Strange bedfellows: anti-abortion and disability rights advocacy

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To characterize the atmosphere surrounding abortion in the United States as a contentious one would be an understatement: few other social issues have inspired such vitriolic rhetoric, divisive legislation, and overt acts of violence as those wrought by pro-life extremists. Though the fight over how and when a woman should be able to terminate a pregnancy has been ongoing, the crusade against abortion has recently taken an innovative twist as pro-life advocates have begun to craft legislation that uses disability rights as a smokescreen to further their cause. In 2016, two states attempted to roll out sweeping pieces of legislation that criminalize abortion when it is sought because of a ‘genetic abnormality’ in the fetus: Louisiana’s House Bill 1019 (HB 1019) and Indiana’s House Enforced Act 1337 (HEA 1337) were passed in April and June of 2016, respectively; however, both laws were enjoined by a Federal judge shortly after passage and are temporarily blocked from taking effect.

Because laws such as these purport to, in theory, protect the lives of individuals with disabilities, traditionally conservative pro-life advocates now paradoxically find themselves on the same side of the abortion debate as traditionally liberal disability rights advocates. In practice, however, laws that criminalize abortion on the basis of genetic abnormality simply carry the veneer of enhancing the position of disabled individuals in society as a means to a very specific end—to discourage abortion. This paper will

1 HLS 16RS-2023 House Bill No. 1019, Abortion: Prohibits Abortion Based on Genetic Abnormality. https://www.legis.la.gov/legis/ViewDocument.aspx?d=996372 (accessed Aug. 29, 2016).
2 Guttmacher Institute, Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly. https://www.guttmacher.org/state-policy/explore/abortion-bans-cases-sex-or-race-selection-or-genetic-anomaly (accessed Aug. 29, 2016).
discuss the various ways in which states have politicized disability rights as a means of legislating key aspects of the patient–doctor encounter.

THE CONTROVERSIAL NATURE OF PRENATAL TESTING

Advances in the field of medical genetics have only relatively recently made it possible to detect abnormalities in a fetus through prenatal genetic diagnosis: it has been possible to detect chromosomal abnormalities like Down syndrome through the sampling of amniotic fluid, or amniocentesis, only since the 1960s. Prior to that time, the only possible way to identify a hereditary birth defect was after an affected individual had already been born and the only available solution for preventing subsequent recurrences of the defect was simply to stop having children. After accurate human karyotyping (ie the technology that allows us to visualize an individual’s chromosomes) became possible in the 1950s, it was discovered that some birth defects caused by an abnormal number of chromosomes could be identified relatively easily; therefore, screenings for chromosomal abnormalities became more widespread as technology advanced, with screenings for Down syndrome in particular becoming systematic in the 1990s. Currently, it is possible to both screen for and diagnose many heterogeneous conditions via different techniques, one of which (cell-free fetal DNA testing) can yield results even as early as after 9 weeks of gestation.

Within the world of prenatal genetic testing, there already exists an inherent tension between facilitating reproductive choice and preventing the birth of children with disabilities. Advocates of prenatal diagnosis assert that it gives a woman the right to freely choose whether or not she wishes to give birth to a disabled child. Conversely, critics of prenatal diagnosis argue that the process itself is eugenic in nature, and that the decision to terminate a pregnancy of a child deemed ‘defective’ is ‘morally problematic, and...driven by misinformation’. Throughout the prenatal diagnosis process, a woman is presumably under the auspices of a genetic counselor: a ‘neutral’ medical professional who is able to provide the information necessary in order for the woman to reach the most appropriate decision. Bioethicist Arthur Caplan describes the role of genetic counselors:

The ethical norm governing genetic counselors involved in testing and screening for genetic conditions related to reproduction has been strict neutrality since the early 1970s: doctors and counselors were obligated to simply provide people with information to help them make decisions without actually guiding them toward a particular decision. What patients do with test results in terms of deciding whether to have a child or to

