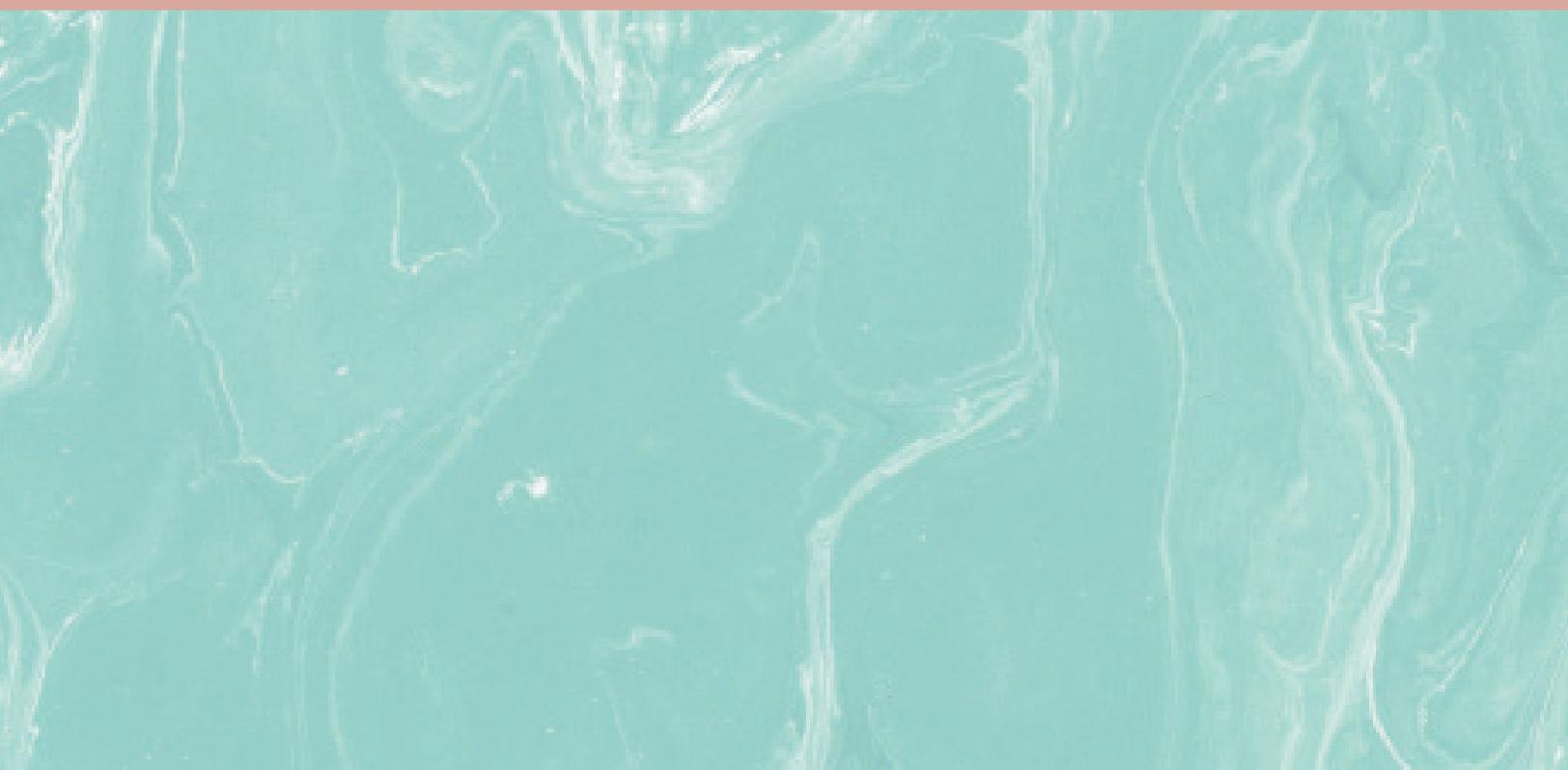




TEACHING HUMAN DIGNITY

*Prenatal Diagnosis &
Disability Selective Abortion*

AN EXPERT GUIDE BY MARY O'CALLAGHAN





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Defining Disability Selective Abortion

