

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

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Abstract

The key aim of this chapter is to highlight the oft-under-represented narrative of how persons with disabilities (specifically, those with intellectual disabilities) may access the benefits that genome editing may offer. Firstly, this chapter reflects on the critical need for a paradigm shift in how we view intellectual disabilities, and centering the rights of persons with disabilities to allow them to access the broad scope of their right to health under various international law instruments (including the complementary right to habilitation under Article 26 of the CRPD). Secondly, the chapter evaluates the legal provisions in the CRPD and other international instruments relating to the rights of persons with intellectual disabilities, and their access to genome editing technologies. This analysis intends to demonstrate that human rights in disability discourse be complemented with emancipatory, participatory, and transformative research. Finally, the chapter argues for a reinvigorated line of thinking that expands on the social model of disability: to align with inclusive, contemporary disability discourse that embodies greater responsibility and innovation in perpetuating better access to genome editing technologies for persons with intellectual disabilities.

Keywords

genome editing – intellectual disabilities – disability discourse – empathy – non-discrimination – right to health – right of habilitation – health innovation – techno-legal adaptations

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) recently 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 chapter therefore, is to highlight the oft-under-represented narrative of how persons with disabilities (specifically, those with intellectual disabilities) may access the benefits that genome editing may offer. For example, since CRISPR first made the headlines in 2012, it has remained the subject of fiery legal and ethical debates centered around human genome editing and possibilities of ‘designer babies’⁶ in our foreseeable future. In the meantime, disability discourse in the context of genome editing has been equally controversial. These include Peter Singer’s controversial utilitarian philosophy, where he regards that “killing them

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- 1 J.A. Doudna and E. Charpentier, ‘The New Frontier of Genome Engineering with CRISPR-Cas9’, *Science* 346 (2014) 1258096.
 - 2 H.T. Greely, ‘CRISPR’d Babies: Human Germline Genome Editing in the “He Jiankui Affair”’, *Journal of Law and the Biosciences* 6 (2019) 111–183.
 - 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* (Geneva: World Health Organization, 2021), available online at <https://apps.who.int/iris/handle/10665/342484> (accessed 4 October 2021).
 - 5 World Health Organization, *Human Genome Editing: Recommendations* (Geneva: World Health Organization, 2021), available online at <https://apps.who.int/iris/handle/10665/342486> (accessed 4 October 2021).
 - 6 E. Yong, ‘The Designer Baby Era Is Not Upon Us’, *The Atlantic* (2017), available online at <https://www.theatlantic.com/science/archive/2017/08/us-scientists-edit-human-embryos-with-crisprand-thats-okay/535668/> (accessed 19 September 2017).

[infants], therefore, cannot be equated with killing normal human beings, or any other self-conscious beings. No infant — disabled or not — has as strong a claim to life as beings capable of seeing themselves as distinct entities existing over time.”⁷ It may be observed that tackling disability discourse raises a much more complex ELSI (ethical, legal, and social implication) question that makes it uncomfortable to comprehend.

Viewed in context of rights of persons with intellectual disabilities (ID), primarily with reference to the United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁸ and other relevant international and/or regional instruments,⁹ this chapter first highlights the alignment of a right to health (broadly)¹⁰ for persons with ID. Specifically, the argument that is being made, is that persons with ID need equitable access to genome technologies, so that they can fully realize their right to health, which includes a right to habilitation (narrowly) under Article 26 of the CRPD.¹¹ Whilst the CRPD has been touted to be a landmark convention that addresses the human rights needs of persons with disabilities on a large scale, and appears to have been

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

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

9 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.

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

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

“1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

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

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

relatively successful in terms of protecting such rights¹² — there does appear to be a lack of concerted effort or will in addressing their human rights in the context of new and emerging technologies. Article 26, which deals with habilitation and rehabilitation of persons with disabilities, should, in theory, address such access to technologies (including genome editing technologies).

Thereafter, the chapter evaluates the legal provisions on non-discrimination and equality relating to genome editing technologies, contained in the CRPD and other international instruments, considered through the lens of persons with ID. The intention is to highlight any shortcomings that needs to be addressed to allow persons with ID to fully realize their right to health *vis-à-vis* existing legislation. This is especially telling in light of the fact that 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 ID. Finally, the chapter suggests a reinvigorated line of thinking that expands on the social model of disability: to align with inclusive, contemporary disability discourse that embodies greater responsibility and innovation in perpetuating better access to genome editing technologies for persons with ID.

