

1-1-2020

## Screening Syndromes Out: Updating the International "Genocide" Vernacular for a Changing Technological Age

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### Recommended Citation

Nur I. Kara, *Screening Syndromes Out: Updating the International "Genocide" Vernacular for a Changing Technological Age*, 45 N.C. J. INT'L L. 163 (2020).

Available at: <https://scholarship.law.unc.edu/ncilj/vol45/iss1/3>

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# SCREENING SYNDROMES OUT: UPDATING THE INTERNATIONAL “GENOCIDE” VERNACULAR FOR A CHANGING TECHNOLOGICAL AGE

*Nur Iqbal Kara†*

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## **I. Introduction**

Humans have skillfully manufactured a golden age of science. The fusion of medical, biological, and technological innovations has led to vast insight into human development and treatments for conditions previously undiscovered. By offering highly subsidized genetic combination and sequencing tests to pregnant women, paired with legal abortions for fetuses with chromosomal abnormalities, Iceland is one country, among others, that has managed to nearly eradicate the next generation of Down syndrome

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babies.<sup>1</sup> Similarly, the use of CRISPR technology to alter the genes in twin embryos has resulted in the birth of healthy girls to an HIV-positive father in China.<sup>2</sup> In this race to better the whole, science and medicine have outpaced technological regulation. The absence of clear international and domestic laws concerning how, when, and to what degree prenatal genetic testing and gene editing should be used, including the absence of sanctions for their misuse, has triggered competing ethical, medical, legal, and sociopolitical views on their value.<sup>3</sup>

Although medical marvels have made clear that genetic technologies have tremendous potential to eliminate communicable and fatal conditions, lesser-known debates must also be stressed. When such technologies work to instead eliminate entire populations—namely, groups among the larger disability community, as in Iceland’s case—anxiety over a return to the eugenics era arises. “The disability community lacks a voice in the genetics policy arena,”<sup>4</sup> yet a scientific revolution is underway to prevent their very birth. The ultimate question is then: is this modern-day genocide? Are genetic researchers and resulting practitioners, who intend to eradicate peoples with specific chromosomal abnormalities that naturally occur, violating international human rights law? Should deliberately destroying or being complicit in the destruction of genetic diversity, albeit for

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<sup>1</sup> See Sarah Klucznik & Holly Slepian, *Iceland’s Abortion Policy Concerning Children with Down Syndrome: An Ethical Analysis*, 4 J. HEALTHCARE ETHICS ADMIN. 45, 46 (July 15, 2018).

<sup>2</sup> See Rob Stein, *Chinese Scientist Says He’s First to Create Genetically Modified Babies Using CRISPR*, NAT’L PUB. RADIO (Nov. 26, 2018), <http://www.npr.org/sections/health-shots/2018/11/26/670752865/chinese-scientist-says-hes-first-to-genetically-edit-babies> [<https://perma.cc/YCU4-HETT>]. See *Questions and Answers About CRISPR*, BROAD INSTITUTE, <https://www.broadinstitute.org/what-broad/areas-focus/project-spotlight/questions-and-answers-about-crispr> [<https://perma.cc/KRT6-WNHW>] (explaining that “CRISPR” stands for Clustered Regularly Interspaced Short Palindromic Repeats, the bases of a bacterial defense system that allows the use of CRISPR-Cas9 genome editing technology. CRISPR-Cas 9, CRISPR-CPF1, and other systems can be programmed to edit DNA at precise locations of genetic code in order to modify genes in living cells and organisms and correct disease-causing mutations).

<sup>3</sup> See Adam Conti, *Drawing the Line: Disability, Genetic Intervention and Bioethics*, 6 LAWS 1, 12–14 (July 17, 2017).

<sup>4</sup> See Paul Steven Miller & Rebecca Leah Levine, *Avoiding Genetic Genocide: Understanding Good Intentions and Eugenics in the Complex Dialogue between the Medical and Disability Communities*, 15 GENETIC MED. 95 (Feb. 2013).

alleged communal good, be punished?

The elements required to satisfy the legal definition of genocide match this phenomenon, but the language of the United Nations' Convention on the Prevention and Punishment of the Crime of Genocide ("Genocide Convention") is long outdated.<sup>5</sup> The Convention's provisions have not been updated since the Convention's adoption by the United Nations General Assembly in December 1948. Thus, this note considers an important renovation of the genocide vernacular. A *jus cogens* or non-derogable international legal principle,<sup>6</sup> the doctrine of genocide must be reevaluated in order to effectively assist states in: (1) classifying otherwise-omitted groups requiring protection, and (2) accurately assessing when genetic testing and fetal termination, as examples of this technological age's destructive actions, are justifiably practiced. Mere moral and ethical opposition to these technological practices are insufficient to determine their legality.

This note demonstrates how genetic technologies can reform society's global makeup on a population-wide scale. It does not debate pro-life or pro-choice principles on an individual level, but instead contemplates the culpability of state, scientific, and medical actors when they systematically engineer an ideal, homogenized society. Part I focuses solely on the use of prenatal genetic tests for and against the interests of the disability rights community, in an effort to remain timely, as CRISPR's growth is constantly underway. Part II provides a legal and social background on the status of disabled persons, concentrating on Iceland's present model for Down syndrome, and roots this status in international eugenics movements. The Down syndrome population provides a clear illustration, as the genetic condition is common, well-researched, and manageable with the rise of integrated medical and social

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<sup>5</sup> See G.A. Res. 260 A (III), Convention on the Prevention and Punishment of the Crime of Genocide (Dec. 9, 1948) [hereinafter G.A. Res. 260 A (III)] (outlining the legal elements of genocide as "any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group, as such: (a) Killing members of the group; (b) Causing serious bodily or mental harm to members of the group; (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part; (d) Imposing measures intended to prevent births within the group; (e) Forcibly transferring children of the group to another group.").

<sup>6</sup> See *Genocide*, U.N. OFF. ON GENOCIDE PREVENTION & RESP. TO PROTECT [hereinafter U.N. Genocide], <https://www.un.org/en/genocideprevention/genocide.shtml> [https://perma.cc/YU8M-HBKX] (last visited Oct. 4, 2019).

support systems; however, this note should be read with an eye towards the potential misuse of genetic technologies on the broader disability community. Part III details the etymology of genocide in international legal standards, connecting actions to eradicate Down syndrome to the crime's elements. Parts IV-V propose a judicial model to update and extend the Genocide Convention's reach and suggest alternate regulatory frameworks with clear language against novel destructions, so as to protect additional groups.

## II. Prenatal Genetic Testing For and Against Disability

To estimate a child's potential for developmental disorders, providers are able to administer highly accurate prenatal tests for expectant mothers, such as amniocentesis,<sup>7</sup> chorionic villus sampling,<sup>8</sup> and, now, a noninvasive analysis of cell-free fetal DNA<sup>9</sup> in a pregnant woman's blood.<sup>10</sup> Genetic disorders may occur by aneuploidy (missing or extra chromosomes), trisomy (an extra chromosome), monosomy (a missing chromosome), and inherited gene mutations.<sup>11</sup> As such, results may range from fatal Trisomy 13—Patau syndrome, a chromosomal condition causing the death

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<sup>7</sup> Amniocentesis is an invasive procedure in which a sample of amniotic fluid is removed from the uterus to test fetal cells and proteins for certain genetic conditions, such as Down syndrome, lung maturity, and fetal infections. See *Amniocentesis*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/amniocentesis/about/pac-20392914> [https://perma.cc/CC2S-S25U] (last visited Oct. 4, 2019).

<sup>8</sup> Chorionic villus sampling is an invasive procedure in which a sample of placental tissue is removed to reveal chromosomal conditions in the fetal genetic makeup, such as Down syndrome and cystic fibrosis. See *Chorionic Villus Sampling*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/chorionic-villus-sampling/about/pac-20393533> [https://perma.cc/9MHG-3LTW] (last visited Oct. 4, 2019).

<sup>9</sup> Prenatal cell-free DNA screening is a noninvasive method to screen for chromosomal abnormalities in the fetus, such as Down syndrome, trisomy 13, trisomy 18, and rhesus blood type, by extracting DNA from the mother and fetus through a maternal blood sample. See *Prenatal Cell-free DNA Screening*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/noninvasive-prenatal-testing/about/pac-20384574> [https://perma.cc/K5L4-YJYL] (last visited Oct. 4, 2019).

<sup>10</sup> See Kruti Acharya, *Prenatal Testing for Intellectual Disability: Misperceptions and Reality with Lessons from Down syndrome*, 17 DEVELOPMENTAL DISABILITIES RES. REV. 27 (2011); Gareth M. Thomas & Barbara Katz Rothman, *Keeping the Backdoor to Eugenics Ajar?: Disability and the Future of Prenatal Screening*, 18 [J]AMA ETHICS 406, 406 (Apr. 2016).

