

SHIFTING THE FRAME ON DISABILITY RIGHTS FOR THE U.S. REPRODUCTIVE RIGHTS MOVEMENT

Cover art

"At 54" by Riva Lehrer https://www.rivalehrerart.com

Artist Statement: Self portraits have been a way for me to explore my evolving relationship with my own body. These works also allow aspects of formal experimentation that do not have an impact on anyone else's self-image. When I work with a portrait subject I am acutely aware of the extent to which I hold their ego in my hands. In working with my own body, I can go in directions that would be difficult to ask of another person. Through the combination of these two streams—looking at others, and looking at myself—I have evolved and deepened my sense of connection to other human beings.

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Center for Reproductive Rights

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The Center's Mission and Vision

The Center for Reproductive Rights uses the law to advance reproductive freedom as a fundamental human right that all governments are legally obligated to protect, respect, and fulfill.

Reproductive freedom lies at the heart of the promise of human dignity, selfdetermination, and equality embodied in both the U.S. Constitution and the Universal Declaration of Human Rights. The Center works toward the time when that promise is enshrined in law in the United States and throughout the world. We envision a world where every woman is free to decide whether and when to have children; where every woman has access to the best reproductive health care available; where every woman can exercise her choices without coercion or discrimination. More simply put, we envision a world where every woman participates with full dignity as an equal member of society.

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INTRODUCTION

As a legal advocacy organization working to promote reproductive freedom around the world, the Center for Reproductive Rights (the Center) works in partnership with human rights movements at the national, regional and global levels. In recent years, largely as a result of the growing momentum and visibility of the disability rights movement, our work has increasingly intersected with disability rights in the regions and forums where we work. At times, an intersectional analysis has prompted collaborations to advance a shared agenda, for example in challenging policies and practices that allow forced sterilization. However, we also recognize that historical tensions—particularly surrounding the issues of prenatal genetic testing for markers of disability and abortion on grounds of fetal impairment—continue to divide the two movements, jeopardizing the realization of human rights that are universal and indivisible.

We believe it is imperative to assert our movements' common human rights principles of bodily autonomy, self-determination, equality, and inclusion. It is also critical to address historical and current conflicts and challenges in an honest and collaborative manner. We have produced this briefing paper to provide recommendations for how the reproductive rights movement can take steps to reclaim our shared values with the disability rights movement, repair trust with disability rights activists, and build alliances that will advance an inclusive policy agenda.

The paper captures learnings from staff at the Center regarding an internal process our organization undertook to integrate disability rights into our work. Over a four-year period, the Center sought out partnerships with disability rights groups, educated our staff about disability rights, challenged our own assumptions and biases, and identified areas where our substantive work, and workplace, could incorporate perspectives of people with disabilities. This process was not linear, or comfortable. We do not claim to have all the answers. We do aim to challenge the relative absence of disability rights perspectives in our movement, and offer some suggestions for how we can bridge this gap to the benefit of both movements.

The cost of ignoring tensions between the disability rights and reproductive rights movements is high. For example, the outbreak of the Zika virus caught the reproductive rights movement off-guard, exposing the lack of a clear conceptual framework to explore intersections with the disability rights movement, the lack of relationships across both movements to harness opportunities for advocacy, and the absence of a long-term strategy to advance shared priorities. As a result, we lost the opportunity to respond in a timely and coordinated way to a global public health emergency that directly affected both movements. Meanwhile, in the United States, the antiabortion opposition is actively working to exploit divisions between both the disability rights and reproductive rights movements by proposing legislation that invokes disability rights as a justification for restricting abortion. Although many in both movements recognize these bills as a blatant attempt to co-opt disability rights in order to restrict abortion access, the movements lack a collaborative strategy to respond effectively to these threats.

This paper is directed at the reproductive rights movement with the goal of encouraging a frank conversation about disability rights within our movement. We focus on the reproductive rights movement in the United States because, in the wake of the 2016 elections, there is renewed urgency for both the reproductive rights and disability rights movements to build collaborative strategies that advance their shared goals. Early filings of state bills, and the probable introduction of federal legislation banning abortion on the grounds of disability, race, and sex, indicate that the strategy of co-opting disability rights to serve an anti-abortion agenda will gather momentum under a Trump administration. Abortion opponents are also likely to be emboldened by Vice President Mike Pence's support of Indiana's disability selective abortion ban while governor. And

On Language: Disabled People vs. People with Disabilities

The global disability rights movement is divided on whether to use the term "disabled people" or "people with disabilities." The latter term is consistent with the "people-first" terminology adopted by the UN Convention on the Rights of Persons with Disabilities, and is generally preferred by disability rights activists in the United States. For these reasons, we use "people with disabilities" throughout this paper. However, we also recognize that others within the disability rights movement prefer the term "disabled people" as a political identification, and feel that this terminology more accurately reflects the structural barriers to social inclusion as the main problem, rather than the impairment itself.

while the targeting of women and people with disabilities during the presidential campaign revealed persistent stigma against both groups, these attacks also presented a unique opportunity to align and build collective power. Both movements now stand to gain by jointly leveraging resources and strategies to resist an emboldened opposition, and to advance a rights-based vision that centers the experiences of people who face this injustice in their daily lives.

In Section I, we recognize the common foundations of the disability and reproductive rights movements. In Section II, we locate the different, and often intersecting, stigmas that around disability, sexuality and reproduction. In Section III we address how this stigma manifests in law and policy, preventing women and girls with disabilities from exercising their sexual and reproductive rights. In Section IV, we outline the key fault lines that divide the reproductive rights and disability rights movements, as well as the ways that abortion opponents have exploited these tensions with a policy agenda aimed at restricting abortion rights under the guise of protecting disability rights. The paper concludes in Section V where we outline recommendations for how stakeholders in the U.S. reproductive rights and justice movement can proactively integrate disability rights perspectives into our work.

COMMON FOUNDATIONS OF DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS

Both the disability rights and reproductive rights frameworks are built on universal human rights principles of bodily autonomy, self-determination, equality, and inclusion. Both movements share a vision of a world where every person has the rights, resources, and respect to live to their full potential. Over the past several decades, the disability rights and reproductive rights movements have pursued similar strategies to translate this vision into legal protections at the global and national levels. Increasingly, both movements now also challenge the structural inequalities that prevent their core constituencies from realizing their fundamental human rights.

In the United States, disability rights and reproductive rights also share similar historical trajectories as movements that emerged from the 1960s civil rights movement. The goals of the early disability rights movement were to challenge the harmful stereotypes about people with disabilities that perpetuated their exclusion and discrimination, and to demand legal and institutional change that would grant them equal access and opportunities. Beginning in the 1970s, the movement's efforts led to the passage of several federal statutes eliminating discrimination in the areas of employment, public services, and education, culminating with comprehensive civil rights protections under the 1990 Americans with Disabilities Act

(ADA).⁴ These laws reflected a societal shift in understanding that the social and economic exclusion of people with disabilities was a result of discriminatory policies and practices rather than the inevitable consequence of a person's mental or physical impairment.⁵

Like the reproductive justice framework that women of color developed in the 1990s, "disability justice" emerged in the mid-2000s to center the experiences of those living at the intersection of multiple axes of oppression, especially women of color and queer and gender non-conforming people with disabilities. This group of activists challenged the rights-based strategies of the mainstream disability rights movement, as well as the centering of people with mobility impairments over those with other types of disabilities. Instead, disability justice focuses on movement building aimed at transforming the social, economic, and political systems of oppression that exclude and

Social Model vs. Medical Model

The UN Convention on the Rights of Persons with Disabilities adopts the "social model" definition of disability, which understands disability as the interaction between an individual's impairment—physical, psychosocial, intellectual, or sensory—with barriers that exist in the person's social and material environment. In contrast to the "medical model" of disability, which views the impairment itself as the problem, the social model recognizes that negative social attitudes as well as a lack of resources and barriers are the causes of oppression for people with disabilities.

harm people with disabilities.⁸ The goal of disability justice is thus to fulfill a vision of a world where disabled bodies are seen as powerful, and difference is celebrated in all of its forms.⁹

Today, both the disability rights and reproductive rights movements are vibrant global social justice movements that have played key roles in securing human rights protections. One of the most significant legal developments in human rights over the past decade is the enactment of the UN Convention on the Rights of Persons with Disabilities (CRPD). This treaty was drafted with the significant participation of people with disabilities and with substantial assistance from the U.S. government. The treaty provides a framework for understanding the dignity and fundamental rights of people with disabilities as well as the obligations of governments to respect, protect, and fulfill these rights. Notably, the CRPD currently has the clearest articulation of sexual and reproductive rights of any of the nine major international human rights treaties.

