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About IASSIDD

The International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) is an international and inter-disciplinary scientific non-governmental organization with official relations with the World Health Organization. IASSIDD's mission is to promote worldwide research and an exchange of information on intellectual and related disabilities. The association (originally named the International Association for the Scientific Study of Mental Deficiency) was founded in 1964. It sponsors regional conferences as well as a trirennial World Congress, conducts studies of research issues and practices, and publishes reports and publications in conjunction with a variety of publishers throughout the world. IASSIDD is the first and only worldwide group dedicated to the scientific study of intellectual disability.

Journal of Policy and Practice in Intellectual Disabilities

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Editorial

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Abstract

This special issue is a contribution to stimulate discussion and debate in the community of scholars in the field of intellectual and developmental disability around the ethical issues of ending the lives of people with intellectual disabilities. It features a stimulus paper and then a series of invited commentaries. An initial, large monograph was shared with a group of scholars, scientists, and researchers in the global community who were invited to provide commentary. The monograph is available on the webpage of the International Association for the Scientific Study of Intellectual and Developmental Disability's Ethics Special Interest Research Group. An abridged version of the monograph is published as the first article in this special issue. In keeping with the process followed by journals such as Lancet and journals of The Royal Society, this paper has not been peer-reviewed in a blind process. The review is in the commentaries that follow. A range of opinions and perspectives indicate the complexity of this important topic and the critical value of debate and discussion.

Keywords: ethics, intellectual disability, journal publishing

Main Document

This is an important issue for the Journal of Policy and Practice in Intellectual Disabilities (JPPID) and unique in the journal's history so far.

From antiquity, humans have been gathering to learn from each other and advance understanding of importance to our species and our interaction with the world around us. In modern times, conferences and scientific meetings have been an avenue for furthering fields of endeavor. Publications through journals have been a more recent innovation, but still have a long history (The Philosophical Transactions of the Royal Society of London was founded in 1665). Journals exist to be a place to develop intellectual endeavors in areas of human knowledge.

One feature of longstanding in journals is the opportunity to engage in conversation and debate with other members of the learned society. *Lancet* publishes Correspondence and Responses. *The Royal Society* publishes Opinion Pieces. It is out of this tradition that JPPID publishes this special issue concerning a topic of great importance to the members of IASSIDD, the International Association for the Scientific Study of Intellectual and Developmental Disability.

This special issue is a contribution to stimulate discussion and debate in the community of scholars in the field of intellectual and developmental disability around the ethical issues of ending the lives of people with intellectual disabilities. An initial, large monograph was shared with a group of scholars, scientists, and researchers in the global community who were invited to provide commentary. This paper is available on the webpage of the IASSIDD Ethics Special Interest Research Group. An abridged version of the monograph is published as the first article in this special issue. In keeping with the process followed by journals such as Lancet and journals of The Royal Society, this paper has not been peer-reviewed in a blind process. The review is in the commentaries you will read to follow. A range of opinions and perspectives indicate the complexity of this important topic and the critical value of debate and discussion. The forthcoming World Congress of IASSIDD to be held in Glasgow in August 2019, will serve as a venue for continuing discussion.

As editors, we are honored to be able to contribute to the advancement of this field of importance to humanity and look forward to the ensuing discussions.

Rhonda Faragher and Laurence Taggart
Co Editors in Chief, JPPID

Contributors

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Ivan Brown, PhD, is an Adjunct Professor in the graduate program of the Department of Applied Disability Studies at Brock University in Canada. Previously, he was a long-time research professor at the University of Toronto, where he oversaw provincial and national research programs in intellectual disabilities, quality of life, and child welfare. Dr. Brown is the editor/author of 13 scholarly books in disability and has published more than 250 journal articles, book chapters, government reports, scholarly bibliographies, measurement scales, and editorials in this field. He was the founding editor of the Journal on Developmental

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Disabilities in 1992, a scholarly online journal that has developed a specialty in publishing the research of graduate students. Dr. Brown has demonstrated active leadership in local disability organizations, especially as Board Chair of the Ontario Association on Developmental Disabilities. Internationally, he is a long-time member and Fellow of IASSIDD, and past Chair of IASSIDD's Quality of Life Special Interest Research Group. He is currently the Director of IASSIDD's Academy and is IASSIDD's Vice-President, Education and Policy.

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The Quiet Progress of the New Eugenics. Ending the Lives of Persons With Intellectual and Developmental Disabilities for Reasons of Presumed Poor Quality of Life

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Abstract

This paper considers recent developments in terminating human life affected by intellectual and developmental disability. It brings these developments together under the heading of a progressing eugenics. It argues that the acts under discussion are eugenic with regard to their moral justification, even if not in their intention. Terminating human life in contemporary society is aiming at the alleviation of suffering, not the enhancement of the human gene pool. Three distinct cases are traced in the literature: ending the lives of severely disabled prematurely born infants, terminating pregnancies after positive outcomes of genetic screening and testing, and ending the lives of persons with IDD by means of euthanasia. It is shown from the literature that in each of these cases the justifying reason is the prospective judgment of a 'poor' quality of life, which ties these acts to the justification of terminating human life within the history of eugenics. The pervasive judgment of poor quality of life is criticized as ignoring alternative views, most of all the views of persons and families directly implicated who do not consider living with IDD identical with a life full of suffering.

Keywords: ethics, eugenics, quality of life, terminating human life

Introduction

With rare exceptions, "eugenics" is generally speaking not a term that is favorably used. In the context of this article, the term refers to terminating human life affected by intellectual and developmental disability (IDD). In support of such acts, people frequently say they are justified on the ground that human life can be "defective", and that human suffering caused by IDD can be prevented. Their critics regard medical practices constituted by these acts as "eugenic" because they see them as aiming at improving the human condition by eradicating its negative aspects. "Eugenics" is not a term that the agents and recipients engaged in these medical practices use themselves. Instead, they assert that what they are supporting aims at ameliorating human suffering; it is not about improving the human condition. Therefore, they reject being motivated by a notion of inferiority of the lives of the human beings involved.

Before we start elaborating on these two perspectives, it is important to put in a caveat on how they should be read. The opposing perspectives seek to identify two positions that are rationally reconstructed. In reality, distinctions neatly separating these positions are often intertwined, and hybrid variations occur. Regarding the many issues that will be discussed, readers may find themselves switching positions, depending on experience and expertise.

Mapping the landscape as characterized by two opposing perspectives is motivated by the aim of the present article, which is to discuss medical practices that objectively question human life affected by IDD. In taking this aim, the article pursues a particular interest. Scientists and advocates who have devoted their professional life to improving the lives of persons with IDD and their families are called upon to reflect on the questions raised. The article takes its inspiration from the Convention on the Rights of Persons with Disabilities (CRPD) adopted by the *United Nations* in 2006 (United Nations, 2006), and joins disability advocates in their concern about how "the new eugenics" may effectively undermine CRPD's mission. The overall goal of the article is to support disability advocates in their struggle for social justice and equality, and make this position publicly known by preparing the case for a position statement to be proposed at the 16th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) in Glasgow, August 2019.

The present discussion article is a shorter version of an original research article (Reinders, Stainton, & Parmenter, 2019)

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with extensive references to the literature on which the argument is based. The original version has been abridged for reasons of space in this special issue. The full manuscript is available on the webpage of the Ethics and Intellectual Disabilities Special Interest Research Group of IASSIDD.

Eugenics

In this article, the focus is on the termination of human life affected by IDD in three different contexts. It describes current developments that involve ending the lives of infants that are born with a severely disabling condition ("mercy killing"), of future infants that will be born with a disabling condition when carried to term ("preventing suffering"), and of other persons with IDD directly or indirectly subject to practices of euthanasia or physician assisted suicide.

In bringing the termination of human life in these three quite distinct areas under the heading of the term "eugenics" the article makes two moves. First, as indicated, it draws attention to a common theme underlying all justifications of the acts involved. Second, in order to examine their qualification as "eugenic," it draws attention to earlier episodes in which such acts were practised.

Eugenics started as a program of social and moral reform that aims to improve the quality of human life by improving the human gene pool (Agar, 2004). People with IDD have always been a key target group of this program. Its central tenet was that a strong and healthy society cannot afford to accept or ignore the presence, let alone the procreation, of members affected by IDD (Hawkins, 1997). Using legal instruments such as forced sterilization, western countries aimed at protecting themselves against being burdened—socially, morally, and economically—by perceived unfit and inferior human beings (Trent, 2017). The goal of protecting society against the burden of inferior human beings indicates how the rising eugenics movement provided the pretext for the massive killing of people with IDD in The Third Reich.

To bring contemporary medical practices within the historical purview of "eugenics" implies the challenge to see whether, notwithstanding the crucial differences, there is also a similarity. To answer the question, the article will make a distinction between eugenic *motivation* and eugenic *justification.* In our days, these practices are not embedded in explicitly laid out policies operated by public institutions or government agencies. As will be discussed later, they are much more "consumer-" or "market-driven" than they are "state-driven" (Reinders, 2000). Nor are these practices motivated by the same ideology of moral superiority as the "old" eugenics, but rather by the goal of alleviating human suffering. Nonetheless, as the article will show, there is also a similarity. This similarity regards the moral justification of terminating human life affected by IDD in current medicine. Both then and now the practices at issue are justified because the lives of the human beings that are at stake are considered "defective" and of "poor quality." This holds for the practices of euthanasia and physician assisted suicide too, even though these practices are not commonly linked to eugenics. This article takes a critical stance with regard to descriptions such as "mercy killing," or "the prevention of suffering" or "procreative beneficence" and opposes the utilitarian ethics that generates them.

Lest the intention of the article be misunderstood, its authors do not mean to defame healthcare professionals by the emotive use of inflammatory language. The term "eugenics" was coined by a historical movement with identifiable objective characteristics, which makes it possible to ask in which respect the practices discussed in this article are similar, and in which respect they are different. Supporters of these practices strongly reject any use of the term "eugenics" with regard to what they support. They insist that terminating human life affected by IDD is only acceptable when particular moral and legal 'safeguards' are in place. All existing euthanasia and abortion laws do in fact specify conditions that have to be fulfilled for ending human life in the context of medicine to be justifiable and legitimate. This article will consider whether such moral and legal qualifiers actually succeed in limiting the case for ending people's lives in medical contexts in a way that exempts categories of vulnerable people such as persons with IDD.

Disability

In looking at the social and cultural context in which the intended practices in contemporary medicine evolve, we take a different perspective on the relevant issues. The difference lies in the understanding of two key concepts that are crucial to the debate, which is the concept of disability, and the concept of quality of life.

In the last decades, thinking about disability has changed in ways that have influenced governments, politicians, lawmakers, public officers, and executives in the world of human services. Particularly, in studying the world of IDD, the social sciences have gradually abandoned thinking about it in essentialist terms, meaning that the disabling condition is no longer understood as intrinsic to the person, and in that sense, is not definitive of that person as a distinct "kind" of human being. A new way of thinking is based on the premise of a common humanity, which makes difference in respect of ability a secondary phenomenon. This new way of thinking has "diversity" as a key notion in understanding human nature, which in the social sciences is recognized in various ways. On the level of semantics, it is expressed in "people first" language, meaning one does no longer speak of "disabled people" as if "disabled" is an adjective defining the people involved as a "natural kind." On the level of social philosophy, it has received recognition in arguments against organizing social arrangements and institutions in ways that condemn persons with IDD to segregated environments, a view that is positively expressed in the goal of "inclusion." On the level of health policy, the new approach has been accepted by adopting a different conceptualization of IDD as a complex social reality of intertwining factors rather than a biological characteristic. This conceptual innovation found recognition in the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001). Finally, on the level of international law that has incorporated these changes in the UN Convention mentioned before. Taken together, all of these changes indicate a different agenda for the sciences involved in the study of disability.

In the context of medicine, IDD continues to be thought of, generally speaking, as inherent to the physical, and/or mental conditions of the persons involved. This conventional view is

based on a conception of health as the absence of illness and disease, which for practical purposes requires the presupposition of "normal functioning." Recognizing developmental delay in a toddler, for example, presupposes a standard, that is, derived from developmental stages that toddlers "normally" go through. Some human beings are born with or have acquired conditions that bar them from functioning in the way other human beings do. Hence, the parameters of normal functioning.

In the social sciences, in contrast, the dominant perspective has shifted academic ways of thinking to the effect that the "social model" of disability is commonplace by now. It expresses the view that disability is the result of the interplay between individual and environmental factors, such that an individual trait may or may not result in a disability, or may result in a disability in different ways, depending on how a person's socio-cultural environment responds to its manifestation (Shakespeare, 2006). The perspective from the social sciences tends to look at the prevailing views on IDD and its various aspects as social constructs. The clearest example is the assumption that living a life affected by IDD involves suffering, which implies that living with a profound condition of IDD involves profound human suffering. For many involved in the world of disability, including medical professionals, this assumption is plainly false. Not only does it presuppose that people "normally" do not suffer in the same sense, which is questionable, it is also known to be untrue for persons who experience living with their condition of IDD as the kind of life they are familiar with.

Given the different conceptualizations of disability there is a corresponding difference in response. If one takes IDD as a condition with devastating effects that is inherent to the person, then the option of ending that person's life presents itself as thinkable. On the other hand, if one adopts the conception of disability as the result of social interaction then the most likely response is to ask which factors creating the environmental response are amenable to change. Different conceptions of disability, in other words, invoke different strategies of responding to the person's needs.

Quality of Life

As indicated in the Introduction, the notion of "poor quality" is a key in the justification of the contested practices, which shows the crucial role of the concept of quality of life (QoL). Particularly in connection with IDD, scientists and "lay people" may find themselves in dispute about what "truly" constitutes quality of life. Three different angles can be distinguished. In a medical context, the focus usually is on health-related quality (HQoL). As such, the concept often functions in prospective judgments regarding performances in health as predicted by medical professionals.

In the context of support services, however, the concept of quality of life is taken in a much wider sense (Brown & Brown, 2003; Cummins, 2000; Parmenter, 1992; Renwick, Brown, & Raphael, 1994; Schalock et al., 2002; Schalock & Verdugo, 2002). A number of "life domains" are taken into consideration to determine a person's QoL, of which "health" is only one, complemented by a number of other domains such as relationships, social inclusion, material well-being, and rights. The implication is that poor outcomes in one domain may be compensated, eventually, by higher outcomes in other domains. A life in good health but without friendships does not obviously outrank a life in poor health that is shared with many good friends.

As a consequence of these diverse conceptualizations, the measurement instruments used in both contexts differ. HQoL instruments provide information about the effects of a specific treatment or therapy on the patient's condition. This approach implies the possibility of using the obtained information in clinical practice to assess end-of-life decisions. Whether they *actually* are so used depends on particular circumstances and local jurisdictions.

In contrast, QoL measurement instruments in the social sciences provide information about the effects of policies, programs, and treatments in a support context. The information in this context is not exclusively related to health conditions, nor is it used in connection with end-of-life decisions. A Dutch professor, Ad van Gennep, coined the term "kwaliteit van bestaan" ("quality of existence") to avoid any association with the medical use of "quality of life" in the context of end-of-life decision-making (Van Gennep, 1989). In the world of IDD services in the Netherlands, the alternative term has become the standard use.

Particularly, in the past 20 years, research has established that QoL-oriented services and supports can have significant positive effects on the lives of people with intellectual disabilities and their families (Brown & Brown, 2003; Schalock, 2004).

With regard to differences between disciplinary perspectives on QoL, the concept of "quality adjusted life year" (QALY) also must be mentioned here. Originally, the term referred to assessing the relative benefits of medical interventions when compared with alternative treatments (Parmenter, 1996). Now gradually the notion of QALY's seems to have trickled down into the clinical practice of neonatal intensive care units (NICUs) to assess when life-sustaining interventions on (very) preterm neonates ought to be withheld. As we will see, introducing QALY's in the prospective assessment of these interventions includes the question of how the foreseeable effects of IDD may determine children's QoL (Kind, Lafata, Matuszewski, & Raisch, 2009). What the approaches within distinct scientific disciplines share on the other hand, is the drive toward "measurable" QoL, even when the actual instruments used for measurement are different. In this respect both are different from a third perspective that reflects the world of "lay" people who are experienced in living with IDD, or in sharing their lives with someone with such condition (Hatton, 1998). Measured QoL not necessarily coincides with experienced QoL. Personal experience may typically change people's perceptions, especially when the rewards of overcoming bleak medical prognoses are ignored (Reinders, 2013). What according to objectively measured outcomes in statistics and tables amounts to a life of "poor quality" is not experienced as such, particularly when factors of social belonging and affection are considered.

Returning to different approaches between scientific disciplines, it should be noted that the use of HQoL as an indicator for end-of-life decisions occurs only in the medical world, and even there is not generally accepted. This medical approach does not easily accord with what social scientists consider their core business, which is to improve people's QoL by improving the supports they need. Again, we emphasize that the perspectives distinguished here are reconstructed mainly for the sake of argument. In reality, different views and approaches cut across distinct scientific disciplines. Members of the same discipline

may hold different opinions on the issues raised. For example, both in geriatrics and pediatrics there are those who in principle oppose end-of-life decisions that aim directly or indirectly at their patients' death. They emphatically will assert that improving QoL of their patients is also their core business. At the same time, social scientists in IDD may accept that end-of-life decisions are in general undesirable, but some may add that incidentally such decisions may be morally acceptable. As indicated, conceptual boundaries drawn to demarcate distinct views on the matter are blurred in reality, and opposing positions are represented across disciplines and perspectives.

To warrant the claim that there is quiet progress of eugenic practices it is necessary to produce reliable factual accounts. This is a complex and difficult task, the result of which will not remain uncontested. One aspect of these regards the disputed nature of eugenics. What some regard as clear-cut examples of rising eugenics is for others a manifestation of a more benign and compassionate way of practising medicine.

The Task of Fact-Finding I: Neonatology

The debate on terminating the lives of infants that are born prematurely and face a life with conditions of severe IDD focuses for a large part on the so-called Groningen Protocol (GP) (Verhagen & Sauer, 2005). This protocol has been developed since 2004 in the hospital of the University of Groningen in the Netherlands. It proposes a system of rules to determine when the lives of newborn infants with life threatening conditions can be legitimately terminated. Legitimacy here refers to legal standards. The GP was developed by pediatricians, though in close cooperation with a local criminal prosecutor. It was an attempt to enable pediatricians to come clean about cases of "mercy killing" they had performed at a time when Dutch law did not provide a legal space to do so. By holding themselves publicly accountable, pediatricians wanted to push the courts to draw the line between legitimate and illegitimate killings of newborn infants. Not only had such killings been reported from advanced centers of pediatric medicine in various countries, there also seemed to be public support against incriminating well-meaning, benevolent doctors (Cuttini et al., 2000). According to the authors of the GP, the newborn infants whose lives had been terminated faced a life of "unbearable suffering," while their prospect would inevitably be limited to a life of "poor quality." Putting these children—and their parents—out of their misery was depicted as a benign act.

The authors reported three kinds of cases that involved decisions to withhold or withdraw life-sustaining treatment of "neonates," two of which are apparently generally uncontested by pediatricians (Verhagen & Sauer, 2005). We shall return to this distinction below, but here the aim is to look at what the GP argues with regard to the third case: disabled infants that will survive their illness on their own, even after life-sustaining treatment is withdrawn, but whose fate in the eyes of their doctors and parents is too horrific to contemplate. Theirs will be a life of unbearable suffering.

This claim by the GP is highly questionable. If the suffering in case stems from pain, as a physiological and neurological response to some kind of affliction, it can be treated by palliative care, even in severe cases. Physical pain can be unbearable, but unbearable pain can be alleviated even when this can negatively impact people's QoL. Research has claimed that unbearable suffering from pain in newborn infants is unnecessary (Himelstein, Hilden, Boldt, & Weissman, 2004). But it appears that the GP rather has a different kind of suffering in mind, which can be called "psychological" or "existential". People can suffer from anxiety, or loss, or disappointment, or hopelessness. This kind of suffering cannot always be alleviated, because it originates from how people experience that their lives are going. It is hard to see how newborn infants can suffer in this sense, however. Such experiences are usually mediated by mental representations about some aspect of one's life, which require the operation of cognitive faculties that newborn infants have not yet developed (Chervenak, McCullough, & Arabin, 2006). Given the description of infants in this third category it is unlikely that they will develop such cognitive abilities in the future, which means that "unbearable suffering" for these children is a far from clear proposition.

An analogous problem holds with regard to the notion of "poor quality." To date there is no theory that is purely objective in its conceptualization of QoL. Theories agree that QoL is at least partly dependent on people's own experience. This again raises the question whether the concept is at all applicable to newborn infants. In their case, the claim of "poor quality" can only be prospective. What remains of the argument from the GP is, then, that the children in this category will at some point in the future, live a life that, in the eyes of the parents and doctors involved, amounts to a life of "poor" quality. The authors of the GP acknowledge this when they state that at some point these children will experience what parents and medical experts deem to be unbearable suffering (Verhagen & Sauer, 2005).

The Similarity of "Old" and "New" Eugenics

As it stands, the argument reveals what the authors of the GP believe to be true about IDD. Public support for their practice suggests that, presumably, a significant number of people outside medicine largely believe the same. The attempt to get their practice legalized depends on the notion that they have served their patients' best interest by sparing them a life of unbearable suffering, and therefore ought to be exempted from prosecution. The conclusion presents itself that the prospect of a "poor" QoL for disabled infants necessarily depends on representations of what other people believe to be true about their lives. But accepting such representations as decisive is seriously flawed (Jotkowitz & Glick, 2006). In particular, children with congenital disabilities have never known themselves other than with these conditions. The assumption that *the child's* projected response to this condition will amount to "unbearable suffering" is unwarranted. To them living with a disability is the "normal" state of being, in which they experience the world around them. No doubt "parents and medical experts" may regard living with their condition unbearable, but it does not follow that the children will experience the same. If suffering occurs in the life of these children, it is most likely the effect of beliefs held in their social and cultural environment assuming that their lives must be unbearable to the point of not being worth living.

It is at this point that the similarity with the "old" eugenic practices of killing disabled newborn infants becomes apparent. Ultimately, the justification of these killings depends on the assumption that some infants with ID ought to be spared a life that humans ought not to live. This indicates why the termination of human life under the GP constitutes one of the practices of the "new" eugenics. The justification is questionable for a number of reasons. First, experiential accounts of quality of life by disabled children do not differ from accounts from within their peer group without similar conditions (Tyson & Saigal, 2005). More generally, self-reports often rate living with a disability less negatively than nondisabled people do. Second, it has been shown that doctors and other healthcare professionals tend to underestimate disabled persons' quality of life as compared to self-reports (Leplege & Hunt, 1997). Third, medical predictions about quality of life do not appear to be very reliable (Chervenak et al., 2006). If the contested practice of terminating the lives of newborn infants regards those infants who in the future are unlikely to hold any view on their own lives, the conclusion is strengthened that the justifying reason is derived from the negative judgments held by others.