<sup>11</sup> *FAQ Prenatal Genetic Diagnostic Tests*, AM. C. OBSTETRICIANS & GYNECOLOGISTS (ACOG), <https://www.acog.org/Patients/FAQs/Prenatal-Genetic-Diagnostic-Tests> [https://perma.cc/USF3-STQ4] (last visited Oct. 4, 2019).

of infants with severe intellectual disabilities and physical defects within the first week of life<sup>12</sup>—to manageable Trisomy 21, also known as Down syndrome, a common genetic disorder causing a distinct facial appearance, intellectual disability, developmental delays, and a higher likelihood of cardiovascular concerns.<sup>13</sup> Prenatal genetic tests can be more than 99 percent accurate in diagnosing chromosomal abnormalities, especially Down syndrome.<sup>14</sup> Additionally, the physical risks associated with most prenatal tests, such as spontaneous miscarriage, are small.<sup>15</sup>

Prenatal testing can be beneficial to inform parents about a fetus' normal or abnormal genotype and assist providers in adequately managing both the mother and baby's care.<sup>16</sup> As expectant parents are often instinctively nervous about their unborn child's physical and cognitive development, test results enable parents to prepare for raising a potentially disabled child, or assist in guiding their decisions to terminate a pregnancy.<sup>17</sup> Parents' exercise of agency and control during this process empowers them to receive: (1) accurate medical information on diagnostic probabilities; (2) psychosocial information on what the child's physical and mental capabilities may be; (3) support from a trained counselor as referred by their medical provider; (4) advice from other parents of disabled children; and, overall, (5) the time and space to process the diagnosis before deciding whether to continue forward with the pregnancy.<sup>18</sup> Moreover, pro-information laws, endorsed by disability activists, further require doctors and genetic

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<sup>12</sup> *Trisomy 13*, GENETICS HOME REFERENCE, NAT. INST. OF HEALTH (NIH), <https://ghr.nlm.nih.gov/condition/trisomy-13> [<https://perma.cc/SBM8-Q6QR>] (last visited Oct. 4, 2019).

<sup>13</sup> *Down syndrome*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/down-syndrome/symptoms-causes/syc-20355977> [<https://perma.cc/YBJ6-X8XP>] (last visited Oct. 4, 2019).

<sup>14</sup> *Chorionic Villus Sampling: CVS*, AM. PREGNANCY ASS'N, <http://americanpregnancy.org/prenatal-testing/chorionic-villus-sampling/> [<https://perma.cc/RP67-3YS6>] (last visited Oct. 4, 2019); *Amniocentesis*, DARTMOUTH-HITCHCOCK, <https://www.dartmouth-hitchcock.org/obstetrics/amniocentesis.html> [<https://perma.cc/L7J6-7GMZ>] (last visited Oct. 4, 2019).

<sup>15</sup> See Ruth Graham, *Choosing Life With Down Syndrome*, SLATE (May 31, 2018), <https://slate.com/human-interest/2018/05/how-down-syndrome-is-redefining-the-abortion-debate.html> [<https://perma.cc/4Z4V-MZ6Q>].

<sup>16</sup> See Acharya, *supra* note 10, at 1.

<sup>17</sup> See *id.* at 2.

<sup>18</sup> See Graham, *supra* note 15.

counselors to deliver a more “balanced” portrait of disability at diagnosis.<sup>19</sup> Parents receive expert-prepared information on developmental, educational, and psychosocial outcomes, as well as contacts for resource centers, clearinghouses, and support services.<sup>20</sup> Although the pro-information movement initially garnered support from pro-life, pro-choice, and disability rights groups, it has recently shifted to a partisan anti-abortion movement in pursuit of a greater agenda prohibiting pregnancy termination.<sup>21</sup>

Before discussing the historical, legal, and social status of individuals with disability, particularly how their diagnoses have been perceived, it is important to note the limitations of genetic testing that may render termination premature. Prenatal genetic screenings cannot predict the precise cognitive abilities of a child in utero that has been diagnosed with an abnormal genotype or an inherited condition.<sup>22</sup> Prenatal tests cannot determine if a child will show any symptoms of the disorder, how severe the symptoms will be, or whether the disorder will progress or improve over time.<sup>23</sup> Thus, screening results presently lack the detailed accuracy required to develop clear treatment strategies for many genetic disorders.<sup>24</sup> The publicity accompanying prenatal screenings has also primarily labeled them advantageous for diagnosing and subsequently avoiding Down syndrome, but 90 percent of intellectual disability is attributed to other conditions, some of which are still unknown.<sup>25</sup> With false negative tests, results may state that a particular condition is absent, yet the condition or other abnormalities could be present—“it is unknown how explicitly genetic counselors and

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<sup>19</sup> See *id.*

<sup>20</sup> See Arvind Suresh, *Are laws pertaining to Down syndrome genetic counseling cause for concern?*, GENETIC LITERACY PROJECT (Aug. 24, 2015), <https://geneticliteracyproject.org/2015/08/24/are-laws-pertaining-to-down-syndrome-genetic-counseling-a-cause-for-concern/> [<https://perma.cc/8SWM-S8CJ>].

<sup>21</sup> See Graham, *supra* note 15.

<sup>22</sup> See Acharya, *supra* note 10; see also Thomas & Rothman, *supra* note 10, at 408 (Diagnostic tests can only tell if a fetus does or does not have a specific chromosomal marker, not the “level of the physical or cognitive impairments the child would have . . . [or the] severity or the breadth of impairments that may follow . . .”).

<sup>23</sup> See *What are the Risks and Limitations of Genetic Testing?*, NAT. INST. OF HEALTH (NIH) [hereinafter “NIH, *Risks and Limitations*”], <https://ghr.nlm.nih.gov/primer/testing/riskslimitations> [<https://perma.cc/AC3D-PDX3>].

<sup>24</sup> See *id.*

<sup>25</sup> See Acharya, *supra* note 10, at 30.

physicians inform patients of this fact.”<sup>26</sup> Non-invasive direct-to-consumer tests via the internet or popular companies, such as 23andMe,<sup>27</sup> may prove even less predictive with their debated accuracy and the general dearth of global safety regulations in this space.<sup>28</sup> Additional emotional, social, and financial consequences may plague a patient with positive results, triggering poor mental health, family tension, and possible genetic discrimination in employment or insurance claims and actuarial calculations.<sup>29</sup>

### III. Eugenics and the Socio-Legal Status of Disability

Over time, tailored innovations have significantly extended the life expectancy of persons with disabilities—for Down syndrome, to almost 60 years today as compared to 12 years in 1949—and expanded their acceptance in the larger global community.<sup>30</sup> The global Disability Rights Movement, led by disabled activists in the 1970s, resulted in the landmark United Nations Convention on the Rights of Persons with Disabilities (CRPD) passed in 2006.<sup>31</sup> Ratified by more than 170 countries, the CRPD has ensured a shift in global disability initiatives, incorporated in the 2015 Sustainable Development Goals, and has influenced disability advocacy groups to collect and aggregate data on how people with disabilities fare in

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<sup>26</sup> See *id.* at 28.

<sup>27</sup> 23ANDME, INC., <https://www.23andme.com/> [<https://perma.cc/PT9J-9J4S>] (last visited Sept. 11, 2019).

<sup>28</sup> See Heather Skirton, *Direct to Consumer Testing in Reproductive Contexts – Should Health Professionals Be Concerned?*, 11 LIFE SCI., SOC’Y, & POLICY 4 (Dec. 2015).

<sup>29</sup> See NIH, *Risks and Limitations*, *supra* note 23. See, e.g., Kathleen Stanton, *The Unwanted Ones*, PHOENIX NEW TIMES (Mar. 1, 1989), <https://www.phoenixnewtimes.com/news/the-unwanted-ones-6412883> [<https://perma.cc/2SF8-3SLZ>] (explaining how Blue Cross & Blue Shield of Arizona would not cover a family’s daughter with Down syndrome in their new policy because “she was uninsurable” due to medical statistics that children with Down syndrome have a higher incidence of heart defects and other illnesses. Note: This article pre-dates the Affordable Care Act); Birgit Kuschke, *Disability discrimination in insurance*, 51 DE JURE (PRETORIA) 50, 52–53, n.10 (2018) (discussing that, in various countries, insurance companies are in the business of discrimination, as they must segregate insureds into different risk pools based on risk profiles and most commonly price premiums based on age, gender, and disability. For example, coverage eligibility differs for an individual with Down syndrome, as their life expectancy can be relatively short, they must receive consistent medication, or they require specialized treatments at great cost).

<sup>30</sup> See Graham, *supra* note 15.

<sup>31</sup> G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Jan. 24, 2007).



society as compared to non-disabled peers.<sup>32</sup> Resultant universal design mechanisms are increasingly enabling disabled individuals to navigate their communities, such as access to urban structures, computer and smartphone services, medical treatments and supplies, psychosocial services, and integrated classroom education.<sup>33</sup> While larger strides are required to include disabled individuals in employment, prioritize their wellbeing in emergency and disaster relief, and equalize their social opportunities to marry and procreate, the global community has come a long way towards acceptance in recent times.<sup>34</sup> Notably, improving societal systems has led individuals with Down syndrome to attain higher degrees; become mainstream award-winning actors, models, and singers;<sup>35</sup> and even serve as public officials, such as Angela Bachiller, a Spanish city councilor of the People's Party,<sup>36</sup> and Kayla McKeon, the first registered Capitol Hill lobbyist with Down syndrome.<sup>37</sup>

#### A. *Wrongful Life and Birth Suits*

Though there have been positive advancements, not all changes in the disability realm have been progressive. With the advent of genetic screening technologies, a range of wrongful life and wrongful birth tort lawsuits have arisen that rely on and reiterate the notion of living with a disability as defective and deficient—an ongoing injury requiring a remedy.<sup>38</sup> Wrongful life claims are actions brought by or on behalf of a child against his parents for his

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<sup>32</sup> See Nora Ellen Groce, *Global Disability: An Emerging Issue*, 6 THE LANCET 724, 725 (July 1, 2018).

