



The Paradox of Disability in Abortion Debates

Sujatha Jesudason (Generations Ahead) and Julia Epstein (Disability Rights Education and Defense Fund)

There is a curious paradox on both sides of abortion debates involving how we talk about disability. Reproductive rights advocates may employ a view of disability as a tragic state that always justifies a decision to terminate a pregnancy, even a planned and wanted pregnancy, while anti-abortion advocates state their value for all life, including individuals with and without disabilities. Yet the anti-choice camp, wanting these children to be born, sometimes opposes policies that make it easier to meet the needs of families raising children, including children with disabilities, whereas the pro-choice side, arguing for the right to terminate these pregnancies, tends to champion funding for the social services and support programs all families need, including families of children with disabilities.¹

Disability rights and reproductive rights inexorably entwine and sometimes come into conflict, particularly on the issue of later abortion. In acknowledgment of the disability community perspective and in alignment with the values of the reproductive rights movement, it is critical to untangle these paradoxical stances and to work to improve the ways in which we understand and talk about the intersection of disability and abortion for women, families, and reproduction, as well as for our larger society. Particularly in the case of attacks on late abortions, reproductive rights groups should be very careful not to throw disability rights under the bus when fighting for the rights of women.

On April 13, 2010, the Nebraska legislature enacted a new law making later abortion more difficult to obtain, changing the parameters from the 24-week viability definition to a concept of the fetus' ability to experience pain at 20 weeks. The primary strategy of the national pro-choice organizations involved in this fight has been to raise the specter of pre-natal diagnoses of potential or confirmed congenital disability as the *sine qua non* for protecting access to abortion in the third trimester. Unfortunately, the language used to discuss this dilemma all too frequently can be perceived as anti-disability and reveals a disturbing disconnect from the reality of disability.

In attempts to personalize difficult late abortion decisions, some pro-choice organizations recount stories of particular families struggling with the "excruciating choice" to terminate a

-

There are, of course, some anti-choice advocates who embrace disability-friendly public policies, and some pro-choice advocates who have harmful values when it comes to disability or are unaware of the disability rights movement. This is a complex issue, pitting fiscal conservatism and opposition to "entitlements" against progressive rights and services. But the paradox we frame here, while no doubt an overgeneralization, holds true enough to highlight the problems with how people on both sides of the abortion debate speak about disability.

wanted pregnancy because their fetus has received a diagnosis of disability. Disability in this context is described as a "tragedy" and a "defect"— using the language of pain, suffering and devastation. The focus is on the potential suffering a child with a disability will allegedly experience and inevitably bring on parents and other siblings. The fetus with a disability is often branded as damaged goods.

On the other side of the debate, anti-abortion advocates use much more empowering language about the experience of parenting children with disabilities and living as an adult with disability. The Abortion73.com website contains, for example, the remark that "abortion advocates ... argue for the right to abort children who might grow up with a disability, as if disease or handicap somehow strips a person of their right to live and relegates them to a life of misery. Such a suggestion is barbaric and inhumane and has no place in a just society. There are children of all ages, and adults too, who are alive today and are living through all manner of disease and disability. Do these physical limitations make them less than human?"²

The National Right to Life Committee uses similar language: "Aborting a child with a disability or illness is the height of prejudice. When a family learns that the child they are expecting may have a special need, that family needs support and good solid medical information—not the death of their most fragile member. Society must flee this attitude that uses arbitrary yard sticks to measure peoples [sic] worth."

Both approaches grossly oversimplify the nature and complexity of disability and abortion, and neither is doing enough to provide families with the kind of support they need to have and raise children, whether or not they have disabilities. Pro-choice advocates tend to demonize disability in prenatal diagnosis while fighting for social services and family support policies such as early intervention programs, special education services, family resource centers, respite care, and developmental disability services, while anti-choice advocates tend to idealize disability while opposing the entitlement programs and government funding of social services that would make raising a child with a disability more possible.

Ultimately, this paradox—respectful disability language but no policy follow-through by antiabortion advocates, and troubling language but with supportive policy positions from pro-choice groups—does not serve either the reproductive rights movement or the disability rights movement. Reproductive rights groups are not anti-disability rights and are well aware of the complex challenges women face in deciding to keep or terminate a pregnancy. The unrelenting attacks on abortion rights have often resulted in pro-choice advocates choosing to use reactive messages that don't express their core values of dignity, human rights, and self-determination for *all* people and *all* families, including those with disabilities. The oversimplification of disability as always tragic, pitiful, or inspiring, the erasure of the difficulties in obtaining abortion services, and the discounting of family support policy agendas and their critical importance in abortion debates are not in alignment with these values.

The question, however, is: how can we break away from this paradox?

