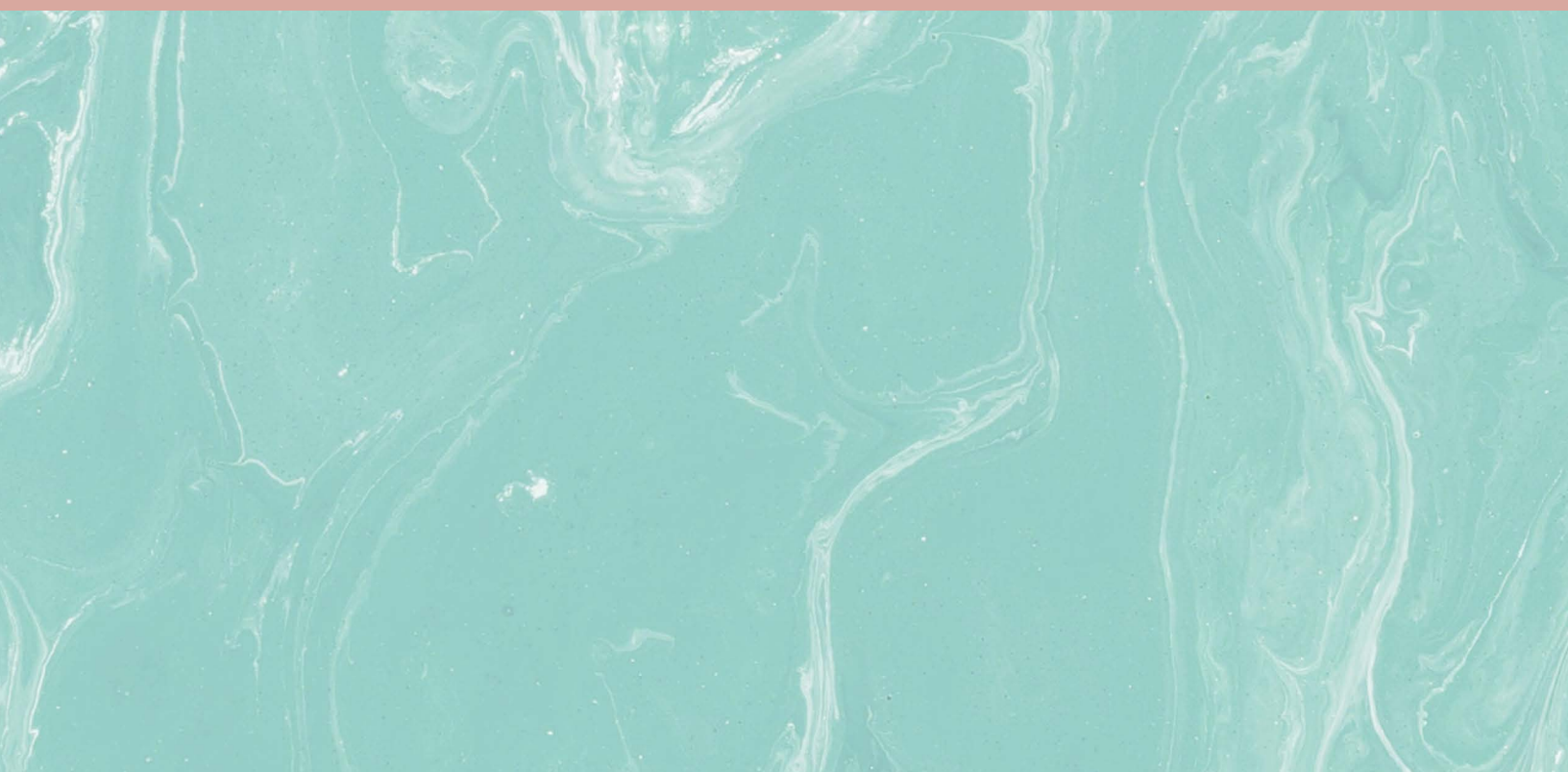




TEACHING HUMAN DIGNITY

*Prenatal Diagnosis &
Disability Selective Abortion*

AN EXPERT GUIDE BY MARY O'CALLAGHAN





Dr. Mary O'Callaghan is a developmental psychologist and a Public Policy Fellow at the diNicola Center for Ethics and Culture, and an adjunct professor of Statistics in Mendoza Business School at the University of Notre Dame. Dr. O'Callaghan received her Ph.D. from Notre Dame under a grant from the National Institute of Health to study developmental disabilities.

Dr. O'Callaghan works on ethical and policy issues related to individuals with disabilities, in particular prenatal diagnosis and disability selective abortion. She is currently researching the economics of prenatal testing in public health care policy, focusing on the “cost-effectiveness” research which evaluates screening and diagnostic protocols.

Her policy work has included testifying before the Indiana and Kentucky state legislatures in support of disability-selective abortion bans, and in Indiana as an advocate for infants with disabilities in support of a ban on fetal dismemberment abortions. She has also testified before the United Nations concerning the scope of international abortions of children with Down syndrome. In addition, Dr. O'Callaghan has spoken at several conferences in the Vatican on disability and mercy, and is the co-founder of and volunteer for *Miriam's Blessing*, a diocesan Perinatal Hospice program which supports parents who receive a poor prenatal diagnosis.



Table of Contents

Defining Disability Selective Abortion	4
History of Disability and Disability Selective Abortion.....	5
Role of Medicine and Technology in Disability Selective Abortion	5
The Role of Law and Public Policy in Disability Selective Abortion.....	8
Intersection of Disability Selective Abortion and Human Dignity	10
Why Is it Important for Us to Know About Disability Selective Abortion?.....	10
References	11



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 metaanalysis 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 3000 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