University of Pittsburgh School of Law

Scholarship@PITT LAW

Articles

Faculty Publications

2015

Normalizing Disability in Families

Mary Crossley

University of Pittsburgh School of Law, crossley@pitt.edu

Follow this and additional works at: https://scholarship.law.pitt.edu/fac_articles

Part of the [Civil Rights and Discrimination Commons](#), [Disability Law Commons](#), [Disability Studies Commons](#), [Dispute Resolution and Arbitration Commons](#), [Family Law Commons](#), [Family, Life Course, and Society Commons](#), [Health Law and Policy Commons](#), [Law and Gender Commons](#), [Law and Society Commons](#), [Legislation Commons](#), [Other Anthropology Commons](#), and the [Reproductive and Urinary Physiology Commons](#)

Recommended Citation

Mary Crossley, *Normalizing Disability in Families*, 43 *Journal of Law, Medicine and Ethics* 224 (2015).

Available at: https://scholarship.law.pitt.edu/fac_articles/411

This Article is brought to you for free and open access by the Faculty Publications at Scholarship@PITT LAW. It has been accepted for inclusion in Articles by an authorized administrator of Scholarship@PITT LAW. For more information, please contact leers@pitt.edu, shephard@pitt.edu.

Normalizing Disability in Families

Mary Crossley

In “Selection against Disability: Abortion, ART, and Access,” Alicia Ouellette probes a particularly vexing point of intersection between ART and abortion: how negative assumptions about the capacities of disabled persons and the value of life with disability infect both prospective parents’ prenatal decisions about what pregnancies to pursue *and* fertility doctors’ decisions about providing services to disabled adults. This commentary first briefly describes what I view as Ouellette’s key points and her article’s most valuable contributions. It then suggests further expanding the frame of reference for Ouellette’s discussion. Viewing decisions about who can reproduce and what children will be born as fundamentally decisions about family suggests ways of drawing on intersectional approaches and growing public acceptance of nontraditional families to promote acceptance of people with disabilities as valued family members — without limiting reproductive liberties.

Ouellette’s Contributions

Ouellette’s starting point is the “disability critique” of prenatal selection, an interlocking set of arguments describing harms associated with future parents’ decisions to screen embryos or fetuses for potentially disabling traits in order to permit decisions about whether to proceed with a pregnancy. The critique asserts that these practices devalue the lives of persons living with the trait selected against, are based on misinformation, and harm the parent-child relationship.¹ This critique is not new, but Ouellette points to several circumstances meriting its reconsideration: the predicted advent of whole genome prenatal sequencing, the recent growth of state laws prohibiting sex-selective abortions, and evidence that some fertility doctors refuse to provide ART services to adults with a disability because of concerns about their capacity to parent.²

Ouellette is right about prenatal trait selection’s renewed currency. With recent reports of researchers sequencing a fetal genome from cell-free fetal DNA in a pregnant woman’s blood, ethicists are pondering the potential uses of the broad range of genetic information soon to be available earlier in pregnancy.³ Many state legislators, by contrast, are focusing narrowly on prohibiting prenatal selection based on fetal sex. As the public dialogue on prenatal trait selection heats up, Ouellette’s reminder of the implications of parental selection against disability for people living with disabilities is valuable.

Mary Crossley, J.D., is a Professor of Law at the University of Pittsburgh School of Law. Her research has focused on the law’s response to instances of inequality in health care financing and delivery, particularly with respect to persons with disabilities.

Ouellette's contribution, however, lies primarily in connecting the disability critique of prenatal selection against disability and the emergence of laws prohibiting sex-based selection to the continuing discrimination that many adults with disabilities face when seeking assistance from fertility clinics.⁴ Ouellette links prenatal decisions selecting against disability to fertility specialists' refusal to serve disabled adults by situating both practices as "part of the same culture of pernicious discrimination in medicine."⁵ Research reports and anecdotal accounts of physicians' negative attitudes toward the value of life with disability and failures to build inclusive practices provide context for how prospective parents are counseled about prenatal testing and for the specialists' decisions.⁶

Ouellette is right about prenatal trait selection's renewed currency. With recent reports of researchers sequencing a fetal genome from cell-free fetal DNA in a pregnant woman's blood, ethicists are pondering the potential uses of the broad range of genetic information soon to be available earlier in pregnancy.

