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Informed Consent or Institutionalized Eugenics? How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome

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ABSTRACT: Many women are unprepared to make prenatal decisions about fetuses diagnosed with Down Syndrome because of societal pressures to have “normal” children, a negative view of persons with disabilities by many in society, a fear of legal liability by those in the medical community, the lack of genuine informed consent before undergoing genetic testing and abortion, and the failure of non-directive pre-abortion counseling in the medical community. Moreover, medical professionals fail to communicate correct and unbiased information before and during the genetic screening, diagnostic testing, and abortion decision-making process. This article addresses the contributing factors and causes that ultimately lead to a lack of informed consent and a very high abortion rate for fetuses diagnosed with Down Syndrome.

There are numerous contributing factors to what some may call a high termination rate of fetuses that have tested positive for Down Syndrome. One major factor is the direct and indirect influences of medical professionals, which include genetic counselors, family physicians and obstetricians and gynecologists. In this article, I

* B.A., University of Pittsburgh, *summa cum laude*, 2005; J.D., University of Pittsburgh School of Law, 2008. I wish to thank professors Elizabeth Gettig, Elizabeth A. Balkite, and Ellen Wright Clayton for answering numerous questions and providing insight into the world of genetic counseling. I am deeply grateful to professors Ann Sinscheimer, Stella L. Smetanka, and Kevin Deasy of the University of Pittsburgh School of Law for their encouragement, suggestions and feedback throughout the research and writing of this article. I owe a great debt to the enduring patience, love and encouragement of my mother, Aunt Inger, and Uncle Kerry. As always, my greatest debt is to Joanna McKee, R.N., whose support, advice and insight enriches all that I do.

support the ethical principle of nondirective counseling and the genetic counselors who seek to achieve nondirectiveness. However, I suggest genetic counselors and many medical professionals have a deference to the use of medical technology and the belief that patients desire the maximum amount of information. This ingrained deference hinders most medical professionals from being neutral and often causes a subtle promotion of prenatal testing and abortion. Overall, increased prenatal testing contributes to the high abortion rate of fetuses diagnosed with Down Syndrome, a lack of genuine informed consent, greater intolerance of people and especially children with disabilities, and less money for research and development of effective treatments. To the extent that women are encouraged to terminate their pregnancies, prenatal testing and abortion of affected fetuses cannot be considered morally justified because the decision lacks genuine informed consent.

Similarly, other medical professionals, such as family physicians, obstetricians and gynecologists, contribute to the problem. Initially, almost all women seek prenatal treatment from a family physician or obstetrician and gynecologist. However, these medical professionals tend to spend significantly less time with patients compared to genetic counselors, which can result in miscommunications. Moreover, these professionals may encourage prenatal testing and the use of “up front” consent forms to reduce legal liability. In addition, these medical professionals typically receive inadequate genetic training, which can result in the misinformation, and most discouraging, undue influence, bias or prejudice against persons with disabilities, which circumvent informed consent. Time constraints, fear of liability, little genetic training and the practice of directiveness can easily result in a negative tone that manifests itself in phrase such as, “I’m sorry,” or “Unfortunately, I have some bad news to share” and conversations void of the positive reality that many individuals with Down Syndrome can become semi-independent and with good medical care can live into adulthood. Lastly, both medical professionals and patients and their families may overly rely on genetic technologies, which are far from perfect. The assumption that these technologies are 100% accurate can lead to many injudicious and erroneous choices depending upon the degree of inaccuracy. Yet, medical information is only part of what women and their families use to make their decisions. Their decisions are likely more substantially swayed by societal influences and pressures.

It is important to realize that genetic counselors and other healthcare professionals bring their own values into the prenatal testing process, with patients also adding different and competing values and background knowledge to the process. Furthermore, patients’ values reflect a combination of individual perspectives and social norms. While a great deal of variation exists among patients, some trends may be observed. Some women reject prenatal testing because they know they would not have an abortion for moral, religious or personal reasons. Others reject such testing because of the risk of miscarriage. But a vast majority of women at increased risk (those for whom it is medically indicated) of chromosomal or other detect-

able conditions under the old guidelines choose prenatal screening and/or testing.¹ Several factors contribute to this trend. Just as medical professionals are not neutral about the value of information, neither is our society, which views the gathering of information as a sign of responsible behavior and good decisionmaking.² In the context of prenatal testing, patients may believe that getting information about the fetus is not only the right thing to do, but a form of reassurance and a way to get a sense of control over the potentially overwhelming experience of reproduction.³ This trend contributes to the massive increase in prenatal testing and the need to know whether a child has a disability.

This article does not propose the elimination of prenatal testing. Rather, it proposes that the genetic testing and counseling should not be biased against the birth of children with disabilities. Genetic testing and counseling should not convey directly or indirectly the message that the lives of persons with disabilities are worth less than other lives, or that the only practical alternative is to prevent their existence through abortion.

Overall, prenatal testing should be a way for women and their families to reduce the stress and anxiety associated with the unexpected birth of babies with special needs and also a conduit through which women are given information to help them appreciate the value of children with special needs and expand their knowledge of available services and treatment options for such children. However, the practical result of prenatal testing tends to be an increased termination rate of fetuses diagnosed with Down Syndrome or other genetic anomalies.

Is Abortion the Solution to Down Syndrome?

On May 9, 2007, Amy Harmon of the *New York Times* wrote an article titled, “*Prenatal Testing Puts Down Syndrome in Hard Focus.*”⁴ In this article she stated that 90% of women who receive a positive diagnosis of Down Syndrome choose to have an abortion. The *New York Times* received thousands of emails and letters by readers, such as George F. Will, who found the 90% percent statistic to be morally problematic, probably untrue, and a sign of medical procedural failure. This article will discuss the human, societal, and medical aspects of prenatal genetic testing of Down Syndrome fetuses that contribute to a high abortion rate.

Before examining the various contributing factors, it should be noted that the statistic that “90% of women who receive a positive fetal diagnosis of Down Syndrome

¹ BARBARA KATZ ROTHMAN, *THE TENTATIVE PREGNANCY: HOW AMNIOCENTESIS CHANGES THE EXPERIENCE OF MOTHERHOOD* 16, 63 (1986). See also Gwen Anderson, *Nondirectiveness in Prenatal Genetics: Patients Read Between the Lines*, 6 *NURSING ETHICS* 126, 129 (1999).

² “In genetics, clinicians and researchers believe that knowledge and genetic science are moral goods.” Anderson, *supra* note 1 (noting the public’s acceptance of the “moral imperative to know”). Also, observing the medical profession’s view that genetic testing will further the well-being of fetus, siblings, parents and society. *Id.*

³ Sonia Mateu Suter, *The Routinization of Prenatal Testing*, 28 *AM. J. L. & MED.* 233, 246 (2002).

⁴ Amy Harmon, *Prenatal Testing Puts Down Syndrome in Hard Focus*, *N.Y. TIMES*, May 9, 2007, (unpaginated), available at <http://www.nytimes.com/2007/05/09/us/09down.html?ex=1336363200&en=ccf8eef18ff478e4&ei=5088>.

choose to have an abortion”⁵ may be too high. That number may be overestimated and the source should be questioned for several reasons. First, although no official data exists, medical professionals report that often women abort when they discover there is mental retardation or a serious anatomical birth defect, sometimes incompatible with life.⁶ But some argue that the women who choose to have prenatal testing are the women most likely to be considering abortion, so the population having prenatal testing is more likely to be predisposed to have an abortion.⁷ Second, some doctors do not refer patients for genetic counseling or prenatal testing if they say they would not consider abortion.⁸ Third, all the numbers are suspect because there is no birth certificate when a baby is aborted and a lot of states do not track abortions (e.g., Pennsylvania) which results in a lack of good epidemiology.⁹ Fourth, many cities like Pittsburgh have Down Syndrome clinics that are instrumental in helping children develop and become a part of the community.¹⁰ Fifth, after extensive research, it appears the abortion rate varies significantly by region.¹¹

Professor Elizabeth Gettig,¹² MS, CGC, stated that during the 1980’s she practiced genetic counseling in North Carolina and after a positive Down Syndrome diagnosis, almost 100% of the women aborted because of a lack of economic re-

⁵ It should be noted that the 90% statistic is not completely unfounded. Some experts agree that around ninety percent of women whose fetuses are diagnosed with birth defects elect to have abortions. See Ronald Kotulak & Peter Gorner, *Couples No Longer Have to Roll the Genetic Dice to Determine the Kind of Children They Want*, CHI. TRIB., Mar. 3, 1991, at C14. Moreover, a 2005 article in the *Washington Post* described the high rates of abortions due to “prenatal diagnoses of Down Syndrome” and noted that the rates of abortion for Down Syndrome fetuses have been estimated at “80 to 90 percent.” Patricia E. Bauer, *The Abortion Debate No One Wants To Have*, WASH. POST, Oct. 18, 2005, at A25; and Ralph L. Kramer et al., *Determinants of Parental Decisions After the Prenatal Diagnosis of Down Syndrome*, 79 AM. J. MED. GENETICS 172, 172-73 (1998) (finding an elective termination rate of 86.9%, regardless of race, religion, or insurance).

⁶ D. I. Bromage, *Prenatal Diagnosis and Selective Abortion: A Result of the Cultural Turn?* 32 MED. HUMANITIES 38 (June 2006). “Again, no official data exist but Mark Evans, a Professor of Obstetrics and Gynecology in the United States has said that ‘most couples whose results show their child would have a serious chromosomal defect choose to terminate the pregnancy’ and Dr. Peter Brocklehurst, director of the National Perinatal Epidemiology Unit and leader of the NICE group behind the new guidelines, has acknowledged that offering prenatal tests for Down’s Syndrome to all pregnant women will result in an increased detection rate and an increase in abortion for Down’s Syndrome.” *Id.* It should be noted that I obtained a significant amount of information from interviews conducted with nationally recognized genetic counselors. I thought it was important to rely upon the observations and knowledge of those with a lifetime of experience as well as research studies because research studies typically provide a limited amount of information.

⁷ E-mail from Elizabeth A Balkite, Executive Director, American Board of Genetic Counseling, to Darrin P. Dixon (July 9, 2007) (on file with author).

⁸ *Id.*

⁹ Interview with Elizabeth Gettig, Associate Professor, Human Genetics; Director, Genetic Counseling Program, University of Pittsburgh Department of Human Genetics, in Pittsburgh, PA (June 29, 2007).

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

sources.¹³ In contrast, in Pittsburgh she found that about half of the women with a positive diagnosis for Down Syndrome continue the pregnancy and about half abort.¹⁴ She gives several reasons for this disparity. First, the Pittsburgh region has a higher percentage of Catholics. Second, there are more services than most cities in Pittsburgh to assist children who have disabilities.¹⁵ Lastly, the new federal law protects all children with disabilities so that from ages 0-3 parents of children with disabilities receive free services for the disabled child and all children at age three receive an Individual Educational Plan so that they can start developmental day-care and other services before going to school.¹⁶ Furthermore, because the services are better, the child has a better chance of living independently and becoming an integral part of the community.

Other genetic counselors, journalists and medical professionals find different statistics. Elizabeth A. Balkite,¹⁷ stated that in her own experience she believes the termination rate for Down Syndrome pregnancies to be roughly 60%.¹⁸ She thinks that the other 40% keep the baby or place the baby up for adoption.¹⁹ Ellen Wright Clayton, M.D., J.D., believes the number is closer to 50 percent.²⁰ In the January 29, 2007 *Newsweek* article titled "Golly, What Did Jon Do?," George F. Will stated, "At least 85 percent of pregnancies in which Down Syndrome is diagnosed are ended by abortions."²¹

The 90% *New York Times* statistic is suspect because it was based on the results of one research study rather than different regional averages.²² Furthermore, nationwide abortion numbers do not exist. In sum, although Professor Gettig experienced a 100% termination rate in the 1980's in North Carolina and the *New York Times* reported 90%, these numbers may to be overestimated because of the increased financial channels and educational groups and programs available to assist parents with their Down Syndrome children.

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ Balkite, *supra* note 7.

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ E-mail from Ellen Wright Clayton, Rosalind E. Franklin Professor of Genetics and Health Policy; Professor of Pediatrics, Professor of Law; Co-Director, Center for Biomedical Ethics and Society, Vanderbilt University School of Law, to Darrin P. Dixon (June 29, 2007) (on file with author).

²¹ George F. Will, *Golly, What Did Jon Do?* NEWSWEEK, Jan. 29, 2007, (unpaginated), available at <http://www.newsweek.com/id/70159>.

²² Moreover, that research study involved participants in the United Kingdom rather than the United States. National Center for Biotechnology Information, available at <http://www.ncbi.nlm.nih.gov/pubmed/10521836?dopt=AbstractPlus>.

The Medical Background

The genetic counselors I interviewed agreed that the most common reason for aborting a fetus with Down Syndrome is the financial, emotional, physical and time constraints that accompany raising a child with Down Syndrome.²³ Additionally, there is immense societal pressure to produce children that are “normal” (meaning children that are disease and mental retardation free). The most direct consequence of widespread prenatal genetic testing, maternal serum fetal cell sorting²⁴ (“MSFCS”) or maternal plasma DNA recovery²⁵ (“MPFDR”), is a decrease in the number of babies born with genetic diseases and chromosomal abnormalities.²⁶ Prenatal testing for many is a desired way to avoid children with genetic disease. The burdens to the child, family, and society are great enough to make a parental choice against children with this trait rational, understandable, and to some, even desirable. The above makes the Down Syndrome abortion issue a commonplace medical problem.

What is Down Syndrome?

Down Syndrome²⁷ is the most common chromosomal problem in live born babies.²⁸ It is a congenital condition resulting from a chromosomal defect that causes varying degrees of mental retardation and some physical abnormalities.²⁹ The word “syndrome” means that many different characteristics are usually seen together. For example, in Down Syndrome, these features include low muscle tone, small stature, a single crease across the center of the palms, small amounts of extra skin at the corner of one’s eyes, bright “speckles” in the iris called Brushfield spots, flat nasal bridge, small mouth, small ears, excessive skin at the nape of the neck, a deep fissure between the first and second toes, flatness of the back of the head and an upward slant to the eyes.³⁰ Although the above features are common in Down Syndrome, they are not all found in every child with Down Syndrome.³¹ Besides

²³ Gettig, *supra* note 9; Balkite, *supra* note 7; Clayton, *supra* note 20.

²⁴ MSFCS refers to the process of isolating fetal cells in maternal blood for genetic purposes. Joyce A. Martin et al., *Births: Final Data for 2003*, NAT’L. VITAL STATS. REPS., Sept. 8, 2005, at 8, 48 (Centers for Disease Control & Prevention, Atlanta, GA).

²⁵ MPFDR refers to the process of isolating cell-free fetal DNA in maternal blood for genetic purposes. *Id.*

²⁶ *Id.*

²⁷ The condition is called “Down” Syndrome after Sir John Langdon Haydon Down, who first described its symptoms, comparing them with those of “Mongols.” See RAYNA RAPP, TESTING WOMEN, TESTING THE FETUS: THE SOCIAL IMPACT OF AMNIOCENTESIS IN AMERICA 295-96 (1999). Rapp also cites Down Syndrome as the most common condition for which women seek prenatal testing. *Id.* at 223.

²⁸ National Association of Genetic Counselors, *An Information Booklet for Parents of Babies Diagnosed during Pregnancy with Down Syndrome* (1993), available at <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/2/442> (hereinafter *Genetic Counselors*).

²⁹ Will, *supra* note 21.

³⁰ *Genetic Counselors*, *supra* note 27; Will, *supra* note 21; American Academy of Pediatrics Committee on Genetics, *Health Supervision for Children with Down Syndrome*, 107 PEDIATRICS 442-49 (2001) (hereinafter *American Academy*).

³¹ *Genetic Counselors*, *supra* note 28.

the above listed physical features, a child with Down Syndrome will resemble other family members.³²

The most commonly known feature of Down Syndrome is mental retardation. Mental retardation simply means that the child will have “below normal mental functioning.”³³ The degree of mental impairment is unpredictable, ranging from mild (IQ: 50-70) to moderate (IQ: 35-50), and only occasionally severe (IQ: 20-35).³⁴ There is an increased risk of “congenital heart defects³⁵ (50%); leukemia³⁶ (<1%); hearing loss (75%); otitis media³⁷ (50%-70%); Hirschsprung disease³⁸ (<1%); gastrointestinal atresias³⁹ (12%); eye disease (60%), including cataracts (15%) and severe refractive errors (50%); acquired hip dislocation (6%); obstructive sleep apnea⁴⁰ (50%-75%); and thyroid disease⁴¹ (15%).”⁴² The social aspect of the development of a child with Down Syndrome may be improved with early intervention techniques, although the level of function varies.⁴³ Some children with Down Syndrome function better in social situations than might be expected from their IQ.⁴⁴ There is no way either prior to birth or early in life to determine how severe a Down Syndrome child’s learning disability will be.⁴⁵ However, with good education, Down Syndrome children can learn throughout their lives and most will learn to walk, talk, and often read and write with some extra help in school. Many

³² *Id.*

³³ *Id.*

³⁴ American Academy, *supra* note 30.

³⁵ Congenital heart defect refers to heart defects present at birth. Cleveland Clinic Health System, available at <http://www.clevelandclinic.org/heartcenter/pub/contact/>.

³⁶ Leukemia refers to a cancer of developing blood cells in the bone marrow. KnowledGENE.com, available at http://www.knowledgene.com/public/glossary_content.php3.

³⁷ Otitis media refers to a bacterial or viral infection of the middle ear (the space behind the eardrum). Cleveland Clinic Health System, available at <http://www.cchs.net/health/health-info/docs/1900/1945.asp?index=8615>.

³⁸ Hirschsprung disease refers to a congenital abnormality (birth defect) of the bowel in which there is absence of the ganglia (nerves) in the wall of the bowel. Nerves are missing starting at the anus and extending a variable distance up the bowel. This results in megacolon (massive enlargement of the bowel) above the point where the nerves are missing. The nerves are needed to assist in peristalsis, the wave-like movement of the muscles in the lining of the bowels. Emedicine Health, available at <http://www.emedicinehealth.com/script/main/art.asp?articlekey=3760>.

³⁹ Gastrointestinal atresia refers to is the absence or marked narrowing of the lumen (the passage inside) of the gut (gastrointestinal tract) at birth. Your Surgery.com, available at <http://www.yoursurgery.com/ProcedureDetails.cfm?BR=1&Proc=77>.

⁴⁰ Obstructive sleep apnea refers to sleep apnea resulting from blockage of the airway. Harvard Health Publications, Harvard Medical School, available at <http://www.health.harvard.edu/dictionary/Improving-Sleep.htm>.

⁴¹ Thyroid disease refers to is a condition in which thyroid hormones are elevated due to an overactive thyroid gland. Thyroid disease can increase the risk of AF. St. Jude Medical, AF Answers, available at <http://www.afanswers.com/glossary.html>.

⁴² American Academy, *supra* note 30.

⁴³ *Id.*

⁴⁴ *Genetic Counselors*, *supra* note 28.

⁴⁵ *Id.*

individuals with Down Syndrome can become semi-independent and with good medical care can live into adulthood.⁴⁶

In roughly 95% of children with Down Syndrome, the condition is due to a nonfamilial disorder caused by the presence of three 21st chromosomes rather than the usual pair.⁴⁷ In approximately 3% to 4% of persons with the Down Syndrome phenotype, "the extra chromosomal material is the result of an unbalanced translocation between chromosome 21 and another acrocentric chromosome, usually chromosome 14."⁴⁸ Almost three-fourths of these unbalanced translocations are *de novo*,⁴⁹ and approximately one-fourth are the result of familial translocations.⁵⁰ In the remaining 1% to 2% of persons with the Down Syndrome phenotype, two cell lines are present: one normal and one trisomy 21.⁵¹ This condition is called mosaicism. People with mosaicism, on average, may be phenotypically less severely affected than persons with trisomy 21 or translocated chromosome 21, but their conditions are generally indistinguishable in all other aspects.⁵² Mosaic Down Syndrome usually occurs after conception, due to a mistake early in the formation of the baby's cells.⁵³ Because only some of the cells are involved, children with mosaic Down Syndrome may have fewer health and learning problems.⁵⁴

The actual risk of Down Syndrome in a woman who is thirty-five is one in 385; the risk of her having a fetus with other anomalies is one in 434, making her total risk of chromosomal anomaly one in 204.⁵⁵ The likelihood of having a child with a chromosomal anomaly is minor. However, one could argue the low risk of anomaly creates an incentive for women to abort their fetus with Down Syndrome and try again to have a child without a chromosomal anomaly because the chances of having another fetus with Down Syndrome are low. At the same time, others contend that even a small possibility of harming one's fetus during a prenatal test is too great. Because the symptoms of Down Syndrome are treatable and the child can

⁴⁶ *Id.*

⁴⁷ American Academy, *supra* note 30. See also University of Virginia Health Systems, available at http://www.healthsystem.virginia.edu/UVAHealth/peds_genetics/downs.cfm.

