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## Note

### Of Mosquitoes, Adolescents, and Reproductive Rights: Public Health and Reproductive Risks in a Genomic Age

Luke Haqq\*

Until recently, microcephaly was an uncommon condition, with the Centers for Disease Prevention and Control (CDC) estimating it typically affects between two and twelve babies per 10,000 live births in the United States.<sup>1</sup> The current pandemic emerged in French Polynesia in 2013.<sup>2</sup> By the end of 2014, the Brazilian government had already initiated an investigation into several thousands of cases of microcephaly, a birth defect that typically affected 150 infants annually in Brazil.<sup>3</sup> The vi-

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1. Nat'l Birth Defects Prevention Network, *Major Birth Defects Data from Population-Based Birth Defects Surveillance Programs in the United States, 2006–2010*, 97 CLINICAL & MOLECULAR TERATOLOGY S1 (2013); *Facts About Microcephaly*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/birthdefects/microcephaly.html> (last updated July 25, 2016).

2. See Van-Mai Cao-Lormeau et al., *Gillain-Barré Syndrome Outbreak Associated with Zika Virus Infection in French Polynesia: A Case-Control Study*, 387 LANCET 1531 (2016); Erwan Oehler et al., *Zika Virus Infection Complicated by Guillain-Barré Syndrome – Case Report, French Polynesia, December 2013*, 19 EUROSURVEILLANCE 1 (2014); Louise Watrin et al. *Guillain-Barré Syndrome (42 Cases) Occurring During a Zika Virus Outbreak in French Polynesia*, 95 MED. e3257 (2016).

3. Donald G. McNeil, Jr. et al., *Short Answers to Hard Questions About Zika Virus*, N.Y. TIMES (July 29, 2016), [http://www.nytimes.com/interactive/2016/health/what-is-zika-virus.html?\\_r=0](http://www.nytimes.com/interactive/2016/health/what-is-zika-virus.html?_r=0).

rus threatens to infect as many as four million people globally in 2016,<sup>4</sup> and the World Health Organization and CDC have declared that there is scientific consensus, not just anecdotal reports, that the *Aedes aegypti* mosquito-borne virus causes microcephaly,<sup>5</sup> among other birth defects.<sup>6</sup> The virus has spread from Oceania to South and North America, with CDC data revealing 2920 laboratory-confirmed, travel-associated cases in every state but Alaska, South Dakota, and Wyoming, twenty-four of which were sexually transmitted.<sup>7</sup> On July 4, 2016, “a patient entered an emergency room in Miami-Dade County with a fever, a rash and joint pain,”<sup>8</sup> the first of forty-three cases confirmed to be transmitted in the United States through local mosquitoes.<sup>9</sup> Some microcephalics can develop normally.<sup>10</sup> Some cases may not become apparent until symptoms like seizures develop in childhood, but when the birth defect is pro-

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4. *Id.*

5. Michaeleen Doucleff, *Zika Is Linked to Microcephaly*, *Health Agencies Confirm*, NAT'L PUB. RADIO (Mar. 31, 2016), <http://www.npr.org/sections/thetwo-way/2016/03/31/472607576/health-agencies-confirm-zika-is-linked-with-microcephaly>.

6. A preliminary *New England Journal of Medicine* report tracked eighty-eight pregnant women in Rio de Janeiro from September 2015 to February 2016. Patrícia Brasil et al., *Zika Virus Infection in Pregnant Women in Rio de Janeiro—Preliminary Report*, *NEW ENG. J. MED.*, Mar. 4, 2016, at 1. Of these eighty-eight women who had exhibited a rash, eighty-two percent tested positive for Zika. *Id.* at 3. The preliminary report concludes that it causes not only microcephaly but also “appears to be associated with grave outcomes, including fetal death, placental insufficiency, fetal growth restriction, and [central nervous system] injury.” *Id.* at 1. One Zika expert suggests microcephaly “may just be the tip of the iceberg” of effects that Zika can have on fetuses. Lena H. Sun, *Zika Expert: ‘Microcephaly May Just Be the Tip of the Iceberg’*, *WASH. POST* (Feb. 9, 2016), <https://www.washingtonpost.com/news/to-your-health/wp/2016/02/09/zika-expert-microcephaly-may-just-be-the-tip-of-the-iceberg>. For example, preliminary evidence has shown pregnant women infected with Zika virus may give birth to babies that are not microcephalic but do have neurological lesions. *Id.*

7. *Zika Virus: Case Counts in the US*, *CTRS. FOR DISEASE CONTROL & PREVENTION* (Sept. 7, 2016), <http://www.cdc.gov/zika/geo/united-states.html>.

8. Pam Belluck, *Patch of Miami Is Ground Zero for the Zika Virus*, *N.Y. TIMES* (Aug. 8, 2016), [http://www.nytimes.com/2016/08/09/health/zika-virus-florida.html?\\_r=0](http://www.nytimes.com/2016/08/09/health/zika-virus-florida.html?_r=0).

9. *Zika Virus: Case Counts in the US*, *supra* note 7.

10. One mother, for example, describes her six-year-old with microcephaly as “the busiest guy ever . . . . He walks, runs . . . rides bikes, plays soccer, rides horses, you name it.” *Sean’s Story*, *PMGAWARENESS.ORG* (Sept. 9, 2012), <http://pmgawareness.org/seans-story>. At the same time, the woman also noted that, during her pregnancy, she and her husband “were never taken aside and told what [m]icrocephaly really meant and what it may or may not involve.” *Id.*

nounced, the vast majority born with it die in infancy or childhood.<sup>11</sup>

It is only in recent times that parents have had access to robust “reproductive choice information,”<sup>12</sup> including information about mosquito-borne teratogens, environmental toxins, pharmaceutical side effects, carrier status, and gene variants that could lead to birth defects in future progeny.<sup>13</sup> Developments including ultrasonography, chorionic villus sampling, in vitro fertilization, preimplantation genetic diagnosis, and, perhaps most importantly, the abortion right<sup>14</sup> further lowered the rate of birth defects in the United States. In the past decade, abilities to prevent defects have become even more refined with the advent of clinical genomic sequencing. Preconception, pre-

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11. See, e.g., Yoko Imaizumi, *Prevalence and Mortality Rates of Microcephaly in Japan, 1969–1992*, 34 CONGENITAL ANOMALIES 131, 131 (1994) (finding the mean age at time of death for microcephalics rose from three years in 1969–1971 to thirteen from 1990–1992).

12. “Reproductive choice information,” as used in this Note, is that which is germane to reproductive autonomy, and is synonymous with results or information of “reproductive significance” or “reproductive importance.” It is not synonymous with “reproductive health information.” Reproductive choice information guides the deliberations one makes about reproduction generally, such as whether to use natural family planning, contraception, abortion, and genetic testing. Further, it includes information on options like prenatal vitamins, and pharmaceuticals labeled as Category D or X by the Food and Drug Administration. Reproductive *health* information, in contrast, refers more to issues of fertility, birth control, cancer screening via pap smears, and sexually transmitted infections.

13. Still, there is ample evidence that parents have acted on rudimentary forms of such information throughout history. Selective infanticide, for example, was “ubiquitous in most preliterate cultures, ranging from about a third or more of all children born . . . [C]ensus figures from antiquity show boy/girl ratios as high as 400 boys to 100 girls—a believable figure since, as Poseidippos said, ‘even a rich man always exposes a daughter.’” Lloyd DeMause, *A History of Child Abuse*, 25 J. PSYCHOHISTORY 216, 226 (1998). In the decade before *Roe v. Wade*, the United States experienced two massive spikes in birth defects during the 1960s. EVA R. RUBIN, ABORTION, POLITICS, AND THE COURTS 21 (1982); GERALD N. ROSENBERG, THE HOLLOW HOPE: CAN COURTS BRING ABOUT SOCIAL CHANGE? 259 (1991). National Institute of Child Health and Human Development efforts since the 1960s have successfully prevented the debilitating effects of the birth defect phenylketonuria (PKU), just as the rate of neural tube defects dropped once women began using prenatal vitamins following discoveries that linked defects to folate deficiency. *Brief History of Newborn Screening*, NIH EUNICE KENNEDY SHRIVER NAT’L INST. OF CHILD HEALTH & HUM. DEV. (Apr. 12, 2013), <https://www.nichd.nih.gov/health/topics/newborn/conditioninfo/Pages/history.aspx>.

14. See, for example, sources cited *infra* note 37 (noting over fifty years of data showing that most women who are informed of a fetal abnormality will choose to abort).

natal, and neonatal sequencing offer promising ways to prevent the existence of, diagnose, treat, and cure hundreds of serious birth defects early on, conditions that may otherwise go unnoticed until a point when they are no longer correctable. This information is important because it can expand reproductive autonomy, it can offer information to people considering sexual activity and reproduction that may be germane to moral choices, and it can make a palpable difference in the lives of future children.

With such reproductive choice-generating technologies available in the U.S., parents can now access much of their child's health information from sources including routine maternal serum tests during pregnancy visits, specific tests parents may request be done on the fetus prior to birth or the infant after birth, and state-run newborn screening programs. This increased access to information offers parents reproductive choices, helps prevent the existence of birth defects, and can mitigate their effects if they do occur. Crucially, however, this paradigm shift also raises concerns because neither the federal government nor the majority of states recognize that the child whose health information is obtained has any rights to keep that information private, and these concerns will be magnified in a genomic age. In nearly all states, unemancipated minors have no presumptive rights to refuse if parents want to have their child's genome sequenced. If parents do elect for sequencing, prevailing medical recommendations permit parents to choose that the results not be returned to the child, with the exception of results revealing a life-threatening condition.<sup>15</sup>

This framework is problematic because sequencing a child often reveals that child's reproductive choice information.<sup>16</sup> No laws protect this aspect of the genome even though the same information receives heightened privacy protections in non-genomic contexts.<sup>17</sup> Reproductive choice information, though, is

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15. See Laurence B. McCullough et al., *Professionally Responsible Disclosure of Genomic Sequencing Results in Pediatric Practice*, 136 PEDIATRICS e974 (2015); Laine Friedman Ross et al., *Technical Report: Ethical and Policy Issues in Genetic Testing and Screening of Children*, 15 GENETICS MED. 234 (2013).

16. McCullough et al., *supra* note 15; Ross et al., *supra* note 15.

17. Ellen Wright Clayton, *How Much Control Do Children and Adolescents Have over Genomic Testing, Parental Access to Their Results, and Parental Communication of Those Results to Others?*, 43 J.L. MED. ETHICS 538, 539 (2015).

an aspect of the genome especially germane to a child's sexual and reproductive choices. As such, privacy protections under the Health Insurance Portability and Accountability Act (HIPAA), Title X of the Public Health and Safety Act, and state laws should be construed to protect that aspect of the genome as an adolescent's private information. Further, public health interests are served by encouraging people to be informed by their reproductive choice information before they become sexually active. Public funding, such as Medicaid expansions under the Affordable Care Act and the Children's Health Insurance Program, should promote general knowledge about genomics and reproductive choice information through state-run sex education curricula that introduce key concepts like genetics, inheritance, and reproductive risks.<sup>18</sup>

This Note stresses the importance of having access to one's reproductive choice information—a particular problem for adolescents in a genomic age. Part I presents an overview of the recent emergence of genomics in the clinical setting, with focus given to problems it creates for adolescent reproductive healthcare. Part II analyzes prevailing medical recommendations regarding the return of reproductive choice information and uses judicial precedent to show how clinicians can face substantial liability if they fail to return reproductive risks. In many cases, courts have found this failure to violate the abortion right. Part III provides a legal and policy framework that supports private return of reproductive risks to adolescents individually in the clinical setting, as well as sharing general knowledge of reproductive choice information and genomics via sex education programs.<sup>19</sup> In arguing for the importance of knowing reproductive choice information, this Note aims to promote conditions that equip individuals to contribute to decreasing the prevalence of birth defects.

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18. *E.g.*, Sherree Kassuba, *Environmental Causes of Birth Defects*, YALE-NEW HAVEN TEACHERS INST., <http://teachersinstitute.yale.edu/curriculum/units/1982/7/82.07.07.x.html> (last visited Nov. 1, 2016) (detailing a unit on birth defects designed for ninth grade students).

