

# *Challenging Underlying Assumptions of Wrongful Birth*

## *Prenatal Counseling and Self-Perceptions of People with Down Syndrome*

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*Abstract.* The concept of wrongful birth, which is based on the premise that a person would have been better off never having been born, is a serious matter for Catholic obstetricians, especially in the context of prenatal screening. This principle, in conjuncture with the belief that individuals with disabilities have a decreased quality of life, has been used to promote a eugenic mentality. Consequently, prenatal screening tests often are used to identify fetuses with disabilities, who subsequently are aborted. Not only is this practice ethically reprehensible, but its presuppositions about quality of life find little support in the medical literature. In fact, in the case of Down syndrome, there is considerable evidence to the contrary: individuals living with Down syndrome have a high quality of life and are accepted by their families. These data illuminate the discrepancy between how physicians portray Down syndrome to expectant parents and what the literature shows regarding this condition. *National Catholic Bioethics Quarterly* 19.1 (Spring 2019): 37–45.

In 2003, *60 Minutes* told the story of eight-year-old Jade Fields, a severely disabled child who could not walk and who was able to say only a few words. Her mother, Cynthia, stated, “I really did not know how much work it really was, you know. It’s

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so much work.” Cynthia could not “wait to get home to see [Jade], to see her smiling face. . . . What she feels, I feel, ’cause she’s my heart.” All of this seemed very appropriate for the mother of a child with disabilities, but then Cynthia said, “Jade is the best thing that could have ever happened to us, I mean she’s our foundation, she’s our rock. But if we had known, I didn’t have an option.” Cynthia would have had an abortion if she had known of Jade’s condition.<sup>1</sup> Imagine hearing your mother or father say these things to you. The issue of so-called wrongful birth is a serious matter for those who practice obstetrics according to the *Ethical and Religious Directives for Catholic Health Care Services (ERDs)*. The legal subtleties of wrongful birth are beyond the scope of this discussion, which will address this subject from an obstetrical point of view. By examining one of the most common situations where the idea of wrongful birth is raised—pregnancies in which a fetus has been diagnosed with Down syndrome—it can be shown that current practices in prenatal counseling must be modified to more accurately represent the realities of living with a disability.

Ivo Giesen, a professor of private law at the Utrecht University School of Law, in the Netherlands, defines *wrongful birth* as follows:

A so-called *wrongful birth* claim involves a claim for damages *by the parents* of a child for, most importantly, the costs of bringing up the child. The claim is filed because the parents did not want any (more) children, for whatever reason, or did not want the child in question to be born (because of a genetic disability detected during pregnancy), but became parents (again) anyway because of the fault of a third person, that is, the doctor, by not preventing the conception from occurring . . . by not terminating the pregnancy correctly after it has come about (failed abortion) or by not correctly performing the necessary genetic tests.<sup>2</sup>

Wrongful birth is virtually inseparable from the concept of wrongful life, which Giesen defines as “a life full of suffering because of a handicap while the child was not supposed to have been born at all but is born anyway because of a negligent act by the doctor or assistant.”<sup>3</sup> Regardless of one’s view on the morality of wrongful birth claims, the assumption that these individuals suffer must be challenged. If, contrary to common belief, individuals living with disabilities do not suffer significantly because of their conditions, then it is difficult to claim a wrongful birth. As we proceed, we will review some of the medical literature regarding the lives of people with disabilities and their families. But first, let us start with a review of current prenatal testing options and the complexities that surround them.

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1. Rebeca Leung, “Is ‘Wrongful Birth’ Malpractice?,” *60 Minutes*, June 19, 2003, <https://www.cbsnews.com/>.

2. Ivo Giesen, “Of Wrongful Birth, Wrongful Life, Comparative Law and the Politics of Tort Law Systems,” *Journal of the Contemporary Roman Dutch Law* 72.2 (June 2009): 259, original emphasis.

3. *Ibid.* This claim is made “*by a [disabled] child . . . issued by its representatives, that is, most notably the parents,*” original emphasis.

## Prenatal Screening and Diagnosis

To understand more fully the claim of wrongful birth, it is necessary to understand the vast array of available prenatal screening and diagnostic options. Wrongful birth claims allege a failure to diagnose or disclose a birth defect or genetic problem. The rapid expansion of genetic testing options, as well as the ever-increasing pressure to see more patients, puts the physician in a difficult situation. In today's medico-legal climate, it can be difficult to find time to discuss the limitations, risks, and benefits of all available tests with patients. If an error occurs in administering or interpreting these tests, an abnormality might not be diagnosed until after birth even though it was medically possible to detect it in utero.