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3 Ilana Löwy, *How Genetics Came to the Unborn: 1960–2000*, 47 STUD. HIST. & PHIL. SCI. PART C: STUD. HIST. & PHIL. B I O L. BIOMED. SCI. 154–62 (2014).
4 Id.
5 Ilana Löwy, *Prenatal Diagnosis: The Irresistible Rise of the ‘Visible Fetus’,* 47 STUD. HIST. & PHIL. B I O L. BIOMED. SCI. 290–99 (2014).
6 American College of Obstetricians and Gynecologists Society for Maternal-Fetal Medicine, Committee Opinion—Cell-free fetal DNA Screening for Fetal Aneuploidy, http://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Genetics/Cell-free-DNA-Screening-for-Fetal-Aneuploidy (accessed Sept. 23, 2016).
7 Erik Parens & Adrienne Asch (eds), *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in P R E N A T A L T E S T I N G A N D D I S A B I L I T Y R I G H T S (2000).
continue a pregnancy after a diagnosis of Down syndrome, counselors were taught, is strictly up to them.\(^8\)

The tenets of nondirectiveness and noncoerciveness that are central to the genetic counseling profession were largely adopted due to previous eugenic practices, and were intended to prevent ‘coercion of reproductive decisions for an individual or couple whose fetus is found to be affected with a certain condition’.\(^9\) In practice, however, it has been argued that the offer of prenatal genetic testing itself is inherently biased. Though screening and diagnostic techniques have greatly advanced, treatments for most diagnosed conditions have not, placing before the mother a potentially disturbing decision: The only viable ‘treatment’ option for a fetus found to have a genetic abnormality has remained termination of the pregnancy.

While prenatal screening was previously only offered to women thought to be at risk of having a child with a disability, in 2007 the American College of Obstetricians and Gynecologists (ACOG) amended its guidelines on chromosomal abnormalities to recommend that all pregnant women in the first trimester of pregnancy be screened for certain biochemical markers associated with risk of their fetus having Down syndrome as well as other chromosomal abnormalities and defects.\(^10\) This recommendation effectively ‘places in the path of every pregnant woman the possibility of facing a decision about the continuation of her pregnancy based on the presence of a birth anomaly’.\(^11\)

As the profession of genetic counseling has evolved, a paradigm shift has occurred from strict nondirectiveness of the counselor to acknowledgement of the need for more flexible approaches to counseling based on ‘client and family needs and values, clinical circumstances, and desired counseling outcomes’ more reflective of patient choice.\(^12\) Perhaps in order to address this shift within the field, the ACOG released this statement following publication of their 2007 guidelines on chromosomal abnormalities:

We are not recommending that all pregnant women be screened, but rather we are recommending that all pregnant women be offered screening. Physicians are ethically obligated to fully inform our patients of their health care options, including prenatal testing. Therefore, it is entirely up to the patient to decide whether or not she wishes to be screened for fetal chromosomal abnormalities without judgment from the physician.\(^13\)

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\(^8\) Arthur L. Caplan, *Chloe’s Law: A Powerful Legislative Movement Challenging a Core Ethical Norm of Genetic Testing* 13 PLoS Biol. e1002219 (2015).

\(^9\) Barbara Bowles Biesecker & Lori Hamby, *What Difference the Disability Community Arguments Should Make for the Delivery of Prenatal Genetic Information*, in *Prenatal Testing and Disability Rights* (Erik Parens & Adrienne Asch eds., 2000).

\(^10\) Amy J. Sehnert et al., *Optimal Detection of Fetal Chromosomal Abnormalities by Massively Parallel DNA Sequencing of Cell-Free Fetal DNA From Maternal Blood*, *57 Clin. Chem. 1042–49* (2011).

\(^11\) Nancy Anne Press & Carole H. Browner, *Collective Silences, Collective Fictions*, in *Women And Prenatal Testing: Facing The Challenges Of Genetic Technology* (Karen H. Rothenberg ed., 1994).

