

*Legal Seat – Helsinki, Finland*

**WORLD FEDERATION OF THE DEAF**

An International Non-Governmental Organisation in official liaison with ECOSOC, UNESCO, ILO,

WHO and the Council of Europe. WFD was established in Rome in 1951.

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The World Federation of the Deaf (WFD) welcomes the Human Rights Council resolution 35/6 designing a study on Bioethics and Disability made by the UN Special Rapporteur on the rights of persons with disabilities.

The World Federation of the Deaf is an international non-governmental organisation comprising of members from 125 countries and representing the interest of around 70 million deaf people globally. WFD is also a founding member and member of the International Disability Alliance (IDA).

1. **Introduction**

In 2006, the United Nation General Assembly adopted the UN Convention on the Rights of Persons with Disabilities (CRPD). At the time I am writing those lines, this instrument has been ratified by 180 countries. This treaty is capital for the human rights of persons with disabilities, including deaf people because it operates a paradigm shift from the medical model of disability to the social model of disability. For years, deafness has been viewed under a medical construction and societal standards of normalcy perspectives defining deafness as pathology and deficit.

The paradigm shift to the social model of disability bring deafness to be considered as the lack of consideration for accessibility through sign language in society. Furthermore, as highlighted in its [position paper on Complementary or diametrically opposed: Situating Deaf Communities within ‘disability’ vs cultural and linguistic minority’ constructs](http://wfdeaf.org/news/resources/wfd-position-paper-complementary-diametrically-opposed-situating-deaf-communities-within-disability-vs-cultural-linguistic-minority-constructs/), WFD considers the deaf community to belong not only to the disability community but also as part of a cultural and linguistic minority. Deaf people and their use of sign languages are resources holding contribution to the cognitive, creative and cultural dimensions of human diversity (Bauman and Murray, in press).

1. **Deafness as contributor of cultural and social diversity of society**

To name but a few of those contributions, sign language studies have offered insights into the development of language and the elasticity of the human brain in acquiring language (Bauman and Murray, in press). The visual processing of information, and kinaesthetic expression of language that characterise deaf people offer insights into “multiple intelligence”. Deaf people’s cognitive-communicational process is a unique form of intelligence with rich language products (Bauman and Murray, in press). Sign language users bring new sensory and spatial perspectives to the development of film, literature, theatre, architecture and other form of creativity. The sociality of the deaf and their attention to community and collective culture offer lessons that could offset alienating aspects of the today’s world. For example, sign language users engaged in a conversation position themselves in triangular or circular configurations so that everyone can access the discussion (Bauman and Murray, in press).

WFD believes these Deaf qualities are valuable inputs to human and social diversity. Therefore, those should be respected, valued and encouraged for the social good. Deaf people are actors and contributors of the diversity of society to make it inclusive and accessible for all.

1. **Contemporary medical response to deafness: the case of genome editing**

Yet, despite the adoption of CRPD and its paradigm shift, deafness is still being viewed as an impairment with an impediment to cure to gain normalcy. Deafness, Disability and Normalcy are concepts created by society (Akinola, Legg and Peel, 2009). The medical model pathologies deafness and looks to medicine and related professions to effect a cure, or falling a cure, to normalise the individual as far as possible.

To illustrate the current practise of the medical sector toward deafness, WFD will refer to “[Russia’s CRISPR “Deaf Babies”: The Next Genome Editing Frontier?](https://www.geneticsandsociety.org/biopolitical-times/russias-crispr-deaf-babies-next-genome-editing-frontier)”, an article written by Jackie Leach Scully and Teresa Blankmeyer Burke.

In June 2019, a Russian molecular biologist, Denis Rebrikov, revised plan to use CRISPR technology to correct a mutation that lead to hereditary deafness. According to the [2018 Second International Summit statement on Human Genome Editing II](http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b), genome editing should only be tested in humans if the condition is serious and if there is no available alternatives. Furthermore, the UK’s Nuffield Council on Bioethics report on [Genome Editing and Human Reproduction](http://nuffieldbioethics.org/wp-content/uploads/Genome-editing-and-human-reproduction-FINAL-website.pdf) similarly proposed that any future use of genome editing must satisfy two ethical principles: 1) The intervention should be intended for the welfare of the future person. 2) Its use should not foreseeably increase social inequalities or marginalisation of particular groups.

1. **Discussion**

The WFD strongly disagrees with the idea that deafness is a “serious” condition severly compromising any chance of having a good life. Indeed, deaf communities globally consider themselves as members of cultural groups using minority languages, the national sign languages.

In addition, the use of hereditable genome editing is likely to increase social injustice and marginalisation as it will legitimate fear and will harden public hostility towards deaf people in general. Genome editing could encourage people to think that deafness is optional with the risk of having a belief that parents have a social obligation to use editing techniques to “correct” their future children.

1. **Conclusion**

In conclusion, the WFD strongly condemn the use of genome editing to erase deafness as it is a purely medical-based response to disability and diversity. Such practises tends to overpass the recognition of deaf communities as part of a cultural and linguistic minority. On the contrary, the use of genome editing tend to correct diversity to reach normalcy over the promotion of inclusion and diversity. In addition, such practises and policies do not take place with an extensive consultation of association of the deaf, contravening Article 4.3 CRPD. Therefore, this constitutes a flagrant violation of the spirit of the Convention on the Rights of Persons with Disabilities, which promotes and hightlights the human rights model of disability.

**References:**

Akinola, Taye, Legg, Janelle, and Peel, Kristina. Annotated Bibliography Project: Deafness, Disability, Genetic and Biotechnology. By *Gallaudet University Student Working Group, Course DST 712 “Enforcing Normalcy: Deaf and Disability Studies”*.

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***About the World Federation of the Deaf***

*The World Federation of the Deaf (WFD) is an international non-governmental organisation representing and promoting approximately 70 million deaf people's human rights worldwide. The WFD is a federation of deaf organisations from 125 nations; its mission is to promote the human rights of deaf people and full, quality and equal access to all spheres of life, including self-determination, sign language, education, employment and community life. WFD has a consultative status in the United Nations and is a founding member of International Disability Alliance (IDA). (*[*www.wfdeaf.org*](http://www.wfdeaf.org)*) Email:* info@wfd.fi