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Is Down Syndrome Doomed?

How State Statutes Can Help Expectant Parents Make Informed Decisions about Prenatal Down Syndrome Diagnoses[*]

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INTRODUCTION

Giving birth to a child with Down syndrome is a choice and one that should be well-informed. It has become a trend for expectant parents to abort fetuses with Down syndrome before fully weighing their options.[1] Expectant parents may automatically assume that an individual with Down syndrome will not lead a worthwhile life and that raising the child will pose too many challenges for them.[2] In order to minimize the number of fetuses with Down syndrome that are being aborted (which may be greater than 90%),[3] expectant parents need access to up-to-date, comprehensive information about all aspects of raising a child with Down syndrome, including the many positive aspects. Whatever decision a parent makes regarding raising a child with

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[*] I would like to thank my sweet brother-in-law, Michael Carcioppolo, for inspiring this note. I would also like to thank Sharona Hoffman for her extensive guidance throughout the writing and research process.

[1] *See generally* STEPHANIE WINCIK, MAKING A CASE FOR LIFE: A NEW DEFINITION OF PERFECTION (2009).

[2] *See id.* at 21–23.

[3] In a study involving the United States, the United Kingdom, New Zealand, France, and Singapore, "approximately 92% of women who receive a definitive prenatal diagnosis of DS choose to terminate their pregnancies." Brian G. Skotko, *With New Prenatal Testing, Will Babies with Down Syndrome Slowly Disappear?*, 94 ARCHIVES OF DISEASE IN CHILDHOOD 823, 823 (2009); *see also* Joseph Cannon, *Op-Ed., Down Syndrome: A Modern-Day Death Sentence*, DESERET MORNING NEWS, Feb. 15, 2009, at G01.

Down syndrome, the parent's knowledge on the subject is indispensable. Such an important decision should not be based on fear, ignorance, prejudice, or a doctor's directive opinions.[4]

This note aims to help expectant parents overcome the initial shock of a prenatal Down syndrome diagnosis and to assist them in making an informed decision. The flow of information will allow parents to feel confident about the decision they make and will lead to other positive effects such as protecting the Down syndrome community and propagating support systems and programs for those with Down syndrome. State legislative intervention is an appropriate vehicle for addressing these concerns. Part I of this Note delves into background information on Down syndrome, specifically: (1) genetic makeup and causes of Down syndrome, (2) common traits of individuals with Down syndrome, and (3) health conditions associated with Down syndrome. Part II discusses prenatal diagnoses and ethical issues arising from these diagnoses. In particular, Part II addresses how the prenatal diagnostic process works and the role genetic counselors play in this process. Then, it compares the differing perspectives of the Down syndrome community's role in society—whether Down syndrome should be prevented or whether it can be an asset.

Part III explores state statutes relating to abortion and the state's broad power to regulate and restrict abortion. For example, state statutes may call for post-viability restrictions, abortion-specific informed consent, parental consent or notification for minors, mandatory waiting periods, or spousal

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[4] Upon discovering that a patient's fetus has Down syndrome, numerous doctors automatically assume that this is a problem that must be remedied by termination of the fetus. *See* WINCIK, *supra* note 1, at 22–23; *see also* Matthew Diehr, *The State of Affairs Regarding Counseling for Expectant Parents of a Child with a Disability: Do ACOG's New Practice Guidelines Signify the Arrival of a Brave New World?*, 53 ST. LOUIS U. L.J. 1287 (2009); James A. Long, *Genetic Plastic Surgery: How Neoeugenics Creates a Culture of Stage Moms*, 7 U. ST. THOMAS L.J. 203 (2009); Darrin P. Dixon, *Informed Consent or Institutionalized Eugenics? How the Medical Profession Encourages Abortion of Fetuses with Down Syndrome*, 24 ISSUES L. & MED. 3 (2008); *see also* Skotko, *supra* note 3.

consent. Part IV examines current state and federal laws that require healthcare providers to give information to expectant mothers who receive a prenatal Down syndrome diagnosis. Part IV also addresses why a law requiring post-Down syndrome diagnosis information is not unduly burdensome. Specifically, Part IV looks closely at the Prenatally and Postnatally Diagnosed Conditions Awareness Act and state statutes in Missouri, New Jersey, Alabama, and Virginia.

Part V discusses why laws already enacted on this issue are inadequate and proposes a model statute that all states can follow in crafting their own similar laws. Finally, Part V addresses potential concerns related to the proposed law like cost, enforcement, and First Amendment rights, and how those issues may be resolved.

I. BACKGROUND INFORMATION ON DOWN SYNDROME

A. GENETIC MAKEUP AND CAUSES OF DOWN SYNDROME

Down syndrome is the most common genetic irregularity among humans—one in every 691 babies is born with the condition.[5] Down syndrome may result from three distinct genetic anomalies: Trisomy 21, mosaicism,[6] and translocation.[7] Trisomy 21 accounts for ninety-five percent

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[5] DOWN Syndrome Q & A, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=55&Itemid=75 (last visited Mar. 14, 2011) [hereinafter DOWN SYNDROME Q & A].

[6] Mosaicism occurs when either the sperm or egg fails to separate its twenty-first chromosome and thus contributes an extra twenty-first t chromosome. Only one of the initial cell divisions following fertilization occurs in such a way. This condition creates a mosaic of normal cells with forty-six chromosomes and abnormal cells with forty-seven chromosomes. Individuals with mosaicism represent one percent of those with Down syndrome. WHAT CAUSES DOWN SYNDROME?, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=60&Itemid=77 (last visited Mar. 14, 2011) [hereinafter NDSS]; *see also* DOWN SYNDROME: CAUSES, MAYO CLINIC (Apr. 7, 2011), http://

of individuals with Down syndrome.[8] Ordinarily, an embryo receives one 21st chromosome from each parent, and thus has two 21st chromosomes.[9] In the case of an embryo with Trisomy 21, the egg cell or sperm cell divides abnormally[10] and creates a third 21st chromosome in every cell in the body.[11]

Currently, the cause of chromosomal rearrangements leading to Down syndrome is unknown.[12] Research shows a strong correlation between a

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www.mayoclinic.com/health/downsyndrome/DS00182/DSECTION=causes [hereinafter MAYO CLINIC].

[7] Translocation occurs during cell division when part of the twenty-first chromosome breaks off and attaches itself to another chromosome, usually the fourteenth chromosome. Although individuals with translocation possess the typical forty-six chromosomes, their twenty-first chromosome has an extra part, which produces characteristics of Down syndrome. Individuals with translocation account for four percent of those with Down syndrome. Translocation is the only type of Down syndrome that can be inherited (about two percent of Down syndrome cases are inherited). NDSS, *supra* note 6; *see also* MAYO CLINIC, *supra* note 6.

[8] NDSS, *supra* note 6.

[9] *Id.*

[10] During cell division, 46 chromosomes come from each parent, adding up to 92 chromosomes. The chromosomes line up in pairs (one maternal and one paternal) along the nucleus' midline. The pairs split apart to the nucleus' poles. The entire cell then divides into two cells, each cell normally possessing 46 chromosomes. Trisomy 21 occurs from a phenomenon called nondisjunction, when chromosome pairs do not split properly. Either the sperm or egg contributes two 21st chromosomes instead of one each, creating 47 (instead of 46) chromosomes in all the cells of the body. LORI B. ANDREWS, MAXWELL J. MEHLMAN & MARK A. ROTHSTEIN, GENETICS: ETHICS, LAW AND POLICY 34–35 (2002); NDSS, *supra* note 6.

[11] NDSS, *supra* note 6.

[12] FACTS ABOUT DOWN SYNDROME, NAT'L DOWN SYNDROME CONG., http://www.ndsccenter.org/?page_id=614 (last visited Mar. 14, 2011).

mother's age and the likelihood of having an infant with Down syndrome.[13] While the likelihood of giving birth to a baby with Down syndrome rises as a mother ages, women under thirty-five give birth to eighty percent of individuals with Down syndrome due to their higher fertility rates.[14] Men may also contribute the extra 21st chromosome.[15] Some studies show that if a father is over fifty years of age, the likelihood of conceiving an embryo with Down syndrome also rises.[16] Incidences of Down syndrome are not correlated with race, ethnicity, or socio-economic status.[17]

B. COMMON TRAITS OF AN INDIVIDUAL WITH DOWN SYNDROME

Many individuals with Down syndrome possess similar, identifiable characteristics. Common physical features may include a flattened face, a protruding tongue, an upward slant to the eyes, a short neck, irregularly shaped ears, a deep crease across the center of the palm, white spots on the iris of eyes, poor muscle tone, loose ligaments, increased flexibility, small

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[13] For example, if a mother is twenty years old, there is a likelihood of one in 2000 that she will give birth to a baby with Down syndrome. With every passing year, the likelihood rises. For women at age thirty, the probability is one in 900, by age forty the chances rise to one in one hundred and at age forty-nine the probability is one in ten. INCIDENCES AND MATERNAL AGE, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=61&Itemid=78 (last visited Mar. 14, 2011).