Mary Norton and colleagues expressed concern about the rapidity with which genetic tests were being released into clinical care after the first commercial cell-free DNA screening test for fetal aneuploidies was released in 2011.<sup>4</sup> They urged physicians who were going to use this new technology to exercise restraint, in part because it was introduced so rapidly. This did not allow health care providers to keep up with the developments pertaining to the use of this technology, which led to the test's being used incorrectly. Physicians were already struggling to provide adequate counseling regarding screening for Down syndrome. How were they going to catch up with this new technology? Norton placed the burden on health care providers to accurately interpret the test results and counsel patients on them. However, expectant parents do not necessarily appreciate the many subtleties of interpreting the results of prenatal tests. Because wrongful birth requires the physician to have either not disclosed this information or not explained it correctly, let us review the differences between screening and diagnostic tests in the context of prenatal genetic counseling.

A screening test gives a patient her risk for a certain genetic outcome; it will not give her a diagnosis, because it does not give a yes-or-no result. For example, screening tests for Down syndrome will not reveal if the unborn child has the disease; they will provide only a risk estimate. When using screening tests, it is important for physicians to consider the sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV). Generally, the more sensitive a screening test, the more likely it is to screen positive if the condition is present. The more specific a screening test, the more likely it is to screen negative if the condition is not present. Screening tests aim to detect as many affected patients as possible, so they are designed to maximize sensitivity at the expense of high specificity. This increases the number of false positives and can cause a great deal of unnecessary anxiety.

PPV and NPV further complicate the picture. PPV refers to the probability that a person has the disease if she screens positive, and NPV refers to the probability that a person does not have the disease if she screens negative. In prenatal screening tests, these can vary on the basis of maternal age: If a fifteen-year-old screens positive, she has a 48 percent chance of having a fetus with Down syndrome. If a

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4. Mary E. Norton, Nancy C. Rose, and Peter Benn, "Noninvasive Prenatal Testing for Fetal Aneuploidy: Clinical Assessment and a Plea for Restraint," *Obstetrics and Gynecology* 121.4 (April 2013): 847–850, doi: 10.1097/AOG.0b013e31828642c6.

forty-year-old screens positive, she has a 93 percent chance of having a fetus with Down syndrome.<sup>5</sup> This discrepancy has to do with the patient's a priori risk and with the sensitivity and specificity of the test that is being performed. In the case of Down syndrome, risk increases with maternal age. The physician must take this fact into account not only when interpreting the results, but also during pretest counseling.

Diagnostic testing is a little easier for patients to understand because it simply provides a diagnosis. For example, a biopsy of a breast mass can be observed under a microscope to determine if cancer is present. The physician actually can see the tissue and make a diagnosis. These tests are more invasive than screening tests and often are administered to verify positive results. While these tests are not completely perfect, they are accurate enough to inform treatment decisions.

Two types of diagnostic tests can be offered to obstetrics patients: chorionic villus sampling and amniocentesis. CVS can be performed from eleven to thirteen weeks of pregnancy, and amniocentesis can be performed as early as fifteen or sixteen weeks. Both tests can cause miscarriage, and the risk when administered by an experienced clinician is between 1 in 300 and 1 in 5,005.<sup>6</sup> Diagnostic testing, then, offers a definitive diagnosis at the risk of pregnancy loss. Screening tests do not involve that risk but are less accurate.

This is not to confuse the reader, but rather to show that even a simple discussion of screening and diagnostic testing can be difficult for the physician to explain in a fifteen-minute prenatal visit. We can see how easily one could forgo the testing and later regret this decision. While we will not spend any significant time examining the role of ultrasound in diagnosing genetic conditions and birth defects, this tool makes the situation even more difficult for the patient to understand.

Aside from the challenges presented by the nuances of prenatal testing, the Catholic health care provider must use these tests within the confines of the *ERDs*. While many of these tests are not intrinsically wrong and can be offered to patients by the Catholic physician in good faith, they can also be used for evil intentions. As discussed explicitly in the *ERDs*, "prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect."<sup>7</sup>

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5. To calculate predictive value, see National Society of Genetic Counselors, "NIPT/Cell Free DNA Screening Predictive Value Calculator," accessed April 30, 2019, <https://www.perinatalquality.org/>.