Many of the CRPD's guiding principles are also foundations of the reproductive rights movement, including:

- Respect for inherent dignity and individual autonomy
- Freedom and independence to make one's own decisions
- Non-discrimination and intersectionality
- Full and effective participation and inclusion in society
- Accessibility
- Equality before the law, both formal and substantive
- Gender equality

Under the CRPD, governments must ensure that people with disabilities have equal access to health care, including sexual and reproductive health, and that services must be based on the principle of informed consent.¹² The treaty also protects the rights of people with disabilities to non-discrimination in family, marriage, parenthood, and relationships.¹³ This includes the ability to make decisions around the number and spacing of one's children, access to reproductive health and family planning information and education, and the right to retain their fertility on an equal basis with others.¹⁴

The CRPD recognizes that disability rights and reproductive rights are interdependent and indivisible: one set of rights cannot be realized without, or at the expense, of the other. Central to both movements are the concept of self-determination and the goal of full participation in social, economic, and political life. Reproductive rights rest on the principle that all people have the inherent right to make fully informed and meaningful decisions—free from violence, discrimination, and coercion—about their sexuality and reproduction.¹⁵ Indeed, without the ability to make important life decisions about their sexuality and reproduction, people with disabilities face human rights violations that are both similar to and distinct from those faced by non-disabled people. For example, people with disabilities remain underserved in sexual and reproductive health programs due to stigma around their sexuality as well as harmful stereotypes about their capacity to reproduce or parent. Additionally, women and girls with disabilities face unique barriers in exercising their reproductive rights that differ from men and boys with disabilities, such as disproportionately high rates of sexual abuse and forced sterilization. The CRPD recognizes that governments cannot ensure sexual and reproductive rights for all unless they tackle discrimination from an intersectional perspective in all its forms, including gender and disability.

The CRPD was largely modeled upon the ADA, a seminal piece of U.S. legislation adopted in 1990 that has served as the basis for ensuring the equality and non-discrimination of people with disabilities. This cornerstone of civil rights protection prohibits discrimination against people with disabilities in employment, state and local governments, public accommodations, transportation, and telecommunications. Drafters of the CRPD took inspiration from U.S. disability rights advocates who have utilized the ADA mandate to work towards the full inclusion of people with disabilities in society.

Abortion, Disability, and the Right to Life Under International Human Rights Law

The Universal Declaration of Human Rights states definitively in Article 1 that "All human beings are *born* free and equal in dignity and rights." Accordingly, there is no recognized right to life for a fetus under international human rights law. Human rights treaties therefore protect the right to life without defining when life begins. The interpretation of these treaties by authoritative sources clarify that these protections do not apply before birth and recognize that to protect an absolute right to life before birth would contradict human rights protections for women. As a consequence, international and regional human rights treaty monitoring bodies and courts have consistently found that women have a right to access reproductive health services, including abortion, in order to ensure that their full range of human rights—including their right to life—is respected, protected, and fulfilled.

Indeed, the drafters of the CRPD rejected attempts to include language calling for restrictions on abortion for reasons of disability, while also recognizing that prospective parents of children with disabilities could encounter coercive laws or practices aimed at influencing their decision-making or lack access to unbiased information when deciding whether to proceed with or terminate a pregnancy.⁴ The language of the CRPD upholds the sexual and reproductive health and rights of people with disabilities while refusing to recognize the right to life of a fetus.

¹ Universal Declaration of Human Rights, G.A.w res. 217A (III), art. 1, U.N. Doc A/810 at 71 (1948).

² See CRR, Whose Right to Life? Women's Rights and Prenatal Protections under Human Rights and Comparative Law, Section II (2014).

³ See, e.g., K.L. v. Peru, Human Rights Committee, Commc'n No. 1153/2003, U.N. Doc. CCPR/C/85/D/1153/2003 (2005); CRC Committee, General Comment No. 15: The Right of the Child to the Enjoyment of the Highest Attainable Standard of Health, (62nd Sess., 2013), in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, para. 70, U.N. Doc. CRC/C/GC/15 (2013); L.C. v. Peru, CEDAW Committee, Commc'n No. 22/2009, para. 8.15, U.N. Doc. CEDAW/C/50/D/22/2009 (2011). Even where article 4 of the American Convention on Human Rights does recognize a right to the protection of life, in general, from the moment of conception, the Inter-American Court of Human Rights has found that the "right to life should not be understood as an absolute right" and must be balanced with other rights, including women's reproductive rights. Artavia Murillo et al. ("In Vitro Fertilization") v. Costa Rica, Preliminary Objections, Merits, Reparations and Costs, Judgment, Inter-Am. Ct. H.R., para. 258-263 (Nov. 28, 2012).

⁴ CRPD, Comments, Proposals and Amendments Submitted Electronically, Comments by the Gov't of Kenya and Int'l Disability Caucus (4th Sess., 2006), available at http://www.un.org/esa/socdev/enable/rights/ ahcstata11fscomments.htm.

The United States signed the CRPD in 2009, but has yet to ratify it and incorporate its provisions into U.S. law. The treaty would allow U.S. advocates to address disability-based discrimination beyond the ADA's focus on elimination of formal discrimination in law and policy. In particular, it clarifies that governments play a proactive role in creating an environment where people with disabilities can participate as full and equal members of society by eliminating stigma and stereotypes and promoting access to justice. 17 For example, Article 6 of the CRPD requires that governments address "the social structures and power relations that frame laws and policies, as well as... [the] economic and social dynamics, family and community life, and cultural beliefs" 18 that impact gender equality. The CRPD also makes it possible to address multiple and intersecting forms of discrimination, allowing women with disabilities to seek redress for discrimination based on both gender and disability unlike the separate claims currently required under U.S. law. 19

LOCATING STIGMA AROUND DISABILITY, SEXUALITY, AND REPRODUCTION

People with disabilities are a diverse group with impairments spanning many types—physical, psychosocial, intellectual, and sensory—and different levels of functional limitations. They represent a range of genders, races, religions, and perspectives that impact their individual experiences, and have varying levels of support that affect their ability to exercise their fundamental human rights.

People with disabilities face many kinds of discrimination due to stereotypes, assumptions and fears about disability. These are often compounded by other forms of discrimination (based on race, ethnicity, gender, sexuality, or other status) and on their individual contexts and identities, which include, but are not limited to:

- *Direct discrimination*, including discriminatory treatment due to a disability, formal discrimination against people with disabilities enshrined in laws and policies (e.g., the failure to recognize the legal capacity of a woman with intellectual and psychosocial disabilities), and the denial of reasonable accommodations under U.S. law;
- *Indirect discrimination*, including laws, policies, and practices that appear neutral but have a disproportionately

- negative impact on people with disabilities (e.g., lack of accessible materials or equipment in health facilities);
- Discrimination by association with a person with a disability (e.g., the failure of a health facility to offer services or information for sexual partners of people with disabilities);
- **Structural or systemic discrimination**, including patterns of discriminatory institutional behaviors, cultural traditions, or social norms that are based on harmful stereotypes about people with disabilities (e.g., the lack of prosecutions for sexual violence perpetrated against women with disabilities as a result of the disbelief or dismissal of such crimes by law enforcement and judicial officers);²⁰
- Intersectional discrimination against people with disabilities based on their disability as well as their race, sexual orientation, gender identity, or other status.²¹ These intersecting forms of discrimination often have a disproportionate impact on women and girls with disabilities, placing them at heightened risk of violence and leading to numerous violations of their sexual and reproductive rights.