[14] DOWN SYNDROME FACT SHEET, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=54&Itemid=74 (last visited Feb. 22, 2012) [hereinafter DOWN SYNDROME FACT SHEET].

[15] DOWN SYNDROME Q & A, *supra* note 5.This accounts for about 5% of all Down syndrome cases.

[16] NAT'L DOWN SYNDROME CONG., DOWN SYNDROME 7, http://www.ndsccenter.org/resources/dsBrochure.pdf (last visited Feb. 22, 2012) [hereinafter NAT'L DOWN SYNDROME CONG.].

[17] *Id.*

hands and feet, and small stature.[18] All individuals with Down syndrome experience cognitive delays usually ranging from mild to moderate in severity.[19] It is impossible to know at birth what an infant's cognitive capacity will be and to what extent a baby with Down syndrome will be affected by mental developmental delays.[20] Because IQ measures intelligence and does not measure social or emotional aptitude, "[c]hildren with Down syndrome often function better in social situations than might be expected from their IQ."[21] Dr. McGuire, Director of Psychosocial Services at the Adult Down syndrome Center in Park Ridge, Illinois, remarks that generally, individuals with Down syndrome are very affectionate, caring towards others, and frequently give out spontaneous hugs.[22]

C. HEALTH CONDITIONS ASSOCIATED WITH DOWN SYNDROME

Certain health conditions generally affect those with Down syndrome.[23] Forty to forty-five percent of those with Down syndrome are born with heart

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[18] GENERAL INFO, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=63&Itemid=85 (last visited Mar. 14, 2011); DOWN SYNDROME, NAT'L INST. OF CHILD HEALTH & HUMAN DEV., http://www.nichd.nih.gov/health/topics/down_syndrome.cfm (last updated Feb. 17, 2012); DOWN SYNDROME, MAYO CLINIC, http://www.mayoclinic.com/health/down-syndrome/DS00182/ DSECTION= symptoms. (last updated Apr. 7, 2011).

[19] Committee on Genetics, *Health Supervision for Children with Down Syndrome*, 107.2 AM. ACAD. OF PEDIATRICS 442 (2001).

[20] LEARNING ABOUT DOWN SYNDROME, NAT'L HUMAN GENOME RESEARCH INST., http://www.genome.gov/19517824 (last updated Dec. 12, 2010).

[21] *Id.*

[22] Dennis McGuire, *If People with Down Syndrome Ruled the World*, NATIONAL ASSOCIATION FOR DOWN SYNDROME, http://www.nads.org/pages_new/news/ruletheworld.html (last visited Feb. 23, 2012).

[23] NAT'L DOWN SYNDROME CONG., *supra* note 16, at 6.

defects.[24] The most common congenital heart conditions are correctible through surgery.[25] Some individuals with Down syndrome have gastrointestinal abnormalities.[26] For example, celiac disease, a gluten allergy affects ten to sixteen percent of the Down syndrome population.[27] Thyroid disorders are also fairly common among individuals with Down syndrome.[28] One in one hundred individuals with Down syndrome will develop leukemia.[29] Also, approximately one-fourth of individuals with Down syndrome will develop Alzheimer's disease.[30] Most of the above conditions are treatable, curable, or controllable. Since 1983, the life expectancy of those with Down syndrome has increased from twenty-five years to sixty years.[31] As the National Down

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[24] *Id.*

[25] THE HEART AND DOWN SYNDROME, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=181%3Athe-heart-and-down-syndrome&catid=60%3Aassociated-conditions&Itemid=88&showall=1 (last visited Mar. 20, 2012).

[26] NAT'L DOWN SYNDROME CONG., *supra* note 16, at 6.

[27] NASREEN TALIB, SCREENING FOR CELIAC DISEASE IN CHILDREN WITH DOWN SYNDROME, CHILDREN'S MERCY HOSP. & CLINICS, http://www.childrensmercy.org/content/view.aspx?id=12514 (last visited Feb. 29, 2012).

[28] NAT'L DOWN SYNDROME CONG., *supra* note 16, at 6; *see also* ENDOCRINE CONDITIONS AND DOWN Syndrome, Nat'l Down Syndrome Soc'y, http://www.ndss.org/en/Healthcare/Associated-Conditions/Endocrine-Conditions-and-Down-Syndrome/ (last visited Apr. 18, 2012) ("Studies of adults with Down syndrome vary widely, but the incidence of thyroid disease in adults with Down syndrome is believed to be between 13 and 50 percent").

[29] Most forms of leukemia (acute megakaryoblastic leukemia) develop from zero to three years of age and are easily cured. A transient type of leukemia vanishes spontaneously two to three months after birth. DOWN SYNDROME Q & A, *supra* note 5.

[30] Likewise, about one fourth of individuals without Down syndrome will develop Alzheimer's disease. Individuals with Down syndrome, however, will develop the disease after age thirty-five, about twenty-five years earlier than those without Down syndrome. DOWN SYNDROME Q & A, *supra* note 5.

[31] DOWN SYNDROME FACT SHEET, *supra* note 14.

Syndrome Society acknowledges, "[m]any feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future."[32]

The Down syndrome population demonstrates strong resistance to the two leading causes of death in the United States: heart disease and cancer.[33] Individuals with Down syndrome possess a protein that resists development of tumors.[34] Environmental factors may also play a part in Down syndrome's resistance to heart disease.[35]

II. PRENATAL DIAGNOSIS OF DOWN SYNDROME AND CORRESPONDING ETHICAL IMPLICATIONS

A. HOW DOCTORS PRENATALLY DIAGNOSE DOWN SYNDROME

Doctors can diagnose Down syndrome prenatally through screening and diagnostic testing.[36] While screening merely estimates the chances of giving birth to an infant with Down syndrome, diagnostic tests identify Down syndrome with almost one hundred percent accuracy.[37] It is important for

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[32] *Id.*

[33] People with Down syndrome very rarely suffer from atherosclerosis, the condition that causes hypertension, heart attack, and stroke. By contrast, 64 million Americans suffer from atherosclerosis, a condition largely caused by preventable unhealthy habits like smoking, overeating, and lack of exercise. WINCIK, *supra* note 1, at 16–17; *see also Down Syndrome Protein Reduces Tumor Growth*, SCIENCEDAILY, Nov. 19, 2004, *available at* http://www.sciencedaily.com/releases/2004/11/041119014444.htm [hereinafter SCIENCEDAILY].

[34] SCIENCEDAILY, *supra* note 34.

[35] Since individuals with Down syndrome live less of an independent lifestyle than most people, their caretakers may help them avoid harmful habits like smoking, overeating, and getting little exercise.

[36] NDSS, *supra* note 6.

[37] *Id.*

parents to understand the difference between screening and diagnostic testing, since screening is by no means determinative. Doctors screen for Down syndrome with blood tests and ultrasounds.[38] Screening yields both false positives and false negatives.[39] If screening reveals that the chances of giving birth to a child with Down syndrome are high, doctors will recommend diagnostic testing.[40] Two invasive diagnostic tests are available to establish Down syndrome prenatally: chorionic villus sampling ("CVS")[41] and amniocentesis.[42] Both of these procedures carry a one percent risk of

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[38] Blood tests measure levels of various substances in the mother's blood and ultrasounds check for "markers" or characteristics of an individual with Down syndrome. Doctors look to these factors in conjunction with the mother's age to determine whether she has increased chances of giving birth to a child with Down syndrome. *Id.*

[39] In an aggregation of four separate studies amounting to 103,856 patients, researchers identified 328 cases of Down syndrome at an eighty-four percent detection rate in the first trimester. Sixteen percent of the cases yielded false negatives, and five percent yielded false positives. Press Release, Am. Coll. of Obstetricians and Gynecologists, Screening Guidelines on Chromosomal Abnormalities: What They Mean to Patients and Physicians (May 7, 2007) [hereinafter ACOG].

[40] MAYO CLINIC, *supra* note 6.