6. Steven Gabbe et al., *Obstetrics: Normal and Problem Pregnancies*, 7th ed. (Philadelphia: Elsevier, 2017), 210–211.

7. US Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 6th ed. (Washington, DC: USCCB, 2018), dir. 50.

From this standpoint, it is illicit for either the physician or the parents to use these tests with the intention of terminating the pregnancy. However, Catholic physicians still have an ethical obligation to offer these tests to their patients because, as Pope St. John Paul II states in *Evangelium vitae*, these tests can be used for the “serene and informed acceptance of the child not yet born.”<sup>8</sup>

### **Do Individuals with Disabilities and Their Families Suffer?**

The primary claim made by advocates of wrongful birth is that the individuals with the disability and their families will endure suffering throughout their lives because of the disability. We will first review the findings of a study that examined the experiences of families living with a child with Down syndrome. We will then examine the views of women who terminated their pregnancies following a diagnosis of Down syndrome. Finally, we will investigate how societal misperceptions about this condition likely played a role in that decision.

Brian Skotko, a board-certified medical geneticist and the codirector of the Down syndrome program at Massachusetts General Hospital, evaluated how parents of children with Down syndrome feel about their lives. He found that 99 percent of parents loved their children with Down syndrome, and 97 percent were proud of their son or daughter. Only 4 percent regretted having their child. Seventy-nine percent felt that their outlook on life was more positive because of their child, and 95 percent felt that their children without Down syndrome had a good relationship with their child with Down syndrome. Eleven percent reported that their child with Down syndrome placed a strain on their marriage. Interestingly, 11 percent also felt that their children *without* Down syndrome placed a strain on their marriage.<sup>9</sup>

Perhaps the most striking example of the incongruence between negative societal perceptions of life with Down syndrome and reality is illustrated by the self-perceptions of people living with the condition. Skotko’s group administered a validated questionnaire to persons with a wide range of functional skills. Overall, 99 percent were happy with their lives, and 97 percent liked who they were. Ninety-six percent liked how they looked, and only 4 percent were sad about their lives. Ninety-nine percent loved their families, and 97 percent loved their brothers and sisters. Those living in a group home were less likely to make friends easily compared with those living with roommates, by themselves, or with their parents.<sup>10</sup>

Participants were asked what advice they had for new parents of children with Down syndrome. Thirty-five percent stressed that parents should love their baby and

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8. John Paul II, *Evangelium vitae* (March 25, 1995), n. 63.

9. Brian G. Skotko, Susan P. Levine, and Richard Goldstein, “Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers,” *American Journal of Medical Genetics Part A* 155.10 (October 2011): 2339, 2340, doi: 10.1002/ajmg.a.34293.

10. Brian G. Skotko, Susan P. Levine, and Richard Goldstein, “Self-Perceptions from People with Down Syndrome,” *American Journal of Medical Genetics Part A* 155.10 (October 2011): 2362–2364, doi: 10.1002/ajmg.a.34235.

that their baby loves them. They said, “If everyone was as happy as me, that would be great,” and “Don’t be afraid. Your baby will have a wonderful life.”<sup>11</sup> Their voices and perspectives are considerably more powerful than anyone else’s.

Imagine if a new medication ensured that 99 percent of those who took it would be happy with their lives, and 97 percent would like how they looked. It would be a top seller and make the pharmaceutical company a great profit. This medication would be of great value to society. Yet a Dutch study looking at the reasons women terminate their pregnancies after a diagnosis of Down syndrome showed that a very different perception of it is being shared in prenatal counseling.

Marijke Korenromp and colleagues looked at seventy-one women in eight Dutch hospitals who elected to terminate their pregnancies following a diagnosis of Down syndrome. These fetuses did not have anomalies that were incompatible with life, indicating that the decision was not influenced by a poor postnatal prognosis. Almost half of the study population had a college degree or equivalent, and their mean age was thirty-eight years. Investigators surveyed women four months after termination regarding their motivations, reasons for doubt, perceived influences and pressures, and satisfaction with the health care they received. Ninety-seven percent wanted the pregnancy prior to the diagnosis.<sup>12</sup>

Overall, child-related motivations were the most common reasons for termination, yet all women reported motives of self-interest. Ninety-two percent believed that the child would never be able to function independently, and 90 percent believed that the anomaly was too severe. Eighty-three percent believed that the burden of living with Down syndrome would be too heavy for the child. Seventy-three percent were concerned about the welfare of their other children, and 61 percent thought that they would be unhappy being the mother of a child with Down syndrome.<sup>13</sup>

Only 21 percent expressed high levels of doubt with their decision to terminate the pregnancy. Eighty-nine percent were pleased with the amount of information about Down syndrome they received prior to the decision to terminate, and only 6 percent reported having insufficient knowledge regarding Down syndrome prior to the decision to terminate the pregnancy.<sup>14</sup> Comparing these findings with those from the Skotko study clearly shows a great disconnect between parental expectations and the reality of life with Down syndrome.