<sup>33</sup> See *id.*

<sup>34</sup> See *id.*; see also Miller & Levine, *supra* note 4, at 97–98.

<sup>35</sup> See *List of People With Down Syndrome*, WIKIPEDIA, [https://en.wikipedia.org/wiki/List\\_of\\_people\\_with\\_Down\\_syndrome](https://en.wikipedia.org/wiki/List_of_people_with_Down_syndrome) [https://perma.cc/PT9J-9J4S] (last visited Sept. 11, 2019).

<sup>36</sup> See Alba Tobella Mayans, *Valladolid Appoints Spain's First Down Syndrome Councillor*, EL PAÍS (Aug. 8, 2013), [https://elpais.com/elpais/2013/08/08/inenglish/1375970149\\_703675.html](https://elpais.com/elpais/2013/08/08/inenglish/1375970149_703675.html) [https://perma.cc/2DY4-KEBH].

<sup>37</sup> See Courtney Perkes, *New York Woman Is Nation's First Lobbyist With Down Syndrome*, DISABILITYSCOOP (Jun. 26, 2018), <https://www.disabilityscoop.com/2018/06/26/new-first-lobbyist-down-syndrome/25237/> [https://perma.cc/SF76-WNDG].

<sup>38</sup> See Paola Frati, et al., *Preimplantation and Prenatal Diagnosis, Wrongful Birth and Wrongful Life: A Global View of Bioethical and Legal Controversies*, 23 HUMAN REPROD. UPDATE 338, 343–44 (May 1, 2017).

birth, claiming that he has to endure a life not worth living,<sup>39</sup> whereas wrongful birth claims are brought by the parents against a physician for not fully informing the parents of the potential for disability or not offering amniocentesis to avoid the birth of their unwanted disabled child.<sup>40</sup> For both suits, damages may amount to maintenance costs for the disability.<sup>41</sup> Although courts worldwide have been reluctant to acknowledge wrongful life claims—owing to contested ethical concepts of existence and survival as injuries, whether there is a right not to be born, and non-existence as a better alternative to a disabled life—international judicial systems have acknowledged wrongful birth actions.<sup>42</sup> The majority of U.S. states allow wrongful birth actions, as do many European countries, which have awarded substantial compensation for the disabled child's support costs, parents' loss of earnings, and special disability education expenses.<sup>43</sup>

It may be logically flawed, however, to substantiate wrongful birth claims by medical malpractice. In this context, negligence occurs when healthcare professionals breach a duty of care owed to expectant parents and, thereby, violate parents' self-determination to pursue or terminate a pregnancy, leading to additional costs of raising a child.<sup>44</sup> The physician's negligence can take the form of failing to conduct prenatal genetic tests, failing to counsel the patient on the results, and failing to offer or conduct an abortion.<sup>45</sup> The physician's negligence here, however, is not a direct or proximate cause of the fetal abnormality. The child is or would be disabled or chronically ill, regardless of the physician's actions.<sup>46</sup> That global courts are amenable to wrongful birth tort claims and award sizable damages reinforces eugenics underpinnings, devaluing the life of children born with impairments.<sup>47</sup> In this

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<sup>39</sup> *See id.* at 346–48.

<sup>40</sup> *See id.* at 343–46.

<sup>41</sup> *See id.* at 343.

<sup>42</sup> *See id.* at 343–48 (“[T]he international scenarios highlights the fact that the courts have overwhelmingly rejected wrongful life actions while at the same time approving those for wrongful birth.”).

<sup>43</sup> *See Frati et al., supra* note 38, at 344–45.

<sup>44</sup> *See id.* at 351.

<sup>45</sup> *See id.*

<sup>46</sup> *See id.* at 352.

<sup>47</sup> *See id.* at 348–49 (providing examples of two Australian courts' decisions in 2006 not to calculate damages because a disabled person's life should not be devalued and there

manner, the injuries of physician negligence and interference with patient autonomy are conflated with a labeled injury of a disabled life. Some disability rights groups maintain that, through wrongful birth suits, disability is judicially upheld as an unwanted and undesirable trait for parents, the child, and society.<sup>48</sup> In other words, by offering a compensatory remedy, courts buttress the rhetoric of disability as a tragedy that is certain to cause a poor quality and painful life, deserving of substantial damages.<sup>49</sup>

*B. Effects Felt by the Disability Community: "Ashley X" and Iceland's Example*

This view of disability is not without influence on the disability community. When medicine and science are constantly searching for a cure to eliminate various disabilities, "the disability community hears an aggressive lyric that is paternalistic and perhaps genocidal."<sup>50</sup> What procures a rich and fulfilling life for the disabled, however, differs among the group and the severity of disability experienced. In the 2004 incident of "Ashley X," a 6-year-old girl in the U.S. with developmental disabilities, this clash of opinion was apparent when her parents sought hormonal treatment, a hysterectomy, and had her breast buds removed to keep her "permanently small" and to prevent her from sexually developing.<sup>51</sup> Her parents rationalized doing so by their personal beliefs concerning what would better Ashley's future and quality of life, and what appearance would fit the condition that left her with the cognitive ability and physical development of an infant.<sup>52</sup> Despite sanctions by local disability authorities for infringing on Ashley's fundamental liberty and privacy without a court order, her physicians continued to perform the "Ashley Treatment," an involuntary sterilization, on other disabled children at parents'

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is an absence of causal relationship between medical practice and the birth of a disabled child).

<sup>48</sup> See Frati et al, *supra* note 38, at 344–46.

<sup>49</sup> See *id.*

<sup>50</sup> See Miller & Levine, *supra* note 4, at 98.

<sup>51</sup> See Ed Pilkington, *The Ashley Treatment: 'Her Life is as Good as We Can Possibly Make It,'* THE GUARDIAN (Mar. 15, 2012), <https://www.theguardian.com/society/2012/mar/15/ashley-treatment-email-exchange> [https://perma.cc/4BU8-RSLU].

<sup>52</sup> See *id.*

requests.<sup>53</sup>

In Iceland's case, the combination of highly subsidized genetic screenings, subsequent counseling of expectant mothers, and liberal abortion policies have dramatically decreased the number of children born each year with Down syndrome.<sup>54</sup> In 1975, Iceland legalized abortion up until 16 weeks of pregnancy, enabling legal termination past the 16-week mark if the mother's life or health was compromised, or if the fetus was expected to have deformities or a serious genetic abnormality.<sup>55</sup> Yet in May 2019, Iceland's Parliament passed a contested law that extends abortions until the end of 22 weeks of pregnancy.<sup>56</sup> The law also presents the possibility of abortion after the 22-week mark if the fetus is not considered "viable," as defined by physicians.<sup>57</sup> Although the law insists that an extension on abortion strengthens women's health and rights, medical professionals have stated that later abortions present greater health risks.<sup>58</sup> Þuríður Harpa Sigurðardóttir, the chair of The Organisation of Disabled in Iceland, has voiced her disappointment with the law, stating: "We should bear in mind that we're talking about halfway through a pregnancy. This raises questions about what the intent is supposed to be. It must be in order to make it possible to end the life of a fetus with abnormalities or disabilities."<sup>59</sup>

Iceland's universal healthcare system, operated by the Ministry

<sup>53</sup> See *id.*

<sup>54</sup> See Klucznik & Slepian, *supra* note 1, at 45.

<sup>55</sup> Act on Counseling and Education Regarding Sex and Childbirth and on Abortion and Sterilisation Procedures, 1975 (Act No. 25/1975) (Ice.), amended by No. 23/2016, [https://www.government.is/media/velferddarraduneyti-media/media/acrobat-enskar\\_sidur/Act-on-counselling-and-instruction-etc-No-25-1975-as-amended-2017.pdf](https://www.government.is/media/velferddarraduneyti-media/media/acrobat-enskar_sidur/Act-on-counselling-and-instruction-etc-No-25-1975-as-amended-2017.pdf) [<https://perma.cc/YWZ8-9GVZ>].

<sup>56</sup> See Jelena Ćirić, *Abortion Bill Passed in Icelandic Parliament*, ICE. REV. (May 14, 2019), <https://www.icelandreview.com/news/abortion-bill-passed-in-icelandic-parliament/> [<https://perma.cc/8ZC4-JZ3X>].

<sup>57</sup> Christophe Foltzenlogel, *Abortion in Iceland: Increasing Medical Risks in the Name of the Right to Health*, THE EUR. POST (Apr. 29, 2019), <http://europeanpost.co/abortion-in-iceland-increasing-medical-risks-in-the-name-of-the-right-to-health/> [<https://perma.cc/Z886-NG45>].