Disability selective abortion is the termination of pregnancy that follows a diagnosis of an anomaly prior to birth. Abortions have been reported for minor anomalies such as polydactyly (an extra finger) and cleft lip or palate, but the children most at risk are those with serious chromosomal disorders such as Down syndrome, medical conditions such as cystic fibrosis and/or structural defects such as brain, heart, or kidney malformations. Many genetic disorders detected in utero are associated with multiple problems such as cognitive deficits, physical abnormalities, and other medical issues. Some conditions detected are considered to be “life-limiting,” meaning the child is expected to die during the pregnancy or shortly after birth.

Abortion rates for such serious problems are thought to be consistently and similarly high across disorders. In the United States, comprehensive data on reasons for terminations is not recorded, so disability selective abortion rates consist of estimates from a variety of sources. Recent data suggests that concerns over the “health of the fetus” account for

somewhere between .05% and 3% of all abortions annually. Based on current overall incidence of abortion, it’s estimated that as many as 27,000 infants annually lose their life due to a poor prenatal diagnosis.

There is no readily available data on abortion rates by disorder in this country. The most comprehensive termination rates have been estimated for infants with Down syndrome. Using a meta-analysis of available studies, it’s estimated that between 67% and 90% of these pregnancies end in abortion. Another research group estimated that the net effect of this is that roughly 3,000 infants with Down syndrome are aborted annually. Several studies have estimated that around 80% of children with “life-limiting” diagnoses, including such disorders as Trisomies 13 and 18, anencephaly, and a variety of other potentially fatal conditions are aborted. Abortion rates for cystic fibrosis, from the limited data available, appear to be close to 90%.

History of Disability and Disability Selective Abortion

Disability selective abortion is the latest manifestation of an attitude towards those with disabilities which has taken various forms in recent history, with devastating results. This attitude is that those with serious cognitive or physical disabilities are, at best, non-contributing members of a healthy society, or at worst, detrimental to societal functioning, and their lives are best kept segregated, “prevented” or weeded out in some way.

“*Three generations of imbeciles are enough.*”

—JUSTICE OLIVER WENDELL HOLMES JR.

The eugenics movement in the United States strove to create a “healthy” society by encouraging breeding only among the “fit,” and actively discouraging those considered inferior from reproducing, even to the point of compulsory sterilization. It is best summed up by Justice Oliver Wendell Holmes’ opinion in the Supreme Court Case legitimizing

mandatory sterilization, which declared that “society can prevent those who are manifestly unfit from continuing their kind.” The eugenics movement fell into disfavor in the 1940’s, when Nazi Germany made clear the full horror of this movement when carried to its logical conclusion.

Institutionalization, tied in part to the eugenics movement in our country, but employing different methods, was another “solution” to the problem of those with cognitive disabilities. Based on erroneous assumptions that those with disabilities were not capable of living in mainstream society, most institutions turned into warehouses of humanity where individuals were subject to abusive and inhumane conditions. Exposure of these conditions, fueled by the general civil rights climate of the 1960’s, and accompanied by new educational theories in developmental disability which recognized the potential of these individuals, led to a gradual phasing out of institutionalization in favor of home or small community placements.

Role of Medicine and Technology in Disability Selective Abortion

While abortion has a long history, the advent of disability selective abortion is relatively recent and tied to major advances in diagnostic technologies which occurred in the latter half of the twentieth century. These include amniocentesis, or the removal of maternal amniotic fluid for genetic analysis, and karyotyping, or the mapping of chromosomes

extracted from amniotic fluid. Additionally, ultrasound technology allowed physicians to confirm or evaluate the severity of various disorders as well as signal when genetic testing may be indicated.