Is this disconnect related to the malicious intent of obstetricians and genetic counselors? From the data presented, individuals and families do not suffer significantly because of Down syndrome, yet this is the perception that is given to expectant parents. Dorothy Wertz sampled 499 physicians and 1,084 genetics professionals who provide prenatal counseling. Thirteen percent of respondents reported

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11. Ibid., 2365.

12. Marijke J. Korenromp et al., “Maternal Decision to Terminate Pregnancy in Case of Down Syndrome,” *American Journal of Obstetrics and Gynecology* 196.2 (February 2007): 149.e1–149.e2, doi: 10.1016/j.ajog.2006.09.013.

13. Ibid., 149.e3.

14. Ibid., 149.e3, 149.e4.

overemphasizing the negative effects of Down syndrome so that the patient would favor an abortion, and 10 percent of physicians reported urging patients to have an abortion following a prenatal diagnosis of Down syndrome. Approximately one in four physicians either urged their patients to have an abortion or overemphasized the negative effects of Down syndrome in the hopes that they would have an abortion.<sup>15</sup>

Together, these studies strongly suggest that the decision to terminate a pregnancy after a diagnosis of Down syndrome is often influenced by misinformation. Furthermore, individuals with Down syndrome do not suffer as we are led to believe. Based on these data, it is difficult to claim wrongful birth simply because a child is born with Down syndrome. Instead, there should be a surge in claims for wrongful termination due to biased counseling.

### **Do Wrongful Birth Claims Promote a Eugenic Mentality?**

Is there a conscious or subconscious desire to reduce or eliminate the number of individuals living with Down syndrome? In 2004, the National Board of Health in Denmark introduced new prenatal screening guidelines, which extended early, noninvasive screening for Down syndrome to all women. Previously, testing was recommended for women aged thirty-five years and older or who were otherwise at high risk. It was estimated that the new policy would detect 90 percent of fetuses with Down syndrome with a 5 percent false positive rate. Two years after the guidelines were implemented, the number of infants born with Down syndrome decreased by approximately 50 percent from sixty per year (2000–2004) to thirty-two per year (2006). The guidelines emphasize that this screening should be performed only after an informed choice on the part of the patient. The authors of the study report that only 2 percent of the population declined screening, indicating the presence of a strong societal emphasis on avoiding a Down syndrome birth.<sup>16</sup> Karen Brøndum-Nielsen, from the Kennedy Institute, in Glostrup, Denmark, said, “Although we have not yet studied the whole of the population, these numbers are significant enough to show that the new guidelines have been accepted by a great majority of Danish patients.”<sup>17</sup>

No one has expressed concern that the guidelines were introduced prior to any critical analysis of the psychosocial aspect of this new testing regimen. They failed to understand the psychological effect on a pregnant patient who receives a positive screen for a chromosomal abnormality that many times is not present. This may influence the joy and happiness she should feel about bringing a new life into

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15. Dorothy C. Wertz, “Drawing Lines: Notes for Policymakers,” in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch (Washington, DC: Georgetown University Press, 2000), 279, 282.

16. Charlotte K. Ekelund et al., “Impact of a New National Screening Policy for Down’s Syndrome in Denmark: Population Based Cohort Study,” *British Medical Journal* 337 (November 28, 2008): 1, 3, 5, doi: 10.1136/bmj.a2547.

17. Susan Mayor, “Denmark Halves Down’s Births by Non-invasive Screening in Early Pregnancy,” *British Medical Journal* 334.7607 (June 23, 2007): 1291, doi: 10.1136/bmj.39251.369815.DB.

the world. This approach mimics the ready-fire-aim strategy of implementing programs of change. The most concerning aspect of this study is that its tenor implies that the actual goal of the program is to either reduce or eliminate Down syndrome births! While there is no congratulatory tone, nowhere do the authors express regret or concern over the fact that in two years, Denmark had eliminated approximately one-half of Down syndrome births. It is difficult to not suspect the presence of a eugenic mentality masquerading behind the idea of reproductive freedom. However, the clear outcome of the program is to reduce or eliminate Down syndrome births. A wrongful birth claim, then, is a logical extension of this thought: individuals with Down syndrome should be eliminated, and if they somehow make it to birth, there should be compensation for this mistake.