Discrimination against people with disabilities in the area of sexual and reproductive rights is rooted in stigma, which is in turn based on stereotypes and misperceptions. Some of the most common stereotypes concerning the sexuality of people with disabilities include:

 People with disabilities are asexual. A prominent stereotype encountered by people with disabilities is that they are not sexually inclined or active.²² However, ample research shows that people with disabilities are as sexually active as people without disabilities²³ and experience a full spectrum of sexual desires, expressions, identities, practices, and relationships.²⁴ Although some people with disabilities may face difficulties in fully expressing their sexuality, and the presence of a physical disability may necessitate certain adaptations and support to accommodate limited movement, fatigue, pain sensitivity, or lack of sensation, disabilities do not preclude or present a barrier to sexual pleasure or activity. The assumption that people with disabilities are asexual leads to a corresponding assumption that they do not need sexual or reproductive health services and information.²⁵ Consequently, such information is less readily available for people with disabilities.²⁶

- **People with disabilities are hypersexual.** A counterpoint to the asexuality stereotype is the perception that people with disabilities, especially those with intellectual or psychosocial disabilities, have an out-of-control libido that may endanger themselves or others.²⁷ This view can lead to the denial of education or information about sexuality and reproduction to people with disabilities—and in some cases to their forced or coerced sterilization—in order to deter or control sexual behavior deemed inappropriate.
- **People with disabilities cannot reproduce or are unfit to parent.** Because they are assumed to be asexual, people with disabilities are also viewed as sterile or incapable of reproducing. If they do reproduce, they are often judged for doing so based on the misconception that a disability is always genetically transferred and that such traits should not be passed onto future generations.²⁸ Moreover, people

with disabilities are often considered unfit to parent based on the view that their disabilities prevent them from being able to adequately care for a child.²⁹

- Women and girls with disabilities are incapable of making decisions about their sexuality and reproduction. Research has shown that health care providers often presume that women with disabilities are incapable of making their own decisions about sex and reproduction.³⁰ This stereotype impacts policies and practices that allow third parties, such as parents, guardians, or judges, to make decisions regarding the reproductive capacity of women and girls with disabilities, from coerced contraceptive use to forced sterilization.³¹
- People with disabilities are vulnerable and need protection.
 - Closely related to the stereotype of people with disabilities being asexual is one that views them as helpless and in need of protection.³² This stereotype is often used to justify the forced or coerced sterilization of women with disabilities as a means to protect them from pregnancy as a result of sexual assault. This stereotype at once infantilizes people with disabilities and holds them up as "angelic," or especially deserving of protection, while deemphasizing the social and legal constraints that make the world inaccessible to them.³³ People with Down syndrome are commonly singled out for this stereotype, particularly by abortion opponents who seek to build empathy for those with Down syndrome as they tend to be perceived more positively than people with other forms of disability. The opposition uses this tactic to erode the right to abortion on the basis of a fetal diagnosis of a genetic disability.³⁴

Disability stigma can also attach to non-disabled people by association. In the context of parenting, women who knowingly give birth to a child with a disability may be considered "irresponsible" while adopting a child with a disability makes them a "saint." Both stereotypes place the focus on an individual's parental decision-making rather than on the responsibility of government to ensure adequate social and economic support for families with disabilities.

SEXUAL AND REPRODUCTIVE RIGHTS OF WOMEN AND GIRLS WITH DISABILITIES

Women with disabilities in the United States, as in most of the world, face multiple and intersecting forms of discrimination that extend to every area of their economic, social, and political life, including education, employment, political participation, and access to justice. In the United States, women with disabilities are more likely to live in poverty or face unemployment than non-disabled women or men with disabilities.³⁶ Education barriers also abound; women with disabilities are far less likely to receive a high school diploma or university degree than their non-disabled peers.³⁷

These disparities carry over to the exercise of their sexual and reproductive rights. While women with disabilities are often impacted by the same restrictions as non-disabled women, they also face distinct barriers. For example, women with disabilities report that health facilities are physically, financially, informationally, or culturally inaccessible to them.³⁸ They are also more likely to be forced or coerced into decisions that limit their ability to reproduce or parent based on stigma and stereotypes about their abilities.³⁹ Furthermore, women with disabilities are subjected to violence by partners, caregivers, and family members more often than non-disabled women, leading to their distinct need for reproductive services and information.⁴⁰ The additional barriers and discrimination women

with disabilities face in accessing reproductive health services lead to lower rates of care.⁴¹

Despite the fact that 20 percent of U.S. women,⁴² or approximately 27 million women,⁴³ are living with a disability, the U.S. reproductive rights movement has largely overlooked the concerns of this constituency. This section outlines some key areas where women with disabilities encounter violations of their sexual and reproductive rights that could be integrated into the political agenda of the U.S. reproductive rights movement.

ACCESS BARRIERS

Women and girls with disabilities face distinct barriers in accessing health care, especially reproductive health care services and information, in comparison to non-disabled women and men and boys with disabilities. Five of the most common barriers women and girls with disabilities face include physical barriers to health facilities and equipment, communication barriers with providers, a lack of access to sexual and reproductive information and/or education, economic barriers to services, and discrimination or insensitivity on the part of providers.

• **Physical Barriers:** One of the most common reasons women and girls with disabilities do not obtain preventive reproductive health services is the lack of physical accommodations available to them at health facilities. This may include the lack of accessible exam and diagnostic equipment or the lack of adequate assistance in getting onto or off an exam table. Women and girls with physical disabilities also face access barriers to visiting

health facilities as public transportation is often inadequate or inaccessible for them.

- *Communication Barriers:* Communication barriers can limit the ability of women and girls with disabilities to communicate effectively with reproductive health care providers. Few health facilities have accommodations for women and girls with vision or hearing impairments, including sign language interpreters, audio versions of information, or alternative means of delivering information. People with intellectual disabilities also report communication difficulties with some providers due to the fact that there is often not enough time allotted during visits to have a comprehensive discussion regarding complex health issues, and information is often not delivered in easy-to-understand formats. 48
- Lack of Education and Information: Sexuality education is generally not offered in education programs designed for people with disabilities. 49 Moreover, young people with disabilities are often not fully included in school-based sexuality education programs because materials are not available in accessible formats for them and/or because of assumptions that people with disabilities are not sexually active. 50 Lack of sexuality education leaves women and girls with disabilities without the knowledge and information they need to negotiate consent, have safe and pleasurable sex, prevent sexually transmitted infections or unintended pregnancies, and protect themselves from abusive sexual partners. 51
- **Economic Barriers:** Because women with disabilities have higher rates of unemployment and poverty than the general

population, they are far less likely to have private insurance to cover reproductive health goods and services.⁵² Although they may acquire Medicaid benefits that will cover preventive care costs, not all providers accept Medicaid.⁵³ Women with disabilities also report difficulties in locating and accessing reproductive health care providers and clinics with the requisite training and facilities necessary to meet their needs.⁵⁴

• *Discrimination and Insensitivity by Providers:* Women with disabilities are often subjected to discrimination from health care providers who are influenced by societal stigma against people with disabilities. Research shows that physicians not only lack training in treating people with disabilities,⁵⁵ but also feel uncomfortable and reluctant to treat this population.⁵⁶ For instance, providers are less likely to ask women with disabilities about their use of or need for contraceptives⁵⁷ and are more likely to discourage screening for STIs because they do not perceive that women with disabilities are sexually active.⁵⁸ Many women with disabilities who do receive care often avoid future routine visits to gynecologists because this lack of provider knowledge and sensitivity can lead to embarrassing or painful examinations.⁵⁹

Despite these barriers, very little public health research funding is directed to studying health disparities among women and girls with disabilities, and even less to reproductive and sexual health disparities. The dearth of evidence-based research that exists magnifies the access barriers women and girls with disabilities face because health programs fail to recognize or tailor their programming to address their unique needs.⁶⁰

COERCIVE MEDICAL PROCEDURES

Women and girls with disabilities may also be subjected to coercive medical procedures, including reproductive health procedures, that violate their rights and undermine their dignity. These coercive policies and practices—which include forced or coerced sterilization, forced or coerced contraceptive use, and forced or coerced abortion—are based on harmful stereotypes about people with disabilities in regards to their decision-making capacities, 61 their perceived ability to parent, 62 and assumptions that women and girls with disabilities are asexual or that sterilization will protect them from sexual abuse. 63 In addition, women and girls with disabilities frequently encounter pressure from doctors, guardians, social service workers, parents, and society to abort pregnancies or refrain from becoming pregnant because of misconceptions regarding the possibility of passing on disabilities to their children—even if the disability is not genetic.64

The theory of eugenics, though now widely disfavored, continues to inform many of the harmful stereotypes about people with disabilities and the coercive medical procedures they are susceptible to receiving. The eugenics movement emerged at the beginning of the 20th century based on the prevalent idea that human genetics ought to be "improved" by reducing the ability of people with "undesirable" genetic traits to procreate, especially people with disabilities and those with criminal backgrounds. Starting in 1907, more than 30 states enacted laws allowing for the sterilization of people with disabilities and barring them from marrying until a certain age or engaging in extramarital sex. ⁶⁵ In the 1927 case of *Buck v. Bell*, the U.S. Supreme Court refused to strike down a Virginia sterilization law in which Justice Oliver Wendell Holmes infamously declared,

