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ARTICLE

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Trends in Prenatal Diagnosis: Considerations for Catholic Health Care

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Abstract: Prenatal diagnosis of disability often results in abortion; this is particularly true in the instance of Down syndrome. This article draws upon the example of Down syndrome to illustrate and discuss the environment, uses, and implications of prenatal testing. A discussion regarding prenatal testing and obstetric care in the Catholic tradition informs present day challenges to Catholic health care and its role in providing care consistent with its mission. Paucity of available research suggests examination of the experiences of Catholic health care organizations and providers with administration of prenatal testing and delivering prenatal diagnoses is necessary.

Keywords: Down syndrome, prenatal diagnosis, Roman Catholic ethics, selective abortion

DOWN SYNDROME

Down syndrome (also referred to as trisomy 21) is the most commonly occurring chromosomal condition; it affects one in every 691 babies born (National Down Syndrome Society (NDSS) (2011). Down syndrome occurs when an extra copy of chromosome 21 is present, which results in modifications to brain and physical development. Individuals with Down syndrome have some level of cognitive delay; however, the delay mild to moderate in most individuals who have the condition (NDSS 2011; National Institute of Child Health and Development 2011).

While individuals with Down syndrome have the ability to live meaningful lives, elective choices from parents after receiving a prenatal diagnosis of the condition has led to abortions terminating many of these lives prematurely. Studies cite that as many as 90 percent of parents who receive a prenatal diagnosis of Down syndrome elect abortion (Khoshnood, et al. 2006; Mansfield, Hopfer, and Marteau 1999). These statistics bring forth complex considerations, particularly for Catholic health care.

A PRIMER ON PRENATAL TESTING FOR FETAL HEALTH CONDITIONS

1

¹ National Down Syndrome Society (2011), "Down syndrome Fact Sheet," accessed http://www.ndss.org/index.php?option=com_content&view=article&id=54&Itemid=

² National Institute of Child Health and Development, "Down Syndrome" (2011), accessed http://www.nichd.nih.gov/health/topics/down_syndrome.cfm

³ B Khoshnood, C. De Vigan, V. Vodovar, G. Breart, F. Goffinet, and B. Blondel. "Advances in Medical Technology and Creation of Disparities: The Case of Down Syndrome," *American Journal of Public Health* 96/12 (2006): 2139-2144; C Mansfield, S Hopfer, and T Marteau, "Termination Rates after Prenatal Diagnosis of Down syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review" *Prenatal Diagnosis* 19/9 (1999): 808-812.

Fetal diagnosis of Down syndrome has been possible since the 1960s (Collier 2009).⁴ Noninvasive and invasive testing methods allow for detection of possible fetal anomalies including chromosomal disorders. Commonly conducted prenatal testing methods include maternal serum screening, amniocentesis, and chorionic villus sampling. Maternal serum screening is a noninvasive blood-screening test conducted on the mother that may detect fetal health concerns (Emory University School of Medicine 2008).⁵ Invasive tests include amniocentesis and chorionic villus sampling; both are considered invasive because they introduce a foreign object into the womb to extract cells for analysis. Amniocentesis and chorionic villus sampling pose uncommon risks, however, both pose the rare instance of fetal loss (University of Utah Health Care n.d.).⁶

Wasserman and Asche (2006) argue that amniocentesis and chronic villus sampling "needs to be seen for what it is, or more importantly, what it is not. It is not a medical procedure—that is, a procedure intended to protect or restore an individual's physical or mental health. Rather, it is typically a procedure to identify unwanted organisms." While the former analysis may seem desolate to some, their argument is relevant because literature shows that prenatal diagnosis of a disability frequently leads to elective abortion; this is particularly true in the instance of Down syndrome.

