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**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development**

Written statement* submitted by Associazione Comunita Papa Giovanni XXIII, a non-governmental organization in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[11 February 2019]

* Issued as received, in the language(s) of submission only.



Empowering children with disability in their right to life and right to health

Associazione Comunità Papa Giovanni XXIII (APG23) welcomes the theme of the Annual full-day meeting on the rights of the child “Empowering children with disabilities for the enjoyment of their human rights, including through inclusive education.”¹

APG23 would like to focus on the empowering of children with disabilities in the enjoyment of the right to life and health. The right to life and the right to the enjoyment of the highest attainable standard of physical and mental health are often two faces of the same coin, especially for persons with disability.

The International Covenant on Civil and Political rights clearly specifies in the first paragraph of article 6: “Every human being has the inherent right to life. This right shall be protected by law”.²

The Convention on the Right of the Child states in its preamble that “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth”³

The right to life is intrinsic to the human being, is connatural to its own nature, to the very concept of humanity; to have an “inherent” right means that such a right is deep-rooted in the nature of the human being.

There is still a common perception that the life of persons with disabilities have less value, it is always full of pain and suffering. The persons with disabilities are often perceived as a burden to the society, and children with disabilities are not seen as a value in many environments including the school. Often children with disabilities are stigmatized, considered as useless. Their unalienable right of life is put at great risk, especially in their life before birth.

Article 10 of CRPD affirms that: “States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.”

The Committee on the Rights of Persons with Disabilities in the General comment n° 6 (2018) on equity and non-discrimination states that “dignity, integrity and equality of the person have been denied to those with actual or perceived impairments” and that “the human right model of disability recognizes that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights”⁴.

We have seen in recent years, with some cases of children with disability reaching the news, how the debate on life or death of disabled children, before or after birth, has been often based on a supposed different, apparently worse, quality of life.

The Committee on the Rights of Person with Disabilities in 2017 contributing to the call on the draft General Comment no36 of the Human Rights Committee on article 6 of the International Covenant on Civil and Political Rights wrote that “laws which explicitly allow for abortion on grounds of impairment violate the Convention on the Rights of Persons with Disabilities (Art. 4, 5, 8).” It is further explained that “often it cannot be said if an impairment is fatal. Experience shows that assessments on impairment conditions are often false” and that, “Even if it is not false, the assessment perpetuates notions of stereotyping disability as incompatible with a good life.”⁵

The Foundation Jerome Lejeune has recently publicly reported the situation of countries in which the drastic reduction of births of children affected by Down syndrome demonstrate the selective use of abortion.

¹ A/HRC/40/27

² International Covenant on Civil and Political Rights

³ Convention on the rights of the Child, preamble, paragraph 9

⁴ CRPD/C/GC/6

⁵ <https://www.ohchr.org/EN/HRBodies/CCPR/Pages/GC36-Article6Righttolife.aspx>

In such cases, in fact, the eugenic selection and the selective/therapeutic abortion lead to eliminating the sick person instead of concentrating on the elimination of the disease.

We think that the right to life of children that are in situations of extreme difficulties and vulnerability is better respected and protected by offering measures that will help them and their families to feel less lonely and more supported rather than by facilitating their death.

Recent cases of disabled children whose life was judged non-worth to be lived helped raising many questions on how to value life. We would like to echo the words of Pope Francis: there is no human life that is qualitatively more significant than another.

Regarding the right to health of children with disabilities, its fulfilment is hindered by many factors among which the impact of the social determinants of health on disabilities, the stigma related to disability and the lack of social policies supporting the families and the communities in which these children live.

According to WHO “disability is extremely diverse. While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However, all persons with disabilities have the same general health care needs as everyone else, and therefore, they need access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination.” On the contrary “People with disabilities have less access to health care services and therefore experience unmet health care needs.”⁶

WHO points out that the persons with disabilities may experience greater vulnerability to many conditions (such as secondary conditions and co-morbid conditions) and encounter a range of barriers that put at risk their health. According to our experience this is particularly true for children with disabilities living in poor settings with severe detrimental effect on the dignity and quality of life, not only of the children but also of their whole family and community.

Discrimination or denied access to health care continues to occur. Children with disabilities often represent the weakest and most in need component of families with their enjoyment of the right to health prevented by social determinants of health that may hit harder on situation of poverty. Prohibitive costs, physical barriers, lack of infrastructures, hospitals, lack of specialized equipment, medicines, specialized nurses and doctors play a huge role in the denial of health to these children in poor settings.

We have experienced children with disabilities often denied of basic physiotherapy, of basic epileptic drugs, families incapable of reaching the nearest health centre or the nearest hospital because of lack of transport means for their disabled child, children abandoned in the house because of lack of resources; we have also witnessed the damaging effect of institutionalization on the physical and mental health of disabled children.

We are living in an era in which countries are aiming at becoming “Down Syndrome free” using eugenic selection of embryos and selective abortion,⁷ and other countries are in favour of child euthanasia⁸ forgetting that dignity is inherent to every human being, regardless of his/her health conditions.

Children with disabilities are rights-holders, carriers of solidarity, love and inclusiveness. Without them the world is missing out on the opportunity of being a whole human family in its diversity and potentiality; assuring their empowerment for the enjoyment of all their human rights makes us all more human.

APG23 aims to achieve full recognition of the dignity of persons with disabilities, both physical or mental and of their essential role in building a new humanity and a new society. This is because “the parts of the body that seem to be weaker are all the more necessary,”⁹,

⁶ <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

⁷ <https://www.cbsnews.com/news/down-syndrome-iceland/>

⁸ <http://www.osservatoreromano.va/it/news/leutanasia-dei-bambini>

⁹ 1 Corinthians 12,22

meaning that persons with disabilities must not become mere recipients of charity but a resource, a life-enhancing gift.¹⁰

Families with disabled children should be given the support necessary to accept, welcome and help their children from conception up to the full development of their potentiality. We have already left behind too many children with disabilities.

In his visit to the UN in 2015, Pope Francis said:” The common home of all men and women must continue to rise on the foundations of a right understanding of universal fraternity and respect for the sacredness of every human life, of every man and every woman, the poor, the elderly, children, the infirm, the unborn, the unemployed, the abandoned, those considered disposable because they are only considered as part of a statistic. This common home of all men and women must also be built on the understanding of a certain sacredness of created nature.”¹¹

¹⁰ https://www.apg23.org/en/people_with_disabilities/

¹¹ http://w2.vatican.va/content/francesco/en/speeches/2015/september/documents/papa-francesco_20150925_onu-visita.pdf