<sup>58</sup> See *id.*

<sup>59</sup> Andie Fontaine, *Iceland's Parliament Passes Landmark Abortion Law*, THE REYKJAVIK GRAPEVINE (May 14, 2019), <https://grapevine.is/news/2019/05/14/icelands-parliament-passes-landmark-abortion-law/> [<https://perma.cc/8RQ4-WN27>].

of Welfare for a population of less than 350,000,<sup>60</sup> has maximized efficiency to virtually remove private hospitals and private insurance.<sup>61</sup> Converting from the Icelandic Króna, sequencing a patient's DNA costs less than \$100, and the government mandates that all pregnant women be informed of screening for abnormalities and the low cost of combination genetic prescreening tests, encompassing an ultrasound, blood test, and amniotic fluid test to determine genetic disorders.<sup>62</sup> While the government does not require women to receive testing, around 80 to 85 percent of Icelandic women decide to take the test, and close to 100 percent of women given positive results for Down syndrome decide to terminate the pregnancy.<sup>63</sup> Only one or two babies are born with Down syndrome each year in Iceland, typically due to inaccurate test results.<sup>64</sup> To provide further context, the World Health Organization (WHO) has estimated that the incidence of Down syndrome is between 1 in 1,000 (0.1 percent) to 1 in 1,100 (0.09 percent) live births worldwide.<sup>65</sup> In Iceland, each year about two babies are born with Down syndrome out of 4,000-5,000 live births.<sup>66</sup> Babies born with Down syndrome thus account for only 0.04-0.05 percent of live births in Iceland, a prevalence significantly lower than the WHO's estimate, likely due to Iceland's high abortion rate. According to the Down Pride advocacy group, almost every Icelandic fetus diagnosed with Down syndrome has been aborted since 2008.<sup>67</sup>

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<sup>60</sup> *Iceland Population*, WORLDOMETERS, <http://www.worldometers.info/world-population/iceland-population/> [<https://perma.cc/VS7E-JESE>].

<sup>61</sup> See Gunnar H. Gunnlaugsson et al., *Surgery in Iceland*, 141 JAMA 199, 202 (2006).

<sup>62</sup> See Klucznik & Slepian, *supra* note 1, at 46.

<sup>63</sup> See *id.*

<sup>64</sup> See *id.*

<sup>65</sup> *Marking World Day, Ban urges inclusion, equality for persons with Down syndrome*, U.N. DEP'T. OF ECON. & SOC. AFFAIRS (Mar. 21, 2014), <https://www.un.org/en/development/desa/news/social/world-downsyndrome-day.html> [<https://perma.cc/SYY2-GQUU>].

<sup>66</sup> *Iceland and Down Syndrome: what the numbers really say*, ABORTION RTS. CAMPAIGN (Nov. 28, 2017), <https://www.abortionrightscampaign.ie/2017/11/28/lets-talk-about-iceland/> [<https://perma.cc/XT7Y-2JBC>]; *Fertility rate in 2018 lower than ever before*, STAT. ICE. (Apr. 2, 2019), <https://statice.is/publications/news-archive/births-and-deaths/births-2018/> [<https://perma.cc/3AGC-TSDC>] (stating 4,228 live births in Iceland in 2018).

<sup>67</sup> Grace Carr, *Iceland Legalized Abortion Up Until 28 Weeks Over 80 Years Ago*,

Disability rights advocates maintain that, even without a formal policy, the Icelandic government pushes mothers to terminate their pregnancies by promoting the combination test and free counseling.<sup>68</sup> For example, Helga Sól Ólafsdóttir, at the Landspítali University Hospital, counsels her patients with the phrase: “This is your life. You have the right to choose how your life will look like.”<sup>69</sup> She counsels from the perspective that terminating Down syndrome fetuses should be considered as “end[ing] a possible life that may have had a huge complication” and “prevent[s] suffering for the child and for the family.”<sup>70</sup> Because Iceland’s population is largely racially homogenous, activists argue that further standardizing its population by intellectual ability and genetic composition reflects a negative eugenics agenda that interprets Down syndrome individuals as burdensome for society, requiring constant expensive care, when they are instead people “who may otherwise live and enjoy ordinary li[ves].”<sup>71</sup>

There is merit to the claim that advanced medical and genetic technologies may alleviate certain physiological and cognitive impairments—beneficial in proportion to each condition’s severity, unmanageability, and lack of research. Deeming such treatments and the reversal of natural biological processes as an ultimate solution, however, forces the disability community to fight for its existence and prove its place worthy. It is instead essential to incorporate disabled activists’ distinct point of view and specific needs in research and treatment to best define human dignity and diminish pain and suffering.

### C. Global Eugenics Movements

The original connection between eugenics and primitive genetic interventions cannot be overlooked. The ways in which prenatal genetic screenings now frame disability echo a return to the

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DAILY CALLER (Jan. 28, 2019), <https://dailycaller.com/2019/01/28/iceland-abortion-law/> [<https://perma.cc/EVE7-C399>].

<sup>68</sup> See Klucznik & Slepian, *supra* note 1, at 47.

<sup>69</sup> See Dave Maclean, *Iceland Close to Becoming First Country Where No Down’s Syndrome Children Are Born*, INDEP. (Aug. 16, 2017), <https://www.independent.co.uk/life-style/health-and-families/iceland-downs-syndrome-no-children-born-first-country-world-screening-a7895996.html> [<https://perma.cc/EKU2-2UWQ>].

<sup>70</sup> *Id.*

<sup>71</sup> See Klucznik & Slepian, *supra* note 1, at 47.

eugenics era that globally threatened the existence of disabled individuals under the guise of scientific research and societal progress.<sup>72</sup> In 1883, an English anthropologist, Francis Galton, coined the term “eugenics.”<sup>73</sup> His research studying the effects of human selective mating coincided with Charles Darwin’s notions of desired traits for reproductive success and survival of the fittest,<sup>74</sup> and predated James Watson and Francis Crick’s discovery of DNA.<sup>75</sup> Taken from Greek, “eugenics” defined those “good in stock, hereditarily endowed with noble qualities” and “all influences that tend in however remote a degree to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable.”<sup>76</sup> This pseudo-scientific foundation justified “negative eugenics”—measures to remove “undesirable traits” from the human gene pool that involved the institutionalization of individuals deemed inferior, “feeble minded,” and impoverished, as well as restrictions on their ability to reproduce and marry.<sup>77</sup> Only reproduction of the intellectually and physically superior, or positive eugenics, would progress humanity.<sup>78</sup>

A series of events across the globe, some of which were legalized, led to the forced sterilization, euthanasia, segregation, and genocide of eugenically undesirable persons. Two well-known incidents aptly demonstrate the eugenics zeitgeist and how it has taken form in the modern day. The U.S. Supreme Court’s 1927

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<sup>72</sup> See Miller & Levine, *supra* note 4, at 96.

<sup>73</sup> See Francis Galton, BIOGRAPHY [hereinafter Galton Biography], <https://www.biography.com/people/francis-galton-9305647> (last updated May 14, 2019); see also *Eugenics: Positive vs. Negative*, *Eugenics Archive*, SOC. SCI. & HUMAN RES. COUNCIL OF CANADA (Sept. 14, 2013) [hereinafter *Eugenics Archive*], <http://eugenicsarchive.ca/discover/tree/5233c3ac5c2ec50000000086> [<https://perma.cc/RB53-V2AC>].

<sup>74</sup> See Galton Biography, *supra* note 73; see also *Darwin in letters, 1866: Survival of the Fittest*, DARWIN CORRESPONDENCE PROJECT, UNIV. OF CAMBRIDGE, <https://www.darwinproject.ac.uk/letters/darwins-life-letters/darwin-letters1866-survival-fittest> [<https://perma.cc/7GS2-NDWL>] (last visited Sept. 11, 2019).

<sup>75</sup> See *Watson and Crick History*, BBC, [http://www.bbc.co.uk/history/historic\\_figures/watson\\_and\\_crick.shtml](http://www.bbc.co.uk/history/historic_figures/watson_and_crick.shtml) [<https://perma.cc/3KUW-PEFC>] (last visited Oct. 3, 2019).

<sup>76</sup> FRANCIS GALTON, *INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT* 17, 24–25 (1883).

<sup>77</sup> See *Buck v. Bell*, 274 U.S. 200 (1927); see also *Eugenics Archive*, *supra* note 73.