2 Addressing the Rights of Persons with Disabilities in Genome Editing

2.1 *Disability Discourse Models*

The focus put forward in this chapter is around somatic gene editing (and not human germline gene editing), attracting concerns such as safety, risks versus benefits considerations, and long-term patient care and monitoring mechanisms,¹³ and therefore arguably attracts less of the ELSI debate. The crux of these considerations as a starting point, however, are inadequate when we encounter questions of inequalities and vulnerabilities in disability discourse. It is therefore imperative to reflect on the difficult questions that address the

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

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

13 H.C. Howard, C.G. van El, F. Forzano, D. Radojkovic, E. Rial-Sebbag, G. de Wert, P. Borry and M.C. Cornel on behalf of the Public and Professional Policy Committee of the European Society of Human Genetics, ‘One Small Edit for Humans, One Giant Edit for Humankind? Points and Questions to Consider for a Responsible Way Forward for Gene Editing in Humans’, *European Journal of Human Genetics* 26 (2018) 1–11.

experiential, intersectional, spatial practices of identities and spaces of persons with disabilities.

With the knowledge that genome editing therapies may possibly be successful in curing or treating ID — a crucial question which some may ask is whether we should, indeed, remove, or encourage that these disabilities be removed. This is, however, not an objective question. For some time, disabilities had always been viewed from the perspective of the medical model. The medical model of disability traditionally focuses on the impairment or disability of a person and has been instrumental in influencing the “development and structure of the legislation, and is reflected in people’s attitudes and associated negative outcomes.”¹⁴ From the viewpoint of the medical model, disabilities are often seen as impairments that needed to be ‘fixed’, that persons with disabilities were a problem that had to be cured. Therefore, an incurable impairment, or disability that cannot be rehabilitated, invites unconscious bias and may imply a disabled person’s ‘lesser’ value in society.¹⁵ For example, in the UK, whilst the medical model has been central to the drafting of the Equality Act 2010, parts of the Act that relate to disability discrimination tend to “focus on what a person is unable to do.”¹⁶

The medical model of disability has attracted criticism over the years due to its parochial approach; and disability activism and scholarship have now evolved to a more inclusive perspective, the social model of disability.¹⁷ Disability rights scholar, Mike Oliver, raises three critical points about the social model of disability:¹⁸

Firstly, it is an attempt to switch the focus away from the functional limitations of individuals with an impairment on to the problems caused by disabling environments, barriers and cultures. Secondly, it refuses to

14 The Parliamentary and Health Service Ombudsman, ‘Introduction to the Social and Medical Models of Disability’ (London: The Parliamentary and Health Service Ombudsman), available online at https://www.ombudsman.org.uk/sites/default/files/FDN-218144_Introduction_to_the_Social_and_Medical_Models_of_Disability.pdf.

15 S. Bunbury, ‘Unconscious Bias and the Medical Model: How the Social Model May Hold the Key to Transformative Thinking about Disability Discrimination’, *International Journal of Discrimination and the Law* 19 (2019) 26–47.

16 The Parliamentary and Health Service Ombudsman, *supra* note 14.

17 M. Oliver, ‘The Social Model in Action: If I Had a Hammer’, in: C. Barnes and G. Mercer (eds.), *Implementing the Social Model of Disability: Theory and Research* (Leeds: The Disability Press, 2004), available online at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-2.pdf> (accessed 13 January 2022).

18 *Ibid.*, 20.

see specific problems in isolation from the totality of disabling environments: hence the problem of unemployment does not just entail intervention in the social organization of work and the operation of the labor market but also in areas such as transport, education and culture. Thirdly, endorsement of the social model does not mean that individually based interventions in the lives of disabled people, whether they be medically, rehabilitative, educational or employment based, are of no use or always counter-productive.

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

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

19 The Parliamentary and Health Service Ombudsman, *supra* note 14.

20 *Ibid.*

21 *Ibid.*

22 World Health Organization, *Disability and Health* (24 November 2021), available online at <https://www.who.int/news-room/fact-sheets/detail/disability-and-health> (accessed 14 January 2022).

23 C. Devandas-Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities: Right to Health of Persons with Disabilities* (New York, NY: United Nations General Assembly, 2018) A/73/161 8–15.

To answer the question earlier posed in this section, as to whether we should remove, or encourage that these disabilities be removed: the answer this chapter provides is “it depends on the person”; because the answer is strictly premised on the capacity, autonomy and integrity of such persons with the disability making that full and informed decision; absent prejudice, interference, interjections and influences of the social and economic order of things. Essentially, this is a question that can only be answered on a very personal level. Additionally, to enable such full and informed decision to be made, full, clinical and neutral information must be provided. What can also be done further is to bring emphasis to the voices of persons with disabilities as a way to continue targeting discrimination and inequality. Whilst the journey in fighting discrimination will always continue, the tools that are available on that journey can now be different, powerful and yet, transformative. Therefore, the author of this chapter views this question as no longer being about eradicating disabilities; but for the attainment of maximum independence and being able to access any kind of therapies that would allow persons with disabilities to attain this maximum independence, and to enjoy their right to health (even if this right to health is ultimately, on their own volition, to eradicate disability).²⁴ Besides this, it may also be that the presence of ID could also impede free choice and democratic decision-making — in which case, it becomes more urgent to switch the dialogue and truly incorporate solidarity and inclusion.²⁵

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

The right to health, now recognized as a universal and fundamental human right, is a central component of the argument made in this chapter which links to how persons with disabilities (specifically, ID) should access genome editing technologies to realize their right to health. In the 1946 Constitution of the WHO, the preamble provides an encompassing definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”²⁶ This also includes the understanding that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political

²⁴ *Ibid.*

²⁵ C. Devandas-Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report on Disability-Inclusive International Cooperation* (New York, NY: United Nations General Assembly, 2020) A/75/186.