"Quiet" Progress

What remains to be shown is how the developing eugenic practice in neonatal care is quietly progressing. To date the GP has not been formally adopted in other jurisdictions, so it can hardly be claimed to indicate a growing sympathy for the practice it defends. Indeed, do not the extensive debates and criticisms of the GP suggest just the opposite? Well, yes, and no. "Yes" to the extent that many in the field of pediatrics have taken a stance against it, but "no" because careful reading of their criticisms reveals they are conceding similar beliefs about the lives of disabled newborn infants. This regards the two other categories of newborn infants, the death of which as a desirable outcome is uncontested according to the authors of the GP. They turn out to be right in the sense that some of the critics of the GP concede that in the case of absence of developmental cognitive capacity of a newborn child, not starting life-sustaining treatment is the morally superior option (Chervenak et al., 2006).

In reviewing the deaths of infants in neonatal intensive care units (NCIU's), American pediatricians found that from 1989 to 1999 two-third of the deaths in NICU's involved decisions to withhold or withdraw life-sustaining treatments. While the overall number appeared to be stable, they found significantly increased use of withholding care, that is, the decision not to start such treatment (Weiner, Sharma, Lantos, & Kilbride, 2011). In view of these findings, it appears difficult to warrant strong claims about the "progress" of eugenic practices, but the expanding "gray zone" seems reason to be cautious. Death can be the intended result of medical decision-making at various stages of early human lives, whenever this outcome is preferred above a predicted future life of "poor quality." The GP paves the way to identifying such cases openly, but the opposition against it in no way rules out covertly spreading decision-making driven by a similar preference. Nor is it the case that the GP has significantly changed the practice of neonatology in the Netherlands. For instance, since its inauguration in 2007, the monitoring committee has encountered only one case of ending the life of a newborn child in these circumstances. But, it has made explicit the justification of the act of ending a child's life in terms of "poor quality" in an unprecedented way.

In this connection, we need to come back to the notion of QALYs, for its introduction in "high-tech" neonatology seems to point in the same direction. An example is found in an American study that looked at the practice of nonresuscitating vs. resuscitating neonates with very low birthweights by using QALYs to determine which of these two practices was most cost-effective (Robertson et al., 2012). The researchers found that nonresuscitation is the dominant strategy, which they attribute to its being less expensive and more effective. Similar findings on the cost-effectiveness of admitting very premature infants to neonatal intensive care were reported in an early Canadian study (Boyle, Torrance, Sinclair, & Horwood, 1983). The relevant point here is that the HQoL measurement involved in computing QALYs can be either based on preferences from patients that have had the treatment, or on social preferences that reflect the views of the general population (Kind et al., 2009). In the case of newborn infants, relying on patient preferences is no option. The study hypothesized nonresuscitation as the preferred strategy, which meant that 60% of the studied cohort would have survived without a severe disability, as a consequence of relying on popular views.

The Task of Fact-Finding II: Prenatal Screening and Testing

More than 20 years ago a well-known molecular biologist from Princeton University by the name of Lee Silver predicted in his book *Remaking Eden* that in a few decades it would be considered entirely acceptable to choose the quality of one's offspring by looking for specific features (Silver, 1997). Referring to Aldous Huxley's *Brave New World*, Silver claimed that Huxley got the science right but the politics wrong. Improving the human condition by improving its gene pool will be achieved by the cumulative effect of random individual reproductive choices, it is not the declared object of any government program.

Twenty years later, Silver's prediction appears to be supported by the rapid growth of the global market for testing products, but it remains a matter of dispute whether seeking a preferred quality in their offspring is what drives customers to enter this market. Early initiatives like the Repository for Germinal Choice attracted strong criticism as the "Nobel Prize winner's sperm bank" but the growth of the market has more to do with customers facing some kind of medical problem like infertility.

Evidently, both providers and users of these services do not have children with cognitive impairments on their minds. This does not mean that these children are not implicated. Service users are expected to decide about the "quality" of the eggs and sperm to be selected for procreation, which indirectly pushes towards preventing the birth of children with IDD by means of prenatal screening and testing (PST).

In various countries the option of genetic screening for pregnant women is routinely given. The declared aim of this policy

is not to prevent the birth of children with IDD because that would render public authorities vulnerable to the charge of a negative view of such children. Since the introduction of "non-invasive prenatal testing" (NIPT) public authorities have reconfirmed that general distribution of these procedures is an "option," the aim of which is to enhance informed reproductive choice. People ought to have the option of choosing whether their future child will live with a genetic disposition to develop a disease or a disability. Consequently, they should be given relevant information about personal risk factors as well as the risks attached to invasive testing methods.

The crucial question here is what counts as "relevant information." What should people know to make informed decisions? Looking at practices of genetic counselors, one finds that they usually focus on information derived from a risk analysis, leaving the task of weighing various possible outcomes to the "patient." In a major study in California, women were encouraged to consider all their options—including the option of foregoing testing altogether—in the light of their own values. The findings of their study show that they were less likely to opt for invasive testing (Kuppermann et al., 2014). The wider approach to relevant information for informed decision-making not only improved patient knowledge of the risks involved, but also showed that weighing these risks in view of their own values created a moral space to decide not to participate that earlier studies suggested women did not experience. This raises doubt about their decision-making and the voluntary nature of their participation. Routinely presenting the option of prenatal testing through information from providers influences women's perception and knowledge of these procedures (Press & Browner, 1997; Tsouroufli, 2011). Yet what the study did not consider was adding information about the condition that one was tested for. This appears to be true of most if not all studies in this area.

Here we will focus exclusively on the condition of Trisomy 21, known as Down syndrome. It has become the paradigm case for discussing what the effect of PST on the lives of people with ID may be.

Testing for Down Syndrome

To date, Down syndrome (DS) is the most studied and discussed chromosomal "abnormality." The introduction of NIPT in recent years has raised the question whether it may result in eliminating this condition. Numbers of infants born with DS are reported to be decreasing, numbers of "elective" abortion are reported to be increasing. At the same time, children with DS seem to be doing better in various respects due to early intervention. Particularly the combination of these data invokes the question whether information on what it means to be living with DS is included in the practices of genetic counseling.

The pertinence of this question received support from studies on experienced well-being by persons with DS. An American study published in 2011 showed that from a sample of 294 people with DS in the U.S., ages 12 and older, nearly 99% indicated being happy with their lives, 97% liked who they are, and 96% liked how they look. Nearly 99% people with DS expressed love for their families, and 97% liked their brothers and sisters (Skotko, Levine, & Goldstein, 2011a). Research from Japan designed after this American study reports similar findings (Wakai et al., 2018).

Therefore, the question is how accurate information about living with the condition of DS may affect women's informed choices. A qualitative study on effects of NIPT on the prevalence of DS in the Netherlands found that parents of children with DS think accurate information is lacking for both users and providers (Van Schendel et al., 2017). Similar studies in other countries support these findings. A study from Canada evaluated 20 "decision aids" to support participants involved in testing procedures, but the questionnaire used for this study failed to ask whether these "aids" entail information about living with DS (Leiva Portocarrero et al., 2015).

Until about 2010, research on genetic counseling was concerned with uptake numbers, which means that "results" are rated in terms of the overall "success" of participation in screening and testing programs. In general, it seems fair to say that genetic counselors were aware of their responsibility for clarifying that participants understand what they are consenting to when they decide to participate. They are usually silent on clarifying the condition that they are tested for (Alexander, Kelly, & Kerzin-Storrar, 2015). A study by Williams, Alderson, and Farsides (2002) found that knowledge of the condition of DS is very limited among pregnant women, while the information about living with DS these women received from professionals in their study did not exceed "medical textbook knowledge." They also found that these professionals had no direct experience with DS in their social environment. This finding was corroborated in later studies by Brian Skotko. Being a pediatrician and the sibling of a young woman with DS, Skotko found very inadequate knowledge and understanding of living with this condition among his colleagues early in his career (Kidder & Skotko, 2001). He subsequently studied mothers' experience with Down syndrome in the light of what they had learned about it from their doctors and saw these findings again confirmed (Skotko, 2005a, 2005b; Skotko, Capone, & Kishnani, 2009; Skotko, Levine, & Goldstein, 2011b).

A concern frequently voiced in the recent literature is the objection against "routinization" in PST because of the introduction of NIPT (Alexander et al., 2015; Lewis, Silcock, & Chitty, 2013; Van Schendel et al., 2014). In a very short period, it has become the preferred screening method for DS. In over 90 countries it is now recommended by professional societies as an advanced screening test, which has triggered concern with regard to tolerance and support for those living with Down syndrome (Griffin, Edwards, Chitty, & Lewis, 2018; Kaposy, 2013; Lewis et al., 2013; Van Schendel, 2016; Van Schendel et al., 2014). The potential impact of routinization of a "simple" blood test is unlikely to increase the quality of informed decision-making, and may undercut the moral space for women to decide for themselves whether to take a test. Such pushbacks against the routinization of NIPT have begun to draw attention toward its potential effect on people living with DS.

The Disappearance of Down Syndrome

Is DS a disappearing condition? Answers to this question suggested in the media often refer to abortion rates of 90% and higher as "proof" for this claim. While abortion rates are an indication of what is going on, in reality the issue is more

complicated. To mention just one thing, the number of pregnant women participating in screening and testing programs—the so-called "uptake" ratio—widely differs. Some countries have test uptakes of over 90% (Denmark) where others do not even reach 50% (the Netherlands) (Van Schendel, 2016). Relatively high abortion rates combined with relatively low uptake rates means there will be more children born with DS than suggested by high abortion rates per se. For example, Denmark combines high-test uptake rates (>90%) with similarly high abortion rates (>90%); in the Netherlands high abortion rates (>90%) go with very low-test uptake rates (25% reported in 2013 climbing to 45% in recent years) (Verweij, Oepkes, & de Boer, 2013). Another variable is "advanced maternal age." As the median age for first pregnancies rises, it is not unlikely that uptake ratios may rise. But this does alter the fact that abortion rates may fall. More women may decide not to follow up on a NIPT screening result with a more invasive test to confirm an expected diagnosis, partly because they do not want to risk losing their pregnancy, and partly because they did not intend to terminate their pregnancy to begin with (Natoli, Ackerman, McDermott, & Edwards, 2012).

At the same time, there are reports pointing in the opposite direction. Denmark and Iceland are the most frequently mentioned countries where DS is said to disappear. In Denmark, the introduction of NIPT led to a marked increase in prenatal diagnoses of DS whereupon the number of DS births decreased suddenly and significantly (Lou et al., 2018). Official figures from 2016 mention 137 pregnancies diagnosed with this condition of which four were born, 133 were terminated. Another well-known example is Iceland. With two or three children with DS born each year, Iceland is reported to be close to becoming the first "Down-free" country (Quinones & Lajka, 2017).

Research from China reports that during 2003–11, the high termination rate (90%) led to 55% reduction in the overall DS perinatal prevalence rate with a variation of 62 and 36% decrease between urban and rural areas. Posts on internet fora and social media suggest that the social stigma of DS is high in China with the effect that children with DS are frequently abandoned (Koetse, 2016).

Reports about termination rates from European countries other than Denmark and Iceland seem to vary. A large study shows a much more mixed picture. Significant variations in maternal age, number of pregnancies affected by DS, and abortions were found in nine European countries between 2005 and 2009 (Austria, Ukraine, UK, France, Spain, Ireland, Germany, Switzerland, and Denmark). Of the total number of 1598 prenatally diagnosed cases, 14% were born alive; and 83% were aborted (ranging from 58% in Ukraine to 97% in Spain) (Loane et al., 2012).

A similarly mixed picture comes from a recent review study comparing findings from a variety of studies (with significant differences in research questions and study designs) from the UK, the United States, the Netherlands, France, Spain, China, Taiwan, Hong Kong, and Singapore. Noticing very different outcomes, the message seems to be that the number of live births with DS is relatively stable because of two factors. With the increase in maternal age, the prevalence of pregnancies affected by DS is rising, but the effect is "neutralized" by the equally rising number of abortions (Hill et al., 2017).

In view of these findings, the question whether DS is a disappearing condition cannot be answered fully because there are trends pulling in opposite directions. Striking in this connection, however, is the silence in the scientific literature on the connection between testing for DS and affluence. In the future, DS is likely to become a condition the prevalence of which is characteristic for middle- and low-income countries. The world may not witness the disappearance of the condition of Down syndrome altogether. Children with DS will still be born, and therefore people living with DS will be around for decades to come. But the most likely they will be found primarily in poorer countries. Quite possibly the same might be true with regard to the lower socioeconomic strata in high-income countries.

It is commonplace for public authorities responsible for national screening programs to underline that children with DS are as welcome as any other, and that they should enjoy the same opportunities as other people. The Danish government, for example, declared it does not pursue disappearance of DS but only intends to enhance the option of informed choice for pregnant women. There is reason to pause here. A recent study found that the introduction of national guidelines resulted in marked shifts in screening procedures and that this was a crucial factor in producing the outcomes for live births with DS in Denmark (Lou et al., 2018). Governments can stick to the declared policy of providing their citizens with the option of reproductive choice, but given their authorization and support for nationwide screening and testing programs, they cannot deny responsibility for the result of diminishing their population with DS.

Summarizing the picture that emerges from the research: what stands out is the failure of investigating the absence of accurate information about living with the condition of DS. As to the reason why (most) scientists do not think this absence is an issue, one can only speculate, but traditional medical views on a child born with DS as a "tragedy" probably have a lot to answer for. When users' views of NIPT are largely shaped by what they hear from medical professionals, it appears that not many will find reason to question the presumption that always equates DS with suffering. This is surprising in light of the available data on the success of early intervention that has stimulated development of children with DS in ways that were considered impossible only a few decades ago (Guralnick, 1998, 2005, 2017; Spiker & Hopmann, 1997).

Widening the Scope of Prenatal Screening and Testing

The focus on DS represents a stage in PST that is rapidly becoming obsolete, because NIPT opens the avenue toward targeting many more genetic conditions. Currently no less than 7000 are known. As a consequence, the "standard" justification of enabling reproductive choice is called into question. The issue is this. The proliferation of these technologies is rapidly developing by provision of "direct-to-customer" tests without interference by healthcare professionals. A private research company published the report Newborn Screening—Global Market Outlook (2017–23) accounting for a market growth reaching the level of over a billion USD in 2023 (MarketWatch, 2018). It claims that the growing range of testable conditions, together with a growing public awareness and government initiatives in

this area, produce attractive conditions for further growth. Fuelled by growing economic interest, the market will unlikely correct customers buying these tests in acting on whatever prejudices they may have. On the contrary, providers have a stake in expanding "preconception care" for future parents while leaving their prejudices on living with a disability intact. Munthe (2015) provides examples of how the marketing of for-profit providers works. In other words, providers have no interest in offering balanced information on living with a disability as it may undermine customers' propensity to buy their products.

Assuming that NIPT remains embedded in a public health scheme, on the other hand, governments cannot avoid "weighing" the seriousness of targeted conditions. There simply will be too many options for a medical follow up covered by public health programs. The inevitable question will be which conditions to target. The result will be that potential users find their reproductive freedom curtailed due to a limited range of conditions about which they can get the information they seek regarding their future offspring (De Jong & De Wert, 2015).

A further question is whether people are free to decide what to do with such information. With regard to IVF, for example, utilitarian imperatives may lead healthcare professionals to act on the principle of "procreative beneficence." This proscribes that they should decide to use any carrier information in order to work for a future child with the best possible prospects. Thus far, organizations such as the European Society for Human Genetics have resisted a utilitarian approach toward genetic selection. The primary object of expanding carrier screening must remain what it thus far has been, which is "to strengthen reproductive choices and decision-making of couples" (Dondorp, Page-Christiaens, & De Wert, 2016; Henneman et al., 2016). As technological advances increase the number of conditions that users can be tested for, the demand for a medical follow up will push the question of which conditions are "serious enough" to be targeted by public health programs. The irony here is that recognition of the danger of discriminating effects of PST may lead to the rehabilitation of the "medical model" of IDD that in many ways is responsible for the negative views that people may have of this condition in the first place. Munthe (2015) proposes a limited scope of publicly funded programs for which he relies on the claim that the severity of some conditions is beyond dispute, leaving testing for all other conditions unrestricted to the market.

Against this possibility, it has been argued that from a disability rights perspective, the effect of restrictive policies may well be more stigmatizing for people actually living with a targeted condition, which can be taken as a reason against such restrictions. If one is born with a condition that appears on an authoritative list of "serious" conditions, how could that not be stigmatizing (Chen & Wasserman, 2017)? One is inadvertently reminded of Lee Silver's comment about Aldous Huxley who supposedly had the science right but the politics wrong (Silver, 1997). Whenever governments want to curb discriminatory effects of privatized PST procedures, they will have to make decisions about the genetic conditions to be covered by their regulations. That is to say, they will find themselves making decisions about the kind of disabilities that are the legitimate target of these procedures, a position that Huxley anticipated, be it under very different political circumstances.

The Task of Fact-Finding III: Other Practices Implicating Intellectual Disability

The two areas of developing eugenic practices that have been discussed so far are tied in with technological developments in two separate areas: life support for prematurely born infants and PST respectively. The third task of fact-finding regards medical practices that are more difficult to categorize. Perhaps "euthanasia" will do to categorize most of the cases involved, but certainly not all. That is, if we take a defining characteristic of euthanasia to be a patient's request to have his or her life ended, the practices we have in mind here are hard to categorize. We have already extensively looked at ending the lives of newborn infants as described in the GP. The justification adduced for these acts was that living with certain conditions could be so harsh for these children that it is morally preferable not to "condemn" them to life. In view of developing practices of euthanasia, however, these cases will fail to qualify as such.

Something similar will hold true for most of the cases to be discussed in this third part. In a sense, the problem of categorization is the main subject under discussion here. Generally speaking, practices of terminating human life in a medical context are mostly discussed under the headings of "end-of-life decisions," "euthanasia," "physician assisted suicide," "dying with dignity," sometimes also as the "right to die." In such cases, a person's own views on how to die are a most important consideration in medical decision-making. Looking at the facts, however, one finds cases involving persons whose intellectual ability to express their own views are uncertain, if not absent altogether, such as persons with (severe) IDD, or dementia. Failing to fit the standard euthanasia case, these acts cannot be justified on the grounds of the person's own views. Instead, their justification appears to be grounded in judgments of "poor" QoL, which is sufficient reason to include them in this discussion.

The underlying issue here is the well-known "slippery slope" argument. Supporters of this argument reason as follows. "End-of-life-decisions" involving the termination of patient lives by their doctors are illegal and should remain so. The fact that there are patients explicitly and repeatedly requesting to have their lives ended is not a sufficient reason to legalize such acts and take them off the penal code. Legalizing euthanasia may in due course result in the termination of lives of patients outside this category, for example persons with an advanced stage of dementia. At some point, the argument goes, the legal justification for euthanasia will be extended to people who should be exempted from it because they cannot decide for themselves. Therefore, society had better not embark on this journey at all. The slippery slope objection, in other words, questions the viability of safe-guarding end-of-life-decisions and keeps them limited to the category of requested killings.

Blurred Demarcations

From the perspective of explicitly limited definitions of Euthanasia and Assisted Suicide (EAS), ending people's lives without their explicit request is morally and legally doubtful at the best, and unquestionably criminal at worst. It appears,

however, that this demarcation does not always stand to draw the line. There have been incidental reports about cases where health care professionals decided to put their patients or clients out of "their misery" and make an end to their suffering by making an end to their lives. Since "compassion" is frequently adduced as the main motive in such cases, one could categorize them as "mercy killings," but it would be wrong to put them in the same box as the killings of newborn infants as described by the authors of the GP. The latter were not done secretively, but in open and intense communication with these children's parents. Rather than to qualify the acts reported here as "mercy killings" the description of "bad samaritanism" comes to mind.

Are lethal crimes against people with diminished intellectual abilities that are mendaciously justified as "mercy killing" in any way related to developing practices of EAS? In defense of EAS, it is denied that any such connection exists. A clear demarcation of distinct categories must be maintained. Noticeable in this connection, however, is that proponents of legalizing EAS as a distinct and separate category do not insist on the verdict of "murder" when such acts are involuntary, that is, performed without an explicit request. The relevant difference lies, presumably, in the fact that the performing medical doctors are intentionally subjecting themselves to the transparency and accountability of public scrutiny, as we have seen with regard to the GP.

In view of the tendency to accept certain "involuntary" cases, the question is whether legal EAS can be convincingly claimed as pertaining to the case of patients explicitly requesting to have their lives ended. The demarcation is obviously blurred. Apparently EAS is deemed acceptable in cases where there is no request because the patient is believed to be suffering unbearably, as shown by the GP. The demarcation does not appear to separate cases as objections to the "slippery slope" argument suggest. There is an intermediate range of cases that are presented as acts of "mercy-killing" even though there is no expression of a patient's will. From the perspective of strictly voluntary EAS, such cases can be qualified as "murder."

Also noticeable in this connection is the repeated assertion that disability advocates have nothing to worry about because legal safeguards send the message their lives are not at stake. Receiving this message appears to be less than reassuring in that disability advocates and self-advocates usually begin to worry at this point. The very fact of these assertions is felt as a performative contradiction. If their lives would in no way be implicated, it would not have to be asserted. So, the remaining question is whether the suspicions of self-advocates can be reduced to a form of collective hysteria in view of open discussions of EAS. Looking at the perceptions of disability in western culture, these discussions appear less than innocent. The qualification of "western" here should not be taken to mean that other, non-western cultures hold persons with disabilities in higher esteem. The point is simply that the available data on this issue in relation to EAS originate mostly from western countries.

Two areas of concern suggest that "death" has a different meaning in connection with disability than it has with regard to nondisabled people. In a study examining over 200 news reports between 2011 and 2015 from North America about the murder of people with disabilities by their caregivers, the motive routinely given for these acts of killing was "hardship" (Perry, 2017). The "hardship narrative"—describing the life of the disabled person and his/her family as unbearably difficult—appears to be acceptable to news media without much questioning. More significantly, the same appears to be true for the courts before these killings are tried. The law does not excuse them, but in practice they do seem as excusable given the fact that imprisonment for the killers is relatively short, or is not ordered at all. Looking at these reports it seems that "explaining" them as "mercy killings" produces killer-oriented rather than victim-oriented stories in which the actual lives of the disabled persons involved tend to disappear (Perry, 2017). Of course, the obvious disparity with EAS is the absence of a medical context in these murders, but the verdict of unbearable suffering in the medical cases is not dissimilar to what the study identifies as the "hardship narrative." The conclusion suggests itself that illegal killings of persons with IDD are more readily seen as excusable, even when criminal, which is a reason to be concerned.

