

## Balancing Risks: PND and the “Prevention of Disability”

### “Flawed” Fetuses and Disabled People

The aim of seeing “what is about to be born” is preparing for the future. Prenatal diagnosis evaluates the probability of giving birth to a disabled child, and describes the kind of disability—or frequently, the spectrum of disabilities—the child may have.<sup>1</sup> The official discourse of PND experts affirms that women’s/parents’ awareness of their future child’s potential problems helps them to be ready for the care of a special-needs child. In practice, when abortion for a fetal indication is legal—or available for those who can afford it—such preparation is not infrequently a preparation for the child’s nonbirth. Selective abortion of impaired fetuses has become the main focus of public debates about PND. Termination of pregnancy for a disability risk, critics of this approach argue, gravely harms people living with disabilities by sending a strong signal that their lives have less value than the lives of able-bodied persons.

One of the consequences of the new focus on links between PND and disability rights is a growing difficulty in speaking openly about “selective reproduction.” In the twenty-first century, the professionals’ official discourse, especially but not exclusively in the United States, no longer mentions the “prevention of disability” as a desirable individual or social goal. Even when all the stakeholders know that an early diagnosis of a given fetal malformation will nearly always lead to the termination of pregnancy, it is not acceptable to say this explicitly. In discussing the inclusion of chromosomal microdeletions in non-invasive prenatal testing, the CEO of Natera, the company that produces this test, explained that “nobody in the twenty-first century should have a pregnancy without being screened for these microdeletions. Routine checking for microdeletions could enable more families to prepare for children with special needs.”<sup>2</sup> It is, however,

highly unlikely that Natera's CEO did not know that several among the microdeletions included in Natera's new test (cri du chat [cat's cry] syndrome, Angelman syndrome, 1p36 deletion) cause very severe inborn impairments, and that nearly all the women who receive a diagnosis of one of these conditions would elect an abortion.

Pioneers of PND had a dramatically different point of view. They developed the new diagnostic technology with the explicit aim of helping women to have healthy children by giving them the option to abort impaired fetuses.<sup>3</sup> Contributors to early discussion about PND viewed the termination of pregnancy as the normal—and, for many, desirable—outcome of a diagnosis of genetic anomaly of the fetus. As one of the participants of a 1970 conference on scientific and ethical aspects of PND, organized by the US National Institutes of Health, put it, "It seems to me that all the gentlemen agree, some more explicitly than others, that to abort is a good thing and should be encouraged."<sup>4</sup> In 1975, in discussing the results of a report on the safety of amniocentesis, Theodore Cooper from the US Department of Health, Education, and Welfare strongly defended extending the use of this technique: "Few advances compare with amniocentesis in their capacity of prevention of disability . . . with this technique we can assure the older woman who is pregnant that she need not fear the birth of a child with Down's syndrome and her consequent lifetime devoted to the care of a handicapped child."<sup>5</sup> When the social epidemiologists Mervyn Susser and Zena Stein proposed in 1973 to generalize the use of amniocentesis for the detection of Down syndrome, they argued that "the lifelong care of a severely retarded person is so burdensome in almost every human dimension that no preventive program is likely to outweigh the burden."<sup>6</sup> In the early days of PND, this technology was presented by its promoters as indisputable progress. This view was, however, rapidly contested.

In the 1970s and 1980s, the opposition to PND and selective abortion of "impaired" fetuses came mainly from two groups: pro-life activists, opposed to abortion in general but especially the selection of "fit" fetuses and the disqualification of "unfit" ones, and a fraction of feminist activists opposed to the medicalization and instrumentalization of pregnancy. In the 1970s, opponents of legalized abortion employed "extermination" language and an analogy with the Nazi regime to describe pregnancy termination for a fetal malformation. Thus, in 1974 French parliamentarians opposed to the decriminalization of abortion invoked Nazi physicians, genocide, racial eugenics, and concentration camps. Legalized abortion, they argued, would be the first step in a "monstrous regression" that would lead to the euthanasia of the disabled and the murder of those defined as "useless people."<sup>7</sup> At

that time, Christian theologians in Europe—Catholic, Protestant, and British Anglican—did not have a uniform position on abortion. Some justified termination of pregnancy when its continuation threatened the well-being of the mother or her family. Others explained that the element which makes life as “human life” possible is not the physiological conception but human acceptance.<sup>8</sup> Moreover, in the 1960s and early 1970s, progressive Catholics in the United States did not unconditionally reject termination of a pregnancy as murder. Their opposition to abortion was rooted in their equating the protection of the fetus with the defense of the weak and the vulnerable.<sup>9</sup> The sociologist Kristin Luker, who studied US pro-life and pro-choice groups in the early 1980s, discovered that while public opinion polls indicated that an abortion to prevent the birth of a severely impaired child was acceptable to more than four-fifths of Americans interviewed and had much higher approval ratings than an abortion for “social” reasons, this practice was seen as the least acceptable by pro-life activists. For them, an abortion for a fetal anomaly meant that a human being could be ranked along a scale of perfection, and that people who fall below a certain arbitrary standard of “fitness” could be excluded. Amniocentesis, they claimed, was a “selective genocide against the disabled.”<sup>10</sup>

Feminists opposed PND from a different point of view. They supported women’s aspiration to control their fertility, including through abortion, but at the same time viewed the selective termination of pregnancy as tantamount to transforming women into “producers” of healthy children. Such children will be able to contribute to the economic well-being of society, instead of being a “burden” on it.<sup>11</sup> Abortion for a fetal malformation, some feminists argued, is qualitatively different from an abortion for an unwanted pregnancy. The first they perceived as an unacceptable “quality control” of maternal productivity, while the second was seen as a legitimate exercise of woman’s inalienable right to decide whether she wishes to be a mother in a given moment of her life.<sup>12</sup> Moderate opponents of abortion held an opposite view: they perceived abortion for “social reasons” as the totally unacceptable killing of a future child, but believed that in some cases a termination of pregnancy after a diagnosis of a severe fetal problem could be seen as a lesser evil. Feminists and moderate abortion opponents agreed nevertheless that an abortion for a fetal indication is qualitatively different from an abortion for refusal of maternity.

In the 1980s, abortion for a fetal indication acquired the label *eugenics*.<sup>13</sup> Some participants in the PND debate linked PND with positive eugenics and the parental dream of a “perfect child.”<sup>14</sup> For others, the term *eugenics* pointed to links between PND and negative eugenics, especially the Nazi

extermination of disabled people.<sup>15</sup> The linking of PND with negative eugenics, first advanced by pro-life activists and a small fraction of radical feminists, gained strength through its rapid adoption by disability rights activists, and its integration into their struggle against negative attitudes toward people with disabilities. However, the Danish sociologist Lene Koch points out the dangers of an indiscriminate use of the term *eugenics* to denounce tendencies one wishes to criticize:

Eugenics is open to pejorative use because it is rarely, or only superficially, defined. We may begin by questioning the effects created by the rhetorical use of the term “eugenics.” It seems that the reference to eugenics, perhaps precisely because it is poorly defined, serves the purpose of rendering the activity in question ethically unacceptable. . . . As long as we choose to remain ignorant of the history of eugenics, the term will remain a demon available to all sorts of abuse. The witless reference to “eugenics” with no further specification is empty and more often a function of our own projections and intentions than a reference to history. In addition to its problematic uses as a reference to the past it has the dubious advantage in the present to be able to absorb all sorts of worries and fears from both sides of the genetic negotiation table.<sup>16</sup>

The historian of eugenics Diane Paul has put it more concisely: “To assert that a policy with undesirable effects is also ‘eugenic’ does not add anything substantive to the accusation. What it does add is emotional charge.”<sup>17</sup> The emotional charge of associating PND with Nazi extermination of disabled people steered debates about this diagnostic approach toward discussions about broad moral principles—and away from examining the technical aspects of PND, its contextualized uses, and the interests, including financial, involved in the dissemination of this biomedical technology.

### Birth Defects and Disability

Birth defects include conditions defined mostly as a disability, and those defined mostly as a chronic disease. The term *chronic disease*, the historian of medicine George Weisz had shown, first appeared in the United States in the 1920s and 1930s. The rise of a specific category known as chronic disease was a consequence of attempts to plan and control health costs and address the growing health needs of aging populations.<sup>18</sup> In the United Kingdom and in France, this category was introduced only after World War II. Moreover, entities defined as chronic diseases in the United States, the United

Kingdom, and France were not identical: situated uses of this classificatory category reflected local, social, and political needs. The term *disability*—and its earlier variant, *handicap*—had also arisen as a situated answer to specific social and political problems, above all a need to manage the consequences of human-induced impairments: wars and workplace accidents. The term *disability*, the historian Beth Linder proposes, became increasingly popular throughout the twentieth century, largely because of its usage in the emerging social welfare state. In the early twentieth century, *disability* became a household word for American families with next of kin who had served in the Union army during the American Civil War. Upon their military discharge, injured soldiers would receive “disability ratings” according to a schedule used by the federal government to assign monetary worth to body parts lost in battle. The loss of each body part was correlated to the impact such a loss would have on a man’s ability to perform manual labor.<sup>19</sup>

