. The Individualism of individual social rights has dangers. And if we are going move away from Independence and Individualism, I think we are also going to have to move away from Normality. Of course, we do need disabled people to achieve independence and individualism and normality more than they ever did before. We need to remove barriers to independence and individualism and normality. But these cannot be our goals.

Conceptually, where can we find the answers? I would say in two or three places. The first, which I am not going to say much about, is in Virtue ethics, and the Aristotelianism which talks about *eudaimonia*, which as you know is Greek for flourishing. Because I think flourishing should be our aim, and I am much happier about striving for this than in trying to achieve Individualism, Independence or Normality. The second, is in Feminist Ethics of Care, which is people like Selma Sevenhuisen and Joan Tronto, and probably Eva Feder Kittay would sit fairly well in this group. As you know, this approach does not talk so much about rights and independence. They talk more about responsibilities and interdependence. They talk about mutuality and emotions. Kittay criticises John Rawls, the great contractarian liberal philosopher, for failing to take into account dependency. She says liberal ideas of equality are an illusion, because they take the idea of dependency for granted. She wants to make the capacity to care intrinsic to the theory of justice. But Kittay and Tronto and Martha Nussbaum, the great Capabilities Theory scholar, all come from a North American tradition, where individualism is in the water they drink and the air that they breathe.

A third option is the African concept of Ubuntu. Rather than the individualism of our Western tradition, this is the concept you find in John Mbiti: "I am who I am because of who I am in other people". *An African Path to Disability Justice* by Oche Onazi is a very thorough and helpful analysis of African philosophy. Perhaps our way forward lies in the relational community which he talks of. Where the only criterion for being treated as human is being human, as Geoffrey Tangwa says (Onazi 2020, 122). What matters is relationships, not capacity, as we see in the L'Arche communities. It is doing things with, not doing things for, let alone doing things by oneself. Here, mutuality is not about the abilities you can bring, but in the relationality you can share, and in particular the gift of companionship, which all persons with disabilities possess, even if sometimes it is the only thing they can do. We are compelled to take ethical action without waiting for the other to reciprocate, because that is what it means to be human, as we also read in the existential philosophy of Immanuel Levinas.

Of course, this ethical action is not automatic. We require Ubuntu moral education, as Etieyibo (2017) writes, to nurture children to become good civic citizens, to nurture the moral and intellectual virtues, where virtue is an acquired quality of character that contributes to the flourishing of individuals. Now, the more cynical readers will respond by saying this is only so much philosophical hot air. We cannot achieve such a world. Individualism has gone too far. We are inevitably selfish beings. We cannot do better than capitalism, competition and individual rights.

Global trends

I want to mention three developments briefly, which show that the old ways are no longer the necessarily best ways. The first is AI. Capitalism is being rapidly transformed, to the extent that humans are not required to work in the same way. Mass production and mass automation increasingly destroy jobs, whether blue collar or white collar. This offers us the great potential to decouple the work you do from the value you have. In this future, those who cannot work have potential nevertheless to have value.

The second is Universal Basic Income. The popularity of this idea is related to the great manufacturing change on which we are engaged. But again, UBI decouples, to some extent, your value to society from the work you do for society. Where everyone enjoys a basic income, just because they are human, then the division between those who work for a living, and those who have a welfare benefit from the state, is eroded.

The third is the Climate Crisis. We now must all know that we cannot go on working, producing and consuming in the old way. Individualism breeds selfishness which goes towards catastrophe. Human life, indeed all life, is unsustainable in the old way. We are in an age of mass extinction. If we are to have any chance of survival, we are going to have to do things very differently.

In this context, we cannot afford individualism, because it leads to selfishness. We cannot afford the old normal, because it leads to unsustainable solutions which destroy the environment. And we cannot think in terms of independence, because we realise how interdependent we all are, and how dependent we are on the health of the ecosystem and the choices made by others.

Let me repeat: We require moral education to nurture children to become good civic citizens. We need, as a society, to nurture the moral and intellectual virtues, where virtue is an acquired quality of character that contributes to the flourishing of individuals. Ubuntu is an option. Christian moral teaching is an option.

The problem with these options, which appear more communitarian, and more based on values, is that the individual may be lost. For example, many good Christians send money or otherwise support institutions in which individuals are silenced. In many families, the father speaks for the rest of the people in the household. Often the big man, or the boss man, gets to rule everyone. In the disability world, this can be paternalism, silencing of people with disabilities, care which equals control, even segregation in the best interests of residents.

We need some of the human rights approach, some of the individual rights approach, but this needs to be tempered with moral values and a more communitarian way of life, a more Ubuntu way of life, a more Christian way of life, in which people are valued not for what they earn or how much they are in the media, but because everyone is equally valued, citizens of society, or part of God's Kingdom, or simply in connection, in communion with all.

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RESEARCH AND INNOVATION FOR THE INCLUSION OF PERSONS WITH DISABILITIES: A SCIENCE POLICY SURVEY

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Abstract

The paper is about science policies meant to tackle the challenge of achieving a society in which inclusion, innovation and reflection are implemented. The first part focuses on the inclusive society as addressed in policy documents. The second part focuses on the role of social innovation in meeting the needs of persons with disabilities. The third part proposes experiences of good practices of inclusion in the fields of education, lifelong learning, healthcare, social services. Several e-inclusion technologies for students with disabilities are presented. E-inclusion requires a shift from already structured, open but essentially immobile systems to the creation of learning situations and communities that can dynamically and continuously structure themselves based on the characteristics and needs of individuals. The paper concludes with a focus on global perspectives on inclusion.

1. Inclusive, innovative, and reflective societies

Let me begin with the general definition of a *policy agenda* as “the list of issues or problems to which government officials, and people outside government who are closely associated with those officials, devote some serious attention at any given time” (Kingdon 1995, 3). It is within a policy agenda that a *scientific research and innovation agenda* – a process consisting of exploration, commitment and prioritization, integration, programming, and implementation – is laid out to make explicit what the state requires of researchers to relate their studies to real-world problems, to validate their research, and to access research funds allocated by a government agency. A scientific research and innovation agenda is about evaluating different options, which in turn leads to “recommendations for a reorientation of policymaking” (Fischer et al. 2007, 501).

Launched in 1984 to bring together the expertise of all Member States that participate in the European Research Area, the until now nine framework programs for research and innovation have become an important part of research cooperation in Europe, growing progressively in size, scope, and ambition. They have evolved from supporting cross-border cooperation in science and technology to a truly European coordination of activities and policies. The societal challenge 6, *Understanding Europe in a changing world: Inclusive, innovative and reflective society*, has given shape to one of the main science policy objectives of the European Union's 8th framework program for research and innovation *Horizon 2020* (2014-2020), which was adopted on 10 December 2013: it was individuated to provide funding instruments to support social sciences and humanities research on horizontal issues such as (a) the creation of smart and sustainable growth, (b) social and cultural transformations in European societies, (c) political inclusion and democratic participation, (d) the role of media and the formation of the public sphere, (e) social innovation, (f) innovation in the public sector, (g) Europe's position as a global actor (EC 2024, 2015).

Supporting inclusive, innovative, and reflective societies is a prerequisite for sustainable cohesion. Speaking of inclusion, science policy is about mapping, synthesizing, and making accessible research fundings for the inclusion of persons with disabilities, how to use them, and to whom they should be directed (King and Lulle 2016). In the 9th framework program for research and innovation *Horizon Europe* (with a budget of 95.5 billion to be distributed over seven years 2021-2027), the inclusive society is currently addressed in cluster 2 of pillar II, *Culture, Creativity and Inclusive Society*, which funds scientific and technological research and innovation in the areas of (a) sustainability, (b) job creation, (c) improved working conditions and a sense of belonging to Europe through continuous engagement with citizens, social partners and economic sectors, (d) the development of new technologies, (e) the creation of a knowledge-based society, (f) the transition to new forms of work, ensuring the social inclusiveness of such transformations and attracting, protecting and retaining a skilled workforce, and (g) the full potential of cultural heritage, arts and cultural and creative sectors and industries (EC 2021a).

2. Research infrastructures for the inclusive society

The inclusion of persons with disabilities depends on social services, which in turn are provided by social infrastructures. Social infrastructures are a powerful tool for creating inclusive growth and strengthening the social fabric of a country. They are a tool for development because of their impact on people (education, health management, care services), the environment, culture, and civil liberties. In the following pages, I will present experiences of good practice in health and social care in the fields of special pedagogy, sociology, and sport, understood as a rehabilitative and inclusive opportunities from the perspective of education and lifelong learning (EC 2019a).

Social innovation occurs when a service responds positively to societal issues, i.e., does the innovation solve the problem? Is it cost effective? Is it widely accepted? (EC 2017, 17-18). Social innovation should be the "backbone of all European research policies", as the President of the Republic of Portugal, Marcelo Rebelo de Sousa, made clear in his speech at the *Opening up to an Era of Social Innovation Conference* in Lisbon on 28 November 2017 (EC 2019b, 115). Social infrastructures are generally built and maintained at national, regional and local levels. They provide services for education: (1) from preschool to university; (2) lifelong learning, libraries, vocational and continuing education; for health: (3) healthcare; (4) long-term care, persons with disabilities and the elderly; and, finally, for cities: (5) affordable housing, urban regeneration; (6) mobility: commuter networks, urban transport (EC 2019a).

Social and cultural innovation is a concept that includes two syntagmata. Since 2012, it has become current among researchers, as it is the name chosen by the European Strategy Forum Research Infrastructures (ESFRI) for its working group on projects and milestones primarily related to social sciences and humanities. Founded in 2002, ESFRI supports a coherent and policy-driven approach to research infrastructure policymaking in Europe. The *Strategy Working Group Social and Cultural Innovation* proposes possible solutions to address the societal challenges of today. It also proposes methods through which social sciences and humanities can be used as an evaluation criterion for the activities of other research infrastructures in the ESFRI roadmap (e.g., social impact, etc.). Finally, the working group explores how research infrastructures can contribute to social innovation or better knowledge transfer to society (ESFRI 2021, 105-114).

Research infrastructures are public goods. They are planned, built, and managed to serve large research communities operating in diverse sectors. They are facilities that provide resources and services to research communities to conduct research and foster innovation; they can be used beyond research, e.g., for education or social services, and can either be located on single sites or distributed, or virtual. Their main objective is to provide innovative solutions to current and future challenges.

There are different types of research infrastructures. In Europe, communities can apply for inclusion in the ESFRI roadmap, which currently lists about 50 projects and milestones and is updated every three years. More specifically, ESFRI facilitates multilateral initiatives leading to better use and development of research infrastructures at European and international level. Scientific communities can apply for substantial funding from the European framework programs for research and innovation, which is becoming essential, given that today researchers in social sciences and humanities are confronted with increasingly complex and large amounts of data in highly interdisciplinary settings. Think of the research teams engaged in the *European Social Survey* (ESS ERIC), or of those committed to collecting data on the aging population for the *Survey of Health, Ageing and Retirement in Europe* (SHARE ERIC).

3. Digital equity and inclusion in education

Since the launch of the 8th framework program for research and innovation *Horizon 2020* in 2013, European science policy has been implementing the triple aim of (a) strengthening social, economic, and political inclusion, (b) fighting poverty, (c) promoting human rights, digital and educational inclusion, equality, solidarity, cultural diversity, and intercultural dialogue. Funding instruments for interdisciplinary research, indicator development, technological advances, organizational solutions and new forms of cooperation and co-creation have thus been established.

Digital technologies support the inclusion of diverse student groups in education in several ways, including improving the accessibility of educational content, increasing personalization, and providing distance learning opportunities (EC 2021b). Persons with disabilities have equity issues, and – as Thomas Scanlon (2018) has argued – equity matters. Two concepts have emerged. First, *digital equity in education*, defined as “the distribution and use of tools in a way that does not disadvantage or reduce the learning opportunities of certain groups”. Second, *digital inclusion*, as “minimizing digital inequalities, thereby widening access and also improving the quality of teaching and learning, with the intention of providing a fair and equitable education” (OECD 2023, 8-9). Hence, scholars have started lines of research to study and experiment with models of inclusive situations implemented with the support of digital technologies (UNESCO 2009).

E-inclusion addresses the relationship between education and students with special educational needs (e.g., disabled, immigrant, learning disabled, or unable to attend school normally), and is modeled on the notion of special needs education (UNESCO 1994), which envisions the inclusion of students with disabilities, no longer simply within an already structured, open, but essentially immobile system, but rather through the creation of learning situations and communities that can dynamically structure themselves within themselves, based on the characteristics and needs of individuals.

Although most teachers are informed about the functioning of the mind and the brain and are often involved in training activities on the subject, research has shown an alarming diffusion in several countries of *neuromyths*, i.e., beliefs resulting from an oversimplification of neuroscientific findings in the field of education (Lancellotti 2017). Educational neuroscience, as ITD-CNR researcher Chiara Fante has made clear, is concerned with the study of variables that can maintain student motivation and a good attitude towards challenges and possible difficulties. Scientific evidence suggests that a *growth mindset* is crucial to promote a positive attitude towards studies and school activities, especially in students traditionally associated with greater failure. In the Italian context, as argued by Chiara Malagoli, also of ITD-CNR, law no. 170/2010 has recognized *dyslexia*, *dysorthographia*, *dysgraphia* and *dyscalculia* as specific learning disorders. Therefore, it is necessary to emphasize the importance of individualized and personalized teaching, to promote the use of compensatory tools and dispensatory measures, and to protect the right to learning of people with disabilities.

One of the critical aspects of independent living in groups of people with intellectual disabilities (especially Down syndrome) is the need for a constant presence of an educator in the organization of the educational apartments provided by the associations and institutions that provide care. Researchers aim to extend and complete the functionalities offered by cloud-mobile platforms so that caretakers can provide comprehensive support to people with intellectual disabilities who experience independent living. In the *Smart Home* vision, researchers are investigating how ambient assisted living modules can be extended and adapted to support independent living in sheltered housing for people with intellectual disabilities.

Social sharing systems allow the sharing of digital resources that are useful for visual rehabilitation and the evaluation of proven accessibility in the field, where anyone can collaborate, users with disabilities, their families, schools, and rehabilitation professionals. Aggregators of software, games, videos, self-created resources, links, and information accessible to the entire large community of professionals and family members are set up to improve the skills and abilities of children with visual impairments give persons with disabilities the opportunity to grow and reach their full potential.

One of the strengths of our society is the education and research that takes place in universities. However, too many people with disabilities find it difficult to access this right due to numerous barriers and obstacles. As Pope Francis (2015) has pointed out, the *university experience of students with disabilities* poses significant challenges for both them and their teachers. These challenges often stem from a lack of accessible digital resources and a lack of digital skills among academic staff to adequately address the needs of fragile students. Teachers and accessibility liaison officers often do not know how to support students with disabilities. There is an undeniable gap in cross-national research on the specific needs of students with disabilities regarding accessible educational materials and the needs that arise from distance learning, as well as the knowledge and experience of academic staff and accessibility liaisons in universities regarding different forms of accessible materials and the provision of courses in accessible distance learning.

4. Global Perspectives on Inclusion

The reduction of inequalities and social exclusion has proven to be a key challenge for the development of science policies for an inclusive society. At the same time, there is great potential in the opportunities offered by new forms of innovation and citizen engagement. Given the urgency of making a constructive contribution to the Social Doctrine of the Church on the inclusion of persons with disabilities, it is urgent to bring to the attention of science policy institutions the need to improve science and technology efforts in this direction. What our world seems to be expecting from scholars is to take up the historical challenge of reassessing the meaning, scope, and boundaries of social sciences and humanities as well as of their 21st century offspring (i.e., computational social and cultural analysis, and innovation in religious studies) for the foundation of innovative, reflective, and inclusive societies on a global scale (Fiorucci 2020). Hence the science policy survey presented in this paper ought to be complemented by analogous endeavors focused on Africa, Asia and the Americas. Most importantly, the inclusive society cannot be understood without a reference to the family (Donati 2023), which is currently missing in most policy documents.

An articulated notion of the inclusive society is still a *desideratum*. It is time for scholarly communities in the social sciences and humanities to (a) recognize cross-cultural inclusiveness as an irreversible orientation in the contemporary world, (b) give due value and recognition to the world cultural heritage and to approaches that enhance the plurality of human civilizations, (c) incorporate them into standard academic tasks (Pozzo 2021). The experience of *Horizon 2020* has made it clear that the best way to implement interdisciplinarity with the full involvement of social sciences and humanities is collaborating in an atmosphere of mutual respect (EC 2021a, 6). The challenge to tackle remains, however, to react to the fact that we are apparently still unable to go beyond established disciplinary paradigms. Here, too, reflection is mobilized to involve social sciences and humanities in research in all fields of science for the benefit of social innovation, the backbone of all European science policies. In this direction, a useful reference can be made to taking up two central tenets of Kantian philosophy: the dignity of man (*homo noumenon*) and the moral law. If it is beyond doubt that Kant has proved vital to mankind since the end of World War II for his framework of world peace, it is to be expected that Kant will again prove vital to what remains of the twenty-first century for his shaping of an inclusive society.

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TOWARDS A NEW WELFARE OF RIGHTS. PEOPLE WITH DISABILITIES AND THEIR FAMILIES AS PROTAGONISTS OF CHANGE

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Abstract

The disability world is not a world apart. It is part of the world. Let's start from these words to outline a definition of what the term 'disability' means today and to explain how, for eighteen years, i.e. since 2006, there has been a real change, dictated by the approval of the UN Convention on the Rights of Persons with Disabilities, the first UN Convention of the new millennium.

The Convention, which became Italian Law 18/09 in 2009, speaks clearly and must be the main point of reference for everyone: "Persons with disabilities are those with an enduring physical, mental, intellectual, neurodevelopmental or sensory impairment that — in interaction with barriers of various kinds — may hinder full and effective participation in the various contexts of life on an equal basis with others".

The turning point was epochal and can be summarised as follows: an individual is more or less a person with a disability depending on his surroundings, and on if it is more or less adequate to allow people with disabilities to have the same opportunities as everyone else. In other words, it depends on where and how a person lives.

The consequence is logical and suggests that the welfare of protection adopted so far to 'protect' persons with disabilities, which during the Covid pandemic, for example, did not fulfil its function of 'protection' at all, must in particular make space for a welfare of inclusion, territorial proximity and participation; a welfare, in short, based precisely on human rights and on the concrete application of what the UN Convention establishes.

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As is well known, the spread of the Covid virus in our country and worldwide, the fourth anniversary of which we are celebrating in these very months, has severely tested the entire Italian system and in particular our National Health System and that of Social Protection. Remembering the thousands of victims is a duty, to say the least, but so is thinking back to the state of great concern in which so many people have lived.

These concerns, with all the associated difficulties, were even greater for the thousands of persons with disabilities in our country, whose living conditions were already largely determined by levels of protection and social inclusion that were not properly and adequately fulfilled.

The impact of the pandemic on our communities, therefore, constituted a further, dramatic milestone, obliging us to reshape certain priorities in a direction that envisages, first and foremost, the guarantee of greater protection of the health and safety of all citizens, but even more so of those who are most vulnerable and exposed to health-related risks.

If, therefore, from a cultural point of view, people with disabilities demand protagonism over all their life choices, with the overcoming of a welfare system that 'protects' them from above and from outside, what happened between 2020 and 2022 makes it clear that the system has failed from its very assumptions.

In our country, too, there has been a recent change, from a regulatory point of view, with the approval of Law 22 of 2021, which has been delegated to the government in the field of disability, and whose various implementing decrees are now being finalised.

This regulation, in fact, immediately establishes new assessment criteria based on the definition of persons with disabilities, referring precisely to the before mentioned first article of the UN Convention on the Rights of Persons with Disabilities, and sanctions a functioning profile that takes into account the person in his or her enablement, awareness and self-determination, through customised projects that see the person himself or herself fully involved in decisions on how, where and with whom to live.

Two Implementing Decrees have already been published in the Official Gazette, namely Legislative Decree No. 222 of 2023, containing Provisions on the upgrading of public services for inclusion and accessibility, in implementation of Article 2, paragraph 2, letter e), of Law No. 227 of 22 December 2021, and Legislative Decree No. 20 of 2024 (Establishment of the National Guarantor Authority for the Rights of Persons with Disabilities, in implementation of the delegation conferred on the Government).