⁴⁸ American Academy, *supra* note 30.

⁴⁹ The medical form of the word *de novo* means anew. The term is often applied to particular biochemical pathways in which metabolites are newly biosynthesized. The Centre for Cancer Education, available at <http://cancerweb.ncl.ac.uk/cgi-bin/omd?de+novo>.

⁵⁰ *Id.*

⁵¹ *Id.* "Trisomy" refers to the fact that the affected person has an extra chromosome, i.e., three chromosomes instead of two; "21" indicates which chromosome pair is affected. Cathleen M. Harris & Marion S. Verp, *Prenatal Testing and Interventions*, in *GENETICS IN THE CLINIC: CLINICAL, ETHICAL, AND SOCIAL IMPLICATIONS FOR PRIMARY CARE* 59, 161-63 (Mary B. Mahowald et al. eds., 2001). Cynthia Powell, *The Current State of Prenatal Genetic Testing in the United States*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 44, 45 (Erik Parens & Adrienne Asch eds., 2000).

⁵² *Id.*

⁵³ *Genetic Counselors*, *supra* note 28.

⁵⁴ *Id.*

⁵⁵ Verp, *supra* note 51.

live without major disability, some couples refuse prenatal screening or abortion to prevent such births.⁵⁶ However, because there are no guarantees in advance about the severity of a particular case, and because even the best situations will require substantial supportive efforts by parents, many couples are unwilling to bring such a child into the world.⁵⁷

What is Prenatal Testing and Diagnosis?

Prenatal testing and diagnosis refers to “all the technologies currently in use or under development to determine the physi(ologi)cal condition of a fetus before birth.”⁵⁸ There are two major types of prenatal diagnosis: amniocentesis and chorionic villus sampling (CVS).⁵⁹ Amniocentesis is usually performed between 16 and 20 weeks of pregnancy.⁶⁰ This test involves inserting a needle through the abdomen into the uterus to draw off a sample of amniotic fluid.⁶¹ This fluid contains skin cells from the baby which can be used to do a chromosome test.⁶² The chance of miscarriage is between 0.5 percent and 1%. CVS is typically performed between 10 to 12 weeks of pregnancy.⁶³ It involves inserting a thin, plastic catheter through the vaginal canal to withdraw some placental tissue, which usually has the same chromosome makeup as the baby.⁶⁴ One version of this test, called transabdominal CVS, uses a needle, inserted through the abdomen, to collect the tissue sample.⁶⁵ A sonogram is done before or during each test to guide the catheter or needle. Also, there are different testing methods such as “ultrasound and the maternal serum alfafetoprotein3 blood test (MSAFP3) for neural tube defects and Down Syndrome.”⁶⁶ CVS has the disadvantage of being an invasive procedure, and it has

⁵⁶ John A. Robertson, *Genetics Selection of Offspring Characteristics*, 76 B.U.L. REV. 421, 433 (1996).

⁵⁷ Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990s 17, 59-101 (S. Cohen & N. Taub eds. 1988); Adrienne Asch, *The Human Genome and Disability Rights*, DISABILITY RAG & RES., Jan./Feb. 1994, at 12; Blumberg, L., *The Politics of Prenatal Testing and Selective Abortion*, 12 SEX DISABILITY 135 (1994); A. Buchanan, *Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion*, 13 SOC. PHIL. POL'Y 18 (1996).

⁵⁸ Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J. L. & MED. 15, 19-21 (1991).

⁵⁹ *Id.*

⁶⁰ *Genetic Counselors*, *supra* note 28.

⁶¹ *Id.*

⁶² *Id.*

⁶³ Gettig, *supra* note 9; Mary B. Mahowald, *Genes and Disability: Defining Health and the Goals of Medicine: Aren't We All Eugenists? Commentary on Paul Lombardo's "Taking Eugenics Seriously"*, 30 FLA. ST. U.L. REV. 219, 230-34 (2003); Montefiore Medical Center, *Reproductive Genetics and Prenatal Genetic Testings*, available at <http://www.montefiore.org/services/coe/womenshealth/prenataltesting/>.

⁶⁴ *Genetic Counselors*, *supra* note 28.

⁶⁵ *Id.*

⁶⁶ An ultrasound test is not a genetic test per se, but it is often utilized to clarify the results of an AFP screening. ELENA O. NIGHTINGALE & MELISSA GOODMAN, BEFORE BIRTH: PRENATAL TESTING FOR GENETIC DISEASE 11-26, 31 (1990). When used to screen for Down Syndrome, ultrasound has been shown to vary greatly depending upon the technician's skill and the methods used, with detection rates ranging from 31% to 75% and false positive rates as high as 8.5% among high risk women. U.S. Preventive

a small but significant rate of morbidity for the fetus; the mortality rate is about 0.5 to 1% higher than for women undergoing amniocentesis and is 0.5%-1% over the general population risk.⁶⁷

There are two dominate themes regarding prenatal diagnosis: (1) the public health model and (2) the reproductive autonomy model.⁶⁸ In the “public health” model, prenatal diagnosis is viewed as a way to reduce the frequency of selected birth defects.⁶⁹ Thus, under the public health model, prenatal diagnosis is a contributing factor to the high termination rate of fetus’s diagnosed with Down Syndrome. In the “reproductive autonomy” model, prenatal diagnosis is viewed as a conduit through which women are given information to expand their reproductive choices.⁷⁰ Thus, under the reproductive autonomy model, prenatal diagnosis is a method to increase prenatal choice. Both approaches are active in our society and both approaches fail to recognize a major function of prenatal diagnosis. For many women, prenatal diagnosis is a way of avoiding “disaster.” Through the use of prenatal diagnosis women can avoid the family distress and suffering associated with the unpredicted birth of babies with genetic disorders.⁷¹

The Disability Rights Perspective

The premise of the disability rights movement is that persons with disabilities are disadvantaged far more by negative social attitudes than by their disabilities.⁷² Disability rights advocates contend that tests like amniocentesis often are performed because a value judgment has been made that there is merit in identifying a fetus who could become a person with a disability. The premise of the expressivist⁷³ ar-

Services Task Force, *U.S. Dept of Health and Human Services, Guide To Clinical Prevention Services, Section 1. Screening: Congenital Disorders: Screening for Down Syndrome* (2d ed. 1996), available at <http://odphp.osophp.dhhs.gov/pubs/guidecps/PDF/CH41.PDF> (last visited Mar. 5. 2007). More recent results have found overall ultrasound sensitivities of about 80%, when screening for Down Syndrome. See Vintzelios et al., *Indication-Specific Accuracy of Second-Trimester Genetic Ultrasonography for the Detection of Trisomy-21*, 181 AM. J. OBSTETRICS & GYNECOLOGY 1045 (1999).

⁶⁷ Lippman, *supra* note 58; Mahowald, *supra* note 63.

⁶⁸ Edward C. Klatt, *The Internet Pathology Labatory for Medical Education* (2007), available at <http://library.med.utah.edu/WebPath/TUTORIAL/PRENATAL/PRENATAL.html>.

⁶⁹ Lippman, *Access to Prenatal Screening: Who Decides?*, 1 CANADIAN J. WOMEN L. 434 (1986). Kolker, *Advances in Prenatal Diagnosis: Social-psychological and Policy Issues*, 5 INT’L J. TECH. ASSESSMENT HEALTH CARE 601 (1989); Dalgaard & Norby, *Autosomal Dominant Polycystic Kidney Disease in the 1980s*, 36 CLINICAL GENETICS 320, 324 (1989) (placing importance on “selective reproduction prevention”).

⁷⁰ Loane Skene, *Patients’ Rights or Family Responsibilities?—Two Approaches to Genetic Testing*, 6 MED. L. REV. 1, 3-4 (1998).

⁷¹ Peggy McDonough, *Congenital Disability and Medical Research: The Development of Amniocentesis*, 16 WOMEN & HEALTH 137, 143-44 (1990). “McDonough notes that three rationales for amniocentesis emerged from her survey: ‘The procedure offered those at risk the possibility of ‘health’ [it] provided parents with reassurance and avoided abortion [and it] prevent[ed] disease and disability.’”

⁷² Asch, *supra* note 57.

⁷³ Expressivists argue that prenatal testing sends the message to people with disabilities that their lives are not worth living. Mahowald, *supra* note 63, at 229. Allen E. Buchanan is noted for

gument is that prenatal testing is morally problematic because it expresses negative or discriminatory attitudes about both impairments and those who carry them.⁷⁴ Its central claim is that prenatal tests that expose disabling traits express a hurtful attitude about and send a hurtful message to people who live with those same traits.⁷⁵ In the late 1980s, Adrienne Asch, a bioethicist at Wellesley College, put the concern this way: “Do not disparage the lives of existing and future disabled people by trying to screen for and prevent the birth of babies with their characteristics.”⁷⁶

Persons or families with disabled children have claimed that a policy that encourages abortion of fetuses with genetic anomalies is a public statement that the lives of people with disabilities are worth less than those of the able-bodied.⁷⁷ In addition, such a policy reduces the number of persons with those disabilities, thus reducing their political effectiveness. It also may manipulate couples into carrier and prenatal screening to avoid children with such characteristics.⁷⁸ In short, it engenders or reinforces public perceptions that people with disabilities should not exist, making intolerance and discrimination toward them more likely.⁷⁹

The message sent, from this perspective, is that a child with the condition would be unacceptable to the prospective parents. This devaluation appears more subtly in the promotion of prenatal genetic testing as helping prospective parents to guarantee that they will have “healthy” children.⁸⁰ This rhetoric of good health fails to acknowledge that some traits screened for do not necessarily affect a child’s health, although they may impair the child’s abilities.⁸¹ A perfectly physically healthy child with Down Syndrome or with deafness is a prime example. Viewed in this light, the appeal to good health, while unobjectionable on its face, may promote eugenic attitudes that individuals with some disabilities are properly excludable, not only from society, but also from existence.⁸²

This is a powerful charge, and at the very least should remind us to look more closely at the effects of genetic selection programs on persons with disabilities, and to change the programs if they are in any way harmful, denigratory or disrespectful to people with disabilities. However, the charge is not irrefutable. Surely one can

developing the “expressivist argument.” Allen E. Buchanan, *Choosing Who Will be Disabled: Genetic Intervention and the Morality of Inclusion*, 13 *SOC. PHIL. & POL’Y* 18 (1996).

⁷⁴ *Id.*

⁷⁵ Robertson, *supra* note 56.

⁷⁶ *Id.*

⁷⁷ Asch, *supra* note 57, at 60-70 (“life with disability can be valuable and valued, and therefore, we must carefully consider the consequences of our disability prevention activities”); Martha A. Field, *Killing “The Handicapped”—Before and After Birth*, 16 *HARV. WOMEN’S L.J.* 79, 123-24 (1993). The article states that the government cannot attempt to eliminate particular disabilities “without disparaging existing persons with that condition by suggesting . . . that life with that disability is worse than no life at all.”

⁷⁸ Julia Walsh, *Reproductive Rights and the Human Genome Project*, 4 *S. CAL. REV. L. & WOMEN’S STUD.* 145, 160-68 (1994) (“arguing that state regulation of prebirth genetics has the potential to infringe upon a woman’s right to reproductive freedom”).

⁷⁹ Robertson, *supra* note 56, at 482.

⁸⁰ Mary A. Crossley, *Choice, Conscience, and Context*, 47 *HASTINGS L.J.* 1223, 1230-34 (1996).

⁸¹ *Id.*

⁸² *Id.*

find a particular living situation less preferable than others yet still respect persons in that situation. A policy to prevent accidents that cause paraplegia does not harm existing paraplegics, nor prevent us from supporting programs that make their lives easier. Similarly, a program that enables people to avoid the birth of children with disabilities does not have to denigrate existing persons with those conditions. However, this is not the current state of prenatal genetic testing in this country with regards to Down Syndrome.

While genetic counselors around the world offer prenatal testing as an opportunity to maximize a couple's reproductive choices, disability scholars have recently condemned prenatal testing as typically done with the goal of identifying an affected fetus so that the fetus may be aborted.⁸³ This message has important, indeed critical, significance for the profession of genetic counseling and should not be overlooked. The disability rights⁸⁴ perspective has two central claims: first, prenatal testing is morally problematic; and second, prenatal genetic counseling is driven by misinformation.⁸⁵ However, advocates of prenatal testing argue the widespread use of prenatal testing enables parents to prepare emotionally and financially for the special needs of a child with Downs Syndrome.⁸⁶

Another concern is that prenatal genetic testing encourages reductivism.⁸⁷ Here, the concern is that using prenatal testing for trait selection (or deselection) purposes will encourage the identification of a specific child with his selected trait(s)

⁸³ Erik Parens & Adrienne Asch, *The Disabilities Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, 29 HASTINGS CENTER REP. 51 (1999).

⁸⁴ This critique, also called "[t]he disabilit[ies] rights critique" is well-developed by Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS 3* (Erik Parens & Adrienne Asch, eds. 2000).

⁸⁵ *Id.*

⁸⁶ TRACEY HOTCHNER, *PREGNANCY AND CHILDBIRTH: THE COMPLETE GUIDE FOR A NEW LIFE* 26-35 (1984). Cf., DOROTHY C. WERTZ, ET AL., *WHO HUMAN GENETICS PROGRAMME, REVIEW OF ETHICAL ISSUES IN MEDICAL GENETICS* 62 (2003) (setting forth policy recommendations by health care professionals, including that "prenatal diagnosis can be used to prepare for the birth of a child with a disability instead of making a decision about abortion"); Brian G. Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670, 675-76 (2005) (Consequently, health care providers should appreciate that many women consent to prenatal testing with ambivalence or no intent whatsoever to abort). Driven by a desire to know, many parents will undergo genetic screening even if their only option is to deliver their child: In examining women at risk for having children with sickle cell disease, one investigator who interviewed thirty women found that the majority of them would want prenatal diagnosis even though only one quarter would abort an affected fetus. Another group of researchers who looked not at what women said but what they did found that of twenty-two pregnant women who were at risk for having a child with sickle cell anemia, fourteen had amniocentesis, and of the four fetuses found to be affected, three were aborted. Ellen Wright Clayton, *Screening and Treatment of Newborns*, 29 Hous. L. Rev. 85, 116 (1992).

⁸⁷ Reductivism means the "use of the fewest and barest essentials or elements." Answers.com, available at <http://www.answers.com/topic/reductivism>.

or, more generally, the identification of all persons with their selectable traits.⁸⁸ The identification of individuals primarily with a single, physical trait rather than with their personhood is precisely opposed to disability rights advocates' efforts to promote "people first" language in describing persons with disabilities.⁸⁹ The possibility of reductivism appears particularly troublesome for two reasons. First, it threatens the loss of an intangible aspect of how we view our fellow humans.⁹⁰ Our very respect for the dignity of the individual seems premised on our understanding that each individual is greater than the sum of his or her parts.⁹¹ If, by contrast, we were to view our children or the persons with whom we interact in society as simply a combination of traits, then persons with similar traits would begin to appear largely interchangeable, and we would lose an important sense of the humanity and individuality of persons.⁹²

Second, reducing our understanding of individuals to the sum of their traits also threatens to create new, and exacerbate existing, bases for social division.⁹³ Many of the seemingly intractable social divisions of our day are traceable, at least in part, to social groups focusing on one "part" of individuals (for example, their race, ethnicity, religion, or sexual orientation), rather than on their humanity.⁹⁴ It is easy to hate and chastise a label; it is more difficult to hate an individual when one views that individual as being a bundle of humanity - with joys, fears, dreams, concerns, vulnerabilities, and strengths.⁹⁵ By encouraging us to conceptually break down persons into traits, prenatal genetic testing threatens to reinforce our existing and destructive reductivist tendencies.⁹⁶

Many of the problems we have regarding the normalcy of children center around the fact that we, in the United States, live in a celebrity oriented and visually oriented culture.⁹⁷ As long as the status quo remains, the abortion rate will always be high. A common exercise in genetic counseling classes involves asking students whether or not they would choose the traits of their child if they had the option. Furthermore, if they did have the option, would they choose for their child to be taller or shorter, lower or higher body fat, attractive or unattractive features, athletically gifted or intellectually talented, or neither and so on.⁹⁸ Almost always

⁸⁸ Susan M. Wolf, *Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism*, 23 J.L. MED. & ETHICS 345, 347 (1995).

⁸⁹ "The 'people first' approach prefers describing a person who has a disabling condition as a 'person with a disability,' rather than a 'disabled person.'" See Allan H. Macurdy, *Disability Ideology and the Law School Curriculum*, 4 B.U. PUB. INT. L.J. 443, 443 n.1 (1995).

⁹⁰ Crossley, *supra* note 80.

⁹¹ *Id.*

⁹² *Id.*

⁹³ Wolf, *supra* note 88, at 347-49.

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ *Id.*

⁹⁷ Gettig, *supra* note 9.

⁹⁸ *Id.*

students say they would choose their child's traits and that they would choose the more socially advantageous traits.⁹⁹ This shows the students value physical appearance, intellectual ability and cosmetic attributes. The root of the problem is that we as a society value some things more than others. More likely than not, children with Down Syndrome do not tend to be thought of as having the above attributes that appear to be desired by parents and the vast majority of society.¹⁰⁰ This problem will not be solved until we as a society accept people who are differently abled and demonstrate that acceptance in our choices and values.

The Negative Perceptions of Persons with Disabilities

It is estimated that 19.7 percent of people in the United States have characteristics that are considered disabilities.¹⁰¹ With such a large percentage of people with disabilities in the United States, one might think discrimination against persons with disabilities would be non-existent. Unfortunately, this is not the case.

In passing the Americans with Disabilities Act in 1990 (ADA), Congress recognized that millions of the nation's population continued to be treated differently and pejoratively by the non-disabled majority: "Individuals with disabilities are a discrete and insular minority who have been subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society resulting from assumptions not truly indicative of the ability of such individuals to participate in, and contribute to, society."¹⁰²

The disadvantages associated with impairments have their source in pervasive attitudes of contempt and disrespect.¹⁰³ Like people of color, people with disabilities are not regarded as equals by the larger society, and the disadvantages they face reflect their devaluation.¹⁰⁴ Professor Ron Amundson explains the devaluation as follows: "Rehabilitation literature is full of examples of how able bodied people think of disabled people not as having specific disabilities, but as being generally incompetent. This social image reinforces the illusion that global disadvantages and handicaps flow from nature itself."¹⁰⁵ In turn, the prejudice against people

⁹⁹ *Id.*

¹⁰⁰ Mahowald, *supra* note 63, at 233.

¹⁰¹ "According to the 1997 Survey of Income and Program Participation taken by the U.S. Census Bureau, 19.7 percent of the population 'had some level of disability and . . . 12.3 percent of the population . . . had a severe disability.'" Jack McNeil, *Americans with Disabilities: Household Economic Studies 1*, U.S. Dep't of Commerce, Pub. No. P70-73 (2001), available at <http://www.sipp.census.gov/sipp/p70s/p70-73.pdf> (last visited Dec. 6, 2002). The term "disability" means, with respect to an individual- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment. Americans with Disabilities Act of 1990, 42 U.S.C. § 12101(a)(7) (2000).

¹⁰² Americans with Disabilities Act, *supra* note 101.

¹⁰³ Asch, *supra* note 57, at 329.

¹⁰⁴ David Wasserman, *Distributive Justice*, in *DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY* 147, 175 (Anita Silvers eds., 1998).