<sup>78</sup> See *Eugenics Archive*, *supra* note 73.

ruling in *Buck v. Bell*<sup>79</sup> is a key first example of how the movement reached so far as to be judicially upheld. The Court classified Carrie Buck as an 18-year-old “feeble-minded white woman,” the mother of an “illegitimate feeble-minded child,” born to a “feeble-minded mother,” and all three individuals—Buck, her child, and her mother—were committed to a Virginia institution for epileptics and the “feeble-minded.”<sup>80</sup> A state statute approved the sterilization of “mental defectives” and endorsed the determination of each institution’s superintendents for when sterilizing patients would be in society’s best interest.<sup>81</sup> Buck, however, brought a claim against her superintendent’s order for sterilization.<sup>82</sup> The state interest was to promote the patient’s purported health and society’s welfare, given the “important part [of heredity] in the transmission of insanity, imbecility, etc.,” thus, the law preconditioned a patient’s release on their becoming sterile, in order to prevent the “menace” of the patient’s offspring and to ensure that the patient become “self supporting.”<sup>83</sup> While the law gave notice to the patient and the opportunity of a hearing and appeal, the circuit court of the county retained ultimate consideration of the evidence and entrance of the order—there was no guarantee of an appellate review.<sup>84</sup>

In response to Buck’s petition, the Supreme Court, nonetheless, rationalized three reasons for holding that Buck had been provided due process of law: (1) the statute respected patients’ rights; (2) sterilization was a procedure devoid of serious pain or substantial danger to life; and (3) Buck’s case saw “scrupulous compliance” with the law.<sup>85</sup> Furthermore, the Court found that because the plaintiff was provided asylum from institutionalization back into society, she was not denied equal protection under the Fourteenth Amendment and, as a result of her sterilization, “the equality aimed at [would] be more nearly reached.”<sup>86</sup> Justice Oliver Wendell Holmes, Jr. wrote:

We have seen more than once that the public welfare

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<sup>79</sup> See *Buck v. Bell*, *supra* note 77.

<sup>80</sup> See *id.* at 205.

<sup>81</sup> See *id.* at 205–06.

<sup>82</sup> See *id.*

<sup>83</sup> See *id.*

<sup>84</sup> See *id.* at 206–07.

<sup>85</sup> See *Buck v. Bell*, *supra* note 77, at 206–07.

<sup>86</sup> See *id.* at 205–08.



may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices . . . in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . . Three generations of imbeciles are enough.<sup>87</sup>

Consequently, *Buck v. Bell* enabled 27 states to continue implementing sterilization laws for the intellectually disabled until the late-1960s.<sup>88</sup> These statutes were upheld under the Equal Protection Clause of the Fourteenth Amendment, so long as due process rights were “protected,” as in Justice Holmes’ interpretation of Carrie Buck’s case, and a compelling state interest was found, such as “a legislative dual purpose to prevent the birth of a defective child or the birth of a non-defective child that cannot be cared for by a defective parent.”<sup>89</sup> The subsequent rise of anti-miscegenation laws persisting until *Loving v. Virginia* in 1967 also served to preserve white racial purity, ban interracial marriage and, though not explicit, preclude the birth of “lesser” mixed-race offspring.<sup>90</sup>

The second infamous international eugenics movement took form in Nazi Germany, resulting in the Holocaust.<sup>91</sup> In 1937, Adolf Hitler ordered the sterilization of (1) the *Rheinlandbastarde*, a derogatory term referring to the mixed children of German mothers and Africans who served as French colonial troops after World War I; (2) the children of German settlers and missionaries who married or had illegitimate children with women of other ethnicities; and (3) mental patients.<sup>92</sup> These forced sterilization laws resulted in 300,000 to 400,000 sterilizations, further practiced on Jews in Auschwitz concentration camps.<sup>93</sup> Also at this time, the Nazi

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<sup>87</sup> See *id.* at 207.

<sup>88</sup> See Miller & Levine, *supra* note 4, at 97.

<sup>89</sup> See *id.* (citing North Carolina Ass’n for Retarded Children v. North Carolina, 420 F. Supp. 451, 457–58 (M.D.N.C. 1976)).

<sup>90</sup> See *Loving v. Virginia*, 388 U.S. 1 (1967).

<sup>91</sup> See Eugenics Archive, *supra* note 73.

<sup>92</sup> See *id.*

<sup>93</sup> See Susan Benedict & Jane M. Georges, *Nurses and the Sterilization Experiments*

regime implemented racial segregation laws and anti-miscegenation laws, the combination of which inevitably led to one of the world's most destructive genocides to exterminate racially undesirable individuals.<sup>94</sup> As such, the Nazis aimed to retain the pure blue-eyed, blonde-haired Aryan peoples that would racially and morally cleanse the German population.<sup>95</sup>

These two cases commonly exhibit one group's intention to eliminate another undesired group. The methods for elimination vary between institutionalization, sterilization, anti-miscegenation, racial segregation, encampment, and murder—each a technology of the time in which these incidents took place, resulting in the riddance of a class of people. It is possible to transfer these intentions to present genetic technologies, sometimes intentionally used to screen out and terminate fetuses with disabilities. If the prior incidents were termed genocide, an analysis of the traditional genocide etymology may enable the same today.

#### IV. The Etymology of Genocide as a *Jus Cogens*

Polish lawyer, Raphael Lemkin, coined the word “genocide” in 1944.<sup>96</sup> *Genos* in Greek means race or tribe and *cide* in Latin means killing.<sup>97</sup> Developed in part due to the Holocaust, Lemkin campaigned for genocide to be codified as an international crime, ensuing in the 1946 United Nations General Assembly Resolution 96(I) and the 1948 Convention on the Prevention and Punishment of the Crime of Genocide (“Genocide Convention”).<sup>98</sup> The original Resolution articulated:

Genocide is a denial of the right of existence of **entire human groups** [*emphasis added*], as homicide is the denial of the right to live of individual human beings; such denial of the right of existence shocks the conscience of mankind, results in great losses to humanity in the form of cultural and other contributions represented by these **human groups** [*emphasis added*], and is contrary to moral

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*of Auschwitz: A Postmodernist Perspective*, 13 NURSING INQUIRY 277 (Jan. 2007).

<sup>94</sup> See Eugenics Archive, *supra* note 73.

<sup>95</sup> See *id.*

<sup>96</sup> See U.N. Genocide, *supra* note 6.

<sup>97</sup> See *id.*

<sup>98</sup> See *id.*

law and to the spirit and aims of the United Nations. Many instances of such crimes of genocide have occurred when **racial, religious, political and other groups** [*emphasis added*] have been destroyed, entirely or in part.<sup>99</sup>

By January 2018, 149 states had ratified the Convention; yet, irrespective of ratification, all states are bound by the same obligation to prohibit and sanction the crime.<sup>100</sup> This is because the International Court of Justice has held genocide to be a *jus cogens*, a peremptory norm of international law that all states, including those abstaining from the Convention, may not derogate from under any circumstance, peace or war, and, therefore, may not denounce.<sup>101</sup>

Article II of the Genocide Convention defines the crime, resulting from the negotiations of U.N. member states in 1948.<sup>102</sup> It is defined in the same terms in the Rome Statute of the International Criminal Court in Article 6, as well as in the statutes of other international jurisdictions.<sup>103</sup> Article II of the Genocide Convention, however, narrows the 1946 General Assembly language by removing the broad application to “other groups”<sup>104</sup>:

[G]enocide means any of the following acts committed with intent to destroy, in whole or in part, **a national, ethnical, racial or religious group** [*emphasis added*], as such:

- (a) Killing members of the group;
- (b) Causing serious bodily or mental harm to members of the group;
- (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part;
- (d) Imposing measures intended to prevent births within the group;
- (e) Forcibly transferring children of the group to

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<sup>99</sup> G.A. Res. 96(I), U.N. Doc. A/RES/96-I (Dec. 11, 1946) [hereinafter G.A. Res. 96(I)].

<sup>100</sup> See U.N. Genocide, *supra* note 6.

<sup>101</sup> See *id.*

<sup>102</sup> See *id.*

<sup>103</sup> See *id.*

<sup>104</sup> See G.A. Res. 96(I), *supra* note 99 (“[C]rimes of genocide have occurred when racial, religious, political or other groups have been destroyed, entirely or in part.”).

another group.<sup>105</sup>

The crime's key chapeau elements,<sup>106</sup> or the predicate acts that the perpetrator must satisfy, are a mental element—the “intent to destroy”—and a physical element, involving acting upon any of the five forms of destruction enumerated in Article II.<sup>107</sup> A group, and not its individual members, must be deliberately targeted, but genocide can also be committed against only part of a group, as long as that part is identifiable and substantial.<sup>108</sup> Since the “physical destruction” of a group, in whole or in part, might take generations to occur, the International Law Commission has used the term “biological destruction” to determine whether the crime of genocide has been completed.<sup>109</sup> Actual destruction, itself, is not a reliable source.<sup>110</sup>

Articles III-VI find the following acts punishable for any perpetrators involved, whether state rulers, public officials, or private individuals, upon a trial by a competent tribunal of the state in the territory where the act was committed:<sup>111</sup>

- (a) Genocide;
- (b) Conspiracy to commit genocide;
- (c) Direct and public incitement to commit genocide;
- (d) Attempt to commit genocide;
- (e) Complicity in genocide.

The differences between the 1948 Convention and the 1946 General Assembly Resolution are easily identifiable, namely that the Convention removed the broader “human groups” and “other groups” language. It is unclear exactly why the Convention narrowed the pool of protected groups against genocide, but there is evidence that the drafters did consider ideological, linguistic,

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<sup>105</sup> See G.A. Res. 260 A (III), *supra* note 5.