Improved in the text, thanks also to the collaboration with the Institutions of our Federation, the Decree on the new National Guarantor, which will become fully operational from the beginning of 2025, will create an independent guarantee body, homogeneous in structure and competences to the Guarantor Authorities already active in the legal system, whose task is to promote and protect human rights and to fight discrimination phenomena.

Very importantly, access to the National Guarantor will be free of charge and will allow an authoritative opinion to be obtained within a few months, an opinion that will be notified to the entity and/or person who has discriminated against a person with disabilities. The opinion, although not on the same level as a court ruling, depending on the seriousness of the discrimination implemented, will, on the one hand, commit the entity or person discriminating to eliminate the discrimination within a short period of time, through "reasonable accommodation", with the overcoming of the discrimination or the commitment not to repeat it, and, on the other hand, it will contribute to the understanding of the respect of the human rights of persons with disabilities within society in all its articulations, to ensure full participation, inclusion and full citizenship.

It will certainly be important that the figures called upon to make up the body have an in-depth knowledge of the world of disability and know how to listen to the requests of persons with disabilities and their families, but in any case, this is another important step forward for the full and effective implementation of the UN Convention, relaunching the fundamental role that persons with disabilities and those who represent them must have to promote their rights.

From the point of view of practical developments, the other Implementing Decree published so far in the Official Gazette is equally important, because it marks a big step forward for the accessibility and inclusion of people with disabilities in working contexts.

But that is not all: in addition to guaranteeing the accessibility of Public Administrations to persons with disabilities and the uniformity of the protection of employees with disabilities in the Public Administrations all over the national territory, for the purpose of their full inclusion, in compliance with European and international law on the matter, the approved text provides an even more complete definition of accessibility, speaking of it as "on an equal basis with others, of the physical environment, of public services, including electronic and emergency services, of information and communication, including computer systems and information technologies in Braille and in formats that are easily readable and comprehensible, including through the adoption of specific measures for the various disabilities or of assistance mechanisms or the provision of reasonable accommodation".

And last but not least, on the cultural front, the draft decree, whose approval is imminent, is perhaps even more significant, and a valuable stimulus to a truly new 'culture of disability'. It defines the condition of disability, the basic assessment, the reasonable accommodation and the multidimensional assessment for the elaboration and implementation of the arranged and participatory individual life project.

In fact, it is a text that introduces substantial changes in the Italian legislation on disability on the definition of the condition of disability, basic assessment, reasonable accommodation and multidimensional assessment for the elaboration of a personalised and participatory individual life project.

Among the main innovations, particularly noteworthy is the reunification and simplification of assessments for civil invalidity, disability and work disability in an all-inclusive definition of disability status, not to mention the introduction of a multidimensional disability assessment for the creation of customised life projects.

These are certainly fundamental steps to substantially change our system and increasingly meet the needs of citizens with disabilities, where we speak, for example, of wanting to analyse and regulate disability itself from the point of view of the individual perspective, but also of interaction with the environment: in other words, as mentioned at the beginning, it is one of the crucial points of the UN Convention.

And finally, there is a further aspect that has always been a priority for our Federation: with the approval of this decree, even at the legislative level, the language on disability will become more substantial, with the word 'handicap' disappearing from legal terms and being replaced by the words 'condition of disability'. And as far as persons are concerned, we will no longer speak of 'handicapped', 'handicapped persons', 'differently abled', 'persons with disabilities' or 'disabled persons', but only and exclusively of 'persons with disabilities', again in line with the UN Convention.

Everything, of course, will have to be verified and punctually monitored, in the coming years, at the time of the concrete application of the provisions mentioned above, but we believe that the road taken is the right one, to finally respond to the request for full and integral citizenship of persons with disabilities and their families, arriving at a more just, cohesive society, respectful of the many diversities. Arriving, in other words, at that substantial reform of the present welfare system, based on the protection system, in favour of a new model based on human, civil and social rights.

SESSION 6. PROMOTING SOCIAL JUSTICE IN PARTICIPATORY SOCIETIES: A GLOBAL PERSPECTIVE

PEOPLE WITH DISABILITIES IN REMOTE INDIGENOUS COMMUNITIES[1]

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People with disabilities face distinct challenges in remote indigenous communities as compared to other societies. There are institutional, cultural and ecosystem characteristics that create distinct contexts worldwide. This requires new approaches and innovative solutions.

An illustration of this distinction is the fact that snakebites are a major public health problem in indigenous forest communities, leading to acute local and systemic damage with resulting deficiencies. Access to antivenom treatment is poorer for indigenous peoples compared to other societies. Snakebites at an early stage of life may deprive children of sensory and social experiences and of learning their future roles in their communities.

From an institutional point of view, indigenous communities are frequently neglected by governments as they often have low political weight in elections and demand higher costs for public services. Governmental institutions are often completely absent and, when present, are weaker and poorly equipped to deal with different realities of indigenous communities. Public schools do not have adequate infrastructure and well-trained staff to deliver appropriate education for students with disabilities. Community health agents do not have adequate training to work with people with disabilities.

There are deep cultural differences between indigenous and non-indigenous societies. Some indigenous societies have strong prejudices against people with disabilities, including murder at birth. On the other hand, indigenous peoples often have collective approaches, including food sharing practices, that benefit people with disabilities. Outside interventions pose ethical and methodological challenges.

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[1] Webinar for the 2024 PASS Plenary Session on "Disability and Human Condition. Changing the social determinants and building a new culture of inclusion", Casina Pio IV, 9-10-11 April 2024.

Indigenous peoples have close relationships with natural ecosystems where they live. Livelihoods depend on activities such as agriculture, fishing and forest gathering. Differently from urban societies where there are jobs that can be available to people with disabilities, indigenous communities often have few work opportunities for people with disabilities. Climate change poses threats but also new opportunities.

New approaches and innovative solutions are needed. This includes health programs to reduce avoidable disabilities (e.g. snakebites), education programs to offer fair opportunities, respectful dialogue to bridge cultural divides and work opportunities that tap new technologies, including those aimed at adaptation and climate justice.

THE VULNERABILITIES OF PERSONS LIVING WITH DISABILITIES IN NIGERIA

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Abstract

In Nigeria, around 25 million individuals, or 15% of the population, live with a disability. On March 30, 2007, the government ratified the United Nations Convention on the Rights of Persons with Disabilities, and the Optional Protocol was adopted in 2010. Discrimination against people with disabilities (PWD) is prohibited under Nigerian law, and the National Commission for Persons with Disabilities seeks to prevent discrimination while also ensuring equal rights and opportunities for PWD. However, many disabled Nigerians experience discrimination and ostracism in their communities. They frequently live in extreme poverty, face violence and shame, and lack proper housing, education, and healthcare. Access to governmental services and opportunities is commonly limited. The majority of Nigerians are Christians or Muslims, with others practicing indigenous religions. Indigenous faiths' traditional beliefs frequently regard disability as a spiritual illness or curse that necessitates a spiritual cure. PWDs encounter different problems depending on the type and impairment severity. Many people with disabilities, including children, become street beggars and may not have access to formal education. The vulnerabilities of people with disabilities in Nigeria are explored to provide insights and answers to important challenges and recurring problems. This paper discusses ways for addressing some of these vulnerabilities.

1. Introduction

According to the World Health Organisation (WHO) key facts, an estimated 1.3 billion people experience significant disability and 80% of these are in low-middle income (developing) countries, such as Nigeria (World Bank, 2020). Nigeria is one of the most densely populated countries in Africa, with over 200 million people (National Bureau of Statistics, 2022). About 25 million people in Nigeria are living with one form of disability or another (Ayub & Abubakar, 2022; Umoh & Unaka, 2019; Obiakor & Eleweke, 2014; Centre for Disability and Development Innovations, 2016, WHO, 2011). It is also estimated that nearly 40% of people with disabilities in Nigeria have multiple impairments (Thompson, 2020). Thus at least three million out of the 25 million Persons with Disability (PWDs) in Nigeria are said to be severely afflicted and unable to independently function physically and/or socially (Ibekwe &Aduma, 2019).

The most prevalent forms of disability in Nigeria include (1) visual impairment; (2) hearing impairment; (3) physical impairment; (4) intellectual impairment; and (5) communication impairment (Umeh & Adeola, 2013). The prevalence of disability in Nigeria has been attributed to untreated preventable diseases, congenital malformation, birth-related incidents, and physical injury due to frequent road traffic accidents, psychological dysfunction, and outbreaks of infectious diseases. Other reasons for the prevalence of disabilities in Nigeria include drug misuse, unchecked chronic illness, and results of conflicts (Akinkugbe, Lucas, Onyemelukwe, Yahaya, & Adamu; 2010; Uduu, 2020; Ebenso & Eleweke, 2016). According to Smith (2011) and Adewokan (2019), most causes of disability in Nigeria can be traced to preventable diseases, injuries, and unhealthy environments. Inadequate immunization exposure to childhood preventable diseases also results in some forms of childhood disabilities (Department for International Development, 2000). Smith (2007) attributed the significant number of disabilities in infants in the country, further to poor maternal and neonatal care. Furthermore, according to Smith (2007), poor trauma care in health facilities in Nigeria contributes to infections that increase disabilities. Also, poor nutrition is believed to increase disabilities among poor people. Furthermore, due to the battle or one-sided violence arising from insurgency in the North-East since the beginning of the twenty-first century, the region has the highest number of people with disability in the country (Uduu, 2020; UNDP, 2021).

Looking at the various reasons for the high disability rate in Nigeria, the position of PWDs in Nigeria has been described as *historically bleak*, because *most disabled persons lacked access to education, healthcare, and employment opportunities that could lift them out of the vicious cycle of poverty and debility* (Ibekwe & Aduma, 2019 p. 137).

2. Poverty and Disability

Poverty and disability are indeed a vicious cycle. According to Adewokan (2019), a body of research shows that disabled people are the poorest and most marginalised persons in the world. Omiegbe (2021) asserts that disabled people are among the poorest of the poor. Poverty is a state or condition in which one lacks the financial resources and essentials for a certain standard of living (see UN, 2020), and Aigbokhan (2000) defines poverty as the inability to attain the least quality of life. Disability is further worsened by poverty. Poverty makes a major difference in the vulnerability of PWDs in Nigeria. PWDs who are from comfortable homes can afford facilities that can assist them. Though these PWDs may face discrimination in some aspects, life is made more comfortable for such persons. It is an observed fact that while a disabled person from a well-to-do-home can afford the facilities, education, health care, and other opportunities to make life bearable, the disabled person who lives in poverty is more vulnerable. It has been estimated that approximately 9 out of 10 PWDs in Nigeria live below the poverty line (NILS 2010).

Disability can be viewed as both the cause and consequence of poverty (Smith, 2011). The relationship between disability and poverty has been continually referred to as a vicious cycle. Yeo (2005) describes disability and poverty as interconnected manifestations of the same processes. This is because disability can reduce access to education, employment, opportunities, and resources, increasing the risk of poverty. Correspondingly, poverty-stricken persons can develop disabilities because of very poor nutrition, unhygienic environments, untreated diseases, and inability to access health care services (Smith, 2011). The disabled are at a greater risk of poverty due to inadequate immunization, unemployment, injuries, and infectious diseases (Elwan, 1999). Poverty and disability are seen to repeatedly reinforce each other, creating a vicious cycle (Inclusive Futures, 2020).

Ibekwe & Aduma further describe disability thus: *... a vicious cycle as it is both caused by poverty and causes poverty. It is caused by poverty when able-bodied people develop disability due to inadequate nutrition, disease, unclean and dangerous environments, inefficient and inaccessible healthcare services, poor infrastructure, and poor lifestyle choices often caused by ignorance and lack of education. Disability causes poverty by reducing access to education, employment, developmental opportunities, and resources* (Ibekwe & Aduma 2019, p. 140). The World Health Organization reports that 'on average, persons with disabilities and/or households with a disabled member experience higher rates of poverty and deprivation, including food insecurity, poor housing, lack of access to safe water and sanitation, inadequate access to healthcare, and have fewer assets than persons without a disability' (WHO, 2011). It is noted that PWDs and older persons (OPs) and those who live on less than US$1.9 per day in line with the international standards are more vulnerable than other members of a population (Aluko, Balogun, Iyoho & Wadinga, 2023). Therefore, disability inclusion plays an important role in addressing the relationship between disability and poverty.

Adewokan (2019) asserts that how disability is seen or perceived in different cultures and societies will give meaning to how it should be addressed. Therefore this paper focuses on PWDs and poverty in Nigeria, by highlighting their peculiar vulnerabilities; it also makes recommendations for alleviating their plights. The position of the Nigerian government and non-governmental organisations are discussed, while the lapses thereof are brought to light to be addressed.

3. The Nigerian Government's Approach to Disability

The 1999 Constitution of the Federal Republic of Nigeria (Constitution of Nigeria, 1999) confers definite rights fundamental to the existence of all its citizens, which include PWDs. These are inalienable rights and PWDs cannot be deprived of them. These rights include the Right to Freedom from Discrimination; Section 42(2) of the Constitution stipulates that "no citizen of Nigeria shall be subjected to any disability or deprivation merely by reason of the circumstances of his birth". This indirectly addresses the issues of PWDs providing for their access to equal and fundamental rights for all (Doma, 2020). Nigeria ratified the United Nations Convention on the Rights of Persons with Disability (CRPD) on 30 March 2007 and its Optional Protocols on 24 September 2010.

On 23 January 2019, Nigeria's President signed into law the Discrimination against Persons with Disability (Prohibition) Act (2018) (Human Rights Watch, 2019). The law enshrines the recommendations of the Convention on the Rights of Persons with Disabilities by providing for penal damages to be paid to victims of discrimination who are living with disabilities. According to section (1) of the law, anyone found guilty of discriminating against a person with a disability would be liable to a fine of N100,000 in the case of an individual perpetrator, or N1 million in the case of an institution or a term of six months in jail or both. The law prohibits discrimination against people living with disabilities (PLWD), and sanctions those who contravene this law with fines. Furthermore, a five-year provisional period was stipulated for the modification of amenities, particularly in public buildings, and fixing assistive tools in vehicles to make them accessible and usable for people with disabilities.

In line with the Prohibition Act of 2018 bill, the Nigerian President in 2018 also approved the establishment of the National Commission for Persons with Disabilities (NCPWD). The Commission is to prevent discrimination against persons with disabilities and to make every one of them have equal rights and opportunities like their counterparts with no disabilities. The act is divided into eight sections as follows:

a) Prohibition of discrimination and awareness of programmes
b) Accessibility to physical structure
c) Road transportation
d) Seaports, railways and airport facilities
e) Liberty, right to education, health, and first consideration in queues, accommodations and emergencies
f) Opportunity for employment and participation in politics and public life
g) Establishment of the National Commission for Persons with Disabilities
h) Appointment and duties of executive secretary and other staff.

Nigeria, through this act, took the first major step towards the fulfilment of the CRPD, and nine out of the 36 states in Nigeria have state-level disability laws (Wahab, Jawando & Oyenuga, 2022). Since Nigeria ratified CRPD in 2007 and the Optional Protocol in 2010, civil society groups and PWDs have called on the government to put it into practice. The Discrimination against Persons with Disabilities (Prohibition) Act, of 2018 is known to have been the effort of relentless advocacy by disability rights groups and activists (Ewang, 2019). Nigeria has numerous Non-Governmental Organisations (NGOs) for PWDs in the country.

4. Vulnerabilities and Challenges of Persons with Disabilities in Nigeria

Despite the Nigerian Government's positive approach in committing to key international and domestic instruments towards PWDs, and the activities of NGOs in support of PWDs, several PWDs still suffer significant levels of discrimination and are often prevented from participating in their communities in Nigeria. Since the Nigerian government ratified the United Nations Convention on the Rights of Persons with Disabilities in September 2010, it has not submitted a report to the UN on the CRPD, due to the lengthy processes. This has limited the impact of UNCRPD in Nigeria (Wahab et al., 2022).

Many PWDs in Nigeria face human rights abuses such as stigma, discrimination, violence, and lack of access to healthcare, housing, and education. Many disabled citizens are known to live in relative and abject poverty, and are often hampered in their access to public services and opportunities. The several challenges PWDs face include negative treatments and attitudes which stem from some members of the society. It has been indicated that evidence abounds that people with disabilities in the country continue to experience discrimination, and exclusion, and encounter barriers in accessing various services and opportunities in the country (Eleweke, 2013; Obiakor & Eleweke, 2014). Furthermore, Okakwu (2019) emphasises that despite the new law, Nigerians living with disabilities lament discrimination.

Poverty has been a major factor that has led to the discrimination of PWDs in Nigeria. Coupled with their preponderant economic inadequacies, there are not enough well-established governmental social welfare programmes to cater to this category of persons. It has been stated that in many developing countries, the government is not supportive of the human capital development of people with disabilities (Aiyeleso, 2016). According to Ajuwon, Ogbonna, & Umolu (2014), socio-economic difficulties and lack of government policies and support are the reasons why families with persons with disabilities are unable to meet their needs. It is further reported that there are no adequate social protection schemes (World Bank, 2020).

Apart from poverty, another major factor that makes PWDs vulnerable to exclusion is prevalent cultural and religious beliefs. Nigeria is a country of immense ethnic, cultural, linguistic, and religious diversity. The exact number of ethnic groups in the country is not known, but it is estimated to be between 374 and 610 (Osaghae, 2002). Each of these ethnic groups has their unique indigenous forms of religious beliefs before the introduction of Christianity and Islam. Many Nigerians can now be described as devout Christians or Muslims. However, for many, their traditional beliefs still shape their understanding of disability (Doma, 2020). Disability is usually seen as a spiritual sickness or curse. The causes of disability are attributed to a number of factors, such as violations of ancestral and societal norms; offenses against the gods of the land; breaking laws and family sins; misfortune; witches and wizards; and adultery (Eskay, Onu, Igbo, Obiyo, & Ugwuanyi, 2012).

Religion and cultural beliefs negatively affect the realisation of the rights of persons with disabilities. According to Doma:

> *… some cultures are still repugnant to natural justice equity and good conscience. They see disabilities as evil, carriers of evil, bad luck, ill luck, mis-*

> *fortune, death, and curse bearers and carriers. In some Nigerian cultures, if a child is born deformed, such a child is thrown into evil forests and the deities are appeased for the cleansing of that family. Those who survive the ordeal are always isolated, marginalized, and not allowed to participate fully in society. They are not allowed by such communities to mingle and enjoy the same rights and privileges as others in the community and are forbidden from participating in cultural activities* (Doma, 2020, p. 14).

Apart from cultural beliefs, some people also use the Bible and the Quran to claim that PWDs are in their condition as a result of a curse from God or that of their parents and forefathers (Eskay et al., 2012; Doma, 2020). This further leads PWDs to be isolated, rejected and discriminated against. Some people with disabilities are even denied access to worship centres because of their condition (Doma, 2020).

There are also labelling and derogatory names used to describe persons with disabilities according to the perceived sin or offence committed. For example, in Yoruba, names like Abirun (handicapped), Abami (strange person), Didinrin (imbecile), and Alawoku (mentally retarded) are used to describe PWDs (Adewokan, 2019). These names are believed to further cause grievous pains and barriers that limit PWDs inclusion (Eskay et al., 2012). These also affect their attitude as deduced by some scholars (Etieyibo & Omeigbe, 2016; Eskay et al., 2012; Maurya & Parasar, 2017); they discussed attitude and culture as contributing factors to the discrimination of people with disabilities. This negative attitude affects PWDs in several ways, further worsening their exclusion. Attitudinal and physical barriers are also among the major challenges that prevent persons with disabilities in Nigeria from obtaining gainful employment (World Bank, 2020). The false and harmful beliefs about disability can have implications for all aspects of the lives of persons with disabilities and their families.

As a result of the cultural and religious beliefs and attitudinal position held towards some PWDs, stigmatisation of, and discrimination against PWDs abound. The World Bank disability inclusion assessment in Nigeria in the year 2020 revealed that persons with disabilities lack access to basic services and that attitudinal barriers represent a major impediment to their socioeconomic inclusion. Furthermore, inclusive policies were either non-existent, weak, or inadequately implemented (World Bank, 2020).