19. *Cf.* Jayne Lucke, *Better Sex Education for Young People Is a Public Health Solution to the Problem of Advanced Maternal Age*, 15 AM. J. BIOETHICS 58 (2015) (recommending to promote reproductive choice by discussing the risks of infertility associated with advanced maternal age in sex education programs).

## I. GENOMICS AND ADOLESCENT REPRODUCTIVE RIGHTS

Genomic sequencing will be the backbone of healthcare's turn to precision medicine. Indeed, the "dramatic drop"<sup>20</sup> in the cost of sequencing over the past few years was a catalyst for the Precision Medicine Initiative, announced in President Obama's 2015 State of the Union Address.<sup>21</sup> Though there is debate as to whether personalized medicine will increase or decrease healthcare costs, if the latter is to be possible, a public health perspective is imperative to create the data to support genomic healthcare.<sup>22</sup> With NIH-funded initiatives underway that are exploring the benefits of routine newborn genomic screening, genomics is being "rapidly introduced into pediatric clinical practice."<sup>23</sup> Additionally, the availability of several direct-to-consumer (DTC) genetic tests have expanded testing outside hospitals and clinics; since 2008, people could submit a hundred dollars and a sample of saliva via mail to learn about their risks of developing "everything from macular degeneration to restless leg syndrome."<sup>24</sup>

This Part provides a background that shows how adolescent reproductive rights will be implicated as precision medicine and genomics become part of standard clinical practice. The first Section explains how parents have rights to determine their child's healthcare decisions and access the child's health information. These presumptive rights begin before their future

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20. Rita Rubin, *Precision Medicine: The Future or Simply Politics?*, 313 J. AM. MED. ASS'N 1089, 1089 (2015).

21. Barack Obama, Remarks by the President in State of the Union Address (Jan. 20, 2015), <https://www.whitehouse.gov/the-press-office/2015/01/20/remarks-president-state-union-address-january-20-2015> (stating that the Initiative would "give all of us access to the personalized information we need to keep ourselves and our families healthier").

22. Muin Khoury et al., *Beyond Base Pairs to Bedside: A Population Perspective on How Genomics Can Improve Health*, 102 AM. J. PUB. HEALTH 34, 36 (2012) ("[O]nly a population perspective can fulfill the promise of genomic medicine."); see also Muin Khoury, *The Public Health Approach to Genetic Testing in the 21st Century: Saving Lives and Saving Unnecessary Healthcare Costs*, CTRS. DISEASE CONTROL & PREVENTION GENOMICS & HEALTHCARE IMPACT (Mar. 15, 2012), <http://blogs.cdc.gov/genomics/2012/03/15/the-public-health-approach-to-genetic-testing> ("[A] public health approach to genomic medicine is essential if the new technology is to be used in a way that saves lives and saves healthcare costs at the same time.").

23. McCullough et al., *supra* note 15, at e974.

24. Ricki Lewis, *A Brief History of Genetic Testing: What the First Generation of Tests Can Tell Us About the Latest*, SCI. PROGRESS (May 5, 2008), <http://scienceprogress.org/2008/05/a-brief-history-of-genetic-testing>.

child is born and continue until the child reaches adulthood. The second Section introduces the recommendations of prominent medical organizations regarding returning genomic results to minors. These organizations recommend returning a child's results to parents rather than directly to the child.

#### A. PARENTAL VIS-À-VIS MINOR RIGHTS TO REPRODUCTIVE HEALTHCARE

As sequencing capabilities have been improved and refined, and as they have dramatically dropped in price,<sup>25</sup> more individuals have been able to access their genomic results in clinical settings and at home, through DTC testing companies like 23andMe, Full Genomes, Gene by Gene, Sure Genomics, and YSEQ.<sup>26</sup> In the clinical context, prenatal and neonatal sequencing raise especial concerns about what rights, if any, adolescents have with respect to genomic testing and return of testing results. DTC options lacking established clinical validity exacerbate these issues, for parents (or a minor with access to a credit card) can access these options outside the physician-adolescent relationship.<sup>27</sup>

This Section shows how parents presumptively have full control over their children's health information. The first Subsection explains how federal abortion jurisprudence protects a woman's right to have unrestricted access to her child's genomic information throughout her pregnancy. The next shows how both parents additionally have virtually unlimited access to their child's genomic information in infancy and childhood. The third Subsection describes how the presumption of parental control begins to shift in adolescence, with federal and state laws granting minors rights to access reproductive services privately from parents, to obtain their own health information,

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25. Rubin, *supra* note 20.

26. 23ANDME, <https://www.23andme.com> (last visited Nov. 1, 2016); FULL GENOMES DNA SEQUENCING, <https://www.fullgenomes.com> (last visited Nov. 1, 2016); GENE BY GENE, <https://www.genebygene.com> (last visited Nov. 1, 2016); SURE GENOMICS, <http://suregenomics.com> (last visited Nov. 1, 2016); YSEQ DNA ORIGINS PROJECT, <http://yseq.net> (last visited Nov. 1, 2016).

27. 23andMe's privacy statement, for example, implies the benefits of direct-to-consumer genomic testing can extend to children as early as age thirteen. *Full Privacy Statement*, 23ANDME, <https://www.23andme.com/about/-privacy> (last updated Sept. 29, 2016) ("Neither 23andMe nor any of its Services are designed for, intended to attract, or directed toward children under the age of 13.").



and to refuse genetic and genomic testing if they do not want it done.

### 1. Parental Rights To Obtain a Child's Genomic Results in Utero

To understand the lack of control minors have over their genomic information, it is crucial to consider federal and state abortion law as a backdrop. In *Roe v. Wade*, the Supreme Court recognized abortion as a woman's constitutional right.<sup>28</sup> Revisiting that holding two decades later in *Planned Parenthood v. Casey*, Justice O'Connor provided the undue burden test as an alternative to *Roe*'s strict scrutiny analysis, recognizing that "there is a substantial state interest in potential life" not only post-viability (as was the case under *Roe*) but throughout a pregnancy.<sup>29</sup> The Court held in *Casey* that abortion restrictions that are "unduly burdensome" will be struck down as unconstitutional.<sup>30</sup> Under *Casey*'s analysis, "[a] burden may be 'undue' either because [it] is too severe or because it lacks a legitimate, rational justification."<sup>31</sup>

Thus, under federal abortion jurisprudence—which the Supreme Court updated for the first time since 2007 in *Whole Women's Health v. Hellerstedt*<sup>32</sup>—it is unclear whether a state could ever deny a woman from using an available prenatal test. Sequenom's MaterniT 21, for instance, is a non-invasive fetal sequencing option commercially available since 2011 that detects Down syndrome, among other trisomies and mutations.<sup>33</sup> This reproductive choice information enables women to choose whether or not to continue their pregnancies after diagnosis. Congress and roughly half of state legislatures have considered bills in the past few years seeking to prohibit abortions to select against the fetus's sex, race, or health, thus not prohibiting fetal testing per se but rather the abortions that may ensue.<sup>34</sup>

28. *Roe v. Wade*, 410 U.S. 113 (1973).

29. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 876 (1992).

30. *Id.* at 874.

31. *Id.* at 920 (Stevens, J., concurring in part, dissenting in part).

32. The Court upheld *Casey*'s undue burden standard, holding that a Texas law requiring doctors who perform abortions to have admitting privileges at a local hospital did not serve a legitimate state interest. *Whole Women's Health v. Hellerstedt*, 136 S. Ct. 2292, 2311–13 (2016).

33. *MaterniT21 Plus*, SEQUENOM, <https://laboratories.sequenom.com/test/reproductive-health/maternit21-plus> (last visited Nov. 1, 2016).

34. *E.g.*, Assemb. B. 2336, 2013–2104 Leg., Reg. Sess. (Cal. 2014); S.B. 2790, 129th Leg., Reg. Sess. (Miss. 2014); H.B. 1585, 97th Gen. Assemb., 2d

Though it may seem that such laws would overstep *Casey's* "undue burden" standard, North Dakota has had such a ban in force since 2013,<sup>35</sup> and Indiana has had one on the books since March 2016.<sup>36</sup>

One justification states could assert for denying access to genetic testing is that this promotes the state's interest in fetal life, since studies have shown for decades that women will be more likely to obtain an abortion if they learn of a fetal abnormality than if they never had such information.<sup>37</sup> States could also argue such testing makes selective, expressively discriminatory abortions possible because of the fetus's sex or genetic status; such laws might have a rational, legitimate connection to a state interest in protecting the civil rights of the unborn.<sup>38</sup>

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Reg. Sess. (Mo. 2014); H.B. 4034, 77th Leg. Assemb., Reg. Sess. (Or. 2014); H.B. 7383, 2014 Leg., Reg. Sess. (R.I. 2014); S.B. 2376, 2014 Leg., Reg. Sess. (R.I. 2014); H.B. 98, 2014 Leg., Reg. Sess. (Va. 2014); H.B. 2371, 81st Leg., Reg. Sess. (W. Va. 2014); H.B. 1131, 69th Gen. Assemb., 1st Reg. Sess. (Colo. 2013); S.B. 56, 69th Gen. Assemb., 1st Reg. Sess. (Colo. 2013); H.B. 845, 115th Leg., Reg. Sess. (Fla. 2013); S.B. 1072, 115th Leg., Reg. Sess. (Fla. 2013); H.B. 1430, 118th Gen. Assemb., 1st Reg. Sess. (Ind. 2013); S.B. 183, 118th Gen. Assemb., 1st Reg. Sess. (Ind. 2013); S. File 13, 85th Gen. Assemb. (Iowa 2013); H.B. 1567, 188th Leg., Reg. Sess. (Mass. 2013); Assemb. B. 2533, 236th Leg., Reg. Sess. (N.Y. 2013); S.B. 2286, 236th Leg., Reg. Sess. (N.Y. 2013); H.B. 309, 83d Leg., Reg. Sess. (Tex. 2013); Assemb. B. 217, 101st Leg., Reg. Sess. (Wis. 2014); S.B. 201, 101st Leg., Reg. Sess. (Wis. 2014); H.B. 5731, 96th Leg., Reg. Sess. (Mich. 2012); Assemb. B. 2157, 215th Leg., 1st Reg. Sess. (N.J. 2012); H.B. 570, 129th Gen. Assemb., Reg. Sess. (Ohio 2012); H.B. 1155, 2009–2010 Leg., Reg. Sess. (Ga. 2010); S.B. 529, 2009–2010 Leg., Reg. Sess. (Ga. 2010); H.B. 693, 60th Leg., 2d Reg. Sess. (Idaho 2010); H. File 1196, 86th Leg., Reg. Sess. (Minn. 2009); S. File 1073, 86th Leg., Reg. Sess. (Minn. 2009).

35. N.D. CENT. CODE, § 14-02.1-04.1 (2013).

36. Tribune News Serv., *Indiana Governor Oks Fetal Defects Abortion Ban*, CHI. TRIB. (Mar. 24, 2016), <http://www.chicagotribune.com/news/nationworld/midwest/ct-indiana-abortion-ban-genetic-abnormalities-20160324-story.html>.

37. See Tamsen Caruso et al., *Impact of Prenatal Screening on the Birth Status of Fetuses with Down Syndrome at an Urban Hospital, 1972-1994*, 1 GENET. MED. 22 (1998); Mathias Forrester & Ruth Merz, *Epidemiology of Down Syndrome*, 65 TERATOLOGY 207 (2002); Ralph Kramer et al., *Determinants of Parental Decisions After the Prenatal Diagnosis of Down Syndrome*, 79 AM. J. MED. GENET. 172 (1998); Caroline Mansfield et al., *Termination Rates After Prenatal Diagnosis for Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review*, 19 PRENAT. DIAGN. 808 (1999); Jaime Natoli et al., *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995-2011)*, 32 PRENAT. DIAGN. 142 (2012).

