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Addressing Cognitive Vulnerabilities Through Genome & Epigenome Editing: Techno-Legal Adaptations for Persons with Intellectual Disabilities

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1. Introduction

Over the last several years, issues and concerns relating to genome editing have gained considerable traction on a global level. The gene editing tool, CRISPR/Cas9¹ has demonstrated successes and promises since its invention – but it particularly became more scrutinized due to the case of Dr. He Jian Kui.² Whilst there have been a variety of international instruments that deal with the use and governance of genome editing,³ the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing (Committee) published two reports: *Human Genome Editing: A Framework for Governance*,⁴ and *Human Genome Editing: Recommendations*.⁵ These reports represented a new governance framework that builds on identifiable tools, organizations and situations that integrate the practical difficulties of regulating human genome editing.

One of the fields in which the potentiality of genome editing is still under-represented is in disability discourse. The key aim of this paper, therefore, is to highlight the oft-under-

¹ Jennifer A Doudna and Emmanuelle Charpentier, ‘The New Frontier of Genome Engineering with CRISPR-Cas9’ (2014) 346 *Science* 1258096.

² Henry T Greely, ‘CRISPR’d Babies: Human Germline Genome Editing in the “He Jiankui Affair”’ (2019) 6 *Journal of Law and the Biosciences* 111.

³ These include, amongst others, the European Convention on Human Rights; the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (the Oviedo Convention); the UNESCO Universal Declaration on the Human Genome and Human Rights; and the UNESCO Universal Declaration on Bioethics and Human Rights.

⁴ World Health Organization, *Human Genome Editing: A Framework for Governance* (World Health Organization 2021) <<https://apps.who.int/iris/handle/10665/342484>> accessed 4 October 2021.

⁵ World Health Organization, *Human Genome Editing: Recommendations* (World Health Organization 2021) <<https://apps.who.int/iris/handle/10665/342486>> accessed 4 October 2021.

1 represented narrative of how persons with disabilities (specifically, those with intellectual
2 disabilities) may access the benefits that genome editing may offer. For example, since
3 CRISPR first made the headlines in 2012, it has remained the subject of fiery legal and ethical
4 debates centered around human genome editing and possibilities of ‘designer babies’⁶ in our
5 foreseeable future. In the meantime, disability discourse in the context of genome editing has
6 been equally controversial. These include Peter Singer’s controversial utilitarian philosophy,
7 where he regards that “killing them [infants], therefore, cannot be equated with killing normal
8 human beings, or any other self-conscious beings. No infant - disabled or not - has as strong a
9 claim to life as beings capable of seeing themselves as distinct entities existing over time.”⁷ It
10 may be observed that tackling disability discourse raises a much more complex ELSI (ethical,
11 legal, and social implication) question that makes it uncomfortable to comprehend.

12 Viewed in context of rights of persons with intellectual disabilities (ID), primarily with
13 reference to the United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁸
14 and other relevant international and/or regional instruments,⁹ this paper first highlights the
15 alignment of a right to health (broadly)¹⁰ for persons with ID. Specifically, the argument that
16 is being made, is that persons with ID need equitable access to genome technologies, so that
17 they can fully realize their right to health, which includes a right to habilitation (narrowly)
18 under Article 26 of the CRPD.¹¹ Whilst the CRPD has been touted to be a landmark convention
19 that addresses the human rights needs of persons with disabilities on a large scale, and appears
20 to have been relatively successful in terms of protecting such rights¹² – there does appear to be
21 a lack of concerted effort or will in addressing their human rights in the context of new and
22 emerging technologies. Article 26, which deals with habilitation and rehabilitation of persons
23 with disabilities, should, in theory, address such access to technologies (including genome
24 editing technologies).

25 Thereafter, the paper evaluates the legal provisions on non-discrimination and equality
26 relating to genome editing technologies, contained in the CRPD and other international

33 ⁶ Ed Yong, ‘The Designer Baby Era Is Not Upon Us’ [2017] *The Atlantic*
34 <<https://www.theatlantic.com/science/archive/2017/08/us-scientists-edit-human-embryos-with-crisprand-thats-okay/535668/>> accessed 19 September 2017.

35 ⁷ Peter Singer, *Practical Ethics* (3rd edn, Cambridge University Press 2011).

36 ⁸ United Nations, ‘Convention on the Rights of Persons with Disabilities and Optional Protocol’ (2006)
37 <<https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>> accessed 15 January 2022.

38 ⁹ These include, amongst others, the European Convention on Human Rights; the Convention for the Protection
39 of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine:
40 Convention on Human Rights and Biomedicine (the Oviedo Convention); the UNESCO Universal Declaration
41 on the Human Genome and Human Rights; and the UNESCO Universal Declaration on Bioethics and Human
42 Rights.

43 ¹⁰ OHCHR and WHO, ‘The Right to Health’ (Office of the United Nations High Commissioner for Human Rights)
44 <<https://www.ohchr.org/Documents/Publications/Factsheet31.pdf>> accessed 10 March 2020.

45 ¹¹ Article 26 of the CRPD on Habilitation and Rehabilitation reads:

46 *1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons*
47 *with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational*
48 *ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize,*
49 *strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in*
50 *the areas of health, employment, education and social services, in such a way that these services and programmes:*
51 *a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and*
52 *strengths;*

53 *b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are*
54 *available to persons with disabilities as close as possible to their own communities, including in rural areas.*

55 *2. States Parties shall promote the development of initial and continuing training for professionals and staff*
56 *working in habilitation and rehabilitation services.*

57 *3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed*
58 *for persons with disabilities, as they relate to habilitation and rehabilitation.*

59 ¹² Adam Conti, ‘Drawing the Line: Disability, Genetic Intervention and Bioethics’ (2017) 6 *Laws* 9, 10.

1 instruments, considered through the lens of persons with ID. The intention is to highlight any
2 shortcomings that needs to be addressed to allow persons with ID to fully realize their right to
3 health *vis-à-vis* existing legislation. This is especially telling in light of the fact that there are
4 currently specific points of interest around the potential use of epigenome editing therapies for
5 treating, or even reversing some genetic mutations that cause ID. Finally, the paper suggests a
6 reinvigorated line of thinking that expands on the social model of disability: to align with
7 inclusive, contemporary disability discourse that embodies greater responsibility and
8 innovation in perpetuating better access to genome editing technologies for persons with ID.
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10 2. Addressing the Rights of Persons with Disabilities in Genome Editing

11 2.1 Disability Discourse Models

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13 The focus put forward in this paper is around somatic gene editing (and not human germline
14 gene editing), attracting concerns such as safety, risks versus benefits considerations, and long-
15 term patient care and monitoring mechanisms,¹³ and therefore arguably attracts less of the ELSI
16 debate. The crux of these considerations as a starting point, however, are inadequate when we
17 encounter questions of inequalities and vulnerabilities in disability discourse. It is therefore
18 imperative to reflect on the difficult questions that address the experiential, intersectional,
19 spatial practices of identities and spaces of persons with disabilities.
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21 With the knowledge that genome editing therapies may possibly be successful in curing
22 or treating ID – a crucial question which some may ask is whether we should, indeed, remove,
23 or encourage that these disabilities be removed. This is, however, not an objective question.
24 For some time, disabilities had always been viewed from the perspective of the medical model.
25 The medical model of disability traditionally focuses on the impairment or disability of a
26 person and has been instrumental in influencing the “development and structure of the
27 legislation, and is reflected in people’s attitudes and associated negative outcomes.”¹⁴ From the
28 viewpoint of the medical model, disabilities are often seen as impairments that needed to be
29 ‘fixed’, that persons with disabilities were a problem that had to be cured. Therefore, an
30 incurable impairment, or disability that cannot be rehabilitated, invites unconscious bias and
31 may imply a disabled person’s ‘lesser’ value in society.¹⁵ For example, in the UK, whilst the
32 medical model has been central to the drafting of the Equality Act 2010, parts of the Act that
33 relate to disability discrimination tend to “focus on what a person is unable to do.”¹⁶
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35 The medical model of disability has attracted criticism over the years due to its
36 parochial approach; and disability activism and scholarship have now evolved to a more
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50 ¹³ Heidi C Howard and others, ‘One Small Edit for Humans, One Giant Edit for Humankind? Points and Questions
51 to Consider for a Responsible Way Forward for Gene Editing in Humans’ (2018) 26 *European Journal of Human
52 Genetics* 1.