[41] CVS can be done either through the cervix or the abdomen. The doctor inserts a thin plastic tube (transcervically) or needle (transabdominally) into the mother to remove a small piece of placental tissue. CVS testing occurs in the first trimester between nine and eleven weeks of gestation. CHORIONIC VILLUS SAMPLING, MEDLINE PLUS, http://www.nlm.nih.gov/medlineplus/ency/article/003406.htm (last updated June 5, 2010).

[42] Amniocentesis involves inserting a needle into a woman's uterus to collect and test a sample of amniotic fluid. The amniotic fluid retains some of the fetus' cells. Amniocentesis is performed in the second trimester between fourteen and twenty weeks of gestation. AMNIOCENTESIS, AM. PREGNANCY ASS'N, http://www.americanpregnancy.org/prenataltesting/amniocentesis.html (last updated Apr. 2006).

miscarriage.[43] Currently, researchers are developing new, non-invasive diagnostic tests that pose no risks to the mother or fetus.[44] With the advent of easier, safer prenatal testing, the need for complete, up-to-date information on Down syndrome for expectant mothers also increases. As prenatal testing becomes increasingly ubiquitous, so does the ease of terminating pregnancies. Thus, it is important that expectant parents of fetuses with Down syndrome understand, appreciate and are well-informed about the choice they are about to make.

B. GENETIC COUNSELORS AND PRENATAL DIAGNOSIS

Genetic counselors[45] play an important role in prenatal diagnosis by interpreting genetic information[46] and counseling families affected by genetic conditions.[47] If prenatal screening reveals that the chances of giving birth to a child with Down syndrome are high, doctors may then refer the woman to a

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[43] NDSS, *supra* note 6.

[44] Skotko, *supra* note 3.

[45] Genetic counselors are medical professionals who have specialized graduate degrees in both medical genetics and counseling. FAQS ABOUT GENETIC COUNSELORS AND THE NSGC, NAT'L SOC'Y OF GENETIC COUNSELORS, http://www.nsgc.org/About/FAQsaboutGeneticCounselorsandtheNSGC/tabid/143/Default.aspx (last visited Mar. 14, 2011).

[46] Genetic counselors interpret genetic information by analyzing inheritance patterns of genetic disorders and risks of recurrence among families. This type of assistance especially helps couples pre-conception. *Id.*

[47] Genetic counselors help expectant parents decide whether giving birth to a child with a genetic disorder is appropriate for them by "review[ing] available options with the family," "provid[ing] supportive counseling to families," and supplying "information and support to families who have members with birth defects or genetic disorders." These types of counseling services help families post-conception, and especially after expectant parents receive a prenatal diagnosis of a genetic anomaly. *Id.*

genetic counselor. Genetic counselors are taught non-directive[48] counseling techniques, which afford expectant parents the chance to make an informed decision that is right for them. "Non-directiveness is understood to mean non-prescriptive" and "is often equated with value neutrality."[49] Nondirective counseling is achieved by asking the patient open-ended questions so the patient forms her own beliefs and comes to her own conclusions appropriate for her individual lifestyle.[50] This non-directive practice increases patient autonomy, as genetic counselors would ideally never impose their own personal beliefs or opinions upon their patients.

C. IS PRENATAL PREVENTION THE CURE TO DOWN SYNDROME?

Some physicians believe that the "cure" to Down syndrome has already been found through prenatal prevention.[51] Prenatal diagnoses and corresponding abortions have the power to eliminate Down syndrome altogether.[52] If people continue to support the viewpoint that the cure to Down syndrome is abortion, support systems for Down syndrome, government services for Down syndrome, and Down syndrome itself will disappear.[53] As enthusiasm

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[48] "Nondirectiveness appealed to the genetics community as a way to distance itself from the eugenics movement associated with Nazi Germany." ANDREWS, MEHLMAN, & ROTHSTEIN, *supra* note 10, at 334–35.

[49] ANDREWS, MEHLMAN, & ROTHSTEIN, *supra* note 10, at 335.

[50] Genetic counselors may discuss topics including the stability of the expectant parents' marriage, the flexibility of their careers, their finances, and potential psychological and physical challenges of raising a child with Down syndrome. Dixon, *supra* note 4, at 32–33.

[51] *See* Press Release, Am. Coll. of Obstetricians and Gynecologists, *supra* note 41.

[52] *See* Cannon, *supra* note 3; *see also* Skotko, *supra* note 3.

[53] *But see* Giovanni Neri & John M. Opitz, *Down Syndrome: Comments and Reflections on the 50th Anniversary of Lejeune's Discovery*, 149A AM. J. MED. GENETICS 2647, 2653 (2009).

continues for prenatal prevention of Down syndrome, the Down syndrome population will continue to wane.[54]

Numerous doctors believe this is a positive trend and question why people should have to tolerate increased stress and challenge in their lives if it can be remedied by genetic testing and a simple surgical procedure.[55] Most expectant parents dream of the perfect healthy baby as one without anomalous genetic conditions. Accordingly, the American College of Obstetricians and Gynecologists ("ACOG") strongly recommend genetic screening for an expectant mother to determine her chances of giving birth to an infant with Down syndrome.[56] ACOG sees this as an opportunity to increase a patient's autonomy and ability to choose whether to carry her pregnancy to term.[57] Yet, it also increases the ability of doctors to directly influence that decision by automatically recommending abortion to patients under these circumstances as if it were standard protocol.

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[54] Increasingly, women are waiting until later in life to give birth. Because the chances of giving birth to an infant with Down syndrome rise as a woman ages, one would logically assume that Down syndrome is on the rise. Instead, the opposite trend is occurring. From 1989 to 2005, researchers anticipated a thirty-four percent increase in Down syndrome births in the United States. Instead, Down syndrome births decreased by fifteen percent. Thus, the realized change amounts to a forty-nine percent decrease in Down syndrome births. Per year, the average realized change is a three percent decrease in births of individuals with Down syndrome. Skotko, *supra* note 3, at 823–24.

[55] *See* Press Release, Am. Coll. of Obstetricians and Gynecologists, *supra* note 41.

[56] James D. Goldberg, MD, a member of ACOG's genetics committee, insists that an expectant mother deserves peace of mind or an opportunity to prepare for "a baby with a genetic defect." *Id.*

[57] *See id.*

D. COULD DOWN SYNDROME BE AN ASSET TO SOCIETY?

While numerous doctors view the progress of prenatal testing positively, others see prenatal testing and its corresponding side effect, widespread elimination of fetuses with Down syndrome, as a leap in the wrong direction.[58] Parents of children with Down syndrome worry that opportunities for their children will diminish as people with Down syndrome vanish from the community.[59] They also fear that as the Down syndrome population shrinks, the general population will be less welcoming and open toward their children.[60] Some simply believe that society is enriched by the differences between individuals.[61]

Currently, approximately 200 families in the United States[62] and others throughout the world[63] are on waiting lists to adopt a child with Down syndrome.

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[58] *See* Arthur Caplan, *Disability-Free World May Not Be a Better Place*, MSNBC.COM (Feb. 18, 2011, 5:59 PM), http://www.msnbc.msn.com/id/35463644/ns/ health-health_care/.

[59] *See id.*

[60] *See id.*

[61] *See* Thomas Armstrong, *Special Education and the Concept of Neurodiversity*, NEURODIVERSITY—THE BOOK (Jan. 1, 2010), http://thehumanodyssey.typepad.com/neurodiversity_the_book/2010/01/special-education-and-the-concept-of-neurodiversity.html.

[62] Michael Allison Chandler, *A Leap of Love: Adoptions of Children with Down Syndrome on the Increase*, WASH. POST, Nov. 9, 2008, at C01. Some families on these lists want to adopt because they are currently raising one or more children with the condition and know first-hand the rewards and benefits that come with raising such an individual. Others who hope to adopt individuals with Down syndrome include those who hold certain religious beliefs or who are special education instructors. *Id.*

[63] *Id.*

III. HOW STATE LAWS CURRENTLY REGULATE ABORTION

Currently, state laws have numerous restrictions on abortion. States may regulate abortion to protect the life and health of the mother and to protect potential fetal life post-viability (after the fetus is able to independently live outside the womb). Restrictions on abortion are constitutional so long as they do not impose an undue burden on women attempting to obtain an abortion.[64] The most common ways that states regulate abortion include post-viability restrictions, abortion-specific informed consent laws, parental consent or notification for minors, waiting periods, and spousal consent.

Twenty-seven states have enforceable (not unconstitutional, preempted, or proposed) post-viability restrictions on abortion.[65] These laws may define viability as a specified number of gestational weeks such as twelve, sixteen, or twenty.[66] Other laws simply prohibit abortions after the fetus is viable,

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[64] *See* Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 878 (1992).