PRENATAL TESTING

Intentions and Uses

Practice guidelines recommend that obstetric patients, regardless of age, receive information regarding prenatal screening tests from their health care provider (Nagle, et al. 2008).8 Various views exist in regards to the purpose and intent of prenatal testing. Lawson and Pierson (2007) suggest that prenatal testing provides parents more control over the birth of a child with a disability. Family preparations for the arrival of a child with Down syndrome (for example), as well as allowance of time to facilitate adoption of a baby prenatally diagnosed with the condition are additional reasons expectant mothers undergo prenatal testing (NDSS n.d.).9

Research has examined why patients elect prenatal testing. In qualitative study of 26 expectant mothers, the second most cited reason to undergo such testing was the need to avoid giving birth to a baby with Down syndrome. Participants viewed a baby with Down syndrome as a burden. Their assessment was that burdens included those that are economic, social, and psychological in nature. Participants also expressed that their desire to avoid having a baby with Down syndrome stemmed from concerns over what was best for themselves as well as the baby. One reason for undergoing prenatal testing ranked higher than the avoidance of having a baby with Down syndrome, and this was that study participants viewed the testing as routine and therefore assumed such testing to be customary (Chiang, Chao, and Yuh 2006). These findings highlight that despite sociopolitical advances toward inclusion and acceptance of individuals with Down syndrome, many continue to see the lives of these individuals as diminished.

Lawson and Pierson (2007) published a review of existing research on why women opt for prenatal testing and make reproductive choices as a result. Their review indicated that existing research on the uses of prenatal testing results almost exclusively examines the issue from a rational-choice model approach. They explain that rational-choice models "assume that people are logical decision makers who will weigh the various options and choose a course of action they believe will maximize

⁴R Collier, "Prenatal DNA Test Raises Both Hopes and Worries" *Canadian Medical Association Journal* 180/7 (2009): 705-706, accessed doi: 10.1503/cmaj.090349

⁵ Emory University School of Medicine, "About Maternal Serum Screening" (2008) accessed http://genetics.emory.edu/pdf/Emory_Human_Genetics_About_Maternal_Serum_...

 $^{^6}$ University of Utah Health Care, "Prenatal Diagnosis," accessed http://library.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.html

⁷ D Wasserman and A Asche, "The Uncertain Rationale for Prenatal Disability Screening" Virtual Mentor, 8/1 (2005): 53-56.

⁸ C. Nagle, S. Lewis, B. Meiser, J. Gunn, J. Halliday, and R. Bell, "Exploring General Practitioners' Experience of Informing Women about Prenatal Screening Tests for Foetal Abnormalities: A Qualitative Focus Group Study," *BMC Health Services Research*, 8/114 (2006), accessed doi: 10.1186/1472-6963-8-114

⁹ National Down Syndrome Society, "Understanding the Diagnosis of Down Syndrome," available http://www.ndss.org/index.php?option=com_content&view=article&id=202:und...

¹⁰ H-H Chiang, Y Chao, and S Yuh, "Informed Choice of Pregnant Women in Prenatal Screening Test for Down's Syndrome," .*Journal of Medical Ethics* 32 (2006): 276-277, accessed doi: 10.1136/jme.2005.012385

benefits and minimize risks". They caution, however, that reproductive decisions are not made within silos. Instead, the authors argue that reproductive decisions are made "within social contexts that may constrain the choices they make. Personal beliefs and experiences, family circumstances, medical norms, and the contemporary sociopolitical climate all affect the use of prenatal testing and may limit the extent to which women make fully informed and autonomous decisions". Because of the influential factors noted previously, the authors contend that it is uncertain that rational-choice models are most appropriate for examining how women approach prenatal testing. The analysis by Lawson and Pierson may suggest that a knowledge gap exists in terms of understanding subsequent reproductive decisions that occur because of prenatal testing results.

Other Relevant Considerations

While prenatal tests may offer preliminary or diagnostic information related to a fetal diagnosis of Down syndrome, they are not 100 percent accurate. Emory University School of Medicine (2008) notes that maternal serum screening, for example, detects Down syndrome in 69 – 81 percent of cases where the unborn has Down syndrome; they explain that even with an abnormal maternal serum screening result, a likely outcome is a normal pregnancy. Compounding the uncertainty of prenatal diagnosis of Down syndrome, the environment and delivery of prenatal genetic testing is largely unregulated. There are no laws that restrict or prohibit prenatal genetic testing as a means to garner prenatal fetal diagnoses. According to the Human Genome Project Information page provided by the United States government (2010), there are also no regulations in place that evaluate the accuracy and reliability of genetic testing.