53 ¹⁴ The Parliamentary and Health Service Ombudsman, ‘Introduction to the Social and Medical Models of
54 Disability’ (The Parliamentary and Health Service Ombudsman)
55 <[https://www.ombudsman.org.uk/sites/default/files/FDN-
56 218144_Introduction_to_the_Social_and_Medical_Models_of_Disability.pdf](https://www.ombudsman.org.uk/sites/default/files/FDN-218144_Introduction_to_the_Social_and_Medical_Models_of_Disability.pdf)>.

57 ¹⁵ Stephen Bunbury, ‘Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to
58 Transformative Thinking about Disability Discrimination’ (2019) 19 *International Journal of Discrimination and
59 the Law* 26.

60 ¹⁶ The Parliamentary and Health Service Ombudsman (n 15).
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1 inclusive perspective, the social model of disability.¹⁷ Disability rights scholar, Mike Oliver,
2 raises three critical points about the social model of disability:¹⁸

3 Firstly, it is an attempt to switch the focus away from the functional limitations of
4 individuals with an impairment on to the problems caused by disabling environments,
5 barriers and cultures. Secondly, it refuses to see specific problems in isolation from
6 the totality of disabling environments: hence the problem of unemployment does not
7 just entail intervention in the social organization of work and the operation of the labor
8 market but also in areas such as transport, education and culture. Thirdly, endorsement
9 of the social model does not mean that individually based interventions in the lives of
10 disabled people, whether they be medically, rehabilitative, educational or employment
11 based, are of no use or always counter-productive.

12 Because the social model of disability was created by persons with disabilities themselves, its
13 main objectives anchor disabilities as experiences, instead of impairment or limitations.¹⁹ In
14 addition, the *leitmotif* of this model is forward-looking and prospective. With disabilities being
15 viewed as experiences, the idea is that any kind of barriers (that would prevent persons with
16 disabilities from fully participating in the vicissitudes of daily life) should be eradicated. This
17 includes accessibility to public spaces such as work and education, independent living instead
18 of institutionalization, and other unconsciously formed biases or challenges towards those with
19 disabilities.²⁰ The social model of disability is now the preferred model for engaging in
20 meaningful discussions about persons with disabilities, and has been endorsed by the
21 Government Equalities Office in the UK in 2014.²¹

22 There are many non-profit or non-governmental organizations that have been devoted
23 to the advancement of rights and interests, and awareness of persons with disabilities and their
24 experiences. Inclusion and adaptability in society are seen as the key components for the
25 integration of persons with disabilities, into daily life. Notwithstanding, persons with
26 disabilities still continue to face discrimination and iniquity in their daily lives, including but
27 not limited to fully exercising their right to health.²² This was also highlighted by the UN
28 Special Rapporteur in report number A/73/161 on the rights of persons with disabilities.²³

29 To answer the question earlier posed in this section, as to whether we should remove,
30 or encourage that these disabilities be removed: the answer this paper provides is “it depends
31 on the person”; because the answer is strictly premised on the capacity, autonomy and integrity
32 of such persons with the disability making that full and informed decision; absent prejudice,
33 interference, interjections and influences of the social and economic order of things.
34 Essentially, this is a question that can only be answered on a very personal level. Additionally,
35 to enable such full and informed decision to be made, full, clinical and neutral information
36 must be provided. What can also be done further is to bring emphasis to the voices of persons
37 with disabilities as a way to continue targeting discrimination and inequality. Whilst the
38 journey in fighting discrimination will always continue, the tools that are available on that
39 journey can now be different, powerful and yet, transformative. Therefore, the author of this
40 paper views this question as no longer being about eradicating disabilities; but for the
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49 ¹⁷ Mike Oliver, ‘The Social Model in Action: If I Had a Hammer’ in Colin Barnes and Geof Mercer (eds),
50 *Implementing the Social Model of Disability: Theory and Research* (The Disability Press 2004) <[https://disability-
51 studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-2.pdf](https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-2.pdf)>
52 accessed 13 January 2022.

53 ¹⁸ *ibid* 20.

54 ¹⁹ The Parliamentary and Health Service Ombudsman (n 15).

55 ²⁰ *ibid*.

56 ²¹ *ibid*.

57 ²² World Health Organization, ‘Disability and Health’ (24 November 2021) <[https://www.who.int/news-
58 room/fact-sheets/detail/disability-and-health](https://www.who.int/news-room/fact-sheets/detail/disability-and-health)> accessed 14 January 2022.

59 ²³ Catalina Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Right
60 to Health of Persons with Disabilities’ (United Nations General Assembly 2018) A/73/161 8–15.

1 attainment of maximum independence and being able to access any kind of therapies that would
2 allow persons with disabilities to attain this maximum independence, and to enjoy their right
3 to health (even if this right to health is ultimately, on their own volition, to eradicate
4 disability).²⁴ Besides this, it may also be that the presence of ID could also impede free choice
5 and democratic decision-making – in which case, it becomes more urgent to switch the dialogue
6 and truly incorporate solidarity and inclusion.²⁵

7 8 **2.2 Realization of the Right to Health for Persons with Disabilities** 9

10 The right to health, now recognized as a universal and fundamental human right, is a central
11 component of the argument made in this paper: which links to how persons with disabilities
12 (specifically, ID) should access genome editing technologies to realize their right to health. In
13 the 1946 Constitution of the WHO, the preamble provides an encompassing definition of health
14 as “a state of complete physical, mental and social well-being and not merely the absence of
15 disease or infirmity.”²⁶ This also includes the understanding that “the enjoyment of the highest
16 attainable standard of health is one of the fundamental rights of every human being without
17 distinction of race, religion, political belief, economic or social condition.”²⁷ In a Fact Sheet
18 jointly prepared by the WHO and the Office of the United Nations High Commissioner for
19 Human Rights, this right to health is a complete and inclusive right, which includes within its
20 scope, the rights to entitlement as well as availability, accessibility, acceptability and good
21 quality of services, goods and facilities.²⁸

22 Such is the importance of the right to health that it has been enumerated in numerous
23 international conventions too. In the UN Universal Declaration of Human Rights 1948,²⁹
24 Article 25 states that “everyone has the right to a standard of living adequate for the health and
25 well-being of himself and of his family, including food, clothing, housing and medical care and
26 necessary social services.” The concept of the right to health is also further enumerated in
27 Article 12 of International Covenant on Economic, Social and Cultural Rights 1966.³⁰ In
28 Europe, under Title V, Article 35 of the EU Charter on Fundamental Rights,³¹ health is
29 presented in terms of healthcare: “Everyone has the right of access to preventive health care
30 and the right to benefit from medical treatment under the conditions established by national
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38 ²⁴ Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Right to Health
39 of Persons with Disabilities’ (n 28).