"Three generations of imbeciles are enough." The U.S. Supreme Court did not invalidate a sterilization law for people with disabilities until 1942, when it held that procreation is a fundamental human right. 67

Although most states have subsequently repealed their involuntary sterilization statutes, as of 2016 ten states still retain statutory language authorizing a court to order the involuntary sterilization of a person with a disability.⁶⁸ Today, U.S. courts remain divided on the legal capacity of women with disabilities to make decisions about their reproductive lives, particularly in the context of sterilization.⁶⁹ The question of whether people with disabilities can exercise their legal capacity to provide consent remains a contentious legal issue. This is particularly the case for those who may not be able to exercise their legal capacity without significant assistance or intervention. Disability rights advocates have promoted the concept of "supported decisionmaking," whereby people with disabilities receive support to make decisions and exercise their legal capacity. This presents a shift from the previously dominant model of "substituted" decision-making," whereby control resides with the parent or legal guardian of a person with a disability.⁷⁰

In addition to involuntary sterilization, women and girls with disabilities are also at risk of being subjected to other kinds of medical procedures without their free and informed consent. In fact, they are more likely to have hysterectomies, an irreversible procedure that permanently deprives a woman or girl of her ability to become pregnant, at younger ages and for non-medically necessary reasons, including at the request of a parent or guardian.⁷¹ Caretakers may also consent to hysterectomies for women or girls with disabilities as a means of controlling their menstrual cyces or to ensure that they do

Growth Attenuation and Sterilization: The Case of Ashley X

In 2004, surgeons at Seattle Children's Hospital removed the uterus and breast buds of "Ashley X," a six-year-old girl with developmental disabilities, at the request of her parents. The series of interventions the child received, which also included high levels of hormones, were intended to protect her from the possibility of getting pregnant and the discomfort caused by her monthly menstruation. Her parents argued that the treatments were in Ashley's best interests because by stunting her sexual development they could better protect her against the possibility of sexual abuse by caregivers. Ultimately, the hospital ethics board approved the requested treatments without obtaining a court order. Following an outcry from the disability rights community and an independent investigation, the hospital eventually acknowledged its mistake and changed its procedures to protect the rights of minors with disabilities. Nevertheless, at least 12 children have undergone the full "Ashley Treatment," and more than 100 have received hormone treatments to stunt their physical and sexual development.

Sources: Ashley's Mom and Dad, The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels," PillowAngel.org, available at http://pillowangel.org/Ashley%20Treatment.pdf (last updated Mar. 17, 2012); Genevieve Field, Should Parents of Children with Severe Disabilities be Allowed to Stop Their Growth?, N.Y. Times (Mar. 22, 2016), http://www.nytimes.com/2016/03/27/magazine/should-parents-of-severely-disabled-children-be-allowed-to-stop-their-growth.html; Disability Rights Washington & National Disability Rights Network, Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights 19-26 (2012), available at http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Devaluing_People_with_Disabilities.pdf.

not become pregnant as a result of sexual abuse or otherwise.⁷² The American Congress of Obstetricians and Gynecologists emphasizes that hysterectomies should only rarely be performed on adolescents, including adolescents with disabilities, and that the procedure will not prevent sexual abuse or sexually transmitted diseases.⁷³

RIGHT TO PARENT

Discrimination on the basis of disability may also affect a woman's experiences around conception and conceiving. For example, women with disabilities are more likely to be denied access to assisted reproductive technologies (ARTs) because of provider bias. Although the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in public accommodations, some ART providers engage in discriminatory practices in screening patients, including on the basis of personality, psychosocial disability, perceived intelligence, and genetic disorders. 74 This discrimination appears to be the result of ART providers' views that they are obligated to consider the welfare of a future child before providing services, combined with providers' perceptions about the ability of women with disabilities, particularly those with intellectual or psychosocial disabilities, to raise a child.⁷⁵ Additionally, ART providers may have concerns about the impact of gestation on the health of a woman with disabilities and the potential for their future child to inherit a disability.⁷⁶

After a person with disabilities becomes a parent, they are also more susceptible to discrimination in retaining their parental rights, and more likely to have their parental rights terminated or limited than other non-disabled individuals.⁷⁷ The right to

parent without interference by the state is protected by the U.S. Constitution; a state can only terminate parental rights when it is in the best interest of a child and a parent is deemed "unfit." Two-thirds of states, however, allow courts to find a parent unfit based solely on their disability. Furthermore, all states allow courts to consider disability in determining a child's custody arrangements without necessarily demonstrating how a parent's disability harms their child. For example, in 2010 the state of Missouri temporarily separated a newborn infant from her parents and placed her in protective custody solely on the grounds that her parents were blind. Legal discrimination against mothers with disabilities in child protection proceedings frequently result in loss of contact with their children or loss of custody altogether.

VIOLENCE AND ABUSE

Due to discrimination in both the private and public sectors, women with disabilities are two to three times more likely than non-disabled women to experience violence, including but not limited to sexual and domestic violence. They are almost twice as likely to be sexually abused as young people, and as adults they are more likely to be in unstable and potentially violent relationships. Women with disabilities may also have fewer options to leave an abusive relationship because of the legal, social, and economic barriers they face specifically because of their disability. This includes dependence on a partner or spouse as a caregiver and the unavailability of safe houses or shelters that can accommodate their needs.

Violence against women with disabilities occurs in various spheres including the home, community, and public and private

institutions. The forms of violence that women and girls with disabilities are subjected to are varied, including physical, psychological, sexual, or financial violence as well as neglect, social isolation, entrapment, degradation, detention, denial of health care, and forced psychiatric treatment, among others.⁸⁷ The lack of capacity to make decisions about one's sexuality and reproduction can also lead to violence against women and girls with disabilities, including forced medical interventions and forced sterilization.⁸⁸

Women with disabilities are also less likely to access justice mechanisms to obtain remedies for the discrimination or violence they encounter. They face barriers in filing complaints because of the lack of information about assistance available to them, or because their abuser may be the individual on whom they rely for personal care or mobility. The judicial system also lacks accommodations for people with disabilities, deterring many women from seeking justice. Even when charges are filed, perpetrators are often not held accountable for their actions due to assumptions about the sexuality of the woman with a disability alleging the abuse, or prejudice against her credibility as a witness. 12

FAULT LINES BETWEEN THE DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS MOVEMENTS

The relationship between the disability rights and reproductive rights movement has never been an easy one. The reproductive rights movement's early tolerance of eugenics arguments in legal fights for contraception and abortion access excluded people with disabilities as key constituencies. This has led to an absence of women with disabilities in leadership positions at sexual and reproductive rights organizations and, consequently, a neglect of disability perspectives in the movement. Today, women with disabilities who support abortion rights may feel unwelcome or invisible in reproductive rights spaces, as their reproductive health needs are often not adequately addressed in the reproductive rights movement's policy or program priorities.⁹²

Meanwhile, the mainstream disability rights movement, which has historically lacked the inclusion and leadership of women with disabilities or of LGBTQ people, has not made sexual and reproductive rights a priority issue for its movement. At times, the disability rights movement has in fact alienated feminists by forging strategic alliances with anti-abortion groups to advance shared priorities, or by remaining silent on the abortion issue in order to avoid controversy within their own movement.

Consequently, women with disabilities who support abortion rights may find themselves at odds with other disability rights advocates who favor restrictions on abortion access in cases where fetal genetic variance is diagnosed.⁹³

The notion that the frameworks of the disability rights and reproductive rights movements are inherently oppositional deserves greater scrutiny. This presumption causes harm by marginalizing women with disabilities within both movements and by thwarting opportunities for cross-movement collaboration on advocacy and movement-building strategies. It also leaves both movements vulnerable to divisive tactics by the antiabortion opposition to exploit these tensions in order to serve their own agenda. This section explores these opposition wedge tactics, and analyzes the responses of both movements to date.

OPPOSITION TACTICS

In recent years, abortion opponents have co-opted the disability rights framework in order to appeal to a broader political base of moderates who generally support abortion rights but may be uncomfortable with abortion under certain circumstances, and as a strategy to divide the reproductive rights and disability rights movements. Tactics used by abortion opponents include:

• Linking abortion to eugenics. Linking abortion to the history of eugenics has allowed abortion opponents to pivot from abortion as a women's rights issue to laws permitting abortion for reasons of fetal impairment as a legal tool for the "extinction" of people with disabilities. 94 These arguments resonate with many disability rights activists who have experienced ongoing discrimination stemming from the origins of eugenics theory.