38. See Susan B. Anthony and Frederick Douglas *Prenatal Discrimination Act of 2011: Hearing on H.R. 3541 Before the Subcomm. on the Constitution of the H. Comm. on the Judiciary*, 112th Cong. 1 (2011) (statement of Rep. Trent

One might argue denying in utero testing cannot be unduly burdensome because it does not affect the legality of or access to abortion. This is unlikely given the Supreme Court's articulation of abortion as falling within a woman's liberty rights. As the Court remarked in *Casey*, decisions whether or not to terminate a pregnancy are "choices central to personal dignity and autonomy, [and] are central to the liberty protected by the Fourteenth Amendment,"<sup>39</sup> which includes a woman's autonomy to "determine her life's course"<sup>40</sup> and exercise "control over her destiny"<sup>41</sup> by opting to terminate the pregnancy. Thus, even if a state can posit a legitimate interest in discouraging post-diagnosis abortions, a prohibition on in utero testing could be found unconstitutionally burdensome for violating the woman's decisional autonomy regarding her abortion choice. Indeed, Planned Parenthood recently filed suit to enjoin Indiana's abnormality-selective abortion ban from going into effect.<sup>42</sup> One upshot of these considerations concerning the nature of in utero testing as a liberty found within the abortion right, in sum, is that parents can have unrestricted access to their child's genomic information prior to birth.<sup>43</sup>

## 2. Parental Rights To Obtain a Child's Genomic Results in Infancy and Childhood

From the in utero context to state-run newborn screening to testing in infancy and early childhood, the child whose health information is obtained has virtually no rights for that information to be kept private from parents.<sup>44</sup> In addition to the possibility of prenatal testing, genetic results are routinely obtained shortly after birth, as is the case in the newborn screening programs mandated by law in all fifty states and the District of Columbia, except Wyoming.<sup>45</sup> These programs identify

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Franks) (describing the Prenatal Nondiscrimination Act).

39. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 851 (1992).

40. Gonzales v. Carhart, 550 U.S. 124, 172 (2007) (Ginsburg, J., dissenting).

41. *Casey*, 505 U.S. at 869.

42. Emma Green, *Indiana Tried To Raise Ethical Challenges to Abortion, but Will Probably Fail*, THE ATLANTIC (July 1, 2016), <http://www.theatlantic.com/politics/archive/2016/07/indiana-tried-to-raise-ethical-challenges-to-abortion-but-will-probably-fail/489746>.

43. Clayton, *supra* note 17, at 540.

44. *See id.*

45. Michelle Huckaby Lewis & Aaron Goldberg, *Return of Results from Researching Using Newborn Screening Dried Blood Samples*, 43 J.L. MED.

roughly 12,500 children annually with metabolic, endocrine, hematologic, or functional disorders.<sup>46</sup> If clinically significant results arise, state laboratories notify clinicians, who relay the information to parents to enable them to seek diagnostic confirmation.<sup>47</sup> Prevailing medical guidelines are to return to parents diagnoses and risk assessments for conditions that are life threatening or can be ameliorated only in childhood.<sup>48</sup> The National Institute of Child Health and Human Development is now exploring the possibility of newborn *genomic* screening programs.<sup>49</sup> Several state statutes explicitly grant parents control over their child's newborn screening results.<sup>50</sup> If a child exhibits symptoms of an undiagnosed condition in infancy and early childhood, parents might have further reason to gain access to the child's genomic information. Beyond early childhood, genomic testing of children is uncommon.<sup>51</sup>

### 3. Genetic Testing and Reproductive Rights in Adolescence

Legal and ethical issues concerning pediatric sequencing become more complex in later childhood, adolescence, and near-adulthood, as unemancipated minors become more capable of comprehending and making decisions in light of their personal health information. In these contexts, questions arise concerning the extent to which the broadly protected rights of parents to choose how to raise their children—among the earliest of substantive due process rights<sup>52</sup>—allow them to control the minor's healthcare. It is possible that this permission for parents to control their children's healthcare can run into tension with

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ETHICS 559, 560 (2015).

46. *Id.*

47. McCullough et al., *supra* note 15, at e979.

48. *Id.* at e978.

49. *NIH Program Explores the Use of Genomic Sequencing in Newborn Healthcare*, NAT'L INST. HEALTH (Sept. 4, 2013), <http://www.nih.gov/news-events/news-releases/nih-program-explores-use-genomic-sequencing-newborn-healthcare>.

50. *E.g.*, CAL. HEALTH & SAFETY CODE § 124980 (2015); N.H. STAT. § 132:10a (2015); TEX. HEALTH & SAFETY CODE § 33.0111 (2015).

51. Ross et al., *supra* note 15, at 234.

52. *E.g.*, *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 534 (1925) (holding a law requiring children's attendance at public schools unconstitutional because it interfered with parental rights to "direct the upbringing" of their children); *Meier v. Nebraska*, 262 U.S. 390, 400 (1923) (finding a law restricting foreign-language education to violate parents' rights to choose their children's education, a right protected by the Due Process Clause of the Fourteenth Amendment).

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the heightened legal protections accorded to adolescent reproductive services and information in other (non-genomic) contexts. This Section describes federal and state laws giving adolescents private access to reproductive services, protections for keeping adolescent reproductive information secure, and professional guidelines concerning adolescent rights to refuse genetic and genomic testing.

*a. Protections for Adolescent Access to Reproductive Services*

A first set of exceptions to the presumption of parental control over the healthcare of their children concerns the minor's right to *access* services related to their reproductive choices privately from parents. Supreme Court precedent regarding adolescent reproductive rights came in the wake of decisions finding a privacy right to access contraception within the Constitution's "penumbras" and "emanations,"<sup>53</sup> as well as in the wake of *Roe's* recognition of the abortion right. In *Carey v. Population Services International*, the Supreme Court recognized that minors possess constitutional rights to obtain non-prescription contraceptives without parental consent.<sup>54</sup> In *Bellotti v. Baird*, the Court also extended to minors a right to obtain abortion services without parental consent, though states can require judicial approval in lieu of it.<sup>55</sup> The Court refrained from extending *Roe's* full protection to minors, stressing their "inability to make critical decisions in an informed and mature manner and the importance of the parental role in child rearing."<sup>56</sup>

Federal and state statutory law also promotes the abilities of adolescents to access services related to their reproductive choices privately from parents. The family planning program established in 1970 under Title X of the Public Health and Safety Act provides federal funds for family planning clinics to provide low-income patients with services "including natural family planning methods, infertility services, and services for adolescents"; in the case of adolescents, providers must encour-

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53. *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965); *see also Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972) ("If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.").

54. *Carey v. Population Servs. Int'l*, 431 U.S. 678, 697–99 (1977).

55. *Bellotti v. Baird*, 443 U.S. 622 (1979).

56. *Id.* at 634.

age but cannot require family involvement.<sup>57</sup> Additionally, all states have statutes permitting minors access to certain clinical services without parental permission, such as services related to sexual activity, drug and alcohol abuse, and mental health.<sup>58</sup> The majority of states have explicit statutory authorizations for pregnant minors to obtain prenatal and delivery services without parental notification or consent, and state “lawmakers have generally resisted attempts to impose a parental consent or notification requirement on minors’ access to reproductive health care and other sensitive services.”<sup>59</sup>

*b. Protections for Adolescent Access to Reproductive Information*

In addition to these protections for adolescents to access healthcare services and products like contraception, abortion and counseling, federal and state laws also provide an exception to the presumption of parental control over an adolescent’s right to access health *information*. Under the Health Insurance Portability and Accountability Act (HIPAA), “protected health information” is defined as “individually identifiable” health information,<sup>60</sup> where “health information” is any oral or recorded information “created or received by a health care provider”<sup>61</sup> and “relates to . . . the provision of health care to an individual.”<sup>62</sup>

Parental rights under HIPAA are covered in the section on personal representatives.<sup>63</sup> That section states that “if under [the] applicable law [a person] has authority to act on behalf of . . . an unemancipated minor in making decisions related to health care, a covered entity *must* treat such person as a personal representative.”<sup>64</sup> At the same time, HIPAA states that, with regard to protected health information pertaining to a

57. 42 U.S.C. § 300(a) (2012).

58. See ABIGAIL ENGLISH ET AL., *STATE MINOR CONSENT LAWS: A SUMMARY* (3d ed. 2010) (summarizing the laws in each of the fifty U.S. states and the District of Columbia that allow minors to give their own consent for health care).

59. Heather Boonstra & Elizabeth Nash, *Minors and the Right To Consent to Healthcare*, 3 GUTTMACHER REP. PUB. POL’Y 4, 4 (2000).

60. 45 C.F.R. § 160.103 (2014).

61. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 § 1171(4)(A) (1996).

62. *Id.* § 1171(4)(B).

63. 45 C.F.R. § 164.502(g) (2013).

64. *Id.* § 164.502(g)(2) (emphasis added).

healthcare service, parents “may” not be representatives when “minor[s] may obtain such services lawfully without parental consent.”<sup>65</sup> In other words, HIPAA requires that parents be treated as representatives who act on behalf of their child in making healthcare decisions, unless there is judicial precedent—such as *Carey* and *Bellotti*, or other applicable federal or state laws giving the minor rights to access healthcare without parental involvement.

*c. Adolescent Rights To Refuse Testing*

Lastly, concerning not the right to *access* but the minor’s right to *refuse* genetic and genomic testing, “unemancipated minors have virtually no access to the courts to enjoin parental behavior.”<sup>66</sup> In part, this is because of the wide latitude granted to parents in choosing how to raise their children.<sup>67</sup> It is also because child protection agencies would be unlikely to intervene to uphold a minor’s refusal to be tested because, absent a risk of serious harm to the child, non-invasive testing cannot qualify as neglect or abuse.<sup>68</sup> Still, physicians have discretion to refuse parental wishes if they deem them to be “inappropriate” for the child,<sup>69</sup> which could plausibly include obtaining samples for sequencing from a teenager who expressly does not want it done. Indeed, professional ethical standards are that clinicians should not perform testing on minors who object if they are “older school-age children.”<sup>70</sup> Though the physician’s assessment of appropriateness could initially parry parental rights, the riposte is that parents are free to find another clinician willing to perform such tests in these situations, and, as discussed, they are free to have the child’s genome sequenced in utero.

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65. *Id.* § 164.502(g)(3)(i)(B).

66. Clayton, *supra* note 17, at 540.

67. *Id.*

68. *Id.*

69. Arthur Kohrman et al., *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 317 (1995) (issuing a statement by the American Academy of Pediatricians that older-age children “frequently have decision-making capacity and the legal authority to accept or reject interventions, and, in that event, no additional requirement to obtain parental permission exists. However, the Academy encourages parental involvement in such cases, as appropriate”).

70. *Id.* at 316; *see also* Am. Acad. Pediatrics, *AAP Publications Reaffirmed and Retired*, 130 PEDIATRICS e467 (2012) (reaffirming ethical standards on assent for older minors).

In sum, this Part has thus far shown how minors have legal protection for some aspects of their sexual and reproductive information. Protections exist for information generated through services *they* access in the clinical setting, and even records from school health services.<sup>71</sup> However, there are no protections for reproductive information generated by services *accessed by their parents*. Yet this is precisely the problem created by pediatric genomics: it is not a health service that adolescents can access on their own but rather an option their parents may elect for, generating large amounts of the child's health information when the child is too young to consent or is not yet born. As such, current laws are inadequate to protect an adolescent's reproductive choice information in a genomic age.

#### B. MEDICAL VIEWS ON RETURN OF GENOMIC REPRODUCTIVE INFORMATION TO MINORS

Federal laws such as HIPAA and Title X of the PHSA, state laws, and contraception and abortion jurisprudence are not the only sources of guidelines for returning results of reproductive significance to minors. Rather, there is an extensive literature on best practices for returning results of "reproductive significance,"<sup>72</sup> in both clinical<sup>73</sup> and research settings.<sup>74</sup>

71. A student's school health records at the elementary and secondary levels are considered "education records" under FERPA, thereby releasable to parents. They can be kept private from parents only if the student is over eighteen or attends a postsecondary institution. See Family Education Rights and Privacy Act, 20 U.S.C. § 1232g (2012); U.S. DEP'T OF HEALTH & HUMAN SERV. & U.S. DEP'T OF EDUC., JOINT GUIDANCE ON THE APPLICATION OF THE FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT (FERPA) AND THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996 (HIPAA) TO STUDENT HEALTH RECORDS 1 (2008).