In a high profile 1993 case in Canada, Robert Latimer, a Saskatchewan farmer, murdered his 12-year-old daughter, Tracy, who lived with both physical and intellectual disabilities. He characterized his act as "mercy killing", citing her pain, quality of life and disability as motivating factors. While the act itself was shocking, what is more concerning for our purposes here was the widespread support he received from both the public and the lower courts, initially being given a minimum sentence well below the legal threshold for murder. This was eventually overturned in the Canadian Supreme Court (Council of Canadians with Disabilities, 2000).

In 2012, Latimer appeared on a prominent Canadian public affairs program 16×9 in support of Annette Corriveau, a mother of two disabled adult children who was seeking the right to "euthanize" them. The case, as presented in the program, indicated the bias of what the above study calls a "killer-oriented" rather than a "victim-oriented" story. It was announced as "*a mother's plea for mercy*" and "*a father who has been down this road before*" for which both have paid a price (Tryon, James, & Rowney, 2012). Subsequently, Corriveau appeared on the popular Dr. Phil Show to make her case. Her audience voted 90% in support for her plea for "mercy" (Tada, 2012).

The second area of concern is from another study from the US regarding physician assisted suicide. It notices that since the Oregon Death with Dignity Act (1994) various proposals for legalizing assisted suicide have assigned physicians with the authority to decide whose request for assisted suicide is to be acknowledged. The study looked at how physicians tend to evaluate requests that involve disability (Gill, 2000). The findings indicate that in the case of people with disabilities, the barrier against suicide seems to be much lower. Physicians and other health professionals would assist in suicide by persons with incurable conditions, but they turn to suicide prevention regarding the request for assistance from individuals who are seen as 'healthy.' Disability advocates have criticized this by arguing that the difference in approach is apparently based on negative assessments of the QoL of people with disabilities (Gill, 2000). Again, the findings of this study suggest that the death of a person with a disability is of lesser weight than the death of a 'healthy' person, which adds to the view of a socio-cultural environment in which the justification of EAS is more readily accepted when it regards people with IDD.

Legalized Euthanasia in the Netherlands

There are other examples of blurred distinctions and categorizations. In the late 1990s, the Netherlands legalized EAS, as is well-known, after two decades of public discussions of pioneering cases. Individual doctors had decided to take matters in their own hands and terminated the life of a patient, sometimes because that patient wanted to die, sometimes because of advanced dementia in a patient who had expressed his or her will not to have to exist in that condition, and sometimes because the patient was suffering unbearably in the final stage of his/her life. These doctors were prosecuted and convicted by the courts, but the courts occasionally withheld from punishing their crimes (Gevers, 1996; Thomas, 1984).

This paved the way for the Dutch version of legalized euthanasia, defined as ending the life of a patient on his or her explicit and repeated request. To be legally acceptable, this act can only be carried out by a doctor, has to be reported to the coroner as an act of killing, and still can be prosecuted if the doctor has failed to meet legally established criteria for "careful" acting. Regional Review Committees (RRC's) are established to rule whether these criteria have been met in individual cases. The public prosecutor will indict a doctor when a RRC reports legally disputable circumstances (Weyers, 2002). Contrary to what many assume, euthanasia remains a criminal offense in the Netherlands. It can be punished with imprisonment of up to 12 years when a doctor is convicted in a court of law.

However, in the decades since this framework was established, some developments indicate a widening scope of legally accepted cases of euthanasia. Recent studies about euthanasia in Belgium report similar findings. Not only in the sense of a steep curve of rising numbers: from 1923 in 2005 to 6091 in 2016, a rise of 217%, (Regional Euthanasia Review Committees, 2002–17) but also in the sense of the changing profile of cases accepted as legally justified by the RCCs.

For example, while it was asserted time and again that persons with intellectual disabilities would not fit the paradigm case of a patient repeatedly asking for euthanasia, the changing perception of these persons brought them—at least in principle—within the purview of competent agents. Accordingly, it became possible to consider the request of a person with IDD as valid in view of the established requirements. Thus a Dutch study reported nine cases involving seven persons with IDD in the period 2012–16 and found that a key problem was to determine in what sense and to what extent there was an explicit and repeated request that was actually understood as such by the person involved (Tuffrey-Wijne, Curfs, Finlay, & Hollins, 2018).

Based on an analysis of RCC dossiers, it has been reported that the interpretation of criteria for "careful acting" has changed on at least three significant points (Boer, 2018). The original support for legalized euthanasia in the 1980s and 1990s in the Netherlands was based on the widely shared view that in the final stage of their lives, people who are unbearably suffering and for whom no other relief can be given, should be able to ask their family doctor to end their lives. The vast majority of cases concerned terminally ill cancer patients facing imminent death. Twenty years later, things have changed significantly. First, the presupposition of a longstanding relationship with a family doctor is no longer in place. This change is due to the emergence of experts who perform euthanasia but have no obligation to consider other options than the termination of life. Second, the life expectancy of patients involved can exceed the period of a few months to go beyond 2 years. This is due to an uncritical acceptance of self-reported unbearable suffering by euthanasia-requesting patients. Finally, there has been an expanding range of relevant diagnoses. Numbers of euthanasia cases reported respectively in 2002 and 2016: cancer 1658 and 4137, heart-vascular 28 and 315, neurological 61 and 411, pulmonary 40 and 214. In 2002 other conditions included cases of psychiatry and dementia *95*; in 2016 the findings showed dementia 141, psychiatry 60, age related 244, combination 465, and other 10 (Boer, 2018).

Such changes apparently confirm the earlier point about how particular moral and legal justifications may be transferred from "paradigm" cases to other cases of ending people's lives. To mention just one thing: the development of the GP—as discussed before—would not be possible in a society that had remained highly critical toward the justification of terminating human lives of incompetent patients. Euthanasia as a voluntary request was introduced in the Netherlands largely to take the privilege from doctors to decide whether a patient's suffering was unbearable or not. In other words, to end unbearable suffering has been the prime concern of any form of euthanasia to begin with. Boer (2018) argues that RCC's tend to accept the formal criterion of an explicit and repeated request as sufficient indication for the condition of unbearable suffering. Thus, it seems that a necessary but intermediate step was taken to tie the evaluation of "unbearable suffering" to the voluntary expression of the will to die by a fully conscious individual patient.

A final fact about recent developments in the Netherlands in support of this claim is the opening of the so called "End-of-Life Clinic." The Clinic recognizes patients whose requests for assisted dying are more complex and often denied by their own physician, and mentions as examples: psychiatric patients, people with dementia, or patients with nonfatal diseases. In other words, the End-of-Life Clinic specializes in cases that were intentionally excluded from the legalization of EAS in 2004 (Levenseindekliniek, 2012).

Throughout the early years of public debate on legalizing EAS, its proponents in bioethics and health law in the Netherlands have been quick to dismiss the "slippery slope" argument. If there are certain categories of people that need to be excluded from its justification, such as people with IDD or dementia, then that is where society draws the line. In other words, slippery slopes are controlled by safeguarding regulations enacted into law. The obvious shortcoming of this rejection is that the "slippery slope" objection was interpreted as a prospective concern, whereas in fact it is confirmed in the Netherlands as a justified concern in retrospect.

Canada's Medical Assistance in Dying Act

The observed link between the condition of disability and death arises also in connection with the recent passage of legislation allowing *Medical Assistance in Dying* (MAiD) in Canada. Among the criteria for being "eligible" for this kind of assistance are the usual safeguarding requirements (a minimum age of 18, a voluntary

request free from external pressure, full information about alternative options). But, there is also a demarcation of patient conditions. Eligible are patients who "have a grievous and irremediable medical condition." The definition of such medical conditions entails "a serious and incurable illness, disease, or disability" that is in "an advance state of irreversible decline in capability," and causes "enduring physical or psychological suffering that is intolerable [to the patient]" (Statutes of Canada Bill, 2016).

The explicit inclusion of disability here brings IDD in the purview of conditions for which the law opens the option of EAS. Naming "disability" as distinct from "illness" and "disease" indicates that as such it can qualify as a condition that makes one eligible for EAS, provided it is "serious and incurable." The potential impact of this has been foreshadowed with the killing of a man who was unable to secure appropriate supports and hence found his life "unbearable" (Laucius, 2016). There was also a recent case of a physician providing the unsolicited advice to a mother of an adult woman with IDD that assisted dying was now legal, despite his interpretation of the law being completely wrong as it would not allow for MAiD in this situation (Bartlett, 2017).

To summarize, the Canadian law is intended to safeguard the demarcation of a category of eligible patients, but there is little reason to be assured that this demarcation will prove to be stronger than has been found in the Dutch euthanasia practice. Furthermore, the Canadian law is also subject to expert review that considers expansion to include persons with psychiatric conditions and mature minors as well as the use of advance directives which opens up the space for "proxy" decision-making (Council of Canadian Academies, 2018). Again, these challenges to the demarcation that the law provides raise the question of how one can be assured that there will be no slippery slope in this case.

Conclusion

Describing the various practices of terminating human lives affected by ID in terms of the "new eugenics" is not an innocent move. Given the emotivist force of the term "eugenics" in view of its past, using that term in the present connection suggests a link with horrible crimes against humanity that have been perpetrated in its name, particularly in the third reich. Insofar as the proponents of the practices described above are concerned, there is no such link. Their ranks are filled with scientists, doctors, healthcare professionals, lawyers, politicians, ethicists, none of whom has in mind or is engaged in acts that the Nazis had in mind or were engaged in. None of the current practices is motivated by the same eugenic ideology. As opposed to the collectivist ideal of a purified German race that led them to eradicate human beings whose lives contradicted it, the underlying concern of medical scientists and professionals engaged in what has been described above primarily seeks to alleviate suffering for the human beings involved. The contemporary perspective on ending human life affected by IDD is individualist rather than anything else, and the understanding of suffering is primarily subjectivist.

Furthermore, the motivation in support of these practices is driven by "choice." The implicit question is whether persons living with IDD and their families would have chosen their kind of life if they had had a choice. This is readily seen in the first two practices we have described—neonatology and PST. The moral imagination leading proponents to support these practices feeds on the assumption that the answer to that question is negative. The people involved presumably would have rejected living their kind of life. Indirectly, the same underlying presumption is also seen in the third, more complex case. In considering EAS, the often difficult-to-read expressions of individual will from persons living with IDD are perceived in light of the wish to die, even though in many cases their understanding of the relevant information appears to be questionable.

Given the need for all these qualifications of our historical equation, then why describe these practices in terms of "eugenics" anyway? The reason is the similarity that objectively links the justification for the kinds of acts that have been reviewed in this article with the "old" eugenics. In one way or another, it is based on the preconception of a life lived with IDD as a life of "poor quality"; that is, the cause of unbearable suffering for the persons and families involved. This preconception is disproven in too large a number of cases to be credible. People with IDD rarely describe their own lives in negative terms. Even when they do it is often because of the environmental responses of rejection they have to deal with.

If this is empirically true, of which we have no doubt, then the received justification of terminating human lives affected by IDD appears in a different light. Looking at these lives "we"—as individual people, professionals, scientists, observers, as "the public"—are inclined to think that "they" would rather not exist in the way they do. Seen in this light the medical practices of terminating human lives affected by IDD are driven by a collective preconception that will be contradicted frequently by the persons involved or their advocates when their voice is heard.

Perhaps the most pertinent question coming out of our review of developing practices in medicine and the scientific research behind it, is this. If in matters of life and death our society trumps individual views and concerns of the people involved above anything else, why is this not the case here? Is it because given their cognitive impairments, one cannot really take seriously what people living with IDD tell us either in words or gestures? In other words, is it because the presumed inability of giving a truthful account of oneself is for many of "us" precisely what it means to be affected by IDD?

These are by no means rhetorical questions. They indicate the sense in which a conception of what our culture takes to be a human life properly so called appears to be at odds with the condition of IDD. To the extent that this happens to be the case, empirically, there is truly a link with what the supporters of the "old eugenics" believed in the late 19th and early 20th century. The link regards the justification of terminating human lives affected by IDD in current medical practices as described in this article. Ultimately, these practices appear to be driven by the view that these lives of poor quality are in defiance of what a human life properly so called is like.

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"Because of His Intellectual Disability, He Couldn't Cope." Is Euthanasia the Answer?

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Abstract

In 2018, the authors published their analysis of nine online case reports by the Euthanasia Review Committee in the Netherlands, involving people with intellectual disability and/or autism spectrum disorder who were given euthanasia. In this commentary, they reflect further on the challenges of assessing "unbearable suffering without prospect of improvement," which is one of the Dutch legal due care criteria. Two more recent case reports are presented in detail, where doctors struggled to assess and sometimes came to divergent conclusions. In both cases, limitations resulting from the intellectual disability and autism spectrum disorder were seen by physicians as causes of unbearable suffering, leading them to agreeing to the patient's euthanasia request. The authors discuss their concern about the implications of accepting the effects of lifelong disability as reasons for euthanasia, not only for individuals but for society as a whole.

Keywords: autism spectrum disorders, euthanasia, intellectual disabilities, legislation, the Netherlands

Euthanasia in the Netherlands

In 2017, 4.4% of deaths in the Netherlands (more than 1 in 25) were physician-assisted deaths. Most of these (96%) were deaths by euthanasia, where a physician administers a lethal injection, rather than physician-assisted suicide, where patients take the lethal medicine themselves. This means that almost everyone (including many people with intellectual disabilities) will know about euthanasia through immediate experience within their own circle of family and friends. In the Netherlands, euthanasia is socially accepted. It is talked about as a viable, indeed sometimes preferable, way to die.

We investigated the effects of Dutch euthanasia legislation on people with intellectual disabilities and autism spectrum disorders. We are in the unique position of not only having significant clinical and academic expertise in the fields of intellectual disability and palliative care but also sharing between us a good understanding of the languages and the cultures of both the Netherlands and the United Kingdom—two countries who have translated the key ethical principles of autonomy, beneficence, non-maleficence, and justice into divergent legal frameworks. We were helped by the laudable transparency of the Dutch system, where all cases of euthanasia must be reported to a Euthanasia Regional Review Committee (RRC), as described in Reinders et al.'s position paper on *Eugenics.* The task of the RRC is to scrutinize whether six legal "due care criteria" are met (Regional Euthanasia Review Committees, 2019a). The RRC not only produces an annual report but also publishes a selection of case reports online.

We searched the RRC online database for cases of euthanasia involving people with intellectual disability and/or autism spectrum disorder. Between 2012 and 2016, there were 25,930 notifications of euthanasia or assisted suicide; 416 case reports were put online (in Dutch only, although a handful have now been translated into English and put onto the English version of the RRC website). We found six case reports of people with intellectual disability and three of people with autism spectrum disorder. We published our analysis of these reports last year (Tuffrey-wijne, Curfs, Finlay, & Hollins, 2018); our study is briefly described in the longer version of the *Eugenics* position paper.

A range of challenging issues arose from our analysis, including the difficulties in assessing whether the patient had made a "voluntary and well-considered request" (one of the legal due care criteria), which is closely linked to an assessment of the patient's decision-making capacity. We had serious concerns about the apparent lack of stringency in these assessments.

In this commentary on the *Eugenics* position paper, however, we would like to focus on the second of the legal due care criteria, "unbearable suffering without prospect of improvement," which is the cornerstone of Dutch euthanasia legislation. This requirement poses a key challenge in relation to euthanasia requests from people with intellectual disabilities

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and/or autism spectrum disorder, particularly if the nature of suffering for which euthanasia is sought is related to, or affected by, their disability.

For this commentary, we have updated our online search of the Dutch database. In 2017 and 2018, 161 online case reports included four cases of people with intellectual disabilities, one of whom also had autism spectrum disorder; and three further cases of people with autism spectrum disorder (Regional Euthanasia Review Committees, 2019b). We will present two of these cases as the basis of our discussion. A full English translation of the case reports is available from the corresponding author on request.

Unbearable Suffering Without Prospect of Improvement

The RRC gives the following guidance:

> "The patient's suffering is considered to be without prospect of improvement if the disease or disorder causing the suffering is incurable and there are no means of alleviating the symptoms so that the suffering is no longer unbearable." (Regional Euthanasia Review Committees, 2019a)

It is important to note the absence of any description of the causes of suffering for which euthanasia is allowed, although a 2002 court case and subsequent RRC verdicts have made it clear that the suffering must be the result of a medical condition. This can be either somatic or psychiatric; it can also be an accumulation of conditions related to old age. There is no mention of life expectancy, opening the door to euthanasia for people who could have lived for many more decades. Two of the people with autism spectrum disorder (but without intellectual disabilities) were aged between 18 and 30 (case 2017–80 and 2018–24). They died from euthanasia after their physicians agreed that their suffering, stemming from the autism spectrum disorder itself, was unbearable and could not be relieved.

There has been much debate around the ever-widening parameters of what constitutes "suffering" with regards to the Dutch legal due care criteria, as well as the lack of the need for a short life expectancy. The debate, and indeed fierce criticism, has centered particularly on the growing number of cases of euthanasia for people with non-life-threatening psychiatric conditions. However, it can be argued that this widening of scope is inevitable, or at least logical. If the purpose of assisted dying legislation is to relieve suffering, then it could be seen as illogical and inequitable to allow euthanasia for some kinds of suffering but not others. Psychological suffering can be as unbearable as physiological pain. It is also worth noting that even people with terminal somatic conditions do not give pain as the main reason for wanting euthanasia, but state overwhelmingly that they suffer most from functional limitations, dependence on others and a reduced ability to engage in enjoyable activities (Oregon Public Health Division, 2018).

What is not made specific within the legislation and guidelines is whether the "unbearable suffering" that must underpin a euthanasia request may be the result of a lifelong disability, including the effects of an intellectual disability or autism spectrum disorder. The following case summaries highlight the difficulties doctors have in assessing whether the lifelong nature of such limitations is indeed a valid reason for approving a euthanasia request. In reading these reports, it is important to note that the Dutch due care criteria include the need for the doctor to consult at least one other, independent physician, although there is no obligation to have a consensus and the advice of the independent consultant can be disregarded.

Case 2018–69

The patient was a man in his 50s with intellectual disabilities. He had been given a diagnosis 30 years previously of "borderline state in an autistic, socially isolated, obsessive personality of a pre-psychotic man." He had functioned quite poorly within society, but had managed to cope without professional help, thanks to the structure, and support in his life.

Three years before the euthanasia, he was referred to mental health services following the death of one of his parents. The professionals diagnosed a grief response in a vulnerable man with autistic and psychotic characteristics, for whom a heavy life burden could trigger depression. Over the following years, he had two brief in-patient episodes because of suicidal tendencies. He received various forms of treatment and support, including medication, sessions with a psychiatrist, and support from a community mental health nurse. He started doing voluntary work, creative therapy, and psycho-education. All this helped, but did not diminish his perceived burden of suffering. His psychiatrist concluded that further psychiatric treatment was unlikely to help, but he might benefit from supported living in a setting that offered structure and care. There was a waiting list, but the patient eventually moved to such a setting, 9 months before his death. However, the forced interactions with other people meant that this did not relieve his suffering either.

The patient had previously asked his GP for euthanasia, but his GP did not agree to his request. Two years before his death, the patient went to the End of Life Clinic (which offers support with euthanasia trajectories for people whose GP has turned them down). His request was initially rejected by a nurse from the clinic, due to the short time frame since his parent's death. A year later, he referred himself to the clinic again. Nine months before his death, he met with one of the clinic's physicians (who eventually carried out the euthanasia). This doctor met him four more times in the 3 months before the death. The doctor also consulted his GP, his psychiatrist, his mental health nurse, and his support worker.

The doctor then consulted a psychiatrist for a second opinion with regards to the diagnosis and treatment options. This psychiatrist concluded that autism spectrum disorder was the primary diagnosis, for which there were hardly any treatment options. He suggested treatment for his depressive or psychotic symptoms, but the patient refused this. The doctor was similarly of the opinion that the patient's suffering was caused almost exclusively by his autism spectrum disorder. Treatment of any other conditions would make little difference to his suffering.

This suffering was described as follows: everything was too much for the patient; he had nightmares and panic attacks; he was overstimulated, particularly through his interactions with

other people. After the death of one of his parents, he was suffering due to an increased dependence on carers. His inflexible and compulsive way of coping meant that he could not adapt to constantly changing people in his environment. He had lost the overview of his daily life. He felt powerless in his inability to function in today's society and was not the person he wanted to be, with a job and a family. He experienced his suffering as unbearable. His doctor agreed.

As part of the euthanasia trajectory, the doctor consulted another independent psychiatrist for a second opinion on whether the patient met the due care criteria. This consultant saw the patient twice. He found the patient strongly preoccupied with his death wish, but unable to explain the nature of his suffering, or why it was so hopeless. The consultant found that the patient did have decision-making capacity, but was unable to judge the available alternatives and possibilities. The consultant thought that improvements might be possible and stated that an inability or reluctance to accept help does not justify euthanasia. He concluded that the due care criteria were not met.

The doctor disagreed with this conclusion. He was of the opinion that the patient's inability to consider alternatives or accept help was in fact part of his condition that caused him such suffering, and this was impossible to relieve. The psychiatrist's report did not change the doctor's mind, and she carried out the euthanasia.

The RRC questioned this. The doctor explained that she herself was neither in doubt about the unbearable nature of the patient's suffering nor of the lack of prospect of improvement; that she had not wanted to burden the patient with further assessments; and that she did not want to give the impression of "doctor shopping." The RRC found that the consultant's report was too brief and inadequately argued, and the doctor should have sought another second opinion. The RRC concluded that the doctor had not acted in accordance with the due care criteria and referred the case to the Board of Procurators General and the General Health Care Inspectorate.

Case 2018–27

A man in his 60s with a mild intellectual disability had, for the past 5 years, been suffering from unexplained severe pains that started in his abdomen and radiated to his back and legs. He had undergone very many investigations and treatments, including medication, surgery, and therapies, to no avail. Cognitive behavioral therapy and psychotherapy were not considered to be worthwhile, due to the patient's limited intelligence. He had abandoned several treatments, turned down suggestions, and refused further investigations. He asked his GP for euthanasia.

The first independent physician who assessed the euthanasia request found that the nature of the patient's suffering was "subjective" to a higher-than-average degree—in other words, it was less "palpable" to the physician than usual. He stated, however, that the burden of suffering should be seen in light of the patient's limited coping ability, resulting from his intellectual disability and almost complete inability to reflect on his situation. This physician concluded that the man's suffering did not have a demonstrable somatic cause, nor was it based on psychiatric illness. He concluded, therefore, that the due care criteria were not met, and euthanasia would contravene the 2002 court case verdict that specified the need for an underlying classifiable medical condition.