40 ²⁵ Catalina Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report
41 on Disability-Inclusive International Cooperation’ (2020) A/75/186.

42 ²⁶ World Health Organization, ‘Constitution of the World Health Organization’ (2006)
43 <https://www.who.int/governance/eb/who_constitution_en.pdf> accessed 16 November 2021.

44 ²⁷ *ibid.*

45 ²⁸ OHCHR and WHO (n 11).

46 ²⁹ ‘Universal Declaration of Human Rights’ (1948) <<http://www.un.org/en/universal-declaration-human-rights/>>
47 accessed 1 August 2018.

48 ³⁰ OHCHR, ‘International Covenant on Economic, Social and Cultural Rights’ (UN OHCHR, 16 December
49 1966) <<https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx>> accessed 29 September 2021. Article
50 12 reads:

51 *The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest*
52 *attainable standard of physical and mental health. The steps to be taken by the States Parties to the present*
53 *Covenant to achieve the full realization of this right shall include those necessary for:*
54 *The reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;*
55 *The improvement of all aspects of environmental and industrial hygiene;*
56 *The prevention, treatment and control of epidemic, endemic, occupational and other diseases;*
57 *The creation of conditions which would assure to all medical service and medical attention in the event of*
58 *sickness.*

59 ³¹ ‘Charter of Fundamental Rights of the European Union 2000/C 364/01’ (Official Journal of the European
60 Communities) <https://www.europarl.europa.eu/charter/pdf/text_en.pdf> accessed 21 November 2019.

1 laws and practices. A high level of human health protection shall be ensured in the definition
2 and implementation of all Union policies and activities.” It is safe to presume that the right of
3 health is not disputed, and that this right must be accessible to every single human being in the
4 world.

5 In respect of persons with disabilities, CRPD also provides for a right to health. The
6 relevant Article 25 provides for this, where “State Parties recognize that persons with
7 disabilities have the right to the enjoyment of the highest attainable standard of health without
8 discrimination on the basis of disability.”³² This has been reiterated by the UN Special
9 Rapporteur in report number A/73/161 on the rights of persons with disabilities³³ where special
10 attention was drawn to Article 25. In the report, the UN Special Rapporteur highlighted the
11 keen knowledge of the history of persons with disabilities being treated as patients, and not
12 active participants to their own health and well-being.³⁴ Central to the recommendations made
13 in this report³⁵ is the acknowledgement of shared decision making and informed consent of
14 persons with disabilities³⁶ (which is consistent with the arguments made in this paper). What
15 has also been acknowledged in practice is the struggle faced by persons with disabilities:
16 “poorer access to health care and poorer health outcomes than the general population owing to
17 several structural factors, such as stigma and stereotypes, discriminatory legislation and
18 policies, barriers to accessing primary and secondary care, limited availability of disability-
19 specific services and programs, poverty and social exclusion.”³⁷

20 With particularized emphasis on emerging technologies in biomedicine, such as
21 genome editing, this paper identifies that Article 26 of the CRPD concerning the right to
22 habilitation and rehabilitation, must work in complementarity with the right to health under
23 Article 25. The complementarity nature of Article 25’s right to health is also recognized in the
24 UN Special Rapporteur’s report.³⁸ Hence, this paper reiterates that persons with ID need
25 equitable access to genome technologies, so that they can fully realize their right to health
26 (broadly), which is complemented by a right to habilitation (narrowly) under Article 26 of the
27 CRPD.

32 Article 25 of the CRPD reads:

33 *States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable*
34 *standard of health without discrimination on the basis of disability. States Parties shall take all appropriate*
35 *measures to ensure access for persons with disabilities to health services that are gender-sensitive, including*
36 *health-related rehabilitation. In particular, States Parties shall:*

37 *a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care*
38 *and programmes as provided to other persons, including in the area of sexual and reproductive health and*
39 *population-based public health programmes;*

40 *b) Provide those health services needed by persons with disabilities specifically because of their disabilities,*
41 *including early identification and intervention as appropriate, and services designed to minimize and prevent*
42 *further disabilities, including among children and older persons;*

43 *c) Provide these health services as close as possible to people’s own communities, including in rural areas;*

44 *d) Require health professionals to provide care of the same quality to persons with disabilities as to others,*
45 *including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity,*
46 *autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for*
47 *public and private health care;*

48 *e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance*
49 *where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*

50 *f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

51 ³³ Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Right to Health
52 of Persons with Disabilities’ (n 28).

53 ³⁴ *ibid* 4.

54 ³⁵ *ibid* 20–22.

55 ³⁶ *ibid* 6.

56 ³⁷ *ibid* 21–22.

57 ³⁸ *ibid* 7.

2.3 Epigenome Editing to Reverse Genetic Mutations: Examples of Treatment of Intellectual Disabilities

This section now provides examples where genome editing has been used for the treatment of some IDs. In this regard, these examples represent possibilities for persons with ID to engage with technologies as part of their right to health (Article 25 CRPD) and right to habilitation (Article 26 CRPD). There are currently specific points of interest around the potential use of epigenome editing therapies for treating, or even reversing some genetic mutations that cause cognitive or ID. Some recent studies have shown that it is possible to use CRISPR-Cas9 for targeted in-vitro editing and can be very effective in mammalian and human tissue-derived disease models.³⁹

For example, a modified CRISPR system may be used to reverse the genetic mutations that cause WAGR Syndrome. According to the National Human Genome Research Institute, WAGR Syndrome is a rare genetic condition “caused by a deletion of a group of genes located on chromosome number 11.”⁴⁰ Children who are born with WAGR Syndrome suffer from eye problems and are at a higher risk of developing mental and intellectual retardation and developing some types of cancer, including Wilms’ Tumors.⁴¹ However, there appears to be great promise in using a modified CRISPR genome editing system to treat this condition, conducted by researchers at the Johns Hopkins University School of Medicine.⁴² This epigenome editing approach “reversed a brain abnormality that is common in individuals with WAGR Syndrome”⁴³ by changing the epigenome that regulates the gene without changing its genetic code. It appears that this approach was very successful in mice, and could be very useful for humans.

Another promising area of research utilizing CRISPR is in the treatment of Fragile-X Syndrome. Fragile-X Syndrome is another genetic condition where a single gene, the FMR1, shuts down and causes a range of ID and learning and behavioral challenges.⁴⁴ In 2018, researchers from the MIT’s Whitehead Institute for Biomedical Research reported that CRISPR-Cas9 was used to “remove the molecular tags that keep the mutant gene shut off in Fragile-X neurons.”⁴⁵ The results of the study⁴⁶ demonstrated that some of the neurons began to produce protein normally and continued to do so even when the cells were transferred into mice.⁴⁷ Whilst these studies were conducted in a petri dish, and not in live mice, the researchers had used CRISPR in such a way that reactivated the FMR1 gene without damaging the gene

³⁹ Muhammad Ilyas and others, ‘The Genetics of Intellectual Disability: Advancing Technology and Gene Editing’ (2020) 9 F1000Research 22.

⁴⁰ National Human Genome Research Institute, ‘WAGR Syndrome’ (*Genome.gov*) <<https://www.genome.gov/Genetic-Disorders/WAGR-Syndrome>> accessed 9 July 2021.

⁴¹ *ibid.*

⁴² Cyril J Peter and others, ‘In Vivo Epigenetic Editing of Sema6a Promoter Reverses Transcallosal Dysconnectivity Caused by C11orf46/Arl14ep Risk Gene’ (2019) 10 Nature Communications 4112.