- Misrepresenting disability discrimination within the health care system. Health care providers are not immune to biases and misconceptions about people with disabilities, and undoubtedly some medical professionals continue to treat disability as a medical issue requiring intervention rather than as a social construction requiring societal change. Abortion opponents point to this powerful history of ableism, the discrimination of people with disabilities, in the health care system to claim that prenatal genetic counselors "discriminate" on the basis of disability when they screen for genetic markers and counsel expecting parents on their options if a disability is detected. This argument builds support for the concept of fetal personhood, or the idea that a fetus has the same rights as a person, while obscuring patterns of systemic discrimination against women and girls with disabilities that exist in the health care system.
- Alleging that the abortion of a fetus with a genetic diagnosis of a disability constitutes discrimination. Abortion opponents have used the language of anti-discrimination laws to call for limits on access to prenatal genetic testing, which may reveal genetic markers for disability, or abortion in cases where a pregnant woman receives a diagnosis of a fetal impairment. They argue that it is within the purview of the state to limit testing and access to abortion in these circumstances because such limitations serve to promote the state's interest in preventing disability discrimination, hotwithstanding the fact that state and federal anti-discrimination laws do not apply to a fetus. Rhetorically calling abortion a form of disability-based discrimination is another strategic move by abortion opponents to build support for fetal personhood.

For the past several years, the Americans United for Life's annual policy guide has included a "prenatal nondiscrimination act." This model legislation includes a ban on fetal impairment ("disability selection") as a basis for abortion, relying on the above arguments for justification. The 2016 version of this act was coupled with a sex selection ban, which is now law in seven states (though only coupled with the disability selection law in one state). During the 2016 legislative session, the language and framing of this fetal impairment ban was incorporated into bills introduced in state legislatures across the country.

To date, these kinds of disability abortion wedge legislation measures have fallen into two main categories: (1) bans on abortion due to the diagnosis, or potential diagnosis, of Down syndrome or other fetal anomalies; and (2) restrictions on the provision of information about abortion as an option for patients receiving a diagnosis, or potential diagnosis, of a fetal impairment.

Prior to 2016, only one state—North Dakota⁹⁹—had enacted a reason-based fetal impairment ban. Passed as a provision of an omnibus bill, this ban requires the state to show that a woman seeking an abortion was doing so solely on the grounds of a prenatal diagnosis of a fetal impairment, and prove that the physician knew that this was the reason she was terminating the pregnancy. In the 2016 legislative session, several versions of this legislation were introduced in nine states. Ultimately, two states—Louisiana and Indiana—enacted this type of ban into law. Louisiana passed a law banning abortions at or after 20-weeks post-fertilization in cases of fetal impairment. ¹⁰⁰ Indiana enacted an omnibus law that included a ban on abortion, "solely because of... [a] diagnosis or potential diagnosis of the fetus having Down syndrome or any other

disability."¹⁰¹ Legal challenges in both states have prevented these laws from taking effect.¹⁰²

In recent years, a handful of states have passed laws requiring health care professionals to provide pregnant patients with information at the time they receive a diagnosis of fetal Down syndrome or other genetic conditions or impairments. 103 Often these bills mandate that genetic counselors or health care providers provide patients with comprehensive pregnancy options and offer evidence-based, up-to-date, unbiased information about the indicated developmental disability and any medical concerns, resources, or services available for the child as well as their parents and families. 104 These bills—known as "pro-information" bills—are generally supported broadly by a coalition of disability self-advocates, parents, health care providers, and lawmakers. Their aim is to counter implicit disability bias in the medical community that can lead expecting parents to receive incomplete or inadequate information about Down syndrome or other genetic disabilities, which may then lead them to experience pressure to terminate a pregnancy. 105

In recent years, abortion opponents have tried to co-opt these "pro-information" bills by introducing language that would seek to deter pregnant patients from receiving information about abortion as one of the options following a prenatal diagnosis of Down syndrome or another genetic condition. The first of these "faux-information" bills was passed by the state of Louisiana in 2014. HB 1058 included a provision making it unlawful for a health care provider to, "engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition." 106

These types of "faux-information" bills are another blatant attempt by abortion opponents to drive a wedge between the disability rights and reproductive rights movements.

MOVEMENT RESPONSES

The disability rights community is fractured in its response to "disability selection" bills, which ban fetal impairment as a basis for abortion. Some individual disability rights activists and local groups have spoken out publicly against these types of bills. For example, The Arc of Indiana, an organization dedicated to advocating for progressive legislation to protect the rights of and improve services for people with developmental disabilities, publicly expressed opposition to the state's legislation banning abortion on the grounds of fetal impairment, asserting their unwillingness to be used as "pawns" in the abortion debate. 107 Pro-choice parents of children with Down syndrome have been particularly vocal in denouncing "disability selection" bills calling instead for legislation that would improve the lives of children with disabilities, including inclusive education, rehabilitative health care, and employment opportunities. 108 However, to date no national disability rights organization has taken a position on these types of legislation. On the other hand, some local disability groups have endorsed fetal impairment bans on abortion, citing fears that technological advances in prenatal testing will lead to earlier diagnosis, and consequently higher rates of termination based on disability. If fewer people are born with disabilities as a result of such bills, proponents argue that governments will be more likely to cut social services for people with disabilities or diminish their civil rights protections altogether. 109

The ambivalence of taking a position on "disability selection" bills is not new. During a 2009 cross-movement discussion on the topic of genetic technologies led by Generations Ahead, an organization whose mission was to bring diverse communities together to expand the public debate and promote policies on genetic technologies that protect human rights, disability rights leaders explained their reluctance to take an institutional position on abortion even though they recognized and affirmed the shared value of bodily autonomy with the reproductive rights and justice movement. 110 First, they expressed discomfort in directly supporting abortion rights, even if individual groups or leaders agreed, citing wide disagreements within the disability rights movement on the issue and fears of excluding members of their core constituency. Second, they argued it was strategically important for them to build alliances with movements and groups across the political spectrum, including those that may oppose abortion, in order to advance a disability rights policy agenda. However, other disability rights leaders pushed back on this analysis arguing that discussing abortion was essential to building alliances with reproductive rights and justice groups, and that working with anti-abortion groups would be inconsistent with the disability rights movement's social justice framework. Despite these disagreements, disability rights leaders recognized a growing urgency to engage reproductive rights advocates and avoid having their messages co-opted by the anti-abortion movement.

Some disability rights advocates, including those who are prochoice, have critiqued the reproductive rights movement for abortion rights advocacy that perpetuates harmful stereotypes about the value of life for people with disabilities. ¹¹¹ In the United States, such critiques have focused both on the strategies and messaging used by abortion rights advocates and the messaging

that advance their movement. For example, in 2010 when the state of Nebraska enacted a law limiting access to abortion from 24 to 20 weeks, disability rights advocates challenged the decision of reproductive rights organizations to center the experiences of women who had received a diagnosis of a fetal impairment after 20 weeks in their advocacy efforts. For years, there have been disability rights advocates who have argued that the framing used to counter these types of bills, including the use of fetal impairment stories, uncritically reinforce the misconception that the diagnosis of a genetic disability is a "tragedy" and will be "inimical to a rewarding life" for both the child and their parents.

In the face of this criticism, some reproductive rights organizations have since modified their strategy and messaging to avoid reinforcing disability stigma. To that end, one step the reproductive rights movement has taken is to refrain from using language of tragedy and pain to describe a woman's decision to terminate a pregnancy following a diagnosis of a fetal impairment. Instead, more recent messaging focuses on a pregnant woman's right to make an informed, autonomous decision about what is best for herself and her family. This approach pivots away from a focus on the fetus and its impairment, and instead reaffirms women's right to bodily autonomy.