In the twentieth century, *disability* was linked with the provision of invalidity pensions and free or subsidized health care to veterans and people harmed by their work conditions. Disabled/handicapped people were expected to receive compensation that would make them more equal to able-bodied individuals. Like handicapping in sports, such compensation aimed to offset an unequal capacity to compete in the labor market.<sup>20</sup> Thus, from the early days of its introduction, the term *disability* had a bureaucratic implication: access to specific rights and privileges.<sup>21</sup> In the first half of the twentieth century, this term covered permanent impairments and chronic diseases. Some of the most commonly cited disabilities to warrant payment from the US Civil War-era Pension Bureau were chronic diarrhea, tuberculosis (consumption), asthma, epilepsy, hernia, rheumatism, and malaria.<sup>22</sup> The inclusion of infectious diseases in this list can be explained by the permanent physical, sensorial, and intellectual impairment caused by such diseases: for example, smallpox caused blindness, and tuberculosis caused irreversible malformations of the spine.<sup>23</sup> Moreover, pathologies such as tuberculosis or syphilis were seen as one of the main causes of hereditary birth defects.<sup>24</sup>

Chronic diseases were lumped with disability as late as the 1980s. One of the first peer-reviewed journals in the domain of disability, established in 1982, was *Disability Studies and Chronic Disease Quarterly*. In 1985, its editors decided to remove the words *and chronic disease* from the title.<sup>25</sup> This decision to dissociate disability from chronic disease was related to the rapid development of disability studies as a distinct area of scholarship, and a parallel rejection by the disability rights community of the medical model of disability, which was replaced by the social model of disability. The medical model of disability, scholars and activists maintained, conceptualizes

disability as a long-term or permanent illness or injury and proposes to “fix” it, or at least to attenuate its negative effects at the level of individual functioning. It is a model based on the assumption that an impairment is a deficit that affects every aspect of the life of the person with the disability. Having a disability is associated with the need for medical treatment, financial help, psychological support, and adequate care.

By contrast, the social model of disability stresses that the problems of disabled people originate primarily in prejudices and physical barriers created collectively by able-bodied people, not in the presence of a specific impairment. Physiological impairment is a biological reality, but disability is above all the product of a disabling society, and can be eliminated through social interventions such as adapted education, living conditions, and care—and especially the disappearance of prejudices and discrimination. The medical model became anathema for those disability scholars reluctant to identify disability with disease. As a consequence, these scholars tend to focus on the “healthy disabled”—those who do not use medical services and who can best approximate the activities of nondisabled people.<sup>26</sup> People such as these, especially if they do not suffer from severe physical or intellectual limitations, are also those most likely to live on their own, hold jobs, and participate in social life. The focus on healthy disabled may stem from the importance of groups such as the Deaf community in developing the argument that one should speak about difference or different ways of being in the world rather than “disability.” It may also stem from the important role of organizations of people with stable physical impairments, such as the powerful Association of French Paralyzed People (*l’Association des Paralysés de France*), within the disability movement. As Susan Wendell argues, by minimizing the struggles of illness, these disability activists led many disability scholars to neglect the realities of an impairment coupled with a disease. Consequently, the unhealthy disabled—who seek out medical interventions and live their lives frustrated and disheartened by pain, fatigue, depression, and chronic illness—were relegated to the margins of the disability movement.<sup>27</sup>

The opposition between advocates of the medical and the social models of disability is often not absolute. Disability activists who resist the medical model of disability may at the same time seek recognition from the medical establishment of their special needs, because such an “official” recognition initiates opportunities for receiving targeted help. Societies that tolerate high levels of inequality in other domains such as education or living conditions still aspire to provide equal, or at least not strikingly unequal, access to health care. Biological misfortune is often judged differently from economic or cultural misfortune.<sup>28</sup> In an era of “bureaucratized medicine,” an official

recognition of disability, which often includes a specific diagnosis, is an essential first step in gaining access to institutional advantages.<sup>29</sup> Parents of children with genetic impairments may resist a reductionist definition of their child's condition, yet at the same time eagerly use it to obtain access to special medical and educational services.<sup>30</sup> Nonetheless, people with certain inborn disabilities/diseases increasingly define their condition not as a disease but as an important element of their identity.

Disability activism facilitated the rise of groups of individuals linked through a recognition of shared genetic heritage, a phenomenon named "biosociality" by the anthropologist Paul Rabinow.<sup>31</sup> In turn, the rise of disability-focused identity policies intensified opposition to PND, in the name of defending human diversity and rejecting a utilitarian view of human beings which measures people only according to their productivity. From the late 1980s onward, disability rights activists have become the most visible opponents of PND and selective abortion, and the most powerful advocates of the equation of pregnancy termination for a fetal indication with a "eugenic" extermination of disabled people. The grounding of disapproval of PND in broad moral principles in turn blurred distinctions between highly variable situations, settings, and interventions.

### Disability Rights and PND

Early debates about PND were firmly situated within a public health agenda and were guided by an explicit aspiration to prevent the birth of children with disabilities.<sup>32</sup> In the 1960s, 1970s, and 1980s, this argument was also supported by mothers/parents of disabled children. Mothers of children with hereditary diseases such as hemophilia or thalassemia pressed researchers to find a way to diagnose this condition before birth to allow them to have healthy children, and were willing to go to great lengths to prevent the birth of another disabled child. Mothers of children harmed by rubella fought for better state services for their children, and also backed the development of anti-rubella vaccine.<sup>33</sup> Then from the 1990s onward, a positive view toward efforts to limit the birth of impaired children was replaced with a strong critique of such efforts by disability rights activists.<sup>34</sup> The feminist and disability rights activist Marsha Saxton, one of the most eloquent promoters of this opposition, explained:

The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are "too flawed" at our very DNA core to exist, unworthy of being born. This message is painful to

confront. It seems tempting to take on easier battles or even just to give in. But fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality: we are indeed worthy of being born, we are worth the help and expense, and we know it! The great opportunity with this issue is to think and act and take leadership in the place where feminism, disability rights and human liberation meet.<sup>35</sup>

The German advocate of disability rights Theresia Degener, born without limbs because her mother took the drug thalidomide during pregnancy, has argued that the introduction of prenatal testing strongly resonates with eugenics aspirations and is contrary to a feminist ethos.<sup>36</sup> PND, Degener explains, “transformed pregnancy into a medical production process in which women, at most, constitute the means of production, with production management having long since passed into the hands of gynecologists and human geneticists.”<sup>37</sup> A selective abortion of a malformed fetus is qualitatively different from a termination of an unwanted pregnancy. While the latter is a reaction to elements in the woman’s life that are unrelated to the fetus—such as the woman’s living conditions, family relationships, and how she wants to shape her life—termination of pregnancy for a fetal indication reflects a wish to opt for a so-called normal child and reject a disabled one. The widespread acceptance of the definition of what a normal child/human being is, Degener concludes, is very dangerous, because it can be implemented only within the framework of a politically motivated control program that potentially militates against the interests of all people—men and women, able-bodied and disabled.

Many disability rights activists have strongly protested against an automatic and unthinking description of the birth of a disabled child as a “tragedy,” a description they regard as insulting to all impaired people. Some extended this protest to an argument that the widespread use of PND for a fetal malformation—whatever it may be—is an implicit statement that life with a disability is worthless.<sup>38</sup> This emotionally powerful argument was later renamed the “expressivist objection” to PND and selective abortion.<sup>39</sup> Such an objection, when not connected with opposition to abortion in general, is grounded in the assumption that a woman who discovers that she is pregnant always instantaneously knows whether this is an unwanted or a wanted pregnancy. In the first case, she has the right to decide whether she wants to be a mother; in the second, she has a duty to accept the fetus she is carrying, independently of the traits of her future child.<sup>40</sup> This view also assumes that a pregnant woman either immediately and unconditionally

accepts a disabled child, or swiftly rejects this child.<sup>41</sup> In summarizing the expressivist objection to PND, the disability scholar Claudia Malacrida explains that an abortion of “any” child should be a woman’s right, while abortion of “this” (disabled) child should not.<sup>42</sup>

The development of the expressivist objection to PND was closely associated with the rise of a social model of disability. Not so long ago, advocates of this model argue, Black people were viewed as born with a “racial handicap,” that is, endowed with lower intellectual capacities and an inferior moral sense compared with White people, while homosexuals were perceived as sick people who suffered from a psychiatric disorder. When homophobic and racist views became unacceptable, Blacks and homosexuals were “cured” of their ills. The same will happen, disability activists propose, when a “healthist” and “ableist” society recognizes that nobody is immune from accidents, sickness, and old age, and learns to perceive the variability of human shapes and abilities as an asset, not a problem. People will continue to have different bodies that will function in many ways, but these differences will be not seen anymore as obstacles to full participation in society. Prenatal testing for fetal anomalies will then become unnecessary.

Scholars such as Marsha Saxton, Theresia Degener, and Adrienne Asch, who promoted this point of view, developed fine-grained arguments and engaged in stimulating debates with colleagues who questioned their arguments. Other disability rights activists developed a less nuanced discourse grounded in an analogy between PND and Nazi-style aspirations to exterminate disabled people. Such a view may reflect a long-standing frustration with negative attitudes of many health professionals toward disability, the slow progress of disability rights, and the persistence of discrimination against disabled people. The growing acceptance of the expressivist objection to PND may also be associated with its effective promotion by opponents of abortion, who coupled their own strong objection to the classification of human beings along a scale of perfection with arguments developed by disability rights activists, such as a critique of a utilitarian, neoliberal society in which only “productive” people are seen as entitled to full human rights, while those unable to contribute to the collective well-being through the production of goods or supply of services are perceived as a “burden.”