⁴³ International WAGR Syndrome Association, ‘Epigenome Editing Could Lead to Treatment of Brain Abnormalities in WAGR Syndrome’ (2014) <<http://wagr.org/research-updates/epigenome-editing-could-lead-to-treatment-of-brain-abnormalities-in-wagr-syndrome>> accessed 20 October 2021.

⁴⁴ Dan Whiting, ‘Fragile X 101’ (*National Fragile X Foundation*) <<https://fragilex.org/understanding-fragile-x/fragile-x-101/>> accessed 20 October 2021.

⁴⁵ Katie Clapp, ‘Can CRISPR Cure Fragile X Syndrome?’ (*Fragile X Research - FRAXA Research Foundation*, 28 February 2018) <<https://www.fraxa.org/can-crispr-cure-fragile-x-syndrome/>> accessed 7 October 2021.

⁴⁶ X Shawn Liu and others, ‘Rescue of Fragile X Syndrome Neurons by DNA Methylation Editing of the FMR1 Gene’ (2018) 172 Cell 979.

⁴⁷ Clapp (n 46).

1 itself, nor make any changes to the coding sequence.⁴⁸ Another study published in Nature
2 Biomedical Engineering⁴⁹ used an alternatively developed version of CRISPR, called CRISPR-
3 Gold⁵⁰ to “effectively edit an autism-associated gene in a mouse model of Fragile-X.”⁵¹

4 Whilst these are only a couple of examples where CRISPR has shown promise in the
5 treatment of genetic ID, what this means for persons with ID is the likelihood that more types
6 of hereditary genetic conditions that result in ID may be reversed, corrected, or treated in the
7 future.

8 Bearing in mind that there are still other types of ID that are not yet adequately
9 researched into, with levels of disabilities ranging from mild to severe to profound, these
10 examples are only the tip of the iceberg in terms of genome editing therapies being developed
11 to treat genetic ID. It may also be that ID and the research conducted thus far, are difficult to
12 define, and to quantify in terms of severity, and how it may impact on a person’s life.⁵² For
13 example, whilst WAGR Syndrome and Fragile-X Syndrome appear to be ID that could
14 someday be treated, the same may not be true of more profound ID where a basic awareness
15 of the self and surroundings are completely impaired, where round-the-clock care is
16 necessitated, and where there is full dependence on others for daily care. In such instances, this
17 impacts their ability to participate in democratic decision – making processes.

18 There may also be instances of ID, coupled with mental illness such as schizophrenia,
19 which may be “maximally disabling.”⁵³ The complexities that enter the picture, linking human
20 rights, health, and biomedical laws, demonstrate to us that if there is an opportunity for
21 technologies to be accessed as part of these persons’ right to health, then we should enable
22 access and enlarge the measures that can be taken to enjoy this right.

23 3. Legal Provisions in the CRPD and other International Instruments: Adequacy and 24 Efficiency in light of Genome Editing Technologies for Persons with Intellectual 25 Disabilities 26

27 In the Introduction of this paper, it was highlighted that the CRPD is the most comprehensive
28 and updated international convention that addresses the rights of persons with disabilities.⁵⁴ It
29 is acknowledged that the CRPD has advanced the rights of persons with disabilities in
30 transformative ways, treating such persons as rights-holders in ways that superseded the
31 previous medical model of disability. It is, indeed a convention that “highlights the need to
32 remove all societal structures, barriers and practices that limit the full and equal enjoyment of
33 the right to the highest attainable standard of health by all persons with disabilities”.⁵⁵
34 Notwithstanding, there has also been equal amount of criticism directed towards the CRPD.
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45 ⁴⁸ *ibid.*

46 ⁴⁹ Bumhee Lee and others, ‘Nanoparticle Delivery of CRISPR into the Brain Rescues a Mouse Model of Fragile
47 X Syndrome from Exaggerated Repetitive Behaviours’ (2018) 2 Nature Biomedical Engineering 497.

48 ⁵⁰ Li Duan and others, ‘Nanoparticle Delivery of CRISPR/Cas9 for Genome Editing’ (2021) 12 Frontiers in
49 Genetics 673286.

50 ⁵¹ Iqra Mumal, ‘CRISPR-Gold Edits Fragile X Gene in Mice to Ease Exaggerated Behaviors’ (18 April 2019)
51 <[https://fragilexnewstoday.com/2019/04/18/crispr-gold-using-non-viral-carrier-edits-fragile-x-gene-in-mouse-
52 model-to-ease-exaggerated-behaviors/](https://fragilexnewstoday.com/2019/04/18/crispr-gold-using-non-viral-carrier-edits-fragile-x-gene-in-mouse-model-to-ease-exaggerated-behaviors/)> accessed 6 October 2021.

53 ⁵² ‘Intellectual Disability and Severity Codes’ <[https://www.mentalhelp.net/intellectual-disabilities/and-severity-
54 codes/](https://www.mentalhelp.net/intellectual-disabilities/and-severity-codes/)> accessed 14 November 2021.

55 ⁵³ Pranit K Chaudhury, Kamala Deka and Dhrubajyoti Chetia, ‘Disability Associated with Mental Disorders’
56 (2006) 48 Indian Journal of Psychiatry 95.

57 ⁵⁴ George Szukler, “Capacity”, “Best Interests”, “Will and Preferences” and the UN Convention on the Rights
58 of Persons with Disabilities’ (2019) 18 World Psychiatry 34, 34.

59 ⁵⁵ Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Right to Health
60 of Persons with Disabilities’ (n 29) 6.
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1 The key of these criticisms center on the inadequacy of the CRPD in dealing with issues of
2 mental health in persons with ID. For example, one study (amongst many others⁵⁶) employing
3 a systematic literature review finds that there is not enough research in mental health “reflecting
4 the importance of the [CRPD]”⁵⁷ and that “empirical research on the aspects of CRPD are still
5 scarce”.⁵⁸ Another study highlights the reality that ill mental health factored amongst the
6 highest in persons with ID compared with the rest of the population⁵⁹ and is attributable to
7 reasons ranging from the biophysical to psychosocial.⁶⁰

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9 Another criticism levied against the CRPD raises questions about the manner in which
10 the CRPD frames “practices of inclusion and accommodation at the individual, rather than the
11 structural level”⁶¹ and this invites the risk of “inclusive marginalization”.⁶² Hence, whilst the
12 intention is noble, a lack of action to address the structural and systemic inequalities for persons
13 with disabilities may be seen as an inadequacy gap to counter discrimination.

14
15 In the meantime, this paper argues that where new and emerging technologies are
16 concerned (that could be of benefit to persons with ID), the provisions in the CRPD currently
17 do not account for this evolution of technologies, especially where genome editing technologies
18 such as CRISPR is concerned. If this is the case, this paper further argues that the lack of will
19 or effort to address genome editing technologies for persons with disabilities *vis-à-vis* Article
20 26 CRPD, is akin to restricting their rights to full enjoyment of health under Article 25.
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23 **3.1 Legal Provisions in the CRPD in the context of Genome Editing Technologies**

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25 As briefly mentioned in the preceding section, this paper argues that the CRPD currently does
26 not consider the impact of technologies such as genome editing technologies, and how this
27 might be used or adapted to assist persons with disabilities. As far as existing literature⁶³ on
28 genome editing and persons with disabilities is concerned,⁶⁴ much of the legal scholarship has
29 been focused on human germline genome editing⁶⁵ and the manner in which this can affect
30 persons with disabilities.⁶⁶ Indeed, much of the headlines of mainstream newspaper articles
31 also weigh in on the impact of human germline genome editing.⁶⁷ A cursory search using the
32 keywords ‘human germline gene editing’ and ‘disability’ will reveal the voluminous amount
33 of scholarship on the subject matter; but there is much less when considering *somatic genome*
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38 ⁵⁶ Jason Buckles, Ruth Luckasson and Elizabeth Keefe, ‘A Systematic Review of the Prevalence of Psychiatric
39 Disorders in Adults With Intellectual Disability, 2003–2010’ (2013) 6 *Journal of Mental Health Research in*
40 *Intellectual Disabilities* 181.