The GP then consulted a second independent physician, a psychiatrist, who diagnosed a somatoform disorder, possibly influenced by traumatic experiences in early life. The psychiatrist concluded that the patient had become so preoccupied with his physical condition that it had become part of his identity. This, combined with comorbid depressive symptoms, made for a poor outlook. The psychiatrist thought there were no realistic treatment options for the patient.

At the GP's request, a third independent physician visited the patient 2.5 months before the death. This physician found a discrepancy between the descriptions the patient gave of his suffering and his observable behavior. The third physician saw no signs of tiredness or other suffering and was unable to say that there was "palpable" unbearable suffering. He also concluded that due to the patient's limitations, his request was not "well-considered." The due care criteria, therefore, had not been met.

The GP consulted a fourth independent physician, who was a geriatric psychiatrist, who visited the patient a week before the death. She diagnosed a classifiable psychiatric condition causing suffering without prospect of improvement, with no reasonable treatment options. She dismissed the first physician's concern about contravening the 2002 court verdict.

The patient saw no future for himself. He only wanted to die, and he was utterly fixated on this wish. The GP finally concluded that the patient's pain was indeed unbearable, and that he possessed insufficient coping strategies to manage his symptoms. The patient's pain experience was largely psychological. This could be significantly affected by his dependent personality, his intellectual disability, and his loneliness.

Following the euthanasia, the RRC's verdict was that the patient "could not cope with his complaints, due to his intellectual and cognitive limitations (…) This justifies the conclusion that the suffering was without prospect of improvement and that there were no alternatives." The RRC found that the GP had come to a reasonable conclusion, had handled with due care, and had acted within the law.

How Can "Unbearable Suffering" and "No Prospect of Improvement" Be Assessed?

It is unusual for the RRC to pass a verdict of "due care criteria not met"; in 2017, this happened in only 12 of 6,585 cases (0.18%). Mostly, failure to meet the criteria is related to procedural failings, as in case 2018–69, where the doctor failed to secure an adequate second opinion. Doctors who did not meet the due care criteria are almost always cleared at the next stage; in fact, so far only one case has ever been referred to the prosecutors (in 2018, related to euthanasia of a patient with dementia).

The unbearable nature of the patient's suffering is not reviewed or questioned by RRC. The responsibility for assessing whether the patient's suffering is bad enough and hopeless enough to warrant euthanasia, rests solely with their physician.

The obvious problem is that suffering is an unavoidably subjective concept. If the patient consistently states that he can no longer bear his suffering, how can any doctor refute this? There is a strong emphasis within Dutch society on the right to individual autonomy, and there are calls for a more accessible euthanasia route. But at present, the doctor being asked to give the lethal injection must assess and agree that the suffering is unbearable. The RRC Code of Practice stipulates that doctors must be able to empathize with the patient's suffering to such an extent that they can "feel" the suffering: it must be "palpable." The two cases show how difficult this is if the patient's suffering stems from disabilities that affect communication and social interaction. Some of the doctors involved in both cases raised concerns. In the other cases we studied, it was mostly accepted by doctors that suffering could consist of psychological pain, dependency, social isolation, loneliness, and a lack of coping mechanisms that were a result of intellectual disability. There were also several examples of rigid thinking, where the patient was fixated on the idea of euthanasia and unable or unwilling to consider alternatives. In a society where, as we have seen, most citizens are aware that they can ask for euthanasia if they feel their suffering is hopeless, it is inevitable that people with intellectual disabilities can ask for it too; and as equal citizens, they have a right to do so. But the fact that the disability itself, rather than an acquired medical condition, can be accepted as a cause of suffering that justifies euthanasia is deeply worrying. Furthermore, disabled people reject the medical model of disability, arguing that disability is a social construction.

If the "unbearable suffering" does indeed result from living with the limitations of intellectual disability or autism spectrum disorder, then it is inevitable that there is "no prospect of improvement". This, too, is evident from the case reports. In cases of persistent treatment refusal, or persisting problems despite having tried many different approaches and treatments, physicians tend to reach the conclusion that euthanasia is the only remaining option for the patient. Reading the case reports, we are in no doubt that these patients did indeed suffer deeply and consistently. However, we know that people with disabilities experience severe inequalities in opportunities and in health and social care provision, which may well play a part in their lack of "prospect." Current society is not a level playing field, where everyone has a full range of life choices and can make autonomous choices about them. The bereaved man in case 2018–69 was able to live adequately for many decades, but society was unable to support him after his parent died. The difficulty with legalized euthanasia is that it becomes normalized, as we have seen. This makes it perhaps all too easy for people to request euthanasia, and to be granted such a death as a "way out" of painfully difficult situations and circumstances, rather than addressing underlying issues of inequality and a lack of adequate support for people with very complex needs. We are not convinced that euthanasia is a suitable solution in the cases we reviewed.

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Soft Words for Strident Times

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Abstract

This commentary considers what the three different issues that the authors combine have in common, what the evidence is for them, and social science research that reveals the complexity of conversations between doctors and patients about serious health conditions. It examines their implicit claim that there are no questions to answer about the quality of life experienced by people with all types of ID and their families, and what labelling these three issues as "eugenics" is likely to achieve.

Keywords: ethics, eugenics, neoliberal individualism

According to historian Wright (2011), the first of many warnings that eugenics had returned to intellectual disability was sounded by Wolfensberger in 1987 when he wrote about "neo-eugenics" and "deathmaking." Reinders et al. use the umbrella term "eugenics" to scrutinize technological and social changes that have an impact both upon people with ID and those involved with them. This commentary considers what the three different issues that the authors combine have in common, what the evidence is for them, and social science research that reveals the complexity of conversations between doctors and patients about serious health conditions. It considers the influence of our cultural context, NeoLiberal Individualism (NLI), which fosters privatization and escalates competition between different interest groups. It concludes by considering two issues. (1) Their central if implicit claim that there are no questions to answer about the quality of life experienced by people with all types of ID and their families. (2) What labelling these three issues as eugenics is likely to achieve in terms of ethical treatment of people with IDs and their families.

Odd Bedfellows

Reinders et al. examine "three medical practices considered to question human life affected by IDD". Legalized euthanasia of persons with ID; the death of infants in neonatal intensive care units; and the practices of Non-Invasive Prenatal Testing (NIPT) for Down syndrome including high rates of termination following identification.

Reinders et al. provide scant evidence that the first two of these affect many, if any, people with ID. They identify no examples of legalized euthanasia of persons with ID in the Netherlands. They cite a Canadian news agency's report of just one mother's claim that a doctor had told her assisted dying was legal for her very ill daughter with ID. I elaborate below reasons for not accepting this as evidence that lives are being ended that justifies ethical intervention.

The second issue concerns deaths in Neonatal Intensive Care Units (NICUs). The authors report there being no increase in such deaths across a decade in the US, and that the available data do not warrant the claim that eugenic practices are increasing. With regard to ending the life of severely disabled newborn infants in the Netherlands under the Groningen Protocol, they report that the vast majority of these decisions concern either not starting or withdrawing life-sustaining care, rather than active "mercy killing." Only one case has come before its formally constituted review committee since the Protocol's inception 11 years ago.

These numbers are surely too small to justify inviting a major international organization to take a stand against the "new eugenics." They may be viewed alongside Emerson's (2009) estimate that the population of children and adults with PMID is increasing by 4.8% year on year, as a result of the survival of a growing number of neonates with multiple and complex needs. Comparison across longer periods is inevitably approximate because of different measures and terms, but the proportion of severely disabled children has clearly increased rather than decreased. For example, a study by O'Connor & Tizard (cited in Clarke & Clarke, 1958) estimated that people with IQs below 20 similar to the current "PMID" group comprised 3% of this population. By contrast, Hatton, Glover, Emerson, and Brown (2016) reported that 15% of children with ID in England had PMID. A systematic historical examination of changing incidence and prevalence across time is of course well beyond this commentary, but there is evidence that rather than ending the lives of people with severe and complex IDs, medical advances continue to support significant increases to this population.

The third issue differs in terms of numbers and impact. NIPT for Down syndrome is a substantive issue creating changes for significant numbers of people in many countries. The authors provide a wide-ranging summary of available policies, practices, and research concerning individuals with ID. Their exposition of the importance of generating an appropriate moral space for parental decision-making that provides

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an even-handed account of life with Down syndrome, but the rarity with which this occurs, gives cause for concern.

Yet am I the only clinician struggling to accept the amazingly positive ratings of life-satisfaction cited by these authors, presumably from studies of high-functioning people with Down syndrome? It does not include the frustrated young people whose job applications are repeatedly rejected: encouragement to hope for employment rarely mentions that only 5% of the ID population have paid jobs, and that the number in employment is falling rather than rising (Moore, McDonald, & Bartlett, 2018). Nor does it include the 97% of over-35s with Down syndrome who develop dementia in the next 20 years (McCarron et al., 2017), not least those unable to digest news of their mother's death who become distraught each time they (re)discover her absence.

Finally, there is a troubling lack of consideration of the many and varied reasons why women and their partners decide to terminate any foetus, including those with no identified impairment or disorder. As long as nation states place the responsibility for bringing up infants onto parents, a responsibility that becomes lifelong for many parents of people with ID, then making a commitment to proceed with pregnancy matters. The expansion of ethical dialogue to encompass relationships (i.e., to include parents in the analysis and not just the person with ID) finds theoretical support from Braidotti (2012), who showed how ethics is not confined to the realm of rights, distributive justice or the law. Single standpoint ethics that assert a position without reference to other parties has been characterized as 20th century thinking. Sadler, van Staden, and Fulford (2015) characterize applied ethics in the 21st century as having moved away from designating right and wrong actions, to focus instead on processes that enable people to identify or negotiate the better action from a range of possibilities.

Accounts of Difficult Consultations

The Canadian news story offered in evidence of inappropriate Medical Assistance in Dying (MAiD) concerned a doctor having, reportedly, proposed this to the mother of a seriously ill daughter with severe ID. The account may be viewed through the lens of sociological research into "vocabularies of motive" talk (Scott & Lyman, 1963). This examines what people report powerful others have said to them, by separating the reasons people give for their actions both from what actually happened, and from what they thought at the time. Rather than the realist assumption that what people say is an accurate portrayal of an event and contemporaneous thoughts, this research tradition regards such motive talk as giving access to no more than the informants' moral universe as they give their account.

Stimson and Webb's (1975) examination of the way patients report their conversations with doctors developed this topic. Researchers asked patients about their medical consultation immediately afterwards. Accounts given by a sub-set of patients had a particular narrative pattern: they cast themselves as having heroically challenged the doctor by asserting their own perspective, when the doctor reportedly admitted being in the wrong and backed down. They termed these accounts "atrocity stories." Yet there was no evidence of these types of exchange on accompanying video-records of medical consultations. Stimson and Webb concluded that patients present their consultation in this atrocity story format to achieve something important through their conversation with the researcher. They argued that difficult consultations about serious health conditions that inevitably occur between doctors and patients from time to time are likely to threaten patients' sense of self. Reporting the consultation to the researcher in the form of an atrocity story functioned to repair some of this damage.

The example Reinders et al. give of the discussion of MAiD reported by a mother contains elements of an atrocity story: an indignant anti-doctor account given to a third party about a medical consultation concerning her seriously ill daughter. To reiterate, vocabularies of motive do not reveal what actually happened in the past, which is unknowable: they reflect the teller's current moral universe. Instead of evidencing an "increase in medical practices that objectively question human life affected by IDD," all this brief news-agency report reveals is how a mother in a complex situation used narrative to cope.

Neoliberalism 1: Privatization of NIPT

It is nearly 20 years since Reinders' (2000) significant ethical analysis showed us how little liberal culture has to offer people with ID. Fine and Saad-Filho (2017) show how Hayek's Neo-Liberal Individualism (NLI) asserted that markets have a way of knowing that exceeds the human mind, redefining the relationship between economy, state, society, and individuals: it works best for people with social and financial capital and fails to reach those who struggle. NLI always seeks to shrink the state and make competition the organizing principle, pitting interest groups against one another as they battle for diminishing resource. The associated NLI ideas of choice, and work as the solution to disadvantage, clearly both inform and reinforce ID policies and services in the developed world.

The authors certainly raise new matters for concern by highlighting the questionable practices and motivations of for-profit NIPT providers marketing directly to customers. The only way to counter this is by funding public agencies to provide both testing and balanced information about risks and experiences.

Neoliberalism 2: Concept Inflation

Achieving satisfactory recognition is considered to be one of the problems of the age (Bauman, 2001), caused by unstable social ties, the dissolution of collectives, and vulnerable groups having to compete for diminishing resource. Concerns about the growing invisibility of people with ID mount as their quality of life deteriorates (Clegg & Bigby, 2017), whereas adjacent groups are accorded legislation that compels public services to improve (Autism Act UK, 2009) and allocates significant development funds to achieve this (Autism CARES Act, USA, 2014). Only the philosopher Hacking (2010) has drawn attention to the remarkable explosion of interest in, and services for, autism across the world. What might it tell us about our world that there is legislation for autism but not, say, schizophrenia or

personality disorders? Will it inspire groups representing other conditions and disorders to press for similar legislation?

Competition for resource as NLI cultures shrink the public sphere encourages what Bauman and Donskis described as "concept inflation." This imports emotional terms from radically different situations and amplifies them to generate a shocking narrative of victimhood. They cite vegetarians claiming that Thanksgiving is a "holocaust" for turkeys as an example. "We have to become a celebrity or a victim in our liquid modern times to get more attention and, therefore, to be granted visibility, which is the same as social and political existence nowadays…. The more we try to think the unthinkable and speak the unspeakable, the more likely we become to qualify for a niche in a power structure" (Bauman & Donskis, 2013 p. 123).

In their conclusion, Reinders et al. note that their argument that these three issues amount to eugenics is emotive. They acknowledge that none of the professionals involved are engaged in acts that the Nazis had in mind, but justify using the term on the grounds that the life of the person is mistakenly believed to be poor quality, or to involve unbearable suffering. There is an alternative view.

> *This plot narrative grossly simplifies and misrepresents the complexities of the antenatal encounter and obscures the way in which women, and their partners, take responsibility for difficult decisions about their pregnancies…. Eugenics has become a powerful slur word to denounce contemporary practices, but it carries no commonly agreed meaning apart from the general implication that anything eugenic must be bad…. It is offensive both to physicians and to those prospective parents who agonise long and hard about testing and termination, to use highly emotive rhetoric to denounce modern antenatal screening, and those who hold different moral positions on abortion or disability.* (Shakespeare, 2014, pp. 117–9)

Advice that Nobel prize-winning poet Seamus Heaney (1990) received from a mentor is worth heeding: "Don't have the veins bulging in your biro" (p. 89). Using powerful terms like eugenics is not the solution to a neoliberal individualism that overlooks the vulnerable. In *The Festival of Insignificance* (Kundera, 2013), Kundera refuses rather than confronts power, confident that social change emerges from indirect resistance and laughter. To sidestep competition for diminishing resource and avoid simply shouting louder using terms like eugenics, we need to state our own case: articulate a new agenda that delineates well-being and what it means for people with all types of IDs to live a life of dignity.

Discussion

Reinders, Stainton, and Parmenter's paper will and should get groups talking. Not about eugenics but about the way NIPT for Down syndrome is presented to prospective parents, and its impact on the population. Their analysis of the baleful influence of NLI privatization on the way NIPT is marketed to parents is significant in its failure to engage in any way with how life is experienced by different people affected by Down syndrome and as the parents of that person. Yet the contented individual satisfied with their quality of life frequently conjured by the authors bears a passing resemblance to the romantic image of ID deployed by policymakers that has attracted criticism from opposite sides of the world. Gleeson (1999) and Burton and Kagan (2006) argue that imagining all persons with ID to have a mild cognitive impairment, no additional mental or physical health problems, a supportive family, and to live within a welcoming community, impedes the social transformation necessary for people with ID to become genuinely valued and included.

This commentary has raised questions about Reinders et al's claim that there is a "quiet progress" of "eugenics." Their case that "quiet progress" was being made in two of the three issues they raise was less than convincing. There was neither demonstration of the euthanasia of people with ID in countries where such legislation exists nor an increase in the death of neonates in NICUs. In fact, epidemiological data show significant increases in the incidence of PIMD resulting from medical advances that enable more neonates with multiple and complex needs to survive.

The other claim is that we should label the difficult decisions parents and doctors face in NICUs and following NIPT with the term "eugenics." Shakespeare's (2014) condemnation of it as offensive is compelling. It also feeds the vilification of medicine although the change-creating social model falls short because it fails to encompass the embodied difficulties underpinning physical and/or mental health problems for 84% of this population (Lin et al., 2014; Shakespeare, 2014). Moreover, although criticizing the decisions that prospective parents make is unlikely to change any minds, alienating feminists is likely to fuel mothers' resentment of professionals who already make them feel judged and found wanting (Dreyfus & Dowse, 2018; Todd & Jones, 2003). Services need to reduce, not exacerbate, tensions between professionals and parents.

"This sterile phase won't necessarily go on indefinitely. For the moment just about all one can do is set up networks to counter it" (Deleuze, 1995, p. 27). NLI culture encourages people involved with ID to become strident but it will not and should not always be this way. We need to look forward not back: make sure people get accurate information but also develop new ideas about patterns of support for a slightly different population. This probably will contain fewer people with Down syndrome and more people with PMID. I urge rejection of 20th century standpoint ethics that takes a narrow focus. Creating new 21st century social institutions where we can bridge perspectives and develop new forms of social cohesion will take all our energy and imagination.

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A Quality of Life Perspective on the New Eugenics

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Abstract

Quality of life is a concept that has had robust development and application in the field of intellectual disability in recent decades. It functions as an apt goal for individuals to enhance their lives, as well as for policy and disability support. Quality of life helps address ethical issues by acting as a key guidepost in ethical considerations. Current philosophical and human rights approaches to disability support the view that intellectual disability is no reason to assume poor quality of life. Moreover, individuals with intellectual disabilities themselves typically rate their own quality of life quite high. Similarly, families perceive disability as contributing to family quality of life in some ways, although this is tempered by social constructs, especially normalcy, that support marginalization and discrimination. Disability Studies, and critical disability theory that constitutes much of its foundation, offer an alternative perspective of intellectual disability that values its contribution to larger society-intellectual disability as a positive and necessary aspect of the diversity within the human mosaic. It is argued that this perspective of intellectual disability negates the necessity of new eugenics practices.

Keywords: disability studies, eugenics, intellectual disability, quality of life

Quality of life is a term that has come into wide use in recent decades, both in the popular and the academic realms. Its focus on positive aspects of life positions it well as an appropriate concept for constructing goals to which people might aspire and to assess the degree to which improvements might be made to enhance people's lives. Based on this general understanding, the concept, quality of life, has made its way into innumerable mission statements of organizations and stated purposes of societal institutions in recent decades. Indicators of quality of life have also been tracked and recorded in many venues and for increasing numbers of purposes, but particularly to evaluate supports and services of various kinds and to assess how they might be improved.

Quality of life and family quality of life—as both concepts that include principles and value statements, and as areas for research and application—have developed robustly within the field of intellectual disabilities (ID). An international consensus on quality of life conceptualization, measurement, and application was first published by Schalock et al. in 2002, and has since expanded (Brown, Cobigo, & Taylor, 2015).

Quality of life in ID deals with both how life is judged by others, and how life is experienced by individuals and families themselves. Others judge life conditions as assessed by sets of objective indicators relevant to specific cultural contexts (health, education, income, housing, etc.), or by people's satisfaction with indicators within pre-determined life domains (Brown, Hatton, & Emerson, 2013). For individuals and families, though, quality of life emerges from their own perceptions of how good life is for them. It is the personal and sometimes unique set of thoughts and feelings that reflect their particular views of the world around them and their lives within that world. It includes exercising personal choice, developing self-image that well may include disability, and is increasingly relevant across the lifespan as people with ID form a larger part of their societies and as they live much longer than was the case in the past. In the field of ID, an objective approach to assessment can be of interest in constructing social policy and organizational objectives (Schalock & Verdugo, 2012), such as improving accessibility and social inclusion in a general way, but the latter approach is essential for addressing quality of life of individuals and families because it is based on perceptions through their eyes of their own bodies, their own set of abilities, their own environments, and their own cultures (Schippers, Zuna, & Brown, 2015).

Assessment and application of quality of life invariably border on matters of ethics. Inasmuch as ethics addresses the best course to follow in a particular situation, quality of life acts as an important guidepost for making ethical decisions. Its main contribution is to focus attention on what, in a particular situation, acts to enhance quality of life, especially from the point of view of the person or family in question.

In this article, we take a quality of life perspective, using quality of life as the key guidepost, to examine ethical aspects of the new eugenics. Building on the original intent of the eugenics movement—to improve the genetic makeup of society by taking action to influence procreation—we take the "new" eugenics to concern itself primarily with more recent methods of minimizing the presence of severe disability within our broader societies. We will argue both from a philosophical perspective and a human rights perspective, that the presence of disability is no reason to assume that life is of inferior quality. We will further

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argue that people with intellectual disabilities generally rate their own quality of life quite high, and that "others" coming to value and understand the lived experience of disability within the family and within society negates the necessity of most eugenics practices.

Current Philosophy and the New Eugenics

Support for new eugenics practices appears to be based on the idea that a life with disability, especially one with severe disability, is troublesome and lacking in quality for the individual with disability and supporting family members. Because of this, it is assumed, there are many cases where it might be ethically prudent to terminate a pregnancy where a disability is detected or not to continue medical treatment where disability seems inevitable and recovery improbable.

Current philosophy that acts as the backbone of Disability Studies worldwide, termed critical disability theory, contradicts this point of view (see Cameron, 2016; Goodley, 2013; Reaume, 2014). Critical disability theory, like its identity and emancipatory theory cousins (especially feminism, race theory, and gender identity theory), recognizes that disability is part of the human spectrum in all societies and that action needs to occur to reconceptualize disability as an equal and valued part of this spectrum. Disability is the result of established concepts, language, and institutional structures that give "ableist" power to nondisabled people, and both marginalize and discriminate against people with disabilities (Procknow, Rocco, & Munn, 2017). Critical disability theory further holds that overt action needs to be taken to redress this wrongful conceptual and power imbalance (Goodley, Liddiard, & Runswick-Cole, 2018). Reaume (2014, p. 1248) wrote, "In the emergent field of critical disability studies…[people's] experiences…are understood in the context of the barriers society placed on the[m]…—barriers that served to pathologize, confine and ostracize them. Above all else, this new discipline allows disability…to be understood from the perspective of the person who experiences it, as much as this is possible." From the critical disability theory perspective, then, individual disability is not seen as something that is troublesome or lacking in quality, but rather as something that results from a lack of understanding of the individual's lived experience and from the strong social and material barriers that have been put in place to devalue disability and to marginalize people with disabilities. New eugenics practices, unfortunately, perpetuate the status quo by using numerous and sometimes insidious methods to devalue the human experience of disability. They act against full social acceptance and inclusion, and in this sense, they are at odds with the current philosophy of the worldwide disability community.