Advocates of the expressivist objection propose a radical distinction between an abortion of an unwanted pregnancy and an abortion of a wanted pregnancy following a diagnosis of a fetal anomaly. Those who reject this approach believe that a woman’s decision whether to continue a pregnancy is always situated. A woman’s refusal to give birth to a special-needs child, they argue, is not qualitatively different from a woman’s refusal to become a

mother in a specific moment of her life.<sup>43</sup> Arguments employed by abortion opponents against termination of pregnancy for social reasons—defending a life-enhancing attitude that glorifies love and care, and radically rejecting a shallow, materialistic “death culture” in which a woman feels free to kill her future child for self-centered reasons such as professional aspirations or considerations relative to the material well-being of her family—are not very different from those employed to criticize women who terminate a pregnancy for a fetal anomaly.<sup>44</sup> In both cases, women decide that they cannot cope—for whatever reason—with additional tasks of motherhood, or “special motherhood.” And in both cases, those who condemn abortions put to the fore the woman’s selfish attitude. When Pope Francis was asked in February 2016 whether a pregnant woman who learns that the fetus has a severe brain malformation caused by an infection with the Zika virus could consider an abortion, he answered that abortion is “what the mafia does,” that is, “a crime, an absolute evil.” He then explained, “You kill one person to save another, in the best case scenario. Or to live comfortably, no?”<sup>45</sup>

The objection of disability rights activists to the presentation of a birth of a severely impaired child in a negative light occasionally affected the discourse of pro-choice activists who defend women’s right to interrupt a pregnancy. One of the main Brazilian militants in favor of abortion rights, Debora Diniz, has criticized an article proposing that Brazilian women who learn that the fetus they carry is severely malformed after infection with the Zika virus should be able to decide to terminate the pregnancy “in light of the severity of the malformations being identified (not just neurological but also of hearing and sight), with likely extreme negative consequences for the families affected.”<sup>46</sup> Diniz strongly disagrees with this presentation of the dilemmas produced by Zika. She and her colleagues, she explains, are submitting a petition to the Brazilian supreme court to allow pregnant women infected with Zika to choose termination, because “women have the right to decide to be freed of psychological torture imposed by the epidemic. It is not the fetus’s future impairments or the ‘extreme negative consequences for the families affected’ that moves our demand, but the urgency to protect women’s rights in the epidemics.”<sup>47</sup>

A woman’s presumed wish to “live comfortably,” criticized by Pope Francis, may include an apprehension that she may be obliged to radically change her life and dedicate herself to the care of a disabled child. The anthropologist Annemarie Mol decided to undergo amniocentesis because, she explains, “given where I am—I have a healthy child and work that fascinates me and it is difficult enough as it is to juggle between them—I follow the advice [to test for Down risk if the woman is over the age of thirty-five].”<sup>48</sup>

Mol's main points are "given where I am" and "juggle." Decisions about whether to continue a pregnancy, be it with a "normal" or an "impaired" fetus, may reveal "how close to the edge many parents feel when they imagine the juggling of work and family obligations should disability enter an already tight domestic economy."<sup>49</sup> Asked about the reasons for their decision to either continue or terminate a pregnancy after a diagnosis of a fetal impairment, French women focused above all on their capacity to welcome this child into their family and integrate her/him into the web of its social and affective relationships in a given moment of their lives. Another important argument was the (potential) suffering of the future child, even when the experts classified the predicted impairments as minor or moderate. As several prospective parents put it, life on this planet is difficult even without the additional problem of having to deal with a disability.<sup>50</sup>

Orthodox Jewish rabbis implicitly acknowledge the situated character of prenatal decisions. Orthodox Judaism opposes abortion for a fetal indication, but such an opposition is not absolute. The Israeli anthropologist Tsipy Ivry describes two ultra-Orthodox Jewish women who received a PND of Down syndrome. One explained to the rabbinic counselor that she will be fine, and her family can raise an impaired child if this is what God sends them. The community rabbi confirmed that this woman did not overestimate her and her family's strength. In a similar case, a woman diagnosed as having a Down syndrome fetus expressed a fear that a Down syndrome child would "ruin" her family. Her community rabbi confirmed that the second woman's family "are strong people; but not in this area, they're not going to withstand this." The rabbinic counselor ruled accordingly that she could have an abortion. He also told her that "although it is you undergoing the procedure [abortion], the one who shouldn't sleep at night is me, not you; I gave you the halachic [the Judaic religious law] permission." The woman, he added, should know that "she has acted according to the halacha and it's okay."<sup>51</sup>

A woman who feels that she cannot cope with the needs of a disabled child in a given moment in her life may feel differently if her life circumstances change.<sup>52</sup> This is especially true for moderate or "borderline" impairments. A French woman who decided to interrupt the pregnancy after finding out that the fetus lacked a limb explained why: she already had one impaired child, and her husband had just been diagnosed as having Hodgkin's lymphoma and begun intensive chemotherapy. She felt unable to cope with the additional stress of a disabled newborn. Another woman who faced the same decision decided to continue the pregnancy, because her family was fine and she already had two healthy children. Moreover, she

was reminded by her mother that the mother's grandfather had lost a hand during World War I: it was possible to inscribe the child's missing limb in the family's history. Both women ended their interview by stating that under different circumstances, they could have made the opposite decision.<sup>53</sup>

Alison Piepmeier's study of the decisions of women who learned they were carrying a Down syndrome fetus led to a similar conclusion.<sup>54</sup> Piepmeier has a daughter with Down syndrome, and her study of decisions after a positive PND was informed by her personal experience. Her initial assumption was that in mapping the decision-making process, she would find important differences between women who elected to terminate the pregnancy and those who decided to continue it, especially as regards the timing of the assignation of personhood to the fetus. She assumed that women who terminated their pregnancy saw the fetus mainly as an abstract biological entity, while those who decided to continue their pregnancy strongly identified the fetus as their child. However, she did not find any qualitative difference between the decision-making processes of these two groups. All the interviewed women found the process extremely stressful and painful, and all explained that they had to decide about their child's (never the fetus's) fate without knowing how severe the child's disability would be and how it would affect their family's dynamics. As Piepmeier points out, however, similar considerations and feelings can nevertheless lead to diametrically opposed decisions. These decisions, she explains, are always situated, and many women among those who elected to continue the pregnancy and those who chose to terminate it stressed that there is no "right" choice.<sup>55</sup>

The expressivist objection to PND, summed up in the influential volume *Prenatal Testing and Disability Rights*, edited in 2000 by Erik Parens and Adrienne Asch, relies on two arguments: moral and epistemological.<sup>56</sup> PND, promoters of the expressivist objection explain, is morally wrong because it harms people with disabilities and their families, places a lower value on "imperfect lives," and implicitly condemns women who fail to prevent such imperfect lives.<sup>57</sup> It is also epistemologically wrong because it is grounded in false knowledge. Medical experts who promote the selective abortion of impaired fetuses have dramatically inaccurate views of the quality of life of people with disabilities. Physicians' opinions reflect their professional prejudice, and are radically divorced from the lived experience of disabled people.<sup>58</sup> The only reliable experts on a given inborn condition are the people who have firsthand experience of life with this condition: disabled people and those who care for them.

In his review of *Prenatal Testing and Disability Rights*, the bioethicist Paul Ford argues that while this volume raises many important questions, it is mostly about disability, not prenatal testing. The book provides an excellent

description of the social injustice experienced by people with disabilities and their emotional reactions to their current needs. The book's discussion of PND is more problematic:

The prenatal testing debate presented in this book is made muddy on at least three accounts: the use of an extremely broad and inclusive definition of disability, the treatment of the moral question of abortion, and the channeling of social injustices experienced by those with disabilities. Although a part of the debate is always about what is meant by disabilities, the term is used in very different ways in this book; at times it means something like trisomy 13 (a lethal mutation), and other times it means something like deafness. This leads to a great deal of miscommunication and misunderstanding.<sup>59</sup>

In his thoughtful comments on the expressivist objection and the diametrically opposed injunction of some bioethicists such as the philosopher Dan Brock that, given a choice, parents may have an obligation to give birth to a child who is free of impairment in order to increase the child's chances in life, the disability rights activist Tom Shakespeare similarly affirms that developing a general discourse on disability and PND is impossible. Disabilities are different, as are the families that make decisions about the fate of pregnancies. It does not make much sense to treat Tay-Sachs disease, Down syndrome, deafness, and cleft palate in the same way. Many of the problems produced today by the presence of an impaired child result from insufficient support for disabled people and their families. Such support, and not the opposition to PND, should be the focus of disability rights activists. The fear that PND will eliminate human diversity, Shakespeare adds, is an imaginary preoccupation. Less than 10% of all disabled individuals have inborn impairments. Even if the prenatal detection of such impairments was 100% effective—and this is very far from being the case today—it could not produce a disability-free society or even one with a much lower proportion of disabled people. Another argument employed by PND critics, that a selective abortion of a fetus with a given disability badly hurts the feelings of people with this disability, is understandable from an emotional point of view, but is insufficient justification for limiting parental choices. Eating meat, Shakespeare adds, may badly hurt vegetarians' feelings, but this is not an adequate reason for restricting other people's dietetic preferences.<sup>60</sup>