Technological advances made disability selective abortions possible, but it was the complex interplay

of this diagnostic technology with legislation, health care policy, and individual parental decisions that contributed to widespread use of this practice.

In 1967, recognizing the capabilities of this burgeoning technology, the American Medical Association (AMA) passed a resolution endorsing abortion in cases where “an infant may be born with incapacitated physical deformities or mental deficiency.” Because abortion was only legal in a handful of states, this statement had limited impact. Shortly after, however, *Roe v. Wade* in 1973 opened wide the door to such abortions. However, it was two lawsuits in 1978 and 1979, respectively, which led to widespread recommendation and use of amniocentesis for diagnosis of chromosomal abnormalities and the abortions which often followed. Both cases involved successful settlement of medical malpractice suits for failing to advise amniocentesis for pregnant women over 35. In both suits, the plaintiffs had given birth to infant girls with Down syndrome. As a result, in 1983 the American College of Obstetricians and Gynecologists (ACOG) recommended offering prenatal screening for all women over 35.

Legalization of abortion and its attendant

“66
“67-90% of children diagnosed with
Down syndrome are aborted.”

philosophies, a litigious health care environment, and policy recommendations had the cumulative effect of increasing abortions by roughly 40% for women carrying babies with both life-limiting diagnoses as well as other serious handicaps. In 1974, an estimated 25% of children with disabilities lost their lives to

abortion; by 1999 this figure rose to 63%.

Using abortion rates of infants with Down syndrome (cited above) as a barometer suggests that this rate has continued to rise, and if the past is any indicator, will continue to do so. This prediction is based on further policy changes and technological advances which have taken place in the past decade or so. In 2007, ACOG updated its screening policy to recommend that all women, regardless of age, be offered prenatal screening. This was motivated by a realization that many children with Down syndrome and other chromosomal abnormalities were going undiagnosed because their mothers were young and considered not at risk. Although age increases risk for certain genetic abnormalities, most children with Down syndrome, for instance, are born to younger mothers simply because overall pregnancy rates are higher for women under 35.

In addition, recent diagnostic innovations have led to the potential for earlier, more detailed, and less invasive prenatal testing. In 2011, the first maternal blood test for chromosomal disorders was announced. This development has the potential to greatly increase the rate of prenatal testing because of its minimally invasive nature. Moreover, it can detect disorders much earlier in pregnancy. Along with this development, technologies such as chromosomal microarray analysis and whole genome sequencing have vastly expanded the scope of fetal characteristics which can be detected during pregnancy.

Taken together, these recent changes in the landscape of prenatal testing indicate that without substantial intervention, the field of prenatal medicine is poised to become an even greater threat to children with disabilities.

This use of diagnostic technology for destruction of fragile lives is certainly not inevitable, and the greatest hope for these children lies in the recovery of a robust model of prenatal medicine. Health care screening and/or diagnosis has traditionally been used as the first step in preventing or treating disease, and this was evident in the work of some pioneers in the first prenatal diagnostic techniques. For example, Jerome Lejeune, who first used karyotyping to detect Down syndrome and other chromosomal conditions, envisioned its use for treating his young patients. Alfred Liley sought to perfect amniocentesis for the diagnosis and treatment of Rh incompatibility in utero. Ian Donald, Scottish developer of the ultrasound machine, was similarly motivated to use his discovery for monitoring the health and safety of unborn children.

The legalization of abortion, as well as the attitudes underlying it, in large part hijacked the field of perinatal medicine with respect to infants with disabilities. Rather than taking the longer and more costly route of developing treatments to respond to poor prenatal diagnosis, the more expedient path of abortion became the standard of care for many conditions. The good of eliminating a disease was cruelly twisted into the evil of eliminating a person. This conflation of a recognized good with an atrocious act perhaps explains why disability selective abortion has thrived relatively unchecked in medicine.