41 ⁵⁷ Christoph Steinert and others, ‘Impact of the UN Convention on the Rights of Persons with Disabilities (UN-
42 CRPD) on Mental Health Care Research - a Systematic Review’ (2016) 16 *BMC Psychiatry* 166, 4.

43 ⁵⁸ *ibid.*

44 ⁵⁹ Erin Louise Whittle and others, ‘Barriers and Enablers to Accessing Mental Health Services for People With
45 Intellectual Disability: A Scoping Review’ (2018) 11 *Journal of Mental Health Research in Intellectual*
46 *Disabilities* 69.

47 ⁶⁰ *ibid.* 69.

48 ⁶¹ Jan Grue, ‘Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their
49 Implications in the United Nations Convention on the Rights of Persons with Disabilities’ (2019) 37 *Nordic*
50 *Journal of Human Rights* 3, 3.

51 ⁶² *ibid.*

52 ⁶³ Felicity Boardman, ‘Human Genome Editing and the Identity Politics of Genetic Disability’ (2020) 11 *Journal*
53 *of Community Genetics* 125.

54 ⁶⁴ Debra JH Mathews and Robin Lovell-Badge, ‘A Path Through The Thicket’ (2015) 527 *Nature* 159.

55 ⁶⁵ Daniel Flaherty, ‘Human Germline Modification Is Coming’ (*Columbia Science and Technology Law Review*,
56 22 November 2017) <<http://stlr.org/2017/11/22/human-germline-modification-is-coming/>> accessed 25 May
57 2018.

58 ⁶⁶ Mathews and Lovell-Badge (n 65).

59 ⁶⁷ Katie Hafner, ‘Once Science Fiction, Gene Editing Is Now a Looming Reality’ *The New York Times* (22 July
60 2020) <<https://www.nytimes.com/2020/07/22/style/crispr-gene-editing-ethics.html>> accessed 15 January 2022.
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1 *editing for persons with disabilities*, and that which is not determined from a pre-implantation
2 embryonic level.

3 There are several areas in the CRPD where there are manifest shortcomings. First, the
4 CRPD does not appear at all to envisage the impact of any new forms of biomedical
5 interventions, emerging technologies, or genome therapies (including genome editing)⁶⁸ which
6 may apply to persons with disabilities. Conti surmises that the absence of words such as
7 ‘eugenics’, ‘genetics’ or ‘bioethics’ are telling of the fact that the CRPD has not considered
8 how tools such as CRISPR-Cas9 may shift a balance of human rights considerations for persons
9 with ID. Since the disability discourse is a continually evolving one, it is uncanny that the key
10 legislation that seeks to protect persons with disabilities, does not also evolve
11 contemporaneously.
12

13 Conti also highlights the disparity of Article 10 of the CRPD,⁶⁹ which provides for the
14 “inherent right to life” and “to ensure its effective enjoyment by persons with disabilities on an
15 equal basis with others.” Whilst this is a crucial consistency in human rights instruments for
16 the protection of lives, it presents an apparent incongruence with the genetic engineering
17 therapies targeted at eradicating mutations that cause disabilities,⁷⁰ or with other diagnostic
18 reproductive technologies such as PGD that involve selecting healthy embryos for
19 implantation.
20

21 Finally, Article 26 of the CRPD (as highlighted in some of the preceding sections
22 herein) does not appear to adequately address clear and proper measures of habilitation for
23 persons with disabilities. Habilitation can be defined as a “process aimed at helping people gain
24 certain new skills, abilities and knowledge”⁷¹ whilst rehabilitation refers to “regaining skills,
25 abilities or knowledge that may have been lost or compromised as a result of acquiring a
26 disability, or due to a change in one’s disability or circumstances.”⁷² Not only is there a lack of
27 representation in the voices of persons with disabilities in science and technology⁷³ – there is
28 also a lack of representation of what kind of measures of habilitation there are for persons with
29 disabilities to partake in.
30

31 The CRPD attempts, as far as it is possible, to enunciate the removal of barriers that
32 may prevent a person with ID to exercise their full human rights under the convention. In this
33 instance, with the advancements that have been made in research, development and scientific
34 and clinical experiments of CRISPR-Cas9, there should be more that is done to equip an
35 individual with ID with specific tools, information, knowledge and resources⁷⁴ that would be
36 needed to access genome editing technologies.
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41 **3.2 Legal Provisions in Various International Instruments in the context of Genome** 42 **Editing Technologies** 43 44 45 46 47 48 49

50 ⁶⁸ Conti (n 13) 10.

51 ⁶⁹ *ibid* 11.

52 ⁷⁰ *ibid*.

53 ⁷¹ Janet E Lord and others, *Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities*
54 (University of Minnesota Human Rights Resource Center 2012) 106.

55 ⁷² *ibid*.

56 ⁷³ Sheryl Burgstahler, ‘Increasing the Representation of People with Disabilities in Science, Engineering, and
57 Mathematics | DO-IT’ (*Disabilities, Opportunities, Internetworking, and Technology*, December 1994)

58 <[https://www.washington.edu/doit/increasing-representation-people-disabilities-science-engineering-and-](https://www.washington.edu/doit/increasing-representation-people-disabilities-science-engineering-and-mathematics)
59 [mathematics](https://www.washington.edu/doit/increasing-representation-people-disabilities-science-engineering-and-mathematics)> accessed 16 January 2022.

60 ⁷⁴ Lord and others (n 72) 107.
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1 In the Introduction, this paper mentions the WHO Committee’s Recommendations. Prior to
2 these Recommendations, there are over-arching international human rights law⁷⁵ that deal with
3 the governance of genome editing technologies. These include the 1997 Convention for the
4 Protection of Human Rights and Dignity of the Human Being with regard to the Application
5 of Biology and Medicine: Convention on Human Rights and Biomedicine (the Oviedo
6 Convention). Other soft law instruments include the UNESCO Universal Declaration on the
7 Human Genome and Human Rights, and the UNESCO Universal Declaration on Bioethics and
8 Human Rights.
9

10 The text in Article 13 of the Oviedo Convention⁷⁶ has always been the subject of
11 enquiry as to whether human genome editing is prohibited. Additionally, Article 3 of the
12 Oviedo Convention is also consistent with the premise upon which this paper is based – that
13 is, equitable access to health care for all persons.⁷⁷
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15 Genome editing is also addressed in the international soft law instruments, continuing
16 the theme of a human rights paradigm. In the 1997 UNESCO Universal Declaration on the
17 Human Genome and Human Rights, the emphasis is on “internationally agreed standards and
18 good practices concerning genetic interventions, which were supported by a broad international
19 consensus at the time of its adoption.”⁷⁸ This Declaration, in Article 1 particularly, stipulates
20 that:
21

22 The human genome underlies the fundamental unity of all members of the human
23 family, as well as the recognition of their inherent dignity and diversity. In a
24 symbolic sense, it is the heritage of humanity.⁷⁹

25 Article 10 of this Declaration continues by emphasizing that human rights, fundamental
26 freedoms and liberties, and human dignity, must always prevail over any research or
27 applications that pertain to the human genome. This illustrates the respect given to key values
28 such as personal autonomy, integrity and informed choice, especially where biology, genetics
29 and medicine are concerned.
30

31 Similarly, the 2005 UNESCO Universal Declaration on Bioethics and Human Rights,
32 in Article 2, aims “to provide a universal framework of principles and procedures to guide
33 States in the formulation of their legislation, policies or other instruments in the field of
34 bioethics.”⁸⁰ Of particular interest in Article 2 are sub-sections (d) and (f), explaining,
35 respectively, the importance of freedom of scientific research (that must take into account
36 human rights and fundamental freedoms and liberties, and equitable access to medical,
37 scientific and technological developments.
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43 ⁷⁵ Rumiana Yotova, ‘Regulating Genome Editing under International Human Rights Law’ (2020) 69 *International*
44 *and Comparative Law Quarterly* 653, 658.