<sup>106</sup> See Sanghul Kim, *Rethinking the ‘Crime of Mens Rea,’* FICHL POLICY BRIEF SERIES, No. 591, at 2 (2016), <http://www.toaep.org/pbs-pdf/59-kim> [<https://perma.cc/3XQX-28EB>] (explaining that the chapeau of the crime refers to the specific or special intent.).

<sup>107</sup> U.N. Genocide, *supra* note 6 (“[The] intent must be to physically destroy a national, ethnical, racial, or religious group.”).

<sup>108</sup> See *id.*

<sup>109</sup> See Kim, *supra* note 106.

<sup>110</sup> See *id.*

<sup>111</sup> See G.A. Res. 260 A (III), *supra* note 5.

economic, and political groups before excluding them.<sup>112</sup> The primary rationale offered by scholarship has been that national, ethnic, racial, and religious groups have each been targets of animosity, characterized by “cohesiveness, homogeneity, inevitability of membership, stability, and tradition.”<sup>113</sup> The former are groups with membership defined by birth, whereas affiliation with political groups has been considered a product of individual choice and freedom that is mobile over time and regime.<sup>114</sup> An alternate suggestion for the exclusion of broader groups posits that the delegates, at the time of the Convention’s inception, wanted to put parallel Soviet extermination practices at Nuremberg “beyond the realm of inquiry”—the Soviets maintained that only an “organic link” between “genocide” and “Nazism” would disallow extermination practices, while other states, such as Poland and Venezuela, similarly opposed the broader protection of political groups in order to continue their suppression of certain insurgencies.<sup>115</sup> Because forced sterilization of specific ethnic, racial, and mentally deficient groups also remained legalized and in global practice well into the 1970s, had the Convention retained a broader victim category, a multitude of involved member states could have been subject to sanctions.<sup>116</sup>

Although the opportunity has presented itself, the text of the Convention has not been revised since its adoption in 1948 and entrance into force in 1951.<sup>117</sup> But now, given the ever-evolving role of technology in crimes, warfare, and medical and scientific procedures, it is of wonder whether the international law community

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<sup>112</sup> See WILLIAM A. SCHABAS, *GENOCIDE IN INTERNATIONAL LAW: THE CRIME OF CRIMES* 117 (Cambridge Univ. Press, 2d ed. 2009).

<sup>113</sup> See Agnieszka Szpak, *National, Ethnic, Racial, and Religious Groups Protected against Genocide in the Jurisprudence of the Ad Hoc International Criminal Tribunals*, 23 EUR. J. INT'L L. 155, 159 (Feb. 2012).

<sup>114</sup> See *id.* at 159–60.

<sup>115</sup> See DAVID L. NERSESSIAN, *GENOCIDE AND POLITICAL GROUPS* 106 (Oxford Univ. Press, 2010); see also SCHABAS, *supra* note 112, at 160 (“The Soviet views were shared by a number of other States for whom it is difficult to establish any geographic or social common denominator: Lebanon, Sweden, Brazil, Peru, Venezuela, the Philippines, the Dominican Republic, Iran, Egypt, Belgium, and Uruguay.”).

<sup>116</sup> See, e.g., *Buck v. Bell*, 274 U.S. 200 (1927); Eugenics Archive, *supra* note 73; Miller & Levine, *supra* note 4, at 97; *North Carolina Ass’n for Retarded Children v. North Carolina*, 420 F. Supp. 451 (M.D.N.C. 1976); *Loving v. Virginia*, 388 U.S. 1 (1967); Benedict & Georges, *supra* note 93.

<sup>117</sup> See U.N. Genocide, *supra* note 6.

should use the *ejusdem generis* approach.<sup>118</sup> This analysis enables general rules of interpretation to suggest an expansion of the doctrine into additional groups that are analogous to those enumerated.<sup>119</sup>

To make the connection explicit in the case of disability, disabled individuals constitute separate groups based on disability type and severity—for example, Down syndrome individuals make up a singular group. Down syndrome is one of the more common, well-researched, and manageable genetic conditions;<sup>120</sup> it is devoid of individual choice with genetic determination before birth; and it is a stable and irreversible trait. Genocide's elements of genocidal intent and target group may be found by physicians recommending prenatal screenings and counseling for pregnancy termination upon a positive result for chromosomal abnormalities, as well as scientists and geneticists continually attempting to find new testing and gene editing methods for the precise purpose to cure and treat compromised conditions. For Down syndrome, this cure-and-treat approach has, instead, meant elimination. The element of destruction then comes from the ultimate result—the termination of the disabled group at an identifiable and substantial scale, “deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part” (Art. II(c)) or “[i]mposing measures intended to prevent births within the group” (Art. II(d)).<sup>121</sup> With the International Law Commission's interpretation of “biological destruction,”<sup>122</sup> these two forms of destruction may not require that the fetus-versus-life debate be solved. Medically recommending termination and ultimately

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<sup>118</sup> See David Shea Bettwy, *The Genocide Convention and Unprotected Groups: Is the Scope of Protection Expanding under Customary International Law?*, 2 NOTRE DAME J. INT'L & COMP. L. 167, 167 n.3 (2011).

<sup>119</sup> See *id.*; see also SCHABAS, *supra* note 112, at 150 (suggesting that “[g]eneral rules of interpretation would suggest an *ejusdem generis* approach; the ‘other groups’ must in some way be similar to or analogous with those that are enumerated.”).

<sup>120</sup> See Bonnie Rochman, *A Change of Mind*, MIT TECH. REV. (Dec. 16, 2015), <https://www.technologyreview.com/s/544531/a-change-of-mind/> [<https://perma.cc/WTM5-AYVG>]; see also Jaime L. Natoli, et al., *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995-2011)*, 32 PRENATAL DIAGNOSIS 142, 151 (2012) (“[A]lthough raising a child with Down syndrome has notable challenges, medical management has progressed in recent decades and individuals with Down syndrome are living longer and healthier lives[.]”).

<sup>121</sup> See G.A. Res. 260 A (III), *supra* note 5.

<sup>122</sup> See Kim, *supra* note 106.

terminating fetuses on a mass scale is destroying the Down syndrome group over generations. That Iceland, just one example of its kind, has managed to eradicate a subsequent generation of Down syndrome individuals by almost 100 percent well-fits this connection.<sup>123</sup> Yet excluding “other human groups” from the language of the Convention ignores the extinction of peoples with Down syndrome and excuses sanctioning those so engaged.

### **V. Recommendations to Update the Genocide Convention and Implement Global Legislation**

The slow but sure elimination of Down syndrome has been a prime case for contemplating the potential misuse of genetic technology because it is one of the most common genetic disorders for which medical, psychosocial, educative, and urban design supports exist and are improving worldwide.<sup>124</sup> Correspondingly, a 2011 survey published by Brian Skotko, a Harvard-trained physician and researcher, found that, of 284 participants with Down syndrome, “nearly 99 percent . . . indicated that they were happy with their lives, 97 percent liked who they are, 96 percent liked how they look,” and 86 percent “felt they could make friends easily.”<sup>125</sup> Many participants encouraged healthcare professionals to value them, emphasizing that they share similar hopes and dreams as people without the condition.<sup>126</sup> The small percentage of participants who did declare difficulties and sadness, however, had uniquely isolating living situations.<sup>127</sup>

Despite progressive individual perceptions on leading life with Down syndrome, termination rates are still increasing upon receiving positive prenatal test results, not only in Iceland, but also in other European and North American countries.<sup>128</sup> Denmark has

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<sup>123</sup> See Klucznik & Slepian, *supra* note 1, at 46.

<sup>124</sup> See Frank Buckley, *New and Old Directions*, 12 DOWN SYNDROME RES. & PRAC. 1 (2007) (explaining how improved social, educational, and healthcare opportunities have helped those “with Down syndrome to achieve more and live longer” with targeted interventions for language development, reading, numeracy, speech, hearing, and memory, as well as clinical studies of the health issues associated with Down syndrome).

<sup>125</sup> See Brian G. Skotko et al., *Self-perceptions from People with Down Syndrome*, 155 AM. J. MED. GENETICS PART A 2360 (Oct. 2011).