¹⁰⁵ Ron Amundson, *Disability, Handicap and the Environment*, 23 J. SOC. PHIL. 105, 109 (1992); Adrienne Asch, *Critical Race Theory, Feminism and Disability: Reflections on Social Justice and Personal*

with Down Syndrome because of their social incapacitation provides an excuse to reject the demands of persons with Down Syndrome for the kinds of environmental modifications that would increase their access to resources and would further their goals.¹⁰⁶ Like the myths that burden women and ethnic minorities, the myths about persons with Down Syndrome are self-supporting.

Attitudes toward congenital disability have not changed markedly. Both pre-modern as well as contemporary societies have regarded disabilities as undesirable and to be avoided. Not only have parents recognized the birth of a disabled child as a potentially divisive, destructive force in the family unit, but the larger society has seen disabilities as being unfortunate. Polls reveal that most Americans support abortion where a fetus has a severe genetic abnormality.¹⁰⁷ Our society still does not tolerate the elimination of diseased/disabled people, but it does urge the termination of diseased/disabled fetuses.¹⁰⁸ The urging is not explicit, but implicit. The dominant culture appears to be moving in two contradictory directions: more accommodating of disabilities in adults, but less tolerant of imperfections in children.¹⁰⁹

The disability rights critique of prenatal testing has been formulated as follows:

(1) Continuing, persistent, and pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities. Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.

(2) In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.

(3) When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely, "to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud."¹¹⁰

Furthermore, disability rights advocates argue that prenatal testing is being justified by mistaken assumptions about the quality of life of people with disabilities, and

Identity, 62 OHIO ST. L.J. 391, 397-410 (2001); Richard K. Scotch, *Models of Disability and the Americans with Disabilities Act*, 21 BERKELEY J. EMP. & LAB. L. 213, 213-18 (2000).

¹⁰⁶ Asch, *supra* note 57, at 329.

¹⁰⁷ Edward Dolnick, *Tests That Reveal Fetal Defects are Raising Ethical Questions*, BOSTON GLOBE, Apr. 29, 1985, at 37.

¹⁰⁸ Natalie Angier, *Joined for Life, and Living Life to the Full, Twins Challenge Old Views*, N.Y. TIMES, Dec. 23, 1997, at F1.

¹⁰⁹ *Id.*

¹¹⁰ Asch, *supra* note 57, at 316.

is demeaning to existing people with disabilities. Disability rights advocates argue that these assumptions are mistaken for several reasons:

- (1) They fail to recognize the extent to which the disadvantages associated with impairments result from discriminatory attitudes and practices rather than anything intrinsic to the impairment.
- (2) They place unwarranted emphasis on the size of one's opportunity range rather than the possibility for meaningful choice and rewarding outcomes within that range.
- (3) They confuse the claim that having a capacity, skill, or experience is good, with the claim that lacking a capacity, skill, or experience is inevitably bad. This confusion is due in part to the failure to distinguish the absence from the loss of a skill, capacity, or type of experience, and in part from the overly-narrow description of what is good or valuable.¹¹¹

The above three points contribute to a negative view of persons with disabilities held by society. Down Syndrome is one of the most readily apparent types of disabilities because the physical characteristics are recognized by most members of society. However, one of the largest contributors to this negative view of Down Syndrome is the prevalence of prenatal genetic testing. A large number of abortions are performed for medical reasons. However, obstetricians say several factors are most likely contributing to a growth in the frequency of terminations occurring after prenatal genetic testing, including broader availability of new screening technologies and more pregnancies among women over 35, who are at greater risk of carrying a fetus with chromosomal abnormalities.¹¹² Moreover, as genetic testing becomes more prevalent, and the public becomes more aware that testing is both available and reasonably accurate, society may reject or otherwise discriminate against children who are born with disabilities and the women who chose to have them.¹¹³

Disability rights advocates argue that the medical establishment is sending a message to patients that the goal is to guard against the birth of children with disabilities.¹¹⁴ Professor Adrienne Asch has said, "By putting them out there as something everyone must do, the profession communicates that these are conditions that everyone must avoid."¹¹⁵ Furthermore, Asch has stated, "[T]he earlier you can get it done the more you can get away with because you never have to

¹¹¹ *Id.*

¹¹² See Kotulak & Gorner, *supra* note 5.

¹¹³ *Id.* Some ethicists believe this is already occurring. Mary Mahowald, of the Center for Clinical Medical Ethics at the University of Chicago, says that the availability of prenatal testing has created a "premium-baby mentality" where society has come to expect perfect babies.

¹¹⁴ Amy Harmon, *The Burden of Knowledge: Tracking Prenatal Health; In New Tests for Fetal Defects, Agonizing Choices for Parents*, N.Y. TIMES, June 20, 2004, (unpaginated), available at <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9402EED91539F933A15755C0A9629C8B63&n=Top%2fReference%2fTimes%20Topics%2fSubjects%2fT%2fTests%20and%20Testing>.

¹¹⁵ *Id.*

tell anybody.”¹¹⁶ Terminating a pregnancy based on non-life threatening defects is causing some doctors to become troubled by what they consider to be a slippery slope from prenatal science to eugenics.¹¹⁷

The moral quandary we find ourselves in challenges the ideal of unconditional love of a child against the reality that most of us would prefer not to have that unconditional-love relationship with a certain subset of children. Adrienne Asch says, “I think the reason that this topic is as loaded and painful as it is, is that prospective parents want to think that they are open to loving whomever comes into their families, and they don’t want to think that they aren’t.”¹¹⁸ What is even more problematic is that people with Down Syndrome are described as having “warm, loving personalities and enjoy[ing] art and music.”¹¹⁹ Some parents claim Down Syndrome children are easier to raise than their unaffected children.¹²⁰ Because children with Down Syndrome are apparently happy, preventing their birth can hardly be justified as a means of preventing suffering and this makes it more difficult for prospective parents to rationalize the abortion of a child with Down Syndrome.¹²¹

Many women abort a fetus with Down Syndrome despite their views on abortion.¹²² This raises an interesting and yet critical point. Woman may distinguish the political question of abortion in law and public policy from abortion as a personal moral choice.¹²³ The political question of abortion is when, if ever, it is permissible to

¹¹⁶ *Id.*

¹¹⁷ *Id.*

¹¹⁸ *Id.*

¹¹⁹ RICKI LEWIS, *HUMAN GENETICS: CONCEPTS AND APPLICATIONS* 210, 212 (2d ed. 1997). Gibson argues that people with Down Syndrome are widely imputed to have traits that are contradictory; they are alleged, for example, to be “affable, mischievous, docile, aggressive, affectionate, stubborn, pleasing and self-willed.” DAVID GIBSON, *DOWN’S SYNDROME: THE PSYCHOLOGY OF MONGOLISM* 111 (1978). Naturally, individuals with Down Syndrome vary in their manifestation of these traits.

¹²⁰ Mahowald, *supra* note 63.

¹²¹ JEFF LYON, *PLAYING GOD IN THE NURSERY* 26-27 (1985).

¹²² Robertson, *supra* note 56, at 447.

¹²³ ROSALIND PETCHESKY, *ABORTION AND WOMAN’S CHOICE: THE STATE, SEXUALITY, AND REPRODUCTIVE FREEDOM* 348-49 (1985) (“[W]e need to distinguish between the *political question*—who should decide—and the *moral question*—whether abortion is right or wrong in a given instance.”); Mary Mahowald, *Abortion and Equality*, in *ABORTION: UNDERSTANDING DIFFERENCES* 177, 178 (1984) (noting that some “approve of the legality but not the morality of abortion”); Mary Segers, *Abortion and the Culture: Toward a Feminist Perspective in Abortion: Understanding Differences* 223, 229 (Sidney Callahan & Daniel Callahan, eds. 1984) (“fact that abortion is legal is not held to be conclusive of its morality”); Gettig, *supra* note 9; Kathryn Kolbert, *The Webster Amicus Curiae Briefs: Perspectives on the Abortion Controversy and the Role of the Supreme Court*, 15 *AM. J. L. & MED.* 153, 167 (1989); Elizabeth Weil, *A Wrongful Birth?* *N.Y. TIMES*, Mar. 12, 2006, (unpaginated), available at <http://www.nytimes.com/2006/03/12/magazine/312wrongful.1.html?ex=1190174400&en=ac95bfefc7a6739b&ei=5070> (“Back home in Orangeburg, Anthony and Donna tried but failed to find solace in the Catholic Church. (Neither had been churchgoers before, though both were raised in religious families; both identify with Catholicism culturally but say that families at times need more leeway than the church allows on family-planning issues.”); Harmon, *supra* note 4 (This article mentions the pressure on many women in anti-abortion regions, quoting the manager of an Internet support group for people

destroy human pre-born life.¹²⁴ The personal moral choice of abortion may turn on an infinite number of other questions such as: (1) Do I have the financial resources to support a child with special needs; (2) Where will *this* child go to school? (3) Will my family accept *this* child; and (4) How will *this* child affect my life?¹²⁵ Some argue that a desire not to have a child with special needs is based on prejudice.¹²⁶ Others claim that a choosy attitude toward fetuses brings a consumerist attitude to childbearing and undermines the moral stature of the family. Still others maintain that the act of aborting children with special needs drags us into a moral abyss, but raising children with special needs enhances our humanity.¹²⁷ The arguments result in two opposing views: (1) Prenatal testing is morally questionable because it leads people to reject fetal life because of a single trait, their disability, and (2) A “healthy” newborn is the best outcome for any parent and no reasonable person would choose disability over normalcy if they have the ability to choose based on prenatal testing. Aborting fetal life because of its below average intellectual or physical ability may be morally acceptable to some people, but aborting a fetal life for non-disabling conditions, e.g., gender, may be morally unacceptable to those same people.¹²⁸ The difference is hard to discern from a moral standpoint. If someone believes that abortion is not justified for gender selection or other genetically determined traits within the “normal” range, why should it be justified for other genetically determined traits, such as Down Syndrome or dwarfism, just because such conditions are statistically less common and deemed “abnormal.”¹²⁹

who have aborted their fetus for fetal health reasons: ‘I cannot turn on the computer any day without getting an e-mail from someone who needs help[.]’... ‘But nobody’s talking about it. Certainly not here in southeastern Virginia[.]’” The decision can be even harder where, as in numerous cases, a woman’s decision “contradict[s] [her] previously held beliefs.” “People will come into my office in tears and say they’ve been against abortion their whole lives,’ [Dr. John Larsen] said, ‘but they’ll make an exception for themselves.’”)

¹²⁴ Mahowald, *supra* note 63.

¹²⁵ Weil, *supra* note 123.

¹²⁶ *Id.*

¹²⁷ *Id.*

¹²⁸ PETCHESKY, *supra* note 123; Michael J. Malinowski, *Coming into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening*, 45 HASTINGS L.J. 1435, nn.120, 144 (1994). It should be mentioned that a woman’s right to decide up until viability whether or not to have an abortion is not dependent on her reasons. *Roe v. Wade*, 410 U.S. 959 (1973). Proponents of allowing gender selection typically argue, “if one is free to have no children by abortion and contraception, it would seem to follow that one is free to take steps not to have offspring with particular characteristics. Similarly, if one is free to have children, it would also seem to follow that one is free to have children with particular characteristics.” Robertson, *supra* note 56, at note 92.

¹²⁹ PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: THE ETHICAL, SOCIAL AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING AND EDUCATIONAL PROGRAMS 18, 56-59 (1983). The President’s Commission discourages genetic screening for gender selection. The report asserts we do not want to send out the message that society values one gender over the other. Robertson, *supra* note 56, at 439.

Disability rights advocates are right to think of genetic counseling as a search and destroy mission because testing will likely ultimately lead to greater intolerance of disabilities and less money for research or treatment. Some doctors do not want to perform abortions when fetuses have relatively minor defects.¹³⁰ At the same time, genetic counselors are right to pursue what is a necessary job, counseling and helping families make the best decision for themselves.¹³¹

What adds to the problem is the fast growth of the medical genetics field. As a result of this fast growth, the evolution of enforceable legal regulations and the formulation of widely understood and accepted ethical policies have lagged behind rapid developments in technology.¹³² The result is a medical genetics field that is loosely regulated.

While individuals may not have the necessary resources to adequately care for people with special needs, society does. Because society has greater resources to provide for children with special needs, it does not have the rationale that some pregnant women may have for genetic testing and abortion of fetuses whose subsequent care may be impossible for them to provide.¹³³ But there are those in society that want to reduce the cost of care by eliminating or at least reducing the numbers of people with disabilities by encouraging genetic testing and the abortion of fetuses that test positive for Down Syndrome.¹³⁴ That this rationale has been effective seems clear from the fact that most women who are told that their fetus has this anomaly choose to abort it more quickly than when they are given other fetal diagnoses, some of which have more devastating medical consequences.¹³⁵ The desire for a “normal” or “better” child contributes to the stigma that people with Down Syndrome live with. Many factors contribute to the social attitude of society and its overall negative impact on persons with disabilities. One thing is clear, this negative view of Down Syndrome will not change until we begin to accept those who are differently abled.

Contrasting the Roles of Physicians and Genetic Counselors

The medical community also contributes to the high abortion rate for fetal life with Down Syndrome. It is important to understand the different roles of doctors and genetic counselors in the prenatal process. Typically a woman makes an appointment to see her doctor as soon as she has a positive pregnancy test result, which could be a week after conception or several months. After the first two months of pregnancy, many of the tests discussed in this article would be inaccurate and, thus, would not be offered.¹³⁶

¹³⁰ *Id.*

¹³¹ *Id.*

¹³² Weil, *supra* note 123.

¹³³ *Id.*

¹³⁴ Mahowald, *supra* note 63.

¹³⁵ *Id.*

¹³⁶ Gettig, *supra* note 9; Montefiore Medical Center, *supra* note 63. However, an abortion can still be performed because viability is generally considered to occur at the end of the second trimester—

There are several types of medical providers. First, and most well known, are obstetrician-gynecologists, also known as OBGYN's. OB is short for obstetrician, a doctor who specializes in pregnancy, delivering babies, and gynecology.¹³⁷ They may have low or high risk patients. These doctors usually work in the hospital setting, although many are opening birthing centers, and a few do home deliveries. GYN is short for gynecologist, a physician who specializes in treating diseases of the female reproductive organs.¹³⁸ Second, family practitioners may specialize in family care, including pregnancy and delivery.¹³⁹ They usually consult with an obstetrician on surgical cases. They practice in hospitals, birthing centers, and home delivery settings.¹⁴⁰ Third, nurse midwives are nurses with training in low risk pregnancy and delivery (about 90% of births fall into this category).¹⁴¹ They practice in conjunction with physicians. They may practice in home, hospital or birthing center settings.¹⁴² Fourth, perinatologists are doctors who specialize in managing high risk pregnancies.¹⁴³ About ten percent of pregnancies fall in this category.¹⁴⁴ These physicians practice in hospital settings, usually in conjunction with a Level III nursery. And fifth, non-nurse midwives who have special training in midwifery only, limit their practice to women with low risk pregnancies and deliveries.¹⁴⁵ Midwives may consult with physicians, and they usually practice in home delivery settings or birthing centers.¹⁴⁶

Doctors typically make the offer for genetic testing in both the first and second trimester, which may be dictated by the desire to avoid legal liability that may result from the unexpected birth of a child with disabilities.¹⁴⁷ Patients see genetic counselors because they are referred by their physician or are self referred.¹⁴⁸ Most people who provide genetic counseling are not genetic counselors but obstetricians, because there are few genetic counselors in many places, especially rural areas.

that is, during the twenty-third or twenty-fourth week of pregnancy. MICHAEL J. FLOWER, *COMING INTO BEING: THE PRENATAL DEVELOPMENT OF HUMANS, IN ABORTION, MEDICINE, AND THE LAW* 437-51 (J. Douglas Butler & David F. Walbert, eds. 1992).

¹³⁷ Robin Elise Weiss, *About.com: Pregnancy & Childbirth* (July 2007), available at <http://pregnancy.about.com/cs/consumerissues/a/pickingprac.htm>; Medicine.net (Nov. 2007), available at <http://www.medterms.com/script/main/art.asp?articlekey=4609>.

¹³⁸ *Id.*

¹³⁹ Weiss, *supra* note 137.

¹⁴⁰ *Id.*

¹⁴¹ *Id.*

¹⁴² *Id.*

¹⁴³ *Id.*

¹⁴⁴ *Id.*

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ Gettig, *supra* note 9; Keith Johnston, *Medical Malpractice and "Wrongful Birth": A Critical Analysis of Wilson v. Kuenzi*, 57 UMKC L. REV. 337 (1989).

¹⁴⁸ Balkite, *supra* note 7; Sarah Parrott & Maria Del Vecchio, *Nat'l Soc'y of Genetic Counselors, Professional Status Survey* (2006), available at http://www.nsgc.org/client_files/career/2006_PSS_RESULTS.doc. (hereafter National Society).

Fewer referrals occur because of this and as a result, obstetricians and primary care physicians provide genetic counseling to their patients.¹⁴⁹ However, this is a problem because these professionals are not as well equipped to deal with substantive genetic counseling issues.¹⁵⁰ In urban areas, there are typically more referrals because urban areas have greater medical resources and there is typically more insurance coverage because of the increased referrals.¹⁵¹ Furthermore, many women only see a genetic counselor if they have an abnormal test result.¹⁵² Some doctors refer all pregnant patients prior to any testing for counseling, education sessions, test coordination, and explanation of results.¹⁵³ However, it is standard for a doctor to refer a woman to a genetic counselor after the test results have been reported for clarification of what the test results mean.¹⁵⁴ Physicians typically do not have the time to explain the risks and benefits, what the detection rates are, and the procedures.¹⁵⁵ Most obstetrician-gynecologists spend about eight minutes with their patients per session.¹⁵⁶ Most genetic counselors spend about forty minutes with their patients per session.¹⁵⁷

Doctors do not receive as much training in genetics as genetic counselors. The amount of genetics taught in a typical medical school is only one week or

¹⁴⁹ Gettig, *supra* note 9. Because primary care physicians typically control the care that their patients receive, it is essential that they become aware of the risks and benefits of genetic testing for different populations of their patients and their at-risk relatives. Susan M. Denbo, *What Your Genes Know Affects Them: Should Patient Confidentiality Prevent Disclosure of Genetic Test Results to a Patient's Biological Relatives?* 43 AM. BUS. L.J. 561 (2006).

¹⁵⁰ ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 87, 234 (Lori B. Andrews et al. eds., 1994) (hereafter ASSESSING GENETIC RISKS).

¹⁵¹ Balkite, *supra* note 7.

¹⁵² *Id.*

¹⁵³ *Id.* Carolyn Jacobs Chachkin, *What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care*, 33 AM. J. L. & MED. 9, 28 (2007). "It is, however, likely that most, if not all, women who currently obtain ultrasound would *also* seek MSFCS or MPFDR." *Id.*

¹⁵⁴ Gettig, *supra* note 9. Individuals might seek carrier testing to determine their risk of having a child with a particular recessive condition. Suter, *supra* note 3, at 236.

¹⁵⁵ *Id.*

¹⁵⁶ *Id.* "Midwives spend an average of twenty-four minutes per visit with each client, while prenatal visits with doctors ranged from less than five minutes to ten minutes." Suzanne Hope Suarez, *Midwifery Is Not the Practice of Medicine*, 5 YALE J.L. & FEMINISM 315, 345-46 (1993).

¹⁵⁷ *Id.*

one course.¹⁵⁸ Moreover, genetics is not taught in every medical school.¹⁵⁹ The likely result is many doctors are ill equipped to discuss genetic issues.¹⁶⁰ Medical schools should offer more genetic counseling instruction since many doctors will recommend genetic testing as a common part of their medical practice. It is very typical for the initial genetic screening to be performed in the doctor's office, the results being given to the patient in the same office, as well as the patient referral to a genetic counselor, all without any detailed explanation by the doctor.¹⁶¹ As a result, women tend to come into a genetic counselor's office ill equipped and uninformed.¹⁶² Moreover, some women may never see a genetic counselor because of financial constraints.¹⁶³ Insurance companies often reimburse for diagnostic tests at far higher levels than for pretest counseling—if they reimburse for counseling at all.¹⁶⁴ As a result, fiscal concerns might lead practitioners to push for testing rather than genetic counselor referrals.