45 ⁷⁶ Article 13 of the Oviedo Convention, titled “Article 13 – Interventions on the Human Genome” reads as follows:
46 “An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic, or
47 therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.”

48 ⁷⁷ Pin Lean Lau, *Comparative Legal Frameworks for Pre-Implantation Embryonic Genetic Interventions*
49 (Springer International Publishing 2019) 193 <<http://link.springer.com/10.1007/978-3-030-22308-3>> accessed 19
50 November 2019.

51 ⁷⁸ Yotova (n 76) 671.

52 ⁷⁹ ‘Universal Declaration on the Human Genome and Human Rights: UNESCO’
53 <http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html>
54 accessed 18 December 2017.

55 ⁸⁰ Henk ten Have and Michèle Jean, *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application* (Unesco 2009)
56 <<https://books.google.com/books?hl=en&lr=&id=njfNpoVVMQ8C&oi=fnd&pg=PA9&dq=%22bioethics+that+Member+States+committed+themselves+and+the%22+%22educational+programmes+for+young+scientists+and+health+care%22+%22to+the+understanding+of+its+principles.+Presenting+an+article%22+&ots=SadeVEft+h6&sig=RVHvF22FAWW32m2cMzJDe5TIOIs>> accessed 17 February 2017.
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1 Hence, as far as governance frameworks go, prior to the Recommendations, there has
2 been some recognition and foresight of the trajectory that biomedical technologies, such as
3 genome editing tools, may take. The reality, however, is of limited applicability, particularly
4 where the technologies evolve rapidly, and the law tries to keep up with such change. However,
5 it is now implicit upon us to adapt the international human rights framework in tandem with
6 the new Committee Recommendations, including working to build “an inclusive global
7 dialogue on frontier technologies”.⁸¹

8 In addition, whilst these regulations are meant to be neutral in nature, it would now be
9 appropriate as human rights legislation that they also take into consideration the rights of
10 persons with disabilities, and their access to these technologies.

11 **3.3 Suggested Habilitation Measures under Article 26 CRPD**

12
13 This paper has consistently maintained that access to genome technologies for persons with ID
14 would be compatible with an exercise of their right to health under Article 25 and 26 CRPD.
15 Nevertheless, there is inadequate scholarship that has been devoted to what might be
16 encompassed under the right of habilitation in Article 26. In most literature regarding the right
17 to habilitation and rehabilitation,⁸² these two concepts are almost always intertwined and
18 considered as if they were one, but the reality cannot be further from the truth. The precarity
19 of this intertwinement means that the right to habilitation is often overlooked in favor of the
20 right to rehabilitation. Any efforts, steps or actions that can be taken on “adapting the social,
21 legal, political and physical environments are often inadequate to create equal opportunities for
22 each person with a disability.”⁸³

23 Now, repositioned within the concept of genome editing technologies, efforts must be
24 made to ensure that an individual with ID, as an example, be granted equal access and
25 information to the use of such technologies, which may entail additional support, specific
26 training or information session, education and awareness, and on a technical basis, perhaps
27 even skills development. If there is a manner in which genome editing technologies may be
28 available to a person with ID, then such measure must be made available accordingly.
29 Dependent on the level of disabilities that is being suffered by a particular individual, this also
30 means that information about habilitation must be provided in an accessible format,⁸⁴ otherwise
31 it would defeat the purposes of Article 26 entirely.

32 Broadly considered, Wolbring and Diep present some pertinent questions which may
33 help to plan the specific measures necessary for habilitation under Article 26. For example:

34 Who will provide for the societal environment that allows disabled people to take part
35 which includes physical access, accessibility of the information material, and access
36 to education that allows disabled people to identify problems? Will disabled people
37 have the ability to provide and inform the network of groups involved in the
38 governance of science, technology and innovation and who within the networks will
39 decide who that network includes? Will disabled people have the ability to access the
40 information needed for them to know that they should get involved and to be able to
41 evaluate the situation? Will disabled people have the ability to know early enough that

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52 ⁸¹ World Health Organisation, ‘WHO Issues New Recommendations on Human Genome Editing for the
53 Advancement of Public Health’ (12 July 2021) <<https://www.who.int/news/item/12-07-2021-who-issues-new-recommendations-on-human-genome-editing-for-the-advancement-of-public-health>> accessed 13 October 2021.

54 ⁸² OHCHR, ‘Report on Habilitation and Rehabilitation of Persons with Disabilities under Article 26 of the CRPD,
55 Including List of Submissions from States and Stakeholders.’ (*United Nations Human Rights Office of the High
56 Commissioner*, 21 January 2019) <<https://www.ohchr.org/EN/Issues/Disability/Pages/Article26.aspx>> accessed
57 16 January 2022.

58 ⁸³ Lord and others (n 72) 107.

59 ⁸⁴ *ibid* 110.

1 they have to be informed so that they can influence the anticipatory governance
2 discourse of topics such as gene editing before the trajectory is already set? Will
3 disabled people have the ability to get involved; that is, will they not be hindered by
4 the struggles of daily life.⁸⁵

5 Additionally, from the perspective of persons with ID, there is even less scholarship or
6 resources that inform how habilitation may take place. Given the fact that persons with ID are
7 particularly vulnerable to human rights violations committed in the name of ‘rehabilitation’,⁸⁶
8 it becomes even more acute why a holistic and inclusive participatory, and emancipatory
9 process is employed to enable them to achieve their personal goals.

10 It may be that genome editing technologies could be adapted in a similar way as
11 assistive technologies, which helps with habilitation and rehabilitation. By adaptation, this
12 means that firstly, concerted efforts should be made to provide awareness and education on the
13 use of genome editing technologies for treating ID, and secondly, by applying the ‘solution’ of
14 emancipatory, participatory and transformative research and innovation measures *with* (and not
15 *for*) persons with ID. Whilst it is likely that addressing the reversal or eradication of ID may
16 take place *vis-à-vis* pre-birth stages, and less likely to be prevalent in adults with ID, the
17 benefits that may be afforded to them through technological adaptations of genome editing
18 tools should further be studied and given equal weight as research and studies into other aspects
19 of human genome editing. For this reason, this paper wishes to draw attention to how we may
20 now think about Article 26 in the context of genome editing technologies, and to find efficacy
21 in this line of thinking. For example, inspiration can be drawn from similar examples for the
22 treatment of other diseases in adults⁸⁷ that have also used genome editing technologies.⁸⁸ If
23 similar adaptations can be made for persons with IDs, then this would be one of the first steps
24 towards true disability-inclusion approaches.⁸⁹

25 Additionally, assistive technologies (ATs)⁹⁰ could be technologies that are quite
26 sophisticated, or even quite low-key, and their purpose would be to support persons with
27 disabilities, such as supporting organization, memory, or other cognitive functions. For
28 different types of disabilities, ATs can be adapted to be much more specialized, using computer
29 software and other networking capabilities to support a user. In this way, ATs enables a person
30 with ID to access technologies that can help them in their daily lives, thereby markedly
31 improving how they are able to exercise their full rights to health.⁹¹ The European Parliament
32 recognizes the importance of these ATs.⁹² Whilst genome editing tools may still be in a
33 developmental stage *vis-a-vis* ATs, taking other steps, such as “targeting wide attitudinal and
34 social change, encouraging co-creation of future ATs, and promoting the emergence of AT
35 professionals” are some ways that could be promoted.