\(^12\) Jon Weil et al., *The Relationship of Nondirectiveness to Genetic Counseling: Report of a Workshop at the 2003 NSGC Annual Education Conference*, *15 J. Genet. Counsel. 85–93* (2006).

\(^13\) American College of Obstetricians and Gynecologists, *ACOG’s Screening Guidelines on Chromosomal Abnormalities*, [http://www.acog.org/About-ACOG/News-Room/News-Releases/2007/ACOGs-Screening-Guidelines-on-Chromosomal-Abnormalities](http://www.acog.org/About-ACOG/News-Room/News-Releases/2007/ACOGs-Screening-Guidelines-on-Chromosomal-Abnormalities) (accessed Aug. 29, 2016).
Because patient–doctor interactions are rarely fully autonomous, and the option of prenatal testing is, in many cases, presented in the context of a lack of viable treatment options, some fear that the offer to test may unintentionally bias the patient toward abortion (even if the medical professionals embrace an inherent commitment to patient autonomy). However, even though the process of undergoing prenatal genetic testing may not be as nondirective in practice as in theory, restricting reproductive rights through not offering testing damages the practice of medicine and the doctor–patient relationship as it does not allow a mother to consider the possibility of making a fully informed autonomous decision regarding her pregnancy. Legislation restricting and mandating surveillance of encounters between a patient and a medical professional is contraindicative to the tenets of autonomy, beneficence, nonmaleficence, and justice that are foundational in Western medical ethics. Additionally, restricting abortion in the name of affirming the dignity of and protecting individuals with disabilities provides pro-life activists an easy way to galvanize support for further restrictions on abortion without actually providing tangible support for individuals with disabilities to succeed in a world that is not amenable, and oftentimes hostile, to their disabilities after their birth.

**STATE LAWS RESTRICTING ABORTION ON THE BASIS OF GENETIC ABNORMALITY**

In March 2016, Indiana became the second state to prohibit abortion for reasons that the fetus may have a genetic abnormality with the passage of HEA 1337. In 2013, North Dakota was the first state to prohibit abortion based on potential fetal abnormality, even if the fetus were to have a condition ‘making it incompatible with life’. Similarly, HEA 1337 goes further than the North Dakota law to prohibit abortions of fetuses performed solely for the reason that ‘the fetus has been diagnosed with a disability or has the potential diagnosis of a disability, or solely because of the fetus’s race, color, national origin, ancestry, or sex’. Indiana’s abortion laws were already some of the most restrictive in the country: abortion is illegal after 20 weeks of gestation (or 22 weeks after a woman’s last menstrual period) and any prospective abortion requires mandatory state-directed counseling, as well as an ultrasound. Indiana Governor Mike Pence’s office has described this bill as a ‘comprehensive pro-life measure that affirms the value of all human life’.

Legislation such as Indiana’s HEA 1337 undermines the doctor–patient relationship and puts an undue burden on health care professionals to police a woman’s reproductive choices. The passage of legislation that restricts the interaction between a pregnant patient and her medical professional upends the state-sanctioned confidentiality within that interaction. Furthermore, it inappropriately injects a pro-life moral imperative into a clinical interaction, and directly challenges the tenets of autonomy and reciprocal