Critical disability theory goes beyond confronting what has been wrong with past conceptualizations of disability and, our responses to it, by suggesting a more positive way forward. In fact, its main objectives, as explained by Brown, Wehmeyer, and Shogren (2017, building on Pothier & Devlin, 2006) are "empowerment, equality… and emancipation" (p. 7). To achieve these objectives, we need to confront the true intent of our current conceptualization of disability and our power structures. For example, treating disability as something that requires support and accommodation only functions to continue to pathologize it (Goodley et al., 2018), while changing the lens to providing environments that enhance quality of life for every citizen and to value the experience and contribution of every citizen functions to expand empowerment, equality, and emancipation. These objectives go beyond merely accepting and tolerating disability, and rather see disability as a positive contributor to human diversity that merits celebration (Campbell, 2008). Although this thrust does not specifically address new eugenics practices, it does strongly suggest that the contribution of disability as one aspect of human diversity is valuable to the entirety of the human experience. As such, it contradicts the view that disability is a condition that inherently lacks quality and value.

Human Rights and the New Eugenics

It is something of an irony in a discussion of the "new" eugenics to note that the "old" eugenics, which was widely adhered to in the Western world as both an ideology and a comprehensive set of practices, came to a crashing halt more than half a century ago. The central concept of the "old" eugenics was that some people within a society were inferior and a detriment to its progress, and therefore were numbered among those who were not wanted in the future. One rationale for this was that, for a person diagnosed as "mentally defective," intellectual development was very limited, giving rise to the phrase "once a defective, always a defective." As history has recorded, this view began to challenge moral limits beginning in the early 1920s (e.g., sterilization of the "feebleminded" and other "degenerate persons" in some countries, a movement that emerged from social Darwinism; Cohen, 2016). This view was extended through World War II, especially in some European countries and in North America, when whole groups of people began to be identified as not belonging within society, and others were deemed a scourge to society. In Nazi Germany, especially, large numbers of people—millions of Jews, tens of thousands of people with mental illness, thousands of children with disabilities, and others—were grouped together and deemed to be not worthy of living (Aly, 1994; Brown, 2018; Friedlander, 1995). When the horrific undertakings of the Nazi concentration camps were finally discerned following the cover of the war, eugenics as a viable ideology suffered a near-death blow. A focus on human rights quickly emerged in its place, as evidenced by the proclamation of the United Nations' *Universal Declaration of Human Rights* on December 10, 1948.

Human rights placed a renewed emphasis on the equality of all humans. The word "renewed" is used here purposely, because Western culture has a very long history of recognizing some rights of people whom we would now describe as having disabilities, from antiquity (Berkson, 2004; Stainton, 2018) through medieval times and the industrial revolution (Bach, 2017; Berkson, 2006; McDonagh, Goodey, & Stainton, 2018). In particular, legal status and personal dignity were supported over several centuries by philosophies such as charity and humanitarianism, in spite of strong pressures to the contrary from social class structures, economic and rural–urban changes brought on by the industrial and technological revolutions, and by human merit increasingly being "scientifically" judged by the standards of rational thought and contribution to progress. Human rights, then, has had a long and sustained presence in Western cultures, and in recent decades it has become more global, exemplified best

perhaps by the proclamation of the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). An important value that emerges from the Convention as a whole is the importance of disability as a viable and worthy part of a diverse human mosaic. This increasing emphasis on rights argues strongly, even if somewhat indirectly, for the equal treatment of all people, including all people with all disabilities (Pinto, Rioux, & Lindqvist, 2017). Consequently, it argues against the unequal treatment of fetuses, infants, children, and adults with disabilities that is evident in the new eugenics.

Happiness, Quality of Life, and the New Eugenics

The quality of life of people with ID began to be studied in some depth beginning in the early 1990s. Personal responses to multi-item quality of life questionnaires obtained by several researchers (e.g., Brown, Brown, & Bayer, 1994; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; see Cummins, 2010, for a review of commonly-used scales) strongly indicate that people with mild and moderate ID can reliably assess their own life satisfaction, and many attempts to assess quality of life of people with severe and profound disabilities have been undertaken (e.g., Petry & Maes, 2008).

In general, people with ID rate their own happiness quite high. When assessing their own happiness, 93% of a large Finnish sample responded that they were happy (Matikka & Ojanen, 2004). Cummins, Lau, Davey, and McGillivray (2010) also noted that adults with ID rate their personal well-being at high levels, and that these are comparable to the ratings of nondisabled people. A large Canadian study found that adults with mild and moderate ID rated their quality of life similarly highly, and significantly higher than did their closest caregivers (family members or staff; Brown, Raphael, & Renwick, 1997; Raphael, Brown, Renwick, & Rootman, 1996). These examples from the available literature point to the fact that people with ID view their own lives as quite positive, and that it may be "others" who primarily see their lives as having lesser quality. Albrecht and Devlieger (1998) referred to this as the "disability paradox" based on their study on people with disabilities perceiving a high quality of life "against all odds" (p. 977). If the new eugenics is basing its practices on the assumption that people with ID lead lives of low quality, it is not reflecting the views of people with disabilities themselves.

One explanation for relatively high quality of life ratings, no matter what disability people may have, comes from Cummins' work on homeostatic effects on subjective well-being (Cummins, 2017, 2018; Cummins, Lau, & Davern, 2011). Based on extensive research that uses databases spanning more than three decades, Cummins has determined that almost all people have set-points of happiness—typically between 7 and 9 on a 0–10 scale—that are genetically determined and protected by homeostatic control. By this, he means that people have a "usual" point on the scale that represents their emotional state, and that we all have built-in homeostatic control that returns us to this set-point when we are elated (very happy or excited) as well as when we are depressed, saddened, frustrated, or angry. The principle of homeostatic effect leads to the strong possibility that people with intellectual disabilities, like all others, have a genetically-driven tendency to see their lives in fairly positive terms, and when life conditions arise that move them up or down from their set-point, they have a natural (noncognitive) ability to return to their usual mood states. This line of thinking also argues quite strongly against "others" predetermining that disability leads to lower life satisfaction or quality of life.

"Others" have made other unwarranted assumptions about the happiness and quality of life of people with ID, and these assumptions have contributed to the new eugenics. One assumption is that people with ID have a lower quality of life because they do not have what nondisabled people have. But as disability advocate Tom Shakespeare (n.d.) has pointed out, people with disabilities live the only life they have ever known, and are not unhappy that other people have abilities they do not. They are used to their bodies as they are, and their identities and self-images have emerged from their own bodies and their own functioning (McLaughlin & Coleman-Fountain, 2014). Their lives are not marked by "unbearable suffering" as the new eugenics sometimes leads us to believe, but are simply the way they experience themselves and the world around them. Another assumption is that people with ID have reduced feelings. However, research of Kyrkou (2018), for example, has pointed out that we have grossly misunderstood what we thought must be a limitation on being able to recognize and experience pain. A final example involves the assumption that nothing medically can be done to help. In fact, the entire new eugenics approach seems to limit societal institutions and some professionals from believing it is worth providing high levels of medical support. However, medical science is advancing at a very fast rate. Blindness was considered to be permanent throughout most of history, but recent advances now strongly indicate that stem cell therapy, gene therapy, electronic device implants, and other interventions are showing results and will bring at least some sight to many blind people within the next few decades. It is important to examine these and other assumptions we have about intellectual disability very closely, because we may have been wrong up to this point. There may be another way of looking at the situation, one that does not indicate compromised quality of life. In any case, medical advances in the future may prove much of our thinking to be faulty or, at the very least, to be outdated.

Family Quality of Life and the New Eugenics

Since 2000, there has been considerable research conducted worldwide on family quality of life. This research assesses families' own perceptions of their satisfaction and attainment with regard to various aspects of family life where disability is included. Overall, the results show some areas of common strength within most families around the world (especially positive family relationships), but it also identifies areas of dissatisfaction, feelings of exclusion, and a perception that the burden of care is onerous (Brown & Schippers, 2016; Schippers & Van Hove, 2017). An argument in support of new eugenics practices is that they help to alleviate such negative feelings.

A plausible explanation for negative feelings in family quality of life, though, and one that argues against new eugenics practices, is the social tyranny of normalcy—the acceptance by most "other" people of the idea that there is a "normal" in society that governs how people should behave and how they should be judged. The concept of normalcy, a relatively recent social construct (Davis, 1995, 2010), has been helpful to the social

sciences in some ways, but it carries the distinct disadvantage of dichotomizing people, their abilities, their behaviors, and their ways of living into "normal-abnormal." Because normalcy is a widely accepted concept, it is not surprising that studies have found that parents perceive themselves as not being able to live a normal life due to disability in their families (Neely-Barnes & Dia, 2008). In a recent in-depth study of family quality of life (Boelsma, Schippers, Dane, & Abma, 2018), this view was corroborated and explained. Families felt confronted by norms—presumed standards related to what is considered normal—in their daily lives through their interactions with others. It was through the social environment, not the internal lived experience of the families, that these norms were imposed on them (thus, the "social tyranny" of normalcy). But, the strength of the concept of normalcy is at odds with the Disability Studies key assumption that society has a responsibility to provide for all of its citizens in an equitable way. It follows, then, that if the "normal-abnormal" dichotomy were reconceptualized as "equal aspects of human diversity," negative family feelings would be mitigated and positive aspects of both the immediate and broader societal environments would support the emergence of positive family quality of life. Such a situation should negate the necessity of new eugenics practices.

Genetic counseling is a clear example of the social tyranny of normalcy that supports new eugenics practices. When expectant parents are faced with the possibility or even the certainty that their child will be born with a genetic or physical disability, genetic counseling is typically recommended. Inherent in this recommendation is the stated or unstated concept of what a "normal" fetus should be, and the notion that the parents are victims of a misfortune because their baby will not be "normal." The principal reason for genetic counseling is to fully inform parents about what lies ahead, but it also typically presents various options to them as courses of action. One of those options, where legal, is abortion. In many parts of the world, including most developed countries, women have the legal right to choose abortion if they wish. Such freedom is widely considered to be a matter of human rights for women, where a woman's control of her own body and freedom to make choices about her body override the right to life of a fetus. Although there is obvious value in upholding such a right, as well as the right of well-informed parents to choose, it can be part of the social tyranny of normalcy inasmuch as women who choose not to abort are then blamed for choosing "abnormal" when they had the opportunity to avoid it.

There seems to be little doubt that, in spite of the many accommodations and the adoption of rights for people with disabilities in recent decades, public policy in most countries of the world has moved rather quickly in a direction away from accepting full social responsibility for disability. Over the past 30 years, governments in most developed countries have reduced or eliminated provision of direct care for both children and adults with disabilities, and instead have increased support for families in their home settings. Although this policy is generally in keeping with the principle of normalization (Wolfensberger, 1972) and our current ideology of community inclusion, it has the disadvantage of placing the primary responsibility on parents and other close family members without providing adequate support (Brown, 2008, 2013; Brown, 2017). This might well be viewed as blaming the victim, with provision of some supports (financial and human) as primarily avoidance of guilt. New eugenics practices offer a rationale for social structures to avoid responsibility for disability, and, simply by being viable, they further reinforce their own value by devaluing disability. In this view, new eugenics practices are pernicious to families both directly and indirectly. A supportive solution is to find new ways to share family and social responsibility for all people, including all people with disabilities. To facilitate this process, it seems essential to reconceptualize disability in such a way that it is understood as an important and valuable part of human diversity. Within such an environment, families would surely flourish as a necessary part of the larger human family, feeling that they belong.

The New Eugenics: What Needs to Be Done

Some tendrils of the original Eugenics movement have remained alive, and challenge us, even today. Individuals with ID are still largely seen by others as deficient and as less than "normal." Because of this view, various other life restrictions are imposed, not just to those with intellectual disability but also to their family members. For example, in most developed countries, when someone wishes to immigrate and has been identified as having a disability, they are assessed by the relevant immigration department. Medical, psychological, or educational tests are required, not always appropriately. Individuals classified as disabled are then said to be a health and education risk or a burden to the social service system, and the individual with disability and the family are denied immigration unless they leave the person with disability behind. This issue is one of "Eugenics follows on," of which there are many other examples. A quality of life approach, in keeping with the main thrust of Disability Studies, would eliminate such practices by stressing equal treatment of all people and a dissolving of the ability-disability dichotomy.

What seems clear from the discussion in this article is that policy, practice, and indeed all the societal structures that constitute the "others" to people with disabilities need to direct their attention first and foremost to the lived experience of people with disabilities in an effort to alter their values and practices concerning the place of disability in our societies. Included in these "others" are academics and researchers who often form research questions and make both recommendations and decisions on behalf of people with disabilities. The core question for "others" is what individuals with disabilities and engaged family members feel about their own lives, what questions they consider in need of being addressed, and what changes need to be made to ensure their happiness and their life quality. Hosking (2008) wrote, "It is only by listening to and valuing the perspectives of those who are living disabled lives that the able bodied can begin to understand that even severe disability does not have to prevent a joyful and desired life" (p. 13).

The new eugenics appears to take a perspective of disability that is no longer espoused by the international disability community. In short, the new eugenics perspective assumes that disability is a problem that we would be better off not to have, and that people with disabilities and their families do not enjoy good quality of life. Our current philosophical and human rights perspective on disability, best articulated by Disability Studies, views disability as a viable and valuable aspect of human social

diversity, and people with disabilities as equal and important members of society. It asserts that people with ID can and do live good quality lives, and that having an intellectual disability by no means automatically signifies a poor quality of life. It recognizes that considerable action is required to confront the entrenched structures that perpetuate marginalization and devaluation of people with disabilities, but it is hopeful of a world where the larger good accepts and welcomes the full participation of all of its citizens. Quality of life for all can be the key guidepost as we work to achieve this goal.

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What Is "Quiet" About the New Eugenics?

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Abstract

In this response to "The Quiet Progress of the New Eugenics," I explore the nature of the silences surrounding practices aimed at ending the lives of people with IDD. Taking as a point of departure philosopher Michel Foucault's claim that silence can be productive, and that it is intimately connected to various strategies and power relations that govern discourse, I ask: What silences and absences permeate these fields of inquiry, techniques, and technologies? Whose voices are heard and with what authority? And, how do the authors reveal and break these silences and make room for more voices? I begin by identifying the ways that the authors unmask the connections between these practices and the "old' eugenics and reveal the underlying assumption that the lives of people of IDD are of poor quality. I then explore three groups whose voices have been silenced or absent: people with IDD who can speak for themselves; people with IDD and other cognitive disabilities who are unable to speak for themselves; and those who are closely connected to people with IDD. I conclude by pointing to further questions and distinctions that are important to address when evaluating and responding to practices aimed at ending the lives of people with IDD.

Keywords: authority, IDD, silence, suffering

> *"Silence itself- the things one declines to say, or is forbidden to name…- is less the absolute limit of discourse, the other side from which it is separated by a strict boundary, than an element that functions alongside the things said, with them and in relation to them within over-all strategies. There is no binary division between to be made between what one says and what one does not say; we must try to determine the different ways of not saying such things, how those who can and those who cannot speak of them are distributed, which type of discourse is authorized…. There is not one but many silences, and they are an integral part of the strategies that underlie and permeate discourses."* (Foucault, 1990, p. 27).

In "The Quiet Progress of the New Eugenics," Reinders, Stainton, and Parmenter examine a series of practices targeted at ending the lives of people with IDD and situate them within the broader history of eugenics. As the authors acknowledge, this is not a neutral or "innocent" move, as there is virtual unanimity regarding the deplorable actions that constituted the old eugenics movement. The authors claim that by classifying prenatal screening, ending the lives of newborns, and instances of physician-assisted suicide and "mercy killing" under the umbrella of a *new* eugenics, they do not mean to implicate the medical community in the atrocities of the past, nor do they believe that these practices are motivated by the same "ideology of moral superiority." Although the *motivation* is different, however, they argue that the *justification* for these current practices is an echo of the past eugenics movement: "both then and now the practices at issue are justified because the lives of the human beings that are at stake are considered 'defective' and of 'poor quality'" (Reinders, Stainton, & Parmenter, 2019, p. 100). Given the increasing frequency of these practices on the international stage, as well as the continued forms of devaluation and marginalization experienced by people with IDD, I am sympathetic to the authors' claims. Although there is much to respond to in this document, I would like to explore what exactly is "quiet" about these practices and their progress. Taking as a point of departure Foucault's claim that silence can be productive, and that it is intimately connected to various strategies and power relations that govern discourse, I ask: What silences and absences permeate these fields of inquiry, techniques, and technologies? Whose voices are heard and with what authority? And, how does this position paper reveal and break these silences and make room for more voices?

In one sense, the progress surrounding these various technologies has not been silent insofar as these are mainstream practices that have garnered ample attention, discussion, and in many cases, support. Debates regarding the fate of severely disabled newborns and policies like the Groningen Protocol have brought public attention to the practices in neonatal medicine and the question of which lives are worth saving. The practices of prenatal screening and testing for many conditions (Down syndrome, as the authors indicate, is one of the most common) are well known and widely promoted in clinical contexts, and the advent of direct-to-consumer testing arguably makes these technologies and debates even more prominent. Moreover, the legal, political, and social battles surrounding EAS have been waged in public (both nationally and internationally), with constituencies on multiple sides weighing in. Finally, although the authors rightly point out in the opening that "'eugenics' is generally speaking not a term that is favorably used" (Reinders

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et al., 2019, p. 99), in my own disciplines of philosophy and bioethics, there are those who deliberately assume this mantle and defend a "new liberal eugenics" (Agar, 2004). Given that, with a few exceptions, these practices, debates, and technologies are not hidden from view, but rather are part of mainstream medical practice, scientific research, and public discourse, it may seem that the term "quiet" is a misnomer. However, I think the term *is* justified, as there are two important ways that the authors' article exposes and disrupts these silences. First, it unmasks unstated justifications and continuities between the past and present; second, it exposes voices that are either absent or silenced and argues for their inclusion.

One form of unmasking that breaks the silence around this progress is to reveal connections with the eugenic past. If these practices are relegated simply to the realm of individual choice, this past can be easily obscured. By establishing a continuity between the "old" and "new" eugenics, the authors are giving voice to disability history, a history that is too often ignored or forgotten. In situating these contemporary practices in historical context, it is possible to better understand both the continuities and discontinuities between them. This leads to the authors' central argument. Although the *motivation* for these practices differs from the eugenic arguments of the past (claiming moral superiority and the desire to improve the human race), the *justification* for terminating the lives of people with IDD remains the same in both cases: namely, the assumption that they are lives of inevitable suffering and poor quality.

In unmasking the eugenic connection between past and present, the authors expose the erroneous preconception that undergirds many of these practices. This unchallenged assumption regarding diminished quality of life lies at the heart of many arguments justifying the termination of disabled lives. By bringing practices in neonatology, decisions to terminate pregnancies as a result of prenatal screening and testing, and end-of-life decisions for people with cognitive disabilities under the same purview and exposing a similar line of justification, the authors are not just showing echoes of the past. They are problematizing defenses that appeal to benevolence and individual choice and situating these decisions in the broader context of ableism. It is important to challenge the self-evident nature of the preconception that lives with IDD are of poor quality and *inevitably* linked to suffering based on the *condition itself* for a number of reasons. First, it can bring into the open cases where, despite overt objections (e.g., to the Groningen Protocol), this assumption may operate covertly in decisions to terminate the lives of disabled newborns (Reinders et al., 2019, p. 102). Moreover, considering the *cause* of suffering can direct attention to societal and structural reasons that people with IDD may experience poorer quality of life. Finally, exposing this mode of justification works to dislodge the continued conflation between IDD and suffering and offers an alternate portrait to what I have called the "face of suffering" that dominates professional, philosophical, and public perceptions of IDD (Carlson, 2009).

To interrogate the silent progress of these practices also means asking whose voices are absent or excluded from the dialogue. Three distinct groups emerge whose perspectives are imperative to include when considering the termination of lives of people with IDD: people with IDD who are capable of voicing their experiences and addressing their quality of life and suffering; people with IDD or other cognitive disabilities who cannot speak for themselves; and finally, those individuals whose lives are connected to people with IDD.

As the authors point out, there is ample evidence to challenge the assumption that the lives of people with IDD are of poor quality and that the degree of suffering they experience justifies ending them. Many people with IDD *themselves* rate their own quality of life as high as non-disabled individuals (Reinders et al., 2019, p. 109). Yet the absence of these voices, or the failure to take them seriously, contributes to the dominance of the tragedy model of disability, and fuels the assumption that these lives must be of lesser quality and necessarily involve suffering. Those who are capable of giving voice to their experiences, of speaking about what matters and what is meaningful to them, must be given the opportunity to share their perspectives in order to generate a more accurate and inclusive dialogue.

Yet it is not enough simply to acknowledge the existence of these voices and expressions. There must be ways for these perspectives to be included in the purview of clinicians, genetic counselors, and policy makers. Moreover, we must consider *why* these voices are discounted and ask: Is it because given their cognitive impairments one cannot really take seriously what people living with IDD tell us either in words or gestures? (Reinders et al., 2019, p. 109). To answer this, further examination is necessary to consider the assumptions and dynamics that render these accounts untrustworthy and dispensable. As Foucault states, we must ask what kind of discourse is authorized and who can and cannot speak.

Not all individuals with IDD are able to verbally express their experiences and sense of wellbeing, however. In these instances, the difficulty remains as to who is in the best position to make determinations about quality of life and suffering, and on what basis one should be granted the authority to do so. There are also elements specific to each form of silence when considering those who cannot speak. In the case of people with profound IDD, although they may not be able to give voice to their experiences through language, it is important to broaden the moral imagination and consider alternate forms of expression when assessing quality of life, suffering, wellbeing, and flourishing. In the NICU, obviously newborns cannot give an account of their current or future state; thus it is up to the medical professionals and the parents to imagine these future lives. Finally, in the case of EAS, the authors include those with Alzheimer's and dementia. However, although some of these individuals are unable to speak in the present, it may be important to consider past expressions of their desires and beliefs regarding the nature of degree of suffering that they would be willing to endure. Thus, even within the group of individuals with IDD and cognitive disabilities who are not able to give voice to their experiences, there are *particular* considerations that are relevant when evaluating their quality of life. To paint all instances of IDD with the broad brush of inevitable, interminable suffering is to mischaracterize a rich tapestry of complex lives and experiences. At the same time, in imagining a response to these misperceptions, specificity is necessary to ensure more accurate accounts of quality of life.