72. *E.g.*, PRESIDENTIAL COMM'N FOR THE STUDY OF BIOETHICS ISSUES, ANTICIPATE AND COMMUNICATE: ETHICAL MANAGEMENT OF INCIDENTAL AND SECONDARY FINDINGS IN THE CLINICAL, RESEARCH, AND DIRECT-TO-CONSUMER CONTEXTS 79–89 (2013) (discussing clinical and research duties regarding results of "reproductive significance"). See generally Diane Korngiebel et al., *Generating a Taxonomy for Genetic Conditions Relevant to Reproductive Planning*, 170A AM. J. MED. GENETICS 565 (2016) (researching best practices and ethical concerns in sharing reproductive planning results); Michael Leo et al., *Patients' Ratings of Genetic Conditions Validate a Taxonomy To Simplify Decisions About Preconception Carrier Screening via Genome Sequencing*, 170A AM. J. MED. GENETICS 574 (2016) (exploring which types of genetic testing information parents want to know in their reproductive planning).

73. See Lisa Parker, *The Future of Incidental Findings: Should They Be Viewed as Benefits?*, 36 J.L. MED. ETHICS 341, 342 (2008); Benjamin Wilfond & Katrina Goddard, *It's Complicated: Criteria for Policy Decisions for the Clini-*



Additionally, though the plaintiffs have typically been adults, neonatal torts can be another source of guidelines for protecting the right to know reproductive choice information in adolescence.

This Section develops an exception to the presumption of parental control over an adolescent's reproductive choice information. The first Subsection introduces recent guidelines by influential professional organizations detailing a clinician's duty of care when genomic sequencing reveals an adolescent's "reproductive risks." The second Subsection discusses the variety of prenatal torts that can be brought against clinicians and others for failing to warn individuals about their reproductive risks.

### 1. Medical Views on Genomics in Adolescence: An Exception for Reproductive Risks

Prominent medical organizations are supportive of pediatric sequencing in a number of circumstances. The American College of Medical Genetics and Genomics (ACMG) and American Academy of Pediatrics (AAP) issued a joint policy statement in 2013 in which they supported the initiation of pediatric genomic testing if parents know of a family history of a mutation, but the organizations otherwise do not favor pre-symptomatic sequencing.<sup>75</sup> In a separate policy statement it issued the same year, the ACMG recommended that when par-

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*cal Integration of Genome-Scale Sequencing for Reproductive Decision Making*, 3 MOLECULAR GENETIC & GENOMIC MED. 239, 239–40 (2015).

74. Robert Klitzman et al., *Researcher's Views on Returning Incidental Genomic Research Results: Qualitative and Quantitative Findings*, 15 GENETICS MED. 888, 888 (2013); Susan Wolf et al., *Managing Incidental Findings and Research Results in Genomic Research Involving Biobanks and Archived Data Sets*, 14 GENETICS MED. 361, 373 (2012) ("[We] suggest[] that findings of reproductive importance should fall in the 'may return' category."); see also Denise Avaré et al., *Pediatric Research and the Return of Individual Research Results*, 39 J.L. MED. ETHICS 593, 599 (2011) ("In some circumstances, research results will reveal the carrier status of the child. Carrier status should generally not be communicated to parents because it has no implications for the immediate future health of the child, but rather should be provided when the adolescent begins to consider his or her reproductive health."); Susan Wolf et al., *Managing Incidental Findings in Human Subjects Research: Analysis and Recommendations*, 36 J.L. MED. ETHICS 219, 229 (2008) ("Including among researcher duties an obligation to offer to disclose to participants [information of] . . . reproductive importance is consistent not only with legal recognition of researchers' special obligations toward participants, but also with legal doctrine imposing a duty to warn of foreseeable harm.").

75. Ross et al., *supra* note 15.

ents obtain pediatric whole genome or exome sequencing in search of a primary indication, incidental findings should be returned to parents if they reveal conditions that are early onset, life threatening, or necessitate ameliorative measures in childhood.<sup>76</sup> The ACMG initially stated in this recommendation that parents should not be permitted to opt out of the analysis of incidental findings.<sup>77</sup> However, after criticism on this point,<sup>78</sup> the organization released a policy update in 2014 permitting parents to opt out of the analysis.<sup>79</sup>

In addition to returning results to parents, the ACMG and AAP support returning incidental findings of reproductive risks to minors, as does the NIH's Clinical Sequencing Exploratory Research Pediatric Working Group (CSER-PWG).<sup>80</sup> The ACMG and AAP do not support screening in the school context, but they suggest clinical carrier screening may be appropriate for adolescents who are "pregnant or considering reproduction."<sup>81</sup> They claim the benefits of clinical carrier screening can "include potentially greater acceptance and integration of status into life plans, avoidance of the shock and resentment that may accrue when disclosure is delayed, and greater opportunity for parental guidance," and "reproductive benefits include avoiding the birth of a child with genetic disease or having time to prepare for the birth of a child with genetic disease."<sup>82</sup>

Meanwhile, CSER-PWG maintains that pediatricians have a "prima facie, autonomy-based ethical obligation to provide adolescent patients, ideally before they become sexually active, with reproductive risk assessment results."<sup>83</sup> However, minors

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76. Robert Green et al., *ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing*, 15 GENETICS MED. 565, 568 (2013).

77. *Id.*

78. Wylie Burke et al., *Recommendations for Returning Genomic Incidental Findings? We Need To Talk!*, 15 GENETICS MED. 854, 857 (2013).

79. Am. Coll. Med. Genetics & Genomics, *ACMG Updates Recommendation on "Opt Out" for Genomic Sequencing Return of Results*, ACMG NEWS (Apr. 1, 2014), [https://www.acmg.net/docs/Release\\_ACMGUpdatesRecommendations\\_final.pdf](https://www.acmg.net/docs/Release_ACMGUpdatesRecommendations_final.pdf).

80. McCullough et al., *supra* note 15, at e979.

81. Ross et al., *supra* note 15, at 237; see also Jennifer Schneider et al., "Is It Worth Knowing?": Focus Group Participants' Perceived Utility of Genomic Preconception Carrier Screening, 25 J. GENETIC COUNS. 135, 135 (2016) (noting a mixture of "certain" and "hesitant" participants with respect to interest in obtaining genomic carrier screening results).

82. Ross et al., *supra* note 15, at 237.

83. McCullough et al., *supra* note 15, at e978.

should be permitted “to refuse to learn or to act on the results of reproductive risk assessment.”<sup>84</sup> In agreement with the ACMG’s 2014 update permitting parents to opt out, CSER-PWG contends that parents do not violate a prima facie ethical obligation to their child by choosing not to tell the child of non-life-threatening incidental findings.<sup>85</sup> The recommendations of these organizations, in other words, is that it would be beneficial to analyze and return reproductive risks to minors, but this is ultimately the parent’s decision.

## 2. Neonatal Torts and the Clinician’s Reasons To Mitigate Liability Risks: A Problem with Medical Recommendations

The ACMG and CSER-PWG recommendations are valuable, particularly because they emphasize that there are good reasons to encourage knowledge of reproductive risks before an individual becomes sexually active. This Subsection argues that these recommendations do not, however, account sufficiently for the risks clinicians face from neonatal litigation—a problem created because they do not recommend returning genomic reproductive choice information *directly* to minors.<sup>86</sup>

The ACMG and CSER-PWG recommendation that parents should have control over their child’s reproductive choice information is problematic because parents are not subject to liability for failing to disclose these risks to their children.<sup>87</sup> By contrast, clinicians, other medical personnel (such as ultrasonographers), and non-medical personnel (such as pharmaceutical companies) in most states can face substantial liability from wrongful life, wrongful birth, wrongful conception, or even wrongful death causes of action that could be brought for failing to warn minors of their reproductive risks.<sup>88</sup> Namely, clinicians can be liable if a court finds such a failure to be the proximate cause of a patient having a child with birth defects, when the patient otherwise would have avoided conception or would have aborted.<sup>89</sup>

In *Molloy v. Meier*, for example, a couple filed a claim against three doctors asserting they were negligent for failing

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84. *Id.* at e979.

85. *Id.*

86. See notes 75–85 and accompanying text.

87. See Carel Stolker, *Wrongful Life: The Limits of Liability and Beyond*, 43 INTL & COMP. L.Q. 521, 534 (1994).

88. *Id.* at 521.

89. *Id.* at 527.

to diagnose Fragile X syndrome in the couple's first child.<sup>90</sup> The parents sought damages for the birth of a second child with the condition, asserting they would have obtained a tubal ligation if they had known; that fact characterized it as a "wrongful conception" cause of action.<sup>91</sup> The Minnesota Supreme Court found that the doctors had breached duties of care both to the second child with Fragile X and also her parents.<sup>92</sup> The court found that, in the course of treating their first child, the doctor should have alerted the parents of the "high probability" their future children would be born with the syndrome.<sup>93</sup> Since the parents would have obtained a tubal ligation, the court found that the cause of action and damages accrued at conception.<sup>94</sup>

The Minnesota Supreme Court in *Molloy* recognized that doctors had breached a duty to the second child; this is curious because Minnesota has a statutory prohibition on "wrongful life" lawsuits.<sup>95</sup> In that type of action, the suit is brought by or on behalf of the *child*, seeking damages as compensation for being born with a condition such as Fragile X as the result of another party's negligence. *Molloy* is puzzling because the court found the doctor had breached a duty to a party that was prohibited from seeking legal compensation for that breach. In the 1960s, plaintiffs seeking compensation for being born "adulterine bastard[s]" brought the first wrongful life cases that arose against parents.<sup>96</sup> Post-*Roe*, many of these suits had the new component that the parents would have exercised the *abortion right*, rather than never conceived, if doctors had warned them of a reproductive risk. On several occasions, for instance, cases were brought on behalf of an infant with congenital rubella syndrome by parents asserting they were unaware that the mother's contraction of the German measles created this reproductive risk. In one such case, the infant plaintiff's mother stated in her deposition that "I would have done the kindest

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90. 679 N.W.2d 711, 714 (Minn. 2004).

91. *Id.* at 716.

92. *Id.* at 719.

93. *Id.*

94. *Id.* at 722.

95. MINN. STAT. § 145.424 (2002).

96. *Zepeda v. Zepeda*, 190 N.E.2d 849, 849 (Ill. App. Ct. 1963); *see also Williams v. State*, 223 N.E.2d 343 (N.Y. 1966) (dismissing a claim that the State was negligent in allowing a hospitalized mother to give birth out of wedlock).

thing that I could have known to have done for her, and that would have been to terminate the pregnancy.”<sup>97</sup>

State legislatures and courts have reacted negatively to the wrongful life cause of action, with all but six prohibiting it by statute or judicial decision.<sup>98</sup> By contrast, though, roughly half of states recognize “wrongful birth” claims, which enable parents to recover for *their* harm in not having the opportunity to make an informed abortion decision because of a doctor’s failure to return reproductive risks.<sup>99</sup> There have been numerous wrongful birth suits, some in which parents have recovered eight-figure settlements against medical personnel and institutions.<sup>100</sup> In comparison, there have been fewer than 200 wrongful life cases.<sup>101</sup> Still, plaintiffs have successfully recovered in at least a dozen of those, with the most commonly litigated and recovered condition being Down syndrome (also the most common birth defect<sup>102</sup>), for which the average settlement award is \$734,639.<sup>103</sup> Others include a New York case in which \$3,837,477 was recovered on behalf of an infant who was confined for the rest of his life to a hospital with multiple severe defects.<sup>104</sup> In that case, the plaintiff’s mother underwent three

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97. *Jacobs v. Theimer*, 519 S.W.2d 846, 847 (Tex. 1975).

98. Deborah Pergament & Katie Ilijic, *The Legal Past, Present and Future of Prenatal Genetic Testing: Professional Liability and Other Legal Challenges Affecting Patient Access to Service*, 3 J. CLINICAL MED. 1437, 1445 (2014).

99. For a systematic overview of statutory responses to wrongful life suits, see William Duncan, *Statutory Responses to “Wrongful Birth” and “Wrongful Life” Actions*, U. FAC. FOR LIFE, <http://www.uflf.org/Vol14/Duncan-04.pdf> (last visited Nov. 1, 2016).

100. See, e.g., Carol M. Ostrom, *\$50M Awarded over Birth Defect; Test Said Baby Would Be Okay*, SEATTLE TIMES (Dec. 10, 2013), <http://www.seattletimes.com/seattle-news/50-m-awarded-over-birth-defect-test-said-baby-would-be-okay>.