Some feminist scholars have proposed that the expressivist objection to PND adequately captures the difficulties of disabled people while sustaining the important concept of the unique worth of every human being. At the same time, the demand of unconditional devotion from mothers overlooks

how such a demand compromises women's autonomy. It disconnects parenting from its social context and disregards major differences in the level of support provided to families of impaired children. It also disregards that in some circumstances, raising a child with a severe disability obliges the child's mother to spend the rest of her life as the main caregiver for this child, and may also deplete the family's financial resources. Our understanding of the ethics of maternity and parenting, these scholars believe, has been deeply influenced by an ideology of motherhood that privatizes child care and prescribes maternal self-sacrifice as part of the natural female role. When societies do not provide adequate care for all their disabled members, a victory for one discriminated group, people with disabilities, may be obtained through the subjugation of another discriminated group, women.<sup>61</sup>

Another problematic aspect of the expressivist objection is its implicit equation of a fetus with an already existing child, an attitude which strongly resonates with the views of radical opponents of abortion. Yet many future mothers/parents distinguish between a potential and an already existing child. In the last chapter of his book *Far from the Tree*, a compassionate and often moving description of parents' experiences with their "differently abled" children, Andrew Solomon talks about the birth of his and his husband's son, conceived with Solomon's sperm and a donor's egg and carried by a surrogate mother. The egg donor was chosen through a careful selection process, which, Solomon recognizes, was quasi-eugenic. He and his partner looked for intelligence, character, health, and appearance: "I did not want to devalue the extraordinary lives I have come to respect, yet I could not deny that I wanted a child who will be familiar enough so that we could soothe him or her with our mutualities."<sup>62</sup> In the early stages of their "child project," the couple also asked the surrogate mother to undergo screening for Down syndrome risk and other fetal anomalies, implicitly considering an abortion in case of a positive result. By contrast, when after the birth of their child the physicians suspected (erroneously) that the newborn might have suffered bleeding to his brain, Solomon immediately and with great emotion identified himself with his son—that is, a child, not a fetus.<sup>63</sup>

### Uncertain Prognosis and Intellectual Impairment

Debates about PND frequently focus on the moral dilemmas generated by this diagnostic approach. PND, the bioethicist Arthur Caplan explained, produces an irreducible opposition between individuals' right to make choices freely about their reproductive and procreative behaviors, including the right to as much information as possible, and the morally contentious

option of terminating the pregnancy, which may result from obtaining certain information, and which includes an implicit assumption that information about the fetus produced by prenatal tests is always reliable and unambiguous.<sup>64</sup> His main concern is the use of this information, especially the risk of unintended outcomes, which may result from the rapidly growing capacity to identify specific fetal traits before birth, increasingly blurring the line between normality and disorder. This advanced technology may also lead to parental indulgence in whims, fancies, and biases: "To the extent to which the lines between choice and whim remain vague, the potential exists for prenatal testing to be enmeshed in the pursuit of the frivolous or to be put in the service of ignorance, prejudice and bigotry."<sup>65</sup>

Caplan, like many other bioethicists, is mainly preoccupied with events that may unfold in an unspecified future.<sup>66</sup> Such concerns are remote from the dilemmas of most pregnant women who undergo PND. In the early twenty-first century, not many prospective parents are so preoccupied with their future child's physical beauty or musical abilities that they would consider an abortion if the fetus does not have the desired traits or talents. By contrast, many prospective parents are being confronted with the diagnosis of a condition with an uncertain prognosis, or a small but significant risk of a severe impairment of the fetus. Fears of such outcomes may only be intensified by the rapid expansion of the scope of prenatal tests.<sup>67</sup> Many pregnant women and their partners are compelled to make a difficult decision about the management of risks for their future child.<sup>68</sup> Moreover, the definition of an acceptable risk of disability is not the same everywhere: the "tyranny of [prenatal] diagnosis" is often a situated phenomenon.<sup>69</sup> In France, many hospital ethics committees (CPDPNs) perceive a 10% risk of a severe mental impairment as enough to justify a woman's request to terminate a pregnancy, while in Germany genetic counselors attempt to dissuade women from having abortions for risk of intellectual impairment even when such risk greatly exceeds 10%.<sup>70</sup>

The risk of disability for the child is at the same time the risk that a disabled child's care will have negative consequences for the family.<sup>71</sup> Disability rights activists, who rightly protest against a systematic and unthinking presentation of the birth of an impaired child as a "tragedy," may be reluctant to recognize the great diversity of inborn disabilities and their consequences. In the early days of PND, promoters of this approach discussed the financial and emotional costs of care for severely impaired children, but this topic became less visible later, partly because of pressure from activists who insisted on the positive value of educating children with disabilities and the importance of public policies that support impaired people.<sup>72</sup> Few people

object to the principle that society should provide sufficient help to disabled persons and their families. But acceptance of this generous principle is hampered by practical difficulties in fulfilling all the urgent and often competing societal needs. In the meantime, in the great majority of societies families continue to carry the main responsibility for caring for special-needs children and, not infrequently, impaired non-autonomous adults. The material and emotional costs of such care vary greatly: they depend on the family's socioeconomic status, relations between their members, their values and beliefs, their psychological makeup, and the precise nature of the disabled person's physical and emotional problems—a child with a partial visual impairment does not need the same investment in care as a child with severe cerebral palsy.

People with significant learning/intellectual disabilities may need an especially high level of intensive maternal/parental investment in their care. Many genetic anomalies detected by PND are linked to significant intellectual impairments, an issue frequently evoked in early debates about PND.<sup>73</sup> The same is true for many structural anomalies of the fetus detected by diagnostic ultrasound. For example, in 2015 scientists discovered that inborn heart defects are associated with a high risk of neurodevelopmental disabilities.<sup>74</sup> Today, scientists and activists often employ the term *learning difficulties* to describe inborn cognitive problems. This term may be misleading, because often the main problem of people with such problems is not their inability to undertake advanced studies, master complex topics, or even hold a full-time job, but their difficulty in developing meaningful interactions with others, living an independent life, and protecting themselves from abuse and self-harm. When the dominant discourse shifted from a uniformly negative picture of children with a disability, especially intellectual, to a focus on inclusion and progress, it became increasingly difficult to admit that some of these children make only limited progress and are violent, are poorly adjusted, or experience mental health or medical problems along with intellectual disability, and that some families break apart under the pressure of these issues.<sup>75</sup> According to the autism activist Mark Osteen,

Disability studies' adherence to the social-constructionist model, with its heavy debt to Foucault, had helped to foster a set of biases and misrepresentations that, ironically, replicate those historically aimed at disabled people. First, disability studies has been unwilling or unable to theorize impairments, suffering and pain—somatic conditions that accompany or precede disability—or to theorize the body itself, perhaps because doing so would seem to yield the floor to medicine. Second, Foucauldian paradigms that view the subjects as

pure products of competition for power minimize human agency. Third, the breadth of its interdisciplinary research has swept together a wide array of different conditions and embodiments, many of which have little in common. Fourth, disability studies' focus on visible physical disabilities has blinded it to the existence of other, perhaps less obvious but equally significant, (and widespread) disabilities. Last, and most important . . . disability scholarship has ignored cognitive, intellectual or neurological disabilities therefore excluding the intellectually disabled, just as mainstream society has done.<sup>76</sup>

Ideally, the sociologist Gil Eyal and his collaborators propose, society should create a "prosthetic environment" that will allow people on the broad spectrum of autism, intellectual disability, and mental disease to be safe and thrive, but it also should extend the boundaries of such a prosthetic environment and promote a greater range of social environments and experiences. Society, they affirm, should adapt to the needs of people that are different and will not stop being different. All children and all adults with developmental delays should receive all the help they need to fully reach their potential and, later, all the collective help they need to be fully integrated in society.<sup>77</sup>

Yet helping people with intellectual disabilities to live in a safe and supportive environment, without a doubt a worthy goal, depends on the level of public investment provided to achieve that goal. Most industrialized countries, and all developing and intermediary ones, struggle with escalating health care costs and difficulties in providing the right level of care to aging populations, while the overall trend in many countries seems to be (in 2018) the dwindling of resources for the welfare state. In such a situation, increasing help to one group of needy people often leads to a decrease in the level of assistance to other groups of equally needy people. It does not seem very likely that in the near future societies will be able and/or willing to provide the ample resources necessary for the creation of a safe "prosthetic environment" for all the people with intellectual disabilities.<sup>78</sup> Absent such an environment, the care of people with intellectual impairments often depends on their parents' (often mainly mothers') skill in navigating bureaucratic mazes, persistence, and above all intense investment of energy and time. Middle-class mothers can delegate some of their care tasks; low-income mothers often do not have that opportunity. In addition, even affluent industrialized societies rarely relieve parents of impaired and dependent children from worrying about their child's future when they become incapacitated or die.