An important function of genetic counseling is to assist parents who have a fetus with a genetic anomaly to deal with the implications of the diagnosis for the

¹⁵⁸ Gettig, *supra* note 9. "A 1995 survey by the Association of American Medical Colleges revealed that only sixty-eight of 125 medical schools in the United States required students to take genetics courses." FINAL REPORT OF THE TASK FORCE ON GENETIC TESTING 60, 65 (Neil A. Holtzman & Michael S. Watson, eds. 1997) (hereafter FINAL REPORT). Another source indicates that in 1991-92, 79 of 126 medical schools required a human or medical genetics course. See also ASSESSING GENETIC RISKS, *supra* note 151, at 220. Adding genetics to the medical school curriculum is likely to require that other disciplines concede some of the hours traditionally devoted to their study. Advocates of genetic education may, thus, face resistance from faculty members and specialists. Mark A. Rothstein, *Genetic Testing, Genetic Medicine, Manage Care*, 34 WAKE FOREST L. REV. 849 n.71 (1999).

¹⁵⁹ *Id.*

¹⁶⁰ "Doctors may find explaining complex technology so difficult and time-consuming that they fall back on a paternalistic or 'trust me, I'll decide what's best for you' approach to the patient. Women are usually eager to do what is best for the baby, so they accept the doctor's instructions." Walsh, *supra* note 78, at 178.

¹⁶¹ Gettig, *supra* note 9; Carolyn Lee Brown, Note, *Genetic Malpractice: Avoiding Liability*, 54 U. CIN. L. REV. 857, 859 (1986). Referral to a genetic counselor is made in order to evaluate the family history, explain inheritance, discuss the benefits, risks, limitations, and psychosocial impact of testing; a medical and surgical oncologist to discuss management options; and a mental health specialist to help in the decision to test, to provide support during the testing process, or to help adjust to the results. The patient should be offered these referrals both before and after testing. OncorMed can help locate a genetic counselor in the client's area, if needed. Michael J. Malinowski & Robin J.R. Blatt, *Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards*, 71 TUL. L. REV. 1211, 1307-08 (1997).

¹⁶² Gettig, *supra* note 9; Walsh, *supra* note 78, at 172-75 (claiming prenatal screening is presented to women as "presumptively a good thing," that complete information often is not given, and that the quality of information is affected by the attitudes physicians have about their female patients).

¹⁶³ Gettig, *supra* note 9; Matthew A. Bower et al., *A Survey of Genetic Counselors' Strategies for Addressing Ethical and Professional Challenges in Practice*, 11 J. GEN. COUNSELING 3, 163-186 (2002).

¹⁶⁴ Suter, *supra* note 3, at 242; ASSESSING GENETIC RISKS, *supra* note 150, at 152; FINAL REPORT, *supra* note 158, at 65-73.

child, the family, and additional children that may be conceived in the future.¹⁶⁵ Genetic counselors seek to be culturally sensitive, personally sensitive and to let people make their own decisions by being non-directive.¹⁶⁶ They try to tell everyone similar information and let them make their own choice. Other health professionals have less training in nondirectiveness than genetic counselors, and are therefore more likely to be directive and to incorporate their own values and judgments in the counseling process.¹⁶⁷ In general, physicians with training in genetic counseling are more directive in their counseling style than genetic counselors.¹⁶⁸ Physicians without such training are even more so.¹⁶⁹ As a result, many patients choose prenatal testing in part because their physician has recommended or even encouraged it. Non-genetic health professionals tend to make such recommendations partly because “the idea that one would not want information is so counter to the medical profession’s world view.”¹⁷⁰ While genetic counselors tend to accept a broad range of reasons for rejecting prenatal testing, physicians are more inclined to encourage testing, unless the patient has a history of infertility or miscarriage.¹⁷¹ One major reason genetic counseling should be offered in medical schools is to inform physicians about the non-directive goals of genetic counseling and educate them on the wide range of functioning that people with genetic anomalies experience.¹⁷²

The choices health professionals offer are typically: (1) an initial genetic screening; (2) additional diagnostic testing; (3) and support if they chose to abort or to continue the pregnancy.¹⁷³ But what is frequently missing from this process is the delivery of comprehensive information on genetic anomalies, resulting range of possible disability, and the support services available in the community.¹⁷⁴

¹⁶⁵ Deborah F. Pencarinha, *Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives*, 1 J. GENETIC COUNSELING 19 (1992).

¹⁶⁶ Jeffrey R. Botkin, *Prenatal Screening: Professional Standards and the Limits of Prenatal Choice*, 75 OBSTETRICS & GYNECOLOGY 875 (1990) (Because the commitment to autonomy (reflected in the norm of nondirectiveness) is greater in genetics than any other discipline, it is not surprising that physicians who were not trained in genetics would be more directive than non-geneticist physicians).

¹⁶⁷ Rothman, *supra* note 1, at 82. Studies have shown that primary care physicians and other doctors are more directive in providing genetic counseling than are geneticists, particularly where reproductive choices are at issue. For example, in one study, women who were counseled by a general obstetrician were more likely to abort a fetus with a sex chromosome abnormality than those who consulted a geneticist. Rothstein, *supra* note 29.

¹⁶⁸ *Id.*

¹⁶⁹ *Id.* at 133.

¹⁷⁰ Suter, *supra* note 3.

¹⁷¹ Gettig, *supra* note 9.

¹⁷² PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES: FINAL REPORT OF THE TASK FORCE ON GENETIC TESTING 60, 66 (Neil A. Holtzman & Michael S. Watson, eds. 97). “Some proposals advanced by commentators to better educate primary care physicians about genetics include the following: (1) incorporating genetics curricula into medical school and residency training programs . . .” *Id.*

¹⁷³ Gettig, *supra* note 9.

¹⁷⁴ Rothman, *supra* note 1, at 82.

In prenatal genetic testing counseling, the genetic counselor typically begins by explaining that all pregnancies have a three to five percent population risk of birth defects, regardless of family history.¹⁷⁵ The counselor then describes the patient's particular pregnancy risk.¹⁷⁶ Next, the counselor describes the information that tests can provide, their limitations—not all conditions can be identified—and the health risks to the patient.¹⁷⁷ Finally, during the screening and counseling process, the genetic counselor works closely with the physicians on a health care team.¹⁷⁸ Contact with community support services or similarly situated women or families is not required.¹⁷⁹ Of course, some patients may independently obtain information about community services for Down Syndrome children from national or local Down Syndrome organizations, or from the Internet.¹⁸⁰

The American Academy of Pediatrics recommends that the medical professional discuss the following topics with the family:

1. The prenatal laboratory or fetal imaging studies leading to the diagnosis.
2. The mechanism for occurrence of the disorder in the fetus and the potential recurrence rate for the family.
3. The prognosis and manifestations, including the wide range of variability seen in infants and children with Down Syndrome.
4. When applicable, additional studies that may refine the estimation of the prognosis (eg, fetal echocardiogram, ultrasound examination for gastrointestinal malformations).
5. Currently available treatments and interventions. This discussion needs to include the efficacy, potential complications and adverse effects, costs, and other burdens associated with these treatments. Discuss early intervention resources, parent support programs, and any plausible future treatments.
6. The options available to the family for management and rearing of the child using a nondirective approach. In cases of early prenatal diagnosis, this may include discussion of pregnancy continuation or termination, rearing the child at home, foster care placement, and adoption.¹⁸¹

If the pregnancy is continued, a plan for delivery and neonatal care must be developed with the obstetrician and the family. Also, a referral to a clinical geneticist should be considered, if it has not already been considered, for a more extended

¹⁷⁵ Suter, *supra* note 3, at 243-44.

¹⁷⁶ *Id.*

¹⁷⁷ *Id.*

¹⁷⁸ Cara Dunne & Catherine Warren, *Lethal Autonomy: The Malfunction of the Informed Consent Mechanism Within the Context of Prenatal Diagnosis of Genetic Variants*, 14 ISSUES LAW & MED. 165, 193 (1998).

¹⁷⁹ *Id.*

¹⁸⁰ Gettig, *supra* note 9; see also, Down Syndrome Association, available at http://www.downs-syndrome.org.uk/DSA_NewParents.aspx; see also, Skotko, *supra* note 86, at 673.

¹⁸¹ American Academy, *supra* note 30.

discussion of clinical outcomes and variability, recurrence rates, future reproductive options, and evaluation of the risks for other family members.¹⁸²

Prenatal genetic screening is being largely left to the discretion of the medical profession and is being performed for the benefit of prospective parents, not their fetuses.¹⁸³ Prenatal genetic screening is about “offering prospective parents difficult choices regarding the sacrifices they are willing to make to be parents, what mental and physical characteristics their children will have, and what kind of lives they want their children to have at a time when abortion is still an option.”¹⁸⁴ The assumption underlying voluntary genetic screening is that prospective parents will be given information and be allowed to act on that information.¹⁸⁵ The choices created through prenatal genetic screening (whether to undergo genetic testing, which tests to run, the option to end a pregnancy based upon a broader spectrum of test results) will expand along with prenatal testing capability.¹⁸⁶ Today, the two options given to prospective parents who receive genetic screening results indicating a genetic abnormality are: delivering a child with a known impairment or propensity for being unhealthy, and aborting the child.¹⁸⁷ The care provided by OBGYN’s, family practitioners and genetic counselors will contribute to the choice women make.

The Role of Genetic Counselors

Even though genetic counselors are not the first persons women see in the prenatal process, they play a major role because they are frequently the most knowledgeable source of medical information on genetic anomalies for pregnant women and their families.¹⁸⁸ The genetic counselors I interviewed all agreed that the women and their families who come for genetic counseling typically understand little about what a genetic counselor does, the training they receive, their professional standards of conduct, medical guidelines for prenatal diagnosis, and ultimately their function as a whole.¹⁸⁹ This section will provide information about genetic counselors, the people who need and use their services, their professional guidelines and standards of conduct, clinical approaches, and the process of genetic counseling. This section will discuss the new prenatal guidelines genetic counselors follow and whether those new guidelines are necessary.

¹⁸² Martin Richards, *Families, Kinship, and Genetics*, in *THE TROUBLED HELIX: SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF THE NEW HUMAN GENETICS* 249, 140-63 (Theresa Marteau & Martin Richards, eds. 1996).

¹⁸³ Kathleen Nolan, *First Fruits: Genetic Screening*, *HASTINGS CENTER REP.*, July/Aug., 1992, at S2. As explained by one observer, “traditionally, the ethics of prenatal genetic counseling has required that prospective parents be given full information and then be allowed to choose which, if any, genetic diagnostic tests to pursue.”

¹⁸⁴ Malinowski, *supra* note 128, at 1478-80; Clayton, *supra* note 86.

¹⁸⁵ Malinowski, *supra* note 128, at 1478-80.

¹⁸⁶ *Id.*; Clayton, *supra* note 86.

¹⁸⁷ Malinowski, *supra* note 128, at 1478-80.

¹⁸⁸ See *supra* notes 158 & 160.

¹⁸⁹ Gettig, *supra* note 9; Balkite, *supra* note 7.

The National Society of Genetic Counselors (NSGC) says that genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease.¹⁹⁰ NSGC asserts that the genetic counseling process involves an attempt by one or more appropriately trained persons to help the individual or family to:

(1) comprehend the medical facts, including the diagnosis, probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the alternatives for dealing with the risk of occurrence; (4) choose the course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards, to act in accordance with that decision; and (5) to make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder.¹⁹¹

Genetic counselors are health professionals with graduate degrees in the areas of medical genetics and counseling.¹⁹² They work as members of a health care team, providing information and support to families who have family members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions.¹⁹³ They provide supportive counseling to families, serve as patient advocates and refer individuals and families to community or state support services.¹⁹⁴ Furthermore, they “identify families at risk, investigate the [genetic anomaly] present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence and review available options with the family.”¹⁹⁵ Most enter the field from an array of disciplines that includes biology, genetics, nursing, psychology, public health and social work.¹⁹⁶ They serve as educators and resource people for other health care professionals and for the general public.¹⁹⁷ Some counselors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counseling.¹⁹⁸

Professor Gettig believes that patients who might have a child with Down Syndrome typically see genetic counselors at two primary points: (1) prenatal testing to determine whether or not the baby has Down Syndrome or (2) after delivery, to diagnosis a child with Down Syndrome and provide information on the available educational and health programs needed for children with Down Syndrome.¹⁹⁹

¹⁹⁰ National Society of Genetic Counselors, Inc. (June 2006), available at www.nsgc.org. hereafter National Society of Genetic Counselors]

¹⁹¹ *Id.*

¹⁹² Robert G. Resta, *Genetic Counseling: Coping with the Human Impact of Disease* (July 2007), available at http://www.accessexcellence.org/AE/AEC/CC/counseling_background.html.

¹⁹³ National Society of Genetic Counselors, *supra* note 190.

¹⁹⁴ *Id.*

¹⁹⁵ *Id.*

¹⁹⁶ *Id.*

¹⁹⁷ *Id.*

¹⁹⁸ *Id.*

¹⁹⁹ Gettig, *supra* note 9.

Similarly, Professor Carolyn Lee Brown argues genetic counseling actually consists of three stages: the patient-counselee must directly approach or be referred to the genetic counselor; the genetic counselor must obtain all necessary information to allow for a proper diagnosis; and, ultimately, the genetic counselor must communicate his diagnosis to the patient-counselee.²⁰⁰

Genetic counseling is typically advised for: (1) Pregnant women who will be 35 years old or older at delivery time (however the guidelines have changed, see *infra Genetic Counseling Guidelines and Professional Standards of Conduct*); (2) Individuals who are known to be at risk for carrying genetic disorders; (3) Parents of a child with a genetic disorder, birth defect or mental retardation; (4) Individuals who have had a laboratory test indicating an increased risk for a genetic disorder; (5) Individuals diagnosed with a birth defect or mental retardation, or who have a family history of a genetic disorder; (6) Individuals of ethnic groups in which particular inherited diseases are more common; (7) Individuals or couples who have had multiple miscarriages or pregnancy losses; and (8) Women exposed to certain medications or drugs, significant radiation, and/or particular infections during pregnancy.²⁰¹

Genetic Counseling Guidelines and Professional Standards of Conduct

A genetic counselor must earn a masters degree from a genetic counseling/human genetics program accredited by the American Board of Genetic Counseling.²⁰² Most genetic counselors are board-certified.²⁰³ Most counselors enter a genetics program with an undergraduate degree in science, psychology, or genetic counseling.²⁰⁴ Each program has slightly different prerequisites and course requirements. However, they are all based on developing specific competencies in genetic counseling.²⁰⁵ Similarly, numerous nurse-counselors and social workers do genetic counseling. In the past, counselors without master's degrees were eligible for board certification, but since the mid-1980s, a master's degree in genetic counseling is required.²⁰⁶

There are two medical organizations that govern genetic counselors: the American Board of Genetic Counseling (ABGC) and the National Society of Genetic Counselors (NSGC). The ABGC certifies genetic counselors and accredits genetic

²⁰⁰ Brown, *supra* note 161.

²⁰¹ University of Maryland Medical Center (July 2007), *available at* <http://www.umm.edu/center/>.

²⁰² At present there are twenty-nine accredited programs in the U.S., three in Canada. American Board of Genetic Counseling, *available at* <http://www.abgc.net/english/view.asp?x=1643> (hereafter American Board).

²⁰³ Malinowski, *supra* note 128, at 1459. A recent study indicates that 73% of genetic counselors have a masters degree in genetic counseling. National Society, *available at* http://www.nsgc.org/client_files/career/2006_PSS_RESULTS.doc.

²⁰⁴ *Id.*

²⁰⁵ American Board, *available at* <http://abgc.iamonline.com/english/View.asp?x=1529>.

²⁰⁶ *Id.*

counseling training programs.²⁰⁷ Graduates of these programs must also pass a certifying examination administered by the Board.²⁰⁸ Genetic counselors that have passed their certifying examination practice in a variety of settings, including hospitals, private offices, laboratories, federal and state government offices, universities, and research facilities.²⁰⁹

The NSGC is the professional membership association for the genetic counseling profession.²¹⁰ Because they offer educational programs, it would be considered a conflict of interest for them to administer the Board exams.²¹¹ In 1991, the NSGC adopted a professional code of ethics entitled "Genetic Counselors and their Clients," which discusses the need to respect clients' backgrounds and cultural beliefs.²¹² If someone violates the NSGC code of ethics or any published practice guidelines, they may lose their certification.²¹³ If a complaint is filed, the issue is reviewed and the review committee of ABGC renders a decision.²¹⁴ According to the NSGC, the average counselor sees about 450 patients per year, with a range of 200 to 1000.²¹⁵

Regarding guidelines, another major consideration needs to be the new professional standard of conduct. Before January 1, 2007, the majority of pregnant American women 35 years of age or older were offered amniocentesis.²¹⁶ It has become standard practice for women older than 35 to be offered genetic counseling and diagnostic testing.²¹⁷ Yet, women under the age of 35 have higher fertility rates and account for 80 percent of children born with Down Syndrome.²¹⁸ Therefore, the new American College of Obstetricians and Gynecologists guidelines recommend

²⁰⁷ Resta, *supra* note 192. American Board, available at <http://www.abgc.net/english/View.asp?x=1606>.

²⁰⁸ *Id.* American Board, *supra* note 207, available at <http://www.abgc.net/english/View.asp?x=1418>. Most states accept ABGC certification in lieu of a licensing exam. For example in Utah, California, Illinois, if you are ABGC certified, you are automatically licensed to practice in that state. American Board, available at www.abgc.net.

²⁰⁹ Resta, *supra* note 192.

²¹⁰ National Society of Genetic Counselors, *supra* note 190, available at http://www.nsgc.org/consumer/faq_consumers.cfm.

²¹¹ *Id.*

²¹² Dunne & Warren, *supra* note 178, at 189-90. National Society of Genetic Counselors, Inc. (June 2006), *Code of Ethics*, available at <http://www.nsgc.org/about/codeEthics.cfm>.

²¹³ Balkite, *supra* note 7.

²¹⁴ *Id.* It should be noted that all disciplinary action against genetic counselors is taken by the ABGC which appears partial to protecting the integrity of the genetic counseling profession and its members. This partially could impact the quality of patient care and decisions. However, no studies have been done to confirm this assumption.

²¹⁵ Malinowski, *supra* note 128, at 1469; National Society, *supra* note 148.

²¹⁶ A. KOLKER & B. M. BURKE, *PRENATAL TESTING: A SOCIOLOGICAL PERSPECTIVE* (1994). See also B. N. CHORDIRKER ET AL., *SOGC CLINICAL PRACTICE GUIDELINES, CANADIAN GUIDELINES ON PRENATAL DIAGNOSIS: GENETIC INDICATIONS FOR PRENATAL DIAGNOSIS* (2001).

²¹⁷ Will, *supra* note 21.

²¹⁸ *Id.*

that all pregnant women, regardless of age, be offered such counseling and testing.²¹⁹ Whether it is good policy to test all women in order inform them whether they are carrying a fetus with a chromosomal anomaly must be judged in the light of the risks to their health, options for treatment, especially of possible life-threatening conditions, and the benefits of knowing in advance that a child with special needs may be born. If the benefits of such testing exceed the risks, then expanding the prenatal guidelines to include all women may be necessary.²²⁰

Many older pregnant women know before they are even pregnant that they will be offered, or even urged, to undergo amniocentesis or another genetic screening if they become pregnant. While women may not know what amniocentesis entails or are confused as to what the test results mean, they know that they are in a high-risk category by virtue of their maternal age alone.²²¹ In contrast, younger women do not consider themselves to be in a high-risk category.²²² In the past, younger women were only referred for prenatal tests if they had a family history of hereditary disease, or if genetic screening suggested a need for diagnostic testing.²²³

Research is being conducted on the cost-effectiveness of having every pregnant woman in the United States undergo prenatal genetic testing.²²⁴ Currently, medical science has no treatment for Down Syndrome itself, but may provide treatment for certain conditions that frequently accompany it. While diagnosing Down Syndrome before birth permits or even encourages parents to choose abortion, it also permits those parents who accept a child that is differently abled to prepare for the arrival of a child with special needs. As more is learned about genetic anomalies, more genetic tests will be recommended.²²⁵ Obstetricians and gynecologists may be adopting policies that have the effect of increasing abortion for genetic anomalies.²²⁶ Is this the result of informed consent, or a reflection of our bias against people with disabilities?