The uncertainty of accuracy in prenatal testing results brings forth ethical concerns regarding elective abortion based on such results. Boyd, Tondi, Hicks, and Chamberlain (2003) found that despite the fact that abortions occurring because of diagnosed fetal anomaly have increased, autopsy rates for aborted fetuses have decreased. Individuals are electing abortions based on somewhat uncertain information; compounding this issue is the fact that little is known about human lives lost through these practices, because parents decreasingly elect autopsy following abortion – for the unborn, their lives and identities are terminated. Aside from moral considerations of the previously mentioned trends, some contend that elective abortion based on prenatally diagnosed disability brings forth considerations related to eugenics.

Garver and Garver (1991) suggest that health care professionals should examine the historical context of eugenics to ensure history not repeat itself. They further argue that respect for human life, including those who have disabilities, is an obligation for those in the health professions. While some may disagree with their assessment, one must recognize eugenic practices that have disenfranchised human life throughout history and consider the possibility that aiming for the "perfect child" is therefore resulting in eugenic practices today. ¹⁵

Leroi (2006) suggests that it is difficult to ignore that abortion based on genetic diagnoses are anything but eugenic practice. He further argues that "these abortions are eugenic in both intention and effect – that is, their purpose is to eliminate a genetically defective fetus and thus allow for a genetically superior child in a subsequent pregnancy." While the term eugenics is not palatable for some to consider, it deserves contemplation in the context of abortion performed because of prenatally diagnosed fetal anomaly.

SECULAR ETHICAL AND LEGAL CONSIDERATIONS

Obstetric care may bring forth ethical dilemmas because of the presence of two patients – the unborn and mother. Chervenak and McCullough (1985) argue that "most often, the moral obligations of a physician to a pregnant woman and her fetus work in concert as the physician and the woman agree on the plan of management that will best serve both the maternal and fetal

¹¹ L Lawson and R Pierson, "Maternal Decisions Regarding Prenatal Diagnosis: Rational Choices or Sensible Decisions?" *Journal of Obstetrics and Gynecology Canada*, 29/3 (2007): 240-246.

^{12 &}quot;About Maternal Serum Screening" (2008)

¹³ United States Department of Energy, "Human Genome Project Information: Gene Testing" (2010)), accessed http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml

¹⁴ P. Boyd, F Tondi, N Hicks, and P Chamberlain, "Autopsy after Termination of Pregnancy for Fetal Anomaly: Retrospective Cohort Study" *British Medical Journal* (2003), accessed doi:101136/bmj.37939.570104.EE

¹⁵ K Garver and B Garver, "Eugenics: Past, Present and the Future," American Journal of Human Genetics 49 (1991): 1109-1118.

¹⁶ A. Leroi, "The Future of Neo-genetics," EMBO Reports 7/12 (2006): 1184-1187.

interests."¹⁷ However, they explain that autonomy-based and beneficence-based obligations to the fetus are equally strong or weighty (to those of the mother) and that moral obligation conflicts often occur in the course of obstetric care. They offer that such conflicts are subdivided into four groups:

- 1) Conflicts between maternal autonomy-based obligations of physician and maternal beneficence-based obligations of physician,
- 2) Conflicts between fetal beneficence-based obligations of mother and the fetal beneficence-based obligations of physician,
- 3) Conflicts between maternal autonomy-based obligations of physician and fetal beneficence-based obligations of physician and
- 4) Conflicts between maternal beneficence-based obligations of physician and fetal beneficence-based obligations of physician.

It is appropriate to consider obligation-based conflicts that may arise when a prenatal diagnosis of Down syndrome is garnered and abortion is considered or elected. For Catholic health care and its practitioners, obligation-based conflicts may be more straightforward; however, the pluralistic reality of society illustrates complexities.

In relation to this article, it is also relevant to consider Roe v. Wade, legalized abortion in the United States. Its landmark ruling cited the ninth and fourteenth Amendments to the United States Constitution as extending a right to privacy so broad that it includes a woman's choice to elect abortion and considers this a decision is most suited to be reached between a woman and her health care provider (United States Conference of Catholic Bishops (USCCB) n.d.). Therefore, on a legal basis, abortions performed on fetuses with Down syndrome and other disabilities are legal. However, the legal nature of the practice does not suggest its moral permissibility. In fact, in Catholic health care, the impermissibility of the act is certain.