Finally, especially given cases above where individuals cannot speak for themselves, it is important to include the

perspectives of those who are close to and care for people with IDD (parents, guardians, etc.). These "lay" perspectives or "experiential accounts" (Reinders et al., 2019, p. 101) offer an additional mode of assessment beyond the "expert" rubrics in medicine and the social sciences (e.g., QoL, hQoL, QALY). Yet departing from formalized measures (measures which, for various legitimate reasons, are themselves contested), raises additional questions: To what extent can an accurate appraisal of the quality of another's life be made? Whose voice is given epistemic and moral authority, and on what basis?[1]

As I have argued above, gathering these practices under the umbrella of eugenics is effective and important insofar as it unmasks certain dynamics and preconceptions, reveals the importance of disability history, and makes room for voices that have been excluded, absent, or silenced. Yet the connections and similarities highlighted by the authors raise additional questions in my mind regarding the specificity and complexities that attend the particular instances in which the termination of disabled lives is justified. Thus, insofar as these technologies and justifications for terminating lives *devalue* disabled lives, we can ask: are all lives with IDD devalued equally? Part of the force of "The Quiet Progress" is its exposure of a deeply entrenched assumption about the lives of people with IDD: that they cannot lead full, meaningful lives that are without significant suffering. In response to this acknowledgement, it is important to further investigate how these determinations come to be, and which specific differences are relevant to the discussion.

First, we might consider to what extent the *kind of disability* bears upon the evaluation of suffering and the nature of the arguments given. For example, as I discussed earlier, when considering how and by whom determinations of suffering are made, there are morally relevant differences between people with cognitive disabilities who are unable to reflect upon and voice their satisfaction with their lives, and those who can. In revealing the disconnect between the assumptions made and the lived realities of Down syndrome and spina bifida, the authors underscore the fact that even *within* a particular condition, there is not a single constellation of abilities/disabilities or mode of being in the world.

There is also a question about the *agent* and *means* involved. All three examples involve terminating a life within a clinical context (although some "mercy killings" are outliers in this regard.) In what ways are these practices dictated by "expert" evaluations? What roles do parental desires and assessments play? What relationship is established between families and clinicians? *Who* is making the decision to end these lives, and through what means are they ended?

Finally, insofar as the paper is exposing the misperceptions about the quality of life associated with IDD, this raises questions regarding the *kind of knowledge* that is produced. Does the knowledge involve genetic information (e.g., results of NIPT), quantitative or qualitative evaluations of quality of life, experiential observations and accounts *about* an individual, or first-person narratives? Are there implicit or explicit knowledge claims being made about the nature of disability itself (e.g., medical vs. social model), the particular condition (e.g., Down syndrome) the individual's current state or prognosis, the individual's preferences or desires, and/or the degree and inevitability of suffering? And accompanying these questions about the *content* of these knowledge claims, is the question of *where and how* is this knowledge produced. Who are the gatekeepers of this knowledge?

Although time does not permit a lengthier discussion, one of the most pressing questions that bears upon the gatekeeper issue is how direct-to-consumer testing will affect the discourse surrounding disability and suffering, and whether it will exacerbate the eugenic nature of certain arguments and assumptions. What are the implications of moving the testing industry into the marketplace, where physicians and genetic counselors are no longer the first point of contact for parents and prospective parents? How does direct-to-consumer testing change the dynamics of decision-making? Will it transform the nature and force of abelist assumptions? Will disability perspectives be further marginalized and silenced? And can disability advocacy play a part in shaping the not-so-quiet progress of direct-to-consumer testing?

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[1]The authors' discussion of "mercy killing" only further complicates the issue of authority. We must ask how the logic of justification functions in these cases of murder, how appeals to hardship and burden further entrench the conflation of disability with suffering.

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Research in the Field of Down Syndrome: Impact, Continuing Need, and Possible Risks from the New Eugenics

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Abstract

Research in the field of Down syndrome is under threat. There are two issues behind this threat: first availability of research funding could be limited by the perception that Down syndrome has become a rare condition. The second is that some believe the important work on Down syndrome is complete. In this commentary, the implications of the "new eugenics" on Down syndrome research are discussed, through reflecting on the impact of research arising from the 40 year Down Syndrome Research Program at The University of Queensland and other studies. This body of research has led to remarkable improvements in the quality of life of individuals with Down syndrome and those around them. The current context, particularly in the time of widespread availability of prenatal screening, gives a renewed imperative for research to improve the broader understanding of disability in the community enabling informed decisions at critical points in time. There are at least two potential benefits for continuing research on Down syndrome: for the individual and family; and for society in general. When a baby with Down syndrome is conceived, what might have been viewed as a tragedy may be seen very differently by those with lived experience. Understanding that lived experience and sharing the findings is the work of researchers in the field of Down syndrome, and there is much more work to be done.

Keywords: Down syndrome, inclusive education, intellectual disability, quality of life, research

Commentary

Recently, I attended the funeral of a 78 year old lady whom I had only met once and yet her good works have had a profound influence on my life.

Maureen Cameron's youngest child, Michael, had Down syndrome and died at the age of 7 years and 2 days. Decades later, in the eulogy at Maureen's funeral, her daughter, Wendy, told of the dark shadow Michael's death had cast over Maureen's life to its end. Barry, Maureen's husband of 60 years, reflected on their long life together and in his tribute, devoted a significant part to their son, their cherished son. He spoke of Maureen's determination to help Michael walk and learn to talk so others could understand him. He told the story of picking his son up from school and watching while the little 6 year olds ran along as one of them called out, "let Michael win!" And, he talked of the family taking part in early research at The University of Queensland. Later, the priest told us all that the altar had a plaque of dedication to Michael, given in his memory and as a tribute by a family who loved him dearly and knew he would always be deeply missed.

What Barry Cameron did not tell the congregation gathered in the overflowing church was that in 1985, his family established the Michael Cameron Fund and to this day, the fund has continued and sustains research in Down syndrome. The Down Syndrome Research Program (DSRP) has been running continuously since 1978, and the original longitudinal study, which forms the bedrock of the program, is the longest most intact study of its kind in the world. This is in no small measure due to the philanthropy of the foundation that has sustained the research program between grant funding for specific projects.

In 1996, my own daughter was born with Down syndrome and the information that was given to me in the hospital to support us and guide her development came from research undertaken as part of those research studies. I now direct that program and in an era of the "new eugenics," some question whether there is any continuing value in learning more about Down syndrome and working to improve the quality of life of all those individuals, families, and professionals living with Down syndrome.

The Value of Down Syndrome Research

Therefore, what is the purpose of research on Down syndrome? What if we move to a society where the only babies born with Down syndrome are those whose mothers did not find out or those who chose to continue with their pregnancy? We could leave them to their own devices, much like the families who first joined the DSRP longitudinal study in 1978, having rejected the common advice at the time to surrender their babies to institutional care, go home, and forget them. Those

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families talk of the gratitude they felt that there were researchers to support them and guide them.

Dr. Patricia Gunn was one of the researchers who established the longitudinal Down syndrome research program. She and others gave their life's work to this field in support of people whom she did not consider "defective" (one of the justifications for terminating lives discussed in the paper by Reinders, Stainton, and Parmenter). Rather, she recognized that lives of poor quality could be improved and this has been achieved by the application of research from her studies and similar work around the world. Research on Down syndrome arising from the DSRP has produced astonishing results with international impact. To date, over 250 publications have been produced on topics that have changed over time. Early studies investigated the interactions of mothers with their babies, documenting the love and mutual benefit that a child with Down syndrome brings to family life (Berry, Gunn, Andrews, & Price, 1981; Berry, Mathams, & Middleton, 1977).

Research interest then turned to child development across the physical, cognitive, social, and language domains. A study published in 1987 (Rauh, Rudinger, Bowman, Gunn, & Berry, 1987) identified the critical importance of early intervention due to the disproportionate impact, when compared to children without Down syndrome, of environment, and health issues on development across intellectual and motor domains.

The DSRP made important contributions at this time to understanding the developmental profile of individuals with Down syndrome who were growing up alongside others in the community. Studies explored behavior patterns, sibling experiences, and psychological aspects such as self-regulation (Cuskelly & Dadds, 1992; Cuskelly, Zhang, & Gilmore, 1998). A major area of investigation studied physical development and activity, countering the myths that people with Down syndrome were averse to physical activity (Jobling, 1994).

As the children in the longitudinal study entered the school years, the research focus explored the development of language (Farrell & Elkins, 1991; Gunn, 1987) and some early work on counting (Caycho, Gunn, & Siegal, 1991). This was at a time when inclusion of students in mainstream schools, rather than in special schools, was becoming more common. Research attention studied the processes and outcomes of inclusive education (Hayes & Gunn, 1988).

Literacy development received particular attention in the DSRP and uniquely followed development into early adulthood (Moni & Jobling, 2001; Moni, Jobling, Morgan, & Lloyd, 2011). The finding that literacy continued to develop, if taught, demonstrated the critical importance of post-secondary education in formal or informal settings.

The value of longitudinal research is in being able to capture development across the lifespan. Participants who have been in the DSRP since its inception are now in their 40s, and therefore, the focus of the research is moving to studies of aging and mental health. Another benefit is that the dataset stretches over 40 years. I initially proposed the hypothesis of developmental dyscalculia being a feature of the phenotype of Down syndrome (Faragher, 2017) which led Monica Cuskelly to design a study to explore the hypothesis using data gathered from psychometric testing of cohorts in the DSRP, with appropriate ethics approval (Cuskelly & Faragher, 2019).

Impact of Research

Research from the DSRP connects with an extensive literature base from studies the world over. One of the many outcomes of research on Down syndrome in these decades has been the impact on family quality of life. Children being brought up in the family home, attending local schools, and accessing community activities such as play groups, sports clubs, and faith communities has changed the life outcomes of not just individuals with Down syndrome, but their families and the wider community as well. These opportunities have been facilitated by outcomes of research and research has followed the changing opportunities.

The emotional response many parents feel at the time of the diagnosis of Down syndrome changes over time as noted by Reinders et al. Why these perceptions change is an interesting consideration. For many, they have not known a person with Down syndrome and therefore have no firsthand knowledge. Their knowledge at point of diagnosis would likely mirror general community awareness based on portrayals in media and entertainment, as well as what might have been conveyed in school or through other education and by health professionals. When my daughter was born, I had to ask how long she would live—the teenage life expectancy of the institutional era was still in my mind. In reality, she can expect to live a long, healthy, and productive adulthood (Torr, Strydom, Patti, & Jokinen, 2010). Ironically, when my daughter studied Biology in her final year of secondary school, she studied a unit on genetics. The case example in the textbook was of Down syndrome and was so out of date as to be laughable, but really, it was disgraceful. Misinformation continues to be promulgated leading to societal understandings that are incorrect and damaging when they form the basis of later decision-making in life and death situations. Understandings of disability in the general community give foundation to decisions that need to be made in a hurry. Families may be given a very short time to decide whether to consent to invasive pregnancy testing or to continue a pregnancy. Before being given test results, they may have had no knowledge or experience of the condition or even disability more broadly. In such cases, societal views and those conveyed by health professionals are influential (Rubel, Werner-Lin, Barg, & Bernhardt, 2017).

Parents' views do change over time (as they do with any child as they grow and become, rather than at birth when they represent hopes and imaginings). We did not know then what we know now. Therefore, how can accurate information about living with disability be promulgated? Aside from family experience, the next most significant context is schooling. Inclusive schooling where all are welcomed, valued and supported in general classrooms has the most promise. Research findings indicate the links between inclusive education and social inclusion (European Agency for Special Needs and Inclusive Education, 2018). High-quality inclusive education is essential, although not always available. Poor inclusive practice has led to families opting for segregated schooling settings (Mann, Cuskelly, & Moni, 2018); however, poor inclusive practice does not justify exclusion. Rather, it should be the spur to making changes to provide better education in regular classrooms.

In recent times, research continues on schooling practices. Through studies the world over, the importance of inclusive education has been demonstrated (for a review, see Hehir et al., 2016)

with some studies specifically related to the inclusion of children with Down syndrome (Buckley, Bird, Sacks, & Archer, 2006). The challenge facing teachers of inclusive classrooms is in the implementation of effective inclusive practice (Faragher & Clarke, 2016). Current research in the DSRP is investigating inclusive mathematics education at the primary and secondary levels. The mathematics education of learners with Down syndrome is receiving research attention from a number of researchers for the first time (a special issue of the International Journal of Disability, Development, and Education was published on this topic in early 2019).

Current Context

At this time, decisions affecting the lives of individuals with disability are being made in Australia at the levels of law, policy, and in practice. The state of Queensland has recently passed the Termination of Pregnancy Act 2018 (Queensland Legislative Assembly, 2018) making it lawful for a medical practitioner to perform a termination after 22 weeks gestation in consultation with another medical practitioner after considering all relevant medical circumstances and the woman's current and future physical, psychological, and social circumstances. There is no requirement in the law for these two practitioners to have any experience or training in disability, nor in genetic counseling.

At the level of policy, the Australian government is considering a proposal to include the costs of non-invasive prenatal screening (NIPS) on the Medicare Benefits Scheme. This would mean the Australian Government would pay a rebate to provide Australian patients with financial assistance toward the cost of the screening test, and it would become a routine part of pregnancy care.

At the practice level, individuals, in consultation with their health care providers, are making decisions about whether to undergo screening or diagnostic tests and then how to act on the results obtained. Evidence would suggest that informed understanding of the tests and implications of the results are limited, even by the medical practitioners themselves (Rowe, Fisher, & Quinlivan, 2006; Van Ness, 2016).

Understanding the implications of results requires more than understanding the immediate information with knowledge of probability, science, and medicine. What is required to make an informed decision is a realistic perspective on what various decisions could mean in the context of the individual and family. This requires a grounded understanding of disability, built over time, and emerging from social inclusion.

In Australia at least, it would seem we have a way to go to build a society where the value of diversity is recognized. Australian society is not always kind to those who are different. My husband was shopping with our daughter in a Canberra supermarket a few years ago. He noticed a young woman with her mother making fun of our daughter. After sending our daughter off to collect an item in another aisle, he asked the young woman why she was making fun of a young girl with a disability. The woman's mother retorted, "what gives you the right to talk to my daughter like that?" My husband was appalled to learn from the young woman's jumper that she was a student teacher studying at the university where I was on staff. What sort of teacher would she be? More deeply, what society does she represent? Those of us in the disability sector who have learned to value human diversity do not, it would seem, have a view that is universally shared. We need research to understand the nature of disability, improve the quality of life of those experiencing disability, and then, to promulgate the findings widely through implementation science.

The Need for Research

Research in the field of Down syndrome is under threat. Could we say that we know enough now and no more research is needed? As Reinders, Stainton, and Parmenter point out, if a perception emerges that Down syndrome has disappeared, not only will there be little funding appetite for early intervention and developmental guidance, convincing funding bodies to support Down syndrome research may become impossible. Research funders may become more likely to support projects where incidence is seen to be more urgent, growing or critical, such as studies on Autism Spectrum Disorder. And yet, so much remains unknown in the field of Down syndrome.

Research on Down syndrome is important for at least two reasons.

1. Research improves the quality of life of the individual and of the family, which has the effect of reducing negative impacts of disability. This has been seen most dramatically over the last 40 years for participants in the DSRP.
2. Research findings have broad implications beyond those with Down syndrome. For example, education techniques found to be effective in supporting learning for students with Down syndrome are helpful for many other learners as well. Medical advances in fields such as dementia of the Alzheimer type have relevance for the aging world population in general.

More research is needed to understand and advance the quality of life of those with Down syndrome and those with whom they interact. Then, implementation science and translation research are required to find ways to bring research findings to all in the community. Research undertaken in low- and middle-income countries is especially required, considering the predicted proportional increase in numbers of people with Down syndrome in those regions of the world where access to prenatal screening is limited.

A Short Life of Immense Value

Let me return to the Camerons' story. Here we can see a family that was not relieved when Michael died, but instead were deeply saddened and remember him fondly to this day. Arguments made about terminating pregnancies based on the ideas of reproductive choice, and tragedy and reduction in family quality of life, can be countered by recognizing that the suffering in the Cameron family was in the loss of Michael following his death. That family tragedy was turned into a lifelong mission of impact. His short life had a profound effect on his whole family and inspired them to benefit families the world over as this research has been shared and applied across the decades. His life mattered.

Then, we see the school boys, already at their young age, recognizing one who belonged in their midst yet needing a little extra support. Swinton (2012) has written about the role of inclusion and the power of belonging in an inclusive society where all are valued for the very diversity that makes us human. We are all the poorer if any one of us is excluded.

All Lives Have Value

There is still much to learn about Down syndrome and its impact on the individual and those sharing their lives. These studies have important influences on family life, education, health, and social inclusion. All lives have value. All of us, including those with Down syndrome, enrich the world by having lived. Understanding that lived experience and sharing the findings is the work of researchers in the field of Down syndrome, and there is much more work to be done.

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Lives Not Worth Living in Modern Euthanasia Regimes

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Abstract

The authors of "The Quiet Progress of the New Eugenics" (QPNE) assert that some current practices, such as euthanasia and/or assisted suicide (EAS) for disabled newborns, imply that some persons with disabilities have lives that are not worth living. I extend the QPNE's analysis in this commentary by exploring whether even in *voluntary* EAS for "unbearable suffering," the question of how we value the lives of disabled persons arises in a way that deserves more public discussion. I argue that the old and modern EAS regimes both create a class of persons whose lives are deemed by society as not worth living. I explain how the modern EAS regime's public goal of relieving suffering and its requirement for autonomous choice obscure but do not erase this fact. Although modern EAS regimes are based on suffering (not eugenics) and voluntary (not state coerced), they have the effect of creating lives that are societally deemed to be not worth living.

Keywords: autonomy, euthanasia, intellectual disability, physician-assisted death, suffering

The old eugenics was inherently discriminatory. Its central thesis was that some human lives are worth more than others, measured by the yardstick of eugenic potential. The central concern of the authors of "The Quiet Progress of the New Eugenics," (Reinders, Stainton, & Parmenter, 2019) (QPNE hereafter) is that some current practices such as euthanasia and/or assisted suicide (EAS) for some disabled newborns imply that some lives—persons with some types of disabilities—are not worth living. In this, the authors contend, the practice is similar to eugenics-inspired policies of some countries in early 20th century. This is a controversial and potentially inflammatory suggestion, because the modern practice of EAS supports individual choice (not state coercion) to relieve suffering (not to improve the gene pool), whereas the historical practice aimed at neither.

Yet, the authors of QPNE are right to call attention to this issue. After all, the "old" eugenics of advocating for policies to improve the human gene pool is not dead (Agar, 2019; Anomaly, 2018). The progress in biological sciences has inspired some philosophers to "reclaim the spirit of authors like Francis Galton" to see the "merits in eugenic thinking" (Anomaly, 2018, pp. 25–27). This means once again taking eugenic goals seriously, a framework in which "dysgenic" means "the proliferation of people with traits that are detrimental to human welfare" such as "extremely low intelligence" (Anomaly, 2018, p. 25). Those who take such eugenic goals seriously worry about, for example, "ambitious and compassionate career women" who choose "to adopt children in middle age rather than having their own," because although it may have "good effects on the adopted children in the short run," it will have "bad effects on the gene pool over the long run" (Anomaly, 2018, p. 27). The problem with Holmes's ruling in *Buck v Bell* is its callous language and flimsy evidence, not its "moral foundations" which is "defensible" (Anomaly, 2018, p. 28). Although he notes that "[d]efending eugenics does not commit us to endorsing state-sponsored coercion" and thus limits his horizons to voluntary reproductive policies, the talk of how some human lives are "better" for the gene pool than others is apparently something we need to continue to deal with.

The authors of QPNE note that in the case of EAS of non-terminally ill, non-competent persons, a judgment regarding the worth of such persons' lives is directly engaged, even when it is filtered through the language of "reducing suffering." In this commentary, I extend their inquiry and explore whether even in *voluntary* EAS for "unbearable suffering," the question of how we value the lives of disabled persons arises in a way that deserves more public discussion. I argue that the old and modern EAS regimes both imply in some intersubjective, societal sense, persons who are eligible for EAS have lives that are not worth living: they both create a class of lives that are not worth living. This is a disturbing consequence but I do not focus here on why the consequence is disturbing, only that such a consequence exists. Finally, my focus is on EAS for persons whose deaths are not proximate, such as persons with disabilities but otherwise healthy. I put aside for now the question of whether my argument applies to end of life EAS.

Is Suffering-Based EAS a Shield Against Societal Judgments that Some Lives are Not Worth Living?

It might be thought that when we move from a eugenics justification to a suffering-based justification for EAS, the issue of

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judging the "worth of human lives" no longer comes into play. I need not rehearse here the brazenly discriminatory language of old eugenics. But the language of suffering seems different; indeed, the motivation to relieve suffering seems hardly discriminatory and in fact appeals to what is noble in us. This appeal to our compassion, however, relies on an equivocal use of "relief of suffering" which requires examination.

It is true that in the ordinary sense of "relief of suffering," no judgment about the worth of the person's life is engaged. But EAS does not provide relief of suffering in the ordinary sense, that is, where non-suffering replaces suffering in the life of the person, like quenching a thirst. Relief of suffering ordinarily means exchanging a life with suffering with a life without that suffering. EAS, however, removes the ground of suffering. To say that this amounts to "relief of suffering" is akin to a tennis player claiming an undefeated season by leaving the sport before the season begins. Because of the way in which "suffering" is erased (rather than relieved) by terminating the life of the person, EAS inevitably raises the question of the worth of that person's life. The logic is straightforward: If we justify ending the life (that would otherwise go on) of a person with D (a disability) because an absence of a life with D is better than a life with D, then that is a judgment that life with D is not worth living.

One might object that this does not show that the authors of QPNE are right in their view that modern practice of EAS for persons with D implies a judgment about the lives of *all* persons with D. We are forgetting autonomy, one might object. Perhaps all we can say is that a person with D who voluntarily seeks EAS is saying *his or her* life is not worth living.

Is Autonomy a Shield Against Societal Judgments that Some Lives are not Worth Living?

"Look," one might say, "I'm not saying that living with D makes every life with D not worth living. I'm only saying that life with D is not worth living *for me*. It is my choice and no one else has a right to interfere with my choice." Autonomy is thus proposed as a shield against the kind of worry that QPNE raises.

But is a claim that one's life is not worth living always a purely private judgment? Consider the following passage written by a man with Parkinson's disease as he observes a fellow patient with a more advanced disease: "Crouched like a frightened bird, he ate his sauerkraut mash while keeping his mouth close to the plate and drooling. From time to time some of the food fell back from his fork or from his raw, red swollen lower lip. When his plate was half empty, a nurse mercifully fed him a few more bites. His chin sagged on to the plate, his gray beard dipping in the cold sauerkraut mash." He then goes on, "My God […] I thought, this is what lies ahead of me. And it won't even kill me" (Blanken, August 10, 2018).