In 2018, the Grassroots Researchers Association (GRA), a leading grassroots research-based non-governmental organization in Nigeria, surveyed the needs and challenges faced by persons with disabilities focusing on the

North-Eastern States seriously affected by the Boko Haram conflict. The majority of those interviewed said they were negatively treated by some members of society, ill-treated, and referred to as beggars.

It has been observed that in most parts of Nigeria, people living with disabilities, especially children who ought to be in schools, are in the street begging for alms. This is a major problem that has contributed to the antisocial behaviours manifested by people living with disabilities, which resulted in the way society views them as people who need to beg for alms to survive (Olawale, 2007). Ammani's (2010) observation of the populations of beggars and street beggars revealed that people living with disabilities ranked first among other categories of beggars. Ebigbo (2003) found out that many of the street beggars were out to beg because of the neglect they had faced based on their physical condition.

People are not being penalised for discrimination against PWDs in Nigeria. According to Umegbolu (2021), access to justice for non-disabled persons is trampled upon every day. To buttresses this fact, it was reiterated that the court system in Nigeria is congested and it takes time for the common man/non-disabled citizens to get justice. This situation is therefore worse for disabled persons (Umegbolu, 2021). Added to it, many of the courts have no *post barriers on gutters, no ramps or handrails to aid disabled persons in the courts. No instructions or guidelines for the hearing impaired, no recorders, no sign language interpreters, and no provision for the blind either… disabled parties cannot access the offices, rooms, including toilets (which are too small), and even the roads are filled with stones, so even if they can afford a mobile wheelchair, the road is unmotorable, hence cannot be used by the disabled* (Umegbolu, 2021, p. 3).

Though education is seen as a panacea for a better life and improved lifestyle, children with disabilities still face challenges enrolling in school, and many never get enrolled at all. Nigeria has a high rate of out-of-school children, and the disabled and the poor are a majority (Ibekwe and Aduma, 2019). In the education of PWDs, assistive devices and technology are not readily available and are unaffordable (World Bank, 2020).

5. Opportunities for Persons with Disabilities in Nigeria

According to the World Bank's (2020) rapid assessment of disability inclusion in *Nigeria, civil society is weak with regard to disability inclusion and disability inclusion is also not a priority for government ministries, departments, and agencies in their policies, budget allocations, basic services provision, programs, and infrastructure*. The Federal Ministry of Humanitarian Affairs, Disaster Management, and Social Development, established on August 21, 2019, have the mandate for disability inclusion. Nonetheless, in Nigeria there are many obstacles that PWDs must overcome to access social services and economic opportunities. These obstacles include stigma, discrimination, and cultural and religious barriers. Even though the government has taken action by ratifying the Discrimination against Persons with Disabilities (Prohibition) Act, for example, it is still difficult to put the law into practice. Despite the dire circumstances surrounding a large number of people with disabilities in Nigeria, certain opportunities should be highlighted.

5.1. Reduction of Poverty

The implementation of the first Sustainable Development Goal, SDG 1 on the eradication of poverty and specific targets, will be of immense value to lessen the plight of PWDs living in poverty. Social protection schemes should adequately include PWDs with tailored interventions to reduce the impact of poverty. The Federal Ministry of Humanitarian Affairs, Disaster Management, and Social Development is invested with immense responsibility to improve the socioeconomic welfare of PWDs. The National Commission for Persons with Disabilities is an agency under this ministry. Thus, deliberate actions should be implemented by local, state, and federal governments, and Civil Society organisations toward the economic empowerment of PWDs (Omiegbe, 2021; Wahab et al., 2022).

Wahab et al. (2022) recommend amplifying the voice of PWDs as a means to reducing their vulnerability. This can be done by empowering, encouraging, and mobilising PWDs to speak out about their plights on stigmatisation and harassment in different communities. This allows for increased awareness and knowledge *against violations of their rights to access public utilities, education, health care, transportation, employment, and inclusion in governance* (Wahab et al., 2022 p 33).

5.2. Cultural and Religious Perspectives

Cultural and religious beliefs are frequently the root causes of negative attitudes towards people with disabilities. These false beliefs, like the idea that sins are connected to disabilities, cause rejection, neglect, and a diminished sense of self-worth. Utilisation of anthropological methods, in collaboration with local communities, religious authorities, and traditional healers, can be crucial in deconstructing these damaging notions. It is possible to incorporate cultural sensitivity training into school curricula, which will help children develop an inclusive mind-set towards PWDs from an early age. As recommended by the World Bank (2020) households; community members such as religious, traditional, and opinion leaders; schools; the media; and the general population should be targeted with measures to reduce the stigma associated with disabilities and persons with disabilities, based on misconceptions and negative attitudes.

5.3. Promoting Awareness and Shifting Perceptions

Decision-makers, legislators, and government representatives must recognise disability as a development issue. Advocacy campaigns that leverage on the inputs of cultural and religious leaders can aid in altering unfavourable attitudes and diminishing stigma in households and societies. It is now required to include disability in religious stories. This can be accomplished by working with religious leaders to integrate messages of inclusivity and acceptance of people with disabilities into religious teachings and practices. Religious spaces can be used as advocacy platforms, and highlighting the common values of empathy, compassion, and hard work that are found in many different faiths. Religious doctrines that highlight the abilities of PWDs can encourage some of them to pursue productive endeavours. Positive portrayals of PWDs in advertisements, TV series, and movies can dispel prejudices and promote acceptance.

5.4. Implementation of Disability Legislation

The Discrimination against Persons with Disabilities (Prohibition) Act of 2018 should be put into effect. It is possible to guarantee that the legal framework results in real improvements in the lives of people with disabilities by fortifying organisations such as the Disability Commission. Creating alliances with local authorities in the religious and community spheres can guarantee that disability laws are easily incorporated into regional traditions. Legislation and other arrangements intended to support the inclusion and well-being of PWDs can be made more adequate and effective by establishing mechanisms for tracking and assessing the effects of interventions. Programme and policy effectiveness can be regularly evaluated to ensure well-informed modifications and advancements.

5.5. Data Collection and Research

For well-informed policymaking, the dearth of data on the prevalence of disabilities must be addressed. Through its comprehension of regional contexts, cultural quirks, and practises pertaining to disability, anthropological research can make a valuable contribution. As evidenced by the 2018 Nigeria Demographic and Health Survey, incorporating disability modules into surveys is a positive move. To ensure a nuanced and culturally sensitive approach, tailored interventions based on regional anthropological insights are required.

5.6. Inclusive Employment and Livelihood Interventions

Inclusive employment initiatives such as the DEI (diversity, equity, and inclusion) model are essential in addressing the high rates of unemployment among individuals with disabilities. Individuals with disabilities can gain economic empowerment through the provision of entrepreneurship training, business advisory services, and support for locally manufactured assistive devices. It is possible to promote PWDs' ease of mobility and ability to take advantage of economic opportunities by implementing inclusive urban planning and accessible infrastructure, which guarantees that public areas, courts, and government buildings have ramps, handrails, and other amenities that meet their needs.

5.7. Empowering Disability-Focused Organizations

Organizations dedicated to disability advocacy and support should be empowered to play a more active role in the inclusion process. This involves providing services to persons with disabilities and their caregivers, ensuring their voices are heard in policymaking. Also, it is essential to sensitise policymakers and implementers to the imperative of strengthening Conditional Cash Transfer (CCT) programmes to considerably address the vulnerability of households in Nigeria (Aluko et al., 2023).

6. Conclusion

To address the issues many Nigerians with disabilities face, a comprehensive strategy that takes into account cultural and religious beliefs is needed. Inclusive policies and initiatives can be implemented with the guidance of anthropological insights. Nigeria can advance its transition to a more inclusive and equitable society by raising awareness, fortifying legal frameworks, gathering pertinent data, and empowering organisations that serve people with disabilities. The national and sub-national governments cannot accomplish their ambitious goal of poverty alleviation and economic growth without actively integrating people with disabilities into the developmental agenda. No matter how gloomy the situation with many PWDs in Nigeria sounds, there are some opportunities for PWDs that can be emphasised and heightened.

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THE INVISIBLE WEALTH OF NATIONS – CARE ECONOMY AND DISABILITY: A COMMUNITY-BASED APPROACH TO PUBLIC POLICIES FROM THE PERIPHERIES

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14.7% of the population of LAC-Latin America and the Caribbean – 85 million people, equivalent to the entire population of Colombia and Peru combined – has some form of disability.

Beyond this global statistic, it is interesting to note that households where people with disabilities live are poorer: in 1 out of every 5 extremely poor households lives a person with a disability; 15% of children with disabilities do not go to school; 1 out of every 2 heads of household with disabilities does not participate in the labor market; illiteracy is 5 times higher among people with disabilities.

The situation of simultaneous poverty and disability also particularly affects women: 6 out of 10 female heads of household with a disabled member are unemployed.[1]

In the case of LAC, this panorama presents a *triple dimension of transition*, reflected in innovations that are still in progress, based on the profound conceptual, programmatic, and technological changes that are taking place in the disability universe, namely:

- **From the bureaucratic to the communitarian.** On the one hand, the innovation of social practices includes attending to the realities of community care, which involves a wide range of supports that seek to protect subjects, families, and the social contexts in which they develop. This social innovation, which has emerged with strength in the most vulnerable reinforce the sense of solidarity and fraternity raised by Pope

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[1] "The Inclusion of Persons with Disabilities in Latin America and the Caribbean: A Path to Sustainable Development". https://www.bancomundial.org/es/news/press-release/2021/12/02/la-inclusion-de-las-personas-con-discapacidad-clave-para-el-desarrollo-sostenible-de-america-latina-y-el-caribe World Bank, 2021.

Francis, especially when he mentions the emergence of popular movements throughout the region.

- **From calligraphic revolution to practical support.** The Convention on the Rights of Persons with Disabilities (CRPD) has been ratified by many countries in the region, but it needs to be translated into concrete funding actions and cross-cutting deployment across all public policies. Simultaneously, a *new new welfare* state must address a profound challenge of innovation, ranging from the proper measurement and statistical recording of disability in its multiple dimensions, also including a set of devices that account for the principle of subsidiarity, overcoming a mere monetary or institutionalist approach to disability and promoting inclusive and effective social policies.
- **From multidimensional barriers to physical and digital autonomy.** At the same time, innovation cannot fail to consider also the technological and scientific level, as it addresses research, medical and therapeutic developments, and a wide range of issues that have to do with accessibility, vulnerability to social networks, social inclusion, promotion, and support of the most disadvantaged sectors.

In times of the digital revolution and considering the experiences developed when Covid-19, it is important to consider not only the risks but also the opportunities offered by new technologies in this field.

In short, whether from the State, from the care economy communities, or from the deployment of new scientific and technological advances, it is a matter of becoming "*social poets of the care economy*", placing special emphasis on overcoming the cruelest or subtlest expressions of the "*discard theory*" of the most vulnerable. The exclusion of people with disabilities can represent a drop of between 3% and 7% of the GDP, which even from an economic perspective and inclusive social productivity means a waste of potential for a concept of integral human development.[2]

1. First innovation

A long and unfinished road to change the way of looking and recording

In the image of the Good Samaritan, the Gospels tell us. "*He saw him and was moved*". While the doctors of the law passed by, the recording of the pain of the neighbor and its practical consequence were a continuum of

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[2] Idem.

mercy that is also important to highlight in these times in the problematic that concerns us.

Throughout social history, the attention to disability has gone through different degrees of conceptual treatment, in a path that has not yet ended despite the normative and practical advances that can be verified in the world and in LAC.

The stations along this path included a traditional model that expressed itself in the extreme of eugenic and shameful discarding and the justification of infanticide – as in ancient Greece; isolation and confinement to hide stigmatization; charitable and beneficent actions that sought to make up for the absence of effective state policies; the emergence of institutional rehabilitation impulses as a consequence of war conflicts and violence; invisibilities and indifference; and more or less eloquent segregation and discrimination.

All this evolution led to a social model, initially in Europe and the United States, generated from movements of organizations of people with disabilities claiming a human rights approach and community-based recovery: "*In this sense, it shifts the locus of disability from the individual to a relational phenomenon between the individual and his or her environment. Conceptual changes regarding disability have occurred in parallel with normative advances to protect and promote the rights of children with disabilities*".[3]

Currently, we could say that we have moved from the biomedical and exclusively social model to the biopsychosocial model, which integrates the above through the terms of functioning, disability, and health. Article 12 of the Convention evolves from a tutelary model to a support model, which enables the autonomy and full exercise of the rights of persons with disabilities.

The Convention seeks to "*promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms*", and defines persons with disabilities as those who have "*long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*". This definition recognizes that disability is a social construct, the result of the interaction between people with impairments and environmental barriers.[4]

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[3] Ullman, Heidi et al. "*Non-Contributory Cash Transfers: An Instrument to Promote the Rights and Well-Being of the Child Population with Disabilities in Latin America and the Caribbean*". ECLAC, 2020 https://repositorio.cepal.org/server/api/core/bitstreams/6fe832a0-3371-4834-b5d7-f8e9f5121bce/content

[4] The principles that govern it are: (i) respect for inherent dignity, individual autonomy and independence, including the freedom to make one's own decisions; (ii) non-dis-

"Disability is not in the person but arises from the interaction of people with environmental barriers (physical space) and attitudinal barriers (society's treatment of them). Once the barriers are eliminated, diversity emerges.[5] *Who are considered persons with disabilities? Some people with long-term physical, mental, intellectual or sensory impairments that affect their full and effective participation in society. The functional alteration may be permanent or prolonged, requiring support for their family, social, educational, or labor integration".*[6]

The conceptual definition is not merely a semantic or grammatical issue but has an impact on the public policies to be implemented. It has consequences on the way in which programs are designed, actions are deployed in the territory and support devices are effective.

Several obstacles still need to be overcome in these conceptualizations:

- Disability cannot be defined as the inability to work, as this vision nullifies processes of social inclusion and integration and causes undesired consequences even in support programs.
- The support and human rights approach is the most appropriate to address this reality, considering the different types of barriers that prevent full and effective social participation on an equal footing with others.[7]

The above leads us to the next point, which is crucial for the deployment of humanized public policies. Without accurate statistics and adequate records that account for this reality, the effectiveness of public policies diminishes and social awareness itself fails to overcome discriminatory or biased views.

Most of the measurement instruments are intended to be applied in censuses and surveys, such as the Model Disability Survey (MDS) and the World Health Organization Disability Assessment Questionnaire (WHODAS 2.0). The Washington Group at the United Nations Statistical Commission

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crimination; (iii) full and effective participation and inclusion in society; (iv) respect for difference and acceptance of persons with disabilities as part of the human diversity and condition; (v) equality of opportunity; (vi) accessibility; (vii) equality between men and women; (viii) respect for the evolving capacities of children with disabilities and their right to preserve their identity. Carcar, Fabiola. Personas con discapacidad: de la prescindencia a sujetos plenos de derecho. *Revista Derecho Laboral*. Buenos Aires, 2015

[5] Argentina, National Agency on Disability https://www.argentina.gob.ar/salud/mental-y-adicciones/salud-mental-y-discapacidad

[6] Idem.

[7] Bietti, María Fernanda. "*Personas con discapacidad e inclusión laboral en América Latina y el Caribe Principales desafíos de los sistemas de protección social*". https://repositorio.cepal.org/server/api/core/bitstreams/1535653e-6f21-456e-bb5a-dc446ff5c8ad/content ECLAC 2023.

developed a short set[8] and a long set, emphasizing comparability and universality of responses across countries.

It is not only the way of looking at the problem that counts, but also the way of asking and recording the problem. Both dimensions are part of the challenge of welcoming and embracing with an expanded way of fraternity and solidarity. The reality of community support also requires special attention when documenting initiatives.

- First, it is interesting to note that instead of using the term "*disability*", a more neutral language is used in the census and surveys, focused on the "*difficulties*" and "*limitation*" to perform basic tasks. In Argentina, Bolivia, Brazil, Colombia, Costa Rica, Guatemala, Nicaragua, Mexico, Dominican Republic, Panama, Paraguay, Uruguay, New Zealand, Italy, Portugal and Israel, among others).
- It is also key to deepen initiatives that must do mainly with the measurement of the care economy phenomenon: measuring its contribution to the gross domestic product with satellite accounts (as Colombia is doing) and within this more general context, not losing sight of the contribution of women in activities related to the care of persons with disabilities, which involve unavoidable challenges of recognition.[9]
- Complying with international standards on how to adequately measure the phenomenon in the educational world and in national censuses is another major challenge. In the case of minors, UNICEF developed specific modules, which have an additional difficulty of implementation because in many cases they are answered by parents or guardians. UNESCO reviewed the methodological framework of the System of Indicators for the Registration of Information on Students with Disabilities (SIRIED).[10]

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[8] It includes questions on six basic domains of functioning: seeing, hearing, walking, remembering, or concentrating, self-care and communication.

[9] "*The System of National Accounts includes within the valuation of the Gross Domestic Product the production of care services, which has a value since it is carried out through market relations. However, the production of care services that does not take place within market relations, that is, unpaid activities that are offered by the household or the community, is left out of the GDP*". Care Economy: literature review, stylized facts and care policies. https://colaboracion.dnp.gov.co/CDT/Desarrollo%20Social/4.%20Documento%20Preliminar%20Econom%C3%ADa%20del%20Cuidado.pdf Care Economy Satellite Account (CSEC) Production and Income Generation Account of Domestic and Unpaid Care Work (TDCNR) Colombia, 2021.

[10] "*It asks directly about disability and medical diagnoses instead of asking about difficulties in performing certain activities of daily living that may limit full and effective participation. – Only the*

- There is another statistical gap with respect to the usual precariousness of children with disabilities who are institutionalized, which is not recorded by household surveys and therefore ignores the vulnerability in which they live, with small spaces, lack of personalized attention, poorly paid staff and the absence of a family support group for more comprehensive support.[11]
- Overcoming the invisible statistics, especially for people with psychosocial or intellectual disabilities, is another enormous challenge.[12] The lack of an adequate diagnosis, the social stigma it causes and the concealment of these situations by the families themselves are major obstacles to progress.[13]
- In terms of evaluating the impact of programs, the situations described above generate a very worrying fog of scientific evidence. "*There are very few studies that analyze the impacts of social protection schemes for people with dis-*

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most severe impairments are asked about, without considering the full spectrum of disability and functionality. – Wide differences are observed in the domains that each country considers without harmonization between countries". Musante, Bianca. "Measuring disability through administrative records of education in Latin America Diagnosis and recommendations to move towards regional harmonization". https://repositorio.cepal.org/server/api/core/bitstreams/b0d4d4a2-e70e-4b8c-9f4e-79c9201dbd54/content ECLAC, 2023.

[11] *Despite this data limitation, it is estimated that 50,000 children and adolescents with disabilities live in residential institutions in Latin America and the Caribbean, most of whom are between the ages of 6 and 18*. "The Inclusion of Persons with Disabilities in Latin America and the Caribbean: A Path to Sustainable Development". https://www.bancomundial.org/es/news/press-release/2021/12/02/la-inclusion-de-las-personas-con-discapacidad-clave-para-el-desarrollo-sostenible-de-america-latina-y-el-caribe World Bank, 2021.