Societies have made major advances in providing help to people with intellectual disabilities. These advances are summarized in a journal article,

"I Am John," which recapitulates, through a synthetic narrative of a man with "mental retardation," the different stages of dealing with people with this condition in the United States.<sup>79</sup> John's narrative ends with an account of recent developments that enable people with intellectual disabilities to live autonomous or semiautonomous, accomplished lives:

I live in an apartment. I'm six feet tall and have brown hair and brown eyes. I work hard in a restaurant. I bowl on Saturdays and swim on Sundays. In the summer, I play on a softball team. I like rock-and-roll music and pizza. I vote. I pay taxes. I have a girlfriend. We go to rock concerts and dances. I also have mental retardation. I am John.<sup>80</sup>

One sentence is missing from this description: "I'm the best-case scenario." "John" is mildly intellectually impaired. He is able to live a quasi-independent life, has friends and a partner, and holds a job. He also, one can assume, received effective help that enabled him to live such a life.<sup>81</sup> Not all people with intellectual disabilities are so lucky.

Andrew Solomon sums up the unique predicament of parents of intellectually impaired children:

In typical circumstances, to have children who won't care for you in your dotage is to be a King Lear. Disability changes the reciprocity equation; severely disabled adults may still require attention in midlife, while other grown-up children are attending to their own parents. The most effortful stages of dealing with a child with special needs are generally held to be his first decade, when the situation is still novel and confusing, the second decade, because cognizant disabled adolescents, like most teenagers, feel the need to defy their parents, and the decade when the parents become too impaired to continue to provide care and worry acutely about what will happen to their child after they are gone. This account fails, however, to reflect that the first decade does not vary so much from the norm as the subsequent do. Taking care of the helpless disabled infant is similar to caring for a helpless nondisabled one, but continuing to tend to a dependent adult requires a special valor. . . . One mother of a twenty-year-old with severe disabilities said to me, "It's as if I'd had a baby every year for the past twenty years—and who would choose to do that?"<sup>82</sup>

The disability activist and mother of a severely disabled child Helen Featherstone provided a thoughtful and balanced view of the rewards but also the difficulties of raising a child with serious developmental delays.<sup>83</sup> She argued that in some cases, parents tend to exaggerate their child's

abilities and character in order to survive psychologically in a difficult situation, a stance she classified as a necessary delusion.<sup>84</sup> Such cases, one may argue, are not “delusions” but examples of good adaptation. Parents adjusted their expectations about their child to a different reality and learned to enjoy this child as s/he is, an excellent coping strategy when it works.<sup>85</sup>

The care of a disabled child can be a source of deep satisfaction. It can also be very challenging. Only rarely, however, do parents of severely impaired children criticize the masking of some of the harsh realities of their children’s lives:

Where is the description of the months or years of grueling hospitalization with the associated gastrostomy tubes, jejunostomy tubes, and funduplications; the tracheostomies, shunts, and orthopedic, eye, and brain surgeries; hyperalimentation, oxygen tanks, and ventilators? Similarly, there was no mention of bankruptcies, divorces, mental and physical breakdowns, deaths in late childhood, neglected siblings, and suicides caused by the extreme burdens of caring for severely medically and developmentally compromised children.<sup>86</sup>

The activist Helen Harrison explained that it may be difficult for parents of impaired children to speak openly about their daily struggles:

Upon becoming parents of a disabled or “high-risk” child, one of the first things we learn to do is lie—to our friends and family, to the doctors, to our child, and to ourselves. We quickly learn that others do not want an honest answer when they ask, “How are you (or your child) doing?” and we oblige by giving the positive and politically correct answer. . . . We don’t lie just to reassure others. An arguably more important motive is the need to comfort ourselves and give positive meaning to the immense physical and emotional difficulties of our lives. . . . We lie to deny, or at least postpone, unpleasant realities. We believe that our children’s problems can be overcome with therapies, interventions, and, of course, the “right” parental attitude. . . .

Our children’s doctors and therapists instruct us in euphemisms: our children do not have cerebral palsy or autism, they have “tight muscles” or problems with “sensory integration.” Our children are not retarded, but “developmentally delayed.” Disability rights advocates caution us against using phrases that begin with the words “suffering from,” even when our children’s condition involves substantial pain. We learn to keep a straight face when we describe our children as “handi-capable,” “not typically developing,” or “severely differently-abled.” . . . Parents who express unhappiness about the conditions of their children’s lives (and their own) may find themselves barred from

support groups for “negativity.” Physicians and therapists label such parents as “angry” and “embittered” and refer them for counseling and even for investigation as potential child abusers. . . . It is clearly dangerous to challenge other people’s coping mechanisms.<sup>87</sup>

Today, disability activists focus on families’ capacity to adapt and on the advantages and gratifications of raising disabled children, especially those with an intellectual impairment.<sup>88</sup> Researchers who are also parents of disabled children have provided thoughtful, fine-grained, and poignant descriptions of “special parenthood,” its struggles and its blessings.<sup>89</sup> At the same time, many health experts continue to view the education of children with such impairments as a source of serious difficulties for their caregivers.<sup>90</sup> One can argue that both viewpoints are accurate but not for the same people, and sometimes for the same people but not at the same moment in their life. Some people are willing to take risks, thrive in risky situations, and derive immense satisfaction from overcoming obstacles and challenges; others are risk-averse and perform less well under stress. Some people find out that a situation they initially thought would be intolerable turned out to be not only acceptable but deeply fulfilling; others find that the situation is indeed very difficult. PND often cannot predict the future child’s precise risk of impairment. It also cannot predict the consequences of the presence of an impaired child for the family. Disability activists usually point out that predicting the future of any child, or the family dynamic after the birth of a child, is impossible. This is an accurate statement, but since the “taming of chance” in the nineteenth century, our societies have calculated risks, and some risks have been perceived as higher than others.<sup>91</sup> The birth of a child with Down syndrome may be viewed as such a risky event.

### **The Down Syndrome Conundrum**

The transformation of PND into population-based prenatal screening was to an important extent driven by the desire to prevent Down syndrome (DS).<sup>92</sup> “Screening for Down” also became a focus of struggles against the selective abortion of impaired fetuses. Parents of children with DS (or, to be more accurate, some parents of children with this condition) are often at the forefront of the opposition to abortion for this indication. Articles written by these parents often describe the child as lively, funny, bright, and happy.<sup>93</sup> Parents of DS children also complain, with excellent reason, about the excessively negative representation of DS and the persistence of prejudice against

individuals with this condition.<sup>94</sup> Attitudes toward people with Down have partly changed thanks to public campaigns which present them as “different” rather than “retarded”; greater visibility of children and adults with this condition, especially those on the high end of DS-related intellectual impairment, in the public space and in the media; and accessible information about DS on the web.<sup>95</sup> Nevertheless, pregnant women who learn that they carry a DS fetus frequently opt for an abortion, including some who initially opposed termination of pregnancy for this indication.<sup>96</sup>

A meta-analysis of studies on women’s decisions following DS diagnoses found out that when the participants were prospective parents recruited from the general population, 23–33% said that they would terminate; when the participants were pregnant women at increased risk of having a child with DS, 46–86% affirmed they would terminate; and in practice, 89–97% of women who received a positive diagnosis of fetal DS during the prenatal period chose termination. They justified this decision by their comprehension of increased difficulties for themselves as primary caregivers of a disabled child, additional problems for their other children, a potential strain on their marriage, fears that the child would never be independent, and worries about the fate of the child after their death.<sup>97</sup> A woman who aborted a DS fetus explains:

I did do this thing for myself and my family. . . . I did not do it for him at all. Maybe he would have suffered. Maybe not. Maybe I did not want to imagine an isolated, lonely, depressed, retarded adult man. So maybe I did spare him that end. But life has no guarantees for any of us. We all face the possibilities of leading a sick, unhappy life. So I cannot insist I did it for him. I did it for me. I did it for my marriage. I did it for my other child. I did it for my home and job and way of life.<sup>98</sup>

A woman who terminated for DS and cardiac anomalies detected during an ultrasound reports:

My husband and I thought we would keep the baby if it was “just Downs.” I even decided against the triple screen test because I knew I would keep it. . . . But there is nothing like hearing those words to your face, and I am no longer confident what I would do in that situation. I never speak for myself anymore unless I’m actually in the situation because it’s so, so hard to know how you would actually react. Reality of the fetal anomaly news hits so much harder than conceptual thinking takes into account.<sup>99</sup>

Another woman draws on her personal knowledge as a teacher of young people with DS to explain why she personally could not see herself as a mother of a child with this condition:

I knew going in what it would mean to have a child with DS. I remember all too well how cute and sweet and loving the little ones could be. I also remembered how hard to manage the teen boys were. Not that all teen boys cannot be hard, but with DS kids it's a different story. I remember in my teaching that we had to make sure they did not get too bored. If they did, they would start masturbating or trying to touch other students. It was hard as a teacher. As a mother I could not imagine it . . . knowing what I knew about when they are no longer so "cute," well I chose not to have Leif.<sup>100</sup>

DS was and is at the very center of efforts to screen all pregnant women for fetal anomalies. In countries such as the Netherlands, a more positive societal attitude toward people with DS, a good level of support for people with this condition, and (probably) a valorization of women's care tasks are expressed in the low uptake of screening for this condition. If a woman does not consider the possibility of aborting a DS fetus, she will usually avoid potentially stressful and risky diagnostic tests. In such a context, professionals do not see testing for DS as a moral obligation for a pregnant woman, and value the advantages of not knowing. In Denmark or Israel, the norm promoted by professionals is that knowledge about the status of the fetus is a positive value, independent of the woman's attitude toward abortion for this condition, although the great majority of women terminates a pregnancy with a Down fetus.<sup>101</sup> In the United States, DS activists do not attempt to dissuade women from undergoing prenatal tests. Such tests are presented as important to help couples to prepare themselves for the arrival of a "special child." The activists' goal is to promote a positive image of people with DS and prevent selective abortion for this indication.<sup>102</sup>