[65] *See* ALA. CODE § 26-22-3 (2011); ARIZ. REV. STAT. ANN. § 36-2301.01 (2011); ARK. CODE ANN. § 20-16-705 (West 2011); CAL. HEALTH & SAFETY CODE § 123468 (West 2011); COLO. REV. STAT. ANN. § 18-6-101 (West 2011); CONN. GEN. STAT. ANN. § 19a-602 (West 2011); DEL. CODE ANN. tit. 24, § 1790 (2011); IDAHO CODE ANN. § 18-608 (2011); 720 ILL. COMP. STAT. ANN. 510/5 (West 2011); IOWA CODE ANN. § 707.7 (West 2011); LA. REV. STAT. ANN. § 14:87.5 (2011); MASS. GEN. LAWS ANN. ch. 112, § 12M (West 2011); MINN. STAT. ANN. § 145.423 (West 2011); MONT. CODE ANN. § 50-20-109 (2011); NEB. REV. STAT. § 28-329 (2011); NEV. REV. STAT. ANN. § 442.250 (West 2010); N.C. GEN. STAT. ANN. § 14-45.1 (West 2010); N.D. CENT. CODE § 14-02.1-05 (2011); 18 PA. CONS. STAT. § 3211 (2011); R.I. GEN. LAWS § 11-23-5 (2011); S.D. CODIFIED LAWS § 34-23A-3 (2011); TENN. CODE ANN. § 39-15-201 (West 2010); TEX. HEALTH & SAFETY CODE ANN. § 170.002 (West 2011); UTAH CODE ANN. § 76-7-302 (West 2010); VA. CODE ANN. § 18.2-74 (West 2011); WIS. STAT. ANN. § 940.15 (West 2011); WYO. STAT. ANN. § 35-6-102 (2011).

[66] *See, e.g.*, S.D. CODIFIED LAWS § 34-23A-3 (2010); COLO. REV. STAT. ANN. § 18-6-101 (West 2011); DEL. CODE ANN. tit. 24, § 1790 (2010).

where viability is not specifically defined.[67] Vagueness allows for flexibility, as the date of viability can change with progressions in medicine. Enforceable post-viability laws provide exceptions for the life and health of the mother.[68]

Twenty-five states have abortion-specific informed consent laws.[69] These laws demonstrate that states' are given wide latitude in regulating abortion. For example, abortion-specific informed consent laws are typically much more thorough and comprehensive than most informed consent laws relating to other surgeries or procedures.[70] While some laws stipulate that a patient must give informed consent prior to an abortion,[71] others delve into much greater detail regarding what constitutes "informed" consent. For

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[67] *See, e.g.*, ALA. CODE § 26-22-3 (2010).

[68] *See, e.g.*, NEV. REV. STAT. ANN. § 442.250 (West 2010).

[69] ALA. CODE § 26-23A-4 (2011); ALASKA STAT. § 18.16.060 (2011); ARIZ. REV. STAT. ANN. § 36-2153 (2011); ARK. CODE ANN. § 20-16-903 (West 2011); CAL. CODE REGS. tit. 22, § 75040 (2011); CONN. GEN. STAT. ANN. § 19a-116 (West 2011); KY. REV. STAT. ANN. § 311.725 (West 2011); LA. REV. STAT. ANN. § 40:1299.33 (2010); MINN. STAT. ANN. § 145.4242 (West 2011); MISS. CODE ANN. § 41-41-35 (West 2011); MO. ANN. STAT. § 188.027 (West 2011); MONT. CODE ANN. § 50-20-304 (2011); NEB. REV. STAT. § 28-327.01 (2011); NEV. REV. STAT. ANN. § 442.252 (West 2011); N.D. CENT. CODE, § 14-02.1-03.2 (2011); OHIO REV. CODE ANN. § 2317.56 (West 2011); OKLA. STAT. ANN. tit. 63, § 1-738.2 (West 2011); 18 PA. CONS. STAT. ANN. § 3205 (West 2011); R.I. GEN. LAWS § 23-4.7-5 (2011); S.C. CODE ANN. § 44-41-30 (2011); S.D. CODIFIED LAWS § 34-23A-10.3 (2011); TENN. CODE ANN. § 39-15-202 (West 2011); TEX. HEALTH & SAFETY CODE ANN. § 171.011 (West 2011); UTAH CODE ANN. § 76-7-305 (West 2011); W. VA. CODE ANN. § 16-2I-2 (West 2011).

[70] *See* Rebecca Dresser, *From Double Standard to Double Bind: Informed Choice in Abortion Law*, 76 GEO. WASH. L. REV. 1599, 1604–15 (2008) (discussing how abortion-specific informed consent laws provide too much biased information for women, which necessarily threatens the physician-patient relationship).

[71] *See, e.g.*, TEX. HEALTH & SAFETY CODE ANN. § 171.011 (West 2011).

example, some states require abortion providers to offer the patient an informational video to view prior to the procedure.[72] Other informed consent regulations require the healthcare provider to notify the patient about availability of printed materials relating to abortion and alternatives to abortion such as adoption.[73] States may also require that materials include depictions of the fetus' gestational progression in color at two-week intervals.[74] Some states mandate that the healthcare provider perform an ultrasound of the fetus prior to the abortion and offer the patient an opportunity to view the ultrasound.[75] Other states require the patient to understand particular minutiae[76] and potential, speculative[77] risks of the abortion procedure.

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[72] *See, e.g.*, ALA. CODE § 26-23A-4 (2011).

[73] *See, e.g.*, 18 PA. CONS. STAT. ANN. § 3205 (West 2011).

[74] *See, e.g.*, TEX. HEALTH & SAFETY CODE ANN. § 171.016 (West 2011).

[75] *See, e.g.*, ALA. CODE § 26-23A-4 (2011).

[76] For example, Montana's statute requires the following: "The materials must inform the pregnant woman of the probable anatomical and physiological characteristics of the unborn child at 2-week gestational increments from fertilization to full term, including pictures or drawings representing the development of unborn children at 2-week gestational increments. The pictures or drawings must contain the dimensions of the unborn child and must be realistic. The materials must include any relevant information on the possibility of the unborn child's survival at each stage depicted. The materials must be objective, nonjudgmental, and designed to convey only accurate scientific information about the unborn child at the various gestational ages. The materials must contain objective information describing the methods of abortion procedures commonly employed, the medical risks commonly associated with each procedure, the possible detrimental psychological effects of abortion, the possible detrimental psychological effects of adoption, and the medical risks associated with carrying a child to term." MONT. CODE ANN. § 50-20-304 (2011).

[77] *See, e.g.*, MINN. STAT. ANN. § 145.4242 (West 2011) (requiring abortion facilities to notify women about their risk of breast cancer after

Thirteen states enforce parental consent requirements relating to abortion.[78] Ten states have enforceable parental notice requirements.[79] A few states require both parental consent and notice.[80] Both types of laws provide exceptions if the minor is able to obtain a court order, if she is emancipated (married or living away from her parents or legal guardian), or if the minor's life or health is threatened.[81] Parental consent usually requires written consent

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having an abortion); *see also* Rachel Benson Gold & Elizabeth Nash, *State Abortion Counseling Policies and the Fundamental Principles of Informed Consent*, 10.4 GUTTMACHER POL'Y REV. 6, 8–11 (2007), *available at* http://www.guttmacher.org/pubs/gpr/10/4/gpr100406.html (noting that both the National Cancer Institute and the British government concluded that there is no correlation between having an abortion and increased risk of breast cancer. Furthermore, "The notion that having an abortion is psychologically riskier for a woman than delivering and parenting a child she did not intend to have or placing a baby for adoption is not supported by the evidence").

[78] ALA. CODE § 26-21-3 (2011); ALASKA STAT. §18.16.060 (2011); ARK. CODE ANN. § 20-16-801 (West 2011); LA. REV. STAT. ANN. § 40:1299.33 (2011); MICH. COMP. LAWS ANN. § 722.907 (West 2012); MO. ANN. STAT. § 188.028 (West 2011); N.C. GEN. STAT. ANN. § 90-21.7 (West 2011); OKLA. STAT. ANN. tit. 63, § 1-740.2 (West 2012); R.I. GEN. LAWS § 23-4.7-6 (2011); S.C. CODE ANN. § 44-41-31 (2011); TEX. OCC. CODE ANN. § 164.052 (West 2012); UTAH CODE ANN. § 76-7-304.5 (West 2011); WYO. STAT. ANN. 35-6-118 (2012).