101. This figure comes from the author’s own research. After reviewing roughly 1200 cases from 1963 up until 2016, there have been roughly 150 cases since the first case, depending on how one defines the “wrongful life” cause of action.

102. *Birth Defects: Data and Statistics*, CTR. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/birthdefects/data.html> (last updated June 22, 2015).

103. *J.C. v. Health Partners Med. Grp.*, No. BC394518, 2009 Jury Verdicts LEXIS 446678 (Cal. Super. Ct. 2009); *Olivares ex rel. G.O. v. L.A. Med. Ctr.*, No. BC352486, 2008 Jury Verdicts LEXIS 57175 (Cal. Super. Ct. 2008); *Unnamed Father ex rel. Unnamed Minor v. Unnamed Hosp.*, 2008 WL 747741 (Cal. Super. Ct. 2008); *Confidential (S99-07-16)*, 1998 Jury Verdicts LEXIS 72413 (Cal. Super. Ct. 1998).

104. *Branca v. Miro*, No. 0735/01, 2004 NY Jury Verdicts Review LEXIS 823 (N.Y. Sup. Ct. 2004).

ultrasounds, all of which she was told were normal.<sup>105</sup> Discovery revealed that the ultrasonographer has signaled a “red flag” to the defendant doctor, which he neglected to convey to the plaintiff’s mother.<sup>106</sup> The negligence claim also asserted the defendant gave her advice not to have an alpha-fetoprotein (AFP) test done, and she opted not to have the test done in reliance on that advice.<sup>107</sup> A case of congenital chicken pox, also involving multiple severe defects, settled for \$3,325,000.<sup>108</sup> There have been seven-figure settlements for a failure to warn about reproductive risks for other congenital conditions as well, such as cystic fibrosis.<sup>109</sup>

In sum, this Part first showed how U.S. laws create a presumption of parental control over their child’s healthcare, but an exception is carved out in adolescence for information and services germane to the adolescent’s reproductive choices. It then discussed pertinent medical recommendations on genomics in adolescence, bringing two lines of criticism against them. First, these recommendations provide inadequate protection for the reproductive rights of adolescents. Second, they fail to reflect the clinician’s full duty of care in this context, with neonatal torts helping to sketch a better picture of that duty.

## II. REASONS TO PROMOTE ADOLESCENT PRIVACY AND KNOWLEDGE OF REPRODUCTIVE CHOICE INFORMATION

Part I argued that while adolescents have protections for the privacy of their reproductive choice information and access to reproductive healthcare services, there are few state and no federal laws extending these protections to genomic results. This is a significant gap because, with the exception of target-enrichment methods of sequencing,<sup>110</sup> whole genome or exome sequencing is not *targeted*; information about reproductive

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105. *Id.*

106. *Id.*

107. *Id.*

108. *Toth-Lewis ex rel. B.T.L. v. Walden*, No. BC391854, 2010 Jury Verdicts LEXIS 51458 (Cal. Super. Ct. 2010).

109. *Confidential v. Confidential OB/GYN*, 2010 Jury Verdicts LEXIS 5322 (2010) (claiming that the failure of a doctor to inform the mother in her first, miscarried pregnancy that she was a carrier for cystic fibrosis resulted in her husband not being tested and a second child being born with the disorder).

110. *See, e.g., Stavros Bashiadres et al., Direct Genomic Selection*, 2 NATURE METHODS 63 (2005) (studying genetic variants by targeting specific genomic regions).

risks and other gene variants will inevitably be revealed by sequencing if those variants exist. A healthcare regime in which sequencing is routine must grapple with what to do with such secondary, incidental findings, especially when they reveal reproductive choice information. This Part analyzes the reasons to withhold and reasons to return results to adolescents and concludes that in the case of genomic results of reproductive significance, there are greater reasons to return than to withhold.

#### A. POTENTIAL REASONS TO WITHHOLD CATEGORICAL RESULTS FROM ADOLESCENTS

Despite the benefits of informing adolescent reproductive choices with genomic information, one reason not to return results is that knowledge of one's genetic or genomic information could induce unwanted anxiety. Brian Hurley, for example, learned from his ophthalmologist at age thirteen that at some point in his life, he would go blind from retinitis pigmentosa.<sup>111</sup> "It was like having a time bomb inside of me," he remarked about the prognosis.<sup>112</sup> His vision did steadily deteriorate after college, and he had lost the majority of his eyesight by the time he was thirty-three.<sup>113</sup> "The irony," he concluded, "is the anticipation was much worse than the actual loss. It was a relief to stop worrying about when the loss would occur."<sup>114</sup> Though this may reflect the experiences of some, systematic reviews have found "insufficient evidence to inform a nuanced understanding of how children respond to genetic testing."<sup>115</sup>

Public health concerns may also counsel against return of results to the extent that knowledge of one's genomic information reinforces unhealthy life choices that produce a public burden. For example, public health genomic policies could attempt to identify genotypes that modulate smoking status, ini-

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111. PRESIDENTIAL COMM'N FOR THE STUDY OF BIOETHICS ISSUES, PRIVACY AND PROGRESS IN WHOLE GENOMIC SEQUENCING 23 (2012).

112. *Id.*

113. *Id.* at 22.

114. *Id.* at 23.

115. Andrea Patenaude, *Save the Children: Direct-to-Consumer Testing of Children Is Premature, Even for Research*, 36 J. PEDIATRIC PSYCHOL. 1122, 1124 (2011); see also Katherine James et al., *Impact of Direct-to-Consumer Predictive Genomic Testing on Risk Perception and Worry Among Patients Receiving Routine Care in a Preventive Health Clinic*, 86 MAYO CLINIC PROC. 933 (2011) (suggesting that patients receiving predicting genomic risk information does not necessarily influence risk assessment or level of worry).

tiation, cessation, and treatments.<sup>116</sup> While using such an initiative to identify individuals who have a high susceptibility to cancer may motivate them to quit, it may also “enable[] those who are unsuccessful in quitting to blame genetic factors, which would thereby decrease motivation.”<sup>117</sup> Facilitating such genetic fatalism affects the public interest not only because of smoking-related disabilities, but also because the testing itself would be an inefficient use of resources if it did not result in changing individual behavior. Further, inasmuch as knowledge of one’s genetic information can cause anxiety about one’s health,<sup>118</sup> the predictive, prognostic role of genomics (its role in providing risk assessments rather than diagnoses) could contribute to unnecessary surveillance and further testing.<sup>119</sup>

An appropriate policy for return of results to minors should be cognizant of such potential negative psychological responses to knowing one’s genomic information, as well as the limited abilities of adolescents to make well-informed, autonomous decisions. Along this line, legal philosopher Joel Feinberg has posited an influential argument that children possess a set of moral rights to an “open future,” that is, rights not to have important life choices determined by others.<sup>120</sup> Numerous authors have applied Feinberg’s argument in the context of genetic testing, claiming it is generally better to delay until adulthood the decision of whether or not to view one’s genetic results.<sup>121</sup> Feinberg’s claim is that it is the autonomy of adults

116. See, e.g., Evy Cleeran et al., *Public Health in the Genomic Era: Will Public Health Genomics Contribute to Major Changes in the Prevention of Disease?*, 69 ARCHIVES PUB. HEALTH 1, 6–7 (2011).

117. Clarissa Allen, Karine Sénécal, & Denise Avar, *Defining the Scope of Public Engagement: Examining the “Right Not To Know” in Public Health Genomics*, 42 J.L. MED. ETHICS 11, 16 (2014).

118. Though not focusing on adolescent populations, recent surveys have found mixed results, with some people experiencing anxiety from knowing genomic results, others equanimity, and others enthusiasm. See, e.g., Jacqueline Duffour et al., *Reproductive Decision-Making in MMR Mutation Carriers After Results Disclosure: Impact of Psychological Status in Childbearing Options*, 25 J. GENETIC COUNS. 433, 439 (2016) (finding that twelve percent of participants experienced a high level of initial stress from learning results, but that stress decreased over time); Schneider et al., *supra* note 81, at 139.

119. See LAURINDA HARMAN & FRANCES CORNELIUS, *ETHICAL HEALTH INFORMATICS* 257 (3d ed. 2015).

120. Joel Feinberg, *The Child’s Right to an Open Future, in WHOSE CHILD? CHILDREN’S RIGHTS, PARENTAL AUTHORITY, AND STATE POWER* 124, 125–26 (William Aiken & Hugh LaFollette eds., 1980).

121. See, e.g., Joseph Millum, *The Foundation of the Child’s Right to an Open Future*, 45 J. SOC. PHIL. 522, 531–34 (2014).



to make informed choices that is valuable, and their “rights-in-trust” should be protected in childhood.<sup>122</sup>

### 1. Adolescent Sexual Privacy

Feinberg contends genetic information should be withheld until adulthood because it is in the future adult’s interest not to know genetic results in childhood but rather only after possessing sufficiently mature autonomy.<sup>123</sup> In other words, there is an appropriate time to *exercise* the right, where appropriateness is determined by relevant decisional capacities. By parity of reasoning, the appropriate time to know reproductive choice information should be determined by the relevant decisional capacities for knowing that information. The point of returning reproductive risks is to inform reproductive and sexual choices. Thus one could be said to possess the relevant decisional capacities by virtue of making such choices. There are consequently reasons to return results of reproductive significance in adolescence because eighteen percent of people have had sex by age fourteen or younger, thirty percent by sixteen, and most older teens (seventeen to nineteen) are sexually active.<sup>124</sup>

If a child’s reproductive choice information is given to parents, this does not guarantee it gets to the right actor. Parents might forget to inform their child—for example, if the results were revealed in infancy). Or they might be motivated by personal moral convictions not to return results, for example, out of a concern that the information will raise the chances the minor will consider abortion. It seems less likely that parents would maliciously withhold results and more likely that they would not know when to divulge them, because they do not know when their child will begin sexual activity. In short, giving parents the authority to be a conduit, as the ACMG and CSER-PWG ultimately recommend, may do little to get the information to minors when it is appropriate for them to have it. It would indeed seem odd to suppose that minors would ask

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122. Feinberg, *supra* note 120.

123. See *generally id.* (concluding certain rights and responsibilities are best left to adults).

124. Lawrence B. Finer & Jesse M. Philbin, *Sexual Initiation, Contraceptive Use, and Pregnancy Among Young Adults*, 131 PEDIATRICS 886, 886 (2013); see also Gladys M. Martinez & Joyce C. Abma, *Sexual Activity, Contraceptive Use, and Childbearing of Teenagers Aged 15–19 in the United States*, 209 NAT’L CTR. FOR HEALTH STATS. DATA BRIEF 1, 1 (2015) (finding that, of fifteen to nineteen year-olds, forty-four percent of females and forty-nine percent of males had had sexual intercourse).

their parents for this information prior to becoming sexually active.

## 2. Increased Birth Defects in Adolescent Pregnancies

Pregnancies in adolescence are attended by certain birth defect risks less likely to occur later in life. One source of increased birth defect risks is that certain fetal abnormalities will be more likely to develop in adolescent pregnancies. For instance, most pregnancies in adolescence are unplanned: the rate of unplanned pregnancies in sexually active teenage girls is twice that rate in all women.<sup>125</sup> When this unplanned nature is combined with teenage drinking and lower uses of contraception in adolescents than adults, it leads to an increased risk of fetal alcohol syndrome.<sup>126</sup> Further, women planning pregnancies are more likely to be taking prenatal vitamins like folic acid; the greater prevalence of unplanned pregnancies in adolescents consequently poses an increased risk of central nervous system defects.<sup>127</sup>

Another source of increased birth defect risks in adolescent pregnancies is the lower likelihood that those pregnancies will end in abortion. In 2014, eighty-five percent of abortions in the United States were sought by women in their 20s and 30s, while, according to Guttmacher Institute data, fewer than twelve were sought by women younger than twenty.<sup>128</sup> In preliminary data for 2015, the CDC reports that the U.S. fertility rate was 22.3 per 1000 women in the fifteen-to-nineteen-year-old age group, or 249,078 births annually.<sup>129</sup>

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125. Lawrence B. Finer, *Unintended Pregnancy Among U.S. Adolescents: Accounting for Sexual Activity*, 47 *J. ADOLESCENT HEALTH* 312, 313 (2010).

