

PLENARY SESSION ON

DISABILITY AND THE HUMAN CONDITION

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



9-11 April 2024 Casina Pio IV, Vatican City





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)

Concept Note

here 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 people¹. 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 variable², 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. Meanings and ideals are variable in time and space³. 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 life⁴. 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

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.

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.

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 relationships 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" (FT 107).

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" (FT 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"" (FT 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.

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

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		
	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

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: Vi	ttorio 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
12.10	Discussion
12.15	
-	General Discussion
12:25	General Discussion Lunch at the Casina Pio IV
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THURSDAY APRIL 11, 2024

8:00	PAPAL AUDIENCE	
9:30	Coffee Break	
Special Session Celebration of the 30 th 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

AGBONTAEN-EGHAFONA Kokunre A.

PASS Academician Department of Sociology and Anthropology, Acting Dean, Faculty of Social Sciences, University of Benin, Nigeria

ALFORD Helen, O.P.

PASS President Dean, Faculty of Social Sciences, Pontifical University of St Thomas (Angelicum), Rome, Italy

ALKIRE Sabina

PASS Academician Director, Oxford Poverty and Human Development Initiative (OPHI) Department of International Development, University of Oxford, UK

ALLMENDINGER Jutta

PASS Academician Professor of Educational Sociology and Labor Market Research at Humboldt University, Berlin, Germany

BAI Tongdong

PASS Academician Dongfang Chair Professor of Philosophy at Fudan University, Global Professor of Law at NYU's Law School, and Adjunct Professor at NYU-Shanghai, P.R. China

BARRERA Albino, O.P.

PASS Academician Professor of Economics and Theology, Providence College, Rhode Island, USA

BELIZ Gustavo Osvaldo

PASS Academician Former Secretary of Strategic Affairs, Buenos Aires, Argentina

BICKENBACH Jerome 🙄 by Zoom

Permanent Visiting Professor at the Faculty of Health Sciences and Medicine at the University of Lucerne and Professor in the Department of Philosophy and Faculties of Law and Medicine at Queen's University, Canada

BUTTIGLIONE Rocco

PASS Academician Professor of Philosophy, Instituto de Filosofia Edith Stein, Granada, Spain

CARTABIA Marta

PASS Academician Professor of Constitutional Law, Bocconi University, Milan; President Emeritus of the Italian Constitutional Court

CUDA Emilce

PASS Academician Secretary, Pontifical Commission for Latin America, Vatican City

DONATI Pierpaolo

PASS Academician Emeritus Professor of Sociology, University of Bologna, Italy

DRAGHI Mario

PASS Academician Former Prime Minister of Italy

ENGEL Christoph

PASS Academician Director, Max Planck Institute for Research on Collective Goods, Cologne, Germany

FALABELLA Vincenzo

Presidente Federazione Italiana Superamento Handicap (FISH), Rome, Italy

FARRELL Justin

PASS Academician Professor of Sociology at Yale University, USA

FERRUCCI Fabio

PASS Academician Professor of Sociology University of Molise, Italy

GLYN Justin S.J.

Adjunct Lecturer, Catholic Theological College, University of Divinity, Australia

GONZÁLEZ Ana Marta

PASS Academician Full Professor of Philosophy at the University of Navarra, Spain

GUERRA LÓPEZ Rodrigo

PASS Academician Secretary, Pontifical Commission for Latin America, Vatican City

GUZMÁN Martín Maximiliano

PASS Academician Professor, Columbia University, USA

HOLLINS Sheila

Baroness, Professor of the Psychiatry of Learning Disability at St. George's University of London, President of the Royal College of Psychiatrists, London, UK

HÖSLE Vittorio

PASS Academician Paul Kimball Professor of Arts and Letters University of Notre Dame, USA

JAYAL Niraja Gopal

PASS Academician

Professor at the Centre for the Study of Law and Governance at the Jawaharlal Nehru University, New Delhi, India.