[12] A focus on invisible work may show that it is, for disabled individuals, necessary not only for daily living, but as an underpinning of and safety net below the formally recognized work. We can define invisible work in this context as *all of the unpaid and/or unrecognized tasks that disabled people are obliged to carry out in order to participate in different areas of society whenever accessibility is absent or insufficient*. Crucially, the invisible work carried out by disabled people contributes to them being able to function as students, employees, customers, recipients of health care – and to fulfilling the role expectations associated with being a romantic partner or spouse, a parent, a caregiver, and so on. It serves to bolster the low rate of employment from even lower levels, and so – much like the gendered invisible work previously identified – serves as an informal underpinning to the formal economy. Jan Grue (2023) The CRPD and the economic model of disability: undue burdens and invisible work, *Disability & Society*, DOI: 10.1080/09687599.2023.2255734

[13] "The Inclusion of Persons with Disabilities in Latin America and the Caribbean: A Path to Sustainable Development". https://www.bancomundial.org/es/news/press-release/2021/12/02/la-inclusion-de-las-personas-con-discapacidad-clave-para-el-desarrollo-sostenible-de-america-latina-y-el-caribe World Bank, 2021.

abilities, particularly because the existing information does not allow distinguishing the population with and without disabilities”.[14]

- This leads to the obvious difficulty of adjusting support to the specific requirements of the universe to be served. “*It is not always possible to verify whether reasonable adjustments have been made to ensure the access of persons with disabilities to social protection systems and, secondly, it is not equivalent to provide a pension to a person living in poverty than to provide it to a person with disabilities*”.[15]
- Unfortunately, this series of shortcomings are not only the heritage of LAC countries. In developed countries there is also an alarming lack of statistics on the condition of people living in processes far removed from classic treatment institutions.[16]
- Finally, it is of primary importance to listen to the voice of community organizations and the beneficiaries of the programs, to promote a “*bottom-up*” approach that overcomes paternalistic bureaucracies, actions that do not meet real needs and “t*echnocratic*” positions. Data from household surveys should be combined with data from administrative records, in order to have an on-line record of needs, and also to be able to take advantage of the benefits of big data in expanding the comprehensiveness of interventions.

“*Lord, let him see*”, is not only the appeal of the blind man in the Gospel, but a request that is needed today to make the phenomenon visible and to take due note from all sectors.

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[14] Ullman, Heidi et al. “Las transferencias monetarias no contributivas. Un instrumento para promover los derechos y el bienestar de la población infantil con discapacidad en América Latina y el Caribe”. ECLAC, 2020 https://repositorio.cepal.org/server/api/core/bitstreams/6fe832a0-3371-4834-b5d7-f8e9f5121bce/content

[15] Idem.

[16] “*There is a serious lack of data (either official statistics or research) in EU countries on people's participation in deinstitutionalization processes, their degree of acceptance by the community, the degree of choice about their living situation or their options for leaving the institution in which they reside, the quality of the support they receive, or their perception of the treatment received in terms of dignity and respect, among other issues*”. Transition from Institutional Care to Community-Based Services in 27 EU Member States: Final report. Research report for the European Expert Group on Transition from Institutional to Community-based Care, European Commission, 2020.

Second innovation

Associative creativity to welcome with universality from the peripheries

All the above leads us to a purpose of social innovation that must be expressed at the level of both the State and community practices. It is important to move towards an approach of *universalism sensitive to differences*, according to ECLAC, which builds "*tangible consequences*" from adherence to the Convention.[17]

Thinking from the peripheries and building responses "from below" (paraphrasing the Pope's request in *Laudate Deum* to renew multilateralism), means abandoning unilateral approaches. Neither the State alone can solve all problems, nor can mercantilism or the organized community provide answers if they are left to the law of the jungle of "*every man for himself*".

We need associative formulas built from the existential peripheries, which consider their cries of pain and prioritize a new multidimensional tenderness.

The *new new welfare state* that embraces and enshrines the effective rights of people with disabilities implies a construction that involves political sensitivity, fiscal prioritization in budgets, and continuity in progress. It does not exhaust the set of interventions, but it is an indispensable social network in LAC.

If we take the case of Argentina,[18] people who accredit their disability through an evaluation board and access the Single Disability Certificate, are entitled to, among other benefits, to: 100% coverage in basic health benefits (medicines, equipment, treatments); non-contributory pension; family allowance for a disabled child for formal workers and in vulnerable situations; maternity allowance for the birth of a child with Down Syndrome; the right to study in regular schools and to receive the necessary support to learn and participate; 4% quota of state employment for people with disa-

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[17] "*Although the Convention has been widely ratified by the countries of the region, this change in perspective has not yet been translated into public policies for the social protection of persons with disabilities*". Bietti, María Fernanda. "Personas con discapacidad e inclusión laboral en América Latina y el Caribe Principales desafíos de los sistemas de protección social". https://repositorio.cepal.org/server/api/core/bitstreams/1535653e-6f21-456e-bb5a-dc446ff5c8ad/content. ECLAC 2023

[18] Argentina passed Law 26.378 (2008) approving and adhering to the Convention on the Rights of Persons with Disabilities. Law 27.044 grants constitutional hierarchy to the Convention.

bilities and tax benefits for the private sector to hire people with disabilities; Free Pass in transportation and tax exemption.[19]

This theoretical and regulatory framework contrasts with the reality of the lack of labor inclusion. In Argentina, more than 87% of people over 14 years of age with a Single Certificate of Disability (CUD) do not have a job. Within this universe, according to the latest statistical yearbook of the National Registry of People with Disabilities, there are more than 3,744 people with CUD who are looking for work and cannot find it. Only 3 out of 10 companies currently include people with some type of disability in their work areas, and more than 60% of these organizations lack programs and policies that promote the incorporation of people with disabilities.[20]

All the above leads us to the dimension that has to do with the social reality of popular neighborhoods, where expressions of solidarity coexist with worrying situations of vulnerability. Wherever the real social protection networks of the visible hand of the state do not reach, community networks of support and shelter emerge.[21]

In the families of working-class neighborhoods in Argentina, 42% of the hours that families devote to producing care are unpaid. Working-class neighborhoods have almost twice as many families with care responsibilities as neighborhoods with adequate infrastructure (46.2% vs. 23.9%); families residing in poor neighborhoods spend 10 hours more per week on unpaid work than those families residing in neighborhoods with adequate infrastructure; women in poor neighborhoods with caregiving responsibilities spend 11 hours more on unpaid work than women in households with-

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[19] The regulations also include systems of reasonable supports and adjustments for autonomous living, which facilitate communication, understanding and the expression of the person's will for the exercise of his or her rights. They cover a wide range of interventions: personal or animal assistance and intermediaries, mobility support, support products and/or technical aids.

[20] https://www.defensorba.org.ar/contenido/discapacidad-y-empleo-el-desafio-de-la-integracion – Office of the Ombudsman of the Province of Buenos Aires. 2021.

[21] Mobilization, containment, fraternal embrace and expressions of community accompaniment played a decisive role in avoiding an escalation of Covid-19, as well as being able to cushion social impacts as a result of the confinement policies. The popular movements organized in cooperatives, productive enterprises, community kitchens, complementary mechanisms of education and novel associative forms of popular economy, played a decisive role in avoiding the escalation of Covid-19, as well as in cushioning the social impacts of the confinement policies.

out caregiving responsibilities, and more than twice as many hours as men spend on these tasks.

The *bonus of solidarity* and community fabric is also expressed in a significant fact: only 8% of families with young children are headed by mothers raising children without the support of other cohabitating adults.

The symphonies of care are varied. The tasks fall mainly on women; they affect more intensely the poorest segments of the population; they tend to distinguish strongly between the stage of childhood (which usually falls on the family group, with clear gender tendencies) and the stage of old age (whose care tends to be commercialized, thus impacting more directly on the family economy).[22]

This national reality, given as an example, extends to other cases in the rest of the LAC countries. Women, the rural population, indigenous peoples, and Afro-descendants suffer more serious consequences in the face of disability. "*In countries as different as Brazil, Costa Rica, Ecuador, Mexico and Uruguay, people with disabilities are on average 24% less likely to complete primary education, but 30% less likely if they also belong to an ethnoracial minority. The imbalances are also multiplied by gender-based inequalities. In most countries in the region, the probability of being vulnerable increases if the household is headed by a female head. When there is a functionally dependent person in a household, the study shows that it is mostly women who are responsible for unpaid care work. The value of unpaid care work ranges between 16% and 25% of GDP*".[23]

This panorama leads us to a set of innovations that need to be addressed in the region from a cooperative dimension between the state and the organized community.

- It is essential that the pensions granted are compatible with the work activity of the beneficiaries, with a more flexible approach to cover the additional expenses derived from the disability, building inclusive and non-exclusive systems that avoid incentives to unregistered work.[24] The

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[22] Observatorio del Conurbano Bonaerense. Universidad de General Sarmiento. http://observatorioconurbano.ungs.edu.ar/Newsletter/2023Mayo/index2.html 2023

[23] "*The Inclusion of Persons with Disabilities in Latin America and the Caribbean: A Path to Sustainable Development*". https://www.bancomundial.org/es/news/press-release/2021/12/02/la-inclusion-de-las-personas-con-discapacidad-clave-para-el-desarrollo-sostenible-de-america-latina-y-el-caribe World Bank, 2021.

[24] "*This is due to the fact that the eligibility criteria for social protection programs and, specifically, non-contributory monetary benefits are subject to poverty and to the determination of an inability to work. This widespread situation in Latin America and the Caribbean should be a warning to gov-*

informality rate of people with disabilities is 11 points higher.[25]

- Promote training for self-employment, adequately monitor compliance with labor quotas, generate incentives and subsidies for private companies to remove prejudices and barriers to access and promotion of people with disabilities, are other strategic elements.
- Disability certificates should be easy to obtain, and informative obstacles should be removed, so that the target population can have access to them.
- Cash transfers should be part of more comprehensive assistance.[26]
- The need to consider the framework of decent work and rights of caregivers and cared-for persons is also central as part of the pending agenda.[27]
- Psychosocial disability is the new old name for vulnerability, with serious mortgages for the future. The experience of *Hogares de Cristo* in Argentina addresses this problem. "*The consumption of illicit drugs and alcohol is mainly causing schizophrenia, bipolarity and depression in the adolescent population, illnesses that consequently lead to psychosocial disability. The situation is serious. Already the World Health Organization (WHO) foresees that this will be the third cause of disability in the world caused, among other factors, by the stress and systematic violence experienced in the world*".[28]

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ernments as it impacts employment by promoting labor informality". "Personas con discapacidad e inclusión laboral en América Latina y el Caribe Principales desafíos de los sistemas de protección social". https://repositorio.cepal.org/server/api/core/bitstreams/1535653e-6f21-456e-bb5a-dc446ff5c8ad/content. ECLAC 2023.ECLAC

[25] "*The Inclusion of Persons with Disabilities in Latin America and the Caribbean: A Path to Sustainable Development*". https://www.bancomundial.org/es/news/press-release/2021/12/02/la-inclusion-de-las-personas-con-discapacidad-clave-para-el-desarrollo-sostenible-de-america-latina-y-el-caribe World Bank, 2021.

[26] "*Closing opportunity gaps for children and adolescents with disabilities not only involves providing monetary support, but also developing accessible and inclusive education and health systems*". Ullman, Heidi et al. "Las transferencias monetarias no contributivas Un instrumento para promover los derechos y el bienestar de la población infantil con discapacidad en América Latina y el Caribe" https://repositorio.cepal.org/server/api/core/bitstreams/6fe832a0-3371-4834-b5d7-f8e9f5121bce/content ECLAC, 2020.

[27] *Community care in Latin America and the Caribbean. "Una aproximación a los cuidados en los territorios*". https://lac.unwomen.org/sites/default/files/2022-11/Cuidados_Comunitarios_09112022.pdf UNDP, UN Women, ILO, ECLAC and Oxfam, 2022.

[28] Defensor. Human Rights Commission of the Federal District of Mexico (2010) Psychosocial disability: unacceptable invisibility.

- The promotion of creative modes of community participation and care that promote personalization and family containment is of high impact. In Uruguay,[29] for example, the Community Care Homes are an early childhood care service provided by an authorized caregiver, who works in his/her home or in an authorized community physical space.
- A significant study conducted in 27 European Union member states showed an alarming lack of statistics on people with disabilities living in a deinstitutionalized way. Only the case of Sweden stands out as the country where community involvement in care is achieved, highlighting the importance of family supports and small-scale habitats, rather than larger and less personalized settings for support and social inclusion tasks.[30]
- Regarding access to justice, it is also important to emphasize those cases in which the person with a disability is a victim of the crime of human trafficking, which, despite aggravating the penalty, is not necessarily approached from the specific perspective of "*disability*", but simply of "*vulnerability*", thus making it difficult to implement appropriate restorative measures.[31]
- Not the least of these is the cluster of actions of a cultural nature that must be promoted in order to remove the stereotypes and prejudices disseminated by the media about this universe.[32]

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[29] https://www.gub.uy/sistema-cuidados/tramites-y-servicios/servicios/casas-comunitarias-cuidados-0

[30] 1,438,696 people live in residential facilities and only a minority reside in small community-based (community-integrated) facilities. Transition from institutional to community-based care in 27 EU Member States: Final report. Research report for the European Expert Group on Transition from Institutional to Community-based Care, European Commission, 2020.

[31] "*Almost ten years after the enactment of the specific aggravating circumstance of disability, judges continue to analyze this condition of the victim within broader socio-legal concepts, such as vulnerability. This is highly problematic, as it results in the invisibility of this group of people, for whom a particular way of aggravating the criminal offense was stipulated and, consequently, a different approach to reparation strategies. Disability and other conditions affecting mental health as aggravating factors in the crime of trafficking. A tour through some sentences and complaints of line 145*". Office of the Prosecutor for Trafficking and Exploitation of Persons. Public Prosecutor's Office of Argentina. 2021. https://www.mpf.gob.ar/protex/files/2021/12/Discapacidad-y-otras-condiciones-que-afectan-la-salud-mental-como-agravante-del-delito-de-trata.pdf

[32] Recommendations for the Responsible Treatment of Disability in the Public Media. https://www.argentina.gob.ar/sites/default/files/2021/04/recomendaciones_para_el_tratamiento_responsable_sobre_la_discapacidad.pdf Buenos Aires, 2021.

3. Third innovation

An exponential leap in equity to take advantage of digital and scientific advances

In conclusion, the issue of accessibility to state-of-the-art technologies, which can improve the quality of life and social inclusion of people with disabilities, cannot be overlooked.

The World Health Organization's Global Report on Assistive Technologies identifies critical points to consider, among others: establishment of adequate standards in the manufacturing processes of the products; innovation eco-systems to promote start-ups that can generate exponential advances; reduction of costs and inclusion of the technologies as part of universal health benefits; promotion of industrial policies that favor their production; training of health personnel and families for their use; and the development and implementation of new technologies in the health sector.[33]

In this context, the following opportunities should be considered:

- Telework implies the possibility of overcoming physical accessibility barriers, as long as the right to connectivity and equipment is guaranteed to people with disabilities.
- Equipment that improves hearing, vision and mobility capacity represents an advance in terms of autonomy and independence, which also requires equal access.
- A regulatory effort and the establishment of standards with the manufacturers of new technologies is required, so that they contemplate the inclusiveness of people with disabilities both at the level of equipment and programming (readability, readability, intuitive comprehension, etc.).
- According to the World Intellectual Property Organization, assistive technologies will tend to reach 2 billion people by 2030, including robotization, smart power applications, brain-computer interfaces, smart glasses, home assistance robots, neuro-prosthetics, 3D manufacturing, exoskeleton suits, etc.

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[33] It is recommended that national strategies involving governments, nongovernmental organizations, families, and professional and scientific groups be developed. "*Policy brief: access to assistive technology*". https://iris.who.int/bitstream/handle/10665/339964/9789240016392-spa.pdf?sequence=1&isAllowed= World Health Organization, 2023.

- The issue of artificial intelligence and its regulation is also of prime importance. In the provisions of the European Union, for example, people with disabilities, minors and the elderly are at risk and in need of special regulatory attention.
- The issues of physical barriers associated with a new urban conception are also essential to continue to deepen with technological advances.
- All these initiatives seek not only to improve the quality of life of people with disabilities, but also to promote their inclusion in society and the labor market.

By way of conclusion

Overcoming the double social madness with a mystique of proximity

I would like to quote the phrases of two lay people – today in the process of beatification – who enlighten contemporary life with examples of contemplation and action from various spheres of public service in the broad sense.

Giorgio La Pira, the mayor of Florence in the post-World War II period, once said that "*unemployment is a form of social madness*". Adapting his phrase to the reality we are discussing, in the case of people with disabilities the main challenge is to overcome this "*double form of social madness*", promoting their inclusion, autonomy and equal opportunities and possibilities. It is not a matter of thinking of isolated initiatives, but of endowing them with an associative and cooperative dimension that mobilizes soul, head, and heart, as Pope Francis asks us to do.

Madeleine Delbrel, the French social activist, poet, musician, example of dedication to the humblest from the simplicity of everyday life, spoke to us around the same time of La Pira of a "*mystique of proximity*". It is not a technocratic paradigm or an endless theoretical discussion that we need, but above all a "*revolution of tenderness*" that frees our deepest attention from the daily kidnapping by the noise of social networks and the culture of polarization.

There is a need for embraces that "*prevail in the culture of encounter*", because "*no one is saved alone*".

There is an invisible wealth of nations that we must value in terms of fraternity and the ethical capital of our societies. As in so many other fields of geopolitics, here too, in our more concrete daily lives, we must avoid the globalization of indifference.

LIVING WITH DISABILITIES: THE CONSEQUENCE OF WELFARE REFORMS IN THE UK AND THOUGHTS FOR THE FUTURE

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Abstract

Down the ages, Christian thinkers have attempted to understand the main characteristics of what it is to be human, relating how humans have moral and practical responsibilities for each other. In that context, disability is often misunderstood when the "normal human" is too rigidly defined and adopted as the basis for our understanding disability. A wider and more satisfactory perspective is that an active and aware Christian society[1] should care for all, including those with physical or mental needs that define disabled people.[2] Indeed, the construction of disability theology should encourage a concept of equality that is intrinsically bound up with our humanity, informed by the love of God and carried through by his Church. Christianity, and significantly the Catholic Church, accepted responsibilities for the disabled and care of the elderly. Over the years many religious institutions gained experience in the disability field, but increasingly struggled to meet care needs because of limited resources, personnel or training. Love defines how best to address disability through care and support. Since the 19th century the state has become an increasingly significant provider of health and care for the disabled, often working hand in hand with religious groups and organisations. In an increasingly secular society, religious influences endure through defining morality and distinguishing right and wrong. Such religious influences should be enhanced, enriched and more widely understood. Ideally, religious voices should be more respected, listened to and discussed. This is an appropriate time in the political cycle in the UK, with

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[1] M. Hill, *Social Policy in the Modern World: A Comparative Text*. London: Blackwell Publishing 2006, pps 23-29.

[2] See: Brian Brock and John Swinton, eds., *Disability in the Christian Tradition*. William B Erdmans, publishing. Michigan USA, 2012. Roy Hanes, Ivan Brown and Nancy Hansen, *The Routledge History of Disability*. Routledge, 2018.

the election of a new government in July 2024, to reconsider disability care. The paper considers the ongoing disability reform programme for the payment of disability benefits. It discusses current approaches to disability in the United Kingdom, with its emphasis on economic costs in the context of the social doctrine of the Church and the role of relational good.

Introduction

Pope Francis gives a succinct summary of the main challenges facing the disabled in a changing world, where the disabled may be dehumanised as economic units of resource. Pope Francis observed:

> "In the end, persons are no longer seen as a paramount value to be cared for and respected, especially when they are poor and disabled, 'not yet useful' – like the unborn, or 'no longer needed' – like the elderly" (*Fratelli Tutti* 18).[3]

The paper outlines the planned reforms of the main disability benefits within the UK linked to its distinctive National Health System (NHS),[4] which is based around the hallmarked "Beveridge principles", broadly-adopted by successive UK governments. Beveridge is premised on the application of the general principle of entitlement to most social care benefits based on need. Beveridge principles are under severe strain as economic policy and austerity has resulted in major policy adjustments calibrated in terms of a public/private split. This has meant tighter controls on disability payments and controls on public payments, together with greater scrutiny of claimants: many poor and severely afflicted people have lost out on discretionary benefits amidst the complexity of applications and delays in processing claims. Matters have deteriorated further due to the combined impact of the Covid-19 pandemic, regulatory changes since Brexit, and the war in Ukraine. Different forms of economic austerity set the context for an unfortunate time to examine disability. The most recent National Audit Office report makes sobering reading as the funding of the NHS has decreased, with many NHS bodies in deficit with its overall financial position weakening, with failure to invest in the estate and post-pandemic recovery. The

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[3] Pope Francis, *Address of His Holiness Pope Francis to the Pontifical Academy of Social Sciences* (11 April 2024).