³ http://www.nrlc.org/abortion/facts/abortionresponses.html

² http://www.abort73.com/abortion/common_objections

Fortunately, a disability rights and a reproductive justice approach together offer a way through this paradox that allows reproductive rights advocates to bring their policies and messages into alignment with their values. A disability rights approach highlights the social stigma attached to disability and the lack of environmental, social, political, and economic supports for families raising children with disabilities and for adults with disabilities. This approach positions the problem outside the person with disability. Thus, disability advocacy focuses on the social and family supports needed to live with disability rather than on medical condition or impairment.

A reproductive justice approach advocates for an affirmative role for the government to play in ensuring that all women have the social, political, and economic power and resources to make the best decisions for themselves and their families. In the context of a prenatal diagnosis of disability, this means ensuring that women have the most accurate and comprehensive information about the diagnosis; this information must include realistic information about living with disability from people with disabilities). A woman in this situation require access to abortion services in a timely manner if she decides to terminate her pregnancy, and the supports necessary to sustain her family if she decides to carry the pregnancy to term. Both approaches shift the discussion away from individual and private family decisions to a broader debate about the kinds of services, education, and supports families and individuals need to embrace disability as a part of the human experience.

What might this cross-sectional approach of disability rights and reproductive justice look like in the Nebraska case of Legislative Bill 1103? Here are five specific suggestions for reproductive rights advocates engaged in the debate this fall:

- 1) Lead with public messages that broadly communicate a values-based, family supportive position on abortion rather than engage in a public debate about the scientific accuracy of fetal pain or discussions about the legal claims being made in the case. Engaging in debates about the scientific and medical aspects of late abortions move us away from the core message of a woman's governance of her own body, and will lead to inappropriate discussions of fetal viability and which disabilities are acceptable or unacceptable. Attempts to draw medical or scientific lines mirror and reinforce anti-choice attempts to draw lines between good and bad women, and acceptable and unacceptable abortions. Scientific and medical claims evolve continually and cannot be codified into rigid policies.
- 2) Pivot away from a "pain" framework. Instead of highlighting the "pain and suffering" women and their families might experience when faced with making "tragic, devastating and excruciating" decisions, reproductive rights advocates should focus on empathizing with families facing unforeseen decisions that are unique to each family and best made within a family. They can emphasize that the role of government in each distinctive situation is to ensure the provision of comprehensive, unbiased, evidence-based information, not to force families to make certain, fixed, and limited decisions. A move away from a "pain" framework also works to stop reinforcing and fortifying the antichoice "fetal pain" construct where people are being asked to choose between the pain

- and suffering of a fetus and the pain and suffering of a woman who might have a child with a disability.
- 3) Shift the overall strategy from fetal anomaly, rape, and incest as the *sine qua nons* for abortion to ensuring that the government provide the supportive and enabling conditions for families to make the best decisions for themselves. This shift permits us to move away from a framework that judges individual women and demonizes disability, to a framework that focuses on public policies that support all families. Rather than assuming a libertarian, hands-off position for the government in these questions, reproductive rights and justice advocates can push for a strong, pro-active role for the government in providing a system for comprehensive information (including information from people with disabilities about living with disability) as well as financial and physical supports for families to make the best decisions for themselves.
- 4) Emphasize and invest in the implementation of the Prenatally and Postnatally Diagnosed Conditions Awareness Act as a way to provide better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a potential disability. This Act recognizes that comprehensive, unbiased, evidence-based information changes often, with new tests, new technologies, and new treatment options, and that public policy cannot be tied to science that is evolving rapidly and constantly.
- 5) Begin a longer and deeper discussion for the long term about health and women's access to abortion based on a "health" exception for the woman and the fetus in which we redefine the concept of "health" to include human variation. The current decontextualized emphasis on health implies that disability is an undesirable condition to be avoided at all costs, and it elevates a normative definition of "health" in an unrealistic way. Disability is a part of the whole human experience; no one can be guaranteed a life of perfect health without disability. By focusing so strongly on normative health reproductive rights advocates could end up supporting access to abortion for only a very limited group of women with diagnosed health issues. This narrow approach will leave behind the women who choose abortion for many different reasons.

If the anti-choice movement has been disingenuous in their portrayal of disability and abortion, the reproductive rights movement has not necessarily lived up to its own highest ideals either. In attempting to highlight the unique decision each woman faces when deciding whether or not to continue with a pregnancy, reproductive rights advocates have often times used language that is unsupportive of disability and families living with disability. Instead of focusing on the supposed pain and suffering of disability, the movement would be more in alignment with its own values of dignity, equality and self-determination for all by focusing on messages that embrace a diversity of families and advocating for public policies that support what's best for women and families, including babies and families with disabilities. If the movement continues to use an anti-disability message when arguing for abortion, our best opportunity might be lost to shift the abortion debate and advocate for what we all really want, strong and diverse women and families.