²¹⁹ KOLKER & BURKE, *supra* note 216.

²²⁰ *Id.*

²²¹ MARION S. VERP, PRENATAL DIAGNOSIS OF GENETIC DISORDERS, IN PRINCIPLES AND PRACTICE OF MEDICAL THERAPY IN PREGNANCY 159, 162-66 (Gloria E. Sarto, ed. 1992); Glenn Schemmer & Anthony Johnson, *Genetic Amniocentesis and Chorionic Villus Sampling*, 20 OBSTETRICS & GYNECOLOGY CLINICS N. AM. 497, 515-16 (1993).

²²² *Id.*

²²³ Will, *supra* note 21.

²²⁴ Suter, *supra* note 3, at 234 (The circumspection regarding knowledge and genetic testing in the context of adult genetics applies equally well in the reproductive context. Yet, the same level of restraint and caution does not exist. Instead, prenatal genetic testing and screening has become *de rigueur*; nearly as commonplace and widely accepted as some of the more routine aspects of prenatal care.) *Id.* Some research as begun. See The American College of Obstetricians and Gynecologists, *A Cost-Effectiveness Analysis of Prenatal Screening Strategies for Down Syndrome*, OBSTETRICS & GYNECOLOGY (2005), available at <http://www.greenjournal.org/cgi/content/full/106/3/562.209>.

²²⁵ Suter, *supra* note 3, at 246.

²²⁶ Bonnie S. LeRoy, *When Theory Meets Practice: Challenges to the Field Of Genetic Counseling*, in PRESCRIBING OUR FUTURE: ETHICAL CHALLENGES IN GENETIC COUNSELING 39, 41 (Dianne M. Bartels et al., eds. 1993).

Non-directiveness: The Unattainable Ideal

A major tenant of genetic counseling is non-directiveness. Genetic counselors are taught to be: educational, nondirective, unconditional, and supportive.²²⁷ The Code of Ethics states that counselors should strive to: (1) seek out and acquire all relevant information required for any given situation; (2) continue their education and training; (3) remain aware of current standards of practice; and (4) recognize the limits of their own knowledge, expertise, and therefore competence in any given situation.²²⁸ With regard to their relationship with their clients, counselors should strive to: “(1) enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences, and (2) refer clients to other competent professionals when they are unable to support the client.”²²⁹

The hallmark of genetic counseling is nondirectiveness.²³⁰ Nondirective, or client-centered, counseling is the process of skillfully listening to a client, encouraging the person to explain his or her concerns, helping the client to understand the relevant issues, and determine a course of action.²³¹ This type of counseling is “client centered” because it focuses on the client, rather than on the counselor. The counselor primarily listens to and tries to help the client discover and follow improved courses of action.²³² They especially “listen between the lines” to learn the full meaning of their client’s feelings.²³³ They look for assumptions underlying the counselee’s statements and for the events the counselee may, at first, have avoided talking about. Counselors often say a person’s feelings may be likened to an iceberg.²³⁴ The feelings and emotions expressed by the patient may be only the “tip” of the iceberg. Underlying these expressed feelings and emotions lay the ultimate dilemma to be faced by the patient, which the patient is almost always reluctant to reveal.

Despite their commitment to nondirectiveness, genetic counselors may subtly promote prenatal testing because of values they hold dear.²³⁵ As stated earlier, medical professionals are not neutral about the value of information, and the view that gathering of information as a sign of responsible behavior and good decision–

²²⁷ Nat’l Soc’y of Genetic Counselors, *A Voice, a Resource and an Educational Environment for the Genetic Counseling Profession* (1991), distributed at the 1997 Annual Genetics Conference, in Baltimore, MD, American Society of Genetics Counselors, available at <http://www.springerlink.com/content/t7366q436n21476p/>.

²²⁸ *Id.*

²²⁹ Integrated Publishing, *Types of Counseling* (July 1, 2007), available at http://www.tpub.com/content/advancement/14144/css/14144_105.htm

²³⁰ *Id.*

²³¹ *Id.*

²³² *Id.*

²³³ *Id.*

²³⁴ Suter, *supra* note 3, at 246.

²³⁵ Anderson, *supra* note 1 (“In genetics, clinicians and researchers believe that knowledge and genetic science are moral goods” (noting the public’s acceptance of the “moral imperative to know.”)).

making.²³⁶ Moreover, genetic counselors and patients tend to believe that getting information about the fetus is not only the right thing to do, but a form of reassurance and a way to get a sense of control over the potentially overwhelming experience of reproduction.²³⁷ Also, some popular books have linked the notion of good parents with prenatal testing.²³⁸ Professor Suter has suggested that more genetic counselors hold stronger views about the “rightness” or “wrongness” of abortion for genetic anomalies and its effect on the overall makeup of society than do most physicians.²³⁹

Most genetic counselors attempt to achieve the goal of nondirectiveness yet there are countless stories of those who do not. As a result, genetic counselors are not without fault. Although they are supposed to be nondirective, many people simply cannot make a decision. Professor Getting, among other genetic counselors, has experienced women continually asking questions such as, “What would you do in my situation?”²⁴⁰

How directive is it to talk patients through the decision-making process? “Talking through” means discussing the things the genetic counselor would consider important and that others have considered important, such as: How stable is the patient’s marriage? Is the patient financially capable of raising this child? Is the patient’s job flexible enough to handle a child with special needs? Should the patient stay at home instead? Will the patient psychologically and physically be able to handle the special needs of this child? What would it be like to raise this child? How would the child affect the patient’s other children? What is the patient prepared to do and not do for the special needs, both physical and psychological, of this child?²⁴¹

Is the above directive or non-directive? It appears the questions asked show value judgments and concern on the part of the genetic counselor. Many genetic counselors believe they can achieve nondirectiveness through consciously being aware of their word choice, body language and maintaining an awareness of the gravity of the information being shared.²⁴² Furthermore genetic counselors argue that being nondirective does not mean that you cannot give directions to people, and distributing information on genetic screening to people is not directive because

²³⁶ Suter, *supra* note 3.

²³⁷ *Id.* at 247.

²³⁸ Suter, *supra* note 3, at 246; Seymour Kessler, *The Psychological Paradigm Shift in Genetic Counseling*, 27 *SOC. BIOLOGY* 167, 168, 176 (1980). This article discusses the shift from the eugenics paradigm, which focused on managing human heredity, to the current paradigm of psychologic medicine, which focuses on helping patients resolve problems and make decisions. Sonia M. Suter, *A Fresh Look at Nondirectiveness in Genetic Counseling* (Jan. 1, 2000) (unpublished manuscript, on file with author).

²³⁹ Gettig, *supra* note 9; Balkite, *supra* note 7; Clayton, *supra* note 20.

²⁴⁰ *Id.*

²⁴¹ *Id.*

²⁴² *Id.*

the patient can choose whether or not to follow those guidelines.²⁴³ Although much discussion has occurred regarding nondirectiveness, there does not appear to be any exact guidelines regarding what is and what is not nondirective.²⁴⁴ The end result is although most genetic counselors may consciously attempt to be nondirective by remaining nonjudgmental and refraining from imposing their beliefs and values, the very words they use and questions they raise may subtly influence the patient's decision more than they realize.

Nondirectiveness, as described in the literature,²⁴⁵ may oversimplify how counselors understand the counseling experience and it may ignore the very real possibility that genetic counselors do not share a uniform understanding of nondirectiveness.²⁴⁶ Indeed, no good empirical data exists regarding what nondirectiveness really means to genetic counselors.²⁴⁷ Moreover, the traditional account of nondirectiveness tends to describe a process that is potentially incoherent or inconsistent in some respects.²⁴⁸

While striving to achieve nondirectiveness is the correct approach, it is impossible to advance one moral viewpoint over another (i.e., deference to technology, knowledge and the like) and be neutral toward all moral viewpoints. Professor Christy A. Rentmeester, Ph.D.²⁴⁹ said it this way, "Despite the best efforts of a counselor to convey "value neutral" facts, risk assessment by the counselee and family is done according to normative analysis, experience with illness, and definitions of health. Each of these factors must be known by the genetic counselor in order to relate those facts which she acknowledges as relevant to the decisions that will be made by those people seeking the genetic information. In the expression of genetic risks, the authority of medical language impacts a person's understanding of epidemiological data."²⁵⁰ Moreover, the strong values genetic counselors place on knowledge, information and technology likely reinforces the public's acceptance and expectation of prenatal testing.²⁵¹ Thus, even a genetic counselor's best effort to be nondirective has some elements of directiveness.

²⁴³ *Id.*

²⁴⁴ Sonia M. Suter, *Genetics and the Law: The Ethical, Legal, and Social Implications of Genetic Technology and Biomedical Ethics: Sex Selection, Nondirectiveness, and Equality*, 3 U. CHI. L. SCH. ROUNDTABLE 473, n.34 (1996).

²⁴⁵ *Id.*

²⁴⁶ *Id.*

²⁴⁷ *Id.* It is beyond the scope of this article to explore those problems, but they should be mentioned. Other authors have discussed this issue. See Suter, *supra* at 239.

²⁴⁸ WILLIAM A. GALSTON, LIBERAL PURPOSES: GOODS, VIRTUES, AND DIVERSITY IN THE LIBERAL STATE 80-81 (1991).

²⁴⁹ Assistant Professor, Creighton University Medical Center, Center for Health Policy and Ethics.

²⁵⁰ Christy A. Rentmeester, *Value Neutrality in Genetic Counseling: An Unattained Ideal*, 4 MED., HEALTH CARE & PHIL. 47-51 (2001), available at <http://www.springerlink.com/content/wu0r2vw-23w42q5p7/>.

²⁵¹ Gettig, *supra* note 9.

Contrasting the Differences Between Genetic Screening and Diagnostic Testing

It is also important to understand the difference between genetic screening and diagnostic testing. To a layperson, the difference between genetic screening and a diagnostic test is subtle. Professor Gettig states that in her experience, pregnant women, at least prior to their genetic counseling session, often find it perplexing to distinguish between the two terms and the medical community has a difficult time communicating the difference.²⁵² The main point is the genetic screening is 80% accurate and is used to identify those pregnancies that are in a higher risk category, and the genetic diagnostic test is 99.9% accurate and can determine whether a specific diagnosis can be made.

Professor Gettig, among other genetic counselors, believes that many women, when told on the basis of genetic screening that their child “has a higher risk of” Down Syndrome, hear, “my child has Down Syndrome.”²⁵³ This assumption is almost always incorrect given the statistical realities. The initial genetic blood test is simply a preliminary screening to determine whether a woman’s risk of having a baby with Down Syndrome is higher than that of the general population.²⁵⁴ In essence, the blood screening indicates that the child *may* have Down Syndrome. The blood screen yields a positive result in about 80% of the cases where children are born with Down Syndrome.²⁵⁵ And if a positive screening result is received, physicians recommend that a woman have further testing to determine whether her

²⁵² *Id.* “Some of this anxiety could be avoided through careful, thorough genetic counseling, in which patients are informed of the distinction between screening and diagnostic tests and the possible need for further testing.” Suter, *supra* note 3, at summary; Peter G. Pryde et al., *Prenatal Diagnosis: Choices Women Make About Pursuing Testing and Acting on Abnormal Results*, 36 *CLINICAL OBSTETRICS & GYNECOLOGY* 496, 499 (1993) (Noting that whether this poor understanding is the result of “policies of ‘universal screening,’ in which an inadequate effort has been made on the part of prenatal care providers to educate and provide informed consent at this level, or whether it is a counseling psychology issue is not yet known”). “There are data to suggest that a majority of women choose to be screened despite a remarkable rate of participants demonstrating, in exit interviews, a poor understanding of the [screening] program. Many patients appear to have a poor grasp specifically about the concept of screening, the value and limitations of the information being sought, the meaning of a positive test, and the potential pregnancy decisions that might be faced in the rather common event of a positive screen result.” *Id.*

²⁵³ Richards, *supra* note 182.

²⁵⁴ Gettig, *supra* note 9; Christopher Cunniff, *Prenatal Screening and Diagnosis for Pediatricians*, 114 *PEDIATRICS* 889, 892 (Sept. 2004). See also Am. C. of Obstetricians & Gynecologist, *Prenatal Diagnosis of Fetal Chromosomal Abnormalities 2*, ACOG Practice Bulletin No. 27 (May 2001) (“estimating detection at approximately 60% for women under 35, and approximately 75% for women over 35”); UNC Center for Maternal and Mental Health, Health Care Professionals, *available at* <http://www.mombaby.org/index.php?c=2&s=31&p=166>. [hereafter UNC].

²⁵⁵ Gettig, *supra* note 9. “In general terms, if a woman has a “screen positive” result, she will be referred for amniocentesis, a diagnostic test that will indicate whether the fetus in fact has the genetic condition that the screening test pointed to as an increased risk.” Erin Nelson, *Reconceiving Pregnancy: Expressive Choice and Legal Reasoning*, 49 *McGILL L.J.* 593 (2004).

child has Down Syndrome.²⁵⁶ As Professor Gettig explains, at this point, a woman is typically referred to a genetic counselor who explains the woman's options and if she desires, a physician who performs the diagnostic test, which is 99.9% accurate.²⁵⁷ In Professor Gettig's professional experience, many women at this initial stage say they do not want to know whether the child has Down Syndrome and do not go through with further testing. When a woman has had a positive genetic screening result for Down Syndrome, she must have a genetic *diagnostic* test to know for sure whether the child has Down Syndrome. The percentage of women that do not choose to have the blood test is unknown.

A lot of women choose the blood screening because there is no risk or danger to the baby. Rather, a blood sample is taken from the mother.²⁵⁸ The maternal serum first trimester blood test correctly yields a positive result indicating an increased risk for Down Syndrome in about 80% of the women whose fetus actually has that condition.²⁵⁹

The genetic screening produces inconclusive results and thus presents the initial challenge to patient understanding and justification for genetic counseling. First, it is a genetic screening, which means it is an estimation of the likelihood one's fetus has a genetic anomaly.²⁶⁰ It is designed to detect pregnancies that are at higher than average risk for certain chromosome differences, birth defects or genetic conditions.²⁶¹ Thus, an abnormal screen does not indicate that a fetus is affected, only that the chance for the fetus to have a certain condition is higher than average.²⁶² Maternal Serum Alpha-Fetal Protein (MSAFP) levels can be elevated for reasons other than neural tube defects, such as "erroneous estimations of gestational age, multiple pregnancies, increased risk of premature delivery, fetal death and other abnormalities."²⁶³ Moreover, in Professor Gettig's professional experience, in over half of the cases, when a woman has an elevated blood level it is because the wrong gestation dates were used.²⁶⁴ The blood tests must be conducted during a specific period of gestation or the results may be incorrect.²⁶⁵

²⁵⁶ *Id.*; Montefiore Medical Center, *supra* note 63.

²⁵⁷ *Id.*; UNC, *supra* note 254, available at <http://www.mombaby.org/index.php?c=2&zs=31&tp=167>.

²⁵⁸ *Id.*

²⁵⁹ *Id.*

²⁶⁰ *Id.*

²⁶¹ *Id.*

²⁶² Sherman Elias et al., *Carrier Screening for Cystic Fibrosis: A Case Study in Setting Standards of Medical Practice*, in *GENE MAPPING: USING LAW AND ETHICS AS GUIDES* 186, 196 (George J. Annas & Sherman Elias, eds. 1992).

²⁶³ Gettig, *supra* note 9.

²⁶⁴ *Id.* The Merck Manuals Online Medical Library, available at <http://www.merck.com/mmpe/sec18/ch257/ch257c.html> (Results are most accurate when the initial sample is obtained between 16 and 18 wk gestation, although screening can be done from about 15 to 20 wk. Normal values vary with gestational age.) (hereinafter Merck).

²⁶⁵ Center for Evidenced Based Medicine, University Health Network, available at <http://www.cebm.utoronto.ca/glossary/spsn.htm>.

Second, women and their families have particular difficulty understanding that, by its very nature, genetic screening may give both false positive and false negative results. These concepts in medical terms are referred to as specificity and sensitivity. Specificity refers to the proportion of people without disease who have a negative test result.²⁶⁶ Conversely, sensitivity refers to the proportion of people with disease who have a positive test result.²⁶⁷ In the attempt to maximize the specificity number, which in turn will decrease the number of false negatives, the genetic screening will unfortunately produce lower sensitivity, resulting in increased numbers of false positives.²⁶⁸ Thus, women who receive an abnormal (positive) MSAFP3 result need to consider the possibility that their result could be a false positive when deciding whether to follow up with amniocentesis, which is an invasive diagnostic procedure.

Third, most doctors recommend that an ultrasound be performed to estimate the age of the fetus, identify or rule out some physical birth defects and to improve the safety and accuracy of a CVS or amniocentesis sampling.²⁶⁹ If there are abnormal results or an ultrasound provides no explanation for elevated levels, or if desired, an amniocentesis is recommended.²⁷⁰ Only about five to ten percent of those who undergo amniocentesis will have elevated amniotic AFP levels, most of which are associated with neural tube defects.²⁷¹ Although 70-90% of fetuses with neural tube defects can be identified through MSAFP screening, the vast majority of pregnancies with positive (elevated) MSAFP levels will not have a fetal abnormality. In other words, the false positive rate is quite high.²⁷²

Fourth, a rarely found chromosomal rearrangement might be detected, the prognosis for which is uncertain, and the child may be completely unaffected or it might suffer some complications or abnormalities. Even relatively straightforward diagnoses provide only limited information.²⁷³ An amniocentesis result of 47, XY,+21, indicates only that the fetus is male and will have Down Syndrome.²⁷⁴ It cannot predict how severely diminished the child's mental capacity will be or whether the

²⁶⁶ *Id.*

²⁶⁷ *Id.* Merck, *supra* note 264 (Lower cutoff values increase sensitivity but decrease specificity, resulting in more amniocenteses.). With triple screening, sensitivity for Down Syndrome is about 65%, with a false-positive rate of about 5%. Merck, *supra* note 266, available at <http://www.merck.com/mmpe/sec18/ch257/ch257c.html>.

²⁶⁸ *Id.*; UNC, *supra* note 264.

²⁶⁹ UNC, *supra* note 264.

²⁷⁰ Elias, *supra* note 262.

²⁷¹ Suter, *supra* note 3, at 254; Jane E. Brody, *Experts Explore Safer Tests for Down Syndrome*, N.Y. TIMES, Jan. 23, 2001, at F6 (describing timing between sixteen and eighteen weeks gestation).

²⁷² N. J. Wald, et al., *Maternal Serum Screening for Down's Syndrome in Early Pregnancy*, 297 BMJ 883-87 (1988) (hereafter Wald).

²⁷³ *Id.*; Louis J. Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 834 (1990).

²⁷⁴ Suter, *supra* note 3, at 254.

child will have heart defects, intestinal obstructions, or other complications.²⁷⁵ And a woman who receives the good news that a child has all forty-six chromosomes with no anomalies still faces a three to five percent baseline risk of birth defects.²⁷⁶ Even with diagnostic testing, there is no assurance that the child will not have undetectable forms of mental retardation, blindness, deafness or susceptibility to serious childhood illnesses.

In summary, prenatal diagnostic screening and testing offers some information, but far from the complete predictive picture many patients imagine.²⁷⁷ None of these medical procedures alone or in conjunction with other testing can offer the complete reassurance that many people want. Medical and genetic technologies are not perfect, and testing results must not be viewed as completely accurate. In spite of these limitations, providers, patients and the public tend to rely on medical knowledge as the most accurate knowledge one could acquire about the fetus. This reliance is dangerous because genetic technologies are far from perfect and the false assumption that these technologies are completely accurate may lead women to abort normal fetuses.²⁷⁸

While abortions are not performed by physicians until diagnostic testing is completed, which in theory prevents the possibility that a woman will make a decision based solely on a false positive genetic screening result, abortion is legal in the United States and nothing prevents a woman from choosing to abort the fetus without taking advantage of genetic counseling.²⁷⁹ It is unclear how often such women elect to have an abortion at an abortion clinic without receiving genetic counseling because such statistics are typically not kept at abortion clinics.²⁸⁰ The fact that

²⁷⁵ *Id.* at 254.