Focusing on the hypocrisy of lawmakers who propose antiabortion legislation in the name of supporting disability rights, yet refuse to back measures that would lead to genuine improvements in the lives of people with disabilities, is another recent tactic reproductive rights groups have used. In response to abortion restrictions based on disability, or to restrictions on later abortion that may prevent some women from accessing abortion after receiving a diagnosis of a fetal impairment, some reproductive rights groups including the Center for Reproductive Rights now promote policies supported by the disability rights community in their advocacy efforts, such as inclusive education and rehabilitative health care for children with disabilities.¹¹⁴

In the United States, as around the world, the reproductive rights movement has fought to secure abortion rights in social and political contexts where abortion is highly contested, stigmatized, and often criminalized. Advocates regularly face strategic dilemmas about how to extend protections for all without jeopardizing hard-won gains for some. The outbreak of the Zika virus brought renewed attention to this dilemma because the virus has an impact on pregnant and parenting women in contexts that respect neither their reproductive rights—including access to abortion and contraception—nor their disability rights. Groups advocating for the rights of women with disabilities, such as Women Enabled International, have provided reproductive rights organizations with critical guidance on how to include both perspectives in their advocacy efforts and messaging. 115 Consequently, many national and global reproductive rights organizations have recommended that governments not only ensure its people have full access to sexual and reproductive health information and services, but also take affirmative steps to reduce stigma against people with disabilities, and provide children born with microcephaly or other Zika-related conditions the social and economic support they need to thrive. 116 This collaborative response to a global health emergency is an example of productive cross-movement work that advances the goals of the disability rights and reproductive rights movements.

RECOMMENDATIONS TO THE U.S. REPRODUCTIVE RIGHTS AND JUSTICE MOVEMENT

The following recommendations are intended for the U.S. reproductive rights and justice movement and for institutional funders that support their work. They echo recommendations that have emerged from prior discussions between reproductive rights and disability rights advocates, 117 as well as lessons learned from our experiences at the Center in engaging in advocacy at the intersection of reproductive rights and disability rights.

TO ACTIVISTS AND ORGANIZATIONS

Be willing to get uncomfortable.

Integrating disability rights into your work requires unpacking your own assumptions and biases about people with disabilities, and wrestling with perspectives that may challenge your own views. In 2012, staff at the Center initiated an internal working group comprised of people from various levels in all programmatic departments to examine disability rights in the context of our work. Creating the space to read, debate, and discuss disability rights perspectives with each other allowed staff to examine their own assumptions and biases. These internal discussions were personally and professionally difficult,

but they were also highly valuable. They gave us the opportunity to reflect on an important issue that impacts our work, and then discuss how to align our institutional positions with our personal values.

Realize that mistakes are unavoidable and can even spur progress.

Staff at the Center made many mistakes when attempting to build relationships with allies in the disability rights movement. At the outset, we did not proactively include people with a disability rights perspective in our collaborations. In 2012, for example, when we hosted an expert meeting on intersectionality, we were prompted to extend an invitation to Women Enabled International (WEI) only after another participant noticed the absence of a disability rights perspective on the meeting's agenda. Moreover, the materials we distributed at the meeting were inaccessible and failed to include any mention of disability. Despite these oversights, WEI came to the table and in the end their participation helped expose our limitations. Later, our efforts to correct these initial mistakes helped us build trust and understanding with WEI, ultimately leading to a successful multi-year partnership where we collaborated on joint advocacy efforts.

Improve accessibility in the workplace and in movement spaces.

Accessibility is perhaps the most important factor in determining the presence and participation of people with disabilities. The reproductive rights movement can practice inclusion by making offices, meeting spaces, retreats, conferences, and other events accessible to people with a range of physical, sensory, intellectual, and psycho-social disabilities. This often requires thinking beyond whether a facility is wheelchair accessible. For

example, it may include making reasonable accommodations on an individual basis, such as building time into a meeting agenda to accommodate those using assistive technologies, welcoming—and funding—the participation of support people, and advertising in meeting announcements whether spaces are accessible. It is also important for event invitations to include a prompt to contact meeting organizers regarding any accommodations needed for participation. Thus, the inclusion of people with disabilities requires foresight and planning to ensure that accessibility needs are considered before meeting locations are chosen and budgets are established. Organizations can also incorporate digital accessibility strategies into their project designs and budgets by, for example, making online resources accessible to screen readers or providing transcripts for podcasts in much the same way that is done for people requiring language translation services.

For the full inclusion of people with disabilities, organizations must go beyond compliance with the Americans with Disabilities Act (ADA).¹¹⁸ Full inclusive extends to hiring practices, access to the digital world, and the design of physical spaces. Many people with disabilities support the concept of universal design, which is defined as "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." The organizing principle of universal design, which predates the ADA, is that it benefits everyone by putting the user at the center of the experience. Applying the principles of universal design to Web design, for example, can make online content better organized and easier to read, thereby improving the experience of all users—not just people with disabilities. For more information on how to improve accessibility in the workplace, please see the resources in Annex C.

Inclusion of people with disabilities requires attention, time, and resources. Consequently, some organizations in the reproductive rights movement are deterred from working on issues that intersect with disability rights because their work spaces are not accessible and they lack the resources to make them so. However, if inclusion is understood as a goal, rather than a barrier, then all organizations can make progress towards inclusion. For example, if an office is inaccessible for wheelchair users, an alternate meeting space that is accessible can be arranged. Every organization, no matter the budget, can always do more; the point is to start where it is possible and build from there.

Mainstream disability rights in reproductive rights advocacy agendas.

The reproductive rights movement can demonstrate its commitment to disability rights by addressing the specific sexual and reproductive rights concerns of women and girls with disabilities in their work. Because the disability rights movement is comparatively under-resourced, the reproductive rights movement is in a stronger position to initiate joint projects and programming. Collaborating with disability rights organizations on these issues would benefit both movements by broadening the base of allies needed to drive a shared agenda. Even prior to engaging in joint efforts, reproductive rights and justice organizations can take small but important steps to integrate disability rights perspectives into their work. For example, disability analysis can be integrated into abortion advocacy by addressing the unique challenges women with mobility issues may face when trying to access an abortion clinic located far away, or by explaining why a medical abortion could particularly benefit women with disabilities. Advocates working on sex and race selective bans could also engage the disability

rights community in coalition efforts to defeat all reason-based bans together.

Support the leadership of women and girls with disabilities.

The lack of leadership positions for women and girls with disabilities in both movements has contributed to the deprioritization of their sexual and reproductive health issues on either movement's advocacy agenda. By proactively inviting women with disabilities to strategy sessions on reproductive rights issues—whether directly related to disability or not—the reproductive rights movement can help build this leadership pipeline.

Avoid reinforcing disability stigma in abortion rights advocacy and messaging.

There are several steps the reproductive rights movement can take to avoid reinforcing disability stigma in their abortion rights advocacy. First, advocates can avoid framing abortion as the assumed choice of a woman receiving a diagnosis of a fetal impairment. Messaging that reinforces abortion as *the* solution feeds into the medical model rather than the social model of disability (or, the perception that the medical diagnosis of a disability is the root of the problem, rather than the failure of society to enable people with disabilities to lead full and active lives). Moreover, doing so may also stigmatize women who decide to carry pregnancies to term notwithstanding such a diagnosis.

Second, reproductive rights groups can focus advocacy efforts on women and their rights rather than on the fetal impairment. This means addressing the external factors that may limit a woman's capacity to parent a child with disabilities, such as inadequate access to economic and social support, the lack of a social support network, or the demands of existing children. Addressing the structural factors that constrain a woman's decision about her pregnancy keeps advocates focused on societal challenges and transformative solutions for people with disabilities and their families, while avoiding a problematic focus on the genetic impairment of the fetus, its future life prospects, or the value ascribed to the life of a person with disabilities.¹²⁰

Prenatal genetic counseling, an issue that impacts both the reproductive rights and disability rights movements, is another area where reproductive rights organizations need to be careful to avoid reinforcing disability stigma. Regardless of their views on abortion, many people in the disability rights community are legitimately concerned about how the prenatal genetic counseling process perpetuates disability stigma. Reproductive rights advocates can join forces with their disability rights allies to develop principles and guidelines that balance the concerns of both movements—confronting ableism in the genetic counseling process *and* ensuring the right to information for expecting parents.

Choose language carefully when discussing abortion and disability.

In abortion rights advocacy, those in the reproductive rights movement can also pay more attention to the language they use. For example, many people in the disability rights movement are offended by terms such as "fetal abnormality," which can reinforce the notion of non-disabled bodies as the norm. Terminology can be challenging, but avoiding language that normalizes certain bodies at the expense of others, and therefore fails to recognize or celebrate human variance, is an

important step reproductive rights advocates can make. When in doubt, consulting allies in the disability rights movement about their preferred terminology is the best way to gain clarity and build trust.

Develop an internal position on abortion and disability.

Legal and policy organizations must often differentiate between public messaging, which can reflect aspirational views (e.g., abortion should be available on demand without exceptions) and tactical decisions (e.g., advocating to include a "fetal anomaly" exception in a restrictive abortion bill). Adopting positions that are consistent with the disability rights movement can be particularly challenging in such situations. This is in part because the public and policymakers may be more favorable toward abortion based on a fetal impairment than for other reasons, such as in the case of later abortion.