Ouellette also highlights a more direct linkage. Laws prohibiting some forms of prenatal selection while permitting disability-based selection embody implicit judgments. These judgments about the value of different lives and the equality of different groups may inform fertility doctors' decisions whether to serve disabled adults. In short, she argues, the laws' seemingly official acceptance of prenatal selection against disability contributes to medical providers' persistent discrimination against disabled adults.⁷

Despite these concerns, Ouellette resists any impulse toward extending sex-selection bans to include disability-based selection, maintaining that legal protections for reproductive freedom should encompass parental freedom to select for any trait. To her mind, the value of reproductive liberty further links prenatal selection against disability and disabled adults' access challenges.⁸ This linkage is less direct, but it is plausible that arguments for laws designed to ensure that prospective parents make the "right" choice about legitimate bases for trait selection might also justify laws (or professional practices) to ensure that disabled adults make the "right" choice about whether to have children.⁹

Expanding the Frame: The Centrality of Family

Ouellette frames prenatal selection against disability and fertility providers' discrimination against disabled adults as interacting within a biased professional culture, and she argues that this culture, not legal protections for individual choice, needs changing. I suggest another important link between the two practices — the centrality of family. Ouellette notes in passing that disability-based selection implicates "familial" as well as reproductive liberty, but she focuses on how professional culture and legal rules affect and constrain individuals' reproductive choices.¹⁰ Expanding the frame of reference to consider these decisions primarily as choices about family, involving a broad and enduring set of relations and experiences, not simply reproductive processes, may suggest additional approaches.

For example, when a woman (or a couple) undergoes prenatal testing and receives results indicating that the fetus has a gene associated with Down syndrome or another disability, the choice is not simply whether to terminate the pregnancy (a decision about reproducing). Instead, the question is how the information affects the prospective parents' expectations regarding parenthood and family. Parents may reflect on what they cherish most in relationships and whether the predicted impairment might detract from or enhance the likelihood of strong parent-child bonds. They may do some soul searching about their capacities to parent a child who differs from them in a particular way.¹¹ And many parents probably consider how the emotional, physical, and financial demands sometimes associated with parenting a child with a disability will affect them and other children already in the family.¹² These considerations, and others, will be filtered through the parents' broader religious, social, or political values.

Similarly, a disabled adult's decision to employ ART to have a child requires anticipating how the disability will affect family life and the parent's ability to provide routine care and nurture. And a fertility specialist's decision whether to provide services to a disabled adult may depend on a subjective assessment of the adult's ability to parent competently over a long period of time. Providers' judgments may rest on misunderstandings about a disabled person's capacities and available supports, as well as a narrow vision of family flourishing. As Ouellette notes, discrimination by fertility clinics is similar to the barriers disabled adults encounter when seeking to adopt a child and their greater risk of losing custody of children when child welfare workers and judges doubt their ability to pro-

vide a safe environment.¹³ Skepticism about a disabled person's parental fitness may reflect a failure to consider the full web of family supports devoted to raising a child. For example, a parent with an intellectual disability may be able to raise a child with support from his own parents or siblings, but judges may focus only on the parent's limitations and not consider the child's full family life.¹⁴

Framing prenatal selection decisions and disabled adults' access to fertility services as choices fundamentally about family may better capture the decisions'

Framing prenatal selection decisions and disabled adults' access to fertility services as choices fundamentally about family may better capture the decisions' complexity and the diversity of values, preferences, and family arrangements entailed.

complexity and the diversity of values, preferences, and family arrangements entailed. Recognizing this complexity and diversity compels rejecting the notion that the government can make better decisions than the individuals whose lives are involved. And recognizing that forces broader and more enduring are at play than the clinical encounters occurring before or during pregnancy suggests strategies — in addition to working to change a biased medical culture — for validating and supporting people with disabilities as family members. This commentary concludes by briefly sketching a few ideas along these lines.

Normalizing Disability in Families

Ouellette argues that, from a disability rights perspective, "chang[ing] the culture in which selection decisions are made" is preferable to legislative constraints on trait selection practices. Most of the specific culture change ideas she suggests, however, involve changing the medical culture and clinical practices surrounding prenatal selection. These worthwhile suggestions should be supplemented by broader efforts to increase the information available about and change popular conceptions of people with disabilities as family members.

Some steps to increase information available to prospective parents are already underway. In 2008, Congress passed the Prenatally and Postnatally Diagnosed Conditions Awareness Act¹⁵ with bipartisan support. The law calls for government funding of projects to

increase the information on a full range of outcomes and supports that prospective parents receive with test results diagnosing Down syndrome or other conditions. Several recent state laws go further, by requiring a professional conveying positive test results for Down syndrome to actually provide parents with both up-to-date information and contact information for support groups.¹⁶

These laws hold the potential to counteract negative assumptions about disability that often color medical advice regarding prenatal selection. But, as Asch and