<sup>126</sup> See *id.*

<sup>127</sup> See *id.*

<sup>128</sup> See Jaime Natoli et al., *Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011)*, 32 PRENATAL DIAGNOSIS 142 (Feb. 2012); see also

an estimated 98 percent termination rate, the United Kingdom at 90 percent, the U.S. at 85 percent, and France at 77 percent.<sup>129</sup> The devaluation and eradication of the Down syndrome community is increasingly apparent on a global scale. Yet without being able to shield disabled groups under genocide's definitional umbrella of protection, their destruction cannot be sanctioned as such.<sup>130</sup>

*A. Prosecutor v. J.-P. Akayesu: A Judicial Model*

The International Criminal Tribunal for Rwanda (ICTR), created by the United Nations Security Council,<sup>131</sup> is one judicial body that has significantly expanded the global jurisprudence of genocide. Its dicta detailing who and what constitutes protected groups and destructive actions, specifically upon hearing *Prosecutor v. J.-P. Akayesu* in 1998,<sup>132</sup> should be viewed as a preliminary model in efforts to update the Genocide Convention. This case centered on Jean-Paul Akayesu, a former mayor of Taba in Rwanda, who was tried for charges of genocide and crimes against humanity for his violent involvements against the Tutsi tribe in Rwanda.<sup>133</sup> Under Akayesu's orders, armed law enforcement, military troops, and other local officials in support of the opposing Hutu tribe systematically subjected Tutsi women to sexual violence, rape, and mutilation, often by more than one attacker and in

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Jeanne Mancini, *People with Down Syndrome are Happy. Why are We Trying to Eliminate Them?*, WASH. POST (Aug. 24, 2017), [https://www.washingtonpost.com/news/posteverything/wp/2017/08/24/people-with-down-syndrome-are-happy-why-are-we-trying-to-eliminate-them/?noredirect=on&utm\\_term=.6150c5b4f414](https://www.washingtonpost.com/news/posteverything/wp/2017/08/24/people-with-down-syndrome-are-happy-why-are-we-trying-to-eliminate-them/?noredirect=on&utm_term=.6150c5b4f414) [https://perma.cc/UBQ7-3Y6C].

<sup>129</sup> Mancini, *supra* note 128.

<sup>130</sup> See SCHABAS, *supra* note 112.

<sup>131</sup> The International Criminal Tribunal for Rwanda (ICTR) was created by Security Council Resolution 955 in 1994. The ICTR Statute states that the Tribunal shall have the power to prosecute persons responsible for serious violations of international humanitarian law, including genocide, crimes against humanity, and war crimes in non-international armed conflict, committed in the territory of Rwanda and Rwandan citizens responsible for such violations committed in the territory of neighboring states between January 1, 1994 and December 31, 1994. See S.C. Res. 955 (Nov. 8, 1994); see also *The ICTR in Brief*, U.N. INT'L RESIDUAL MECHANISM FOR CRIM. TRIBUNALS, <http://unictr.irmct.org/en/tribunal> [https://perma.cc/CH29-EK2Y]; see also Szpak, *supra* note 113, at 156–57.

<sup>132</sup> *Prosecutor v. Akayesu*, Case No. ICTR-96-4-T, Judgment (ICTR Trial Chamber Sept. 2, 1998).

<sup>133</sup> See *id.*; see also Szpak, *supra* note 113, at 157.



public.<sup>134</sup> Under the ICTR's analysis, Akayesu's actions amounted to genocide, with between 500,000 and one million casualties.<sup>135</sup>

The ICTR confirmed that all the elements required for genocide were met by: (1) differentiating between genocide with a specific intent for extermination or attempted extermination, and crimes against humanity as the persecution of civilian populations; (2) determining that the acts of sexual violence were systematically conducted against a protected group through a broader application of the categories in the Convention; and (3) satisfying the destructive requirement under the Convention, again through widening the Article II acts to incorporate others unnamed.<sup>136</sup> As to the first finding, the ICTR innovatively ascertained presumptions of fact from which genocidal intent may be inferred in the absence of a confession from the accused. The ICTR was able to infer that Akayesu possessed the requisite genocidal intent against the Tutsi tribe by examining: the general context of the perpetration of culpable acts directed against the same group; whether such acts were committed by the same offender or by others; the scale of the atrocities committed and their general nature; the commission of the crime in a certain region or country; and whether victims were deliberately and systematically targeted on account of their membership in a particular group while excluding members of other groups.<sup>137</sup> As to the second finding, although Tutsis and Hutus shared the same language and culture, the ICTR departed from a strictly positivist approach to conclude that the Tutsi comprised an independent protected ethnic group. The ICTR inevitably advocated for extending the Convention's protection to any permanent group by focusing on other identifiable factors, such as the Tutsis' geographic stability and immobility; determination by birth and irremediable association; differing social status as well-educated and wealthy cattle breeders; and contrary physical characteristics as taller, lankier, and thinner-lipped peoples than the Hutu.<sup>138</sup> As to the third finding, the ICTR essentially held that the Convention's enumerated acts were too narrow, as written, to

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<sup>134</sup> See Szpak, *supra* note 113, at 157.

<sup>135</sup> See *id.*

<sup>136</sup> See *id.* at 158–161.

<sup>137</sup> See Akayesu, Case No. ICTR-96-4-T, ¶¶ 521–23.

<sup>138</sup> See Szpak, *supra* note 113, at 159–60.

capture the scope of destructive acts that establish genocide.<sup>139</sup> The ICTR stated that bodily or mental torture; inhumane or degrading treatment; and persecution also fall under Article II(b).<sup>140</sup> Subsistence diets; systematic expulsion from homes; and reducing essential medical services below a minimum threshold also fall under Article II(c).<sup>141</sup> Additionally, sexual mutilation; sterilization; forced birth control; separation of the sexes; prohibition of marriages; deliberate impregnation of women by another group's man with the intent to birth a child of the father's group (i.e. Hutu men raping and impregnating Tutsi women so that they would bear Hutu children); rape intended to prevent births when the victim subsequently refuses to procreate (i.e. raped Tutsi women no longer bearing any children); and people led through threats or trauma not to procreate also fall under Article II(d).<sup>142</sup> While urging respect for the original drafters' aims,<sup>143</sup> the ICTR expanded the Convention's application in a novel and necessary manner to hold otherwise fugitive wrongdoers accountable for their specific genocidal intent and systematic extermination of Tutsis in Rwanda.

A similar analysis to the ICTR's may now protect the Down syndrome community and ensure that the doctrine of genocide adapts to rapidly emergent methods of destruction, but the ICTR's jurisdiction as an *ad hoc* tribunal is limited to applying the original Convention.<sup>144</sup> Thus, the ICTR's broader findings are not transferrable and not binding on other courts. Until and unless the doctrine of genocide can take on a customary international law form or the Convention itself can be updated, subsets of the disability community cannot receive their due protection from eradication, despite being cognitively and physically marked by involuntary and irreversible abnormalities assigned at birth. The ICTR's perceptive reasoning, nevertheless, can be used as a critical basis for renovation.

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<sup>139</sup> See Akayesu, Case No. ICTR-96-4-T, ¶¶ 503–04.

<sup>140</sup> See *id.*

<sup>141</sup> See *id.* ¶ 506.

<sup>142</sup> See *id.* ¶¶ 507–08.

<sup>143</sup> See *id.* ¶ 516.

<sup>144</sup> See Szpak, *supra* note 113, at 161.

*B. Alternate Legislative Lessons from the United States to  
Curb Genocidal Effects*

At present, prenatal genetic testing and the subsequent termination of fetuses with Down syndrome is legal in a range of countries, with laws differing as to an upper bound on the weeks at which termination during the pregnancy is permissible. As discussed, however, pro-information laws in the U.S. have attempted to counter the rising termination rates by requiring that doctors and genetic counselors deliver positive information on developmental, educational, and psychosocial outcomes of children with Down syndrome, as well as helpful resources to aid with raising a cognitively impaired child.<sup>145</sup> Pennsylvania's Down Syndrome Information Act enacted in 2014, also known as Chloe's Law named after a child with Down syndrome,<sup>146</sup> and the federal counterpart, the Prenatally and Postnatally Diagnosed Conditions Awareness Act enacted in 2008,<sup>147</sup> are examples of U.S. pro-information laws that initially received support across pro-life, pro-choice, and disability activists before pro-life politicians took over the agenda.<sup>148</sup> Yet one potential method to reap the benefits of prenatal testing while decreasing termination rates may be to amend the pro-information platform to a neutral mandate. Country-specific nonpartisan local and national legislation that require patients to receive neutral, nondirective evidence-based counseling from medical experts, on both the risks associated with Down syndrome and support services available, may enable parents to better contemplate and provide complete informed consent for subsequent actions.<sup>149</sup> Pro-information laws have polarized pro-choice advocates with their goal to deliberately spin Down syndrome in a solely positive light,<sup>150</sup> whereas the Icelandic government's opposing approach involves negative counseling from the perspective that Down syndrome is a complication that

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<sup>145</sup> See Graham, *supra* note 15.

<sup>146</sup> Down Syndrome Prenatal Education Act ("Chloe's Law"), 2014 Pa. Laws 130.

<sup>147</sup> Prenatally and Postnatally Diagnosed Conditions Awareness Act, Pub. L. No. 110-374, 122 Stat. 4051 (2008).

<sup>148</sup> See Arthur L. Caplan, *Chloe's Law: A Powerful Legislative Movement Challenging a Core Ethical Norm of Genetic Testing*, 13 PLOS BIOLOGY 1 (Aug. 6, 2015).

<sup>149</sup> See *id.* at 2.

<sup>150</sup> See *id.* at 2-3.

should be terminated.<sup>151</sup> Legislation mandating comprehensive and neutral counseling, and sanctioning the lack thereof, may again garner multilateral backing.