126. Ramona Allard-Hendren, *Alcohol Use and Adolescent Pregnancy*, 25 *AM. J. MATERNAL/CHILD NURSING* 159, 159 (2000) (“Reports indicate that 33.4% of adolescents engage in heavy episodic alcohol consumption, and that 34.8% of adolescents are sexually active by the age of 15 without using any form of contraception.”).

127. Xi-Kuan Chen et al., *Teenage Pregnancy and Congenital Anomalies: Which System Is Vulnerable?*, 22 *HUM. REPROD.* 1730, 1735 (2007) (stating that folic acid intake decreases neural disorders and teenagers are less likely to take folic acid).

128. JENNA JERMAN ET AL., *CHARACTERISTICS OF U.S. ABORTION PATIENTS IN 2014 AND CHANGES SINCE 2008* 5 (2016).

129. Bradley E. Hamilton et al., *Births: Preliminary Data for 2015*, *NAT'L VITAL STAT. REPORTS*, at 2, June 2, 2016.

### 3. Adolescent Health Information Rights as a Limitation on Parental Reproductive Rights

Reproductive choice information may also warrant in utero protection. This Note has described return of reproductive risks as an *adolescent* right because adolescence is when sexual activity is typically initiated. Under Feinberg's open future analysis, the adult's autonomy right to make a reasoned, mature choice whether or not to see genetic results requires protection throughout childhood before it can be exercised.<sup>130</sup> Similarly, if adolescence is when individuals are beginning to make reproductive decisions, then it may be necessary to securely store reproductive choice information securely until then.<sup>131</sup> Feinberg's argument provides reason for *withholding* certain genetic information from children throughout childhood to protect their reproductive autonomy as adults—i.e., so they can make a mature, better-informed decision about whether or not they want to know that information.<sup>132</sup> For reproductive choice information, though, the child's reproductive autonomy is protected by withholding information from *parents* and *encouraging the child* to access it in adolescence prior to becoming sexually active.

This could bring adolescent reproductive rights into tension with the protections surrounding their mothers' abortion right—namely, when the adolescent was still a fetus. It seems possible, though, to respect both sets of reproductive rights. A pregnant woman, on the one hand, could be permitted to use fetal genomic sequencing as part of her choice to determine whether or not to bring a particular pregnancy to term. On the other, rather than being given *all* clinically significant results, she could only be given access to the subset of the fetus's genome that is contemporaneously relevant to *her* reproductive choices.

For instance, fetal genomic sequencing might reveal trisomy-21 (a missing chromosome that signals that the future

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130. See, e.g., Feinberg, *supra* note 120, at 125 (distinguishing “A-C-rights” possessed by adults and children, such as a right not to be punched, from “A-rights,” such as the right to vote, and “C-rights,” rooted in children's dependency on others for food, shelter, and protection).

131. *Id.* at 125–26 (“When sophisticated autonomy rights are attributed to children who are clearly not yet capable of exercising them, their names refer to rights that are to be *saved* for the child until he is an adult, but which can be violated ‘in advance,’ so to speak, before the child is even in a position to exercise them.”).

132. See Millum, *supra* note 121, at 535–36.

child will have Down syndrome), and that fact could inform the pregnant woman's reproductive choice in such a way that she chooses to abort. If she chooses *not* to abort, accessing that part of the fetal genome would not have violated an (future) adolescent right because Down syndrome is not a condition the child born with it risks passing on to progeny. By contrast, fetal sequencing that reveals the fetus is merely the carrier of a recessive gene would arguably not be especially relevant to the pregnant woman's reproductive choices but *would* be important to the reproductive choices of the adolescent into which the fetus may develop. Thus, regardless of whether the woman chooses to abort, a facet of the fetal genome like carrier status might reasonably be kept private from a pregnant woman without unduly inhibiting her reproductive autonomy. While there may be components of the child's genomic information that could be returned to parents because they reveal the parent's *own* reproductive risks, there remain those results, such as *de novo* mutations, that would never be relevant to parents' reproductive choices.

This Part considered whether there are stronger reasons not to return genomic reproductive choice information to minors than to return it. Concerns that this will cause unnecessary anxiety in adolescents have not yet been substantiated by data. Further, it is possible to withhold some of this information in utero without unduly burdening the abortion right. When added to the goals of decreasing the prevalence of birth defects and reducing the liability clinicians face from neonatal litigation, there are compelling reasons to structure a regime of genomic healthcare to encourage individuals to know their reproductive choice information before they become sexually active. Doing this will require systemic, broad reforms as healthcare turns to precision medicine and genomics. These reforms are achievable and are imperative to the goal of reducing the prevalence of birth defects.

### III. SECURING REPRODUCTIVE RIGHTS IN A GENOMIC AGE

Part II explained why reform is needed to protect adolescent reproductive rights in a genomic age. As Feinberg's analysis showed, this Note's concern is only with adolescent rights for indirect reasons. First, the appropriate time to know reproductive choice information is in adolescence, given statistics on sexual initiation. Second, adolescent rights historically have re-

ceived little protection, which will become a pronounced concern in a regime of genomic healthcare that seeks to protect reproductive choice information. On this analysis, it is *general*, *individual* rights that merit protection, rights to make informed reproductive choices.

In Section A, this Part proposes conditions that will be important to secure in order to promote individual knowledge of reproductive choice information. In Section B, the Part anticipates counterarguments that may be parried against the first Section's proposal. Finally, Section C offers a riposte to these counterarguments that explains how the competing interests at stake are best balanced.

#### A. PROMOTING CONDITIONS TO ACT ON REPRODUCTIVE INFORMATION

This Section discusses the conditions necessary for promoting individual knowledge of reproductive choice information. First, the Section will discuss reforms that will be necessary in state abortion laws. Next, it will suggest reforms to clinical guidelines. Finally, the Section will propose that discussions of birth defects, genetics, and inheritance be incorporated into state sex education curricula.

##### 1. Reforms to Abortion Law and Policies

Abortion law and policies will necessitate change to secure adolescent reproductive rights and promote a reduction in birth defects. First, this Note endorses laws that not only allow but use subsidy to promote the option of pre-viability termination for abnormalities. Second, it also endorses subsidy as a means of making abortion, contraception, and genetic testing meaningful options for all.

##### *a. Ensuring Abortion Restrictions Contain Exceptions for Birth Defects*

Legal reforms should promote access to abortions for fetal abnormalities, rather than criminalizing doctors who perform them, as in North Dakota and Indiana. A decade before *Roe*, several states began permitting abortions for genetic abnormalities after the drug thalidomide resulted in numerous cases of birth defects, following the recommendations of the newly published Model Penal Code.<sup>133</sup> Additionally, the earliest ban on

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133. MODEL PENAL CODE § 230.3 (AM. LAW INST., Proposed Official Draft

motive-based abortions, a 1975 Illinois law, prohibited sex-selective abortions but explicitly created an exception for sex-linked chromosomal abnormalities.<sup>134</sup>

North Dakota's law,<sup>135</sup> in contrast, which was informed by model legislation from Americans United for Life,<sup>136</sup> contains no exception for genetic abnormalities. Nor does the Hyde Amendment, under which an abortion to select against fetal abnormalities is not considered "medically necessary"<sup>137</sup> because such abnormalities do not typically threaten the woman's life. In addition to such bans, anti-abortion efforts have pushed mandatory requirements like ultrasounds and counseling prior to an abortion as ways to *burden* the abortion right and protect the state's interest in fetal life. The attendant opportunity costs, travel time, physical invasiveness, and other facets burden the abortion right in the name of informed consent and a woman's "right to know."<sup>138</sup> Not only should these bans be struck down as violating the abortion right, there are also public health reasons to reject them since the effect of these laws is to *increase* the prevalence of birth defects.

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1962) (stating that if a fetus would have serious defects, abortion would be justified).

134. 720 ILL. ANN. STAT. 510/6(8) (1975).

135. N.D. CENT. CODE § 14-02.1-04.1 (2013). For an article that extensively discusses the constitutionality of North Dakota's law, see Carole Peterson, *Reproductive Justice, Public Policy, and Abortion on the Basis of Fetal Impairment: Lessons from International Human Rights Law and the Potential Impact of the Convention on the Rights of People with Disabilities*, 28 J.L. HEALTH 121 (2015).

136. *North Dakota 2014 Report Card*, AM. UNITED FOR LIFE, <http://www.aul.org/states/north-dakota> (last visited Jan. 16, 2016). Describing itself as "the legal architect and builder of the pro-life movement," Americans United for Life was formed in 1971, with its major objectives including ending all abortions and reversing *Roe*. *Issues*, AM. UNITED FOR LIFE, <http://www.aul.org/issue> (last visited Aug. 15, 2015). It is currently active in most states, and the organization claimed credit for twenty-four of the ninety-two abortion restriction laws that were passed in 2011. It was also the organization spearheading efforts in Virginia to require invasive ultrasounds before an abortion could be performed, and also trying to shut down all abortion clinics in Kansas, among other efforts. Kate Sheppard, *Wham, Bam, Sonogram! Meet the Ladies Setting the New Pro-Life Agenda*, MOTHER JONES, <http://www.motherjones.com/politics/2012/08/americans-united-for-life-anti-abortion-transvaginal-ultrasound> (last visited Nov. 1, 2016).

137. *Harris v. McRae*, 448 U.S. 297, 298 (1980).

138. In *Casey*, the Court found the state's informed consent requirement to be unconstitutional as being merely "under the *guise* of securing informed consent," failing to advance a legitimate state interest. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 934 (1992) (emphasis added).

*b. Ensuring Meaningful Access to Abortion, Contraception, and Genetic Testing*

Instead of burdening the abortion right, a better approach is to make reproductive choice information and reproductive risk avoidance *accessible options*. Prior to its decision in *Harris v. McRae* upholding the Hyde Amendment, the Supreme Court had found constitutional a Connecticut law imposing abortion payments on indigent women, stressing that “Connecticut’s regulation is rationally related to and furthers the state’s legitimate interest in encouraging *normal childbirth*.”<sup>139</sup> Though abnormality-selective abortion bans and the Hyde Amendment’s bar on the use of Medicaid funds for such abortions may promote a state’s interest in preventing the termination of fetal life, they run contrary to the state’s interest in normal childbirth. In making reproductive risk avoidance more accessible, the Strong Start for Mothers and Newborns Initiative of the Department of Health and Human Services is an exemplar in the right direction, funding nearly 200 sites with “enhanced prenatal care approaches” to reduce premature births among pregnant Medicaid or CHIP beneficiaries.<sup>140</sup>

States should also look to California’s comprehensive regulations to decrease birth defect risks.<sup>141</sup> California administers a statewide prenatal testing program offering ultrasound, amniocentesis, CVS, and testing for genetic disorders and birth defects.<sup>142</sup> To this end, the state administers a program of subsidy grants for nonprofit prenatal diagnosis centers to offer such services,<sup>143</sup> and requires that testing at these centers be accompanied by genetic counseling.<sup>144</sup> Overall, the program seeks to educate clinicians and the public “concerning the uses of prenatal testing and the availability of the program,”<sup>145</sup> and implements statewide postings where environmental can increase

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139. *Maier v. Roe*, 432 U.S. 464, 464 (1977) (emphasis added); *see also id.* at 477–79 (repeating the emphasis on the state’s legitimate interest in the normalcy of childbirth).

140. *Strong Start for Mothers and Newborns Initiative: General Information*, CTRS. FOR MEDICARE & MEDICAID, <https://innovation.cms.gov/initiatives/Strong-Start/index.html> (last visited Nov. 1, 2016).

141. CAL. HEALTH & SAFETY CODE § 125050–125119.5 (2015).

142. *Id.* § 125050.

143. *Id.* § 125055(e).

144. *Id.* § 125055(c).

145. *Id.* § 125055(b)(1).

birth defect risks.<sup>146</sup> These are all excellent ways to promote knowledge of reproductive choice information.

## 2. Clinical Reforms To Promote Return of Reproductive Risks

Medical recommendations should be reformed to reflect the liability that clinicians and others face from neonatal torts, and to reflect the heightened legal protections accorded to an adolescent's reproductive choice information. Both goals could be furthered by directly and privately returning adolescents their reproductive risks. If the child's genome has already been sequenced, private return of results could involve withholding reproductive choice information until adolescence and then asking parents to step out of the room before results are disclosed. In this way, clinical reforms could strengthen the adolescent-physician relationship.