[4] House of Commons Library, *The structure of the NHS in England* Number 7206 (10 July 2023).

scale of the challenge is unprecedented.[5] There is an ongoing large-scale reform of disability procedures and processing of payments. Disability payments are intensely debated by the main political parties. Welfare support for the disabled has been affected by the drive for savings and rationing resources. Shortages of medical personnel at all levels have hindered progress. Care and health form a single responsibility for the Secretary of State for Health, but the integration of disabled care and medical health is a work in progress. The National Health Service is under strain, health workers are deeply demoralised, and recruitment is challenging. As a consequence, the UK offers a fascinating study of disability provision within a health care system which is under reform and arguably underfunded.[6] Legal protection for disabilities through anti-discrimination laws provides an essential framework for the provision of health and social care of disability[7] and should not be overlooked.

The paper begins with the main aspects of contemporary welfare reforms in the UK and their potential impact on vulnerable and disabled people. Successive governments have sought to encourage and support disabled people into work.[8] Achieving this aim is coupled to the creation of a single unified welfare system. This is a complex task as there are specially tailored support and assessment systems delivered through costly commercial contracts. The system of assessment and approval has proved complicated and expensive to run. Existing Information Technologies (IT) systems will have to be redesigned and changed to accommodate the large number of disabled applicants. Assessment is complicated and difficult because each application is personal to the applicant, and involves assessing a wide spectrum of

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[5] National Audit Office, *Report, NHS Financial Management and Sustainability Session* 2024-25 HC 124.

[6] A preliminary point is that the term "UK" is misleading as a description. The Health Service is, since 1998, a devolved function to the devolved nations of Scotland. Wales, Northern Ireland. This leaves England as the only sovereign nation that may change and influence devolved policy making. Policy making is mainly driven by England but devolved nations may adjust policy to meet their needs. The NHS is a complex system of integrated care systems, see House of Commons Library Research Briefing, *The Structure of the NHS* (10 July 2023).

[7] *R. v Islington ex parte Rixon* (1997-98) 1 CCLR, *R (Graham) v Secretary of State for Health* [2009] EWHC 574. *Elaine McDonald v the Royal Borough of Kensington and Chelsea* [2011] UKSC 33.

[8] See: Hannah Arendt, *The Human Condition* Chicago University Press, 2018.

different medical conditions.[9] The assessment also and inevitably involves subjective as well as objective judgments. Appraisal is therefore time-consuming, highly specialised and complicated. It takes at least 14 weeks between making a claim for a benefit and receiving an initial decision from the Department of Work and Pensions. Between 2018 and 2022 at least 12% of decisions were overturned on appeal. The reality is that it is difficult to fit the system within any single template or IT app. The ongoing reform and eventual scrapping of the current system of disability payments, such as the work capability assessment scheme, is likely to see cuts in benefits for some.[10] The reforms are most likely to be completed by April 2029, subject to the policy approach of the new Government. It is clear, however, that the future number of claimants is likely to increase. Disability cases are steadily increasing, with many claimants needing to apply for additional benefits, especially as the cost-of-living crisis is greatest amongst the most vulnerable. The paper discusses some of the technical details and the main implications of the planned reforms, notably the findings of the independent *Institute for Fiscal Studies* (IFS), the Public Accounts Committee (PAC) of the House of Commons and the National Audit Office (NAO), which is the independent auditor of departmental public spending. Most controversial is the reform that would scrap the current Work Capability Allowance. This might lead to some existing claimants losing benefits, particularly in the discretionary areas of payments for extra costs associated with their daily lives. However, those disabled in work might be able to receive health-re-

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[9] Contemporary disabled welfare reforms are of long standing and successive government policy focused on the greater employment of disabled people consists of detailed plans set out from November 2017 through a ten-year plan to get more disabled people into work. In March 2023, the Government's plan was published in a White Paper, *Transforming Support*. This had been preceded by a consultation exercise linked to July 2021, *Shaping future Support: the health and disability green paper.* This was accompanied by the *National Disability Strategy* (July 2021). There is also published in July 2023 the *Disability Action Plan* that sets the agenda for the future, subject to consultation. The timetable is that a finalised Disability Action Plan will be published at the end of 2023. The planned general election is set for no later than January 2025. It is highly unlikely than any future government will change the general direction of current policy. The general focus of that policy is to ensure that getting disabled people into work is the main priority. Thus, employment support and support through the benefits system is soon to be reformed for disability after the publication of the Action Plan in late 2023.

[10] *The Guardian*, 15 March 2023.

lated benefits and some other additional benefits.[11] It is too early to be sure what will happen, but one scenario makes it possible that the burden on the taxpayer might increase and not decrease.

The reform plans should be seen in a wider context. Scholars[12] in many countries have detected the spread of "neo-liberal" ideas and the reduction of state regulatory intervention in public services to a bare minimum, with the introduction of market mechanisms to deliver social care and health services.[13] This brings a marketisation of services. Cost savings and efficiencies are claimed as a consequence of market competition. Non-state actors and stakeholders have become more common. At the same time external regulation has increased through expansion of the role of the Care Quality Commission (CQC) and inspections. This may not fit entirely with a "neo-liberal" construction of what should happen.

Disability should be set in the context of modern medical and anthropological studies that have advanced our understanding of the causes and treatment of disability.[14] Inevitably, many past myths have been debunked by modern medicine. Indeed, even recent medical discoveries have opened up possibilities of causes and treatments that would have been impossible a few years ago. There is a consensus that social care, health care and care for the disabled have to fit together in a coherent way. This means working across government departments and administrative systems, which sets considerable challenges, for attitudes, approaches and knowledge base across departments and systems. It is also likely to cause intense competition between disciplines and traditions. Political intrusion is also present, adding another tier of complexity and even unpredictability. There was rather disappointing news in December 2023, of a specially dedicated Cabinet Minister for Disability to be abolished and the job allocated to a more junior minister, an under-secretary of state. The new government has taken an

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[11] IFS Report R283, *The Effects of reforms to the work capability assessment for incapacity benefits*. October 2023.

[12] See: Tanja Klenk and Renate Reiter, "Hospital Privatisation in Germany and France: Marketisation without Deregulation" in Hellmut Wollmann, Gerard Marcou, Ivan Kopric eds., *Public and Social Services in Europe*. Palgrave Macmillan, 2016, p. 265 and T. Clemens, and others, "European Hospital reforms in time of crisis: Aligning cost containment needs with plans for structural redesign?" (2014) *Health Policy*, 117(1) 6-14.

[13] See: Tanja Klenk and Renate Reiter, "Hospital Privatisation in Germany and France: Marketisation without Deregulation" in Hellmut Wollmann, Gerard Marcou, Ivan Kopric eds., *Public and Social Services in Europe*. Palgrave Macmillan, 2016, p. 265.

[14] See: Roy Hanes, et al., *The Routledge History of Disability*. London: Routledge, 2018.

important step of appointing a new Minister to the Department of Work and Pensions for Social Security and Disability benefits, an important step in the direction of better integrating care of the disabled.

The paper considers two different perspectives. The first, is to explain some of the main shortcomings in the proposed reforms for the payment of disability benefits in the UK. The paper identifies an overreliance on financial systems, including IT applications, replacing paper-based applications for payments, that treats disability as it would any other tier of public spending. There are also more general concerns about AI systems being applied to disability claimants. Disability benefits are inordinately complex and hard to understand. There is an acute danger that disability is seen as "a unit of resource" that receives support from scarce public money, rather than a system that must take account of the difficulties facing individual disabled people when making applications. A humanitarian responsibility to disability needs to provide disabled people with ownership and empowerment that is more adaptive to their needs and listens to concerns. The reforms need to be disability led rather than administratively driven.

The second perspective is to consider the social doctrine of the Church and how this might be better informed. It is argued that disabled people are best helped through an approach that places love and care, the essence of belief in God, as the main rationale supporting disability care. A social model approach to disability linked to relational good underpins the needs of disabled individuals. There is the need for regular and sustained continuous education programmes explaining the needs of disability to be delivered across all sectors of society, including parishes and religious organisations. Viewing disability as a relational good seeks to match to the needs of people with disability available and relevant resources. Relational good may help combine the best aspects of economic modelling and a social model approach that emphasises the lived experience of the disabled in day-to-day life as a focus of what needs to be achieved.

Pierpaolo Donati argues persuasively that there are a number of significant approaches that might be taken to advance the needs of the disabled.[15] Caring is a gift and relationship good may be forged from this base. At its heart, human dignity is the guiding principle of understanding disability.[16]

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[15] Pierpaolo Donati, *The Family as a Relational Good: The Challenge of Love*, Vatican 2022.

[16] Pierpaolo Donati, 2022 The Pandemic: An epiphany of relations and opportunities for transcendence". *Church, Communications and Culture* 7(1) 23-57.

The means to engage with disability include creating trust, co-operation, reciprocity, and sharing, such as co-planning and co-producing. The care giver provides to the care recipient based on trust a relational good. In delivering good quality care the disabled are enabled to enjoy independent living, an approach that builds on trust and ultimately independent living.

Part 1. Placing Disability as a Priority Within Health and Social Care Reforms

UK Disability Statistics

The precise number of disabled people in the UK[17] is hard to estimate. There is no national register of disabled people. Local authorities may register people with disability but this is a complicated and a largely voluntary system. There is no standardised system of registration. Official statistics are reliant upon surveys which are unreliable and open to distortion, depending on the methodology used and its accuracy. Much of the data is obtained from self-reporting, rather than from a reliable and independent data set that is subject to strict peer review. Indeed, there is an absence of reliable international data that allows sensible comparison across countries. The *UK House of Commons Library Research Papers* provides some useful data. There are an estimated 16.0 million people in the UK registered with a disability, that is, about 24% of the total population. Disability rises with age – 11% of children, 23% of working age adults and 45% of adults over State Pension Age. The type of disability may also be broken down as follows: for 47% mobility is a problem, followed by stamina, breathing or fatigue 35%, and mental health at 32%.[18] The latter is too often overlooked when the main focus is on physical health.

The National Audit Office (NAO) estimates that, in the next few years, the number of payment claims is likely to increase from about 4.8 million to 5.8 million in 2025-26.[19] The employment rate of disabled people is around 53.7%.[20] The impact of Covid and post-Covid ill-health is largely still-to-be

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[17] House of Commons Library, *UK disability statistics: Prevalence and life experiences*. Number 09602 (23 August 2023).

[18] This is a large number and there may be some that are not reporting their status and are not applying for benefits.

[19] The National Audit Office, Report: Transforming health assessments for disability. Session 2022-23 (23 June 2023) HC 1512.

[20] House of Commons Library: Disabled People in Employment. Number 7540 (19 June 2023).

quantified, but certainly is a factor in the increase in disability cases over the last few months. The King's Fund,[21] an influential independent think-tank, records that in the first year of the pandemic "60% of those that died were disabled".[22] Death rates were highest among those with learning difficulties, compared with deaths amongst the general population. Particularly vulnerable were disabled people who suffer multiple medical conditions and have poor standards of living. Post-Covid the current cost-of-living crisis, including increases in food prices and heating costs, has resulted in poor diet and living conditions. These, together with pressures on health care, are contributing factors to increased vulnerabilities.[23] The cost-of-living crisis exposes the most vulnerable in society to particular risk, a cause for serious concern.[24] The variety of factors at work have all contributed to a marked increase in disability claims. One estimate is that claims have trebled in the last decade. The Office for National Statistics notes a fall in life expectancy, and declining health throughout the country. It should be noted that the UK currently ranks with one of the lowest in terms of generosity in payments for out-of-work benefits, despite being the sixth richest economy in the world.[25]

It is concluded that creating an accurate world-wide data base of disability would provide a significant step in being able to address disability in all its forms and monitor the needs of the disabled. International statistics suffer similar problems with the creation of data bases that allow comparable data sets to be provided and developed, providing an accurate and up-to-date means to monitor trends.

There are increasing concerns that making a claim for benefits is much more difficult than it would appear at first glance. The system known as Personal Independence Payment (PIP) is an example of the problem. The application process for PIP is complicated and by common agreement is not working particularly well, especially as resources are stretched by the rise in numbers of applicants. In many cases, recourse to a Tribunal Adjudication

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[21] The King's Fund, *Towards a new partnership between disabled people and health and care services: getting our voices heard* (27 July 2022).

[22] Ibid.

[23] Ibid.

[24] An informed view may be found in Institute for Fiscal Studies (IFS) Report R245, The Cost-of-Living Crisis: a pre-budget briefing, February 2023, setting out the various strains on the UK economy.

[25] https://commonslibrary.parliament.uk/research-briefings/cbp-9602/

results in 70% of decisions overturned. Solving the challenges of making a claim will take some time and will require skilful initiatives.[26]

There are a number of noticeable trends.[27] Since 2002-03 the prevalence of disability in the UK has risen. As noted above, the largest group is those in the state pension age and above, with a staggering 45% of that cohort reporting disability. There are some generalisable trends:

- Disabled people are most likely to not have a degree and many have no qualifications.
- There are around 3.9 million working-age people currently receiving at least one of the principal disability benefits.
- Disabled people have lower employment rates.
- Disability is prevalent amongst those who rent their housing and are entitled to social rent.
- Disability falls within the categories of some form of impairment, followed by stamina, breathing or fatigue. Mental health impairment features quite strongly. The *Institute for Fiscal Studies*, an independent think-tank, notes that the number of people suffering from mental conditions, including anxiety, depression and stress, all appear to be rising;
- Almost 10% of the population claim extra cost disability, a discretionary payment;
- Disability payments are a significant proportion of the total spending on benefits as a whole, amounting to £35.3 billion (two-thirds paid to people of working age) within the overall context of universal credits and tax credits of £83.0 billion.[28]

Disability and the law

Religious and philosophical discourses have always been influential in approaches to disability. The role of disability rights has taken centre stage in many contemporary approaches to disability, often with a pivotal role. In 2010, the UK set the general legal framework for disability rights in

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[26] *The Guardian*, 12 January 2024, Polly Toynbee, "Britain is a poorer, sicker place. No wonder disability claims have trebled in a decade".

[27] House of Commons Library, *UK disability statistics: Prevalence and life experiences*. Number 09602 (23 August 2023).

[28] The Office of Budget Responsibility (OBR), *A Brief Guide to the UK Public Finances*, 2023. The amount raised from the public sector taxes and other sources us £1,058 billion, a considerable sum. However, the Office of Budget Responsibility (OBR) expects spending totals to be in excess of revenue and spending is £1,189 billion.

the Equality Act 2010.[29] The legislation was an Act of consolidation of some pre-existing laws; it also provided a more comprehensive approach to disability than was possible in the past. The foundational part of the legislation is the prohibition of all forms of discrimination in various areas, including employment, the provision of services and education, as well as the management and organisation of premises. The approach taken in the legislation is based on including disability as "a protected characteristic", which makes it come within the scope of various legal protections. It is impossible to ignore the setting of a legal framework for protecting disability. Political change may adjust or attempt to re-set disability rights, but this would be in vain, given the role and significance of disability protection under the Act.

The definition of disability is related to the concept of "protected characteristic". There are two aspects, namely, a physical or mental impairment and the impairment which must have a substantial and long-term adverse effect on an individual's ability to conduct normal day-to-day activities. There are detailed definitions of what constitutes impairment, which are being driven by medical conditions covering mental and physical conditions. The Equality Act provides some helpful guidance, with additional guidance published by the Government from time to time.

The definition is sufficiently broad to include conditions that are non-visible and ones that recur sporadically. The protection is enshrined in the application of legality. Thus, it is illegal to discriminate against someone because of their protected characteristic. The protection also extends to those caring for disabled people. The form of indirect discrimination applies when a policy applied generally puts disabled people at a disadvantage.

There is also a correspondingly important duty to make reasonable adjustments. This is to ensure that the needs of the disabled are met. There is a new, specific, public sector equality duty. Public authorities, when exercising their functions, must meet various equality considerations, including advancing the equality of opportunity between disabled and non-disabled people. There are some additional requirements for premises and properties to meet disability requirements.

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[29] Northern Ireland has a separate arrangement but the 2010 Act applies to England, Wales and Scotland.

Case law, Judge-made and derived from the interpretation of the Equality Act 2010, provides useful guidance as to how the law should be applied.[30] The ebb and flow of judicial decisions is important in terms of developing protection against harassment and victimization. The Act is a living document as the case law develops. The main point is that the Equality Act provides a clear set of boundaries, as well as fundamental principles for the protection of disabled people.[31]

Disability is also addressed specifically by the UN International Convention on the Rights of Persons with Disabilities[32] agreed in December 2006. The Convention has some clear objectives: to eliminate disability discrimination; to enable disabled people to live independently in the community; to ensure an inclusive educational system; to ensure that disabled people are protected from all forms of exploitation, violence, and abuse. The main significance of the UN Convention is in the oversight it offers to member states in terms of setting obligations and monitoring compliance under the Convention. This is necessary as a means for oversight and ensuring systems of accountability.

In 2016 the UK was the subject of investigation by the UN Committee on Disability, following requests from disability charities and organisations. Their findings were highly critical of the UK. The UN Committee found that "grave or systematic violations of disabled persons rights had taken place because of welfare reforms in the UK since 2010". The areas of concern that were specifically named include arrangements for the payment of benefits, including Housing Benefits, eligibility for Personal Independent Payment and social care, and also ending the Independent Living Fund. The UK government disagreed with the findings and the conclusions. A follow up review, as the First Periodic Review (2017), was undertaken by the UK's Human Rights Commission, which concluded that the UK had taken insufficient action to implement earlier recommendations. However, in 2018 a review panel was set up by the Government, which found that the UK was taking appropriate steps, such as conducting a review of the Mental

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[30] See: *Barrow v Kellogg Brown and Root (UK)(Ltd.)* [2021] ET 23036483/2018, *All Answers Ltd. V W and Anor*. [2021] EWCA Civ. 606, *Adermi v London and South Easter Railway Ltd.,* [2012] EAT /0216/12/KN.

[31] House of Commons Library, *Disability Discrimination* (4 January 2023) Number CBP 9061.

[32] House of Commons Library, *The UN Convention on the Rights of Persons with Disabilities: UK implementation* (10 November 2022) CBP07367.

Health Act 1983. It also agreed that the UK had made significant progress in increasing the number of disabled people in employment. In June 2019, the Government initiated a cross-government approach to disability, including approaches to disability benefits. There is an ongoing review of benefits and a National Disability Strategy set up in 2021 to consider the most appropriate strategy going forward. Cross-government approaches are proving to be difficult and challenging. The new Government in July 2024 has announced a further review of health and social care. There are encouraging signs that cross-party cooperation will take place to provide effective reforms, particularly in mental health delivery.

Disability and employment

Providing employment opportunities for disabled people is the lynchpin of the policy on disability developed by successive governments and has cross-party support. There were 9.58 million people of working age (16-64) who reported they were disabled in January to March 2023. This is roughly 24% of the working age population. There are fluctuations in employment rates and the figures are reliant upon registrations and data collection. Many disabled people are not in employment, or even seeking work opportunities, which is a sizeable challenge for any policy making. Often the unemployed have certain kinds of disability, particularly those with learning difficulties and multi-disability conditions. Many aspirations for increasing disability employment are to be found in the government's *Disability Action Plan* (2023)[33] and related documents that set out the main challenges facing disabled people.

There are also signs that the work patterns of disabled people may vary according to the prevailing economics of the time. High rates of economic inactivity in certain areas of the country are also reflected in the disability statistics. There is a *Work and Health Programme* (2017)[34] designed to help those in Northwest England and Wales in November 2017, areas with historical rates of low economic activity with high unemployment. The programme provides support to help find a job, with referrals from Job Centres.

The Government reported in 2019 that over 275,000 people, including 220,000 disabled, would be supported by the scheme over a five-year

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[33] https://www.gov.uk/government/publications/disability-action-plan

[34] https://www.gov.uk/government/publications/work-and-health-programme-including-jets-provider-guidance/chapter-1-introduction-and-overview

period. The two-year extension of the programme from September 2022 to September 2024 is expected to support 100,000 more people.[35] There is mounting evidence that disability is "a key driver on inequalities across the life cycle" of the disabled.[36] The desirability of achieving cross-party support is essential to address the needs of the disabled.