In discussions about abortion for DS, both sides often implicitly assume the existence of a relatively homogenous entity called Down syndrome, and tend to present people with DS in either a uniformly positive or a uniformly negative light. However, experts who first studied DS (at that time called "mongolism" or "mongoloid idiocy," a term with strong racist undertones) were aware of the great variability in the health and capabilities of people with this disorder. People with DS frequently looked alike, but this superficial similarity masked important differences. In the first edition of his widely read *Textbook of Mental Deficiency* (1907), the British psychiatrist Alfred Tredgold pointed out that despite the great physical similarity of all

the “mongols,” people with this condition display a wide range of mental disabilities: “the milder members generally learn to read, write and perform simple duties with a fair amount of intelligence; the majority belong to medium grade of mental defect, a few are idiots” (that is, severely mentally impaired people).<sup>103</sup> After the redefinition of DS as trisomy 21, specialists stressed that while the presence of three copies of chromosome 21 invariably denotes DS, it fails to provide information about the severity of symptoms in a given individual. The British geneticist Lionel Penrose, one of the leading specialists on DS in the mid-twentieth century, attempted to uncover genetic markers that could be correlated with specific manifestations of DS.<sup>104</sup> He was unsuccessful, as were his followers. In 2018, too, PND of trisomy 21 does not indicate the level of impairment of a trisomic fetus and how much care the child will need.

Parents recruited for research on DS through Down syndrome associations emphasized the positive aspects of educating DS children.<sup>105</sup> Other parents of DS children tell more complex stories. Some who insist on their strong attachment to and unconditional love for their DS child are nevertheless critical of media stories about DS children that tell only how cute and sweet these children are, and fail to report the parents’ difficulties: dealing with the severe health problems that occur in some DS children, confronting their children’s tantrums and disruptive behavior, coping with their children’s limited speech and incontinence, and facing the knowledge that their caregivers’ obligations will never end.<sup>106</sup> Parents’ objections to DS associations’ focusing on high-performing DS people and disregarding children with more severe manifestations of this disorder are not new. In the 1960s, a British mother of a child with DS wrote to the British Down Syndrome Association: “Stuart is nearly six years old. He is not one of the more gifted Down children, in fact the blunt truth is that he is severely retarded. Despite our great efforts to help him to overcome his handicap, . . . he still cannot talk, dress or undress himself.” Another mother complained that the association kept focusing on high achievers among children with Down, and that “they never write or say anything about low-graded Down. My daughter Kelly is 13 years old, but mentally only 2 years old, and I have never read anything from the Association that had anything to do with her, they only seem to like successes. I’m sorry if I sound very bitter, but it’s how I feel very let down by the Association.”<sup>107</sup>

Some parents think that the new rules about the autonomy and dignity of mentally impaired children are a double-edged sword. Despite the caregivers’ good intentions, they can make the situation worse for these children. In the United Kingdom in 2012, a young woman with DS was placed by social services in a flat on her own. After six months, she had put on five

stones (approximately seventy pounds or thirty-two kilograms). Her mother spoke to the social worker, who replied that it was her daughter's choice to eat all day long, then quoted the Human Rights Act. This young woman, her mother believes, is incapable of making such a choice and needs support and guidance, not another bag of potato chips. Alas, she added, individualized supervision and care are expensive, and the conservative British government reduced the funding of care for adults with disabilities. The replacement of the term *mental handicap* with *learning disability* was meant to destigmatize people with intellectual deficiencies, but in fact might have worsened their situation: "The impression created is that we are dealing with people who are just a little bit slow. . . . There is no allowance for the fact that a disabled child will become a disabled adult, seemingly no understanding that a lifelong learning disability is exactly that—lifelong."<sup>108</sup>

Many testimonies of parents and siblings of people with DS give a different, much more upbeat view. They convincingly show that trisomic people can lead happy, fulfilling lives, and that their parents and siblings perceive the experience of living with a DS person as an important source of personal enrichment.<sup>109</sup> On the other hand, the existence of serious educational and care challenges may increase the probability of a less than optimal outcome.<sup>110</sup> All the stakeholders in the polarized debates about PND of fetal anomalies agree to the principle that prospective parents should be able to receive objective and balanced information about the consequences of the detected anomaly for their future child. When dealing with highly variable conditions and with emotionally loaded subjects, the provision of "objective and balanced" information may become a very challenging task. This is nevertheless the goal of recent US laws.

The Prenatally and Postnatally Diagnosed Conditions Awareness Act (Public Law 110-34) was enacted into US federal law in 2008 to increase the provision of accurate, up-to-date, and balanced information about DS to women and families considering prenatal testing. This act, strongly supported by senators Edward Kennedy (Democrat, pro-choice) and Samuel Brownback (Republican, pro-life), is also known as the Kennedy-Brownback Act.<sup>111</sup> Several US states strengthened the federal law through passage of state laws conveying the same message. For example, a Massachusetts law (no. 03825) adopted in November 2011 explains that parents who receive prenatal or postnatal diagnosis of DS should receive at the same time up-to-date, evidence-based written information about DS that has been reviewed by medical experts and national DS associations.<sup>112</sup> A similar act promulgated by the State of Pennsylvania in June 2014, named Chloe's Act for a girl

with DS who inspired the legislation, requires health care providers to make sure that women receive “a full range of factual and supportive information.” The law was adopted by a rare bipartisan vote, with practically no opposition.

Laws that frame obligatory information about DS lump together two distinct situations: pregnant women who learn they are carrying a fetus with DS (today, increasingly during the first trimester of pregnancy) and may face difficult decisions about the pregnancy’s fate, and parents who have just learned that their newborn child has DS and may need material and emotional help to cope with this potentially distressing news.<sup>113</sup> The message implicitly conveyed through the distribution of the same materials to these two different groups is that a DS fetus is identical to a DS child. These materials aim “to correct the incomplete information that leads many women to terminate their pregnancies after a diagnosis or screening.”<sup>114</sup> Tool kits containing information for parents/prospective parents, such as the one produced by the National Down Syndrome Society, contain upbeat, and undoubtedly sincere, testimonies of parents and family members of DS children—those who are coping well with raising a child with this condition. Accordingly, they contain statements such as “The more I interact with someone who has Down syndrome, the more I think I am the one who has one chromosome less, instead of them having one extra. They tend to be loving, caring and forgiving—features we are missing a lot in general society.”<sup>115</sup>

Recently, US anti-abortion activists attempted to bar abortions for DS. In 2013, such a bill was adopted by North Dakota, although no physicians were prosecuted under that law. In 2015, a similar bill was proposed by the Ohio National Right to Life Committee. Mothers of children with Down who testified in favor of passing this legislation spoke about the extinction and culling of DS people. The president of Right to Life explained:

We all want to be born perfect, but none of us are, and everyone has a right to live, perfect or not. You go to any supermarket or mall and see these families who just happen to have a child with Down syndrome, and they will tell you how fortunate they are to have those children. Pretty soon, we’re going to find the gene for autism. Are we going to abort for that, too?<sup>116</sup>

In 2015, the father of a DS girl—born after her parents had learned that the fetus was trisomic, decided to continue the pregnancy, and faced pressures from health professionals to reconsider their decision—wrote an op-ed in the *New York Times* criticizing the proposed Ohio law. Such conservative initiatives, he argues, are insensitive to the dilemmas of parents who

had made a very difficult decision. Moreover, these are not accompanied by a proposal to extend services for special-needs children. The great majority of readers' comments on this piece agrees with the author's two main points: the need to allow women/parents to freely choose whether they want to give birth to a DS child, and the hypocrisy of some conservative politicians, who strongly oppose abortion for a fetal anomaly yet advocate for reducing state assistance for disabled children and adults.<sup>117</sup> These responses also offer contrasting views of DS. Some commentators, often parents or relatives of people with DS, present a very positive view of this condition:

My son defies all the doom and gloom painted here. He is super healthy; works 28 hours a week at a job he has held sixteen years; makes his own meals except dinner, which he shares with us; pays rent and does his chores more reliably than any other family member; uses his iPad and iPhone to talk to his friends; and is generally a delight to be around.

As the father of a 25-year-old with Down Syndrome, I want to assure all respondents offering a long list of rationalizations, that we're OK. Abortion is a personal choice, but the litany of catastrophic consequences attributable to Down Syndrome so many are offering are simultaneously sad, scientifically specious, and unnecessary.

Naia is preparing to go to her high school (11th grade), where she is in an inclusive classroom. Her counselors and team tell us that she is on track for a full diploma.

Twenty years ago my cousin chose to give birth to a child with Down's syndrome. That child is now doing well in college. She never has been a "terrible burden" on anyone, and given her track record, she likely never will be.<sup>118</sup>

Other people, often physicians and educators, give a more pessimistic view of DS:

The poster child for Downs is a grinning little kid who does not reveal the spectrum of Downs disabilities. Yes, many can learn. But many are severely retarded and will never learn. Those who do learn to walk, talk, read a bit, and do simple jobs require a lifetime of extraordinarily hard work from parents. Inch by determined inch, progress is made. Then early-onset Alzheimer's turns it all around. . . . Parent after parent came to my neuropsychology office

(I'm now retired): "He used to be able to fold the laundry." "He used to talk to me." "She used to be able to get dressed on her own." . . . It would be cruel and immoral to force Down's on any pregnant woman. Instead, show them a poster of an adult "child" with Alzheimer's.

