the Pontifical Academy of Social Sciences

Plenary Session on Disability and the Human Condition

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

There is no exact number of people 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, professionals who share many areas of social life with persons with disability. 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 people with disability 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 highly-developed countries from medium- and under-developed ones. Lack of universal health coverage, environmental pollution, 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 people with disability 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 space.[3] Societies have not always recognised equal dignity and the same rights as everyone else for people with disability, who have suffered various forms of social exclusion: from physical elimination to abandonment, from segregation to discrimination.

Knowledge about the living conditions of persons with disability 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 people with disability "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 that still considers disability a 'personal tragedy'. The inadequate support of 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 disability, 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 solidarity of family relationships becomes visible. Solidarity that does not remain confined to the private sphere but takes on a social significance. When these relationships of solidarity and care wear out or fail, institutionalisation of persons with disability 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 for 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 disability.

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 disability, 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 disability 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 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 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 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 disability 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 prerogative 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 people with disability 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 disability 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 Magisterium of the 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 affirmed that persons with disability are fully human subjects with rights and duties. Persons, 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 people with disability, 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 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", shows the condition that unites every human being, and makes 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 explore, 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 disability, creating and supporting works and initiatives through which to promote their inviolable dignity, in social contexts pervaded by the "culture of discard".

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 disability, the associations and movements to which they have given rise is of primary importance. The activation of networks fo solidarity and mutual aid involving persons with disability, their associations, third sector subjects and public institutions shows the multiple ways in which persons with disability contribute to the development of societies, with 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 disability, flourish.

[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.

[5] Compendio della Dottrina Sociale della Chiesa, n. 148.

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