²⁷⁶ *Id.*; Wald, *supra* note 272.

²⁷⁷ Wendy E. Roon, 27 *HASTINGS CONST. L.Q.* 397, 400 (2000) (“Although there are many methods of prenatal genetic testing, no test can detect every genetic defect, and none are one hundred percent accurate.”); Nancy Anne Press & Carole H. Browner, *Collective Silences, Collective Fictions: How Prenatal Diagnostic Testing Became Part of Routine Prenatal Care*, in *WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 201, 202 (Karen H. Rothenberg & Elizabeth J. Thomson, eds. 1994); Chackin, *supra* note 153, at 19 (“The persistence of abnormal cells could lead to a false positive and possibly result in an unnecessary abortion.”).

²⁷⁸ *Roe v. Wade*, 410 U.S. 959 (1973) (*Roe* is the decision that held that women have an unrestricted right to abortion during the first two trimesters of a pregnancy).

²⁷⁹ *Id.*; Barbara Ehrenreich, Op-Ed., *Owning Up to Abortion*, *N.Y. TIMES*, July 22, 2004, at A21.

²⁸⁰ “Women sometimes distinguish themselves from women who have ‘ordinary’ abortions. One woman who aborted a fetus with Down Syndrome stated, ‘I don’t look at it as though I had an abortion, even though that is technically what it is. There’s a difference. I wanted this baby.’” Dorothy E. Roberts, *Privatization and Punishment in the New Age of Reprogenetics*, 54 *EMORY L.J.* 1343, 1358 (2005). “On a website for a support group called ‘A Heart Breaking Choice’ a mother who went to an abortion clinic complains, ‘I resented the fact that I had to be there with all these girls that did not want their babies.’” *Id.*, at 1359. Nancy K. Rhoden, *The New Neonatal Dilemma: Live Births From Late Abortions*, 72 *GEO. L.J.* 1451, 1487 (1984) (It is important to note that a woman having an abortion for a genetic anomaly may desire feticide more explicitly and more strongly than is typical in an ordinary elective abortion. In this situation she wants a baby, but does not want *this* baby. She may believe this infant would suffer dreadfully or would lead such a limited existence that it should not

many women choose to receive genetic counseling may indicate that the pregnancy is wanted and desired,²⁸¹ and an openness to accepting a child with special needs.

Human Error: Genetic Counselors, Family Doctors, Obstetricians and Gynecologists

Women who have seen a genetic counselor or medical geneticist before making a decision regarding abortion are more likely to continue the pregnancy.²⁸² One of the reasons for this may be that genetic counselors try to be nondirective, i.e., let patients make decisions themselves and do not tell the patient what to do.²⁸³ Whereas, non-genetics professionals, such as obstetricians, tend to be directive, i.e. tell patients what to do or make recommendations.²⁸⁴ Some doctors believe that delivery of a child that is abnormal reflects poorly on them, and thus encourage patients to abort.²⁸⁵ The goal of these physicians is to ensure that the woman and her potential child are both healthy; to many, accomplishing that goal may require testing and or abortion of an affected fetus.²⁸⁶ Some individuals report that they feel pressured by physicians to undergo prenatal testing and to abort when the result is positive.²⁸⁷ Given the trust and respect that pregnant patients typically have for their physicians, and the woman's dependence on him or her for care, women may feel pressure to follow the physician's advice.²⁸⁸ The above may contribute to a high abortion rate if patients simply do what their doctors tell them and avoid asking questions.²⁸⁹ To the extent that this is so, prenatal testing and termination of affected fetuses cannot be considered morally justified because the decision lacks individual

be brought into the world. A physician who has performed amniocentesis and recommended abortion likewise may share these beliefs, and therefore, may feel even less inclined to resuscitate such an infant than one born alive from a regular abortion.).

²⁸¹ Gettig, *supra* note 9; Suter, *supra* note 3, at 242; ASSESSING GENETIC RISKS, *supra* note 150, at 152; FINAL REPORT, *supra* note 158; at 65-73. "The majority of these Mothers approached the amniocentesis or CVS either confident that they would continue the pregnancy, no matter what the results indicate, or undecided, needing to gather more information if the results indicated the fetus had Down Syndrome." "Many of the mothers who responded to this survey never planned to terminate the pregnancy..." Professor Gettig, among other genetic counselors, believes that the abortion rate for fetuses diagnosed with Down Syndrome is high because women abort after receiving the initial diagnosis. As a result, these women never see a genetic counselor. Moreover, this may reflect the fact that women who go to genetic counseling desire their pregnancy. Also, this may reflect the small amount of women who go to genetic counselors. *Id.*; Skotko, *supra* note 86, at 675.

²⁸² *Id.*

²⁸³ *Id.*

²⁸⁴ *Id.* Similarly, the writer argues that some doctors even believe women have a "moral obligation to undergo prenatal testing and to terminate their pregnancy to avoid bringing forth a child with a disability." Bauer, *supra* note 5.

²⁸⁵ Mahowald, *supra* note 63.

²⁸⁶ *Id.* A vast majority of women responded strongly to the question, "I felt encouraged by my physician to have an amniocentesis." Skotko, *supra* note 86, at 673.

²⁸⁷ *Id.*

²⁸⁸ Gettig, *supra* note 9.

²⁸⁹ *Id.*; Suter, *supra* note 3, at 242; ASSESSING GENETIC RISKS, *supra* note 150, at 152; FINAL REPORT, *supra* note 158, at 65-73.

decisionmaking and real informed consent.²⁹⁰ The physician and the patient bear equal responsibility for correcting this situation.

Genetic counselors have been described as more committed to patient autonomy than most other healthcare providers.²⁹¹ The focus on informing patients about the technical aspects of prenatal testing and genetic diseases as well as the commitment to nondirectiveness reflects a desire of many genetic counselors to help patients make decisions that are “intentional, substantially noncontrolled, and based on substantial understanding.”²⁹²

There is wide agreement that patients who receive results from genetic testing also must be offered counseling to adequately understand the implications of the test results. Indeed, in the Stanford Recommendations on Genetic Testing For BRCA, fifty percent of health care professionals surveyed bluntly stated that “genetic counseling is the linchpin of good care.”²⁹³ But releasing test results to uninformed or unprepared patients can cause serious psychological harm. Efforts must be made to increase the numbers of licensed and otherwise qualified genetic counselors available to consumers and to make their presence known so that physicians can give ready referrals.²⁹⁴

Even if the number of licensed genetic counselors is increased, human error can lead to incorrect results.²⁹⁵ Even amniocentesis and CVS, highly accurate diagnostic tests, are not infallible. For example, a few medical professionals argue that the testing is not very complicated, yet they concede errors still exist.²⁹⁶ Furthermore, some medical professionals argue Down Syndrome seems to be associated with aging eggs so it is not clear there needs to be a lot of counseling.²⁹⁷ Knowing this fact might encourage women to not try again, try again or to try assisted reproduction

²⁹⁰ David C. Bonnin, *The Need for Increased Oversight of Genetic Testing: A Detailed Look at the Genetic Testing Process*, 4 HOUS. J. HEALTH L. & POL'Y 149, 243 (2003).

²⁹¹ Gail Geller et al., *Genetic Testing for Susceptibility to Adult-Onset Cancer: The Process and Content of Informed Consent*, 277 JAMA 1467, 1468 (1997) (quoting P. S. APPELBAUM ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE (1987)).

²⁹² *Id.*; Kessler, *supra* note 238, at 176; Suter, *supra* note 238, at 242.

²⁹³ Recommendations of the SACGT: “A genetic test is an analysis performed on human DNA, RNA, genes and/or chromosomes to detect heritable or acquired genotypes, mutations, phenotypes, or karyotypes that cause or are likely to cause a specific disease or condition. A genetic test also is the analysis of human proteins and certain metabolites, which are predominantly used to detect heritable or acquired genotypes, mutations, or phenotypes.” SECRETARY'S ADVISORY COMMITTEE ON GENETIC TESTING, NATIONAL INSTITUTES OF HEALTH, ENHANCING THE OVERSIGHT OF GENETIC TESTS: RECOMMENDATIONS OF THE SACGT 1 (July 2000).

²⁹⁴ Suter, *supra* note 3, at 264.

²⁹⁵ Balkite, *supra* note 7.

²⁹⁶ *Id.* “Down's Syndrome is the most common problem of this type, but there are others. There is a progressive increase in the risk of birth defects and mental retardation as age increases. This is all as a result of aging of the eggs.” Randy S. Morris, *Aging and Reproduction*, available at http://www.coolware.com/health/medical_reporter/aging.html.

²⁹⁷ *Id.*

depending on their viewpoint.²⁹⁸ This is just one example of both directiveness and human error.

A lack of nondirectiveness is another type of human error. The profession's commitment to nondirectiveness would suggest that genetic professionals are merely responding to social demands and desires, rather than shaping them.²⁹⁹ By refusing to direct clients toward a particular decision, counselors seem removed from influencing prenatal testing.³⁰⁰ Although nondirectiveness may support patient autonomy,³⁰¹ genetic counselors are far from neutral about many aspects of genetic counseling.³⁰² In other words, many deeply held values shape their approach to genetic counseling.³⁰³

For example, genetic counselors are not neutral about the value of nondirectiveness. Even as the profession's understanding of the term evolves and the notion has come under recent attack, most genetic counselors defend the approach vigorously.³⁰⁴ Counselors defend nondirectiveness on several grounds: 1) the duty to protect patient autonomy; 2) the inability to know what the "best" decision is for someone else; 3) the conviction that nondirectiveness is good for patients; and 4) less frequently stated, the patient's responsibility to make decisions.³⁰⁵ Genetic counselors feel so strongly about these rationales that they can be quite directive about how patients should approach decisionmaking, even though they try not to direct the decision itself.

The fact that counselors try to influence the process, as opposed to the decision, however, can subtly and unintentionally influence the decision itself.³⁰⁶ The genetic counselor's deep and abiding interest in protecting patient autonomy can sometimes translate into a belief that the client has a "right and responsibility" to decide for herself.³⁰⁷ Many genetic counselors are uncomfortable with patients who

²⁹⁸ Suter, *supra* note 3, at 242.

²⁹⁹ *Id.*

³⁰⁰ Kessler, *supra* note 238, at 176; Suter, *supra* note 238.

³⁰¹ Barbara Bowles Biesecker, *Future Directions in Genetic Counseling: Practical and Ethical Considerations*, 8 KENNEDY INST. ETHICS J. 145 (1998). See generally Sonia M. Suter, *Value Neutrality and Nondirectiveness: Comments on "Future Directions in Genetic Counseling,"* 8 KENNEDY INST. ETHICS J. 161 (1998).

³⁰² Suter, *supra* note 3, at 242.

³⁰³ *Id.* at 243.

³⁰⁴ *Id.*; Suter, *supra* note 238.

³⁰⁵ *Id.*

³⁰⁶ Suter, *supra* note 3, at 243.

³⁰⁷ *Id.* "A situation in which a couple repeatedly requested that genetic counselors decide whether they should have prenatal testing for muscular dystrophy illustrates this perspective nicely. The counselors believed the couple's behavior demonstrated their fear of accepting 'responsibility for their actions' and was an attempt to place the responsibility with the genetic counselors." ELEANOR GORDON APPELAUM & STEPHEN K. FIRESTEIN, *A GENETIC COUNSELING CASEBOOK* 78-79 (1983). They defended their refusal to decide for the patient by arguing that "no one has the right to make decisions which will affect the lives and feelings of other people." *Id.* Ironically, the genetic counselors supported the couple's decision to follow the advice of the rabbi. In essence, they supported the couple's refusal to decide as long as they themselves did not decide for the couple.

want to abdicate the role of decisionmaking.³⁰⁸ By trying to urge patients to decide for themselves, counselors might be understood as urging information gathering.

In addition, whether genetic counselors actually believe genetic testing or termination of affected pregnancies is the right for everyone, the majority of genetic counselors have such preferences for themselves.³⁰⁹ These personal biases in favor of testing and termination may inadvertently and subtly be conveyed to patients, even among genetic counselors committed to nondirectiveness.³¹⁰

Similar to genetic counselors, most health-care professionals think that being informed and prepared is better for families that have children with disabilities.³¹¹ Other health-care professionals favor prenatal testing because of their "bias toward termination" when abnormalities are found³¹² and their belief that such terminations

³⁰⁸ Suter, *supra* note 3, at 244. Professor Suter's anecdotal experience, confirmed by empirical data, indicates that even if they are not in a high-risk category, genetic counselors are especially likely to undergo prenatal testing and perhaps even to terminate affected pregnancies. "Most of the counselors [Rothman interviewed] would have [amniocentesis] themselves. More than half would have, or want their daughters to have, an amniocentesis even at 25, a 'low risk age.' . . . Most would have abortions for most abnormalities, half said they would abort for *any* abnormality." Rothman, *supra* note 1, at 46.

³⁰⁹ A number of commentators have questioned the ability to achieve neutrality in the counseling process, particularly when the counselors have personal biases. See, e.g., Karen G. Gervais, *Objectivity, Value Neutrality, and Nondirectiveness in Genetic Counseling*, in *PRESCRIBING OUR FUTURE: ETHICAL CHALLENGES IN GENETIC COUNSELING* 119, 127 (Dianne M. Bartels et al., eds. 1993). The article questions the "concept of objectivity and the fact/value distinction" on which the normative modeling in genetic counseling is based. Dunne & Warren, *supra* note 178, at 188-89, 193 (describing the ways that counselors can be directive by failing to include information about "the human aspects of illness" associated with conditions for which prenatal testing was offered). Dorothy C. Wertz & John C. Fletcher, *Attitudes of Genetic Counselors: A Multinational Survey*, 42 *AM. J. HUM. GENETICS* 592, 600 (1988) (expressing skepticism that counselors can always neutrally support any decision that the patient makes given the moral convictions that geneticists have).

³¹⁰ WERTZ, *supra* note 86.

³¹¹ Weil, *supra* note 123. This article describes the ways in which medical professionals systematically and subtly express this bias, from their manner of and systems for delivering bad news to the way they describe the prognosis and options to families.

³¹² Numerous studies have collected data on the societal and cost benefits of screening and mandatory offer of screening. See, e.g., Press & Browner, *supra* note 277 (citations omitted) ("the Department of Health and Human Services recently made it a goal . . . to "increase to at least 90 percent [from 65%] the proportion of women . . . who are offered screening and counseling on prenatal detection of fetal abnormalities."); Tryfon Beazoglou et al., *Economic Evaluation of Prenatal Screening for Down Syndrome in the U.S.A.*, 12 *PRENATAL DIAGNOSIS* 1241, 1245 (1998) (estimating that "a universal triple test could prevent the birth of 1136 babies with Down Syndrome . . . , while allowing 2057 live births with Down Syndrome. The total financial savings per year are \$140 million"); Jo-Ann Johnson et al., *Prenatal Genetic Screening for Down Syndrome and Open Neural Tube Defects Using Maternal Serum Marker Screening*, 21 *J. SOC'Y OBSTETRICIANS & GYNAECOLOGISTS CAN.* 887, 889 (1999) (the added costs of prenatal screening are "likely to be offset by . . . a higher detection rate of [Down Syndrome] and [spina bifida], a lower false-positive rate and . . . a decrease in the overall number of amniocenteses performed.").

benefit the families and society.³¹³ The professional attitudes in favor of prenatal testing are often communicated to patients, directly or indirectly, which can lead to pressure to undergo such testing. Generally, genetic counselors try to hide any biases they might have in favor of or against prenatal testing, given their commitment to non-directiveness.³¹⁴

Another problematic point is research suggests that counselors may steer patients toward, what has been described as, “starting again with a clean slate.”³¹⁵ As Barbara Biesecker, director of the genetic-counseling training program at Johns Hopkins University, explains, “There’s kind of a trend out there to call people at home and then just refer them back to the hospital”—meaning that the family who has learned that a fetus has a genetic disease is quickly referred to someone who will help get rid of it.³¹⁶ This, according to Biesecker, is “a cop-out.”³¹⁷ Delivering the news on the phone, often without a spouse present, is, she says, “filled with assumptions about what’s right for people—it assumes that they’ll act,” meaning abort.³¹⁸ Similarly, the use of the “clean slate” mentality was confirmed in the State of California. One California study has shown that in response to California’s legal mandate requiring that a prenatal screening be offered, medical professionals provided limited, directive counseling, suggesting they were “more interested in persuading . . . than informing patients.”³¹⁹

Compounding the problem, most of the news that genetic counselors provide to prospective parents about disabilities is negative and clinical.³²⁰ Face-to-face meetings, which often occur before amniocentesis, tend to be filled with mini-science lectures about how chromosomes replicate or how trisomies occur, not the swirling emotions that surround the news that the baby in your belly may not be the baby you dreamed of having.³²¹ In an attempt to rectify the situation, Senators Sam Brownback, Republican of Kansas, and Edward Kennedy, Democrat of Massachusetts, last March sponsored the Prenatally Diagnosed Conditions Awareness Act, a bill designed to mandate that more positive information be given to parents about

³¹³ ROBIN BUNTON, *NEW GENETICS AND NEW PUBLIC HEALTH* 139 (2001) (“adherence to a nonprescriptive (often referred to as ‘nondirective’) approach is perhaps the most defining feature of genetic counseling” and “stems from a firm belief that genetic counseling should—insofar as is possible—be devoid of any eugenic motivation.”) (citing ANN PLATT WALKER, *A GUIDE TO GENETIC COUNSELING* 8 (1998)). See also Sonia M. Suter, *A Brave New World of Designer Babies?* 22 *BERKELEY TECH. L.J.* 897 (2007).

³¹⁴ Weil, *supra* note 123.

³¹⁵ *Id.*

³¹⁶ *Id.*

³¹⁷ *Id.*

³¹⁸ Press & Browner, *supra* note 277, at 201. The study showed that in California, where the offer of such screening was mandated, the acceptance rates for the screening were 85% as compared with the national average of 65%.

³¹⁹ Weil, *supra* note 123.

³²⁰ *Id.*

³²¹ *Id.*

the life of a disabled child.³²² At a news conference to announce the bill was Brian Skotko, a Harvard Medical School student. Skotko published a paper in the *American Journal of Obstetrics and Gynecology* last spring based on his study, the largest and most comprehensive on prenatally diagnosed Down Syndrome.³²³ It showed that obstetricians and genetic counselors failed to give expectant mothers who received a prenatal diagnosis of Down Syndrome encouraging data about raising a child with Down Syndrome.³²⁴ One mother in Skotko's study reported that her genetic counselor "showed a really pitiful video first of people with Down Syndrome who were very low tone and lethargic-looking and then proceeded to tell us that our child would never be able to read, write or count change."³²⁵

One of the most disturbing issues surrounding genetic counseling is that geneticists and their obstetrician colleagues are deciding which fetuses are healthy, what "healthy" means, and indirectly, who should be aborted, and who should be born.³²⁶ As a result, they are greatly influencing the patients' decisions to continue or abort, decisions that pregnant women themselves may not always be ready or capable to make.³²⁷ To the extent that specialists' determine who uses prenatal diagnosis and for what reasons, geneticists will determine which conditions will be marginalized, treated or grounds for abortion.³²⁸

Genetic counselors and other medical personnel should be communicating to patients: reproduction options (the prenatal laboratory or fetal imaging studies leading to the diagnosis.); family support; positive and negative developmental and behavioral information (including the wide range of variability seen in infants and children with Down Syndrome); and the risk of recurrence. Moreover, genetic counselors and other medical personnel should advocate for support groups of all political backgrounds; long-term planning if the family decides to keep the child (discussion of pregnancy continuation or termination, rearing the child at home, foster care placement, and adoption); and when applicable, additional studies that may refine the estimation of the prognosis (e.g., fetal echocardiogram, ultrasound examination for gastrointestinal malformations).³²⁹ All of the aforementioned should be done in a non-directive manner.

Another problem is the communication of results. A fair number of women come to genetic counselors misinformed. Moreover, some women have reported being upset when physicians provided detailed descriptions of pregnancy terminations without first knowing whether they would like to discuss those options.³³⁰

³²² Skotko, *supra* note 86, at 675.

³²³ Lippman, *supra* note 58, at 33-36; Skotko, *supra* note 86, at 674.

³²⁴ Skotko, *supra* note 86, at 675.