²⁶ World Health Organization, *Constitution of the World Health Organization* (Geneva: WHO, 2006), available online at <https://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf?ua=1> (accessed 16 November 2021).

belief, economic or social condition.”²⁷ In a Fact Sheet jointly prepared by the WHO and the Office of the United Nations High Commissioner for Human Rights, this right to health is a complete and inclusive right, which includes within its scope, the rights to entitlement as well as availability, accessibility, acceptability and good quality of services, goods and facilities.²⁸

Such is the importance of the right to health that it has been enumerated in numerous international conventions too. In the UN Universal Declaration of Human Rights 1948,²⁹ Article 25 states that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.” The concept of the right to health is also further enumerated in Article 12 of International Covenant on Economic, Social and Cultural Rights 1966.³⁰ In Europe, under Title v, Article 35 of the EU Charter on Fundamental Rights,³¹ health is presented in terms of healthcare: “Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.” It is safe to presume that the right of health is not disputed, and that this right must be accessible to every single human being in the world.

²⁷ *Ibid.*

²⁸ OHCHR and WHO, *supra* note 10.

²⁹ *Universal Declaration of Human Rights* (New York, NY: United Nations, 1948), available online at <http://www.un.org/en/universal-declaration-human-rights/> (accessed 1 August 2018).

³⁰ OHCHR, *International Covenant on Economic, Social and Cultural Rights* (New York, NY: UN OHCHR, 16 December 1966), available online at <https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx> (accessed 29 September 2021). Article 12 reads:

“The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

The reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

The improvement of all aspects of environmental and industrial hygiene;

The prevention, treatment and control of epidemic, endemic, occupational and other diseases;

The creation of conditions which would assure to all medical service and medical attention in the event of sickness.”

³¹ *Charter of Fundamental Rights of the European Union 2000/C 364/01* (Brussels: Official Journal of the European Communities, 2000), available online at https://www.europarl.europa.eu/charter/pdf/text_en.pdf (accessed 21 November 2019).

In respect of persons with disabilities, CRPD also provides for a right to health. The relevant Article 25 provides for this, where “State Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”³² This has been reiterated by the UN Special Rapporteur in report number A/73/161 on the rights of persons with disabilities³³ where special attention was drawn to Article 25. In the report, the UN Special Rapporteur highlighted the keen knowledge of the history of persons with disabilities being treated as patients, and not active participants to their own health and well-being.³⁴ Central to the recommendations made in this report³⁵ is the acknowledgement of shared decision making and informed consent of persons with disabilities³⁶ (which is consistent with the arguments made in this

32 Article 25 of the CRPD reads:

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

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

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

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

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

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

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

33 C. Devandas-Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities: Report on the Impact of Ableism in Medical and Scientific Practice* (New York, NY: United Nations General Assembly, 2019), A/HRC/43/31, available online at <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/BioethicsDisabilities.aspx> (accessed 17 October 2021).

34 *Ibid.*, p. 4.

35 *Ibid.*, pp. 20–22.

36 *Ibid.*, p. 6.

chapter). What has also been acknowledged in practice is the struggle faced by persons with disabilities: “poorer access to health care and poorer health outcomes than the general population owing to several structural factors, such as stigma and stereotypes, discriminatory legislation and policies, barriers to accessing primary and secondary care, limited availability of disability-specific services and programs, poverty and social exclusion.”³⁷

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

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

37 *Ibid.*, pp. 21–22.

38 *Ibid.*, p. 7.

39 M. Ilyas, A. Mir, S. Efthymiou and H. Holden, ‘The Genetics of Intellectual Disability: Advancing Technology and Gene Editing’, *Frontiers Research* 9 (2020) 22.

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

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 itself, nor make any changes to the coding sequence.⁴⁸ Another study published in *Nature Biomedical Engineering*⁴⁹ used an alternatively developed version of CRISPR,

41 *Ibid.*

42 C.J. Peter, A. Saito, Y. Hasegawa, Y. Tanaka, M. Nagpal, G. Perez, E. Alway, S. Espeso-Gil, T. Fayyad, C. Ratner, A. Dincer, A. Gupta, L. Devi, J.G. Pappas, F.M. Lalonde, J.A. Butman, J.C. Han, S. Akbarian and A. Kamiya, 'In Vivo Epigenetic Editing of Sema6a Promoter Reverses Transcallosal Dysconnectivity Caused by *C11orf46/Arl14ep* Risk Gene', *Nature Communications* 10 (2019) 4112.