PRENATAL TESTING AND OBSTETRIC CARE IN THE CONTEXT OF CATHOLIC HEALTH CARE

A foundational premise of Catholicism is its respect for human life and the sanctity therein; this value system informs the tradition and ministry of Catholic health care. In a secular and pluralistic society, Catholic health care faces complex bioethical issues. The Catholic Church appreciates the unification of science and religion and indeed finds the two compatible. However, troubling statistics and literature previously outlined bring forth considerations in the delivery of obstetric care in the Catholic tradition.

The Catholic Church distinguishes valid uses and applications of prenatal testing; however, recognizes that the temptation to misuse such testing is a powerful one for many (Pacholczyk 2006).¹⁹ Prenatal testing was conceived as a "good". However, "when the intent is accomplished by only delivering healthy babies, while denying life to those deemed less than perfect, a Machiavellian distortion of the good has been achieved" (Hilliard 2010).²⁰ Recognizing increasing capabilities for prenatal diagnosis of Down syndrome and other disabilities, the following explores this issue in the context of Catholic health care.

Ethical and Religious Directives

The Ethical and Religious Directives of Catholic Health Care Services (ERD's) provide guidance for institutions providing health care in the Catholic tradition; its doctrine is relevant to not only organizations, but also to health care professionals who provide care on its behalf. The USCCB (2009) explains that "in a time of new medical discoveries, rapid technological developments, and social change, what is new can either be an opportunity for genuine advancement in human culture, or it can lead to policies and actions that are contrary to the true dignity and vocation of the human person." The influence of prenatal testing in relation to diagnosis of Down syndrome (as well as other disabilities) and related abortion rates provides increasing considerations for Catholic health care; the ERD's offer Catholic health care important guidance.

¹⁷ F Chervenak and L McCullough, "Perinatal Ethics: A Practical Method of Analysis of Obligations to Mother and Fetus," *Obstetrics and Gynecology* 66/3 (1985): 442-446.

¹⁸ United States Conference of Catholic Bishops, "Summary of Roe v. Wade and Other Key Abortion Cases," accessed http://nccbuscc.org/prolife/issues/abortion/roevwade/CaseSummariesforweb...

¹⁹ T. Pacholczyk, "Temptations in Prenatal Testing" in Making Sense out of Bioethics (2006), accessed http://www.ncbcenter.org/page.aspx?pid=286

 $^{^{20}}$ M. Hilliard, "The New Eugenics: Eliminating the 'Undesirable' by Prenatal Diagnosis" (2010), accessed http://www.prenatalpartnersforlife.org/Links/eugenics.pdf

²¹ United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services* 5th ed. (Washington, DC: USCCB, 2009).

Part One of the ERD's addresses issues related to the social responsibility of Catholic health care. In the Catholic tradition, health care is a ministry rooted in commitment to human life and dignity. In this segment of the ERD's, it is stated that "Catholic health care should distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of our society and makes them particularly vulnerable to discrimination". Included in the list of individuals vulnerable to discrimination, the Church specifically speaks to the issue of those who live their lives with a disability. The ERD's indicate, "in particular, the person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate health care as all other persons" (USCCB 2009). The ministry of Catholic health care values all human life and sees no differentiation in individual worth.²²

Part Three of the ERD's speaks to the interpersonal nature of the patient-provider relationship. In this section, the Church addresses various factors that influence patient-provider relationships, including informed consent and decision-making on the part of patients. Prenatal testing in Catholic health care settings should be handled in accordance with the ERD's which state that "each person or the person's surrogate should have access to medical and moral information and counseling so as to be able to form his or her conscience. The free and informed health care decision of the person or the person's surrogate is to be followed so long as it does not contradict Catholic principles."²³ (USCCB 2009). The realities of society suggest that free and informed decisions based on conscience by some patients may lead to a preference to abort their prenatally diagnosed unborn. Catholic teaching is clear on its stance related to the right to life of the unborn and the value it places on human life generally. Catholic health care, therefore, is not obligated to participate in or facilitate abortion services based on the Magisterium of the Church.