There are hopeful signs that the prevailing tides are changing. In 2014, the Pennsylvania state legislature enacted the Down Syndrome Prenatal Education Act, or Chloe's Law. This law passed with wide support from both Republicans and Democrats in the Senate (50-0) and the House (196-4). This law requires health care providers to present factual information regarding Down syndrome, which can be obtained through the Pennsylvania Department of Health.<sup>18</sup> Would the number of Down syndrome births have been reduced so dramatically in Denmark if there had been a Chloe's Law in place? Would an entire country allow the elimination of a syndrome even though more than 90 percent of affected people are happy with their lives and loved by their families? Has it come to the point where we must legislate informed consent because health care providers do such a poor job of obtaining it?

### **After-Birth Abortion**

A discussion of wrongful birth is not complete without including the topic of after-birth abortion. In some ways, this allows one to see more clearly the absurdity of the wrongful-birth argument. If society wants to hold health care providers liable for allowing infants with disabilities to be born, it is not a great leap to suggest that after-birth abortions would be the next step in the "clinical management" of these pregnancies.

After-birth abortion may seem like a preposterous idea, but unfortunately, this has been proposed in the bioethics literature. Peter Singer, a professor of bioethics at Princeton University, claims,

Sometimes, perhaps because the baby has a serious disability, parents think it better that their newborn infant should die. Many doctors will accept their wishes, to the extent of not giving the baby life-supporting medical treatment. That will often ensure that the baby dies. My view is different from this, but only to the extent that if a decision is taken, by the parents and doctors, that it is better that a baby should die, I believe it should be possible to carry out that decision, not only by withholding or withdrawing life-support—which can lead

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18. PA Act 130, Down Syndrome Prenatal and Postnatal Education Act, Gen. Assembly (July 18, 2014).



to the baby dying slowly from dehydration or from an infection—but also by taking active steps to end the baby’s life swiftly and humanely.<sup>19</sup>

He doubles down on his position by stating, “I don’t want my health insurance premiums to be higher so that infants who can experience zero quality of life can have expensive treatments.”<sup>20</sup> This statement is not from someone on the fringes of society. He was named one of *Time Magazine*’s most influential people in the world in 2005, and he is currently the Ira W. DeCamp Professor of Bioethics at the Princeton University Center for Human Values.

In 2013, Alberto Giubilini and Francesca Minerva argued that “what we call ‘after-birth abortion’ (killing a newborn) should be permissible in all the cases where abortion is, including cases where the newborn is not disabled.”<sup>21</sup> Giubilini and Minerva purposely avoid using the term *infanticide* because, as they state, the status of the newborn who is killed is comparable to that of a fetus, not an infant child. It is easier to sell this concept to society at large if one uses the more normalized term *abortion* rather than *infanticide*.

If after-birth abortion is accepted, would a potential defense against a wrongful life suit be that the parents chose not to have an after-birth abortion, thereby implying a decision to keep the child despite its disability? One day, might society accept euthanasia as the solution to wrongful life suits regardless of the age of the individual who is affected? These are interesting, if horrifying, theoretical questions for now. But the necessity of asking them is evidenced by the concerted efforts in the Netherlands to eliminate all cases of Down syndrome. The rise in wrongful birth claims may be the proverbial canary in the coal mine for future atrocities.

### **Wrongful Birth Contradicts the Inherent Value of Each Person**

Wrongful life claims diminish the value of individuals living with disabilities by saying that it would have been better if they had never been born. To make a wrongful life suit, one must demonstrate that an individual with a disability suffers significantly because of this condition. In the example of Down syndrome, however, this claim is not supported by the medical literature, which indicates that these individuals perceive their quality of life to be quite good. Each human life has an inherent dignity that obligates us to look out for that individual’s best interests. Claiming that someone should not have been born contradicts this belief in the inherent and immeasurable value of each person. We must work diligently to defend and teach dignity in all our patient encounters.

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19. Peter Singer, “Frequently Asked Questions,” accessed April 8, 2019, <https://petersinger.info/>.

20. Peter Singer, quoted in Jessica Chasmar, “Princeton Bioethicist Professor Faces Calls for Resignation over Infanticide Support,” *Washington Times*, June 16, 2015, <https://www.washingtontimes.com/>.

21. Alberto Giubilini and Francesca Minerva, “After-Birth Abortion: Why Should the Baby Live?,” *Journal of Medical Ethics* 39.5 (May 2013): 261, doi: 10.1136/medethics-2011-100411.