Bioethicists have noted that any aversion to this practice—treating a disease by attacking a person—has been neatly diverted by simply changing the stated goals of medicine. The gold standard of health screening guidelines, published by the World Health Organization in 1968, clearly states: “There should be an accepted treatment for patients with recognized

“*People say, ‘The price of genetic diseases is high. If these individuals could be eliminated early on, the savings would be enormous!’ It cannot be denied that the price of these diseases is high... It is precisely what a society must pay to remain fully human.*”

—JEROME LEJEUNE

disease.” By 2008, these guidelines had been revised to remove availability of treatment as a criterion. In its place has been substituted: “The program should ensure informed choice, confidentiality, and respect for autonomy.” The rationale behind this is that if prenatal diagnosis does seek to “cure” a disease by killing the patient, but only ensures choice and autonomy for the mother, then no ethical codes have been violated.

Even putting aside concerns about the ability of the mother to “freely choose” in such situations, it should be recognized that both models of medicine are impoverished. If obstetric medicine is treating disease by killing the patient, it has ceased to be medicine, and has become, in the words of Jerome Lejeune, “mad science.” Likewise, a model which promotes “autonomy” at the expense of healing, also abandons the practice of medicine and becomes a political tool subject to the whims of the moment. Children with disabilities deserve a return to the true practice of medicine in this field: diagnosis in the service of healing and treatment, and provision of compassionate care when no treatments are available.

The Role of Law and Public Policy in Disability Selective Abortion

Our country has a strong history of legislative protections enacted on behalf of those with disabilities. The movement to ensure these protections began in earnest with the establishment of the President's Panel for People with Intellectual Disabilities by President Kennedy in 1961. In 1966 President Johnson issued an executive order transforming this into an official advisory committee with the goal of securing the right to a "decent, dignified place in society" for those with disabilities. This goal seems to have been fully realized thirty years later, with the passing of the Americans with Disabilities Act (ADA) of 1990, which was meant to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" and boldly stated that "physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society."

It is interesting to note that the AMA first advocated for disability selective abortion in the late 1960's, coincident with the birth of the disability rights movement. The rise of disability rights and disability selective abortion tracked seemingly parallel temporal trajectories in the legal and medical arenas, respectively. The deep discrimination embedded in the field of prenatal medicine, however, went relatively unnoticed by the disability rights movement for decades. The first scholarly treatment of disability selective abortion as a disability rights issue was not published until the year 2000.

Likewise, the first attempt at federal legislation protecting the lives of unborn children with disabilities was not made until 2007. It came as a

direct response to ACOG's recommendation that all women be given prenatal screening. The bipartisan Kennedy Brownback Bill, formally known as the "Prenatally and Postnatally Diagnosed Conditions Awareness Act" was aimed at increasing "the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions."

This legislation was based on the realization that up to this point, prenatal counseling of parents who receive an adverse prenatal diagnosis lacked consistent standards. Whether presented by obstetricians or genetic counselors, information tended to be inaccurate, outdated, and overwhelmingly negative. In worse cases, parents felt no support for carrying these children to term, and often felt pressure to abort.

A number of states enacted similar legislation, called "information laws," in some cases tying these to specific local support programs. With the increasing recognition that accurate information alone may not be sufficient to save lives, states began to further their protection of unborn children by attempting to enact bans on disability selective abortions entirely. In 2013, North Dakota was the first state to do so, followed by Indiana, Ohio, Louisiana, and Kentucky in subsequent years. In all states except North Dakota, these laws have been challenged as unconstitutional. In Indiana, a 7th circuit court ruled that the law does violate the right to abortion, and the state subsequently appealed to the Supreme Court to decide the matter.

As of Spring 2019, the Supreme Court has declined to hear the case, but an opinion by Justice Thomas suggests that the case may be heard after a body of lower court decisions has accumulated in other states. After stating that “enshrining a constitutional right to an abortion based solely on the race, sex, or disability of an unborn child, as Planned Parenthood advocates, would constitutionalize the views of the 20th-century eugenics movement,” he concludes that, “Having created the constitutional right to an abortion, this Court is dutybound to address its scope.”