Part Four of the ERD's is particularly relevant to prenatal diagnosis of disability. In this segment of the ERD's, the following are noteworthy:

- 1. Prenatal and obstetric care for mothers and their unborn should be provided consistent with the mission of Catholic health care.
- 2. Abortion is impermissible.
- 3. Prenatal diagnosis is permitted insofar as the procedure does not threaten the viability and health of the fetus.
- 4. Genetic counseling is appropriate when the aim is to assist parents in preparation for responsible parenting and preparation for welcoming a child with a disability.²⁴ (USCCB, 2009).

While all directives in the ERD's are important to the delivery of Catholic health care, those in sections One, Three and Four are particularly relevant to prenatal testing and obstetric care.

Challenges to Catholic Health Care

Prenatal testing and abortion arouse complex considerations for Catholic health care as it provides services to a diverse patient population. Patients receiving care from Catholic-affiliated health care organizations may or may not share the views of the Church. As Catholic health care fulfills its ministry in the image of Christ and articulates its mission through the ERD's, it must be prepared for multifarious situations by which patient requests and preferences upon receipt of prenatal diagnosis are not in accordance with the Church and its teachings. The following examines two noteworthy challenges in this context.

Consistent articulation of ministry.

Catholic health care must consistently articulate its ministry in order to avoid dissonance related to its mission. The risks of blurring the message, intent, and values of Catholic health care include losing its identity and thus creating barriers prohibitive to providing compassionate care in His image. For Catholic health care organizations and its practitioners engaging in obstetric care, consistent articulation and adherence to the ERD's ensures a consistent message related to prenatal testing and diagnosis, as well as subsequent prenatal care and genetic counseling. While the environment surrounding Catholic health care may at times pose challenges to consistent articulation of its ministry, doing so is essential.

Existence in a secular and pluralistic society.

Iltis (2006) explains that Catholic health care organizations in the United States routinely face threats to mission integrity; she points to the fact that debate exists in the literature if these threats have hindered the ability for Catholic health care to continue as

²³ Ibid.

²² Ibid.

²⁴ Ibid.

a ministry.²⁵ While Catholic health care in the United States has made accommodations in their operations in response to the increasing pluralism of society, Iltis explains that these organizations have fought fervently to avoid participation in acts they consider intrinsically immoral (such as abortion).

Catholic health care is not exclusionary in its provision of health care services. The former fact is both an illustration of a central tenet of the ministry, as well as noteworthy as to why Catholic health care is continually challenged. However, the Catholic faith and its ministries (including health care) are impervious to actions that detract from the Magisterium. The complexities facing Catholic health care in the age of prenatal testing call for further exploration of its role in obstetric care.

THE ROLE OF CATHOLIC HEALTH CARE

Markwell and Brown (2001) explain that Catholic faith recognizes human life as "as a creation of God and gift in trust . . . beyond human evaluation and authority"²⁶; therefore, access to genetic testing and nondirective counseling as a means for parents to obtain information and prepare for a child's birth is permissible and welcomed. For Catholic health care, its interest and ministry may reach beyond the health care facility (in addition to the compassionate obstetric care it provides patients). The following discusses current and potential efforts by which Catholic health care can further engage to fulfill its ministry.

Patient Education

Patient education is an opportunity for health care providers to ensure that patients have accurate and timely information about medical conditions. Certainly, a prenatal diagnosis of Down syndrome or other disability calls on parents to prepare themselves and siblings (when applicable) for the arrival of a family member who may have unique medical and psychosocial needs. Commonplace in our society, however, is that disability remains stigmatized. Aside from personal bias and inadequate lay knowledge related to disability, there is a propensity among nondisabled individuals to assume that individuals with disabilities view their own lives as diminished (Longmore 1995).²⁷ The former assumption contributes to an environment by which timely and accurate information about disabilities is crucial.

Lawson and Pierson (2007) analyzed available literature related to maternal decisions and prenatal diagnoses. Their findings indicated that in studies by which the majority of participants held negative views about the roles and responsibilities parenting a child with a disability, and more specifically Down syndrome, most (60 percent) had no personal experience with individuals with Down syndrome or other intellectual disability.²⁸ There was also a tendency among study participants to indicate a particular bias against Down syndrome, with this being the prenatal diagnosis most likely to yield an elective abortion. Lawson and Pierson, therefore, argue that these findings underscore the importance of patient education including a realistic discussion of expectations for parents.