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14 National Society of Genetic Counselors. *National Society of Genetic Counseling Code of Ethics,* http://nsgc.org/p/cm/ld/fid=12 (accessed Aug. 29, 2016).
15 Theodore Schleifer, *Indiana Gov. Mike Pence Signs New Abortion Restrictions Into Law,* CNN NEWS, http://www.cnn.com/2016/03/24/politics/mike-pence-indiana-disability-abortion/index.html (accessed May 29, 2016).
16 Guttmacher Institute, *supra* note 2.
17 Indiana General Assembly, *House Enrolled Act No. 1337,* https://iga.in.gov/static-documents/5/1/b/5/51b52d50/HB1337.05.ENRS.pdf (accessed May 6, 2016).
patient engagement (or shared decision making) in prenatal genetic testing. Because a woman seeking an abortion within the legal timeframe of 20 weeks post-gestation is not required to tell a doctor why exactly she is seeking an abortion, this law is effectively unenforceable; however, instead of fostering a trusting relationship between doctor and patient, it creates an adversarial, or at least fettered, one. Fearing punishment under this law, a woman receiving a prenatal diagnosis of potential disability may actually be discouraged from seeking the resources necessary to make an informed choice from her physician: if a medical professional can ‘turn her in’ for wanting an abortion, she therefore has no incentive to discuss her decision. Instead of incentivizing the kind of honest patient–doctor discourse necessary to discuss the realities of caring for a child with a disability, these laws have the potential to hurt both mother and child by injecting shame and fear of punishment into an already emotionally charged situation.

OTHER LAWS LEGISLATING PATIENT–DOCTOR COMMUNICATION
A less overtly restrictive type of law has recently been passed in several states that affects patient–doctor communication in the realm of prenatal diagnosis of Down syndrome in particular. The Pennsylvania Down Syndrome Prenatal Education Act (also known as Chloe’s Law) was passed in 2014 at the behest of the father of an 11-year-old girl with Down syndrome who thought that abortions performed on fetuses at risk of having Down syndrome might be due to a lack of information on the ‘positive’ aspects of raising a child with the condition and sought to make sure information given to pregnant women regarding Down syndrome was fair and balanced through the passage of legislation.

Passed by an overwhelming majority, Chloe’s Law mandates that the ‘Pennsylvania Department of Health…make available up-to-date, evidence-based information about Down syndrome that has been reviewed by medical experts and national Down syndrome organizations’.18 This information would include information regarding ‘physical, developmental, educational and psychosocial outcomes; life expectancy; clinical course; intellectual and functional development; treatment options; and contact information for First Call programs, support services, hotlines specific to Down syndrome, relevant resource centers, clearinghouses and national and local Down syndrome organizations’.19 Although Chloe’s Law and the eight other pieces of legislation that are modeled after it in other states strive for neutrality on their face, the state of Pennsylvania essentially seeks to upend the ethical norms of autonomy and patient centeredness in genetic counseling and prenatal diagnosis by mandating that certain information be provided regarding Down syndrome during the doctor–patient interaction. The Institute of Medicine defines patient-centered care as ‘care that is respectful and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions’.20 Although the information is published by the state, it is collected from organizations with a certain message in mind and there is a natural

18 Pennsylvania General Assembly. Down Syndrome Prenatal Education Act (Chloe’s Law), http://www.legis.state.pa.us/cfdocs/billinfo/billinfo.cfm?year=2013&sind=0&body=H&type=B&bn=2111 (accessed May 5, 2016).
19 Id.
20 Somnath Saha, Mary Catherine Beach & Lisa A. Cooper, Patient Centeredness, Cultural Competence and Healthcare Quality, 100 JAMA 1275 (2008).
concern that laws mandating certain patient–physician communications bias what information patients receive.

**INTERSECTION OF PRO-LIFE AND DISABILITY ADVOCACY**

Disability rights advocates argue that it is not the limitations caused by disability itself but societal discrimination against individuals with disabilities that constitutes the major problem; therefore, it is imperative that individuals with disabilities and their caregivers have access to the support necessary to overcome the challenges of living in a society that may not meet their needs. Though pro-life advocates’ hardline stance against abortion is at first glance couched in this social model of disability, such advocates often actively oppose funding for social service programs for the disabled. As Suratha Jesudesan and Julia Epstein note:

> Anti-choice advocates tend to idealize disability while opposing the entitlement programs and government funding of social services, such as state developmental disability programs, funding for the Individuals with Disabilities Education Act, and the access mandates of the Americans with Disabilities Act that would make raising a child with a disability more possible.22