The UK's Disability Action Plan

The UK government has advanced plans to implement and develop a UK Disability Action Plan, which encompasses a detailed consultation and builds on previous discussion and feedback. It has the primary aim of improving the lives of disabled people. Much of the plan has already been flagged up and discussed. Nevertheless, the plan brings together strands of thinking that are found in the National Disability Strategy. Indeed, much of the document published in February 2024 contains sound common sense and incorporates a number of important plans to encourage cross-government collaboration. It provides a strengthened evidence base for the specific needs of disabled people. The underpinning of any action plan, however, is finance and this is absent from the main analysis. The budget statements in Autumn 2024 will help clarify funding. In total, there are over 52 areas of action. There is a promise that the UK will provide regular updates on implementation at regular intervals after 6 months and 12 months. It is also expected that disability plans might be implemented at devolved levels, subject to respecting the powers and responsibilities devolved to the devolved areas of the country.[37] The new government elected in July 2024 is expected to continue this process.

Disability benefits

The UK provides a number of disability benefits aimed at those who are at working age. There are three such benefits: Employment and Support Allowance (ESA), Universal Credit (UC) and Personal Independence Payments (PIP). The sponsoring department is the Department of Work and Pensions (DWP). There are a number of other benefits and assistance. Underpinning the system of benefit payments is a controversial assessment system, undertaken by three main contractors that are specifically appointed as

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[35] House of Commons Library, *Disabled People in employment* (19 June 2023) Number 7540.

[36] James Banks, et al., "Inequalities in disability" (2024) 3, i529-i548. *Oxford Economics* (2024) 3.

[37] Cabinet Office, *Disability Action Plan,* CP 1014 (February 2024).

contracted out providers. Their task is to scrutinise applications to ensure that funding is directed to the applicants that need it. A staggering £410 million was paid for the administration and operation of the assessment process alone. Claimants seeking two forms of assessment, namely ESA and PIP, require two different forms of work capability assessment. Benefits claims are expected to increase to £73.3 billion overall in 2027/28. These are large sums of expenditure and are subject to UK Treasury oversight.

The complexity of the system has shortcomings, including the likelihood of many errors or mistakes, mainly due to increases in technical difficulty, over time. This may give rise to claims against the government on the basis of errors.[38] Litigation is not uncommon, with legal cases brought by claimants to achieve payments. Cases of discrimination against disabled people are regularly upheld in the courts. For example, in 2023 the Court of Appeal had ruled that a temporary measure introduced during the Covid time had resulted in an unlawful discrimination against disabled people.[39]

Reforming the system of the Work Capability Assessment is challenging. The previous government decided on a two-stage process. The first is to tighten up the Assessment procedures and reduce the number of claimants to save money and make efficient savings. The *Institute of Fiscal Studies* (IFS), an independent think tank, estimates that some claimants will lose out on £390 a month, meaning that the individual will have to conduct additional work to make up the difference. Estimates of any savings in costs to the state are very hard to calculate and this leaves many uncertainties.[40]

The second phase of reform is more radical than the first. It is potentially very far reaching. The aim is to scrap the Work Capability Assessment completely, thus breaking the link between capacity to work and benefit entitlement. Determining the potential impact of the change is very difficult. The IFS estimates that 320,000 will see their entitlements rise by about £390 per month, with an estimated £1.5 billion additional spending.

In order to accomplish the various reforms, the Department of Work and Pensions (DWP) has introduced a new Health Transformation Programme from July 2018. The main focus is digitalisation of both the functional health assessment and the PIP application process. This is intended to

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[38] *The Guardian,* PIP Investigation: Claimant seeks judicial review over assessment flaws. 2 March 2017.

[39] *Philip Wayward and others v Secretary of State for Work and Pensions* [2023] EWCA Civ. 24.

[40] Institute for Fiscal Studies Report R283, Sam Ray-Chaudhuri and Tom Waters, *The Effects of Reforms to the Work Capability Assessment for Incapacity Benefits*. October 2023.

allow access online through an IT portal for applications and consequently make the process simpler, user friendly and more effective through better value for money. Overall, the budget is expected to amount to £1 billion. By March 2023 the Department had already spent £168 million on digitisation. The projected overall benefit of such a shift to digital systems is expected to provide savings of over £2.6 billion, but it is hard to know if this is ever realisable.

One aspect of the phasing in of the reform of disability benefits is how to move some pre-existing claimants who are still claiming "legacy benefits" onto the newer universal credit payment system. This is an essential first step if the IT scheme is to work. The plan is to move 900,000 claimants, by the end of 2024, onto the universal credit system. The signs so far are not encouraging. About 31% have had their legacy benefits stopped without the move to universal credit. The National Audit Office is concerned that some claimants may be incorrectly deprived of support. It is estimated that 1 in 5 people may find their benefits cut because of the changes.[41] It is hard to know how accurate this assessment might be or the difficulties, if any, that may lie ahead.

An important aspect of the disability reforms is that claimants have to undergo a system of "triage" to help identify the most urgent cases, through online IT systems to facilitate their claim. The same information might also be used in different applications processes. The underlining point is that an integrated service will have to work across England, Wales, and Scotland. It is also the case that many disabled claimants may operate in a climate of suspicion that claimants might be defrauding the system, a commonly held concern.

Reforming and improving disability payments

Reforming disability payments is an important part of the DWP, which initiated a new programme (the Health Transformation Programme) aimed at changing the functional assessment and PIP in 2018. The aims are highly laudable and desirable and have received support from many disability charities and organisations. This includes making the system easier, quicker and simpler for users. Underlying the system is a user-friendly approach to applicants. This is one of the most ambitious programmes and the largest transformation of delivering benefits in the Department's current portfolio.

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[41] The Guardian, 27 February 2023.

The National Audit Office and the House of Commons Public Accounts Committee (PAC) each provide useful assessments of the work of the DWP, and specifically the proposed new Programme. Their findings are a means to access the work of the Department. The findings of the PAC make interesting reading. There are a number of serious concerns about the reforms that may be summarised as follows.

The National Audit Office[42] has expressed concerns that functional health assessments are by their nature inherently "judgment based" This makes them resources intensive and difficult to administer in a consistent way. From the Claimant's perspective, it is difficult to know whether their disability is such that it makes it impossible to do certain functions that would qualify them for benefits. Providing documents is also complicated: many are hand-written and in the form of notes. From the assessor perspective the need to review submissions and the documents in a case can prove to be very time-consuming and complicated. This is especially so when the relevant evidence needs to be sifted, assessed and considered, leaving lots of material to be discarded or ignored. The pathway of reform has to be able to allow judgments to be made and evaluated against a set of relevant, transparent criteria contained in complicated regulations.

The NAO also cautions about how public bodies face real challenges when they are contracting out services that they are simultaneously reforming. This can lead to disputes, delays and cost overruns that are often expensive and hard to control or influence.

There are also concerns about the ability for the Department to meet their estimate of savings, currently calculated to be £2.6 billion, over the life of the programme to 2035-36. These substantial savings are supposed to come from efficiency gains on the basis of the working of the functional assessment. It is not certain how this might work out in practice and on predictions made so far in the future. Already there have been revisions, in fact, as recently as March 2023, but a new business plan is expected to be ready some time for September 2024. Clearly, this puts considerable challenges for the Department, particularly how it is going to assess whether the programme will deliver its intended benefits. Inflation, delays in supply chains and the availability of trained personnel may also create costs and expenses that are not fully priced into the costings of the programme.

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[42] NAO, *Transforming health assessments for disability benefits,* review of the Department for Work and Pensions Session 2022-23 HC 1512 (23 June 2023).

There is a clear need to continuously assess the progress of the reform programme. Accountability is the central issue in order to anticipate any problems or unexpected shortcomings in the system. Careful monitoring of the programme will require significant effort and will be challenging, especially if the Department is determined to hide information or even misrepresent events and facts. Monitoring is critical as the move from largely a paper-based application system to one of digital technology is highly problematic, not matter how good the intentions or planning may be. Collaborating with contractors and coping with disputes, time frames and costs will require careful oversight and scrutiny. In all this the Department may be at a disadvantage in comparison to the contractor. Designing and maintaining the system is time consuming. The contractors designing the original system are likely to have an advantage over the award of future contracts. The tax-payer may be at risk of being exposed to liabilities and uncertainties. One option that is worth considering in 2027, after the completion of the first phase of the programme, is for the Department to take the contracts within the Department. There is some precedent for this approach. In Scotland when Social Security Scotland adopted a Departmental-based house contract system. Lessons from the Scottish example might be useful for England and the Department would be best advised to consult with Scotland to discover how the in-house service system is working.

The reform programme has to pass a straightforward test. Will it transform and improve the lives of disability claimants? The answer will require normative, as well as analytical data. There are some underlying fault lines that may de-rail high expectations of success. The first is that government departments often favour process and procedures over substance. Process and procedures are relatively easy to achieve, and can be demonstrated statistically. Quantification is often skewed over qualitative systems. Indeed, the preference for objective criteria is often balanced against subjective measurements and markers. Best value for money and economic measurement are much in vogue. The new Health Assessment Service is likely to be delivered in some form by 2029. However, the Parliament's financial watchdog, the Public Accounts Committee (PAC), fear that the greatest risk might be that the although the delivery "might be achieved", it will not improve the life of disabled claimants.

The programme is in its early stages. It was first reset in 2019 and it was further reset because of the Covid pandemic. Setting up continuity contracts to continue the current arrangements for benefits is ongoing and taking up a large part of the department's time. The programme may prove more difficult than expected, which is always the challenge with large and often time-consuming programmes with long time-frames.

There are further concerns, indeed warnings. The first is related to the UK's history on infrastructure capital spends. The history of large public spending projects is not good in the UK. Large infrastructure projects such as HS2 (fast rail link) have costed more than expected; and are the subject of political interventions and changes with expensive adjustments to the original contracts and plans. The complexity of delivery was under-estimated from the start and costs have escalated because of higher than predicted inflation, problems of staffing and major changes to the management structure and in the delivery system agreed by private companies. At scale, there need to be lessons from this experience across all government departments, in implementing disability benefits reforms.

The second are questions about the rolling out of computer technology, including its design, implementation and monitoring by the Department. Does the relevant government department possess the necessary know-how, experience and understanding to be able to oversee different stages of the project and its iterations? Then there are party-political vagaries of elections, especially the change of government, as well as changes of ministers and financial constraints that are inevitable during the time of the contract. The UK Treasury may delay or query costs and this may cause problems during the life of the project. In the case of disability reforms, there is the proposal of DWP to adopt a Post Office variation of the Horizon style scanning computer system to scan the Bank Accounts of all benefit recipients to detect fraud in applications or unusual activity on Bank accounts.[43] Disability claimants are included in the general category of benefits claimants, which makes separating out any specific issues rather complicated. The aim is to reduce fraud and provide a strong deterrent by suspending benefit payments until any anomaly in the benefits claimed is explained or excused. The Government's response to such concerns about potential computer glitches is that there would be no automatic system of conviction through AI detection alone, as a member of staff would be able to make an independent decision rather than place reliance on an AI detection system. Adopting such a system might produce real savings. Estimates of savings total £360 million per annum, which makes such a programme highly attractive to the

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[43] *The Guardian*, 4 March 2024.

Government. The enabling legislation to introduce such a scheme for social services payments is currently before Parliament and awaits final approval. There are fears that such legislation might lead to mistakes or errors and cause false claims to be made against claimants, as shown by issues raised in the use of surveillance in the Post Office over sub-postmasters. There are serious doubts that the legislation is fair and proportionate and the independent Information Commissioner is concerned about privacy laws and their observance. It must be remembered that many claimants are from the poorest and most disadvantaged and vulnerable sections of society. There is also the troubling aspect of reversing the onus of proof and assuming that all claimants might be guilty of wrong-doing. This is a deeply troubling development in how benefits are overseen and delivered. Many mistakes or errors might result. Stigmas are being created and developed through an approach that may reinforce perceived prejudices that claimants are likely to be dishonest or underhand. Sensitivity in dealing with benefit claimants and treating all claimants with respect and understanding is essential. This is hard to maintain under a culture of suspicion. The introduction of such surveillance measures is troubling. Effectively claimants are being treated as a numerical unit capable of cost savings. There is considerable "group think" that public payments need to receive a uniform approach, notwithstanding the vulnerability of different groups in our society.

IT Lessons from the Post Office Scandal – a cautionary tale

The third issue is the question of the reliability and durability of the computer technology adopted to handle claimants, including the disabled. The UK has still a lot to learn about placing any reliance on AI computer technology. A recent example is indicative of potential problems. The lessons that need to be learned from the failures of the recent and widely publicised Post Office scandal is now at the centre of an independent judge-led statutory public inquiry. The Post Office Scandal arose when false prosecutions and convictions of Post Office Post Masters were made on the basis of a flawed and incorrect computer programme which falsely found deficits in the accounts. False convictions will have to be set aside, pardons granted and compensation paid for the loss of earnings and bankruptcies. Uniquely the government has passed emergency legislation to provide a statutory framework for acquittals to be granted, which is highly controversial as such legislation may impinge on the independent role of the judiciary to find guilt and undertake sentencing. Recent revelations show that the

Business Department was aware of shortcomings in the computer system and the main contractor was able to alter entries in individual post-master accounts without transparency or disclosure. It is too early to summarise all the lessons of the Post Office Scandal,[44] but clearly such lessons will have to be addressed if the Government continues with its plans to use advanced technology for a single system for the payment of benefit claims, including disability claims. It is clear that the worst possible manipulation of accounts and debits is all too easily undertaken in the absence of rigorous transparency or disclosure. Even the Court of Appeal relied on many assurances that manipulation of the accounts was impossible when the opposite was true.[45] It is clear that the UK courts will have to be sufficiently resourced to be able to investigate and hold to account the systems of IT and not accept their so-called infallibility. The dangers of accepting the IT systems on face value may haunt the roll out of any new computerised systems for public service delivery.[46]

The reliance on objective criteria for the evaluation of programmes and the application of value for money considerations is an understandable driver of the Department's system of control and accountability. Disability payments create a challenging set of issues about how to protect the most vulnerable in society. There is a counter-narrative based on the values and ethics that define our humanity. The value of individuals and the need to provide resources to help disabled people live worthwhile and valued lives cannot be put into financial terms or evaluated according to a financial index.

The prosecution of Carers: lessons still to be learned.

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[44] The Horizon Scandal raises serious questions about the reliance on IT and assumptions about its reliability. The Scandal is about the failure of regulation, and the absence of controls over the activities of the Post Office. An informal pressure group, the Sub-postmasters Alliance proved effective in lobbying for their convicted members. There is emerging evidence that the Post Office may have engaged in a "cover-up" of the evidence. In February 2000, an Inquiry was established by the Prime Minister which was made into a statutory inquiry in June 2021. The inquiry is ongoing and is taking evidence in public. His findings are expected to be published at the end of 2024.

[45] Post Office (Horizon System) Compensation Bill, Explanatory Notes Bill-16 EN 58/4.

[46] UK Parliament Post, *Artificial Intelligence: An explainer* (14 December 223). John Croker, *The Law that Shapes Us: Law, Artificial Intelligence and Human Rights:* Connecting the Dots HL Bill 37 of 2023-24 Post Office (Horizon System) Compensation Bill (22 December 2023). UK Parliament POST Use of artificial intelligence in education delivery and assessment (23 January 2024).

Concerns have arisen amongst disability groups that voluntary carers have found themselves prosecuted because of the discovery of alleged overpayments made by the Department of Work and Pensions. Many carers take employment outside their care responsibilities. There is a threshold of £151 and any payment over that amount results in the loss of their entire entitlement. There is no taper relief rather than an automatic cut off. It is easy to make mistakes. For example, one of the carers prosecuted has learning difficulties and over a period of six years he had unwittingly been paid an overpayment. On the claimant's form he had ticked the box as being unemployed, which was an error. He continued to file complicated forms required for payment but was not told about the error. The error was small, about 30p per week, but over many years it built up to a sizeable amount of money. The computer programme knew about the error, and recognised it, but it was not brought to his attention for many years. There appears to be a large number of claimants in similar circumstances. Many commentators, including MPs, feel that there should be no further prosecutions until the issue of delays in informing claimants is explained and assessed.[47]

This is an ongoing example of many of the serious problems facing disabled people when faced with complexity and difficulties[48] in administration that are a pre-requisite for disability payments. The lessons that can be learnt from such prosecutions need to be understood and addressed going forward. It is clear that the needs of disability need to be directly addressed as a special cohort, which is vulnerable to IT systems and errors that may prove a deterrent to making any claims, even though they are qualified for the benefits they apply for.

In conclusion, warning about the use of AI systems is evident from the aftermath of the Post Office Scandal in the UK and the prosecution of unpaid careers for mistakes in their application for benefits. Pope Francis has argued that AI has to be accepted only if it serves the "common good and does not increase inequalities".

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[47] See: *The Guardian*, 24 July 2024.

[48] *The Guardian*, 12 April 2024. Carer convicted over benefit error worth 30p a week fights to clear his name.

Part 2. Addressing the Church's Social Doctrine through a partnership with disabled people and by adopting a social model approach of relationship good for health and care

The Church's social doctrine on disability has been consistent for many years about the necessity of addressing disability[49] in terms of valuing a person and undertaking practical advice to address access and inclusion in the Church. It is clear that much is needed to address the needs of disabled people. The King's Fund, a UK based influential think tank on health and care, has undertaken research into building good relations between the health care system and those with disability needs. The starting point is the legacy of the high number of Covid-related deaths: 60% of those that died in the first year of the pandemic were disabled. Health inequalities left disabled people more vulnerable. The publication of Baroness Hallett's first report from the Covid-19 Inquiry in July 2024, makes sobering reading about the pandemic:

> "The impact of the disease did not fall equally. Research suggests that, in the UK, mortality rates were specifically higher among people with a physical or learning disability and people with re-existing conditions such as dementia and Alzheimer's, heart disease, high blood pressure and diabetes".[50]

The lessons of the pandemic are that designing and planning the future requires more active engagement with disabled people than in the past. The King's Fund research shows that the broad diversity of disabled people's needs should be appreciated. Adopting a social model approach to disability is necessary to be able to address current shortcomings. Expertise in disability must be appreciated and the voice and lived experience of disabled people needs to be respected and understood. Disabled people's organisations should be strengthened through local organisations, including at Parishes, with disability champions to inform strategies to allow a more coherent voice in policy making, including the Church. There is a concern that, too often, current arrangements are tokenistic rather than serious.

One way forward is through the application of a social model approach to disability. The essence of such an approach is to integrate the system of disability payments to meet the challenges facing disabled people in their day-to-day lives. Disabled people should be at the forefront of any reform

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[49] Basil Hume, Archbishop of Westminster, *Valuing Difference: People with disabilities in the life and mission of the Church*, 1998.

[50] Baroness Hallett, *UK Covid-19 Inquiry Module 1 The resilience and preparedness of the United Kingdom,* London, HC 18 (July 2024).

programme. This would be a major step forward in understanding the world of disability through the lens of disability.

The physical and mental challenges vary according to the extent of the disability, and understanding a wide spectrum of medical conditions is essential, including multiple conditions.

Even direct communication with disabled people may prove to be impossible or limited. Recently the major train companies and the Department of Transport engaged in a cost-cutting exercise under the previous government, which would have resulted in no manned ticket booths for the sale of train tickets or the provision of information on the best fare prices. The proposal was cost driven and would have resulted in the UK being the only country in the world where stations did not have manned ticket booths. IT systems were suggested as offering an alternative service to staff in ticket booths. It was claimed that the proposal would allow the release of platform staff who could assist with inquires. The initial consultation was rushed and disabled people felt that it was not sufficiently detailed. Disability organisations took the government to court through an application for judicial review. A fresh consultation was undertaken, with a large response and online objections. The new consultation revealed a detailed explanation of the lived experience of people with diverse disabilities. It proved decisive to the voice of disabled people being heard across society. A petition that collected over 106,156 signatures against closing the train ticket offices proved a remarkable achievement in public interaction and empathy with disabled people. Their "voice" had been heard. This improved the understanding about the life of many disabled people. The previous government and the train operators withdrew their proposals in the face of such strong opposition. It is possible that the train tickets debacle could have a long-term impact on how disability is regarded in society.