A second potential method to avoid mass termination may be to increase funding for Down syndrome research and treatment innovations through federal and state legislation. Diana Bianchi, a neonatal geneticist in the U.S. known for introducing highly accurate noninvasive prenatal tests in 2011, has been analyzing how the results from genetic screenings as early as 10 weeks of pregnancy can assist in developing drugs to address cognitive deficits in utero.<sup>152</sup> Her research remains limited to safe and already-approved drugs, but a Texas hospital has prepared a trial of Prozac in pregnant women with Down syndrome fetuses and a scientist at Cornell has investigated supplementation with choline, an essential nutrient.<sup>153</sup> Such treatments are intended to increase brain development in fetuses with Down syndrome, for which development typically slows down at 15 weeks of pregnancy, and to minimize post-birth cognitive impairment.<sup>154</sup> This field of fetal personalized medicine,<sup>155</sup> particularly used to repair cognitive and birth defects resulting from Down syndrome, has been slow in light of diminishing funding for the condition. According to the Global Down Syndrome Foundation, Down syndrome is one of the least funded conditions in the U.S. and Congress has continually decreased funding to the National Institutes of Health for the condition since 2001.<sup>156</sup> Increased information for parents, who have the choice to terminate or continue with an affected pregnancy, cannot truly be obtained without well-funded research for prenatal therapies.

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<sup>151</sup> See Maclean, *supra* note 69.

<sup>152</sup> See Rochman, *supra* note 120.

<sup>153</sup> See *id.*

<sup>154</sup> See *id.*

<sup>155</sup> See *id.*

<sup>156</sup> See The Denver Post Editorial Board, *Congress should give it up for Down syndrome research*, THE DENV. POST (Dec. 29, 2017), <https://www.denverpost.com/2017/12/29/congress-should-give-it-up-for-down-syndrome-research/> [https://perma.cc/NRU5-XG59].

*C. Alternate Lessons from Global Regulatory Frameworks to Curb Genocidal Effects*

Genetic technologies span a varied regulatory landscape in the global context. While some countries have attempted instating laws to control the use and means of genetic technologies, to date there is no international regulatory body or framework for gene editing or prenatal testing for genetic abnormalities. In waiting for the development of such an international body, there are still lessons to be learned from existing country-specific frameworks. The following two lessons may be adapted towards drafting policies against prenatal testing for the purpose of eliminating specific abnormalities in the global gene pool.

One example is Germany's Embryo Protection Act of 1990, which prohibits the alteration of human germ line cells and the harvesting of embryonic cells.<sup>157</sup> The Act explains germ line cells as leading to fertilization and a resultant human being, and an embryo as an already fertilized human egg cell capable of developing.<sup>158</sup> The Act exempts artificial fertilization or gene selection for the preservation of a child from "falling ill with Duchenne-type muscular dystrophy or a similar severe sex-linked genetic illness, and the illness threatening the child is recognized as being of appropriate severity."<sup>159</sup> Problematic is that the Act's language does not explicitly define "severity."<sup>160</sup> South Korea's Bioethics and Biosafety Act ("BioAct") similarly restricts scientists from conducting genetic experiments and modifications on human embryos and genes, but neither the German nor the South Korean law specifies whether experiments on unviable embryos are prohibited.<sup>161</sup> The scope of "viability"—or which embryonic characteristics are considered biologically survivable and, therefore, of greater consequence for gene editing—remains unclear, as well as the professional perspective from which viability is determined. Transparently defining the bounds of viability from the licensed medical community and codifying the definition among

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<sup>157</sup> See Embryonenschutzgesetz [ESchG] [The Embryo Protection Act], Dec. 19, 1990, BGBl I at 2746, No. 69 (Ger.).

<sup>158</sup> See *id.* § 8.

<sup>159</sup> See *id.* § 3.

<sup>160</sup> See *id.*

<sup>161</sup> See Saengmyeong Yunli Mich Anjeonbeob [Bioethics and Safety Act], Act No. 12844, Nov. 19, 2014 (S. Kor.).

state agencies are actions of importance for prenatal genetic testing and counseling. Individual choices aside, a plain definition would allow certain genetic abnormalities, such as Down syndrome, to be medically and standardly categorized as a more operational condition, should a fetus come to term, in comparison to other abnormalities, such as Patau syndrome, which is fatal within the first week of life. Subsequent genetic counseling would be required to reflect this categorization of viability, with sanctions for state-sponsored actors and organized programs that follow an otherwise pointed, mass abortion agenda.

Another area of uncertainty between the laws of Germany and South Korea is which actions constitute gene therapy or modification.<sup>162</sup> South Korea's BioAct defines "gene therapy" as "a series of procedures to alter genes for the purpose of preventing or treating a disease," but does not explain whether such actions span the administration of drugs, a procedure on embryonic cells, the reprogramming of DNA, or other methods of recombination or modification.<sup>163</sup> Moreover, does Down syndrome fit the disease category? A cursory view of prenatal genetic screening, by itself, may not constitute therapy or modification, but the combined action of screening and counseling geared towards abortion, as in Iceland's case, may very well constitute future genetic modification. Narrow interpretations of "gene therapy" and "disease," again codified into law with corresponding sanctions, may be warranted to capture the extent of actions with editing consequences.

A second relevant example is the 1997 Convention on Human Rights and Biomedicine (the Oviedo Convention), which also aspires to limit the misuse of scientific technologies, but similarly lacks the specific language required to clarify boundaries. As of December 2011, 29 member states of the Council of Europe had ratified the Oviedo Convention, which supersedes individual nation-states' legislation.<sup>164</sup> The Oviedo Convention is purported to

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<sup>162</sup> See generally Na-Kyoung Kim, *Gene-Editing: Interpretation of Current Law and Legal Policy*, 21 DEV. & REPROD. 343 (Sept. 2017) (discussing South Korea's BioAct and its vague usage of "gene therapy" allowing the Act to regulate only research on gene therapy, but not gene therapy itself).

<sup>163</sup> Saengmyeong Yunli Mich Anjeonbeob [Bioethics and Safety Act], Act No. 12844, Nov. 19, 2014, art. 2 para. 16 (S. Kor.).

<sup>164</sup> *Ratification of Oviedo Convention: A Minimum of Ethical Guidelines*, GÉNÉTIQUE (Dec. 1, 2011), <http://www.genethique.org/en/content/ratification-oviedo-convention-minimum-ethical-guidelines#.XWwhdZNKhE4> [https://perma.cc/AA7V-

be the first international text giving a common framework of bioethical principles to signatory states, and it intends to protect human dignity and identity from endangering biological and medical acts against the benefit of present and future generations.<sup>165</sup> Most relevant, Article 11 states that “any form of discrimination against a person on grounds of his or her genetic heritage is prohibited,” and Article 13 states: “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** [*emphasis added*].”<sup>166</sup>

Actions to halt the reproduction of Down syndrome individuals in the future genome pool literally fit the Oviedo Convention’s prohibitions, but the problem lies in the generic language used and the simultaneous allowance that “scientific research in the field of biology and medicine shall be carried out freely . . . ensuring the protection of the human being.”<sup>167</sup> If pregnant women choose to abort fetuses with Down syndrome as a result of targeted and systematic genetic counseling, and a subsequent generation of Down syndrome is eradicated, is this a “modification in the genome of any descendants” in the manner stated by the Oviedo Convention? Does the eradication of Down syndrome peoples by way of genetic technologies constitute a protection or harm of human beings, human dignity, and human identity? And who decides how human dignity is preserved? Although a step in the right direction, the Oviedo Convention, like other global regulatory frameworks, misses the crucial opportunity to clearly categorize, standardize, and compare permitted actions from discriminatory ones.

## VI. Conclusion

It is clear that disability does not fit into the current definition

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<sup>165</sup> See *id.*; see also 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, Preamble, Apr. 4, 1997, E.T.S. No. 164, Preamble, [hereinafter Oviedo Convention], <https://rm.coe.int/168007cf98> [<https://perma.cc/C8P6-AFDS>].

<sup>166</sup> Oviedo Convention, *supra* note 165, arts. 11, 13.

<sup>167</sup> *Id.* art. 15.

for genocide—condition-specific groups do not constitute a national, ethnic, racial, or religious group. As such, Iceland's actions and other countries following suit to eliminate Down syndrome cannot constitute genocide. Yet the disability community has repeatedly experienced trauma. Rather than arising from archetypal genocidal racism, ethnic cleansing, or armed conflict, such trauma has come from inherent biases and misrepresentations about disabled individuals that have continued on since the development of eugenics.<sup>168</sup> Here, “the weapon of destruction is misguided scientific policy for the sake of ‘betterment of the whole.’”<sup>169</sup> Thus, it is worth questioning why the Genocide Convention, embedded in immutable human rights and humanitarian legal principles, should remain as defined with a victim loophole and indistinct destructive acts. This narrow classification permits unnamed groups—with otherwise proven chances of surviving and thriving—to be targeted and destroyed in whole or in part, merely by new technological means. International and domestic legal frameworks are necessary to regulate advancements in science and medicine and, ultimately, prevent disguised discrimination. Updating the Genocide Convention and instating linguistically clear legislation may be a decent start.

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<sup>168</sup> Miller & Levine, *supra* note 4, at 96.

<sup>169</sup> *Id.*