This writer describes an actual patient who has the same disorder as he does, and he skillfully evokes a clearly evaluative perspective: "Crouched," "frightened," "drooling," "raw, red swollen lip," "mercifully," "sagged," "cold." To be clear, I am not debating whether these descriptors are in some sense accurate. There is no doubt that the patient being portrayed is in a difficult state. Although the writer may have intended to illustrate why he himself does not want to live like the man portrayed, that illustration works by way of evoking in us a reaction about the man portrayed. Our first thought in reading the above is not: "Oh, you are talking only about your own subjective valuation of your own state of D—you are saying, for you only and for no one else, not even for the man you portray, you wished D would kill its victim instead of leaving him in such a state." The writer is judging the life before him as not worth living; that judgment is logically prior to and serves to justify why he does not want that life. Judgments about whether a life is worth living, even if it is ostensibly only about one's own life, is not a private judgment. What this author shows the reader is his belief that any life such as the one he sees is not worth living.

As an aside, I note that this need not commit the writer to anything like endorsing state-sponsored involuntary euthanasia of such persons or even to an attitude that the person being described should choose to die voluntarily. It need not imply a disrespectful attitude toward that person. Indeed, in a liberal society, we respect people's choice not to request EAS even when their lives are not worth living.

Some may object at this point that their valuation of one's life as not worth living is indeed a private one. Perhaps what people mean when they say they have a right to end their lives is simply: do not interfere with my life and my choice and with my values; how I see the worth of my life is my business, not yours.

Is EAS Only a Matter of Not Interfering with Someone's Autonomy?

A person's request for EAS is a claim on at least one other human being. The requestor is asking this person to affirm the requestor's judgment that his or her life is not worth living and to *act* on that shared judgment. Whether one performs voluntary or non-voluntary euthanasia, the value judgment required of the performer of EAS is the same: in both, the person who provides the EAS must affirm a value judgment about the person's life—it is not worth living.

Of course, people who provide euthanasia might be tempted to reply, "I'm not making a judgment about the worth of this person's life with D; the question of whether his life is worth living is entirely and only a matter determined by his personal choice." This indeed is the sort of thing that people are likely to say. Let us see if such a response is an open option for the person who performs euthanasia.

First, the obvious point: in the case of non-voluntary EAS, this is not an option because the person receiving EAS is not asking for it.

Is the response available in the case of voluntary euthanasia? I do not think so, at least as reflected in the conventions established on how to think about these things in countries where EAS has been permitted for the longest time. Therefore, here, I put aside the possibility of a jurisdiction legally permitting EAS on demand with no other requirement than informed consent. If a jurisdiction did permit that, then at least legally, the provider of EAS could possibly resort to the kind of response mentioned above. Such a jurisdiction would in fact be promoting a purely individualist, voluntarist basis for determining whether a life is worthy of life. (Some may point to Switzerland here but the actual norms of practice and other supporting legal considerations

make it clear that assisted suicide purely on demand is not endorsed there (Black, 2012).)

Consider one of the most liberal EAS regimes in the world. At least in the Netherlands, the doctor and the patient together must determine that there is no alternative to EAS (Regional Euthanasia Review Committees, 2015). Of course, because a person who is not terminally ill would remain alive unless EAS is given, the requirement really is a value judgment: not living is a better option than any alternative life with D. This is built into the Dutch law on euthanasia.

The Dutch law also requires that the person be suffering unbearably. The Dutch euthanasia review committees (RTE) say that such suffering of course must be seen as a subjective phenomenon, in light of an individual's history, personality, and so on (Regional Euthanasia Review Committees, 2015). However, the RTE is quite clear that a patient merely believing and asserting that he is in unbearable suffering is not sufficient. One can mistakenly believe one has suffering that is unbearable; the doctor may find that the person is not suffering unbearably.

Whether or not your life is worth living or not is not a wholly private assessment in an EAS regime. The person who provides it for you must be convinced of it too, by law. And the committee who monitors and reviews the person who provides it for you must in turn be convinced that the provider (the doctor) is convinced (in fact, the doctor must show s/he has a sufficient basis for being convinced). The Dutch system is quite clear that what makes a life not worth living—from a societal, inter-subjective point of view, not merely a private judgment regarding the worth of one's own life—is something that requires a medical doctor to determine. Not everyone—not even the patient solely by him or herself—can determine whether someone has unbearable and hopeless suffering with no reasonable means of relief. It requires an expert. It is intended to be, in that sense, an objective judgment.

Autonomy's Modest Role in EAS Regimes: Informed Consent

What is the role of autonomy in modern EAS regimes? The modern regime of EAS is, unlike historical national socialist EAS regimes based on old eugenics, liberal in the following sense. It respects those persons who even choose against their own best interests. Thus, even persons whose lives are not worth living yet choose to go on living are given the protection of informed consent as a requirement for EAS (at least in theory). The actual function of "voluntary" requirement might become clearer with an analogy.

Consider how a liberal society handles the tension between the promotion of socially valuable health research with the autonomy of potential research participants. There are many more eligible persons for clinical research than there are people who volunteer. But in a liberal state, even crucially important clinical research cannot justify coercing people into it. Likewise, there are many more people who are, in a modern euthanasia regime, "suffering unbearably and hopelessly," and therefore would be eligible for EAS than who choose it—yet, they are protected from being coerced into it by the requirement of informed consent.

Returning to the goal of this commentary, I end by noting that informed consent does not make a research protocol ethical, nor does it change the social value of the science; it only makes permissible the involvement of the particular individuals. Likewise, informed consent for EAS does not change the assessment of the value of the person's life from a societal perspective. Informed consent only makes an otherwise eligible person's EAS voluntary. But whether or not a person provides informed consent for EAS does not change the fact—nor should it distract us from facing squarely the conclusion—that even in a modern EAS regime, that person's life is a life deemed not worth living.

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The New Eugenics and Human Progress

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Abstract

Human progress has occurred throughout human existence. It is typically regarded as a positive thing in as much as it proceeds on the basis of, and results in, changes to the human condition that we value. Thus, changes associated with progress occur since they are judged, using current moral standards, to be "good" things and the "right" things to do. Eugenics, the practice of purposely bettering society by influencing its genetic makeup, was a philosophical and practical tool used by leaders of European societies and the countries under their influence during the final two decades of the 19th and the first half of the 20th centuries. This was not entirely a new idea, however, as ways of purposely manipulating genetics of plants, animals, and humans have been practiced before recorded human history. The practice of eugenics went "too far" by Nazis during World War II for international moral standards and was quickly abandoned in favor of an international emphasis on human rights. Still, eugenics practices continued and continue to the current time. Today, we are faced with the question of whether or not this is a prudent path to follow, especially given that progress in medical and genetic fields is expanding at a very rapid pace. It is suggested here that rapid progress in these areas in the future may make any current practices of the new eugenic not only outdated, but also irrelevant. Thus, it seems unwise to follow new eugenics practices in a whole-hearted way.

Keywords: eugenics, history, human progress, intellectual disability

Typically, we humans think of progress as a positive concept. We think of it as growth or movement toward our own betterment, both as individuals and as a social species. Throughout human history, progress has been made in many ways, including: in the way we provide ourselves with food, from hunters-gatherers to the industrial production of consumable plants and animals; in the size and complexity of our social organizations, from nomadic tribal units to large countries and empires with millions of people; in our invention and use of technology, from simple tools made of natural materials to tremendously powerful machines that have the power to build very tall buildings and even to travel through space; and in our ability to construct and operate primarily within the realm of concepts (constructs) that we have invented for our own use and convenience—such as health, education, happiness, commerce, government, nations, and numerous others—rather than within the realm of the real things in our environment (Harari, 2014). Progress has enabled humans to achieve to a degree and at a rate that would have been far beyond the imaginations of humans at the dawn of recorded history, about 5,000 years ago.

Yet, progress does not occur without some moral compass. History is replete with examples of one tribe or nation progressing in ways that another tribe or nation does not agree with or considers to be right, and the ensuing disagreements have resulted in any number of inter-tribal or international conflicts, the most vividly recalled and recorded of which are dramatic wars. But in spite of this less-than-smooth journey through history, and despite its ongoing clashes with morality in its many forms, progress has persisted over the millennia and appears to be more abundant now than ever before.

Progress has made use of many tools and traveled down many avenues is its forward, although uneven, march. One of those tools that was ubiquitous throughout Europe and the many countries around the world that were under its influence was known as eugenics. Eugenics, which was adopted wholeheartedly as a philosophy for a period of about 65 years (1880–1945), sought to support progress by improving the genetic makeup of society. As a tool, although, it went "too far" in Nazi Germany during World War II for international moral standards to accommodate, and it fell into philosophical disrepute.

In spite of this, many incidences of ethnic and social cleansing through mass murder have occurred since that time, and eugenics has continued to live on in many other forms. Within the field of disability, and intellectual disability in particular, negative practices such as isolation, sterilization, and moral persuasion have often been blatantly used, and continue to be used today, to curtail sexual activity and reproduction. Moreover, technological and medical advances of the past few decades have made it possible for us to identify many potential disabilities prenatally, to sustain (or not sustain) precarious life of newborns, and to support (or not support) the continuation of life of many who formerly would have died. In the absence of strong ethical standards to guide our decisions on these matters, and within a legal context where laws struggle to keep up with medical advances, an important question that emerges is if there are currently negative "new" eugenics practices—especially decisions not to continue life *just* because of disability—that have gone "too far" for our current moral standards.

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This question is explored in various ways through this special issue. To help set the stage for this exploration of ideas, we take a closer look here at the meaning of both eugenics and human progress. Ultimately, we raise the question of how the concepts of eugenics and human progress intersect, and as these are both social constructs that are subject to human intervention, we suggest that should we continue to act on eugenics at the present time, human progress in the future may make this practice at least imprudent and perhaps unnecessary.

What Was Eugenics?

The term *eugenics*—meaning *well-born*—was purportedly coined in 1880 and popularized in England by Sir Arthur Galton. Galton, a cousin to Charles Darwin, understood the principles of evolution and developed the notion that the genetic makeup of a population could be enhanced as a result of purposive action (Brown & Radford, 2007; Galton, 1904). The philosophical rationale for eugenics was further developed and accepted through the concept of *Social Darwinism*, a set of beliefs that contended that societies themselves are subject to the same evolutionary influences as those observed by Darwin in plants and animals, and thus Herbert Spencer's well-known phrase "survival of the fittest" was considered to apply as much to social orders as it does to organisms in nature. Eugenics, then, was a philosophy—as well as a set of widely accepted beliefs and overt practices—that considered that human progress could be expedited by purposely manipulating the genetic makeup of a society.

As the beliefs associated with the term eugenics became more widely known and accepted throughout Europe and the countries under its influence, eugenic practices were put into place and supported by social leaders and professionals in virtually every walk of life. People of "good breeding" were encouraged to marry and produce large families (positive eugenics). However, limitations on reproduction (negative eugenics) were placed on those considered less desirable through such means as being housed in one of the many forms of institutions, deportation, segregation, moral and religious persuasion, and, later, even sterilization. This widely accepted array of purposeful actions was intended to enable society to function in a better and more efficient way.

But it did not last. Eugenics as a positive and dominant social philosophy met a fast demise at the end of World War II. The discovery of the horrors of the Nazi concentration camps, where approximately 6 million Jews were killed, was supplemented by such discoveries as the T4 program, where at least 5,000 babies and children with disabilities were systematically killed, and the subsequent but equally systematic killing of about 100,000 residents in psychiatric hospitals (Aly, Chroust, & Pross, 1994; Brown, 2018). These horrific attempts at ethnic and physical/mental health cleansing by the Nazis clearly illustrated to the world that negative eugenics could easily be taken too far, much beyond the farthest reach of almost all human moral standards. It was for this reason that eugenics as a philosophy was quickly abandoned internationally and replaced by an emphasis on human rights (e.g., the United Nations Universal Declaration on Human Rights, 1948).

Why Did Eugenics Thinking Not Die Out Completely?

Eugenics as an explicit philosophy may have ended in the late 1940s, but the continuation of numerous eugenic-like practices has been observed many times in the decades that followed. Adults who were *feebleminded* (now referred to as people with intellectual and developmental disabilities) were, for many decades, institutionalized, and this practice continues in many countries to the present time. They are commonly sheltered from, or segregated by, sex no matter where they live. Sterilization and use of birth control among adults with mental and physical disabilities is frequent, compared to their nondisabled peers. As highlighted in the lead paper of this journal, prenatal, neonatal, and end-of life decisions are frequently made using criteria that do not go much beyond the presence of disability and the assumption that those with real or potentially disabling conditions are not sufficiently "well born" to be worthy of continued life (Brown, 2018).

Perhaps one of the best explanations for such continuing practices is the close association between the concepts *eugenics* and *human progress*. The concept of human progress has ancient roots in human history. Multiple and successive attempts to improve the human condition through a vast variety of means, some accidental and some through deliberate action, are evident from even a sweeping examination of human history. We can consider the results of these attempts as human progress, if we accept them as having led to changes that have been, on balance, more positive than negative over time on criteria we value, such as improved communication, living conditions, health, technology, and others. In general, we think of human progress as a "good" thing, both from practical and moral points of view.

Feeblemindedness, however, was not considered to be a "good" thing in the sense that it did not add positively to society, but rather was a detriment to human progress (e.g., Baur, Fischer, & Lenz, 1921; Mostert, 2002). This conceptualization of feeblemindedness, and later of intellectual disability, devalued people labeled this way and viewed them as a negative aspect of progressive societies. Given this way of looking at feeblemindedness and disability more generally, it is not surprising that some forms of eugenics continued to be exercised in the belief that they were helpful to human progress. If human progress were a good thing, and some forms of eugenics represented a method of speeding up human progress, then surely a continuation of these eugenic practices themselves must also be a good thing.

Why Was Eugenics So Easily Accepted as a "Good" Thing?

Eugenics was easily accepted as a "good" thing, and a negative conceptualization of feeblemindedness was strengthened, for a number of interrelated reasons. Four key reasons to explain why eugenics was so easily accepted as a good, and highly acceptable practice are described here: first, that selective breeding was widely known and practiced for millennia in human history; second, that forms of considering some people, particularly babies, not worthy of continuing life were endemic to numerous cultures and civilizations throughout recorded history; third, that well-entrenched social orders provided clear examples of manipulation of human genetic makeup; and fourth, that eugenics was a set of beliefs and practices that could be conveniently acted upon to

alleviate the social problems that emerged along with the industrial revolution. Each of these is briefly explored here.

The Practice of Selective Breeding

Selective breeding has been a millennia-old phenomenon. Throughout recorded history—from the earliest agrarian cultures onward—it was recognized that crops could be improved if the best seeds were saved to sow the next year and if the more inferior seeds were fed to the livestock. Similarly, the practice of breeding goats that produced the most milk and the best meat, and preventing the breeding of the less fruitful ones, resulted over time in a group of animals that was more able to supply the needs of the herd owners and those who depended upon them.

Ever since humans moved from hunter-gatherer to agrarian styles of living, there have been countless examples of the progressive use of selective breeding. Today, this tradition continues with the "invention" of genetically-modified vegetables and, to some extent, animals that are better able to supply our needs by growing bigger and faster, and by lasting longer, than those grown previously. The almost total lack of public outcry over this recent practice is one more example of how deeply embedded the ancient, but ongoing, practice of selective breeding is.

Given this, it is hardly surprising that eugenics was so easily accepted as a "good" thing and as a stride toward human progress. After all, it is perhaps a relatively small step, both conceptually and practically, to apply the practice of selective breeding, so familiar to agrarian societies, to human civilizations.

Practices on Worthiness to Live

It appears that a common method of dealing with inferior human stock in antiquity, and continuing throughout the Middle Ages in some countries, was various forms of infanticide. It has been well documented that newborns in ancient Sparta were examined by a committee of elders to determine their physical potential and to pass judgment on whether they should live or die. Like many other civilizations in Europe and other parts of the world, young Spartan children who were not considered to be viable were left to die, purposely or through neglect, in a variety of ways. One of these ways was the practice of exposure, where an unwanted infant would be abandoned, typically in a remote area or in the water, to die from the effects of harsh elements, drowning, starvation, or from being eaten by wild animals (Berkson, 2004, 2006).

In modern times, infanticide is practiced in other ways: a fetus that is discovered to have atypical genetic makeup may be aborted, or a newborn with severe disabilities may be denied life-saving medical intervention. Denial of life-saving intervention is also practiced throughout the lifespan in most modern countries if it is deemed that life, if sustained artificially, will not be worth living, such as living in a coma (see e.g., Brown, 2018).

Manipulation of Human Genetic Makeup

Manipulation of human genetic makeup was by no means a new idea of the late Victorian era. European history, like the histories of other parts of the world, is clear on the longstanding practice of members of the aristocracy marrying primarily within the aristocracy, and people of other ranks keeping within their "stations" (or castes) for the purposes of marriage, procreation, and life work. Overt selective breeding of slaves was practiced widely in North and South America as late as the mid-nineteenth century for the purposes of replenishing the number of slaves for the owners, economic gain from selling the slave children, producing bigger and healthier slaves, and elevated the social status and value of the slave children who had some characteristics of their owner (Harari, 2014). These and other examples illustrate that the idea of purposely influencing the genetic makeup of a group of humans was not unfamiliar. Denying sexual activity to a feebleminded man is only a small conceptual step from denying sexual activity to one slave in favor of a more robust one.

Alleviating Social Problems

The industrial revolution represented a dramatic move of populations from rural to urban living and from agricultural to industrial production of goods. This revolution occurred rather quickly in historical terms, over just a few hundred years, and brought with it a number of new and perhaps unanticipated social problems. Among these were increases in poverty, homelessness, crime, and disease, accompanied by, and to a large extent resulting from, decreases in community structure, family support, and clean environments. Some people adapted to the changes that the industrial revolution brought better than others. Numerous people who did not adapt well were jailed, institutionalized, conscripted into armies, or deported. Among the least able to adapt on their own were known as *idiots*, and later as *feebleminded.* Eugenics was a set of beliefs and practices that could be conveniently acted upon to alleviate the social problem of them being uncared for in unfriendly towns and cities, and at the same time, to prevent them from reproducing their own kind, thus exacerbating the problem.

Why Was Eugenics Ultimately Not "Good" for Human Progress?

Human progress is not inherently moral or immoral in nature, but it exists within social contexts where morality in various forms exists to guide and judge behavior. For this reason, human progress is always judged by current morality and its very existence has often depended almost wholly on whether it is seen to be a good thing or a bad thing.

Eugenics was considered to be a "scientific" tool for human progress, and because science was thought to be somewhat outside the realm of morality, it escaped some moral scrutiny. Still, our current reading of the history of eugenics also suggests that eugenics itself was, at least in part, a moral philosophy—that is, adding to the "unworthy" genetic pool was a bad thing, while preventing people from doing so was a good thing. The difficulty was that there did not appear to be clear moral limits to eugenics, in spite of the parallel and relatively strong rise of humanitarianism. People could be held in institutions or asylums, they could be deported, they could be isolated, or they

could be subject to all manner of intellectual persuasion. The fact that they could not be killed, at least not on purpose, did not mean that there were not large numbers of people throughout Western cultures who believed their society and the world would be better off if unworthy people, such as those who were feebleminded, did not exist at all. Eradication of a subpopulation through preventing their reproduction was the ultimate goal of eugenics but, as there were no limits set on how this actually might be accomplished, it was only a matter of time before someone went "too far" by instituting practices that could not find moral acceptance, even among eugenics adherents.

That someone who went "too far" was the Nazi regime in Germany under the cover of World War II. International morality intervened, and eugenics was no longer seen as a good tool for human progress.

The New Eugenics and Human Progress Today

In recent decades, human progress—especially technological change, including medical and genetic knowledge and tools—has been occurring at such a rapid rate that it is difficult for morality to assess and judge the value of the "new eugenics" practices. Rapidly occurring progress simply does not lend itself easily to the reflection and discussion that is essential for sound moral assessment. For this reason, we often have to make quick judgments about whether a particular progress is primarily a positive thing, and thus not discouraged from moving ahead (e.g., advances in computer technology and communication), or a potentially negative thing, and thus discouraged (e.g., manipulating the human genome). The practices identified as aspects of the "new eugenics" appear on the surface to be, at best, unsupportive of current humanistic values, and, at worst, to have the potential for malevolence and abuse. For this reason alone, they should probably not be whole-heartedly encouraged.

The rapid rate of progress in today's world—unlikely to abate in future decades, and quite likely to accelerate—provides another rationale for abandoning, or at least pausing, new eugenics practices. It is likely that our technical knowledge and skill regarding the functioning of the human body and mind will continue to increase quickly and bring about a number of positive changes in the human condition. Such progress should apply to both people with and without disabilities. Although we have no real idea what these changes will be, or how they will affect humans and human functioning in the future, it seems prudent to assume they will support human betterment on the whole. It seems imprudent to make judgments about the lives of people with disabilities at the present time when those judgments may well seem ill-advised in the years to come. In short, we may look at a newborn who has physical and mental challenges and think it is better for that infant and her family not to have to face a life of struggle and suffering ahead. But in the future, struggle and suffering may not be the case at all for her or her family. We simply do not know what benefits progress may bring.

What we do know is that over the course of human history, progress appears to drive onward relentlessly. We can only assume this will continue, and it seems wise to judge our current actions, such as whether or not to enable new eugenics practices, within the context of understanding and forecasting what human progress may bring in the future.

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New Eugenics, Old Problems

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Abstract

A parent advocate who is also an officer of Inclusion International examines some aspects of the new eugenics in a humanistic framework. The essay is based on personal experience and the work of self-advocates and includes references to humane letters.

Keywords: advocacy, intellectual disability, parent experience, self-advocate expectations

People with intellectual disabilities want to be valued equally. *Inclusion International* brought together 400 people with intellectual disabilities from around the world in June of 2018 to listen to their demands, and being valued equally was foremost. How can we value all people who have intellectual disabilities if we have protocols about when it is okay to kill them? If we must have the discussions, we should include self-advocates and consider their opinions.

Even with input from self-advocates, language is a poor tool for understanding human life and human struggle. If it were a better tool, there might be a worthwhile overview of *The Death of Ivan Ilyich* or the *Oedipus*. We would not have to slog through them because we would understand what they mean. But slog we must. The value is in the slog. Literature may be the best window into human struggle and it may help us find empathy for each other, but even it falls short. We close the book. We leave the theater. We try to remember what was so heart wrenching. We go back to our lives, and maybe we are more aware of how universal it is to struggle in many aspects of our lives, even the most universal, even birth, and death.