## 3. Introducing Reproductive Risks into Sex Education

Public interests are best served by encouraging knowledge of reproductive risks in early adolescence rather than waiting until adulthood. Teaching individuals about reproductive risks before the average individual is sexually active could be a rational, legitimate means through which to promote state interests in encouraging normal pregnancy outcomes, fewer unwanted pregnancies (those that result in birth defects), and potentially fewer abortions (by encouraging individuals to make pre-conception choices that decrease the prevalence of fetal abnormalities). There are clear differences between supporting choices not to *conceive* after learning of a reproductive risk and choices to *abort* after testing reveals a fetal abnormality. Both pro-choice and anti-abortion advocates are more likely to coalesce over supporting the former.<sup>147</sup>

Those with more conservative views on sex and reproduction may raise potential countervailing interests. These include objections that public sex education in general is an implicit stamp of approval on premarital sexual activity, that it should only be taught in the home, or that it should promote abstinence as the best option.<sup>148</sup> The incorporation of reproductive risks into extant sex curricula, however, would be *cautionary*

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146. *Id.* § 125055(b)(2)(A).

147. *See infra* notes 163–64 and accompanying text.

148. *See generally* *Plan for Defeating PP – Education: Defeating Planned Parenthood's Public School Sex Education Programs*, STOPP INT'L, <http://www.stopp.org/plan/E> (last visited Nov. 1, 2016).



with regard to sex—not a scare tactic but a realistic presentation of birth defect risks faced by the general population and subpopulations, as well as the attendant “moral hazard”<sup>149</sup> of sexual activity created by the possibility of birth defects. General education about these risks would not incline non-sexually active individuals to initiate sexual activity, and it would encourage those who are sexually active to take into account information relevant for responsible sexual and reproductive choices.

Further, public interests in efficient allocation of resources are served by encouraging knowledge of reproductive risks. For example, one could argue it costs taxpayers *less* money to use public funds for abortion, since the alternative might be a greater allocation of funds to support children who otherwise would have been aborted.<sup>150</sup> Public costs are multiplied several fold if the child is born with a serious disorder for which ameliorative, intensive measures immediately after birth can be taken. Costs are even higher than this when congenital impairments cannot be fully corrected, requiring neonatal care and a lifetime of disability-related public entitlements.<sup>151</sup>

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149. Seana Shiffrin, “*Wrongful Life*,” *Procreative Responsibility, and the Significance of Harm*, 5 *LEGAL THEORY* 117, 117–18, 137 (1999) (describing all choices to procreate to be “morally hazardous” under liberal theory, since procreation involves imposing non-consensual harms on the person who comes into existence); see also DAVID BENATAR, *BETTER NEVER TO HAVE BEEN: THE HARM OF COMING INTO EXISTENCE* (2008) (arguing for the “anti-natal” view—that it is always wrong to have children—and discussing how combining the anti-natal view with common pro-choice views about fetal moral status yield a “pro-death” view about abortion at the earlier stages of gestation); Seana Shiffrin, *Harm and Its Moral Significance*, 18 *LEGAL THEORY* 357, 358 (2009) (examining the definition of “harm” from birth defects in a legal and philosophical sense).

150. See, e.g., *Comm. to Defend Reprod. Rights v. Myers*, 625 P.2d 779, 794 (Cal. 1981) (“[W]hatever money is saved by refusing to fund abortions will be spent many times over in paying maternity care and childbirth expenses and supporting the children of indigent mothers.”).

151. Grounding these public interests on cost savings is a delicate matter. It may reasonably offend those living with disabilities if public cost savings is a reason for encouraging fewer people with congenital birth defects from coming into existence. This Note has described return of reproductive risks as a public health issue not because of the healthcare costs associated with birth defects. Rather, by stressing the importance of returning genomic reproductive choice information, this Note has emphasized the value of giving patients the *choice* to know and act on such information, leaving it for them, rather than states, to choose how to act in light of that information. See, e.g., Schneider, *supra* note 81, at 141 (noting that participants “described how offering choice is paramount to making genomic carrier screening ‘worth knowing’ since peo-

Finally, public interests are served by policies that buttress contraception and abortion as fundamental liberty rights, rights to make one's own decisions autonomously and not being unduly burdened in making major life decisions, such as whether or not to have a child. One author gives the example of a woman in her mid-30s who finds her reproductive autonomy constrained because she did not know about the increased risk of infertility she would face because of her age; the lack of education on this front "constrains her ability to make a fully informed choice about when to have children."<sup>152</sup> A lack of information and misinformation can similarly constrain adolescent reproductive autonomy. For instance, many U.S. college-aged women report that the lesson that they learned from their school's sex education was to "be safe and use protection" and "use birth control so you don't get pregnant," which may contribute to a misperception that it is normal to have very high fertility.<sup>153</sup> In the case of reproductive risks, the current absence of discussions about birth defects and genetic testing in public sex education may give adolescents the misimpression that those risks do not exist. In reality, ten to twenty percent of all pregnancies result in abnormalities severe enough that the fetus is miscarried,<sup>154</sup> birth defects occur in one of thirty-three births, and they are the leading cause of infant deaths.<sup>155</sup>

With the goal of informing reproductive decisions when individuals start making them, this education should begin in middle school, since a substantial amount of the population is sexually active by then.<sup>156</sup> The integration in recent years of user-friendly technologies like tablets into both the educational and clinical spheres can support comprehension in early adolescence of key concepts like DNA and genetics. The Integrative Genomics Viewer, for example, allows individuals who have their genome sequenced to view the entire sequence on an iPad, with interactive features enabling them to zoom in to particular

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ple will bring their unique range of emotions, expectations, and prior experiences into their decision-making").

152. Lucke, *supra* note 19, at 58.

153. Tanya L. Boone, *Messages About Sexuality: An Ecological Perspective*, 15 *SEX, SEXUALITY & SOC'Y* 437, 437 (2015).

154. *Miscarriage*, MAYO CLINIC (July 20, 2016), <http://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/basics/definition/con-20033827>.

155. *Birth Defects*, *supra* note 102.

156. *Finer & Philbin*, *supra* note 124, at 888 (stating that around 7.9 percent of adolescents have had sex by their fourteenth birthday).

segments and variants, with explanations of their significance.<sup>157</sup>

In high school, the topic can further be incorporated into classes in the natural sciences, especially through discussions of inheritance in biology.<sup>158</sup> Discussions of contraception and abortion should be supplemented with discussions of genetic and genomic testing, including carrier screening and prenatal diagnosis. Other efforts could highlight the potential effects of environmental toxins, tobacco, and alcohol use while pregnant, as well as the benefit of prenatal vitamins. Reproductive risks are almost entirely absent in most states' sex education curricula and in any federal sex-education "common core,"<sup>159</sup> a lacuna that this Note has argued will become palpable in a genomic age.

## B. ACCOMMODATING POTENTIAL OBJECTIONS

A variety of interest groups may object to the proposals suggested in the first section of this Part. Objections may come from anti-abortion, pro-choice, and disability rights interest groups, as well as groups with conservative sexual values. This Section briefly considers the counterarguments these interest groups might marshal against a regime that promotes knowledge of reproductive information.

### 1. Abortion-Related Objections

Anti-abortion objections only seem to apply inasmuch as knowledge of reproductive choice information is associated with contraception and abortion. Regarding contraception, consider the Pope's recent comment that, in the face of the risk of microcephalic births, contraception may be the "lesser of two evils."<sup>160</sup> More strenuous religious objections would likely focus not on abstinence or birth control as ways of avoiding birth defects, but rather on the use of abortion.<sup>161</sup>

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157. Helga Thorvaldsdóttir et al., *A Genomic Data Viewer for iPad*, 16 *GENOME BIOLOGY* 46 (2015) (explaining the Integrative Genomics Viewer app for iPad).

158. *E.g.*, Kassuba, *supra* note 18 (listing ideas of how to integrate information about genetic disorders in lesson plans).

159. *See* SEXUALITY INFO. & EDUC. COUNCIL OF THE U.S., *GUIDELINES FOR COMPREHENSIVE SEXUALITY EDUCATION: KINDERGARTEN – 12TH GRADE* (3d ed., 2004) (containing no content about reproductive risks).

160. *Zika Virus: Pope Hints at Relaxation of Contraception Ban*, *BRITISH BROADCASTING CORP.* (Feb. 18, 2016), <http://www.bbc.com/news/health-35608324>.

161. *See supra* note 37 and accompanying text.

Pro-choice advocates may raise objections as well. Most notably, it is possible that public subsidies making abortion and genetic testing more accessible could in some cases *inhibit* reproductive autonomy. Jennifer Denbow, for example, puts pressure on the distinction between reproductive choice and reproductive autonomy by noting the example of a woman who fears abuse if she does not obtain an abortion.<sup>162</sup> Tweaking Denbow's example to fit the context of subsidizing genetic testing options, one might imagine a woman with an abusive partner who in no circumstances wants a child born with serious impairments. Such a hypothetical could be even more likely to lead to abuse than the woman's choice not to abort a healthy child. In short, a personalized medicine culture in which genetic testing is widespread will increase reproductive choice, but this will not always thereby increase reproductive autonomy.

At least in the pre-conception context, one would anticipate consensus between anti-abortion and pro-choice interest groups on policies that encourage responsible pre-conception reproductive decisions, by increasing the availability of reproductive choice information. Even in the post-conception context, recent surveys support broad consensus for permitting abortions to select against serious defects; in a 2012 survey by the National Opinion Research Council, 77.1 percent of people polled indicated they believed a woman should be able to obtain an abortion "if there is a serious defect in the fetus,"<sup>163</sup> while a Gallup poll in the same year found that only forty-one percent of Americans identified as pro-choice.<sup>164</sup> Thus there is good reason to think legislative initiatives to provide public subsidy of prenatal testing options would garner broad public support across party lines. Individuals will likely find this increase in reproductive choices valuable,<sup>165</sup> whether or not they utilize such options.

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162. Jennifer Denbow, *Abortion: When Choice and Autonomy Conflict*, 20 BERKELEY J. GENDER L. & JUST. 216, 217 (2005) ("[In] the extreme case of the poor, abused, pregnant woman . . . the option to terminate her pregnancy can act to undermine this woman's autonomy . . .").

163. TOM W. SMITH & JAESOK SON, TRENDS IN PUBLIC ATTITUDES TOWARDS ABORTION (2013), [http://www.norc.org/pdfs/gss%20reports/trends%20in%20attitudes%20about%20abortion\\_final.pdf](http://www.norc.org/pdfs/gss%20reports/trends%20in%20attitudes%20about%20abortion_final.pdf).

164. *Abortion*, GALLUP, <http://www.gallup.com/poll/1576/abortion.aspx> (last visited Nov. 1, 2016).