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44 ⁸⁵ Gregor Wolbring and Lucy Diep, ‘The Discussions around Precision Genetic Engineering: Role of and Impact
45 on Disabled People’ (2016) 5 *Laws* 37, 9.

46 ⁸⁶ Lord and others (n 72) 112.

47 ⁸⁷ Jocelyn Kaiser, ‘A Human Has Been Injected with Gene-Editing Tools to Cure His Disabling Disease. Here’s
48 What You Need to Know’ (*Science*, 15 November 2017) <<https://www.science.org/content/article/human-has-been-injected-gene-editing-tools-cure-his-disabling-disease-here-s-what-you>> accessed 15 January 2022.

49 ⁸⁸ Bryan Walsh, ‘Scientists Used CRISPR inside an Adult Patient’s Body for the First Time’ (*Axios*, 4 March
50 2020) <<https://www.axios.com/crispr-gene-editing-patient-ac724626-05cf-4584-b802-62e0e83388aa.html>>
51 accessed 15 January 2022.

52 ⁸⁹ Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report on
53 Disability-Inclusive International Cooperation’ (n 26).

54 ⁹⁰ Philip Boucher, ‘Assistive Technologies for People with Disabilities’ (European Parliament, January 2018)
55 <[https://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA\(2018\)603218_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/IDAN/2018/603218/EPRS_IDA(2018)603218_EN.pdf)>
56 accessed 16 November 2021.

57 ⁹¹ World Health Organization, ‘Assistive Technology’ (18 May 2018) <<https://www.who.int/news-room/fact-sheets/detail/assistive-technology>> accessed 16 January 2022.

58 ⁹² Boucher (n 91).

4. Expanding the Social Model of Disability: Emancipatory, Participatory and Transformative Research and Innovation for Persons with Disabilities

4.1 Removing Ableism and Emphasizing the Voices of Persons with Disabilities

A big point of contention that is prevalent in disability discourse revolves around the ‘ableism’ arguments, and the equity of technologies viewed from the perspective of the abled and through the lens of disability as a problem that must be solved. This is a point that is emphasized in this paper as an extension of the social model of disability. There is a wealth of scholarship that demonstrate disability–positive arguments, where persons with disabilities may not necessarily wish for their disabilities to be eradicated or “edited” because this creates the (wrongful) narrative that persons with disabilities are less than, trailing on the fringes of ‘other’. Lennard J. Davis, one of the most important, leading disabilities studies scholar whose work focuses on the construction of disability⁹³ states: “...the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person.”⁹⁴ What is needed is a change in how we interrogate our participation in the disability – ability system, and that as able-bodied persons, we will need to rethink how we might impose on persons with disabilities our own presumed values, practices, and experiences.

This is where honest and experiential stories like *Unspeakable Conversations*⁹⁵ becomes relevant. This essay by Harriet Johnson, in all its simplicity, presents conversations had between the author and Peter Singer, extrapolating on the value of the disabled body. Whilst the essay has not been intended to be a piece of critical academic work and critiques are likely to express some confusion about the writing, it nevertheless does shed light on the bodily experiences of persons with disabilities, and the fallacies of Singer’s philosophical arguments about disability. Johnson states: “As a disability pariah, I must struggle for a place, for kinship, for community, for connection”⁹⁶ – further reinforcing Davis’ arguments that assessments of normalcy continue to pervade and be accepted as justification to unconsciously ‘other’ a disabled body.

Is there, however, a difference between physical disabilities and ID viewed from the perspective of therapeutic genome editing? It appears that a majority of disability activism seems to be significantly more opposed to suggestions that physical disabilities such as deafness⁹⁷ and dwarfism⁹⁸ should be eradicated. In France, one of its most prolific cases, argued on the basis of a violation of human dignity, is the Conseil d’Etat’s decision in *Commune de Morsang-sur-Orge v Societe Fun Production et M. Wackenheim*.⁹⁹ In this case, the court stipulated that the activity of dwarf-tossing outweighs freedom of livelihood and commerce, because the violation of their human dignity is much more acute.¹⁰⁰ This decision is consistent

⁹³ Lennard J Davis (ed), *The Disability Studies Reader* (Routledge 2017).

⁹⁴ Lennard J Davis, ‘Introduction: Disability, Normality and Power’ in Lennard J Davis (ed), *The Disability Reader* (Routledge 2017) 16.

⁹⁵ Harriet McBryde Johnson, ‘Unspeakable Conversations’ *The New York Times* (16 February 2003) <<https://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html>> accessed 17 October 2021.

⁹⁶ *ibid.*

⁹⁷ Oliver Feeney and Vojin Rakić, ‘Genome Editing and “Disenhancement”’: Considerations on Issues of Non-Identity and Genetic Pluralism’ (2021) 8 *Humanities and Social Sciences Communications* 116.

⁹⁸ Lisa Marshall, ‘Why This Disability Activist Fears CRISPR’ (11 May 2021) <<https://st-0059284.stprod.webmd.com/children/story/centerpiece-crispr-sidebar>> accessed 23 October 2021.

⁹⁹ *Commune de Morsang-sur-Orge v Societe Fun Production et MWackenheim* [1995] Conseil d’Etat 136727, Cons Etat.

¹⁰⁰ Lau (n 78) 197.

1 with the protection of human dignity as a fundamental principle¹⁰¹ in France, and indeed, in
2 many countries within the jurisdiction of the European Court of Human Rights. The protection
3 of human dignity can also be found in Article 1 of the EU Charter of Fundamental Rights,¹⁰²
4 Article 2 of the Treaty of European Union¹⁰³ and the jurisprudence of the Court of Justice of
5 the EU.¹⁰⁴ Conversely, this may be viewed by some disability activists that disabled bodies
6 need special protection through the notions of human dignity.

7 The tensions between voices in the disability community and the scientific research
8 genetics community have been palpable, and this may largely be due to the under-
9 representation of the disability community in the future developments of genome editing.¹⁰⁵
10 Recent studies conducted¹⁰⁶ have also indicated that persons with genetic disabilities feel that
11 “it would be a loss to society to have fewer people with their particular condition coming into
12 the world”¹⁰⁷ and that a 90% majority of family members would not be comfortable with
13 terminating pregnancies that reveal disabilities.¹⁰⁸

14 Scholars have consistently highlighted the importance of considering the views and
15 voices of the disability community.¹⁰⁹ Even with advancements in genomic technologies such
16 as CRISPR-Cas9, the prioritization of persons with disabilities would remain focused on
17 combatting discrimination and prejudice.¹¹⁰ Felicity Boardman reminds that “the core ethical
18 and social issues that genetic disability eradication and/or minimization present will invariably
19 remain the same.”¹¹¹

24 **4.2 Enablement for the Enjoyment of a Right to Health (and a Right to Habilitation** 25 **through Science)**

26 Instead of questioning if we should encourage the eradication of disabilities – what might be
27 advantageous is to find an alternative way of guiding our understanding of ID, and calculating
28 its relationship with inclusionary and solidifying access to the benefits of genome editing
29 therapies. Framing the narrative for persons with ID, in terms of their access to a right to health,
30 and conversely, the right to habilitation *vis-à-vis* scientific and biomedical developments, is a
31 strong measure that considers the UN Special Rapporteur’s report on how disability-
32 inclusion¹¹² needs to be on the forefront for the immediate futures.