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

44 D. Whiting, 'Fragile X 101', *National Fragile X Foundation* (2021), available online at <https://fragilex.org/understanding-fragile-x/fragile-x-101/> (accessed 20 October 2021).

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

46 X.S. Liu, H. Wu, M. Krzisch, X. Wu, J. Graef, J. Muffat, D. Hnisz, C.H. Li, B. Yuan, C. Xu, Y. Li, D. Vershkov, A. Cacace, R.A. Young and R. Jaenisch, 'Rescue of Fragile X Syndrome Neurons by DNA Methylation Editing of the *FMR1* Gene', *Cell* 172 (2018) 979–992.

47 Clapp, *supra* note 45.

48 *Ibid.*

49 B. Lee, K. Lee, S. Panda, R. Gonzales-Rojas, A. Chong, V. Bugay, H.M. Park, R. Brenner, N. Murthy and H.Y. Lee, 'Nanoparticle Delivery of CRISPR into the Brain Rescues a Mouse

called CRISPR-Gold⁵⁰ to “effectively edit an autism-associated gene in a mouse model of Fragile-X.”⁵¹

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

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

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

Model of Fragile X Syndrome from Exaggerated Repetitive Behaviours’, *Nature Biomedical Engineering* 2 (2018) 497–507.

50 L. Duan, O. Kan, X. Xu, L. Xu, C. Wen, X. Zhou, Z. Qin, Z. Xu, W. Sun and Y. Liang, ‘Nanoparticle Delivery of CRISPR/Cas9 for Genome Editing’, *Frontiers in Genetics* 12 (2021) 673286.

51 I. Mumal, *CRISPR-Gold Edits Fragile X Gene in Mice to Ease Exaggerated Behaviors* (18 April 2019), available online at <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).

52 *Intellectual Disability and Severity Codes*, available online at <https://www.mentalhelp.net/intellectual-disabilities/and-severity-codes/> (accessed 14 November 2021).

53 P.K. Chaudhury, K. Deka and D. Chetia, ‘Disability Associated with Mental Disorders’, *Indian Journal of Psychiatry* 48 (2006) 95–101.

3 Legal Provisions in the CRPD and Other International Instruments: Adequacy and Efficiency in Light of Genome Editing Technologies for Persons with Intellectual Disabilities

In the Introduction of this chapter it was highlighted that the CRPD is the most comprehensive and updated international convention that addresses the rights of persons with disabilities.⁵⁴ It is acknowledged that the CRPD has advanced the rights of persons with disabilities in transformative ways, treating such persons as rights-holders in ways that superseded the previous medical model of disability. It is, indeed a convention that “highlights the need to remove all societal structures, barriers and practices that limit the full and equal enjoyment of the right to the highest attainable standard of health by all persons with disabilities.”⁵⁵ Notwithstanding, there has also been equal amount of criticism directed towards the CRPD. The key of these criticisms center on the inadequacy of the CRPD in dealing with issues of mental health in persons with ID. For example, one study (amongst many others⁵⁶) employing a systematic literature review finds that there is not enough research in mental health “reflecting the importance of the [CRPD]”⁵⁷ and that “empirical research on the aspects of CRPD are still scarce.”⁵⁸ Another study highlights the reality that ill mental health factored amongst the highest in persons with ID compared with the rest of the population⁵⁹ and is attributable to reasons ranging from the biophysical to psychosocial.⁶⁰

Another criticism levied against the CRPD raises questions about the manner in which the CRPD frames “practices of inclusion and accommodation at the individual, rather than the structural level”⁶¹ and this invites the risk of

54 G. Szmukler, “Capacity,” “Best Interests,” “Will and Preferences” and the UN Convention on the Rights of Persons with Disabilities’, *World Psychiatry* 18 (2019) 34, pp. 34–41.

55 Devandas-Aguilar, *supra* note 23, p. 6.

56 J. Buckles, R. Luckasson and E. Keefe, ‘A Systematic Review of the Prevalence of Psychiatric Disorders in Adults With Intellectual Disability, 2003–2010’, *Journal of Mental Health Research in Intellectual Disabilities* 6 (2013) 181–207.

57 C. Steinert, T. Steinert, E. Flammer and S. Jaeger, ‘Impact of the UN Convention on the Rights of Persons with Disabilities (UN-CRPD) on Mental Health Care Research — a Systematic Review’, *BMC Psychiatry* 16 (2016) 166, p. 4.

58 *Ibid.*

59 E.L. Whittle, K.R. Fisher, S. Reppermund, R. Lenroot and J. Trollor, ‘Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review’, *Journal of Mental Health Research in Intellectual Disabilities* 11 (2018) 69–102.

60 *Ibid.*, p. 69.

61 J. Grue, ‘Inclusive Marginalisation? A Critical Analysis of the Concept of Disability, Its Framings and Their Implications in the United Nations Convention on the Rights of Persons with Disabilities’, *Nordic Journal of Human Rights* 37 (2019) 3–17, p. 3.