LEONARDI Matilde

Director of Neurology in the Public Health, Disability Unit and Coma Research Centre at the Carlo Besta Neurogical Institute, Milan, Italy

Mc ELDOWNEY John

PASS Academician Professor of Law, University of Warwick, Coventry, UK

MINNERATH Roland

PASS Academician Archevêché Dijon, France

PAOLINI Chiara

Teacher, Massarossa, Italy

PINILLA RONCANCIO Monica

Deputy Director Centre of Sustainable Development for Latin America and the Caribbean (CODS), Research Associate at Oxford Poverty & Human Development Initiative - the University of Oxford, UK

POZZO Riccardo

PASS Academician Professor of the History of Philosophy, University of Tor Vergata, Rome, Italy

ROWLAND Tracey Anne Patrice 💿 by Zoom

PASS Academician Professor of Political and Cultural Theory and Chair of Theology at the University of Notre Dame, Australia

SACHS Jeffrey 🙄 by Zoom

PASS Academician President of the UN Sustainable Development Solutions Network, Columbia University, New York, USA

SÁNCHEZ GALERA María Dolores

PASS Councillor Senior Research Advisor, Dicastery for Promoting Integral Human Development, Vatican City

SHAKESPEARE Tom

Professor of Disability Research in the Medical Faculty at the London School of Hygiene and Tropical Medicine; previously Professor of Disability Research in the Medical Faculty at the University of East Anglia, UK

SITHOLE Pearl

PASS Academician University Manager Campus Vice-Principal: Academic and Research, University of the Free State, Qwaqwa Campus, Phuthaditjaba, South Africa

STIGLITZ Joseph

PASS Honorary Academician Columbia University, Graduate School of Business, New York, USA

SUÁREZ OROZCO Marcelo

PASS Academician

UCLA Wasserman Dean Emeritus and Distinguished Professor Emeritus; Chancellor, University of Massachusetts, Boston, USA

TURKSON Card. Peter K.A.

PASS and PAS Chancellor, Vatican City

VIANA Virgilio

PASS Academician

CEO at Foundation for Amazon Sustainability (FAS); Special Professor at Dom Cabral Foundation; Guest Professor at National Amazon Research Institute (INPA), Brazil

VIGANÒ Dario Edoardo

PASS Vice Chancellor Professor of Cinema, Photography and Television at the International Telematic University, UNINETTUNO, Italy

WIELECKI Krzysztof

PASS Academician Institute of Sociology, Faculty of Historical and Social Sciences, The Cardinal Wyszyński University in Warsaw, Poland

ZAMAGNI Stefano

PASS Honorary Academician Professor of Economics, University of Bologna. Vice Director, SAIS Bologna, Senior Adjunct Professor of International Political Economics, Italy

Memorandum

- **Dress Code** is business casual.
- Meals: We will provide coffee breaks, lunch and dinner on 9-10 and 11 April. If you have any food allergies or dietary requirements, please let us know in advance.
- Security: invites are strictly personal. Please remember to bring a valid ID.

VIRTUAL ATTENDANCE

A Zoom link will be sent to virtual participants before the event, with the request not share it with external parties.

FOR MORE INFORMATION

Please refer to www.pass.va and www.pas.va for further information on the Academies, the Academicians, and current and past events.

PICKUP SCHEDULE ON 9-10-11 April 2024

- On 9 and 10 April: a bus will leave the TH Carpegna Palace Hotel at 7:00 a.m. to accompany participants to Saint Peter's Basilica, where a concelebrated Holy Mass will be held at 8:00 a.m. After the Holy Mass, a bus will leave the Domus Sanctae Marthae at 8:45 a.m. for the Academy. The same buses will take you back to your hotels after dinner at 8:00/8:30 p.m.
- On 11 April: a bus will leave the TH Carpegna Palace Hotel at 6:30 a.m. to accompany participants to "the Apostolic Palace" for the Papal Audience. At 8:45 a.m. the same bus will accompany participants to the Academy. The same service will be organized to take participants back to the hotel (TH Carpegna Palace Hotel) after dinner at 8:00/8:30 p.m.



WI-FI network: academy-guest Password: G@rdens1936



THE PONTIFICAL ACADEMY OF SOCIAL SCIENCES CASINA PIO IV | V-00120 VATICAN CITY Tel: +39 0669883451 | Fax: +39 0669885218 | Email: pass@pass.va For further information please visit: www.pas.va and www.pass.va