A social model approach provides the means for thinking about disabled people in a positive way, allowing their full participation in the process of health and care decisions. This would allow cross-participation with housing and need. There is an educative element through the Workforce Disability Equality Standard. Staff and clinicians need regular re-training to have a deeper understanding of disability. There is also an aspect about the culture of leadership, which should value direct engagement with disabled people. The need for specialist staff and regular updates on understanding and valuing of the voices of disabled people need to become part of any institutional culture. More generally, education about disability should inform parishes and seminaries of the continued need to listen to the voices of disability with regular and sustained updates of what it means to be disabled in society today – the lived experience.

Disability, a social care model and relational good

The social care model provides evidence for the benefits of understanding disability which can and will have a positive impact on society and the way everyday working is conducted. Relational responsibilities shared between the able bodied and disabled people might forge a relational good that sits comfortably with the values of a familial relationship.[51] This has a positive outcome for all in society. Pierpaolo Donati draws a sharp distinction between a relational constructionist approach and a critical realist approach to relational good. The former is simply a transactional relationship, the latter is related to the creation of structures and networks. There are substantial and transformative outcomes bringing out individualism into a more collective and communitarian outcome. Society becomes less conflicted and more consensual. Building on pragmatic and thematic approaches, the capability of individuals can be harnessed for the common good. This is not a lineal approach, instead it is multi-purposed and it may provide more humanizing outcomes capable of viewing the world from the perspective of disabled and disadvantaged people. Short, medium and longer-term relations are capable of being focused on care and disability. Generating a relational good acknowledges differences and, through the interaction between disabled and able-bodied people, can enhance communication and understanding. It is essential that this is a progressive and supported policy. Institutional understanding must be developed to change pre-existing cultures and prejudices. Education and training are essential and should exist side by side with appropriate processes and procedures. Delivering programmes for disabled people requires both economic systems that are combined with the aims and objectives of what the delivery model is intended to achieve and societal systems embedding our humanity.

The social model approach has the potential to address prejudices and provide equality through an inclusionary approach to disability.[52] The signs are not encouraging. The previous UK government has been reluctant to

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[51] Pierpaolo Donati, *The Family as a Relational Good: The Challenge of Love*. Vatican 2022.

[52] The King's Fund, *Towards a new partnership between disabled people and health and care services*. July 2022.

provide evidence to the UN Committee on Violation of Disability Rights. The UK was found to be in violation of the UN Convention in 2016 and since then has failed to give evidence on the subject.

Defining a single narrative to fit disability is complicated. Often disability rights are contested in religious and philosophical writing. There is a dominant orthodoxy of remaining true to dogma and the teaching of the past. McCrudden[53] and other scholars observe how the orthodox approach to tradition may inadequately take account of more contemporary approaches. This is when the past is treated as a means of ensuring the present and is created as an accurate reflection of what has gone on before. A refreshing suggestion is that sociological and philosophical thought should be explored to discover how the present may best be interpreted. It emerges that tradition is not static but in continuous flux and may be more a reflection of the times than a construct to view the future. Rationality in our thinking suggests that interpreting tradition is about how ideas and learning are transmitted, and change with time. Many writers see that the interaction of reason, faith and tradition can only be for the good. Thus, human dignity through the refinement of secular influences should be re-considered, and better understood in the religious sense. The interaction between religious faith and a secular understanding of dignity and disability is essential to going forward.

Conclusions

In the UK, the number of working-age people receiving disability benefits is currently estimated to be at 3.9 million. This figure is expected to increase over the coming years. More and more workers require long-term support and assistance. This is a worrying trend in the UK's labour market. The UK suffers from lower productivity rates than comparable countries and the rise in long-term illness with disability is not encouraging. A salutary warning comes from many of the causes in the rise in the numbers of disabled people. Disability is linked to education, poor physical health increase with age, poor mental health and inequalities in wealth as set out in the *In-*

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[53] See Christopher McCrudden, *Litigating Religions* Oxford; Oxford University Press, 2018. Pps 159-161.

stitute for Fiscal Studies, Deaton Review of Health.[54] Disabled people[55] struggle in finding work, which is a great challenge in most Western societies. The UK is no exception and arguably has made some real efforts to ensure more disabled people are able to find productive work.[56] The costs are high and undoubtedly put a major burden on public expenditure totals. It is understandable that seeking to find efficiency savings is a focus of any reforms. However, as an end in itself this is highly controversial when set against the need for other goals to enrich and improve the experience of the claimants.

This study of the reform programme points to the need to shift the focus from narrow economic evaluations to a broader, more inclusive approach that considers how best to educate and inform society as a whole about the values that underline the benefit system and particularly how society should treat disabled people. Disabled people have enormous potential and their role in society should not be under-estimated. There is a concern that the result of the UK's reform programme might be to save money and cut expenditure costs, rather than improving the life of the disabled. This would be a disappointment and in part might negate the point of having the reform programme in the first place. There is also a disturbing rise in the use of litigation, such as judicial review prompted by disabled claimants in order to secure their rights and achieve their recognition when making claims.[57] The need for disabled people to be part of the mainstream is essential. Some ideas come from the experience of the Human Rights Act 1998. After the Act was passed there was some delay to allow appropriate education and training on human rights that crossed public and private sectors and included the judiciary. Accompanying the Act was the certification of all legislation as being compatible with human rights, that had to be signed off by the relevant Secretary of State sponsoring the legislation. The certification process is important, as it brings to attention the priority given to human rights. A similar system of certification might be adopted for disability for all relevant Bills. This simple step might alert all government

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[54] James Banks, et al., Inequalities in disability, Oxford Open Economics (2024) 3 pps i529-i548. More generally, see the *IFS Deaton Review of Health* (2024). The Marmot Review, Fair Society, *Healthy Lives Strategic Review of Health*, 2010 and 2020.

[55] Quick Guide: *Disability history*, Leonard Cheshire 2023.

[56] The King's Fund, *Towards a new partnership between disabled people and health and care services: getting our voices heard* (27 July 2022).

[57] See: Lisa Scullion, et al., "Welfare conditionality and disabled people in the UK: Claimants perspectives" (2017) *Journal of Poverty and Social Justice*. Vol 25, no 2 177-80.

departments to the needs and impact of any legislation on disabled people. The certification process might include questions of asking whether there is sufficient trust between the application and interpretation of the legislation and disability groups. This might also include co-operation, reciprocity, co-planning and co-providing. Pre-existing consultation systems often appear to be "tick-box" exercises rather than substantive engagement.

The main argument in this paper is that the UK's reform programme should be more clearly calibrated to prioritise the needs of disabled claimants to ensure that their experience of government support respects their important role in society. Such a focus is inevitably going to be very challenging. Educating the wider community is essential. Indeed, drawing on Christian and other religions beliefs and philosophies may connect relations with disability as intrinsic to being human.[58] Human characteristics are such that it is possible and desirable to discover a unifying common bond to help each other. There are many diverse ways this may be achieved, but the definition of what is normal is not helpful in appreciating what disability means. Instead, it is best to concentrate on bringing those on the margins of society into the mainstream. In the traditions of Saint Augustine, it is possible to show love, meaning that engagement through care and assistance is an essential facet of our Christianity. Transforming the lived experience of disabled people is a craft task – working with groups and disabled people to enable and empower their voice in society. Influencers in society have to exert pressure on the government to ensure that economic delivery of goods and services is not an end in itself but a pathway to improving the life experience of disabled people.[59]

Thus, disability benefits and their distribution to the disabled must be seen as a shared responsibility that seeks to alleviate the stigma associated with disability and enjoin disabled people to be accepted as the mainstream of society. The most important aspect of disability is integration within the broader family of humanity. Seeking an integrated approach that accepts and respects disability means finding a common approach, emphasising all aspects of relational good as a means of discovering the virtues of inclusion within society as a whole.

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[58] See: Brian Brock, "Disability and the Quest for the Human" in Brian Brock and John Swinton, *Disability in the Christian Tradition: A reader,* William B Eerdmans Publishing Company Michigan USA 2012. Pps 1-21.

[59] IFS Report R 283, *The effects of reforms to the Work Capability Assessment for Incapacity Benefits*. October 2023.

Christianity continues on its journey[60] advancing mutual respect, care and understanding and finding the relational love that extends the hand of friendship to all, irrespective of the human condition, including disability, poverty[61] or disadvantage. The aggregation of human resources is necessary to share and encourage mutual respect and understanding, which could form the foundations of an effective reform of disability benefits.

Relational good will flow if disability claimants are better understood by the wider society. Without an overarching approach to disability, it is very likely that the disabled will end up more marginalised and excluded from the mainstream of society. There is a great deal at stake.

Some tentative conclusions may be summarised from this paper. Caring about everyone is essential. Avoiding stereotypes, self-awareness, understanding and sensitivity are all necessary. The key question is, what can we do for others? Many possibilities exist, but the social and political agenda needs to be considered; the lived experience of the disabled needs to be better understood and respected. Public funding for disability must keep pace with the cost of living, while the opportunities for making lives better should be articulated in terms of the moral and religious responsibilities we all share. The UK welfare reforms bring with them some cautionary lessons. Administrative and bureaucratic reforms should not de-humanise disability or create structures of control that fail to honour the responsibility to care for each other. Political constructions of what is or is not affordable should not detract from moral principles of how to make the lives of disabled people more tolerable and liveable.[62]

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[60] Pierpaolo Donati, editor, *The family as a relational good: The Challenge of Love* (The Proceedings of the 23rd Plenary Session 27-29 April 2022) The Vatican 2022. Pope Francis, *Address* pages 16-17.

[61] IFS Report R245 *The Cost-of-living crisis: a prebudget briefing* (February 2023).

[62] See: Scope, *Manifesto for an equal future* 2024.

FINAL STATEMENT

In light of an anticipated rise in disability prevalence in the coming years, the Pontifical Academy of Social Sciences marked its 30th anniversary by focusing on the challenges faced by individuals with disabilities and those who are vulnerable. The Academy set forth a threefold objective: Firstly, to conduct a global analysis of current approaches to these issues and assess their effectiveness; secondly, to re-examine the conceptualization of human rights for people with disabilities from a relational standpoint; and thirdly, to advocate for innovative measures at international, national, and local levels aimed at advancing social inclusion for this demographic.

1. The persistence of social disadvantage and discrimination

Participants agreed that, in most countries, disability continues to be discriminated against despite being an integral aspect of the human condition. Individuals with disabilities encounter disadvantages across critical domains of social life, including health, living standards, education, income, and employment. The global Multidimensional Poverty Index for 2023 covered 110 countries and 6.1 billion people, identifying 1.1 billion individuals (18%) as multidimensionally poor due to a combination of deprivations related to health, education, and living standards. The interplay between poverty and disability is significant. Acquiring a disability can lead to job loss or underemployment, resulting in reduced economic resources. Moreover, the heightened costs of medical care, personal services, transportation, housing adjustments, and other expenses can exacerbate the risk of poverty. Notably, households with children with disabilities often face higher levels of undernutrition. Poverty also contributes to deteriorating health and precarious working and living conditions, all of which can exacerbate disability. Additionally, inaccessible spaces and transportation further restrict social participation for individuals with disabilities. Among disabled populations, adults over retirement age constitute 50%, and older disabled people who are no longer economically active may grapple with poverty, loneliness, and mental health challenges. During times of war, climate change, disasters, and pandemics – such as the Covid-19 pandemic – persons with disabilities face heightened marginalization.

2. Rethinking Human Rights for Persons with Disabilities

It is essential to reconceptualize human rights to honour the inherent dignity of persons with disabilities. This involves their active participation in shaping policies and measures that address discrimination and inequality. Emphasizing subsidiarity, solidarity, and fraternity, we advocate for participatory methods that go beyond merely closing the gap between varying levels of disability and functionality. Our goal is to foster an inclusive society where the universal nature of rights accommodates individual circumstances. Achieving this necessitates a relational understanding of rights that transcends an individualistic or uniform approach. Disability should be viewed as a product of one's social environment, which can either exacerbate or mitigate their challenges.

3. Innovative Strategies for Enhancing Social Inclusion

The Plenary recommends that disabled and non-disabled individuals collaborate to implement innovative strategies that effectively uphold the rights of people with disabilities. These strategies include: a. Prioritizing relational approaches to foster comprehensive social inclusion. This involves co-producing relational goods between people with and without disabilities; b. Proactively eliminating barriers that hinder full participation; c. Providing reasonable accommodation as needed; d. Not defining the needs of people with disabilities in a separate and categorized manner. For instance, cases of violence and abuse against minors and adults with disabilities should be addressed within mainstream protective services rather than in isolation; e. Promoting transitioning from institutional care to community-based support systems. Directing funding toward supporting families with disabled members and enhancing local care services, rather than maintaining traditional institutions like orphanages and care homes.

Practical Actions to Achieve Comprehensive Inclusion

A) International Strategies: Support international efforts to collect and disseminate data on living conditions, challenges, and intervention outcomes for people with disabilities of all ages worldwide. This knowledge base will inform effective actions. Encourage international cooperation to share best practices, resources, and expertise in promoting human rights and full inclusion. In particular, ensure that development programs and humanitarian aid address the unique needs and rights of persons with disabilities and their families in lower-income countries, conflict zones, and during natural disasters or other crises. We recommend promoting and supporting multimedia content structures that use inclusive and positive language and formats for people with disabilities. We also recommend paying particular attention to how disability is portrayed on social media platforms and considering their impact on mental health and safety, especially for children and young people.

B) National Strategies: Develop and strengthen national legislation and policy frameworks in alignment with the United Nations Convention on the Rights of Persons with Disabilities (CRPD); Consider disability policies as integral to all levels of political decision-making; Give greater priority to understanding disability conditions across all sectors of society; Guarantee respect for the rights of people with disabilities; Promote legislation that enables their active participation in service planning and decision-making; Implement universal health coverage to ensure access to necessary healthcare services, rehabilitation, and assistive technologies; Foster inclusive education policies and practices tailored to diverse student needs; Create an environment of equal opportunities within the education system, ensuring that, at any level, the education system supports all learners in realizing their full potential; Promote equal job opportunities, guaranteeing flexible and remote work options for people with disabilities, whilst acknowledging the risk of limiting social inclusion and mental health; Enhance the diversity and specific abilities of people, including neurodivergent or dyslexic individuals, in AI and new technology development; Encourage collaboration with those who have greater support needs, to ensure meaningful occupation for all.

C) Local Strategies: Support self-organized groups of individuals with disabilities; Provide care services and resources for families of individuals with disabilities to ensure they can adequately care for their loved ones while actively participating in community life; Offer leadership support for family members, involving them in innovative service design; Develop community-based programs that actively engage persons with disabilities (including intellectual disabilities) in local decision-making processes and activities, fostering a sense of belonging within the community; Invest in creating accessible public spaces, transportation, and communication infrastructures to facilitate the full participation of persons with disabilities at the local level; Encourage cultural, recreational, and sporting organizations to become more accessible and inclusive for people with disabilities.

The Catholic Church plays a pivotal role in cultivating fraternity and communion by instilling in the faithful the recognition that we form a singular ‘us’ within the Church, rather than ‘us’ and ‘them’. We specifically advocate for specialized training for catechists, seminarians, along with other religious educators on perceiving disability as an intrinsic aspect of human diversity. Furthermore, it is crucial to eliminate physical obstacles alongside sensory impediments during liturgical services and pastoral engagements so as to facilitate unobstructed participation from individuals living with disabilities.

APPENDIX

SPECIAL SESSION – CELEBRATION OF THE 30th ANNIVERSARY OF THE PASS

ARCHBISHOP ROLAND MINNERATH
PASS Academician; Archevêché of Dijon, France

One of the major problems we face is the diffusion of our work. We are happy to be published by the PASS series of the Vatican Library. But these publications are not spread enough around the world and rarely listed or discussed in scientific publications. Not all university libraries possess the series of PASS publications.

May I remind you that in 2018 President Archer wrote to Pope Francis complaining that no Bishops' Conference mentioned our volume on *Human trafficking* and even that, in two speeches, the Holy See's delegation to a UN meeting on trafficking made no reference to PASS obtaining the insertion of Objective 8.7 in the new Sustainable Development Goals. Part of the answer certainly lies with our capability to call the attention of the scientific and political audience.

During the last ten years the topics dealt with were more current events oriented, ranging from Work and employment in 1996 to Human trafficking and modern slavery in 2015, and Disability as right now. How can the Academy enrich the social doctrine of the Church?

The preamble of our statutes states that the Academy "offers the Church the elements which she can use in the development of her social doctrine" and that the Academy "reflects on the application of that doctrine in contemporary society".

In a way these are the two finalities of the Academy. Scientific knowledge provides insights into social reality. Social doctrine shapes the ethical framework undermining social reality. The principles of Catholic social doctrine are based on a natural and rational understanding of the human being, stressing the dignity of each human person and orienting social activities towards the common good. The sphere of investigation of scientific research is methodologically independent; it provides knowledge, not ethical appreciation and action. Ethical assessment comes from a set of values and principles able to call for action. So the results of our investigations should converge to a better understanding of current social trends and ethical challenges.

The political sphere builds narratives around these assessments, not rarely with ideological or partial afterthought. The social doctrine of the Church tends to objectivity and universality.

The results of our work should be studied by the *Dicastery for Promoting Integral Human Development* as heir of the former commission for Justice and Peace. But not only. Social doctrine is taught and deepened in universities and countless associations, NGOs and grouping interested in giving the principles of social doctrine due consideration and application in the challenges met by contemporary society.

Again we come to the question of the diffusion of our contributions, not only within the ecclesial structures but also among the world decision-making instances.

Pierpaolo Donati
PASS Academician; Emeritus Professor of Sociology, University of Bologna, Italy

I would like to underline the fact that PASS has very actively pursued its institutional purpose which, in accordance with its statutes, is to give a contribution to the development of the social doctrine of the Church.

If you read the publications of the PASS on its website, and in particular if you consult all the final statements of the Plenaries, as well as of workshops, seminars and other initiatives, you can see the richness of the contributions offered to the development of the social doctrine: first of all, the PASS has explored the four main principles (the dignity of the human person, the principles of solidarity and subsidiarity, the common good); then the themes of democracy, work, globalization, sustainability, human trafficking, new technologies, intergenerational solidarity and the family, and on this occasion disability.

Eighty academicians have been appointed over the last thirty years and many external experts (hundreds) have participated in PASS activities offering fundamental contributions.

If we examine the composition of academicians according to their characteristics, we see the following:

– as for the representation of gender, the male presence has been prevalent, and yet the female presence has grown from 13 to 30 percent and this gives us hope for a further balance between women and men;
– as to the average age of PASS academicians, there was initially an increase from 1994 to 2014, but subsequently the average age dropped, and I believe it will be important to maintain an orientation towards rejuvenating the average age;
– as for the continent of origin of the academicians, we see a clear prevalence of Europeans (56%) and people from the Americas (25%); naturally, from a sociological point of view, this representation reflects the spread of the Catholic Church in the world in the past years; however, it is clear that the other continents (Asia, Africa and Oceania) deserve a growing presence, which I personally hope will be significant in the coming years;
– as for the disciplines represented, a wide variety was ensured, even if economics and law, and to a lesser extent sociology, respectively 25%, 20% and 16%, accounted for the lion’s share; it is important that a balance is maintained between the various disciplines and above all, in my

opinion, that attention is paid to new disciplines that have to do with social, cultural and technological changes, such as the disciplines of communication and virtual realities (I mean AI and robotics), considering their influence in modifying culture, lifestyles, knowledge itself and the entire communicative environment (the infosphere), which also requires corresponding experts in applied ethics.

Regarding topics and plans for the future, I would like to express some personal observations, and ask for comments and proposals from all of you.