“inclusive marginalization.”⁶² Hence, whilst the intention is noble, a lack of action to address the structural and systemic inequalities for persons with disabilities may be seen as an inadequacy gap to counter discrimination.

In the meantime, this chapter argues that where new and emerging technologies are concerned (that could be of benefit to persons with ID), the provisions in the CRPD currently do not account for this evolution of technologies, especially where genome editing technologies such as CRISPR is concerned. If this is the case, this chapter further argues that the lack of will or effort to address genome editing technologies for persons with disabilities *vis-à-vis* Article 26 CRPD, is akin to restricting their rights to full enjoyment of health under Article 25.

3.1 *Legal Provisions in the CRPD in the Context of Genome Editing Technologies*

As briefly mentioned in the preceding section, this chapter argues that the CRPD currently does not consider the impact of technologies such as genome editing technologies, and how this might be used or adapted to assist persons with disabilities. As far as existing literature⁶³ on genome editing and persons with disabilities is concerned,⁶⁴ much of the legal scholarship has been focused on human germline genome editing⁶⁵ and the manner in which this can affect persons with disabilities.⁶⁶ Indeed, much of the headlines of mainstream newspaper articles also weigh in on the impact of human germline genome editing.⁶⁷ A cursory search using the keywords ‘human germline gene editing’ and ‘disability’ will reveal the voluminous amount of scholarship on the subject matter; but there is much less when considering *somatic genome editing for persons with disabilities*, and that which is not determined from a pre-implantation embryonic level.

There are several areas in the CRPD where there are manifest shortcomings. First, the CRPD does not appear at all to envisage the impact of any new

62 *Ibid.*

63 F. Boardman, ‘Human Genome Editing and the Identity Politics of Genetic Disability’, *Journal of Community Genetics* 11 (2020) 125–127.

64 D.J.H. Mathews and R. Lovell-Badge, ‘A Path Through The Thicket’, *Nature* 527 (2015) 159–161.

65 D. Flaherty, ‘Human Germline Modification Is Coming’, *Columbia Science and Technology Law Review* 22 (2017), available online at <https://journals.library.columbia.edu/index.php/stlr/blog/view/169> (accessed 25 May 2018).

66 Mathews and Lovell-Badge, *supra* note 64.

67 K. Hafner, ‘Once Science Fiction, Gene Editing Is Now a Looming Reality’, *The New York Times* (22 July 2020), available online at <https://www.nytimes.com/2020/07/22/style/crispr-gene-editing-ethics.html> (accessed 15 January 2022).

forms of biomedical interventions, emerging technologies, or genome therapies (including genome editing)⁶⁸ which may apply to persons with disabilities. Conti surmises that the absence of words such as ‘eugenics’, ‘genetics’ or ‘bioethics’ are telling of the fact that the CRPD has not considered how tools such as CRISPR-Cas9 may shift a balance of human rights considerations for persons with ID. Since the disability discourse is a continually evolving one, it is uncanny that the key legislation that seeks to protect persons with disabilities, does not also evolve contemporaneously.

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

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

The CRPD attempts, as far as it is possible, to enunciate the removal of barriers that may prevent a person with ID to exercise their full human rights under the convention. In this instance, with the advancements that have been

68 Conti, *supra* note 12, p. 10.

69 *Ibid.*, p. 11.

70 *Ibid.*

71 J.E. Lord, K.N. Guernsey, J.M. Balfe, V.L. Karr and A.S. deFranco, *Human Rights. Yes!: Action and Advocacy on the Rights of Persons with Disabilities* (Minneapolis, MN: University of Minnesota Human Rights Resource Center, 2012) 106.

72 *Ibid.*

73 S. Burgstahler, ‘Increasing the Representation of People with Disabilities in Science, Engineering, and Mathematics’, *Disabilities, Opportunities, Internetworking, and Technology* (December 1994), available online at <https://www.washington.edu/doit/increasing-representation-people-disabilities-science-engineering-and-mathematics> (accessed 16 January 2022).

made in research, development and scientific and clinical experiments of CRISPR-Cas9, there should be more that is done to equip an individual with ID with specific tools, information, knowledge and resources⁷⁴ that would be needed to access genome editing technologies.

3.2 *Legal Provisions in Various International Instruments in the context of Genome Editing Technologies*

In the Introduction, this chapter mentions the WHO Committee's Recommendations. Prior to these Recommendations, there are over-arching international human rights law⁷⁵ that deal with the governance of genome editing technologies. These include the 1997 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). Other soft law instruments include the UNESCO Universal Declaration on the Human Genome and Human Rights, and the UNESCO Universal Declaration on Bioethics and Human Rights.