Wasserman have argued, their failure to require the provision of information earlier, when women are deciding *whether* to seek prenatal testing, is a limitation.¹⁷ They emphasize the centrality of family to these decisions: "Women who want to test their fetuses prenatally should be able to do so, but they should only be offered testing as part of a process of exploring their goals and values for parenting and family."¹⁸ Providing information earlier, particularly if it includes

the perspectives of disabled persons and their families, may offer another benefit. As Emens suggests, providing an "inside view" of disability to the numerous prospective parents who consider prenatal testing could contribute to broader shifts in public understanding of the value of accessibility and disability inclusion.¹⁹

Beyond strategies to improve the information prospective parents receive about particular disabilities, contemporary shifts in public attitudes toward family diversity may also support efforts to normalize disability as part of family life. Recent demographic changes in family composition and marital patterns have done much to disrupt traditional conceptions of the "normal" family. And the rising tide of the marriage equality movement has been driven in part by narratives of same-sex couples as devoted parents and integral parts of extended families. This remarkable shift in public opinion may offer the disability rights community lessons for promoting public (and medical) acceptance of diverse embodiments of family and parenting.

Thinking about lessons from other movements also suggests how cross-movement efforts might promote commonly held values regarding inclusive and supportive conceptions of family and protection of reproductive autonomy. Historically, the disability rights and reproductive rights movements have not worked together, largely because of their conflicting approaches to prenatal testing and selective abortion.²⁰

In recent years, however, work to bring these communities together has highlighted legal and social constraints that hold women having children responsible for eliminating inequities associated with disability, race, gender and sexual orientation. Roberts and Jesudason describe using an intersectional approach to foster dialogue among women about common experiences of how “interlocking systems of inequity based on gender, race and disability...support policies that rely on women’s management of genetic risk rather than social change.”²¹ By articulating shared values regarding family, reproduction and genetic technology, women identifying with diverse groups were able to identify common policy goals and coordinate their advocacy.²²

Conclusion

These ideas about normalizing and valorizing disability within families, with support for disability and reproductive rights from across movements, suggest a wide (and challenging) frame of reference. But only by changing the political and social context – along with the clinical context – will reproductive choices by disabled adults *and* the prospective parents of disabled children be accurately informed and authentically free.

References

1. A. Ouellette, “Selection against Disability: Abortion, ART, and Access,” *Journal of Law, Medicine & Ethics* 43, no. 2 (2015): 211-223.
2. *Id.*
3. I. Yurkiewicz et al., “Prenatal Whole-Genome Sequencing – Is the Quest to Know a Fetus’s Future Ethical?” *New England Journal of Medicine* 370, no. 3 (2014): 195-197.
4. Nearly a decade ago I suggested that these practices illustrate ways that ART implicates equality concerns. M. Crossley, “Dimensions of Equality in Regulating Assisted Reproductive Technologies,” *Journal of Gender, Race & Justice* 9, no. 2 (2005): 273-289. Ouellette goes further by identifying how laws prohibiting sex-based selection connect the two practices.
5. See Ouellette, *supra* note 1.
6. *Id.*
7. *Id.*
8. *Id.*
9. B. Fordham, “Disability and Designer Babies,” *Valparaiso University Law Review* 45, no. 4 (2011): 1473-1528.
10. See Ouellette, *supra* note 1.
11. See, generally, A. Solomon, *Far From the Tree* (Scribner: New York, 2012).
12. K. Czapanskiy, “Chalimony: Seeking Equity Between Parents of Children with Disabling Conditions and Chronic Illnesses,” *N.Y.U. Journal of Law & Social Change* 34, no. 2 (2010): 253-298.
13. See Ouellette, *supra* note 1.
14. S. Wessler, “Should a Mental Illness Mean You Lose Your Kid?” *ProPublica*, available at <<http://www.propublica.org/article/should-a-mental-illness-mean-you-lose-your-kid>> (last visited April 12, 2015).
15. S.B.1810, Pub. L. 110-374 (2008).
16. M. Leach, “Delaware and Maryland Join Massachusetts and Kentucky in Enacting Laws to Provide Information with a Down Syndrome Test Result,” available at <<http://www.downsyndromeprenataltesting.com/delaware-and-maryland-join-massachusetts-and-kentucky-in-enacting-laws-to-provide-information-with-a-down-syndrome-test-result/>> (last visited April 12, 2015).
17. A. Asch and D. Wasserman, “Informed Consent and Prenatal Testing: The Kennedy-Brownback Act,” *AMA Journal of Ethics* 11, no. 9 (2009): 721-724.
18. *Id.*, at 723.
19. E. Emens, “Framing Disability,” *University of Illinois Law Review* 2012, no. 5 (2012): 1383-1441.
20. D. Roberts and S. Jesudason, “Movement Intersectionality: The Case of Race, Gender, Disability, and Genetic Technologies,” *Du Bois Review* 10, no. 2 (2013): 313-328.
21. *Id.*, at 318.
22. *Id.* (describing the work of the organization Generations Ahead).