[79] DEL. CODE ANN. tit. 24, § 1783 (West 2011); 750 ILL. COMP. STAT. ANN. 70/15 (West 2011); MD CODE ANN., HEALTH-GENERAL § 20-103 (West 2011); MINN. STAT. ANN. § 144.343 (West 2011); MONT. CODE ANN. § 50-20-204 (2011); NEV. REV. STAT. ANN. § 442.255 (West 2011); S.D. CODIFIED LAWS § 34-23A-7 (2011); TEX. FAM. CODE ANN. § 33.002 (West 2011); UTAH CODE ANN. § 76-7-304 (West 2011); WYO. STAT. ANN. § 35-6-118 (2011).

[80] TEX. FAM. CODE ANN. § 33.002 (West 2011); TEX. OCC. CODE ANN. § 164.052 (West 2012); UTAH CODE ANN. § 76-7-304.5 (West 2011); UTAH CODE ANN. § 76-7-304 (West 2011); WYO. STAT. ANN. 35-6-118 (2012); WYO. STAT. ANN. § 35-6-118 (2011).

[81] *See, e.g.*, TEX. OCC. CODE ANN. § 164.052 (West 2011).

of one or both parents, whereas parental notice may require either oral or written notification to one or both parents.[82]

Thirteen states mandate a waiting period.[83] Mandatory waiting periods are frequently a part of abortion-specific informed consent laws and usually last twenty-four hours. Legislators hope that the patient will review the informational materials about abortion during the waiting period. Alabama, for example, requires the physician (or agent of the physician) who will perform the abortion to provide written materials to the patient in person or via certified mail.[84] Informational materials describe risks associated with abortion, alternatives to abortion, and other facts[85] typically included in abortion-specific informed consent laws. The parental notice laws may also including waiting periods, which require the physician to wait to perform the abortion until forty-eight hours after a parent has been notified.[86]

Five states have spousal consent or notice requirements, which vary widely from state to state.[87] A few spousal consent laws exist as an exception

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[82] *See, e.g.*, DEL. CODE ANN. tit. 24, § 1783 (West 2011).

[83] ALA. CODE § 26-23A-4 (2011); ARIZ. REV. STAT. ANN. § 36-2153 (2011); ARK. CODE ANN. § 20-16-1103 (West 2011); KY. REV. STAT. ANN. § 311.725 (West 2011); LA. REV. STAT. ANN. § 40:1299.35.6 (2011); MINN. STAT. ANN. § 145.4242 (West 2011); MO. ANN. STAT. § 188.027 (West 2011); OHIO REV. CODE ANN. § 2317.56 (West 2011); OKLA. STAT. ANN. tit. 63, § 1-738.2 (West 2011); 18 PA. CONS. STAT. ANN. § 3205 (West 2011); TENN. CODE ANN. § 39-15-202 (West 2011); UTAH CODE ANN. § 76-7-305 (West 2011); W. VA. CODE ANN. § 16-2I-2. (West 2011).

[84] ALA. CODE § 26-23A-4 (2011).

[85] *See, e.g.*, MONT. CODE ANN. § 50-20-304 (2011), *supra* note 79.

[86] *See, e.g.*, WYO. STAT. ANN. § 35-6-118 (2010).

[87] COLO. REV. STAT. ANN. § 18-6-101 (West 2011); 735 ILL. COMP. STAT. ANN. 5/11-107.1 (West 2010); LA. REV. STAT. ANN. § 40:1299.33 (2010); 18 PA. CONS. STAT. ANN. § 3209 (West 2010); R.I. GEN. LAWS § 23-4.8-2 (West 2011).

to a parental consent law.[88] When a minor is married, she may be required to obtain her husband's consent.[89] Illinois law allows injunctive relief for the father of an unborn baby when his interests in having the baby outweigh the mother's interests in having an abortion.[90] This law is only applicable if the fetus is viable and if the woman's health is not at risk.[91] Pennsylvania law requires a woman to sign a statement stipulating that she has notified her husband prior to having an abortion.[92] Rhode Island law, on the other hand, requires the physician who will perform the abortion to notify the spouse if reasonably possible.[93]

IV. CURRENT FEDERAL AND STATE LAWS THAT ENCOURAGE EXPECTANT PARENTS TO MAKE INFORMED DECISIONS BEFORE ABORTING A FETUS WITH DOWN SYNDROME

States enjoy considerable latitude in crafting laws that regulate abortion. Importantly, a law offering information to parents about Down syndrome should not be viewed as a constraint on abortion. State controls on abortion nevertheless demonstrate a state's broad power to regulate this realm. Unfortunately, only a handful of states have enacted laws requiring health care providers to give expectant parents complete and accurate information related to raising a child with Down syndrome. Full disclosure about Down syndrome for expectant parents in this situation will assist them in making an informed decision, allow parents to feel confident about the decision they make, and may protect the Down syndrome community by propagating support systems and programs for those with Down syndrome. State governments should help bring these goals to fruition through legislation.

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[88] *E.g.*, COLO. REV. STAT. ANN. § 18-6-101 (West 2011); LA. REV. STAT. ANN. § 40:1299.33 (2010).

[89] *E.g.*, LA. REV. STAT. ANN. § 40:1299.33 (2010).

[90] 735 ILL. COMP. STAT. ANN. § 5/11-107.1 (West 2011).

[91] *Id.*

[92] 18 PA. CONS. STAT. ANN. § 3209 (West 2011).

[93] R.I. GEN. LAWS § 23-4.8-2 (2011).

A. THE PRENATALLY AND POSTNATALLY DIAGNOSED CONDITIONS AWARENESS ACT

On October 8, 2008, President Bush signed into law Congress's Prenatally and Postnatally Diagnosed Conditions Awareness Act ("the federal Act").[94] The federal Act authorizes the National Institutes of Health to "collect, synthesize, and disseminate" information and data relating to Down syndrome[95] and to coordinate "support services for patients receiving a positive diagnosis for Down syndrome" in five ways, by (1) establishing telephone hotlines, (2) launching outreach programs that provide parents with up-to-date information regarding the potential[96] of their child with Down syndrome, (3) expanding and developing "national and local peer-support programs," (4) creating a national registry of parents hoping to adopt individuals with Down syndrome, and (5) initiating education and awareness programs for healthcare providers who inform parents of test results relating to Down syndrome.[97]

However, the federal Act is inadequate for a number of reasons.[98] First, the federal Act does not specify how expectant mothers will receive this

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[94] 42 U.S.C.A. § 280g-8 (West 2012).

[95] *See id.* and note that the federal Act does not deal exclusively with Down syndrome. It also includes "other prenatally or postnatally diagnosed conditions," but only specifically mentions Down syndrome.

[96] "Information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes." *Id.*

[97] *Id.*

[98] E-mail from Jennifer Carroll, Resource Specialist, National Down Syndrome Congress, to Teresa Santin, Law Student at Case Western Reserve University (Mar. 14, 2011) (on file with author) (writing that "[c]urrently, there is no data to support whether this Act is being implemented or not. We have created new materials for physicians and genetic counselors to give to parents at the time of diagnosis or even upon the offering of screenings. While we have been distributing these materials upon the request of clinicians we have not seen a dramatic rise in those requests.").

information. Some women may not wish to receive any information at all, and the law should allow this. Therefore, healthcare providers should offer the information to women, but should not force it upon them. An expectant mother who receives a positive prenatal diagnosis of Down syndrome deserves the utmost sensitivity and compassion, "[t]he majority of mothers reported being frightened or anxious after learning of the diagnosis, and very few rated the overall experience as a positive one."[99] Thus, the law should be tailored to a woman's needs and should be designed to help her, not to contribute additional anxiety to an already stressful situation.

Second, the law should take into account the means of offering the information. It should be available both on paper and online.[100] Some women might prefer to surf the internet individually, while others would be more motivated to peruse the information if healthcare providers put the information directly in their hands in hard copy form. Third, genetic counselors should be readily available to talk with an expectant mother about her situation.[101] Finally, because scientific research presents information concerning Down syndrome in a disproportionately negative light and because "mothers were more apt to feel frightened or anxious" if their doctors focused on negative aspects when delivering the Down syndrome diagnosis,

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[99] Brian G. Skotko, *Mothers of Children with Down Syndrome Reflect on Their Postnatal Support*, 115.1 PEDIATRICS 64, 64 (2005) [hereinafter *Mothers Reflect*]; Brian G. Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued Their Pregnancies Evaluate Their Health Care Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670–77 (2005) [hereinafter *Mothers Continued Pregnancies*] (noting that mothers whose fetuses were diagnosed with Down syndrome expressed frustration with the prenatal diagnosis process).