Providing obstetric patients accurate and timely information, as well as education that examines the realities of life with Down syndrome and other disabilities, should occur in the course delivering prenatal testing results. The role of Catholic health care is not to influence patient choices. However, its role does entail consistent articulation of its ministry that specifically entails respect for all human life.

Spiritual and Pastoral Care

While society in the United States includes a significant segment of individuals who identify as religious or spiritual, research has not revealed how religious and spiritual commitments influence patient responses to prenatal testing results (Fanning and Clayton 2009).²⁹ However, individuals often make health care decisions in the context of personal beliefs and values, which include religion and spirituality. Hospital personnel and health care providers witness the former routinely in the course of caring

²⁵ A Iltis, "On the Impermissibility of Euthanasia in Catholic Health Care Organizations," *Christian Bioethics*, 12/3 (2006): 281-290.

²⁶ H. Markwell and B Brown, "Bioethics for Clinicians: Catholic Bioethics," Canadian Medical Association Journal 165/2 (2001): 189-192.

²⁷ P. Longmore, "Medical Decision Making and People with Disabilities: A Clash of Cultures. Journal of Law," *Medicine and Ethics* 23 (1995): 82-87.

²⁸ K. Lawson and R. Pierson, "Maternal Decisions Regarding Prenatal Diagnosis: Rational Choices or Sensible Decisions?" *Journal of Obstetrics and Gynecology Canada*, 29/3 (2007): 240-246.

²⁹ J. Fanning and E. Clayton, "Introduction: Religious and Spiritual Issues in Medical Genetics," *American Journal of Medical Genetics* (2009) [Part C: Seminars in Medical Genetics]151C (1), accessed doi: 10.1002/ajmg.c.30191

for patients. While Catholic health care cannot instill its values upon patients, it can ensure that comprehensive care provided to patients who have received a prenatal diagnosis addresses the spiritual and pastoral care needs of the individual. Prenatal diagnoses require Catholic health care and its practitioners to not only address the physical and mental needs of their patients, but also consider and provide care for their spiritual needs.

Advocacy

The Catholic Church in the United States has focused efforts on disability issues for several decades. In the early 1970's, the Church began meeting with disability leaders and pastoral workers; these meetings led to the formation of the U.S. Bishops National Advisory Committee on Ministry with Mentally Handicapped People (National Catholic Partnership on Disability n.d.).³⁰ In a 1978 unanimously passed pastoral statement, United States bishops indicated that individuals with disability deserve full inclusion and acceptance in all facets of society (United States Conference of Catholic Bishops 1978).³¹ Today, the National Catholic Partnership on Disability is the organization within the Church in the United States advocating on behalf of individuals with disabilities. In addition to a large-scale focus on disability issues, Catholic health care providers may locate disability support and resources through their local diocese. Catholic health care organizations and providers should rely on local support from the Church when available, and may also find value in other community resources.

CONCLUDING REMARKS

Recognizing that personal beliefs and values of patients influence their goals and intents related to prenatal testing, the obligation of Catholic health care is to provide compassionate care consistent with the ERD's and Magisterium of the Church. The increasing elimination of prenatally diagnosed unborn with Down syndrome or other disabilities requires the attention of Catholic health care. In its ministry, Catholic health care must be aware of trends and outcomes related to prenatal testing. The culture of society and its views on disability may challenge the delivery of Catholic health care. However, through the teachings of the Church, the mission of the ministry is clear in its support and advancement of all human life. Further examination of the experiences of Catholic health care organizations and providers in the context of prenatal testing and diagnosis delivery is worthy; such research may have the ability to inform the institution of Catholic health care on its challenges and opportunities, as well as future roles and obligations of the Church in health care delivery.

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^{30 &}quot;National Catholic Partnership on Disability," NCPD History, accessed http://www.ncpd.org/about/history

³¹ United States Conference of Catholic Bishops, *Pastoral Statement of the U.S. Catholic Bishops on People with Disabilities* (Washington, DC: USCCB, 1978)

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