While the laws restricting abortion on these so-called moral grounds purport to affirm the status of individuals with disabilities, they unfortunately do very little to support disabled individuals or their caregivers following birth. Legislation that criminalizes abortion on the basis of a genetic abnormality presumably seeks to increase the number of individuals that are born with disabilities (by outlawing their ability to be aborted); however, somewhat paradoxically, neither of these laws include any provisions that will provide the disabled individuals they wish to prevent from being aborted or their families with the tools necessary to ensure their well-being or the social support necessary for them to flourish in their respective communities.

**STRANGE, BUT PERHAPS INEVITABLE, BEDFELLOWS**

The issues of abortion and disability rights have become deeply intertwined in recent years, making them strange, but perhaps inevitable, bedfellows. In order to limit a woman’s right to autonomy in her reproductive health choices, pro-life activists have politicized the experiences of disabled individuals to build momentum for abortion restrictions by seeking to proclaim ‘the value of all life, including individuals with and without disabilities’.23 Paradoxically, the traditionally conservative pro-life movement’s goals align with traditionally progressive disability rights groups’ stance that selective abortion based on disability is morally problematic. Laws that criminalize abortion on the basis of the possibility that a fetus could have a disability or genetic abnormality are currently only active in North Dakota (excluding the enjoined Indiana and Louisiana laws); however, Ohio’s House of Representative introduced similar legislation in 2015 that is still pending, and more states may attempt to roll out similar pieces of

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21 Parens and Asch, supra note 7, at 2, 11.
22 Sujatha Jesudason & Julia Epstein, The Paradox of Disability in Abortion Debates: Bringing the Pro-choice and Disability Rights Communities Together, 84 CONTRACEPTION 541–43 (2011).
23 Id.
legislation. Moreover, legislation that mandates that certain information be provided by medical professionals to patients who may be carrying fetuses with a risk of Down syndrome is eerily similar to certain state laws that require doctors to tell patients certain information (for example, that abortions are reversible, or that fetuses can feel pain) and is becoming increasingly more prevalent as well. According to the Guttmacher Institute, as of August 1, 2016, three states require that a woman seeking an abortion undergo counseling on perinatal hospice services ‘if [the desire to abort] is due to a lethal fetal condition’: Kansas requires counseling on perinatal hospice services before any abortion may be performed.

Though laws criminalizing abortion of disabled fetuses and requiring certain materials be provided to women seeking abortions purport to be in service of individuals with disabilities and their families, their primary goal is to legislate extremely private individual and family decisions rather than to focus public policy where it may be more productive, ie by mandating access to services, education, and support for families and individuals caring for individuals with disabilities and embracing disability as a part of the human experience. A distinct variety of lived experiences, values, and preferences will mean that people in similar situations will inevitably make different choices. In the realm of private reproductive choices, the government is rarely, if ever, a better decision-making entity than a provider or patient; however, as anthropologist Rayna Rapp notes, it is important to acknowledge that our private choices are still important for society as a whole: ‘[P]rivate choices always have public consequences. A woman’s individual decision, when resulting from social pressure, or colluding with a ‘trend’, has repercussions for all others in society.’ Whatever the societal repercussions of any one choice may be, restricting the ability to make the choice does little to benefit individuals, disabled and able-bodied alike.

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24 The American Civil Liberties Union of Ohio. *HB 135- Down Syndrome Abortion Ban*, [http://www.acluohio.org/legislation/hb-135-down-syndrome-abortion-ban-2015-2016](http://www.acluohio.org/legislation/hb-135-down-syndrome-abortion-ban-2015-2016) (accessed May 6, 2016).

25 Guttmacher Institute, *supra* note 2.

26 *Id.*

27 Marsha Saxton, *Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion*, in *Prenatal Testing And Disability Rights* (Erik Parens & Adrienne Asch eds., 2000).