[100] *See, e.g.*, S.1369, 214th Leg., Assemb. (N.J. 2010) (proposing to create a website where the information will also be available).

[101] *See infra* notes 145–52 and accompanying text for a discussion of why genetic counselors are valuable in this situation and for a discussion of how economic access to genetic counselors should be considered in a statute.

the information should include the positive aspects of raising a child with Down syndrome.[102]

The federal Act has been valuable, particularly for assistance in drafting state statutes. However, this vague and incomplete federal Act alone is not ideal. First, state laws should build upon the federal Act by providing additional requirements with increased specificity.[103] Second, state lawmakers should exercise better control in overseeing the law's enactment and enforcement. Finally, state laws allow for particularized consideration of the law's regulated community. A state law could facilitate more useful, specific information for expectant mothers based on geography and resources in the area. For example, a law could provide for local support systems throughout the state and referrals to parents of children with Down syndrome in the community who are willing to talk with an expectant parent.

B. CURRENT STATE LAWS—MISSOURI, NEW JERSEY, ALABAMA, VIRGINIA

Missouri recently enacted its own law on the topic at issue ("the Missouri statute").[104] When a woman receives a positive prenatal diagnosis of Down syndrome in Missouri, healthcare providers involved in the diagnosis must supply her with information including: (1) the accuracy of the genetic test; (2) support services for Down syndrome, such as hotlines, resource centers, and clearinghouses; and (3) alternatives to abortion.

The Missouri statute largely echoes the federal Act and similarly lacks specificity. First, it makes no mention of supplying women with hard copies of information. Second, it forces the information upon the expectant mother

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[102] *Mothers Reflect*, *supra* note 99, at 70; *Mothers Continued Pregnancies*, *supra* note 99, at 670–77. ("Mothers were most optimistic when their physicians talked about the positive aspects of DS and provided them with up-to-date printed materials.").

[103] *See infra*, Section V.

[104] MO. ANN. STAT. § 191.923 (West 2011).

instead of giving her the option of receiving the information. The intent[105] behind the Missouri statute focuses both on the fetus and informed consent, yet it does not aim to make the woman's load any lighter. The Missouri statute may very well overwhelm a woman with resources she does not want. Thus, the language of the statute carries out Missouri's objectives, but does so in a way that constrains a woman's freedom of choice. Third, it does not appear that Missouri requires healthcare providers to give expectant mothers comprehensive information on Down syndrome; instead, the Missouri statute requires healthcare providers to give women contact information for resources that have information on Down syndrome. In essence, the expectant mother would be receiving a list of phone numbers and not actual concrete information about Down syndrome. While telephone numbers for resources may be useful, they need to be accompanied by up-to-date, comprehensive information about bringing a child with Down syndrome into the family. Lastly, Missouri's law fails to build upon the federal Act because it lacks increased specificity and requirements.

In 2010, New Jersey proposed its own Prenatally and Postnatally Diagnosed Conditions Awareness Act ("the New Jersey statute").[106] Under

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[105] "The general assembly of the state of Missouri hereby finds and declares that pregnant women who choose to undergo prenatal screening should have access to timely and informative counseling about the conditions being tested for, the accuracy of such tests, and resources for obtaining support services for such conditions. Informed consent is a critical component of all genetic testing and prenatal screening, particularly as the results of such testing or screening and the counseling that follows may lead to the unnecessary abortion of unborn humans with Down Syndrome or other prenatally diagnosed conditions." *Id.*

[106] "The Legislature finds and declares that it is in the public interest to increase patient referrals to providers of supportive services to new or expecting parents who receive positive test results of a test for Down syndrome and other prenatally or postnatally diagnosed conditions, to provide these parents with up-to-date information on the range of outcomes for persons living with the diagnosed condition, to strengthen support services, and to provide these parents with information about the accuracy of the

the New Jersey statute, the state will establish support services including: (1) a telephone hotline; (2) an official department website; (3) local peer support programs; (4) current information about the "range of outcomes" for individuals with Down syndrome; and (5) "awareness and education programs" for health care professionals providing results and diagnoses to parents.[107] When an expectant mother receives a positive prenatal diagnosis of Down syndrome in New Jersey, healthcare providers must supply expectant parents with (1) current, written information about the potential range of outcomes for children with Down syndrome, (2) a referral to support services, (3) contact information relating to peer support programs, (4) "information about registries of families willing to adopt newborns with Down syndrome," and (5) information about accessing the telephone hotline and website.[108]

The New Jersey statute includes particularized details. For example, New Jersey specifically requires both written information and online resources for its citizens.[109] This solves the potential problem of disadvantaging patients without computers. As opposed to being told what to do by a physician, putting the information directly in the patient's hands empowers the patient with knowledge and leaves the decision up to her and her family. It does not require her to scour the Internet for information. Alternatively, women and their families may prefer to look at a website for information on their own time. Expectant mothers should be given the option of perusing written and online materials, and the information should be available in both forms. Like the federal Act, the New Jersey statute emphasizes the importance of stressing the *range* of capabilities a child with Down syndrome may acquire. This helps to dispel the misconception that all individuals with Down syndrome are severely mentally and physically impaired. The New Jersey statute does not neglect to include continuing education for healthcare professionals.

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testing for these conditions." S. 1399, 214th Gen. Assem., Reg. Sess. (N.J. 2010).

[107] *Id.*

[108] *Id.*

[109] *Id.*

Like the Missouri statute and federal Act, the New Jersey statute is also insufficient. The actual language of the New Jersey statute does not satisfactorily and comprehensively support its intent.[110] The overarching goal of the statute is to assist expectant parents in making an informed decision and thus allowing them to feel confident about their decision. Increased access to information allows for knowledge and corresponding power to make a good choice on an individual level. This increased information will also ideally protect the Down syndrome community. Similar to Missouri's law, the New Jersey statute forces women to take information instead of giving her the option of accepting the information. It mandates giving the expectant mother information about Down syndrome after she has received a prenatal diagnosis. It may be better to supply a woman with this information following prenatal screening for Down syndrome, allowing her and her family more time to consider raising a child with Down syndrome, to fully research Down syndrome, and to talk with a genetic counselor. Finally, the statute should refer expectant mothers of babies with Down syndrome to genetic counselors and should account for the fact that some women may not be able to afford genetic counseling.

Alabama's 2009 statute ("the Alabama statute") differs markedly from the statutes above, as does its intent.[111] The Alabama statute requires that public universities (the University of Alabama in Birmingham and the University of South Alabama) expand their medical genetics programs "to

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[110] "The Legislature finds and declares that it is in the public interest to increase patient referrals to providers of supportive services to new or expecting parents who receive positive test results of a test for Down syndrome and other prenatally or postnatally diagnosed conditions, to provide these parents with up-to-date information on the range of outcomes for persons living with the diagnosed condition, to strengthen support services, and to provide these parents with information about the accuracy of the testing for these conditions." *Id.*

[111] "It is declared to be the policy of this state to identify families who have members with genetic disorders that cause birth defects and mental retardation. A part of this policy shall be to encourage prevention of birth defects and mental retardation through education, genetic counseling and amniocentesis when applicable." ALA. CODE § 22-10A-2 (2011).

provide diagnostic facilities, genetic counseling and prenatal testing for genetic disorders."[112] Under the Alabama statute, both universities must (1) "[d]evelop an education program designed to educate physicians and the public concerning genetic disorders and the availability of this program;" (2) "[a]ssure that genetic counseling is available to those Alabama families who need it" (families who have a member with a birth defect, intellectual disability, or other handicapping disorder due to genetic factors, as well as families identified by screening to be at increased risk for having a child with one of these problems); and (3) "[f]ormulate a graduated fee schedule, based on the ability of the patient to pay, to offset the costs of the program."[113] Furthermore, both universities must expand their programs to "assist private physicians and clinics of the Department of Public Health, the State Crippled Children's Service and the Department of Mental Health in referring affected members and their families to the program."[114]

The Alabama statute focuses on availability of genetic testing and counselors for patients of all economic levels. Thankfully, it diverges from its stated policy of prevention and advocates patient autonomy through non-directive genetic counseling. The Alabama statute strongly promotes continuing education and stresses the importance of informed physicians who deliver diagnoses. Alabama promotes the medical progress of genetic testing and provides its citizens with greater information and choice through its public universities. It is also careful to administer testing with ethical checks, safeguarding scientific progress with an appropriate amount of discretion via genetic counselors. This prevents overzealous doctors from imposing personal opinions upon their patients.[115]

Yet, the Alabama statute lacks key components. It fails to offer expectant mothers written and online information regarding Down syndrome. While genetic counselors can greatly assist women and their families, giving

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[112] *Id.*

[113] *Id.*

[114] *Id.*

[115] *See infra* notes 133–34 and accompanying text.

information directly to the patient is important because it allows her an opportunity to think through her situation and her options on her own and privately with her family.