³²⁵ Lippman, *supra* note 58, at 33-34.

³²⁶ *Id.*

³²⁷ Lippman, *Prenatal Diagnosis: Reproductive Choice? Reproductive Control?* in *FUTURE OF HUMAN REPRODUCTION* 182, 187-92 (C. Overall, ed. 1989).

³²⁸ *Genetic Counselors*, *supra* note 28; Will, *supra* note 21; American Academy, *supra* note 30.

³²⁹ Skotko, *supra* note 86, at 675.

³³⁰ *Id.*

Similarly, some women criticize physicians for delivering a diagnosis of Down Syndrome with phrases such as, “I’m sorry,” or “Unfortunately, I have some bad news to share.”³³¹ Professor Gettig stated that sometimes during their first appointment women do not know the exact purpose and reason for the counseling session and state something along the lines of, “my doctor told me to come.”³³² This demonstrates the severity of the misinformation or lack of information some women receive from their physicians.

The failure to correctly inform patients undercuts the goals of genetic counseling—to help patients make decisions consistent with their values, beliefs, circumstances and life plans. At the same time, it is important to note that patients may say that they weren’t told of certain risks like ambiguity in the test results.³³³ Of course, there are patients who do not recall being told about these issues even when they have been covered.³³⁴ There is also the chance that, because so much is raised during a session, the patient cannot remember clearly whether something was said or not.³³⁵ Some centers require that counseling be on a separate day from the procedure to give patients time to think fully through everything.³³⁶ However, critics argue the reality is that many patients have difficulty getting off work, arranging day care, or just traveling to the center if it is far away.³³⁷

These factors may lead to pressure by medical professionals and society to employ existing genetic technologies to justify abortion of most fetuses with genetic anomalies. Seemingly, this is why the American Medical Association (AMA) warns against the “subtle or passive eugenics brought about through a combination of social pressures” to employ existing genetic reproductive technologies.³³⁸ The AMA Council acknowledges that these technologies already provide the basis for decisions about the worth of individual lives, and that this “may constitute an extremely dilute *but acceptable form of eugenic selection*.”³³⁹

³³¹ Gettig, *supra* note 9. “The director of reproductive genetics at a large Detroit hospital reported that at least half of the women referred there with an abnormal amniocentesis result were “uncertain about why they even had the test.” *The Telltale Gene*, 55 CONSUMER REP. 483, 486 (1990). “A genetic counselor similarly notes, “Patients will come in and say, “I am having the amniocentesis because my doctor told me to,’ but really in their hearts they are not so sure that’s right for them.” Roberts, *supra* note 280, at 1354.

³³² Malinowski, *supra* note 128, at 1464.

³³³ *Id.*

³³⁴ *Id.*

³³⁵ *Id.*

³³⁶ *Id.*

³³⁷ Council on Ethical and Judicial Affairs, American Medical Association, *Ethical Issues Related to Prenatal Genetic Testing*, 3 ARCHIVES FAM. MED. 633, 633-35 (1994).

³³⁸ *Id.*

³³⁹ Len Leshin, *Prenatal Screening for Down Syndrome* (2002) (emphasis added), available at <http://www.ds-health.com/prenatal.htm>. The physician-patient relationship now recognizes the physician’s responsibility to receive “informed consent” from the patient, specifically regarding the accuracy of diagnostic approaches and alternative reproductive choices. Shaw, *Presidential Address: To Be or Not to Be? That Is the Question*, 36 AM. J. HUM. GENETICS 1 (1984). See also Peters & Fineberg, *Genetic*

The Subsequent Impact on Informed Consent

One of the most surprising and frustrating problems surrounding prenatal genetic testing is the lack of informed consent. Twenty-years ago doctors were the sole medical decision-makers and now much emphasis has been placed on patient autonomy and self-determination within the medical context. In the United States, the clinical standard of care requires the physician to give accurate information to the parents and forbids the withholding of vital information.³⁴⁰ Moreover, at the beginning of 2007, the American College of Obstetricians and Gynecologists expanded the clinical standard of care to include giving all women regardless of age the opportunity for Down Syndrome screening.³⁴¹ There is an expectation that a physician will inform parents if a possibility exists that a child will be disabled and then offer all alternative actions and therapies that are available, including abortion.³⁴² In many states, no obstetrician, gynecologists or other medical professional can be required to perform embryoscopy or any other prenatal diagnostic procedure.³⁴³ While ideally informed consent would be a process whereby the patient could continually interject by voicing their concerns and by raising issues, each of which would be addressed in a manner fully comprehensible to the patient, the reality is typically different. Written informed consent for prenatal testing is rarely obtained, and when it is, it is by the stroke of pen before any discussion of genetic testing has taken place.

Most practicing geneticists attempt to obtain informed consent and to document outcomes through the use of “up front” consent forms and post-interaction, genetic counseling letters.³⁴⁴ As a result of upfront consent forms, women typically

Counseling and Screening: Standards of Care, Customary Practice and Legal Liability, TRIAL, Jan. 1984, at 82; Fineberg & Peters, *Amniocentesis in Medicine and Law: Practice Standards and Legal Ramifications*, TRIAL, Feb. 1984, at 53, 54.

³⁴⁰ *Id.*

³⁴¹ ACOG News Release, *New Recommendations for Downs Syndrome: Screening Should Be Offered to All Pregnant Women*, Jan. 2, 2007, available at http://www.acog.org/from_home/publications/press_releases/nr01-02-07-1.cfm. “[T]he physician has a duty to inform the patient of the risks involved in amniocentesis so that the patient can decide intelligently whether or not to undergo the procedure.” Belinda L. Kimble, *Wrongful Birth: A Practitioner’s Guide to a New Arrival*, 55 ALA. L. REV. 84 (1994). See also *Keel v. Banach*, 624 So.2d 1022 (Ala. 1993); and George J. Annas & Sherman Elias, *Legal and Ethical Issues in Genetic Screening, Prenatal Diagnosis, and Gene Therapy*, in *ESSENTIALS OF PRENATAL DIAGNOSIS* 393, 398 (Joe Leigh Simpson & Sherman Elias, eds. 1993).

³⁴² See W. Va. Code Ann. §§ 33-42-3(3) to (5) (enacted 1998), 33-42-8 (enacted 1998). State of New Jersey, Assembly No. 2016, page 2 line 12, available at http://www.njleg.state.nj.us/2006/Bills/A2500/2016_11.PDF. Kansas statutes, available at http://kansasstatutes.lesterama.org/Chapter_65/Article_67/65-6709.html. Medical Practice Act, available at <http://delcode.delaware.gov/title24/c017/sc09/index.shtml>.

³⁴³ Elsas, *supra* note 273, at 831; Skotko, *supra* note 86, at 675. One of the studies major recommendations was that results of the amniocentesis or CVS be delivered in person. “Mothers who had learned of the diagnosis by telephone reported intense resentment for their obstetricians and/or genetic counselors.” *Id.*

³⁴⁴ Elsas, *supra* note 273.

do not know they have consented to prenatal genetic testing.³⁴⁵ A typical pregnant woman is accustomed to having her blood taken during her regular prenatal screenings. When the blood test results come back, most women do not know they have had a genetic test done. If the results come back negative, they will likely never know they had the test. Only positive results are reported to the patient.³⁴⁶

Most insurance companies now consider prenatal diagnosis to be a generally acceptable practice and will pay for these medical services.³⁴⁷ Usually, a prospective mother, regardless of age at delivery, will have an amniotic fluid sample sent to a commercial cytogenetics laboratory for chromosomal analysis without adhering to a specific type of testing.³⁴⁸ In a situation where the subject matter at issue is highly-sensitive, a literal matter of life or death in some cases, and of direct impact upon people in a vulnerable state of mind, informed consent cannot exist as a penned mark on a two-sheet disclaimer undertaken during one sitting.³⁴⁹

This lack of informed consent can lead to a lack of preparation for decision-making by the patient, which may cause choice to be misleading.³⁵⁰ Due to the fact that the decisions regarding genetic testing and preconception or prenatal assessments concern matters of an even greater sensitivity than typical treatment-oriented protocols, great care needs to be taken.³⁵¹ The result can be that many women are unprepared for the anxiety and distress that can occur when they are suddenly faced with a positive test result, and the difficult choices that follow.³⁵² Some may even discover that they would not have consented to genetic screening had they understood its larger implications.³⁵³ For some of these women the information from prenatal screening can be toxic—it can cause them more harm than good.³⁵⁴ The failure of providers to tie important considerations to the decision to begin prenatal testing is quite simply a failure of informed consent.³⁵⁵ In particular, it falls far short of the genetic counseling model of informed consent, which strives to encourage decisions consistent with one's goals and life plans.³⁵⁶ But, as some scholars have suggested, this failure may sometimes be collective³⁵⁷ in that patients may be complicit in refusing to press the larger questions.³⁵⁸

³⁴⁵ *Id.*

³⁴⁶ Gettig, *supra* note 9.

³⁴⁷ Elsas, *supra* note 273. This definition, “generally acceptable practice,” is used by managed health programs and insurance companies to justify continuing or discontinuing payment for medical service.

³⁴⁸ *Id.* at 831-32.

³⁴⁹ Dunne & Warren, *supra* note 178.

³⁵⁰ Regina Kenen et al., *To Use or Not to Use: The Prenatal Genetic Technology/Worry Conundrum*, 9 J. GENETIC COUNSELING 204, 213-15 (2000).

³⁵¹ Suter, *supra* note 3, at 256.

³⁵² *Id.*

³⁵³ *Id.*

³⁵⁴ *Id.*

³⁵⁵ *Id.*

³⁵⁶ Press & Browner, *supra* note 277, at 214.

³⁵⁷ Suter, *supra* note 3, at 256.

³⁵⁸ Dunne & Warren, *supra* note 178, at 195.

California legally mandates that all healthcare providers offer maternal serum Alpha-fetoprotein (MSAFP) screening to all pregnant women.³⁵⁹ Only the State of California requires informed consent for the maternal serum screening.³⁶⁰ However, California has found mandating informed consent is not completely effective. As one study has shown, providers limited the discussion of Alpha-fetoprotein (AFP) screening to no more than two minutes and described it as a “simple blood test.”³⁶¹ Little, if anything, was done to emphasize that the screening was voluntary. Providers tended to say almost nothing about its purpose.³⁶² In forty observed sessions, they offered only the most general descriptions of the conditions for which screening was done.³⁶³ None of the providers discussed the decisions a woman might confront in the event of a positive diagnosis, and abortion was discussed only twice.³⁶⁴ In short, so little time was devoted to explaining AFP screening, and patients were told so little about its purpose, that patients rarely had questions, even when given the chance to voice them.³⁶⁵ In response to the legal mandate, providers seemed more interested in persuading, rather than informing, patients about the screening. Not surprisingly, the study conducted by Professor Press & Professor Browner found very high rates of acceptance when compared with the national average.³⁶⁶ If the goal was getting people to take the test, the program succeeded. If the goal was ensuring fully informed, voluntary decisionmaking, in which patients are made aware and given a chance to consider the personal implications of their choice, the program seemed a dismal failure.³⁶⁷

In addition to requiring informed consent from the patient for that specific blood draw before it can be performed, the state of California has required: (1) the State Director of Health Services to create the necessary regulations and standards for hereditary disorders programs, including consent for testing, the confidentiality

³⁵⁹ *Id.*

³⁶⁰ Press & Browner, *supra* note 277, at 213. See also Suter, *supra* note 3, at 252-54.

³⁶¹ Gettig, *supra* note 9; Nancy Press & C. H. Browner, *Risk, Autonomy, and Responsibility: Informed Consent for Prenatal Testing*, HASTINGS CENTER REP., May 1, 1995, at S1.

³⁶² Press & Browner, *supra* note 277, at 213.

³⁶³ *Id.*

³⁶⁴ *Id.* at 228.

³⁶⁵ *Id.* at 202, 205.

³⁶⁶ *Id.* at 209-10. The authors provide clear evidence of just how poorly informed the patients actually were. None surveyed could adequately explain the conditions screened for. Less than one-third even recognized the term “neural tube defect” and, of those, only two-thirds had an accurate idea of what the term meant. Sixty percent recognized the term “spina bifida,” but only half of them could define the condition. Fewer than half of the surveyed patients knew what would happen next if the AFP test result was positive, and more than one-third believed that the state required pregnant women to take the test.

³⁶⁷ The National Human Genome Research Institute (“NHGRI”) Policy and Legislation Database lists the fifty-one California statutes covering diverse genomic issues such as genetic information and discrimination, genetic testing and screening, cloning, and stem cell research. NIH NHGRI Policy and Legislation Database, available at <http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch>. cfm. Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 AVE MARIA L. REV. 611, n.110 (2006).

of information, the licensing of master level genetic counselors, and listing the minimum licensing requirements to use the title of genetic counselor; (2) that screening programs for hereditary disorders comply with the Hereditary Disorders Act §27; (3) that prenatal testing programs for newborns under §§125050-125065 comply with the Hereditary Disorders Act; (4) a genetic disease unit to coordinate genetic disease programs and to promote information, testing, and counseling services, including the testing of pregnant women; (5) State Department of Health Services to administer a statewide program for the prenatal testing for genetic disorders and birth defects; (6) prenatal diagnosis centers to meet standards developed by the State Department of Health Services and to accept patients from certain State-funded or State-administered programs; and (6) the State Department of Health Services prohibited discrimination based on genetic information, including healthcare and insurance plans.³⁶⁸

The California informed consent process is only one example of the pros and cons of mandating the offer of genetic screening to all pregnant women, and requiring informed consent to the procedure. However, California has done more than most states. Dr. Neal Holtzman, head of a Bioethics Committee at Johns Hopkins University, agrees that the current informed consent process is flawed.³⁶⁹ He stresses the need to formulate policies that will make it difficult to violate certain principles in the information transmission process.³⁷⁰ His task force is working to develop safer tests, better quality and delivery of lab services and appropriate use of information by consumer and provider.³⁷¹ Until about ten years ago, most genetic tests were performed as research protocols.³⁷² Dr. Holtzman has said, “Now that a commercial industry is springing up to disseminate, interpret and advise consumers on a vast array of facts and results, which can have devastating effects, the need to institute safeguards in the informed consent process is paramount.”³⁷³ The Johns Hopkins Bioethics Committee has proposed the following steps to insure the patient’s autonomous consent: (1) Know who the participant is (the whole family or the individual); (2) Note the influence of other family members on your client; (3) Work on the clear role of a genetic counselor; (4) Discuss and have a way to withdraw samples; (5) Mention that there is a choice as to whether test results will be discussed; (6) Beforehand, describe the means by which results will be delivered; (7) Mention any future intended use of personal data; (8) Work hard to forego making results public before validity of such results is established.³⁷⁴

³⁶⁸ Anderson, *supra* note 1. “In genetics, clinicians and researchers believe that knowledge and genetic science are moral goods.” See also Suter, *supra* note 3, at 252-54.

³⁶⁹ Weeden, *supra* note 367, at 634-35.

³⁷⁰ Dunne & Warren, *supra* note 178, at 194.

³⁷¹ *Id.*

³⁷² *Id.*

³⁷³ *Id.*

³⁷⁴ Elizabeth B. Cooper, *Testing for Genetic Traits: The Need for a New Legal Doctrine of Informed Consent*, 58 MD. L. REV. 346, 405 (1999). Professor Cooper also outlines a model statute covering

As a general matter, this proposal would require a description of the test and a statement of its purpose; a description of the disease(s) or condition(s) for which a test will be conducted; an explanation of the risks of stigma and discrimination; and assurances that the patient's medical confidentiality will be protected, with any pertinent exceptions specifically stated.³⁷⁵

The first, crucial step in helping patients achieve truly informed consent and make truly informed decisions is to give patients access to information about what Down Syndrome is really like for most children and for their families.³⁷⁶ According to the American Down Syndrome Congress, for example, prospective parents who learn that their fetus has a disabling trait need to receive: "(a) information that seeks to dispel common misconceptions about disability and present disability from the perspective of a person with a disability; (b) information on community-based services for children with disabilities and their families as well as on financial assistance programs; (c) materials on special needs adoption; and (d) a summary of major laws protecting the civil rights of persons with disabilities."³⁷⁷ Also, people with Down Syndrome and parents of people with Down Syndrome should be available to talk with future parents.³⁷⁸ Overall, with well-balanced, newly-adjusted informed consent requirements for the genetic counseling process, the number of children aborted due to misperceptions of their potential and dignity would be greatly decreased.³⁷⁹

The Role of Legal Liability

As mentioned earlier, the purpose of genetic counseling is to help patients make fully informed decisions. But the threat of malpractice motivates the profession to document the process with painstaking care, to develop detailed informed consent forms and to provide patients or physicians with detailed letters describing the counseling session.³⁸⁰ Professor Gettig believes doctors will typically make the offer for genetic testing in both the first and second trimester typically for their own personal benefit, to avoid legal liability.³⁸¹ The doctors must tell the patient of the availability of the test, but the patient does not have to take the test.³⁸² However,

post-test counseling.

³⁷⁵ Ruth Hubbard, *Some Legal and Policy Implications of Recent Advances in Prenatal Diagnosis and Fetal Therapy*, 7 WOMEN'S RIGHTS L. REP. 210 (1982). See also Suter, *supra* note 3, at 252-54.

³⁷⁶ DISABILITY RAG & RESOURCE, *supra* note 57, at S1-S22, available at <http://www.questia.com/googleScholar.qst?docId=5002355820>.

³⁷⁷ *Id.*

³⁷⁸ National Down Syndrome Congress, *Position Statement on Prenatal Testing and Eugenics: Families' Rights and Needs* (1994), available at <http://www.he.net/~altonweb/cs/downSyndrome/index.htm?page=eugenicsndsc.html>.

³⁷⁹ Suter, *supra* note 3, at 251.

³⁸⁰ Gettig, *supra* note 9.

³⁸¹ Leshin, *supra* note 339.

³⁸² James Bopp, Jr. et al., *The "Rights" and "Wrongs" of Wrongful Birth and Wrongful Life: A Jurisprudential Analysis of Birth Related Torts*, 27 DUQ. L. REV. 461, 486-90 (1989). See also Allen J. Belsky,

some argue that doctors are encouraged to practice defensive medicine by encouraging women to take the test.³⁸³

In 1985, the American College of Obstetricians and Gynecologists' Department of Professional Liability issued an "Alert" entitled "Professional Liability Implications of AFP Tests."³⁸⁴ In a climate of heavy malpractice litigation in obstetrics, the Alert declared that it was "imperative that every prenatal patient be advised of the availability of this test and that [member physicians'] discussion about the test and the patient's decision with respect to the test be documented in the patient's chart."³⁸⁵ As a result, MSAFP screening for Down Syndrome became the standard of care, not for medical reasons, but in response to liability concerns.³⁸⁶ Although the MSAFP story is not representative of how the standard of care is generally devised within the genetics/obstetrics community, it illustrates how the law can shape medical practice.³⁸⁷ By the early 1990s, roughly 65% of women in prenatal care received MSAFP screening.³⁸⁸ The rapid increase in MSAFP screening could be a positive or negative development depending on whether one considers MSAFP as helpful or hurtful to persons with disabilities, as supporting patient autonomy, or as morally and ethically neutral.

It is clear, health care providers function in a litigious society. In the arena of prenatal testing, parents have brought numerous claims for wrongful birth and wrongful life against physicians who did not inform them of the availability of amniocentesis.³⁸⁹ The increasing liability imposed on obstetricians is arising out of the judiciary's greater recognition of wrongful birth and wrongful life actions and state legislatures' passage of statutes authorizing such actions. Both causes of action stem from the right of patients to have genetic testing. In the context of prenatal genetic screening, the issue is the right of parents to choose what is best for themselves and for their prospective children.³⁹⁰ Wrongful birth actions are premised

Injury as a Matter of Law: Is This the Answer to the Wrongful Life Dilemma? 22 U. BALT. L. REV. 185, 245 (1993).

³⁸³ Elias, *supra* note 262, at 197 (citing American College of Obstetricians and Gynecologists ("ACOG"), *Prenatal Detection of Neural Tube Defects*, Technical Bulletin No. 67 (Wash., D.C., 1982)).