One way to address this tension is to develop an institutional position on disability and abortion, and then create a "decision tree" to help staff navigate advocacy decisions. The Center mapped out various scenarios about how these questions play out in the context of fetal impairment and created an internal decision tree that provides clear guidance to staff about the strategy and messaging in each scenario. In addition to offering practical guidance, such a tool can help preserve institutional memory during staff transitions.

Rethink the exceptions strategy.

Advocating for broader exceptions to abortion can preserve abortion access under some circumstances that are critically important—such as in the cases of rape, incest, or to save

the life of the pregnant woman—especially in contexts where abortion is highly restricted. However, many reproductive rights advocates have critiqued this kind of exceptions strategy because it requires women to declare and justify their reasons for terminating a pregnancy. Doing so reinforces an "abortion hierarchy" that undermines one of the reproductive rights movement's core values: women's autonomy. 122

In the short term, one approach reproductive rights organizations can take is to advocate for a health exception that conforms with the World Health Organization's definition of health as, "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." ¹²³ This would require taking into account a woman's social and economic circumstances in any assessment of a health risk, in addition to any risk that continuing a pregnancy may pose to the woman's physical or mental health. ¹²⁴ In cases of the Zika virus, for example, where the diagnosis of fetal "anomalies" does not occur until later in gestation, advocates could focus on the need to preserve later abortion access given that many women affected by Zika may lack the social and economic support to raise a child with such a neurological condition.

On the other hand, the outbreak of the Zika virus has also presented the reproductive rights movement with an opportunity to decide whether an exceptions strategy is ultimately a winning one. Public support for access to later abortion is higher when framed in terms of a virus like Zika than for other reasons. ¹²⁵ In fact, some have compared Zika to the outbreak of German measles, also known as rubella, in the mid-20th century, which also caused a variety of disabilities in newborns that posed no threat to the health of pregnant women. ¹²⁶ The public response to rubella changed the perception of abortion and lent support

to the liberalization of abortion laws in many states, paving the way for the passage of *Roe v. Wade*. Similarly, Zika may present an opportunity to challenge stigma around later abortion and restrictions on access. But reproductive rights advocates today should take care to avoid past mistakes like efforts to secure abortion rights by invoking the "tragedy" of children infected with rubella. Such a strategy ultimately reinforced disability stigma while using an exceptions framework that forced advocates to choose between protecting access for all at the expense of some.

Proactively support policies that eradicate disability discrimination.

Reproductive rights organizations can align with disability rights groups to advocate for policies that eliminate discrimination against people with disabilities and promote their inclusion in society more broadly. For example, reproductive rights organizations could tackle policies and practices that discriminate against people with disabilities in accessing assisted reproductive technologies. In addition, the reproductive rights movement could also support "pro-information bills" that promote the disclosure of evidence-based, up-to-date, unbiased information about disability for parents who have received a fetal diagnosis of a genetic disability. Such legislation, which must be distinguished from "faux information" legislation that seeks to interfere with a patient's right to information about all their pregnancy options, includes resources about parenting children with disabilities, as well as connections to support networks for parents of children with disabilities and organizations serving similarly situated families.

As the reproductive rights movement faces increased threats in the current political climate, we may find natural allies in the disability rights community if we broaden our message. For example, we can find common cause with the disability rights movement in fighting the repeal of the Affordable Care Act, recognizing that the expansion of Medicaid and the ADA's non-discrimination measures have greatly improved health care access for people with disabilities. Similarly, the reproductive rights and disability rights movements can align on public policies that promote social and economic support for families, including women who serve as primary caretakers and children with disabilities.

TO INSTITUTIONAL FUNDERS

Encourage the development of cross-movement networking spaces.

Funders can provide resources to train reproductive rights groups on disability rights, and disability rights groups on reproductive rights. More importantly, they can convene crossmovement conversations to help build trust between the disability rights and reproductive rights movements. 127 Closeddoor conversations such as these can allow participants to challenge stereotypes and assumptions and work together to develop non-negotiable principles that each movement can agree to advocate for. These kinds of face-to-face meetings can also help build relationships across movements that lay the groundwork for future collaborations on advocacy or programmatic initiatives. They can also provide an opportunity to support women with disabilities interested in working on issues of reproductive rights and justice who may not have other opportunities to do so, and grow their leadership within the disability rights movement.

Encourage grantees to improve accessibility.

Making workplace and movement spaces more accessible to people with disabilities takes an investment of time and resources. Funders can help improve accessibility for people with disabilities by making it an expectation of their reproductive rights and justice grantees, and by providing dedicated resources to help them improve physical and digital access for people with disabilities. Further, the funding community can provide guidance or training opportunities on the best practices for improving accessibility, especially in the rapidly developing field of technology.

Encourage resource collaboration between the reproductive rights and disability rights movements.

Very little funding provided to the disability rights movement is dedicated to programming aimed at women and girls with disabilities or to addressing the sexual and reproductive rights of people with disabilities. Reproductive rights funders can help close this gap by supporting partnerships between both movements. There are many opportunities for cross-movement collaboration, including culture shift work to destigmatize women with disabilities, particularly around sexuality and reproduction, and advocacy strategies to expand access to reproductive health services and information for women and girls with disabilities. Funding these types of projects signals to both movements that intersectional work on gender, sexuality, and disability can bring more voices to the table and help each movement broaden their base.

Funding such collaborations also has the benefit of building power and visibility for women with disabilities within the disability rights movement. Funders in the reproductive rights field may consider directing funds to disability rights organizations led by women with disabilities, or to specific projects in Organizations of Persons with Disabilities (DPOs) led by women with disabilities, thereby building the pipeline of women's leadership within the disability rights movement.

ANNEX A: TERMINOLOGY AND DEFINITIONS

Americans with Disabilities Act (ADA): The ADA is a federal civil rights legislation that was adopted in 1990. It is a non-discrimination law whose purpose is, "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" and "to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities," including in public accommodations, transportation, telecommunications, and employment opportunities. 128

UN Convention on the Rights of Persons with Disabilities

(CRPD): The CRPD is an international human rights treaty that entered into force in 2008 to address gaps in the international human rights framework surrounding the rights of people with disabilities. With provisions based substantially on the ADA, the purpose of the CRPD is to, "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." A committee of experts, known as the UN Committee on the Rights of Persons with Disabilities, periodically monitors individual country compliance with the CRPD and adopts authoritative interpretations of the treaty.

Disability: 130

• The ADA defines disability as an individual with, "(A) a physical or mental impairment that substantially limits one

or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment." ¹³¹

 According to the CRPD, "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The CRPD further states "that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others." 132

Models of Disability: This term refers to the framework through which individuals understand disability and, therefore, how they think it should be addressed. It is important to note that the international human rights framework for disability rights has adopted and modified the social model of disability and specifically rejects the medical model defined below.

According to the World Health Organization:

- "The **medical model** views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to 'correct' the problem with the individual." 133
- "The **social model** of disability...sees disability as a socially-created problem and not at all an attribute of an individual. On the social model, disability demands

a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment."¹³⁴

• "The **rights model** of disability adheres closely to the social model and specifically enumerates that persons with disabilities are rights holders, particularly in the context of the economic, social, and cultural rights that are essential to their full participation and equality in society." ¹³⁵

Organizations of Persons with Disabilities (DPOs): DPOs are organizations in which persons with disabilities constitute a majority of the overall staff, board, and/or volunteers. These types of organizations advocate for disability rights using the rights and/or social model of disability. According to the Disability Rights Fund, which works to build the capacity of DPOs worldwide, DPOs also include organizations of relatives of persons with disabilities, but only for certain groups such as children with disabilities, people with intellectual disabilities, or the deaf-blind and only "where a primary aim of these organizations is empowerment and the growth of self-advocacy of persons with disabilities." 136

Discrimination on the Basis of Disability:

 According to the CRPD, discrimination on the basis of disability includes, "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation." 137 The ADA prohibits discrimination against persons with disabilities in employment, state and local government, public accommodations, telecommunications, and transportation. It contains separate definitions of discrimination on the basis of disability in several of these contexts.¹³⁸

Reasonable Accommodation:

- According to the CRPD reasonable accommodation includes, "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." 139
- Concerning employment, the ADA states that reasonable accommodation may include: "(A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and (B) job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities." 140

ANNEX B: ORGANIZATIONS WORKING AT THE INTERSECTIONS OF DISABILITY, GENDER, SEXUALITY, AND REPRODUCTIVE RIGHTS

Center for Research on Women with Disabilities (CROWD), located at the Baylor College of Medicine, has a mission to "promote, develop, and disseminate information to improve the health and expand the life choices of women with disabilities." One of their thematic areas of research is sexuality and reproductive health.