In 2007, Virginia enacted the Routine Component of Prenatal Care statute ("the Virginia statute"). The Virginia statute establishes several requirements that apply to diagnosing Down syndrome prenatally.[116] It requires physicians to provide expectant mothers specific information about Down syndrome, but does not require referrals to support services such as hotlines and websites.[117] Virginia delineates the specific information that it requires healthcare professionals to provide: "up-to-date, scientific written information concerning the life expectancy, clinical course, and intellectual and functional development and treatment options for an unborn child diagnosed with or child born with Down syndrome."[118]

On the other hand, the Virginia statute lacks many important provisions. Referrals to support services and genetic counselors are discretionary. This is unfortunate, as bare scientific facts regarding Down syndrome will do little to help an expectant parent gain a holistic perspective on raising a child with Down syndrome. Because healthcare professionals in Virginia are only required to provide patients with scientific information, Virginia's expectant mothers will be deprived of arguably more important first-hand information that only parents and relatives of individuals with Down syndrome may be able to provide.

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[116] VA. CODE ANN. § 54.1-2403.01 (West 2011).

[117] *Id.*

[118] *Id.*

V. ALL STATES SHOULD ENCOURAGE EXPECTANT PARENTS TO MAKE INFORMED DECISIONS ABOUT RAISING A CHILD WITH DOWN SYNDROME

A. MODEL STATUTE

A model statute is a suggested draft of a law that any state may adopt. It provides uniformity, may combine ideal provisions of multiple laws and also reduces costs associated with drafting and passing legislation. States particularly need a model statute on this topic because so few states have enacted a similar statute thus far. The Model Statute ("Model Statute") I propose synthesizes and integrates the federal Act as well as laws in Missouri, New Jersey, Alabama and Virginia. Each of these statutes contributes different positive aspects, but each is insufficient on its own. In order to aid women during a difficult time, to discourage directive counseling on the part of doctors, and to protect individuals with Down syndrome, states should enact the following law:

(a) All doctors screening prenatally for Down syndrome shall offer the patient the following written information:

(1) Information from Down syndrome support groups composed of parents and relatives of individuals with Down syndrome regarding raising a child with Down syndrome;

(2) Accurate, comprehensive and current information about Down syndrome and the range of mental and physical capabilities an individual may have;

(3) Phone numbers and resources for hotlines (of willing parents who currently are raising or who have raised children with Down syndrome), genetic counselors, adoption agencies, and support services such as local family support groups; and

(4) Access to a state website particularly designed for an expectant parent of a child with Down syndrome. The website shall include all of the above information in subparagraphs (1)-(3).

(b) In addition to offering patients the information in paragraph (a), doctors shall personally refer patients to a specific local genetic counselor or genetic counseling service. A financing plan such as a graduated fee schedule shall be arranged for patients who cannot afford genetic counseling.

(c) The state shall also encourage continuing education classes for healthcare professionals interested in gaining knowledge and skill about delivering Down syndrome diagnoses.

B. WHY IS THIS STATUTE IDEAL?

The introduction to section (a) mandates that all doctors who screen prenatally for Down syndrome offer expectant mothers information relating to raising an individual with Down syndrome. The introduction to section (a) is important for three reasons. First, it engages doctors who *screen* prenatally for Down syndrome. Thus, the statute requires those doctors to offer expectant mothers information prior to a prenatal diagnosis of Down syndrome. Research demonstrates that women would prefer to receive the information at this point in the diagnostic process.[119] Supplying women with information following screening allots them additional time to read about and think through raising an individual with Down syndrome. It may also be a more opportune time to discuss implications of having a fetus with Down syndrome with one's family and to seek genetic counseling, so as to begin a discussion sooner.[120] Second, the language of "offer" is important. "Offer" implies choice on the part of the expectant mother. If a mother chooses not to take the information because it does not interest her or because she has already made her choice, doctors need not force the information upon her. Doing so may make an already difficult situation worse. Third, the beginning of section (a) stipulates the format of the information to be given: written. Like the New Jersey statute, it is important to ensure the information is written and physically placed in the hands of the expectant mother if so desired. Merely handing a patient a list of telephone numbers or referring her to a website is not enough. Some women may prefer written information and others may prefer to browse the Internet on their own. Thus, healthcare providers should afford them both options.

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[119] *Mothers Continued Pregnancies*, *supra* note 99, at 670, 674.

[120] *Id.*

Section (a)(1) requires that information derive from families who have children with Down syndrome. Empirical and scientific information cannot begin to express the everyday experiences of families who have children with Down syndrome. Many parents who have children with Down syndrome believe that raising a child with Down syndrome is quite similar to raising a child without Down syndrome.[121] Some expectant parents worry about the burden their other children will bear by growing up with a sibling with Down syndrome.[122] These parents fear that focusing a disproportionate amount of attention on their child with special needs would be unfair to their other children.[123] To the contrary, siblings of individuals with Down syndrome are taught valued qualities of selflessness, responsibility, tolerance, and compassion.[124]

Section (a)(2) requires healthcare providers to provide women with up-to-date and comprehensive scientific information about Down syndrome. Such information is an indispensable aspect of informing expectant parents about Down syndrome and corresponding health implications.[125] Furthermore, expectant parents should know about the *range* of potential their future child might have.[126]

Section (a)(3) echoes the federal Act, the Missouri statute, and the New Jersey statute. Phone numbers, hotlines, genetic counselors, adoption agencies, and support services are all invaluable to increasing expectant

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[121] *See* Priya Lalvani, *Mothers of Children with Down Syndrome: Constructing the Sociocultural Meaning of Disability*, 46.6 INTELL. & DEVELOPMENTAL DISABILITIES 436, 436 (2008) (noting that although traditional research on Down syndrome "pointed to predominantly negative outcomes for parents," researchers are now turning to parents directly for feedback and are drawing opposite conclusions).

[122] *See generally* WINCIK, *supra* note 1.

[123] *See* Lalvani, *supra* note 121.

[124] *Id.* at 441.

[125] *See infra* notes 23–27 and accompanying text.

[126] *See infra* notes 18–22 and accompanying text.

parents' knowledge about Down syndrome. Phone numbers and hotlines for current parents of children with Down syndrome can contribute first-hand knowledge about raising a child with Down syndrome. Genetic counselors can also lend support to families and help them make decisions in a non-directive manner.[127] Adoption agencies are an important tool for expectant mothers in case they wish to carry the baby to term, but would prefer not to raise an individual with Down syndrome. Finally, support systems allow expectant parents to explore opportunities for their potential child at all stages of life.[128]

Finally, section (a)(4) grants expectant parents the opportunity to browse comparable information online and at a time that is convenient for them.

Section (b) mandates that doctors refer patients to a specific local genetic counselor or genetic counseling service. Recent research suggests that healthcare professionals are fueling the phenomenon that is driving Down syndrome to extinction.[129] Doctors contribute to this phenomenon through the

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[127] *See infra* notes 47–53 for a discussion of genetic counselors and nondirectiveness; *see also* Brian G. Skotko, *Words Matter: The Importance of Nondirective Language in First-trimester Assessments for Down Syndrome*, 195 AM. J. OBSTETRICS & GYNECOLOGY 625–26 (2006); Dixon, *supra* note 4.

[128] ELEMENTARY AND SECONDARY EDUCATION: SCHOOLING FROM PRESCHOOL TO 21, NAT'L DOWN SYNDROME SOC'Y, http://www.ndss.org/index.php?option=com_content&view=article&id=58&Itemid=83&limitstart=1 (last visited Mar. 16, 2012). Numerous public and private support systems are available for individuals with Down syndrome and their families at little or no cost. For example, the Individuals with Disabilities Education Act "mandates that local school districts provide a free, appropriate, public education for preschool-age children with disabilities starting at the age of 3."