As a pro-choice woman and physician, there is no debate here for me. I have treated many children with Down syndrome. Some are happy and live fulfilling lives, but many have serious medical, neurodevelopmental and psychiatric issues. The kids we see on TV or hear human interest stories about are the lucky ones who did really well despite their diagnosis. No one is writing stories about the kids and families that I see.

I am a woman whose entire career was spent working with developmentally disabled children of all ages up to 21 years. . . . Children with Down Syndrome are sick more often and often more sick than their age mates without known genetic disorders. I know too that the incidence of divorce and abandonment of family is disproportionately high among families with children with handicapping disorders. . . . My evidence is not of one child but of hundreds of children and their families.<sup>119</sup>

A woman who decided to terminate a pregnancy with a DS fetus and describes the diagnosis and consecutive decision as the "darkest time in my life" makes a passionate plea:

Please don't pick on tri 21; this is a life-altering and life-threatening genetic condition and like in any other such condition, there are best-case and worst-case scenarios. I am often reminded and comforted by the poster I saw when I first entered the clinic—it said only, "TRUST WOMEN."<sup>120</sup>

Information packets provided as a consequence of Chloe's Law and similar legislation, the bioethicist Arthur Caplan argues, are strongly biased toward a positive view of DS. The message they convey is that DS children may have health and learning problems, but medical advances, devoted parenting, and societal resources will overcome the majority of such problems.<sup>121</sup> These laws, Caplan adds, are radically changing the ideal of value-neutral genetic counseling, because disability and pro-life groups want information that puts disability in a positive light and abortion in a negative light to become part of all counseling.<sup>122</sup> Although information about Down is theoretically expected to help the woman decide about the fate of her

pregnancy, the voices of women who elected to terminate their pregnancy after a diagnosis of fetal DS are conspicuously absent from the information packets about this condition.<sup>123</sup>

Materials distributed to prospective parents in the United States rarely dwell on the severity of the medical problems found in approximately half the children with DS. They explain—accurately—that the health issues of these children are treatable, but not that in some cases the treatment may be long, difficult, and unsuccessful: about 10% of children with DS die before the age of five.<sup>124</sup> They seldom provide quantitative data about the severity of mental impairments among people with DS.<sup>125</sup> An additional, rarely discussed issue is the increased risk of sexual abuse for people with intellectual disabilities, especially women.<sup>126</sup> On the other end of the life spectrum, people with Down face a high risk of an early onset of dementia. Specialists estimate that 77% of people with DS aged sixty to sixty-nine years suffer from dementia, as compared with 2% of people of the same age group in the general population.<sup>127</sup> Genetic counselors trained in the United States in the 1990s were invited by the organizers of the training program to visit families with DS children, but not institutions for those with more severe impairments. They also were not invited to meet with parents whose DS child had died.<sup>128</sup>

DS activists often quote a modern fable, “Welcome to Holland,” that compares the parenting of a DS child to people who planned a trip to Italy but unexpectedly land in the Netherlands. Bitterly disappointed at first, they gradually discover the Netherlands’ quiet charm and hidden treasures.<sup>129</sup> Taking into account the variability of effects produced by the presence of three copies of chromosome 21, it might have been more accurate to tell a story about people who think they are going to Italy, then learn in midair that their original destination has changed and that it is impossible to know where their airplane will land: the less spectacular but enchanting and peaceful Netherlands, the beautiful but more challenging Albania, or possibly, a conflict-torn Syria.<sup>130</sup>

Differences in the capacity of people with DS to live autonomous or semiautonomous lives have important repercussions for their caregivers, who often are the mothers/parents. In one study, the lowest IQ found in DS people aged twenty-one to forty-two years was 8 and the highest 67. It also found that 40% percent of people with Down recruited for the study were able to read, about a quarter could stay by themselves during the whole day, and two-thirds were able to feed, dress, and bathe themselves. By contrast, approximately 25% were unable to accomplish any of these basic functions, and 17% could not be left alone even for a very short time.<sup>131</sup> Care of adults with severe Down may become more demanding as they age. A systematic survey of adults with DS in Rome revealed that nearly all went

to mainstream primary schools, and the majority had secondary education. Later, however, they received very limited support from the community. Their overall level of autonomous functioning was low, and diminished greatly after the age of thirty. In the absence of adequate institutional support, nearly all the surveyed adults with DS lived with their aging parents. Only 10% had occupations outside their home, and very few had social contacts with people besides their immediate family.<sup>132</sup>

Parents who undergo prenatal counseling, the sociologists Aliza Kolker and Meredith Burke have argued, should be informed about all the aspects of DS, positive and negative, including a possibility of the child's early death: "We believe that a condition that entails morbidity and mortality of this magnitude cannot and must not be presented as, 'not a disease but . . . one way of being human.' This falsifies reality."<sup>133</sup>

PND of Down syndrome played a key role in the more extensive use of prenatal screening in the 1990s. From 2012 onward, it has been at the center of efforts to generalize non-invasive prenatal testing (NIPT) for DS. Some parents of children with the condition are hostile toward NIPT, perceived, not without reason, as yet another step in the extension of screening for DS. They emphasize the potential for people with DS to have happy and fulfilling lives, and the existence of high achievers with this condition. They also point out the very real risk of accelerating the transformation of screening for Down into a self-evident element of routine pregnancy monitoring.<sup>134</sup> UK parents of DS children have reported professionals' negative reactions to a woman's decision to continue a pregnancy with a DS fetus; pressures from family members and friends to have an abortion; and, after their child was born, disparaging and hostile reactions to this child, including in some cases remarks that children with DS should not allowed to be born. At the same time, Jane Fisher, the director of the British charity Antenatal Results and Choices, whose aim is to support all women's decisions about the fate of their pregnancy, explained in 2015 that women who decide to terminate a pregnancy after a diagnosis of DS may face strong disapproval for wanting a "perfect baby," or are perceived as selfish and unprepared to "put the extra work in." UK women who openly spoke about their termination of a pregnancy with a DS fetus faced a mind-boggling outpouring of vitriol and hate mail. The reality is, Fisher concludes, that mothers are criticized, whichever path they choose.<sup>135</sup>

### **A Rarely Mentioned Risk: Psychiatric Disease**

The care of an intellectually disabled child may be made more challenging by the intertwining of intellectual disability (and sometimes other types

of disability as well) with mental health problems. A moving article about Rosemary Kennedy, the intellectually impaired daughter of Rose and Joseph Kennedy, explained that while “mentally slow,” she was able to participate in her family’s social life and underwent training to become a teachers’ aide. Then in her twenties she “regressed,” had violent tantrums, and attacked people near her. Her desperate father allowed her physicians to perform a prefrontal lobotomy, hoping that this intervention would put an end to Rosemary’s disruptive behavior. The surgery left her severely impaired. The article starts with the description of Rosemary Kennedy as an “intellectually disabled” person, and ends by describing her fate as a “mental health tragedy.”<sup>136</sup> The two conditions are indeed frequently linked. The problems of educating children with intellectual disabilities may be amplified by a difficulty to cope with the child’s psychiatric and behavioral problems.<sup>137</sup> Mothers of children who display disruptive behavior (with or without additional learning difficulties) are often blamed for their child’s unruly conduct, including by other mothers.<sup>138</sup> In some cases, children with intellectual impairments who were easy to care for when young become more difficult to manage as teenagers. They may become angry, agitated, and aggressive, and their parents may find it difficult to cope with the new situation.<sup>139</sup>

Historically, mental impairment has been systematically linked with a higher-than-average frequency of psychiatric and behavioral problems. Such problems, much more than IQ level or educational achievements, were seen as the main obstacle to the successful social integration of people with mild and moderate intellectual disabilities.<sup>140</sup> Connections between “mental retardation” and behavioral/psychiatric problems were often exaggerated in earlier periods, an attitude that contributed to the mistreatment of people with intellectual impairments. Such connections tend to be downplayed today, a possible reaction to past abuses and the persistence of prejudice.<sup>141</sup> Experts continue, however, to report a higher-than-average frequency of psychiatric disorders among children and adults with intellectual impairments. DS children are more rarely affected by psychiatric problems than those with other intellectual difficulties, but this difference tends to diminish with age.<sup>142</sup> People with DS have a lower ability to read other people’s feelings and to adjust to them, and may have difficulties in changing routines and paying attention; some may be prone to uncontrolled anger and other behavioral problems. Those with milder intellectual impairment, more aware of their limitations, may have a more pronounced tendency to become depressed and anxious.<sup>143</sup> Specialists estimate that the frequency of psychiatric and behavioral problems among people with DS is four to five times higher than the frequency of such problems in the general population. Between 20% and 40% of adults

with DS display such problems—or, to put it otherwise, between 60% and 80% of people with DS do not have psychiatric difficulties. The risk of psychiatric problems in people with Down is in all probability amplified by their social isolation and the scarcity of community living opportunities for DS adults.<sup>144</sup>

Intellectual disabilities became increasingly coupled with manifestations on the autism spectrum. The recent “autism epidemics,” the sociologist Gil Eyal and his collaborators propose, was a direct consequence of the deinstitutionalization of people with “mental retardation,” a movement that started in the 1960s. Such deinstitutionalization, coupled with the rise of parents’ activism and of networks of educational and behavioral expertise, led to a reclassification as autistic for many of the children previously defined as having “mental retardation.” The result was a blurring of boundaries between intellectual impairment, psychiatric disease, and abnormal neuropsychological development.<sup>145</sup> Parents of children with autism maintain, more often than those of children with other kinds of intellectual difficulties, the hope of a significant improvement in their child’s condition.<sup>146</sup> They may also be confronted more often with the behavioral difficulties of their child, such as explosive and destructive anger, an obstacle to the child’s successful socialization.