1. Firstly,

I would like to recommend avoiding reiterating what is produced by the magisterium of the Church, and instead anticipating themes and solutions to the social problems of the world;

From this point of view, I believe that President Sr. Helen has in mind a great openness to new themes and above all to a new framework, a kind of relational paradigm, with which to proceed in the near future.

2. Secondly,

it seems to me that some topics have not been explored in depth:

- The topics of human rights ("what is human in human rights?") in the context of today's debate on the individualization and subjectivization of life;
- The way the social doctrine of the Church can confront post-modernity and trans-modernity; I mean how to enter into the after modernity, how to deal with transhumanism in respect to neohumanism;
- The role of the Third Sector which is crucial for the Church with respect to the dominant dualism between State and market;
- The topic of wars and international relations.

3. Thirdly,

with a view to the future, PASS is open to the future. I would like to recommend suggesting not only single issues to address, but also thinking in terms of medium-long term projects, such as for example:

- a project on how to address the development of human rights in such a way that they truly respect human dignity rather than leading us towards a certain trans-humanism and also what (in sociology) we call a-humanism;

- a project on the impact of new technologies that challenge the social doctrine of the Church (I am thinking of genetic manipulation, the hybridization of identities and social relations with digital/virtual reality, new problematic concepts such as the so-called "electronic person" and "artificial consciousness", the manipulation of public opinion pursued with new media technologies, etc.).

Finally, it could also be important to redefine previous long-term projects, such as the project on intergenerational solidarity in the light of the aging of the population in the whole world except for Africa, a continent that deserves special attention for its peculiarities in terms of demographic, economic and cultural diversities, and for the crucial role it shall have in the future. As a scientific academy, we must think originally and look to the future, not remain prisoners of the present, which has many problems, but ones which can only be overcome by establishing priorities within a new vision of the social sciences.

Stefano Zamagni
PASS Honorary Academician; Professor of Economics, University of Bologna.
Vice Director, SAIS Bologna, Senior Adjunct Professor of International Political Economics, Italy

I am in full agreement with the considerations offered to all of us by Sr. Helen Alford, Msgr. Minnerath and Pierpaolo Donati. In particular, I totally support the proposal to rebalance the geographical composition of our constituency, and I also agree with the idea of delivering major attention to present-day relevant topics intriguing our societies.

As a member of the Steering Committee that was appointed by Pope John Paul II in the early 1990s to pave the way towards the establishment of PASS, I still remember that quite a lot of our working time was taken by the discussion of the following two major problems.

First, does any particular characteristic exist that enables us to attribute to social research the qualification of "scientific"? A second, partly related question was: in what sense can we attribute a qualification of truth to scientific propositions that may be presumed to conform with reality?

On several occasions, during the past thirty years, our Academy has tackled, in various modes and levels, these questions. To me, the main result that PASS has been able to achieve is the affirmation of the principle that the unity of the sciences of its pertinence (philosophy, sociology, law, economics, political science, history) is not a unity already existing or that may be found in a particular place (ideal or real), but it is a unity that must be made. It is precisely this "making" that provided the impetus for the working of our Academy.

There is another important achievement that PASS has been able to obtain in the first thirty years of its existence. I am referring to this fact. For a group of scholars to hold in trust an institution such as an Academy, they must articulate and cultivate its larger purpose, that in our case is based on the two pillars suggested in John Paul II's *Ex corde ecclesiae*: the unity of knowledge and the ultimate complementarity of faith and reason.

In this regard, what we learned is the necessity to resist that subtle temptation called teleopathy, expressing itself in a three-stage pattern. First, in the absence of a clear mission and identity, the members of the institution fixate moral or social aspirations as surrogates for the theological dimension. Then they rationalize that voice invoking pluralism in order to eschew a theological vision of faith and reason, which ironically leads to less, not more, pluralism. Third, they detach themselves from the two pillars established in *Ex corde ecclesiae*, resulting in a separation of the Academy from a deeper relationship with the Church. This detachment rarely happens all at once, but discrete decisions over time have a cumulative effect of alienating the mission and the identity of the Academy.

I can say that PASS has systematically managed to avoid this teleopathic pattern, which has allowed it to skip the so-called "cut flowers syndrome": flowers (such as rights, justice, values etc.) may look attractive for a while, but severed from their cultural and spiritual roots, they wither.

Finally, let me say that I really learned a lot while being in this Academy. My experience allows me to confirm that St. Alberto Magno – Aquinas' master – was completely right when he wrote: "In dulcedine societatis, quaerere veritatem" (Searching for truth in the sweetness of fraternity). So let me express my heartfelt gratitude to PASS, whose motto I would formulate as: "Ubi lux lucet, humanitas surgit" (When light shines, humanity revives).

COMMEMORATIONS OF A DECEASED ACADEMICIANS

Herbert Schambeck (12 July 1934 - † 2 October 2023)

Herbert Schambeck was born on July 12th, 1934 in Baden bei Wien in Austria. He graduated in Law. His field of specialization was constitutional and administrative law. In 1967 he was appointed Full Professor of Public Law, Political Sciences and Legal Philosophy at the University of Linz. He gave guest lectures in many countries all over the world. At the same time he engaged in a political carrier, being elected in 1969 as a member of the Federal Council – the senate – of the Republic of Austria. He became Chairman of the Christian Democrat Party in 1975, and continuously President or Vice-President of the Federal Council.

He was married to Elisabeth who died in 1989. They had a daughter.

His ties with the Holy See became notorious, notably since his membership of the Delegation of the Holy See to the General Conference of the International Atomic Energy Agency from 1969 to 2007.

Prof. Schambeck collected multiple academic awards, mainly in the German speaking world and in Eastern Europe.

Ten years ago Prof. Schambeck addressed our Academy on commemorating its twentieth anniversary of foundation. He did not miss recording the role he played in its foundation. I can witness myself to the fact that the very idea of creating such an academy came from him in 1988. He contacted Fr. Schasching, sj, Prof. Weiler and Fr. Utz, op. and informed the then Secretary of State Cardinal Casaroli of the project. I was working with Casaroli at that time and so became involved in the project as well. In 1988 as I moved to the University of Strasbourg I continued to meet Schambeck and Utz in Zürich and Vienna. Finally we wrote a letter to His Holiness Pope John Paul II submitting formally the idea of a Pontifical Academy of Social Sciences. This was finally created with the papal decree on January 1st, 1994.

Later in a private conversation with Pope John Paul the latter said about the Academy : "the initiative came from Austria".

After his 80th anniversary, Prof. Schambeck became honorary member of our Academy in 2015. He died in Vienna on 2nd of October 2023.

ARCHBISHOP ROLAND MINNERATH

Margaret Scotford Archer (20 January 1943 - † 21 May 2023)

We are gathered here today in Casina Pio IV to remember and pay tribute to the memory of our dear friend and colleague, Margaret Scotford Archer, a Founding Member of PASS, who died in Kenilworth (UK) at the age of 80 on 21 May of the past year 2023, the day of the Ascension. We remember her above all as the generous and inspiring President of this Academy from 2014 to 2019, when she acted as an advisor to the Pope, particularly by putting the topics of human trafficking and Artificial Intelligence on the agenda of the Holy See.

Professor Archer spent most of her career at the University of Warwick, from which she retired in 2010. She was a formidable social theorist in her own right. Maggie (as she liked to be called) studied Philosophy, Politics and Economics at the University of Cambridge. She obtained a PhD in sociology from the London School of Economics in 1967. Then, in 1968, she joined Pierre Bourdieu and Luc Boltanski at the Centre of European Sociology in Paris as a postdoctoral researcher. Her work is best known for her association with critical realism. In a series of highly influential books published by Cambridge University Press, she developed the morphogenetic approach as an overarching theoretical framework for the analysis of social, cultural and personal change in late modernity. She got two honorary doctorates, one from the University of Navarra and another one from the University of Warsaw. She also ran a charity for trafficked women in her hometown in the British Midlands.

I met Margaret Archer in New Delhi during the ISA congress in 1986. At that time, she was known for her first important work (*Social origins of educational systems*, 1979), in which she explained the origin and development of different educational systems, in particularly in France and Great Britain – as well as Denmark and Russia – on the basis of different cultures and social structures (hierarchical and centralized *vs* pluralistic and decentralized). In our conversations, she often reiterated to me that, for her, this first work was decisive for all her subsequent production, for at least two good reasons: firstly because the relationship between individuality and sociality is crucial in education; and then because she wanted it to be clear to the academic world that the morphogenetic scheme had already been born in that work, even if she would only fully theorize it later. In fact, precisely in this research she distances herself from Bourdieu, criticizing structuralist constructivism to show that social processes are based on the interplay between agency, culture and structure (the SAC scheme).

Beyond the early works, her scientific production had a first fundamental stage in the book *Culture and agency* (1988), which can be considered as the first milestone in the development of a general social theory in epistemological terms. In this work, I believe, we notice a Weberian streak which leads her to contrast all those structuralist theories which forget or underestimate the connection between personal action and values. This position becomes very clear in the following book *Realist Social Theory: The Morphogenetic Approach* (1995) in which she criticizes a whole series of scholars, and in particular Tony Giddens' structuration theory. In her opinion, much of social theory suffers from the defect of conflating agency and structure, due to the reluctance or inability to theorize the emerging relationships between social phenomena, so that causal autonomy is denied to one term of the relationship. If the causal efficacy of action is privileged, the autonomy of the structure is reduced ("upward conflation)". If we confer causal efficacy only on the structure thinking that it determines the action, we run into "downward conflation". Finally, if action and structure are seen as co-constitutive, in the sense that structure is reproduced through action which is itself simultaneously constrained and enabled by structure, then "central conflation" occurs. This work, which I think should be counted among the great classics of sociology, presents the general scheme of social morphogenesis, applicable to all social processes, and therefore to the change of the entire society. The book is internationally known because in it Archer coined the term *elisionism*, which indicates any theory for which the social and the individual are not separable and therefore characterizes any paradigm that opposes both individualism and collectivism.

Her sociological theory is fundamentally inspired by critical realism, the central core of which can be summarized as follows: (a) the rejection of Hume's "constant conjunctions" as a deficient, because empiricist, basis for conceptualizing social reality and causality; (b) the use of a layered ontology of social order, which supports the emergence and causal consequences of second- or third-order interactions between properties and emergent powers; in turn, this implies the acceptance of ascending and descending causality between strata; (c) the refusal to assign automatic priority to structure (or culture) over agency when accounting for causality in the social domain; (d) explanatory adequacy must be based on the "three pillars" of critical realism (CR), i.e. ontological realism, epistemic relativism, judging rationality.

"I will try to show – so she writes in an essay – how my explanatory program Morphogenetic/Morphostatic (M/M) usefully integrates the above with an interdisciplinary approach to explain change and stability in all social forms and institutions. This framework is obedient both to the four principles above, but also provides a toolkit for those seeking to theorize about the development of particular social processes, practices and policies (and resistance to them) wherever this is situated historically and geographically". With Roy Bhaskar and a circle of other critical realists, Archer created the International Association for Critical Realism (IACR) in 1997, whose manifesto can be considered the volume *Critical Realism: Essential Readings* (1998). On her own initiative, she then founded the *Center for Social Ontology* (CSO) during a teaching period at the École polytechnique fédérale de Lausanne (2011); the CSO was then transferred to the University of Grenoble, where it is currently based.

Between the 1990s and the first decade of the new century, Archer developed her research program by carrying out exceptional work, which, in my opinion, can be properly understood by combining three key words: *critical realism, social morphogenesis and reflexivity as internal conversation*. A cornerstone of these developments is *Being Human: The Problem of Agency* (2000), which was followed by investigations into reflexivity: *Structure, Agency and the Internal Conversation* (2003), *Making our Way through the World* (2007), *The Reflexive Imperative in Late Modernity* (2012). In this period, the theme/issue that has always been central to Archer's work powerfully emerges: the reclamation of the uniqueness of the human person and yet, at the same time, the refusal to give centrality to the individual as such. A perspective that is not easy to support and investigate sociologically, due to a certain apparent internal contradiction, but which constitutes, in my opinion, the heart of her message. In *Being Human* she took a stand against the idea of the hyposocialized individual proposed by the theory of rational choice (in the volume *Rational Choice Theory: Resisting Colonisation*), while at the same time rejecting any hypersocialising approach. In her opinion, the identity of the individual human person is formed as self-consciousness, thought and emotion, albeit in an elementary way, before the acquisition of social identity, and therefore is not a product of society. I believe Maggie has always fought her own scientific battle working on this point. She did it first by seeing in society above all a vexatious reality towards the individual, and therefore taking the individual's side, at the risk of appearing individualistic, and subsequently, starting from the end of the '90, seeking in relational sociology the antidote to individualism (as demonstrated by the book co-written with P. Donati, *The Relational Subject*, 2015).

The insistence on the uniqueness of the human person and at the same time on her sociality constituted the heart of her research program in the years 2013-2021, which resulted in two major projects pursued with the group of scholars of the CSO. First of all, the project on the morphogenesis of contemporary society, which produced five volumes edited by herself in a Springer series (*Social Morphogenesis*, 2013; *Late Modernity: Trajectories towards Morphogenic Society*, 2014; *Generative Mechanisms Transforming the Social Order*, 2015; *Morphogenesis and the Crisis of Normativity*, 2016; *Morphogenesis and Human Flourishing*, 2017). And then the *Post-Human Futures* project which produced four volumes between 2019 and 2021, edited by various members of the CSO, but always animated by her (*Post-Human Institutions and Organisations: Confronting the Matrix*, 2019; *Realist Responses to Post-Human Society: Ex Machina*, 2019; *Human Enhancement, Artificial Intelligence and Social Theory,* 2021; *What is Essential to Being Human? Can AI Robots Not Share It?*, 2021).

From these titles we can see Archer's persistent vocation to investigate the human in the context of new technological realities (AI, robotics), to which she attributed a positive quality, that of being able to become 'friends' of people. Perhaps this was the most discussed phase of her work, when she argued that the most sophisticated AI robots could become 'human' and relational subjects if and to the extent that they were equipped with the ability to act in the first person.

To conclude. I could talk about many aspects of her figure as a scholar and a woman endowed with profound humanity. Her sociology, which she always characterized as an antidote to English empiricism, is a paradigmatic example of how empirical analysis needs a robust social theory, based on a critical realistic social ontology, if one wants to be adherent to reality, but also open to a meta-theory to grasp, as her friend Bhaskar would say, meta-reality. That is, a sociology capable of investigating the horizontality together with the verticality of the social, in openness to the transcendent (as we read in *Transcendence: Critical Realism and God*, 2004, written together with Andrew Collier and Doug Porpora).

Maggie was able to express such an ambitious project because she had a very strong, independent character, demonstrated since she fought against nuclear weapons at the age of 15 and when, upon reaching adulthood, she converted to Catholicism, in contravention of the family's Anglican tradition, without losing her love for her parents and above all for the Anglican nuns who had educated her. Throughout her life she often made choices that went against the grain because she had in her head what she called a '*concrete utopia*', that is, the utopia of a society capable of making the human subject flourish, threatened by postmodernist thought which declared not only the "death of God", but also the "death of man". She reclaimed the potential of the human person as such, assuming that the person forms the sense of the Self before her sociality and beyond society, developing a self-awareness that has a practical, non-linguistic foundation, and which proceeds through that "inner conversation" which constitutes the foundation of the person's transcendence. She remained faithful to her initial research program aimed at showing that the person's identity arises from her own internal dialogue in the context of the identities that social institutions attribute to her and against all social injustices. The book recently published posthumously (*Morphogenesis Answers Its Critics*, 2024) testifies to her lifelong commitment to promoting human dignity always and everywhere.

PIERPAOLO DONATI

Fr. Michel Schooyans (6 July 1930 - † 3 May 2022)

Michel Schooyans was born in Braine-l'Alleud, Belgium on July 6 ,1930. He studied in the Catholic University of Louvain, where he received his Doctorate in Philosophy in 1958. He taught in several universities throughout the world, especially in Latin America. He was called by St. John Paul II to be a member of the Pontifical Academy of Social Sciences in 1994. He is, therefore, one of the founding members of this Academy. He was a Catholic priest and a Jesuit. He died in Brussels, in his home country, on May 3, 2022.

It is impossible to give, on this occasion, an evaluation of his multifaceted personality and of his contribution in the most different areas of social sciences, from political philosophy and social theology, to demography and sociology. He was a very conscientious scholar, but his research was not merely academic. He wanted to produce knowledge in order to shed light on the problems of our time.

We must limit ourselves today to remembering only two aspects of his broad and fruitful cultural heritage. The first regards the totalitarian drift of liberalism. In a more traditional sense, the word "liberalism" is the defence of the human right to pursue truth freely without any external coercion. In this sense, Fr. Schooyans was a stubborn advocate of liberalism. As time goes by, the word "liberalism" has acquired a different meaning. It has emancipated itself from the idea of truth and it has proclaimed the right to affirm one's own preferences and to follow one's own passions without any limit imposed by the obedience to truth.

There is here a shift from the idea of liberalism to the idea of libertinism. We can find this idea already at the beginning of Western philosophy. Plato, in The Republic, makes us acquainted with Thrasymachus, the sophist: without the reference to truth, no rational discussion is possible in the field of politics. The powerful will impose his will on the less powerful, using all means of manipulation and violence. The loss of the idea of truth is the sickness and true death of democracy.

The neoliberals have preached that the philosophy of democracy is relativism. They think that those who pretend to possess truth are inclined to impose their vision on others. Schooyans replied, with the old liberals, that this will not happen if the truth professed encompasses the human right to pursue truth without violence and coercion. He also added, together with Plato, that the fruit of moral relativism is corruption, and the fruit of corruption is the dissolution of the political order. Everybody today can see how prophetical his vision was.

I wish to remember, on this occasion, a second aspect of the scientific activity of Fr. Schooyans: his struggle against the so-called "lifeboat ethics". In the time of my youth, the opinion was absolutely dominant that on this Earth we are too many and that, in a short time, the resources of our planet would be depleted. The situation of mankind on Earth was compared to that of a shipwrecked crew, who must make recourse to extreme and cruel measures that would be unjustifiable under normal circumstances. They cannot save on their boat those who are drowning. They may even be justified if they throw overboard some of their fellow sailors. On this basis, it is necessary to encourage people not to have children at all costs. This includes, of course, policies in favour of abortion or of alternative lifestyles. Young people are invited not to get married and to renounce the possibility of having children.

Fr. Schooyans has documented that the major premise of this syllogism on which the "lifeboat ethics" is based is not just questionable: it is outrightly, egregiously false. It is not true that we are too many, and he gives evidence of this matter of fact in three steps: first, the unsustainable pressure on the natural environment recently denounced by Pope Francis and the Encyclical Laudato si' is dependent upon the overconsumption of the rich and not on the overpopulation of the poor; second, the reason why so many people in the world are starving is not a food shortage – there is food in abundance for all. The problem is that many people do not have the money to buy it. The problem is not that the Earth does not produce enough food for all, but that the income distribution is so unequal that some do not have money to buy food. Third, population growth has stopped. We are reaching a break-even point. Some demographers think we have already reached it. Others, that it will be reached in the next decades. What lies beyond the break-even point is the demographical winter. The population will decrease, and the number of active workers will be too reduced to pay the expenses for the pensions and the health care of the elderly. In many countries there is already a major problem, and the chief cause of the fiscal crisis of our states. It is open to discussion how much of this demographical trend is dependent upon the "lifeboat ethics" measures taken by some states and international organizations, and how much is just dependent upon the autonomous decisions of men and women exercising their responsible parenthood. Such was the force of the campaign in favour of abortion that today many people keep speaking of the demographical bomb and make the Catholic Church responsible for it, while there is, in the science of demography, an unanimous consensus on the fact that the real problem is the demographic winter and reality has not confirmed the expectations of the anti-natalist movement. Fr. Michel Schooyans struggled against this tide in years when nobody dared contrast it. He was often isolated but never intimidated. He was never afraid because he was a man of faith and a scrupulous scientist who took into consideration all available data. He was short of stature, very courageous in the defence of truth, but rather timid and reserved in his private life. He had a winning smile. He loved the Church and was well aware of the fact that man is the way of the Church. He is out of our time; he enters the other that has no end.

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