³⁸⁴ *Id.*

³⁸⁵ *Id.* Professor Suter believes that by encouraging providers to adopt AFP screening as part of the standard of care, ACOG actually made wrongful birth claims based on a failure to offer MSAFP screening much more viable.

³⁸⁶ *Id.* at 253.

³⁸⁷ Press & Browner, *supra* note 277.

³⁸⁸ Malinowski, *supra* note 128, at 1446. For example, In New York the fear of liability has helped to encourage obstetricians to refer virtually all patients who are at any risk to genetic counselors. The result is that twenty-five-thousand women in the state of New York are screened for fetal genetic abnormalities each year. Kimberly Nobles, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081, 2086 (1992).

³⁸⁹ George J. Annas & Sherman Elias, *Legal and Ethical Implications of Fetal Diagnosis and Gene Therapy*, 35 AM. J. MED. GENETICS 215, 216 (1990).

³⁹⁰ George J. Annas, *Mapping the Human Genome and the Meaning of Monster Mythology*, 39 EMORY L.J. 629, 658 (1990) (Wrongful birth actions are cases brought "for failure to counsel about existing

upon the right of parents to abort a fetus due to a genetic abnormality;³⁹¹ wrongful life actions³⁹² are premised upon the right of children not to have been born.³⁹³ In states recognizing such actions, parents are likely to increasingly be told about the most remote possibility of a genetic abnormality.

Moreover, obstetricians are finding themselves subjected to general malpractice liability for: failing to suggest genetic counseling when there is even the slightest indication that it might prove helpful;³⁹⁴ failing to fully inform prospective parents about the tests that are available; failing to explain the risks of testing;³⁹⁵ failing to choose responsible laboratories to run tests; and failing to monitor the quality of test samples.³⁹⁶ Liability may even arise from informing or failing to inform other family members when a malformed gene is discovered.³⁹⁷ Moreover, this liability has been enhanced by the recognition of prenatal genetic counseling as a medical subspecialty, and genetic counseling will expand as additional prenatal genetic screenings are made available.³⁹⁸ Also, because a majority of genetic counselors work in hospitals,³⁹⁹ this fact likely means genetic counselors may be under increased pressure to reduce potential legal liability by encouraging abortions.

Faced with an increased threat of wrongful birth and wrongful life lawsuits, some doctors may push MSFCS or MPFDR on reticent or resistant patients, in order to “cover” themselves in the event of a malpractice action.⁴⁰⁰ More subtly, though, physicians may de-emphasize the voluntary nature of the test, downplay or ignore

technology where the lack of knowledge results in a couple having a genetically handicapped child they would not otherwise have had . . .”).

³⁹¹ *Id.* at 658. Wrongful Life actions are suits, brought on behalf of the child, alleging “that the child would have been better off not having been born, and would not have been born if the physician had properly counseled its parents or properly performed agreed upon screening tests.” *Id.*

³⁹² John A. Robertson, *Procreative Liberty and Human Genetics*, 39 EMORY L.J. 697, 707 (1990); Timothy J. Dawe, Note, *Wrongful Life: Time of a “Day in Court,”* 51 OHIO ST. L.J. 473 (1990).

³⁹³ The Council on Scientific Affairs, a division of the American Medical Association, has summarized the indications for genetic counseling as follows: “birth defects in one or more family members, behavioral problems or mental retardation in a child previously born, advanced age of the mother, certain ethnic backgrounds, drug use by parent, exposure to mutagens by parent, three or more spontaneous abortions, or infertility.” Brown, *supra* note 162, at 865.

³⁹⁴ *Id.* at 870; Kimble, *supra* note 341; Keel v. Banach, 624 So.2d 1022 (Ala.1993).

³⁹⁵ Brown, *supra* note 161, at 870.

³⁹⁶ *Id.* at 878 (“The best answer is for the physician to have the counselee sign an advance statement allowing the physician to disclose necessary information to necessary relatives.”).

³⁹⁷ Malinowski, *supra* note 128, at 1507.

³⁹⁸ National Society, *supra* note 148.

³⁹⁹ Suter, *supra* note 3, at 233 (“noting that, following California’s legal mandate that healthcare providers offer MSAFP screening to all pregnant patients, some doctors ‘tried to make it difficult for women to refuse by telling them to take the test’”).

⁴⁰⁰ *Id.* at 253-54 (“describing how California’s mandate to offer MSAFP screening to all pregnant women ‘profoundly influenced the way in which providers offered, described and discussed MSAFP screening,’ including: calling it a ‘simple blood test,’ spending no more than two minutes discussing the procedure, failing to explain that it was voluntary, or failing to explain the purpose of the test.”).

the potential emotional consequences, or give misleading or incomplete information concerning the procedure and its results.⁴⁰¹ In my opinion, the latter concern is the most dangerous, especially in a regime in which testing would be available to most pregnant women, including many who are poorly educated or do not speak English.⁴⁰² Even well-meaning doctors may not always explain the procedure and its consequences in a way that can be understood by patients, leading to confusion regarding critical facts.⁴⁰³ This potential for misunderstanding and unintentional manipulation underscores the need for training doctors and genetic counselors and developing guidelines for offering and administering the new tests.⁴⁰⁴

In sum, obstetricians⁴⁰⁵ are facing a growing legal duty to refer patients to genetic counselors, and they are beginning to make referrals to counselors when there is even the slightest indication that counseling might prove helpful for “the legal guidelines for doctors in the field of genetic counseling are few and unclear.”⁴⁰⁶ Moreover, it is expected that, in the near future, “many genetic tests will be ordered and interpreted by primary care health practitioners, [rather than] only by geneticists or genetic counselors.”⁴⁰⁷ Some complain that testing might be over-performed due to fear of liability for wrongful birth and wrongful life suits and that people want the perfect, custom-made baby, and they want doctors to insure that they will get it.⁴⁰⁸ In a vast majority of situations, what is in the best interest of patients is that doctors, genetic counselors and other medical professions act within the best interest of their patients, rather than acting to avoid legal liability. Informed consent procedures must be reformed to ensure that patients are receiving the best medical guidance and care available.

The Result: A Lack of Informed Consent

All of the above problems illustrate a lack of informed consent for the pregnant patient. As a result, the big question is whether or not women really have a choice. Many pregnant women who choose to undergo prenatal screening feel that it offers them an overall benefit by allowing them to make an informed choice about their pregnancies.⁴⁰⁹ These women may feel like they have chosen to undergo the procedure for the benefit of themselves, their families, and potentially their fetuses.

⁴⁰¹ Chachkin, *supra* note 153, at 50.

⁴⁰² *Id.*

⁴⁰³ *Id.*

⁴⁰⁴ Similar genetic counselors are potentially open to a malpractice suits at each stage of the counseling process. Brown, *supra* note 161, at 859.

⁴⁰⁵ *Id.* at 858.

⁴⁰⁶ ASSESSING GENETIC RISKS, *supra* note 150, preface, at 2. Genetic testing is no longer just for specialists. Increasingly, primary care providers will be called upon to administer tests, counsel patients, and protect their privacy.” *Id.*, executive summary, at 2.

⁴⁰⁷ Dunne & Warren, *supra* note 178, at 189-93.

⁴⁰⁸ Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 974 (1996).

⁴⁰⁹ Hubbard, *supra* at 375.

It has been argued that current informed consent practices are creating merely an illusion of choice. As Ruth Hubbard has observed, when “choices’ become available, they all too rapidly become compulsions to ‘choose’ the socially endorsed alternative.”⁴¹⁰ Even when women understand conceptually that they have a choice, social norms and beliefs about what is best for their child may make choice illusory. According to a study of women who were offered AFP screening at an HMO in California, many women felt it would be wrong to refuse such testing because they thought it was for the benefit of their child.⁴¹¹ If prenatal testing reflects good parenting and good judgment, how can one refuse it?

In some cases, patients actually believe they have no choice with regard to prenatal screening or testing.⁴¹² Sometimes patients say they are referred to the genetic counselor and had been referred to the clinic because their physicians told them they “had to” have an amniocentesis.⁴¹³ Even if their physicians had only recommended prenatal testing, it is easy to see how they might interpret a physician’s advice as a mandate in light of social attitudes about prenatal testing.⁴¹⁴ The perception that one has no choice is even stronger and more prevalent with respect to prenatal screening.⁴¹⁵ In California, where healthcare providers have a legal obligation to offer MSAFP screening, more than one-third of women interviewed believed (or suspected) the state required pregnant women to take the test.⁴¹⁶

The combination of the manner and setting in which prenatal testing or screening is offered and social attitudes about the value of knowledge makes choice largely illusory. This result is deeply problematic because, without a sense of choice, patients may not have contemplated larger questions raised by prenatal testing and screening.⁴¹⁷ In essence, prenatal diagnosis cannot really be a choice when other alternatives are not available because of medical, professional and social pressures. By enabling prenatal testing to become commonplace, we create a social pressure caused by medical professionals and societies expectations.⁴¹⁸ As Professor Rothman states: “In gaining the choice to control the quality of our children, we may rapidly lose the choice not to control the quality, the choice of simply accepting them as they are.”⁴¹⁹ By correctly and effectively implementing informed consent procedures, we can begin to restore choice by putting it back in the hands of women and their families.

⁴¹⁰ Nancy Press & C. H. Browner, *Why Women Say Yes to Prenatal Diagnosis*, 45 *SOC. SCI. & MED.* 979 (1997).

⁴¹¹ Suter, *supra* note 3, at 255.

⁴¹² Anderson, *supra* note 1 (“[patients’] initial reaction was to assume that it is a medically necessary procedure”).

⁴¹³ Suter, *supra* note 3, at 255.

⁴¹⁴ *Id.*

⁴¹⁵ Press & Browner, *supra* note 277, at 209-10.

⁴¹⁶ Suter, *supra* note 3, at 256.

⁴¹⁷ *Id.* at 269.

⁴¹⁸ Rothman, *supra* note 1, at 11.

⁴¹⁹ Emily Perl Kingsley, *Welcome to Holland* (1987), available at <http://www.our-kids.org/Archives/Holland.html>.

Conclusion

An old story explains having a child with Down Syndrome like this: When you are going to have a baby, it is like planning an extraordinary vacation to Italy. You buy guide books and make your wonderful plans. You may learn some handy phrases in Italian. It is all very exciting.⁴²⁰

After months of anticipation, the day finally arrives. You pack your bags and you're off. Several hours later the plane lands. You look out the window and the sign says, "Welcome to Holland." All of your life you have dreamed of going to Italy. But there has been a change in the flight plan. You've landed in Holland and must stay. The important thing is you haven't been taken to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It is just a different place.⁴²¹

So you must buy new guide books, learn a whole new language, and meet a whole new group of people you would never have met. It is just a different place. It's slower-paced than Italy, less flashy than Italy. But after you have been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills and tulips. The hard part is that everyone you know is busy coming and going from Italy and they are all having a wonderful time there. For the rest of your life, you will wonder what would have been and the pain of that will never go away because the loss of that dream is a very significant loss. However, if you spend your life mourning the fact that you did not get to Italy, you may never be free to enjoy the special and lovely things about Holland.⁴²²

In essence, the women aborting fetuses diagnosed with Down Syndrome are frightened and almost always in a panic because with prenatal genetic testing, they realize in advance that they are going to Holland rather than Italy. The decision then becomes whether to embrace the new place they are about to travel to, cancel the trip or maybe even cancel their trip and begin making plans for a new one. Women should be able to make this decision after being fully and impartially informed about this new opportunity, and without undue influence or misdirection by medical professional or society. The concern is that inappropriate outside influences are encouraging pregnant women to abort based on less than complete information.

The primary question is whether medical professionals and society are giving an accurate picture of this new place or are they discouraging people from embarking upon what could be an amazing new journey. Other factors influencing the decision-making process regarding prenatal testing and subsequent decisions include family background, life circumstances, prior medical knowledge, health providers' advice, financial circumstances, severity of the disease, life experience, particularly the reason for which they were referred for genetic counseling, and the genetic counselor's decision as to what information to highlight and what information to minimize.⁴²³

⁴²⁰ *Id.*

⁴²¹ *Id.*

⁴²² Kenen, *supra* note 350, at 214.

⁴²³ Gettig, *supra* note 9; David C. Reardon, *Abortion Decisions and the Duty to Screen: Clinical, Ethical, and Legal Implications of Predictive Risk Factors of Post-Abortion Maladjustment*, 20 J. CONTEMP. HEALTH L. & POL'Y 33, 71 (2003).

Life circumstances and family background play a major role. For example, because people who already have children may feel that having a child with a disability may be taking away parental time, money and other resources from the other children.⁴²⁴ Also, they may be concerned about their other children's reactions to their child, the financial burden of a child with disabilities, the effect on the other children in the family and many other circumstantial factors.⁴²⁵ The abortion decision may also depend on the prognosis for the disabling condition.⁴²⁶ If the child will not be able to live a "normal" life, oftentimes the women choose to abort the fetus.⁴²⁷

As stated earlier, the *New York Times* statistic stating that 90% of positive diagnoses of Down Syndrome ended in abortion appears to be incorrect. But even if the numbers are incorrect, Professor Gettig suggests that we, as a society, do not embrace diversity and that we do not embrace people who are differently abled. Furthermore, she suggests that we as a society perceive people who are mentally and physically challenged as less human because they are not considered "normal." Professor Gettig has stated in her counseling experience that if given the option, people would almost always take the child with higher intelligence, leaner body mass, and taller and better physical conditions.⁴²⁸ Most people would abort the fetus with genetic predisposition for shorter non-athletic characteristics rather than the fetus with genetic predisposition for leaner characteristics.⁴²⁹ Overall, this observation tells us that we as a society tend to over value rather physical characteristics and competitive advantages. In order to be a compassionate and caring society, we need to embrace people who are differently abled.

The government should not promote programs that increase the abortion rate. Prenatal genetic testing as it currently exists is one of those programs. There are several ways to begin correcting this problem. First, any prenatal genetic testing should be undertaken only with the informed, voluntary, competent, and knowing consent. Second, for those parents choosing to have a child with disabilities, what is

⁴²⁴ *Id.*; Harmon, *supra* note 19 (citing the example of a woman who "knew her marriage would not survive having a severely ill child"). For example, a woman with an unintended pregnancy is less likely to seek prenatal care, more likely to engage in unhealthy activities, more likely to have an abortion and more likely to deliver a low birth weight, ill, or unwanted baby. Unintended pregnancies impose significant financial burdens on the parents in the best of circumstances. If the pregnancy results in a distressed newborn, the costs increase by tens of thousands of dollars. Erickson v. Bartell Drug Co., 141 F. Supp. 2d 1266, 1273 (2001).

⁴²⁵ Gettig, *supra* note 9; Malinowski, *supra* note 128, at 1472-74 (describing a couple's plan to decide whether to abort based on the perceived severity of the condition and the child's potential quality of life because they "could [not] watch a child suffer through life."). Various forces have contributed to genetic counselors' commitment to nondirectiveness, including an attempt to distance themselves from eugenics, the bioethics movement with its commitment to autonomy, and the women's movement with its support of reproductive liberty. *See also*, Suter, *supra* note 244.

⁴²⁶ *Id.*

⁴²⁷ *Id.*

⁴²⁸ Gettig, *supra* note 9.

⁴²⁹ *Id.*

society prepared to do to help these children and their families—schooling, housing, therapies, medical expenses, and so on? Some children with Downs are severely affected. It would be amazing if we lived in a society in which we treated our less abled neighbors as our own and took care of all children regardless of their ability or disability. One of the benefits of prenatal diagnosis has been that people who wouldn't have otherwise risked having a child with a genetic anomaly have been able to complete their families because they can determine with certainty whether their child has a disability. Many parents say that they could handle a child with a genetic anomaly, but that they would not bring such a child into this world, a world that does not accept such children and their needs. The problem is that, if society is never asked to accept these children and their differences, it never will rise to that occasion.

Lastly, the political climate in our country needs to change. Both political parties are unwilling to give an inch on their positions. Republicans do not want to use federal or state monies to fund sexual education programs other than those that recommend abstinence or programs that financially assist women who are unable to support a child. Democrats have not actively advocated for programs that decrease the number of abortions or in any way restrict the “right to choose.” A middle ground needs to be reached in which alternatives to abortion such as adoption are stressed; financial assistance both for the costs of adoption and for the continuing care of adoptive children with special needs are expanded; and comprehensive family life education and policies that support healthy childbearing are adopted. Both political parties need to begin by tackling what can be agreed upon. At present, both parties agree the number of abortions in America need to be reduced. A compromise needs to be reached that does what is necessary to support women in this difficult situation, provides support for those who choose to continue their pregnancies and most importantly, attempts to decrease the number of abortions.

Third, genetic counselors and physicians should be taught—in school or through continuing education programs—how to explain MSFCS or MPFDR in a manner that is thorough, understandable, and culturally as well as religiously sensitive. Such qualities are particularly necessary in a regime in which women of all ages, religions, races, ethnicities, and socioeconomic backgrounds will have access to prenatal genetic testing. Genetic counselors should be required to take continuing education classes on the appropriate ways to counsel patients. In addition, counselors and doctors should approach the topic of testing in a non-directive fashion that includes complete information on the range of special needs that may result, the possible medical interventions, and the community support services available to parents, leaving the ultimate decision to the parents themselves and thus preserving personal autonomy.

Fourth, clear guidelines are needed regarding how to explain test results and review possible consequences and alternatives with patients. Such guidelines, which could be disseminated by professional societies like ACOG or the National

Society for Genetic Counselors, should stress the paramount interest in *providing information*. For example, in every case, counselors or physicians should explain, in plain language, all of the following: the types of tests available, the reliability of the tests, the risks of the tests (including psychological risks), the options (if any) for treatment, the alternatives in the absence of treatment, and the voluntary nature of such tests. Genetic testing should be presented as an alternative, not as a mandatory component of prenatal care.

Fifth, efforts should be made to educate the public more generally about MSFCS/ MPFDR, genetic disorders, and the reality of disability, in order to correct misconceptions and counteract the effects of regional disparities in the quality of counselor/physician training.

Sixth, one thing is clear when the present system of prenatal screening is examined: there is a dearth of qualified genetic counselors. As a result, many pregnant women either receive information from doctors who are inexperienced and untrained in the field of genetics, or they receive little or no information at all. The legislature must place the same degree of emphasis on genetic counseling that it does on efficient programs of mass screening. In order to do this, the government must provide adequate funding for the training of genetic counselors so the supply of qualified personnel can meet the demand for genetic testing and so these issues are addressed by medical professionals. As long as they comply with applicable standards of care for informing patients of their options, physicians and genetic counselors have wide latitude in conveying information and subtly—or not so subtly—influencing patient choices. Physicians who favor avoiding the birth of any child with a genetic disability will likely intentionally or unintentionally steer more women toward prenatal screening. Professional codes and standards of practice will also play an important role, even though they lack the formal legal authority.

Seventh, any public program that encourages or subsidizes prenatal and preconception selection actions should do so in a way that respects people with disabilities. In addition, both public and private programs should require genetic counselors both to stress the person's right to refuse screening and to present fairly a positive view of living with disabled children. Both public and private programs can also assure that persons with disabilities are provided with the means and opportunities for satisfactory living. Together, these efforts will permit public support for genetic selection without denigrating the disabled.

The above suggestions are not all the answers to such a complex problem. However, many of the suggestions in this article can help encourage society to view persons with disabilities as human beings worthy of life and can direct medical professionals on how to maintain patient autonomy by enabling patients to make their decision in a fair and unbiased environment.

With balanced information and support, perhaps more women will make the choice to keep the fetus with a Down Syndrome diagnosis. Our society has become addicted to happy endings and closure. If you watch enough television or

movies you find yourself expecting some kind of neat resolution and happy ending to every crisis. Giving birth to a baby with a disability is one area of life filled with ambiguity, uncertainty and not nearly enough happy endings. Many prospective parents embrace the child with a disability, but many do not. The reality is no matter how many steps the medical profession takes toward improving the prenatal genetic process there will always be those who find it convenient to abort a fetus with a genetic anomaly. With choice comes free will and free will sometimes results in poor decisions. Ultimately, the process encompassing the high abortion rate of fetuses with Down Syndrome lacks informed consent. Genuine informed consent to prenatal screening and diagnostic testing may lead to a more generous spirit toward, and less fear of, living with children and adults who are differently abled. That should be our goal.