The text in Article 13 of the Oviedo Convention⁷⁶ has always been the subject of enquiry as to whether human genome editing is prohibited. Additionally, Article 3 of the Oviedo Convention is also consistent with the premise upon which this chapter is based — that is, equitable access to health care for all persons.⁷⁷

Genome editing is also addressed in the international soft law instruments, continuing the theme of a human rights paradigm. In the 1997 UNESCO Universal Declaration on the Human Genome and Human Rights, the emphasis is on “internationally agreed standards and good practices concerning genetic interventions, which were supported by a broad international consensus at the time of its adoption.”⁷⁸ This Declaration, in Article 1 particularly, stipulates that:

74 Lord et al., *supra* note 71, p. 107.

75 R. Yotova, ‘Regulating Genome Editing under International Human Rights Law’, *International and Comparative Law Quarterly* 69 (2020) 653–684, p. 658.

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

77 P.L. Lau, *Comparative Legal Frameworks for Pre-Implantation Embryonic Genetic Interventions* (Chem: Springer International, 2019), p. 193, available online at <http://link.springer.com/10.1007/978-3-030-22308-3> (accessed 19 November 2019).

78 Yotova, *supra* note 75, p. 671.

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

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

Similarly, the 2005 UNESCO Universal Declaration on Bioethics and Human Rights, in Article 2, aims “to provide a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics.”⁸⁰ Of particular interest in Article 2 are sub-sections (d) and (f), explaining, respectively, the importance of freedom of scientific research (that must take into account human rights and fundamental freedoms and liberties), and equitable access to medical, scientific and technological developments.

Hence, as far as governance frameworks go, prior to the Recommendations, there has been some recognition and foresight of the trajectory that biomedical technologies, such as genome editing tools, may take. The reality, however, is of limited applicability, particularly where the technologies evolve rapidly, and the law tries to keep up with such change. However, it is now implicit upon us to adapt the international human rights framework in tandem with the new Committee Recommendations, including working to build “an inclusive global dialogue on frontier technologies.”⁸¹

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

79 Universal Declaration on the Human Genome and Human Rights (New York, NY: UNESCO, 2017), available online at http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html (accessed 18 December 2017).

80 H. ten Have and M. Jean, *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, Principles and Application* (New York, NY: UNESCO, 2009), available online at <https://unesdoc.unesco.org/ark:/48223/pf0000146180> (accessed 17 February 2017).

81 World Health Organisation, *WHO Issues New Recommendations on Human Genome Editing for the Advancement of Public Health* (12 July 2021), available online at <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).

3.3 *Suggested Habilitation Measures under Article 26 CRPD*

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

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

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

Who will provide for the societal environment that allows disabled people to take part which includes physical access, accessibility of the information material, and access to education that allows disabled people to identify problems? Will disabled people have the ability to provide and inform the network of groups involved in the governance of science, technology and innovation and who within the networks will decide who

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

83 Lord et al., *supra* note 71, p. 107.

84 *Ibid.*, p. 110.

that network includes? Will disabled people have the ability to access the information needed for them to know that they should get involved and to be able to evaluate the situation? Will disabled people have the ability to know early enough that they have to be informed so that they can influence the anticipatory governance discourse of topics such as gene editing before the trajectory is already set? Will disabled people have the ability to get involved; that is, will they not be hindered by the struggles of daily life.⁸⁵

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

It may be that genome editing technologies could be adapted in a similar way as assistive technologies, which helps with habilitation and rehabilitation. By adaptation, this means that firstly, concerted efforts should be made to provide awareness and education on the use of genome editing technologies for treating ID, and secondly, by applying the 'solution' of emancipatory, participatory and transformative research and innovation measures *with* (and not *for*) persons with ID. Whilst it is likely that addressing the reversal or eradication of ID may take place vis-à-vis pre-birth stages, and less likely to be prevalent in adults with ID, the benefits that may be afforded to them through technological adaptations of genome editing tools should further be studied and given equal weight as research and studies into other aspects of human genome editing. For this reason, this chapter wishes to draw attention to how we may now think about Article 26 in the context of genome editing technologies, and to find efficacy in this line of thinking. For example, inspiration can be drawn from similar examples for the treatment of other diseases in adults⁸⁷ that have also used genome editing technologies.⁸⁸ If similar adaptations can be made

85 G. Wolbring and L. Diep, 'The Discussions around Precision Genetic Engineering: Role of and Impact on Disabled People', *Laws* 5 (2016) 37, p. 9.

86 Lord et al., *supra* note 71, p. 112.

87 J. Kaiser, 'A Human Has Been Injected with Gene-Editing Tools to Cure His Disabling Disease. Here's What You Need to Know', *Science* (2017), doi: 10.1126/science.aar5098 (accessed 15 January 2022).