Legal and logical examinations of what we should do in certain situations can be even more confusing, especially when there is a public debate of a particular case. Many of the cases that involve babies and children with profound disabilities fall into this category. The facts may be unequivocal, but interpretations and explanations vary. There is a frisson of delight in deciding that something someone else did is just wrong. We do not want to judge others if we can help it. We try to separate the sin from the sinner. Over time we learn that to be righteous may be a good thing: to be self-righteous is just ugly. What about mercy killings, or preventing suffering, or euthanasia? There is so much to judge.

These topics are personal for me. We raised a son who never spoke or walked and who never said, "I love you." He did not feed, dress, bathe, or toilet himself. He was loud, and he was a living, breathing sleep disturbance. Not giving two hoots for social conventions, he was the original Chaos Muppet. He was often a giant pain in the neck. But his health was never in question. He seemed to be in pain quite often and could not tell us what hurt, but we usually figured it out and his pain was never unremitting. I am glad I was never presented with decisions about life-saving interventions or withdrawal of support. In any case, his disabilities were not evident before or at birth or for many months after. When his disabilities finally became evident, they were so multiple and rare that prognosis was a joke. We decided day-by-day that we would be on his side, that he was more important than social conventions or even than sleep. Charlie lived to be 30 as a powerful member of our little family and his wider community. He had two brothers, one older, and one younger, who miss him to this day, as do his Dad and I and our extended family, and as do several people who worked with him. He loved great music, swimming, sunshine, and good food. He loved being with people. He paid attention to serious things and tried hard in his own way. He was often joyful. He had friends and even admirers. People generally liked him. We loved him. Loving and including him taught us a lot about ourselves and other people. He opened up our lives. Hemingway was wrong: the saddest story in the world is not "For sale. Baby shoes. Never worn."

Therefore, you see I do not hold to the notion that it is possible to decide what a person's quality of life might be based on any calculation or logic. The practice is irredeemably reductionist and it completely ignores the social model. Cultural advances have brought us to a place where we no longer need to kill our disabled family members just so the family or the tribe can survive. I do not see the point in trying to kill people because they are weak or because they are dying anyway. I do not think that is good for us. Care might be hard. But of course, as Dostoyevsky teaches us, everybody dies sometime. Many of us need care. It is also true that not every baby can be saved. We have never saved every baby, in the history of mankind.

If it is somewhat routine for medical professionals to withhold or withdraw life support from infants when neonatal intensive interventions fail, are we asking too much of them to do so quietly in private, to keep it out of the public eye? What is the moral and emotional burden of that privacy? My heart goes out to physicians who make these decisions regularly. How do we invest in helping them decide what, when, and how much to do? How do we help them talk to parents?

And speaking of "mercy killing," how can we address the dreadful fact that some parents and caregivers still murder their

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disabled children at a rate two or three times the rate at which non-disabled children are killed? Murder of a disabled child by a parent of caregiver is often either condoned by a culture or called mercy killing in the press. Too often, stories of filicide focus on how "stressed" the parent or caregiver was. We should wonder whether normalizing the "mercy killing" of profoundly disabled neonates by medical personnel in any way normalizes filicide, or vice versa. The Autistic Self Advocacy Network has posted an anti-filicide toolkit on their website. One of the toolkit's key arguments is that how we talk about filicide in public discourse might influence other parents to become murderers. If so, we should question whether medically accepted "mercy killing" has any effect on filicidal "mercy killing." We know, for example, that filicide follows patterns similar to suicide and is not as sensitive to social forces as is murder. Murder rates change with the economy, but suicide and filicide are more constant. We also know suicide has communicable aspects. One suicide may set off a chain of suicides among young people. I do not think anyone knows whether there are chains of filicides or medical mercy killings, or whether they are related in any way.

As for the prevention of suffering through abortion of fetuses with signs of disability, I often remind myself that not every fetus lives to be born even in the best of circumstances. I have seen reports that about one-third of pregnancies would end in miscarriage (natural abortion) without intervention. Is genetic engineering to excise potentially deadly heritable traits preferable to abortion? Is genetic engineering to remove non-life-threatening traits of disability allowable? It may be possible that genetic selection, abortion, and withdrawing neonatal life support will become increasingly common and accepted with ever-declining birth rates. And although women may request "brilliance" as a characteristic when they make purchases from sperm banks, it might serve them right if intelligence turns out to be X-linked, if the Ivy League turns out to include the shallow end of the gene pool, or if nurture matters more than nature. There's a divinity that shapes our ends, rough-hew them how we will (Hamlet, Act V. Scene 2).

The self-advocate goal of "being valued equally" is useful in these discussions. On a review panel looking at the biomedical ethics of growth attenuation of disabled children, I asked an eminent physician who styled himself a bio-ethicist whether these procedures could be carried out on children who did not have profound levels of intellectual disability. He said no. Therefore, I said I thought the procedure threatened the child's dignity. He said, "These children do not have dignity." And yet the Universal Declaration of Human Rights clearly states, "All human beings are born free and equal in dignity and rights." Some medical professionals, even eminent ones, may not have a good grasp of human rights, which causes them to not value people equally.

The social model of disability should teach us to pay attention to what is around the disabled person. If the social model is real, then the family and the community are also part of how we must consider disability. How do we know that a disabled person whose life seems a misery is not killed because his mother or his doctor simply cannot bear to see how completely ineffective are their own efforts to help? The difference between withdrawing life support and euthanasia seems huge to me, but maybe it is not. My friend Ed slept in an iron lung for 42 years. Is that life support, or is it an accommodation? Would it be different if Ed had an intellectual disability instead of being a genius with polio? And who can say it is better for a family if a profoundly disabled baby dies in 10 hours instead of 10 days or 10 months? I lived through raising such a child to become a man, and I cannot imagine life without him. When I try, it seems empty, sad, and cold. I cannot know what I would have learned differently had he died in the first 10 days of his life rather than dying after 30 years.

There is an intellectual dishonesty in my last paragraph that I fear is present in many discussions about people with profound disabilities: it is the fallacy of the category. I said "I raised a child like that" but, in fact, it is probably true that profoundly disabled people are each an "n" of one. Spina bifida has many forms and outcomes, as does Down syndrome, as does autism, as does almost any diagnosis. Yet we speak of these categories as if they were meaningful. And the more profound the disability, the less likely the person will be like anyone else. Even as diagnoses proliferate, I doubt that they can honestly be treated as categorical to the extent that they can drive life or death decisions.

If each life is different from all others, it is possible that any given disabled advocate or spokesperson does not know what would be good for every disabled person. I do understand that each person's decisions may affect all of society, but people with disabilities should have the same rights to self-determination as all other people have, including the right to suicide with accommodations or euthanasia if needed. Currently, too many disabled advocates seem to be only tenuously committed to self-determination. They support it only when the person's decisions agree with theirs. I only worry more that euthanasia decisions will be imposed on people who are actually unable to consent, much less to request them according to the protocols.

Consent has two sides. One is the ability to consent to euthanasia, and the other is having the right to consent to treatment or to refuse it. Due to the nature of disability, I lived through my son's death from natural causes when he was 30. It, too, was an extraordinary experience and one that is difficult to explain to others. The diagnosis of heart failure was sure and swift, and complete. Prognosis was not a guess. Everyone knew how heart failure goes. On admission, I was told he might have less than a year to live. The next day, they said maybe a few months or weeks. Or maybe days. Charlie died 10 days later, still in ICU.

My main concern, having lived through my own mother's slow death six years earlier, was that he would be subject to last-minute treatments that would only prolong the inexorable agony of dying. We had to protect my mother from medicine and we were prepared to protect Charlie. Our little supported decision-making team of people who knew him best decided that once he stopped breathing, or if his heart stopped beating, CPR would be something we could not possibly explain to him. We knew it was seldom successful, we knew it was often painful, even breaking ribs, and we knew it would at best bring him back for an hour or a day or two. We did not want him to die being tortured. We did not want breathing or feeding tubes to be placed: we knew those were painful, too, and would add to his anxiety.

As it happened, I was alone with him when he was actively dying early in the morning. The medical team was ready to climb up on his bed and start doing CPR. They almost would not take "No" for an answer, even though "Do Not Resuscitate, Do Not

Intubate" was clearly listed everywhere. They kept asking, "Do you want us to start CPR?" I was trying to be with him, to love him so that he could know it, as he died. And they kept asking.

Some people seek life support for a brain-dead child, or believe severely disabled people should have the same right as others to organ transplantation, for example. I am quite certain we need to ask whether it is forced treatment if we require a person with significant intellectual disabilities to submit to transplantation because their parent wants it. Organ transplantation is not easy. It is not like getting new spark plugs. You live with it for the rest of your life, it can hurt a lot, and your active participation is required every day. Many people decide against transplant when presented with the facts. If a person does not understand these facts, then how can someone else consent to a treatment on their behalf? I am sure that medical science will offer ever more treatments every year, maybe ever more barbarous. People with profound disabilities should benefit equally from advances, but I am worried about how consent can be achieved.

Many children and adults with disabilities endure more ordinary torture in the name of treatment, some of it psychological, some of it physical. Much of that is done quietly, too. If mercy killing, prevention of suffering, and euthanasia are designed to remove the problems of disability from our lives, I wonder whether we live in a world where even disabled advocates are trying to erase disability from our awareness. For example, some people say being disabled is okay because the person can be just like someone who does not have a disability. That is to be valued equally *in spite of* disability. For me, that was never the goal. We wanted to love and value Charlie just as he was, *with* his disabilities. We did not expect him to pass for a non-disabled person or to behave like a non-disabled person. I like to think that we would have declined behavioral, medical, or surgical interventions designed to make him more "normal," if any had been offered. We did decline behavioral interventions that seemed like torture or brainwashing. I have friends who declined surgical interventions for their children. Normalization is sometimes misunderstood, I think: it was meant to ensure that people with disabilities would be included in all of the normal activities of life, not that all people could be forced to be "normal" (whatever that is).

Eugenics was a movement designed to improve the human race by improving our genetic profiles. Mihalyi Czikszentmihalyi, in *The Evolving Self,* points out that genetic evolution is responsible for only a tiny part of human progress. Most of our progress is achieved through mimetic evolution, by learning new tools, ideas, and strategies from each other. There is still much to learn and teach each other about severe disability, how to work with it, how to live with it, and how to die with it.

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Commentary on Reinders, Stainton, and Parmenter's Stimulus Paper

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Introduction

I am writing this commentary as a health professional and as an academic/researcher who has worked within this field for over 30 years. I have no conflict of interest with the writing of this stimulus paper. The views expressed within this commentary are my own personal views and do not reflect those of JPPID and IASSIDD.

I have grown up with children and adults with intellectual and developmental disability (IDD) personally and professionally, in the community and also in hospital settings. I have seen the sadness on parents' faces when their child has been diagnosed with an IDD; the fear of the unknown, the challenges of having to negotiate services, having to explain to family, friends and neighbors, and the new journey they have to experience. But I have more often seen the joy on parents' faces, and their brothers and sisters, when their son or daughter with an IDD makes a new step in the world—smiles, starts school, makes a cup of coffee, makes new friends, goes on a date, gets a job, goes to a New Year's ball, and so on.

Purpose of the Stimulus Paper

The aim of the stimulus paper by Reinders, Stainton, and Parmenter is to "*discuss the medical practices that objectively question human life affected by IDD.*" The paper provides two opposing views, those of society and some medics that regard disability as *"negative," "defective,"* and perceiving people with an IDD to be *"suffering"* and therefore deemed to have a "*poor quality of life.*" The paper explores the termination of babies in their mothers' wombs as the result of their disability (*"mercy killing"*), and of *"eradicating,"* and "*preventing further suffering*" as the direct result of a child being born with a disability. This paper further examines the practices of *"euthanasia"* or "*physician assisted suicide*" that could be offered to people with disabilities, and people with IDD, in decades to come.

This is compared to those "*scientists and advocates*" who view and support people with a disability as making significant contributions in their own lives as individuals, to their families, and society and are thereby supported in having a good quality of life. This stimulus paper pivots upon the proposition of a medical professional diagnosing the unborn child as having a genetic condition leading to a disability (e.g., Down syndrome), which this person perceives will lead to a life of *"suffering"* (physically and/or psychologically) and as a consequence will not have a *"good quality of life."* This judgment then justifies the action of terminating the life of the unborn child as observed in some countries recently.

The paper strongly argues that such alleged medical advancements and consequences of medical practices are leading to a *"New Eugenics"* movement that clearly contradicts the *Convention for the Rights of Persons with Disabilities* (CRPD) adopted by the *United Nations* in 2006. This stimulus paper by Reinders, Stainton, and Parmenter provides a critical argument on a highly emotive, controversial, multifaceted subject where there will be no victors. Many of the questions posed are fraught with moral and ethical interrogations given the sensitivity of the topic under discussion. This is a timely stimulus paper that offers readers an insight held by two opposing camps, those against and those supporting "*ending the lives of person with intellectual or developmental disabilities.*" It is left to readers after reviewing the stimulus paper and the commentaries, to make a judgment.

Society's Position on Disability

The growth in offering commercially available blood tests to screen for genetic abnormalities in pregnant mothers in some countries, resulting in abortions, reignites the perceptions held by society of people with disabilities in the early to the middle of the 20th century which often viewed people with a disability as a social, moral, and economic burden. Such beliefs were then justified in the medical practices of terminating the innocent lives of people with disabilities. Despite medical professionals today arguing their case to be different from the old *"eugenics"* motivation and justifications, the authors of this stimulus paper purport today's medical practices are no different in their moral arguments that people with disability are *"defective"* and of *"poor quality"*: hence, the title of this stimulus paper *"The Quiet Progress of the New Eugenics."* These claims will be strongly contested by some medical professionals as they argue that particular laws and moral and legal *"safeguards"* are in place in the decision to terminate a human life based upon the medical condition of the unborn child.

The authors of this stimulus paper provide a succinct summary of how civic society positively views, understands, and engages with people with disability over the last half of the 20th century and moving into the 21st century from a medical model

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of disability to a "*social disability model*" based on the premise of a *"common humanity"* and *"diversity."* The semantics of disability has changed with people first in language; then people with IDD moving from institutions to community with a greater focus on inclusion, participation, and citizenship; greater understanding of health and behavior from a more bio-psychological-social perspective rather than a biological and disabling view. This fundamental shift has been enshrined in the CRPD adopted by the *United Nations* in 2006 and focuses on improving the quality of life and health of all people with disabilities.

As highlighted by Reinders, Stainton, and Parmenter in this stimulus paper, the judged "*poor quality of life*" and *"suffering"* is the clear justification for these disputed practices, therefore defining "*quality of life*" is a central tenet within the paper—whether it be health-related quality, and only health is considered, as within medicine compared to quality of *"life domains"* or within social sciences where other dimensions of quality are considered (e.g., relationships, participation, inclusion, citizenship). Measures of quality of life differ depending when used for the unborn child or an *"end-of-life decision,"* both having strengths and limitations. Differences clearly exist between standardized assessments of quality of life compared with the persons' lived quality of life pertaining to "*social belonging and affection."* But what clearly stands out is the impact person-centered services can have on the quality of life for a person with an IDD and their families: with significant progresses in many countries over the last few decades.

Defense for Contentious Medical Actions

The authors then explore how the decision is taken to legally terminate premature babies with severe disabilities and life threatening conditions: the so called *"mercy killings."* The Groningen Protocol (GP), developed within the Netherlands in 2004, which legally examines withholding or withdrawing life sustaining treatment to neonates with life threatening conditions, is uncontested. But the issue here is those *"disabled infants"* that will survive their illness on their own, even after life sustaining treatment is withdrawn: but will lead to *"unbearable pain"* and *"suffering."* Reinders, Stainton, and Parmenter clearly highlight the serious flaws within the GP that medics, and others in society, hold in the assessment that unborn babies within their mothers' wombs who are identified to have a severe disabling condition, therefore legitimize a termination, based on the judgment of the child's "*future suffering and poor quality of life."* The authors dispel this on three counts: (1) reports of quality of life by children and adults with IDD do not state *"suffering"* and "*poor quality of life";* (2) medics and health professionals under-estimate the disabled person's "*quality of life"* compared to the disabled person's accounts; and (3) medical predictions about quality of life do not appear to be very reliable. Being born and living with a disability, is the *"normal state"* for that person born with Down syndrome or other genetic/chromosomal conditions. If we espouse the GP based upon these prejudiced decisions, then it can be strongly purported we endorse the new *"eugenics movement."*

Recent Genetic Testing

Although genetic screening for pregnant women is routinely offered in many countries, governments do not directly prevent the birth of children with IDD. However, because of "*Non-Invasive Prenatal testing"* (NIPT), public authorities indicate that such procedures are an option with the aim of enhancing informed reproductive choice. Mothers are now given the option of having a child with a genetic disposition who will subsequently develop a medical condition and/or a disability and will experience *"suffering"* and a "*poor quality of life."*

It is recommended that parents should be given information about personal risk factors to inform their decision-making process. But what counts as *"relevant information"* and what is required to make this informed decision? Parents from the Netherlands, Canada, and other countries report that any written information given, and also verbal accounts provided by many medics, fail to provide greater details of what life is like to have a son/daughter with Down syndrome, and more importantly, the positives of having a child with a disability for the whole family. Instead, they are left with the negative stereotypes of disability held by society so often given to parents who have to make these moral and emotionally charged informed-decisions about terminating a pregnancy or giving birth to a son or daughter with a disability. Studies from both the United States and Japan state that children and adults with Down Syndrome are happy with their lives: and many parents report the joys of having a child with Down syndrome.

Disappearance of Down Syndrome

Pre-natal screening via NIPT for Down syndrome is now routinely offered in over 90 countries and recommended by professional societies. Reinders, Stainton, and Parmenter highlight that the routinization of such screening reflects society's intolerance and lack of support for those people with disabilities. A simple blood test cannot offer pregnant women enough information to make an informed decision, yet the number of children born with Down syndrome is decreasing in some countries as a result of elective abortions. There is an increase in some countries of the *"uptake"* ratio of the NIPT blood test (Denmark, Iceland, China, and Spain) with higher abortion rates. And in other countries, although the "*uptake"* rate of NIPT is much lower for the Netherlands with <50%, there are high abortion rates (>90%).

It appears there is a growing disappearance of children with Down syndrome as we move into the middle of the 21st century; with China, Denmark, and Iceland, the most frequently cited countries where Down syndrome is disappearing. However, with increased maternal age in women, and a greater preference to start a family, some women are choosing not to have the NIPT or not to follow-up on the results. Furthermore, the authors highlight that mothers from high income countries are more likely to choose an abortion for their child screened as having Down syndrome, compared to those mothers from low to middle income countries, and also "*lower socio-economic strata in high-income countries.*" The authors struggle to answer whether Down syndrome is disappearing as there are various trends that cancel each other out. Reinders, Stainton, and Parmenter purport that governments

who promote national genetic screening programs and the NIPT, and the subsequent choice of a termination, to offer pregnant women informed reproductive choices, are therefore accountable for the increase in abortion rates.

Reinders, Stainton, and Parmenter argue that children with Down syndrome have greater opportunities to develop and reach their full capacity today, as a direct result of early intervention, the provision of good quality services and inclusive communities in many countries centered around a loving family. However, parents are not given this *"relevant information"* to make an informed decision by medics.

The situation is being further complicated, by the growth in commercial companies offering pregnant women with a blood test direct from their own home, offering detection of some 7,000 genetic and chromosomal conditions. There is now no *"relevant information"* and no involvement of any healthcare providers to support parents in making an informed decision. In fact, these commercial companies have no interest in providing *"relevant information"* on living with an IDD as it *"undermines customers' propensity to buy their products."*

Euthanasia and Assisted Suicide

Reinders, Stainton, and Parmenter further explore the broader category of "*euthanasia"* or *"end-of-life,"* or "*physician assisted suicide"* for adults with dementia, a terminal illness, and now those with a disability. The main argument for euthanasia and assisted suicide appears to be based on "*physical and psychological suffering*" and terminating a life based on the person's "*poor quality of life*"—similar to the reason given for terminating a pregnancy where the unborn child risks developing a disability. Until recently many people make this end-of-life decision themselves but more controversially there are new cases where healthcare professionals and family members who decide to end a persons' life, and put the persons out of their *"misery"*: a *"mercy killing."* Reinders, Stainton, and Parmenter illustrate some recent legal cases where parents have advocated on behalf of their child with IDD to "euthanize" them because of their *"suffering."* In one specific case, the authors highlight the significant support from society in support of these parents' pleas.

The authors explore the current developments and increase of euthanasia and assisted suicide for adults with cognitive disabilities across Europe, Canada, and the United States. These include: (1) not having a long standing relationship with your own physician; (2) life expectancy of patients has changed from a few months to go beyond two-years; and (3) the changing profile of cases from terminal illness such as cancer 20 years ago, to dementia and psychiatry illness today. More recently, *Medical Assistance in Dying* (MAiD) in Canada has for the first time explicitly included people with disabilities, and therefore people with IDD, to be eligible for euthanasia and assisted suicide. This is a serious cause for concern as those with a severe and profound IDD, with limited or no communication, will be left to *"proxy decision-makers."* Canada and the Netherlands have re-positioned the legal safeguards and potentially opened up a "slippery rope."

Conclusion

I concur with the authors of this stimulus paper that given the complexity of this topic conceptually, morally, ethically, and even though not raised, religiously and culturally, boundaries will be blurred in attempting to make an informed decision on this topic. The authors of this stimulus paper state that there are medics (geriatrics and pediatrics) who would argue that the core of their profession is to decrease human suffering and improve quality of life, and thereby, oppose the termination of unborn babies and end-of-life decisions. Whereas, there are some social scientists (health and social professionals) who would purport that end-of-life decisions may be *"morally acceptable"* in terminal medical cases of cancer and dementia where physical and psychological suffering is clearly observable. But as we read this is now to be extended to those with an IDD.

Other authors like Vizcarrondo (2014) also emphasize the silent evolution of this new *"Eugenics Movement"* within liberal society. Vizcarindo argues that medical supporters of the termination of unborn babies as a result of genetic imperfection as detected through genetic and other reproductive technologies, pursues the same deep-rooted rhetoric of the "*old eugenics movement.*" Reinders, Stainton, and Parmenter in this stimulus paper offer readers a detailed argument of the *"The Quiet Progress of the New Eugenics' Ending the Lives of Persons with Intellectual and Developmental Disabilities for Reasons of Presumed Poor Quality of Life."* It is now left for the readers to make a decision on their own stance on this argument. These commentaries will further afford readers a collection of reflective interpretations on this controversial and contentious matter to support each person in making a decision about Reinders, Stainton, and Parmenter's stimulus paper. Perhaps, it is not that people need to make a decision about the statement but rather that they need to reflect on their own stance on the ethical, moral, and religious, issues discussed.

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