33 One way in which we can do so is the following: to suffuse the contemporary evolution
34 of disabilities with much more emancipatory, participatory and transformative disabilities
35 studies research.

36 Returning to the notion that we should not be framing disability as a problem with
37 bodies and therefore needing to associate these bodies with harmful and unsolicited medical
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46 ¹⁰¹ C McCrudden, ‘Human Dignity and Judicial Interpretation of Human Rights’ (2008) 19 European Journal of
47 International Law 655.

48 ¹⁰² ‘Charter of Fundamental Rights of the European Union 2000/C 364/01’ (n 32).

49 ¹⁰³ ‘Treaty on European Union C326/15’ (Official Journal of the European Union, 26 October 2012).

50 ¹⁰⁴ *C-34/10 - Oliver Brustle v Greenpeace eV* [2011] Court of Justice of the EU (Grand Chamber)
51 ECLI:EU:C:2011:669.

52 ¹⁰⁵ Wolbring and Diep (n 86).

53 ¹⁰⁶ Boardman (n 64).

54 ¹⁰⁷ *ibid* 125.

55 ¹⁰⁸ *ibid* 126.

56 ¹⁰⁹ Mathews and Lovell-Badge (n 65).

57 ¹¹⁰ Tom Shakespeare, ‘Gene Editing: Heed Disability Views’ (2015) 527 Nature 446.

58 ¹¹¹ Boardman (n 64) 127.

59 ¹¹² Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report on
60 Disability-Inclusive International Cooperation’ (n 26).

1 treatment or interventions based on a paternalistic model¹¹³ – it should be noted that disability
2 has been recognized as an evolving concept, which may continue to include future types of
3 disabilities, under the CRPD.¹¹⁴ Because of this evolution – then it also logically follows that a
4 framework for protecting persons with disabilities must also evolve. This involves viewing
5 persons with disabilities as actors and active contributors in disability discourse – as opposed
6 to victims, or the subject matter of regulation. According to Nicola Martin:

7 An understanding of the social construction of disability is required in order to engage
8 with the process of eradicating barriers and to pave the way for inclusive practice to
9 minimize disadvantage. Inclusive practice needs to be embedded in institutions’
10 routine practices rather than as compensatory or additional. Inclusive practice starts
11 with the creation of awareness and a non-intimidating environment.¹¹⁵

12 Further, contemporary disabilities studies research is much more emancipatory,
13 participatory and transformative than they used to be – acknowledging that power is a
14 fundamental aspect of all research relationships¹¹⁶ and conversely, research must also “empower
15 the subjects of social inquiry.”¹¹⁷ It is also useful to further navigate these waters through
16 empathy for understanding persons with disabilities – where scholars study the conception of
17 empathy in the design of technologies, and call for “reimagining empathy as guided by the lived
18 experiences of people with disabilities who are traditionally positioned as those to be
19 empathized.”¹¹⁸ To orient empathy with disability activism, the authors proposed the following
20 commitments: first, partnership in the design encounter;¹¹⁹ secondly, a process of ongoing
21 attunement;¹²⁰ thirdly, recognizing and working with asymmetry.¹²¹

22 Enabling the enjoyment of the right to health is also something that can be exemplified
23 through biology, science, and medicine. In the context of this paper, looking at how science
24 can be democratized, and therefore, be accessed more easily, is one of the ways in which we
25 may couple the reimagination of ID. From the perspective of the consumption market, when
26 products of science are placed in a sphere enabling access by ‘consumers’, some scholars have
27 pointed out that public participation in science and technology has democratizing effects.
28 Where non-experts are involved and are allowed to provide input into processes such as
29 “agenda setting, decision-making, policy forming, and knowledge production processes
30 regarding science”,¹²² this has the effect of changing narratives and creating more inclusion –
31 depending on the categories of the kind of participation. Additionally, it makes sense for
32 persons with ID to be part of the conversation that democratizes science, so that they may move
33 towards improvement of public health.¹²³

41 ¹¹³ Devandas-Aguilar, ‘Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report on the
42 Impact of Ableism in Medical and Scientific Practice’ (n 35).

43 ¹¹⁴ Conti (n 13).

44 ¹¹⁵ Nicola Martin, ‘Brief Reflections on Disability Theory, Language, Identity, Equality and Inclusion’ (*Equity,
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47 ¹¹⁶ Victor Jupp and Sage Publications (eds), *The Sage Dictionary of Social Research Methods* (SAGE Publications
48 2006) 88.

49 ¹¹⁷ *ibid.*

50 ¹¹⁸ Cynthia L Bennett and Daniela K Rosner, ‘The Promise of Empathy: Design, Disability, and Knowing the
51 “Other”’, *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (ACM 2019)
52 <<https://dl.acm.org/doi/10.1145/3290605.3300528>> accessed 24 October 2021.

53 ¹¹⁹ *ibid* 9.

54 ¹²⁰ *ibid* 10.

55 ¹²¹ *ibid.*

56 ¹²² Noela Invernizzi, ‘Public Participation and Democratization: Effects on the Production and Consumption of
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58 ¹²³ Faik Kurtuluş, ‘The Democratization of Science’ in David Ludwig and others, *Global Epistemologies and
59 Philosophies of Science* (1st edn, Routledge 2021)

1 Particularly in the context of persons with disabilities and the democratization of
2 science more broadly, Ruha Benjamin states the following:

3 To fully "interrogate equity," we must foster deliberation that moves beyond questions
4 of access to treatment, however important, and think very seriously about the design
5 of research—who does it and with what guiding questions and assumptions—because
6 how research is framed is never neutral, universal, or inevitable. Gene editing
7 techniques are seeded with values and interests—economic as well as social—and
8 without careful examination, they will easily reproduce existing hierarchies, including
9 assumptions about which lives are worth which lives are worth living and which are
10 worth "editing" out of existence.¹²⁴

11 Ruha Benjamin further reminds us that an expansive approach to genetic technologies includes
12 disabled people "at the table and not just on the table of the life sciences."¹²⁵ If we are to truly
13 partake in the democratization of science, and allow the benefits of health technologies for all,
14 then we must exert the creative will to address these social complexities and be open to
15 regeneration of new ideas of body politics.¹²⁶

18 5. Conclusion

19 The promise and potential of genome editing tools and technologies must continue to be refined
20 to contemplate the voices, needs and concerns of persons with ID. A paradigm shift in disability
21 studies discourse must be adequately facilitated in the light of changing definitions of
22 disabilities, and compliance with international law instruments. Whilst existing genome editing
23 tools may not yet be fully ready to treat a wide range of IDs – this does not mean that this
24 sectional group of society should be excluded from basic habilitation measures that can be
25 useful for future deployment. Research and innovations in genome editing should continue to
26 be creative and inclusive, recognizing that persons with ID are no less important. Recognizing
27 the diversity and vulnerabilities of our human population means that we must also be in a
28 position to activate actions and measures that center upon the enablement of technological
29 adaptations in genome editing to remove discrimination, inequalities, segregation and seclusion
30 of persons with disabilities.

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59 ¹²⁵ *ibid* 54.

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