165. Schneider, *supra* note 81 (finding that participants in genetic screening found the experience valuable).

## 2. Disability Rights Objections

The strongest case for increasing knowledge of reproductive risks is the avoidance of especially serious congenital conditions, such as those that are painful and lethal in early childhood.<sup>166</sup> However, this creates a slippery slope. Microcephaly may be accompanied by profound cognitive impairment, but children with it typically can still experience over a decade of life.<sup>167</sup> Down syndrome is associated with cognitive impairment, heart defects, and shortened lifespans, but according to one frequently cited survey, those with the syndrome express a high level of wellbeing and satisfaction with life.<sup>168</sup> Further

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166. Some wrongful life claims brought on behalf of infants born with such conditions. *See, e.g.*, *Viccaro v. Milunski*, 551 N.E.2d 8, 9 (Mass. 1990) (“Adam . . . will require special medical care throughout his life and will suffer substantial physical pain and mental anguish.”); *Iafelice by Iafelice v. Zarafu*, 534 A.2d 417, 417 (N.J. Super. Ct. App. Div. 1987) (discussing an infant being born with hydrocephalus, causing “interventricular hemorrhage and hydrocephalus so that she now functions at the level of a four-month-old infant who will require permanent institutional care”); *Spencer v. Seikel*, 742 P.2d 1126 (Okla. 1987) (discussing an infant being born with hydrocephalus); *Payne v. Myers*, 743 P.2d 186, 187 (Utah 1987) (describing the syndrome as “a rare, genetically transmitted, and progressively degenerative neurological disorder that is characterized by widespread demyelination of the brain sheath, causing severe motor disorders and eventually death”); *Gallagher v. Duke Univ.*, 638 F. Supp. 979 (M.D.N.C. 1986) (discussing how the plaintiff, Jennifer Gallagher, died within three weeks of birth as a result of the defects from Trisomy 9); *Goldberg v. Ruskin*, 471 N.E.2d 530, 532 (Ill. App. Ct. 1984) (“Jeffrey Goldberg . . . alleged . . . he ‘was born with Tay-Sachs disease and has suffered and will continue to suffer loss of motor function, loss of sensory function, blindness, deafness, pain, disability and numerous other injuries resulting in damages of a personal, permanent and pecuniary nature and finally certain death.’”); *Rubin v. Hamot Med. Ctr.*, 478 A.2d 869 (Pa. Super. Ct. 1984) (discussing an infant being born with Tay Sachs disease); *Dorlin v. Providence Hosp.*, 325 N.W.2d 600, 601 (Mich. Ct. App. 1982) (describing plaintiff Desiree’s future prospects as “a life of disease, sickness, and suffering”).

167. Imaizumi, *supra* note 11, at 133.

168. Brian G. Skotko et al., *Self Perceptions from People with Down Syndrome*, 155A AM. J. MED. GENETICS 2360 (2013); *see also* Brian Skotko, *With New Prenatal Testing, Will Babies with Down Syndrome Slowly Disappear?*, 94 ARCH. DISEASE CHILDHOOD 823 (2009) (discussing the potentially decreasing incidence of babies born with Down Syndrome due to prenatal testing); Monica Rafie & Tracy Winsor, *How Can We Stop More Down Syndrome Babies from Being Aborted?*, LIFESITE (Dec. 16, 2011), <https://www.lifesitenews.com/all/date/2011/12/16#article-how-can-we-stop-more-down-syndrome-babies-from-being-aborted> (citing heavily to Brian G. Skotko); Malcolm Ritter, *Comfort or Conflict: Earlier Down Syndrome Test*, WASH. TIMES (June 12, 2011), <http://www.washingtontimes.com/news/2011/jun/12/comfort-or-conflict-earlier-down-syndrome-test> (citing to Skotko as someone against disability-selective abortions); Brian Skotko, *Will America Cull People with Down Syndrome?*, USA TODAY (Nov. 15, 2011), <http://usatoday30.usatoday.com/news/opinion/>

congenital “impairments” could include late-onset conditions like Huntington’s disease, or less severe conditions, like color-blindness or anosmia, the inability to smell. At some point, it is unclear whether such a condition has sufficient normative salience to be considered a reproductive risk.

Normative salience and individual reproductive choices, in turn, will largely be informed by the severity classification of the congenital condition. This is borne out by two 2016 publications offering a reproductive decision aid for patients who undergo preconception screening via genomic sequencing.<sup>169</sup> In developing a taxonomy of birth defects, a taxonomy empirically validated to reflect both patient and expert judgments,<sup>170</sup> there was ample disagreement regarding what conditions should be classified as “serious.”<sup>171</sup> As the authors conclude, “Determining what conditions are described as ‘serious’ is complicated by the subjectivity of the label and the potentially wide-ranging societal implications of that label.”<sup>172</sup>

A particular risk created by the slippery slope of defining severity is the expressive effect it may have on the community of people living with disabilities. This is the sentiment evident behind Indiana’s 2016 abnormality-selective abortion ban,<sup>173</sup> as well as behind failed 2015 legislative bills in Ohio<sup>174</sup> and South Dakota.<sup>175</sup> Similarly, recommending to people that a child with hereditary deafness is a “risk”—as seems implicit in newborn aural screening tests routinized in every state—might smack of ablism to the deaf community.<sup>176</sup>

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forum/story/2011-11-14/blood-test-downsyndrome/51202078/1 (discussing Sequenom’s MaterniT21 test); Rebecca Taylor, *99% of Adults with Down Syndrome Report Being Happy in Life*, LIFENEWS (Oct. 6, 2011), <http://www.lifenews.com/2011/10/06/99-of-adults-with-down-syndrome-report-being-happy-in-life> (“The culture of death says, ‘Better dead than have Downs.’ But 99% of adults with Down Syndrome report they are happy with their lives . . . . [T]he price of embracing the culture of death, of using death as a ‘medical treatment’—it is quite literally the elimination of happiness.”).

169. Korngiebel et al., *supra* note 72.

170. Leo et al., *supra* note 72.

171. *Id.* at 579–80 (“Participants had difficulty distinguishing between mild and serious medical problems . . . the appraisal of severity may be more complex than we anticipated.”).

172. Korngiebel et al., *supra* note 72, at 566.

173. Tribune News Serv., *supra* note 36.

174. H.B. 135, 131st Gen. Assemb. (Ohio 2015).

175. H.B. 1156, 90th Leg. Assemb. (S.D. 2015).

176. A critique of ableism might stress that “disability” and “impairment” are in large part socially constructed concepts. See, e.g., Ron Amundson, *Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics*, in *QUALITY*

To mitigate this potential slippery slope, there should be efforts to provide individuals and potential parents with accurate, unbiased information about reproductive risks. For example, a geneticist known for opposing selection against Down syndrome<sup>177</sup> contends that the obstetric view of the syndrome is overall negative.<sup>178</sup> One response to this concern can be seen in laws in Massachusetts,<sup>179</sup> Virginia,<sup>180</sup> Kentucky,<sup>181</sup> and Missouri,<sup>182</sup> according to which health departments must provide physicians with the most up-to-date information on life with Down syndrome and treatment options. Doctors are encouraged to give this information to all pregnant women who receive a prenatal Down syndrome diagnosis. While the first three states leave dissemination of this information optional, Missouri requires doctors to provide it.<sup>183</sup> Unbiased return of results is part of the basic standard of care required of genetic counselors and other clinical personnel.<sup>184</sup> Holistic information can be a meaningful corrective to any coercive pressures the availability of testing creates—pressures to avoid birth defects—and it can help dispel inaccurate beliefs in the general public about life with disabilities.

Thus this Note concludes that a genomic healthcare system cannot escape problems of choosing which unknown variants to

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OF LIFE AND HUMAN DIFFERENCE: GENETIC TESTING, HEALTHCARE, AND DISABILITY 101, 101–24 (David Wasserman et al. eds., 2005); Harlan Lane, *Do Deaf People Have a Disability?*, 2 SIGN LANG. STUD. 356 (2002); Solveig Reindal, *Disability, Gene Therapy, and Eugenics—A Challenge to John Harris*, 26 J. MED. ETHICS 89 (2000).

177. See *supra* note 168 (concerning specifically works written by author Brian Skotko).

178. Brian Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continue Their Pregnancies Evaluate Their Health Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670, 676 (2005).

179. MA. GEN. LAWS, ch. 111, § 70H(b) (2016) (requiring up-to-date information and contact information on Down Syndrome resource centers).

180. VA. CODE ANN. § 54.1-2403.01(b) (2016) (requiring “up-to-date, scientific information”).

181. KY. REV. STAT. § 211.192 (2015) (requiring “up-to-date, evidence based information”).

182. MO. REV. STAT. § 191.923.1 (2015) (requiring “current information”).

183. *Id.* § 191.923.3 (2015) (“The *physician* . . . shall provide the patient with current information.” (emphasis added)).

184. *E.g.*, Vasantha Muthuswamy, *Ethical Issues in Genetic Counselling with Special Reference to Haemoglobinopathies*, 134 INDIAN J. MED. RES. 547, 548 (2011) (“Nondirective counselling, a hallmark of the genetics profession, is largely in accordance with the principle of respect for patient autonomy and incorporates . . . other ethical principles as well.”).

prioritize in research, which results should be returned to clinicians, and which ones should be returned to parents and adolescents. In making such choices, genomic healthcare will inevitably implicate concerns of the disabled community. This Note has situated return of results in the context of the relationships between adolescent, physician, and parent. In these contexts, individuals have constitutionally protected rights to access contraception and abortion, and neonatal litigation has shown the extent courts are willing to compensate plaintiffs when malpractice is the proximate cause of birth defects. We should not ignore the threats to communities of people with disabilities that could develop in a regime that more effectively sought to eliminate birth defects, but nor should we capitulate in letting those concerns stymie progress in reducing the prevalence of birth defects.

### CONCLUSION

Clinical genomics is a quickly burgeoning field, with collection of individual genomic data already occurring in the prenatal and early childhood contexts at the initiation of parents, and further collection and return to parents likely soon to become routine through state-run newborn genomic screening programs. Such a healthcare regime will necessitate regulatory reform to protect the interests of adolescents, parents, women, clinicians, and future children when sequencing reveals results of reproductive significance.

This Note has endorsed state subsidy of options to increase reproductive choice information, including newborn genomic screening, sex education about birth defects, prenatal testing, and individual pre-conception carrier screening via sequencing. Stressing pre-conception knowledge of reproductive choice information can make options possible that reduce the prevalence of birth defects, promotes reproductive autonomy, and seems acceptable to anti-abortion interest groups. Their interests and those of disability rights groups can be furthered by requiring holistic, accurate information about life with birth defects to be provided to women considering a post-abnormality-diagnosis abortion.

The Note has stressed the values of reproductive autonomy and of decreasing the prevalence of serious birth defects, which implicitly suggests the value of neonatal litigation. That is, the Note has defended the value of knowing reproductive choice information, such that individuals can have a legitimate claim



against clinicians for failing to disclose such information. Neonatal torts have received a hostile reaction from states, yet they will be an important safeguard in a genomic age to ensure clinicians disclose reproductive choice information. There is some traction to the claim that increased liability will induce providers to offer less testing, avoiding a potential source of liability. However, this line of reasoning fails to account for the antecedent professional recommendations that clinicians should return reproductive choice information; given those guidelines, a failure to offer testing itself would breach a clinician's duty of care. If neonatal causes of action are allowed in more jurisdictions, courts should be cognizant that obstetricians already are subject to more liability than any other medical subfield (excepting neurosurgery);<sup>185</sup> coupled with the new role of genomics and the complexity of understanding and conveying genomic results, this should color expectations of what can reasonably be expected of clinicians.<sup>186</sup>

Birth defect epidemics, from the thousands of infants born with congenital rubella syndrome from 1962 to 1965,<sup>187</sup> to the thousands expected to be born with microcephaly in 2016 because of the Zika epidemic, raise public awareness of this Note's topic. But the risk of birth defects attends *every* pregnancy. Thus this Note has proposed structural reforms for the impending regime of genomic healthcare to facilitate return of reproductive choice information. The question of how to respond to the unfortunate reality of birth defects involves having to balance incompatible anti-abortion, pro-choice, pro-parental, and pro-disability interests. Yet rather than allowing this to stymie progress in abortion politics, this Note has proffered a *modus vivendi* that strikes a balance between these competing interests in the service of making headway in decreasing the prevalence of birth defects.

By increasing access to reproductive choice information, as well as access to the reproductive technologies that allow one to act on that information, states can thereby help create the con-

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185. Adam S. Levine, *The Best and Worst States for OB/GYN Practice: A Professional Liability Perspective*, CONTEMP. OB/GYN (Apr. 6, 2015), <http://contemporaryobgyn.modernmedicine.com/contemporary-obgyn/news/best-and-worst-states-obgyn-practice-professional-liability-perspective-0>.

186. The American College of Obstetrics and Gynecology has suggested there may be a shortage of 9000 to 14,000 obstetricians over the next twenty years, in part, because of the cost of professional liability insurance, and because of a fear of being sued. *Id.*

187. RUBIN, *supra* note 13, at 21.

ditions necessary for individuals to make informed reproductive choices. The themes developed in this Note underlie important facets that will continue to take form as the global community seeks to halt Zika virus, however, since the birth defects are not resultant from genetic variation, those issues are not peculiar to genomic healthcare. Still, genetic birth defects are not a rare occurrence, and this Note has attempted to make initial headway in anticipating and resolving some of the myriad issues they will pose in a genomic age.