Timeline

- **1956:** Amniocentesis first used to identify genetic disorders
- **1959:** Karyotyping first used to identify trisomy 21 as cause of Down syndrome
- **1961:** President Kennedy forms President’s Panel for People with Intellectual Disabilities
- **1966:** President Johnson issues executive order to form President’s Committee on Intellectual Disabilities
- **1967:** The American Medical Association passed a resolution endorsing abortion in cases where “an infant may be born with incapacitated physical deformities or mental deficiency.”
- **1960s and early 1970s:** Ultrasound first used clinically to detect and assess the fetus
- **1973:** Roe v. Wade legalizes abortion nationwide
- **1978 & 1979:** Successful settlement of medical malpractice suits for failing to advise amniocentesis for OB patients over 35
- **1983:** ACOG guidelines recommend prenatal testing for all women over 35
- **1991:** Americans with Disabilities Act passed
- **2007:** ACOG revised its guidelines to recommend prenatal testing for all women regardless of age; Prenatally and Postnatally Diagnosed Conditions Awareness Act passed
- **2011:** First non-invasive, early blood test to detect trisomies announced by Sequenom; others follow
- **2012:** First large scale study of CMA (chromosomal microarray) technology for prenatal testing; Whole genome sequencing from fetal DNA in maternal plasma
- **2013:** North Dakota passes ban on disability selective abortions; Indiana, Louisiana, Ohio and Kentucky follow
- **2019:** Supreme Court declines to hear case on constitutionality of disability selective abortion bans

Intersection of Disability Selective Abortion and Human Dignity

Disability selective abortion is a two-fold affront to the dignity of those with disabilities. Primary is the assault on each individual life; characteristics of the child such as cognitive ability and physical health are used as criteria for deciding whether the child will live or die. This brutal sorting of children into those fit or unfit for life fails to recognize the unique, unrepeatable gift and inherent worth of each particular child. It is the ultimate—and lethal—form of discrimination.

Additionally, these abortions threaten the dignity of all those living with disabilities. This concern is known as the “expressivist” argument against disability selective abortion, because these abortions “express” the idea that the lives of those living with disabilities are more burdensome and less desirable than other lives. As one father of a child with Down syndrome put it, they say to his daughter that her life is so different that it merits searching for and destroying other lives like hers.

Why Is it Important for Us to Know About Disability Selective Abortion?

In this first part of the twenty-first century, with strong legislative protections in place and a society which purports to celebrate diversity, it can be tempting to think that the atrocities against persons with disabilities such as eugenics and institutionalization could never take place on our watch. However, violations against human life and dignity are often only acknowledged from the perspective of history. While they are ongoing, it is often difficult to recognize, speak up against, or understand what actions are required to stop them. Disability selective abortion is indeed a grave offense against humanity currently taking place. It is overlooked, perhaps because it is hidden under the guise of routine medical care, and further obscured by the injustice of abortion itself. But, as stated above, it has roots in the same attitudes towards disability which were the source of injustices in the last century, namely that those with disabilities have lives which would be better avoided or eliminated.

It is important to recognize that this attitude persists, albeit in a new form. It is imperative to work to end this practice for the sake of those with disabilities themselves, who are undergoing another large scale and well-orchestrated attack on their dignity and very lives. But it is also important to understand the way in which this practice harms all of us, and this truth is made clear by looking at the effects of similar injustices in the past. After reflecting on the Nuremberg trial for the Nazi medical crimes, for example, Protestant theologian Dr. Karl Barth wrote that “a community which regards and treats its weak members as a hindrance, and even proceeds to their extermination, is on the verge of collapse.” Protecting the most vulnerable among us is in the best interest of us all. ❖

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