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

for persons with IDs, then this would be one of the first steps towards true disability-inclusion approaches.⁸⁹

Additionally, assistive technologies (ATs)⁹⁰ could be technologies that are quite sophisticated, or even quite low-key, and their purpose would be to support persons with disabilities, such as supporting organization, memory, or other cognitive functions. For different types of disabilities, ATs can be adapted to be much more specialized, using computer software and other networking capabilities to support a user. In this way, ATs enables a person with ID to access technologies that can help them in their daily lives, thereby markedly improving how they are able to exercise their full rights to health.⁹¹ The European Parliament recognizes the importance of these ATs.⁹² Whilst genome editing tools may still be in a developmental stage *vis-à-vis* ATs, taking other steps, such as “targeting wide attitudinal and social change, encouraging co-creation of future ATs, and promoting the emergence of AT professionals”⁹³ are some ways that could be promoted.

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 chapter 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

89 Devandas-Aguilar, *supra* note 25.

90 P. Boucher, ‘Assistive Technologies for People with Disabilities’, *European Parliament* (January 2018), available online at [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) (accessed 16 November 2021).

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

92 Boucher, *supra* note 90.

93 *Ibid.*

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 disability⁹⁴ 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.”⁹⁵ 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*⁹⁶ 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”⁹⁷ — 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 deafness⁹⁸ and dwarfism⁹⁹ 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*.¹⁰⁰ In this case,

94 L.J. Davis (ed.), *The Disability Studies Reader* (Abingdon: Routledge, 2017).

95 L.J. Davis, ‘Introduction: Disability, Normality and Power’ in: L.J. Davis (ed.), *The Disability Reader* (Abingdon: Routledge, 2017) p. 16.

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

97 *Ibid.*

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

99 L. Marshall, *Why This Disability Activist Fears CRISPR* (11 May 2021), available online at <https://st-0059284.stprod.webmd.com/children/story/centerpiece-crispr-sidebar> (accessed 23 October 2021).

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

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.¹⁰¹ This decision is consistent with the protection of human dignity as a fundamental principle¹⁰² in France, and indeed, in many countries within the jurisdiction of the European Court of Human Rights. The protection of human dignity can also be found in Article 1 of the EU Charter of Fundamental Rights,¹⁰³ Article 2 of the Treaty of European Union¹⁰⁴ and the jurisprudence of the Court of Justice of the EU.¹⁰⁵ Conversely, this may be viewed by some disability activists that disabled bodies need special protection through the notions of human dignity.

The tensions between voices in the disability community and the scientific research genetics community have been palpable, and this may largely be due to the under-representation of the disability community in the future developments of genome editing.¹⁰⁶ Recent studies conducted¹⁰⁷ have also indicated that persons with genetic disabilities feel that “it would be a loss to society to have fewer people with their particular condition coming into the world”¹⁰⁸ and that a 90% majority of family members would not be comfortable with terminating pregnancies that reveal disabilities.¹⁰⁹

Scholars have consistently highlighted the importance of considering the views and voices of the disability community.¹¹⁰ Even with advancements in genomic technologies such as CRISPR-Cas9, the prioritization of persons with disabilities would remain focused on combatting discrimination and prejudice.¹¹¹ Felicity Boardman reminds that “the core ethical and social issues that genetic disability eradication and/or minimization present will invariably remain the same.”¹¹²

101 Lau, *supra* note 77, p. 197.

102 C. McCrudden, ‘Human Dignity and Judicial Interpretation of Human Rights’, *European Journal of International Law* 19 (2008) 655–724.

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

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

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

106 Wolbring and Diep, *supra* note 85.

107 Boardman, *supra* note 63.

108 *Ibid.* 125.

109 *Ibid.* 126.

110 Mathews and Lovell-Badge, *supra* note 64.

111 T. Shakespeare, ‘Gene Editing: Heed Disability Views’, *Nature* 527 (2015) 446.

112 Boardman, *supra* note 63, p. 127.

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

Instead of questioning if we should encourage the eradication of disabilities — what might be advantageous is to find an alternative way of guiding our understanding of ID, and calculating its relationship with inclusionary and solidifying access to the benefits of genome editing therapies. Framing the narrative for persons with ID, in terms of their access to a right to health, and conversely, the right to habilitation *vis-à-vis* scientific and biomedical developments, is a strong measure that considers the UN Special Rapporteur's report on how disability — inclusion¹¹³ needs to be on the forefront for the immediate futures.

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

Returning to the notion that we should not be framing disability as a problem with bodies and therefore needing to associate these bodies with harmful and unsolicited medical treatment or interventions based on a paternalistic model¹¹⁴ — it should be noted that disability has been recognized as an evolving concept, which may continue to include future types of disabilities, under the CRPD.¹¹⁵ Because of this evolution — then it also logically follows that a framework for protecting persons with disabilities must also evolve. This involves viewing persons with disabilities as actors and active contributors in disability discourse — as opposed to victims, or the subject matter of regulation. According to Nicola Martin:

An understanding of the social construction of disability is required in order to engage with the process of eradicating barriers and to pave the way for inclusive practice to minimize disadvantage. Inclusive practice needs to be embedded in institutions' routine practices rather than as compensatory or additional. Inclusive practice starts with the creation of awareness and a non-intimidating environment.¹¹⁶

113 Devandas-Aguilar, *supra* note 25.

114 Devandas-Aguilar, *supra* note 33.

115 Conti, *supra* note 12.

116 N. Martin, 'Brief Reflections on Disability Theory, Language, Identity, Equality and Inclusion', *Equity, Diversity and Inclusion* (13 May 2011), available online at <https://blogs.lse.ac.uk/equityDiversityInclusion/2011/05/brief-reflections-on-disability-theory-language-identity-equality-and-inclusion/> (accessed 24 October 2021).