Recent books about the history of autism—or rather, on the rapidly expanding category of the autism spectrum—stress the need for society to enlarge the definition of normal and accept and embrace behavioral differences. John Donovan and Caren Zuker end their book *In a Different Key* with a story about an autistic teenager bullied on a bus because of his unusual comportment until another person addressed the main bully: “He has autism; what is your problem?”<sup>147</sup> It is very important to protect people with a nonstandard behavior from being tormented in public spaces. It is also important, but more difficult, to promote the acceptance of such behavior in long-term relationships. And it is even more difficult to encourage tolerance of a truly disruptive behavior. According to some evaluations, a majority of children/teenagers with autism have violent outbursts of anger. In one large study, 68% of autistic children demonstrated aggressiveness to a caregiver, and 48% to non-caregiver.<sup>148</sup> The promotion of a greater tolerance of an unusual conduct is an excellent thing. However, an exclusive focus on people with mild behavioral impairments who display, for example, repetitive movements may paradoxically increase the invisibility and exclusion of those with less easily manageable difficulties.<sup>149</sup>

The aunt of an intellectually impaired child with serious behavioral problems, in protesting the inadequate support of parents of “difficult” children, explains:

Raising a developmentally disabled child is often a thousand times harder than raising a non-disabled child. And the parents of disabled kids love them, so that's not the problem. Imagine a child who screams, bites and kicks through every day. And then becomes an adult who does the same thing. Imagine a child who is never fully continent and weighs 300 pounds at 35. . . . Pregnant women who find out they are carrying developmentally disabled kids must think past the cute stage. They must think about adulthood. Because the disabled child is always the center of everybody's life in a family. And the responsibility never, ever ends. I know that not all developmentally disabled kids are like what I've described above, but many are.<sup>150</sup>

The father of another intellectually impaired child states he would never trade his disabled child for anything, but at the same time criticizes well-meaning but misguided "pro-lifers" who condemn selective abortion for a fetal impairment:

They will never be there for the child when they need care, will never gasp at the size of the medical bills greater than my annual salary, will never look at their normal child and consider whether bankruptcy is an option, they will never bite their tongues while enduring wild behavioral challenges, changing bandages or dealing with the intimately human issues of disabled kids that are very different in public than they are in private.<sup>151</sup>

The father of an autistic child describes his and his wife's plight when their teenage son started to use uncontrolled urination as a way to express his unhappiness, frustration, and anger, an attitude which led to the son's social isolation and a parallel isolation of his parents.<sup>152</sup> A woman whose five-year-old son is on the autism spectrum speaks out, displeased with what she sees as sugarcoated euphemisms employed to describe this condition:

"Agitated?" Here's what agitation looks like at my house . . . when our son's rage and frustration spin out of control he'll lash out by hitting, biting, kicking and spitting. He'll throw his toys, chairs, table and easel; run around breaking things; and become a threat to us and to himself. . . . "Crying." The study talks of the crying. The word pales in the face of our son's dissolutions into tears. These days, if he hears a simple "no" or learns of some change in plans, he might launch into a 10-minute jag, where he argues fiercely with us in between the sobs. Then he can quickly escalate to ear-piercing screams lasting another 15 minutes or more. . . . There's also the isolation. I'm a very social person and before my son developed his "bad reputation," I worked

hard to cultivate friends in the building. But then the play dates and birthday party invitations dried up. It's a terrible thing to be ostracized.<sup>153</sup>

In extreme cases, some psychiatrists employ electroconvulsive therapy to make life with severely disturbed autistic children bearable for their families and for the children themselves.<sup>154</sup> In commenting on the especially tragic—and extremely rare—case of Trudy Steuernagel, a Kent State University professor killed by her autistic son, to whom she was fiercely devoted, Stacy Clifford Simplican, who has a brother with autism, argues that it is important to acknowledge the “complex dependency” of some disabled people. People with developmental disabilities and/or mental pathologies, Simplican explains, are vulnerable, but so are the people around them, family members and paid attendants. Narratives about disability may mask the existence of complex dynamics of power within families that care for disabled people, and an increased risk of abuse of impaired individuals and their caregivers.<sup>155</sup>

Autism is seen today as a condition with a high heritability: it is more frequently found in identical twins; families with one autistic child have a higher-than-average chance of having another child with this condition; such a chance rises dramatically in families with two autistic children; and several genes are linked to this condition. There are no (in 2018) prenatal tests for autism. There are, however, prenatal tests for the rapidly increasing number of genetic conditions—for instance fragile X and DiGeorge syndrome (22q11.2 del)—connected with a higher risk of autism and other psychiatric problems, such as severe attention deficit disorder.<sup>156</sup>

Decisions following a PND of DiGeorge syndrome, a condition linked with many health problems but also a high probability of psychiatric disorders, may be especially difficult because of this condition's great variability of expression. Some people are only minimally affected by this mutation, but nearly half of them will have serious psychiatric and behavioral issues. Care for people with this condition may be especially challenging. Their caregivers—nearly always their parents—explain that a high probability of a psychiatric disorder was their greatest source of anxiety, much more than the health problems associated with DiGeorge syndrome.<sup>157</sup> Many among those who took care of affected adolescents and adults complain about an insufficient level of support for families, and worry about what will happen to their child when their health fails or they die. Typical statements:

In general care-managers have been disappointing, particularly in the area of matching needs to programs.

It is much more difficult to advocate for an adult than a child. Doctors, social workers, teachers etc., want the adult to ask/explain things themselves which can be next to impossible for adults with learning disabilities or with anxiety issues.

Families fall apart under the severity of this illness. You don't know what you're dealing with or how to help—or where to go. It is terrible.

The family provides much support that is at times beyond what we can bear. The added stress that this places on everyone makes life very difficult and strains familial relationships.<sup>158</sup>

A woman facing a diagnosis of chromosomal anomaly linked to a higher risk of mental problems and who decided to terminate the pregnancy explains:

There is a lot about this [chromosomal] deletion that looks like a mental illness. I grew up with a sister who is schizoaffective. I have a lot of fear about that. . . . And lo and behold, those very characteristics are part of the behavioral phenotype that has been identified for the chromosome deletion: it was terrifying. . . . When I began reading about this deletion, I went from being absolutely sure I would not terminate to shaking with terror. How could I have a child like this being the way that I am? . . . If I were a different kind of person, looser maybe, I could do this, I could have had this child, I could have parented this child. But here I am, with my own tremendous limitations.<sup>159</sup>

A positive PND is frequently the notification of a risk: a possibility of the best- or worst-case scenario, and all the options in between. Judgmental, simplified pronouncements, be they in favor of a woman's decision to continue a pregnancy or in favor of a termination, rarely take into account the great variety of ways that people deal with risks: for themselves, their future child, and their families. The writer Ayelet Waldman learned that her ten-week-old fetus had a small but non-negligible chance of having severe physical problems and intellectual delays. Waldman, a self-described pessimist, was convinced that her child would indeed suffer from severe anomalies and immediately decided to terminate the pregnancy. Her husband, the writer Michael Chabon, presented by Waldman as an optimist, was convinced of the opposite, and initially opposed an abortion. Later, however, he accepted his wife's point of view:

I think, really, that we have no choice. If we do what you want, if we have an abortion, and it turned out that Rocketship [the fetus] would have been healthy after all, I can live with your mistake. I can love you, no matter what. But if we do what I want, if we have the baby and it turns out that he is not okay, it's too massive of an error. The ramifications are too lasting, not only for us but for Sophie and Zeke [their children]. My mistake will burden them for the rest of their lives with the care of their brother, and burden us so much that our relationships might be in danger.<sup>160</sup>

PND and other approaches such as preimplantation genetic diagnosis, destined to prevent the birth of "flawed" children, have produced new knowledge, new areas of medical intervention, and new ways of preventing consequences that may be seen as negative by prospective parents. They also have produced new dilemmas and, in some cases, maternal/parental stress and guilt. As the anthropologists Tine Gammeltoft and Ayo Wahlberg explain in their discussion about selective reproduction, such technologies

promise to provide new knowledge and enhanced control of reproductive processes, offering novel pathways to intervene in the making of new children. Yet as practiced and experienced, ethnographic evidence indicates, these strivings for control tend to generate new doubts and unknowns. Rather than producing a brave new world of reproductive mastery, selective reproductive technologies throw their users into social worlds of contingency, ambivalence, and disorientation, worlds in which they must grapple with new and perhaps intensified reproductive anxieties and uncertainties.<sup>161</sup>