[129] *See* Skotko, *supra* note 3, at 823, 825; WINCIK, *supra* note 1, at 22–23; Diehr, *supra* note 4, at 1287; Long, *supra* note 4, at 203; Dixon, *supra* note 4, at 3.

negative approach they use in delivering diagnoses to expectant mothers.[130] Once doctors realize that a pregnant woman's fetus has Down syndrome, many doctors will automatically assume that the woman does not want the child.[131] Accordingly, the doctor will approach the patient and deliver the news in an inappropriate manner, both ethically and with poor word choice.[132] Some will say, "Unfortunately, I have some bad news for you."[133] Doctors often suggest that the mother terminate the current pregnancy and try again for a "normal" baby.[134] When doctors approach patients in this way, they are being directive and suggesting the solution.[135] In a study of 499 physicians, thirteen percent admitted that they "overemphasiz[e] the negative aspects of DS in hopes pregnant women would seek a termination," and ten percent admitted that they "actively 'urge' mothers to terminate."[136] This practice abrogates a patient's autonomy and takes away her ability to accurately and completely think through this unexpected situation.[137] Often, patients will simply follow doctors' advice because they are doctors.

Section (b) is similar to portions of the Alabama statute.[138] Often, genetic counselors are better equipped to discuss this type of situation with a patient than doctors, as doctors often have little to no education in non-

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[130] *See* Skoto, *supra* note 3, at 825; Diehr, *supra* note 4, at 1302; Long, *supra* note 4, at 218; Dixon, *supra* note 4, at 39.

[131] *See* Skoto, *supra* note 3, at 825; Diehr, *supra* note 4, at 1302; Long, *supra* note 4, at 218; Dixon, *supra* note 4, at 39.

[132] *See* Skoto, *supra* note 3, at 825; Diehr, *supra* note 4, at 1302; Long, *supra* note 4, at 218; Dixon, *supra* note 4, at 39.

[133] Dixon, *supra* note 4, at 4.

[134] *See* Skoto, *supra* note 3, at 825; Diehr, *supra* note 4, at 1302; Long, *supra* note 4, at 218; Dixon, *supra* note 4, at 39.

[135] *Id.*

[136] Skotko, *supra* note 3, at 823, 825.

[137] *Id.* at 824.

[138] ALA. CODE § 22-10A-2 (2011).

directive counseling.[139] Genetic counselors may also be more receptive and sensitive to a patient's fears and concerns—issues that doctors may not anticipate. Furthermore, genetic counseling services should arrange a financing plan for patients who cannot immediately afford their services, since insurance may not cover genetic counseling, and since all socio-economic classes should be afforded this assistance. For example, a graduated fee schedule could allow patients who cannot pay fully up-front to pay in installments.

Finally, section (c) requires that the state encourage continuing education classes for healthcare professionals interested in gaining knowledge and skills about delivering Down syndrome diagnoses. A related problem that needs to be addressed is physicians' lack of education in delivering prenatal diagnoses of genetic anomalies. In a survey of 2,500 medical students, deans, and residency directors, 81% reported that they received no training in regards to individuals with intellectual disabilities. Similarly, "[i]n a questionnaire completed by 532 ACOG [American College of Obstetricians and Gynecologists] fellows and junior fellows in 2004, 45% rated their training regarding how to deliver a prenatal diagnosis as 'barely adequate or nonexistent,' and only 28% felt 'well-qualified' in general prenatal genetic counseling."[140] While genetic counseling is not necessarily the job or duty of obstetricians or gynecologists, they still need to learn how to be sensitive to an expectant mother's situation and how to be non-directive in what little communication they have with an expectant mother relating to the prenatal diagnosis. Furthermore, this strengthens the need for referrals to genetic counselors who are much better equipped than physicians to assist expectant mothers in decision-making and nondirective counseling.

Section (c) is largely self-executing and self-promoting in that the statute itself is the mechanism for encouragement. Ideally, section (c) would

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[139] *See* Skotko, *supra* note 3, at 823; *see generally* Brian G. Skotko, Priya S. Kishnani & George T. Capone, *Prenatal Diagnosis of Down Syndrome: How Best to Deliver the News*, AM. J. MED. GENETICS 2361 (2009).

[140] Skotko, *supra* note 3, at 824–25.

motivate state medical boards and state medical associations to offer continuing education classes. Since the state recommends such a course of action via the statute itself, hopefully these groups would detect the need for continued education in this realm. This also helps mitigate potential issues of cost and efficiency by saving state tax dollars and by encouraging the appropriate, knowledgeable groups to act.

C. POTENTIAL FIRST AMENDMENT CONCERNS

One potential concern with a statute of this nature deals with the First Amendment, specifically the patient-physician relationship and a doctor's right to freedom of speech.[141] Judging from the vast array of constraints states currently place on abortion, a law mandating information for expectant parents most likely would not be a problem under the First Amendment. First of all, information provided by the Model Statute would be unbiased information, unlike many state statutes restricting abortion.[142] Second, states would not demonstrate a preference for carrying a fetus to term over abortion; rather, states would be advocating for and preferring expectant parents to make informed decisions. The information will assist parents with an important decision and will give them confidence in their decision. This is also different from many of the biased state restrictions on abortion.[143] Third, the Model Statute requires physicians to offer information to their patients and not to force it upon them. This helps preserve the physician-patient relationship founded on trust. Finally, both the federal government and state governments have already enacted similar laws, which should give other states confidence in the practicality and constitutionality of the laws.

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[141] *Cf.* Rebecca Dresser, *From Double Standard to Double Bind: Informed Choice in Abortion Law*, 76 GEO. WASH. L. REV. 1599, 1604–15, 1620 (2008) (discussing how abortion-specific informed consent laws provide too much biased information for women, which threatens the physician-patient relationship).

[142] *See* discussion *supra* Part III.

[143] *Id.*

D. POSSIBLE ISSUES OF COST AND ENFORCEMENT

States could fund the Model Statute's mandates in a number of ways. States could engage state tax dollars to fund the collection of up-to-date information and establishment of a state website. Alternatively, national or local Down syndrome advocacy and support groups would likely compile and supply the information for free.[144] Individual healthcare facilities could fund the nominal costs of providing written information (paper and ink for printing information from the state website). And as suggested above, state medical boards or associations could fund classes.

State medical boards could ensure enforcement of a law like the Model Statute.[145] Aside from tort and criminal law, the practice of medicine is largely a self-regulating profession. Unless an individual files a complaint with the state medical board, states presume that physicians are complying with state regulations.[146] Both patients and fellow physicians may report complaints to state medical boards if they suspect malfeasance. A state medical board will then investigate the complaint and punish the physician if necessary.[147] Depending on the severity of the offense, punishment could entail a reprimand, probation, suspension, or license revocation.[148] Resorting to criminal or tort law could impose serious issues of cost on states[149] and

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[144] *See, e.g.*, *supra* note 102.

[145] FEDERATION OF STATE MEDICAL BOARDS, STATE OF THE STATES PHYSICIAN REGULATION 3–6 (2009), *available at* http://www.fsmb.org/pdf/2009_state_of_states.pdf (last visited Mar. 14, 2012).

[146] *Id*. at 19.

[147] *Id.*

[148] *See, e.g.*, STATE MEDICAL BOARD OF OHIO, *FY09 Annual Report* 18–19 (2009), *available at* http://www.med.ohio.gov/pdf/Annual%20reports/2009AnnualReport.pdf, (last visited Mar. 14, 2012).

[149] For example, hiring individual investigators to ensure the law is being enforced could pose substantial, unnecessary funding issues for a state.

burdens on physicians.[150] Self-regulation via state medical boards should sufficiently enforce a law like the Model Statute.

CONCLUSION

When expectant parents receive a prenatal diagnosis of Down syndrome, they need access to accurate, complete, and up-to-date information about the condition in order to decide whether to carry their pregnancy to term. Likewise, the possibility of raising an individual with Down syndrome deserves respect and consideration, as research shows that ninety-two percent of prenatal diagnoses of Down syndrome end in abortion.[151] When expectant parents decide to abort a fetus with Down syndrome, it is their choice and a choice that comes with consequences for the Down syndrome community. Thus, it should be a well-informed decision, assisted by access to comprehensive information on the condition, genetic counselors, and other support services. The free flow of information will allow parents to feel confident about the decision they make. It may also incidentally protect the Down syndrome community and propagate support systems and programs for those with Down syndrome. States can and should aid in these goals by enacting statutes based on the Model Statute. State action will undoubtedly help to ensure that expectant parents of individuals with Down syndrome make educated choices—choices that are not based on fear, ignorance, or prejudice.

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[150] A law like the Model Statute is meant to help the patient and not to burden physicians with fears of lawsuits.

[151] Skotko, *supra* note 3, at 823.