Further, contemporary disabilities studies research is much more emancipatory, participatory and transformative than they used to be — acknowledging that power is a fundamental aspect of all research relationships¹¹⁷ and conversely, research must also “empower the subjects of social inquiry.”¹¹⁸ It is also useful to further navigate these waters through empathy for understanding persons with disabilities — where scholars study the conception of empathy in the design of technologies, and call for “reimagining empathy as guided by the lived experiences of people with disabilities who are traditionally positioned as those to be empathized.”¹¹⁹ To orient empathy with disability activism, the authors proposed the following commitments: first, partnership in the design encounter;¹²⁰ secondly, a process of ongoing attunement;¹²¹ thirdly, recognizing and working with asymmetry.¹²²

Enabling the enjoyment of the right to health is also something that can be exemplified through biology, science, and medicine. In the context of this chapter looking at how science can be democratized, and therefore, be accessed more easily, is one of the ways in which we may couple the reimagination of ID. From the perspective of the consumption market, when products of science are placed in a sphere enabling access by ‘consumers’, some scholars have pointed out that public participation in science and technology has democratizing effects. Where non-experts are involved and are allowed to provide input into processes such as “agenda setting, decision-making, policy forming, and knowledge production processes regarding science,”¹²³ this has the effect of changing narratives and creating more inclusion — depending on the categories of the kind of participation. Additionally, it makes sense for

117 V. Jupp (ed.), *The Sage Dictionary of Social Research Methods* (Thousand Oaks, CA: SAGE, 2006), p. 88.

118 *Ibid.*

119 C.L. Bennett and D.K. Rosner, “The Promise of Empathy: Design, Disability, and Knowing the “Other”, *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (ACM 2019), available online at <https://dl.acm.org/doi/10.1145/3290605.3300528> (accessed 24 October 2021).

120 *Ibid.*, p. 9.

121 *Ibid.*, p. 10.

122 *Ibid.*

123 N. Invernizzi, ‘Public Participation and Democratization: Effects on the Production and Consumption of Science and Technology’, *Tapuya: Latin American Science, Technology and Society* 3 (2020) 227–253.

persons with ID to be part of the conversation that democratizes science, so that they may move towards improvement of public health.¹²⁴

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

To fully “interrogate equity,” we must foster deliberation that moves beyond questions of access to treatment, however important, and think very seriously about the design of research — who does it and with what guiding questions and assumptions— because how research is framed is never neutral, universal, or inevitable. Gene editing techniques are seeded with values and interests — economic as well as social — and without careful examination, they will easily reproduce existing hierarchies, including assumptions about which lives are worth which lives are worth living and which are worth “editing” out of existence.¹²⁵

Ruha Benjamin further reminds us that an expansive approach to genetic technologies includes disabled people “at the table and not just on the table of the life sciences.”¹²⁶ If we are to truly partake in the democratization of science, and allow the benefits of health technologies for all, then we must exert the creative will to address these social complexities and be open to regeneration of new ideas of body politics.¹²⁷

5 Conclusion

The promise and potential of genome editing tools and technologies must continue to be refined to contemplate the voices, needs and concerns of persons with ID. A paradigm shift in disability studies discourse must be adequately facilitated in the light of changing definitions of disabilities, and compliance with international law instruments. Whilst existing genome editing tools may

124 F. Kurtulmuş, ‘The Democratization of Science’, in: D. Ludwig, I. Koskinen, Z. Mncube, L. Poliseli and L. Reyes-Galindo, *Global Epistemologies and Philosophies of Science*, 1st edn. (Abingdon: Routledge, 2021), Chapter 12, available online at <https://www.taylorfrancis.com/books/9781003027140/chapters/10.4324/9781003027140-16> (accessed 16 November 2021).

125 R. Benjamin, ‘Interrogating Equity: A Disability Justice Approach to Genetic Engineering’, *Issues in Science and Technology* 32 (2021) 51–54, p. 52.

126 *Ibid.*, p. 54.

127 *Ibid.*

not yet be fully ready to treat a wide range of IDs — this does not mean that this sectional group of society should be excluded from basic habilitation measures that can be useful for future deployment. Research and innovations in genome editing should continue to be creative and inclusive, recognizing that persons with ID are no less important. Recognizing the diversity and vulnerabilities of our human population means that we must also be in a position to activate actions and measures that center upon the enablement of technological adaptations in genome editing to remove discrimination, inequalities, segregation and seclusion of persons with disabilities.