CREA is a feminist human rights organization based in New Delhi, India that works to advance women's human rights and sexual and reproductive rights. CREA offers a "Disability, Sexuality, and Rights Online Institute" open to activists around the world working at the intersection of disability and sexuality. The Institute provides a study of theory and practice for people working in fields such as development, health, and rights, including disability and sexuality. It is conducted by an international group of academics and activists working in the field of disability, with expertise in sexual and reproductive health and rights. CREA, along with Point of View, also hosts **SexualityAndDisability.Org**, an accessible website primarily

designed by and for women with disabilities that discusses a wide range of topics related to sexuality.

Girls with Nerve, a project of Ibis Reproductive Health, provides sexual and reproductive health information and support for teens with epilepsy.

International Network of Women with Disabilities is an informal global network comprised of and led by women with disabilities with a mission to promote the human rights of women with disabilities, including sexual and reproductive rights.

Reproductive Health Matters (RHM) is an international non-profit organization promoting universal sexual and reproductive health and rights (SRHR). RHM's peer-reviewed journal publishes high-quality research, in-depth analysis and critical reviews across the spectrum of SRHR, generating knowledge and evidence and inspiring new thinking and action. An issue on Disability and Sexuality is forthcoming in 2017.

Sins Invalid is a performance project that incubates and celebrates artists with disabilities, centralizing artists of color and queer and gender-variant artists as communities who have been historically marginalized. In 2016, Sins Invalid published *Skin, Tooth and Bone: The Basis of Movement is Our People: A Disability Justice Primer*, an activist handbook on disability justice.

Women Enabled International educates and advocates for the human rights of all women and girls, with a special focus on women and girls with disabilities, in collaboration with organizations of women and girls with disabilities worldwide. It

works to include women and girls with disabilities in international resolutions, policies and programs addressing women's human rights and development. WEI's "Talking Points: Zika, Microcephaly, Women's Rights, and Disability Rights" provide a helpful resource for reproductive rights advocates seeking to incorporate a disability rights perspective into a Zika response.

ANNEX C: RESOURCES FOR WORKPLACE BEST PRACTICES ON ACCESSIBILITY

Employers' Practical Guide to Reasonable Accommodation Under the Americans with Disabilities Act provides a summary of laws and policies related to reasonable accommodation in the workplace, a summary of best practices regarding accessibility, and links to resources for more information.

Disability Etiquette in the Workplace, a publication of the U.S. Dept. of Labor Job Accommodation Network, provides concrete and concise suggestions about welcoming persons with disabilities into the workplace, including in recruitment and hiring and for new employees. It contains common-sense advice for respectful interaction with people with a wide range of disabilities, keeping accessibility in mind.

Recruiting, Hiring, Retaining, and Promoting People with

Disabilities: A Resource Guide for Employers (2015) is a
guide that was created under the guidance of several federal
agencies and is currently hosted on archived website of former
President Obama. The goal of the initiative behind the guide
"is to coordinate and leverage existing resources to increase
employment opportunities for people with disabilities." The
guide provides concrete suggestions about how to provide

reasonable accommodations to employees who need them and links to resources that discuss various accommodations in more depth.

The **Web Accessibility Initiative** is the authoritative resource for guidelines on Web accessibility and tools to assess and validate accessibility.

The concept of Universal Design, its seven guiding principles, and examples for successful implementation can be accessed at the North Carolina State University's **Center for Universal Design**.

ENDNOTES

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- ¹⁴ *Id.* at art. 23(1)(b) and art. 23(1)(c).
- ¹⁵ See generally Center for Reproductive Rights (CRR), Breaking Ground 2016: Treaty Monitoring Bodies on Reproductive Rights (2016), available at https://www.reproductiverights.org/document/breaking-ground-2016-treaty-monitoring-bodies-on-reproductive-rights (providing information about international human rights standards surrounding reproductive rights).
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- See generally Nat'L Council on Disability (NCD), Finding the Gaps: A Comparative Analysis of Disability Laws in the U.S. to the U.N. Convention on the Rights of Persons with Disabilities (2008), available at http://www.ncd.gov/publications/2008/May122008 [hereinafter NCD, Finding the Gaps] (providing a comprehensive analysis of how U.S. law compares to the CRPD).
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- ¹⁹ NCD, Finding the Gaps, *supra* note 17, at 10.
- ²⁰ CRPD, General Comment No. 3, supra note 18, at para. 17.
- ²¹ *Id.* at para. 4c, 10, 13, and 16.
- ²² *Id.* at paras. 30, 38-40.
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- ³² Kulick & Rydström, *supra* note 27, at 5-6.
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- ¹⁰⁰ 2016 La. Sess. Law Serv. Act 563 (H.B. 1019).
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- ¹⁰³ H.B. 2111, Reg. Sess. (Pa. 2014); 2016 La. Sess. Law Serv. Act 563 (H.B. 1019); IND. CODE 16-34-2-1.1 (2016).
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- The Arc of Indiana, ABLE Act, High School Diploma Legislation Pass 2016 Session of General Assembly, The Arc News in Indiana, Spring 2016, at 7, available at http://www.arcind.org/wp-content/uploads/2016/03/The-Arc-News-in-Indiana_Spring_2016.pdf. See also S.E. Smith, Anti-Choicers' Single-Minded Question to Turn Disabled People into Political Pawns, Rewire (Jan. 27, 2016, 11:14 AM), http://rewire.news/article/2016/01/27/anti-choicers-single-minded-request-turn-disabled-people-political-pawns/.
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- Generations Ahead, A Disability Rights Analysis of Genetic Technologies, supra note 8. at 11-13.
- ¹¹¹ See Generations Ahead, Bridging the Divide, supra note 35.

- Sujatha Jesudason & Julia Epstein, The Paradox of Disability in Abortion Debates: Bringing the Pro-Choice and Disability Rights Communities Together, 84 Contraception 541, 541 (2011).
- Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 Am. J. Pub. Health 1649, 1650, 1652 (1999).
- ¹¹⁴ See, e.g., CRR, Centering Human Rights in the Response to Zika (2016), https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/ EN_Centering%20Human%20Rights%20in%20the%20Response%20to%20 Zika_web_0.pdf [hereinafter Centering Human Rights].
- Women Enabled Int'l (WEI), Talking Points: Zika, Microcephaly, Women's Rights, and Disability Rights (Apr. 15, 2016), http://www.womenenabled.org/pdfs/WEI%20Talking%20Points%20Zika,%20Microcephaly,%20Women's%20 Rights,%20and%20Disability%20Rights%20ENGLISH%20June%202016.pdf [hereinafter WEI, Talking Points].
- These include access to health services, reasonable accommodations in schools and the workplace, and individualized supports where needed. *See* Centering Human Rights, *supra* note 114.
- These include, most notably, the structured conversations led by Generations Ahead in 2008-2009 (*see* Generations Ahead, A Disability Rights Analysis of Genetic Technologies, *supra* note 8, and Generations Ahead, Bridging the Divide, *supra* note 35), as well as more recent conversations surrounding the response to Zika that occurred prior to and during the AWID Forum in Brazil in 2016 (*see* Centering Human Rights, *supra* note 114, and WEI, *Talking Points*, *supra* note 115).
- Employers with 15 or more employees must comply with the ADA, which prohibits discrimination against "qualified individuals with disabilities" in all employment practices and activities. These employers are required to provide reasonable accommodations that enable employees or applicants with disabilities to perform essential job functions. See Equal Employment Opportunities Comm'n, "The ADA: Your Responsibilities as an Employer," available at https://www.eeoc.gov/facts/ada17.html.
- About UD, The Center for Universal Design, https://www.ncsu.edu/ncsu/design/cud/about_ud/about_ud.htm (last accessed Nov. 23, 2016).
- ¹²⁰ A more extensive analysis can be found in Generations Ahead, Bridging the Divide, *supra* note 35.
- ¹²¹ See id. at 8-9.
- Merritt Tierce, *This Is What an Abortion Looks Like*, N.Y. TIMES (Sept. 12, 2014), http://www.nytimes.com/2014/09/13/opinion/this-is-what-an-abortion-looks-like. html; Jesudason & Epstein, *supra* note 112, at 542.
- ¹²³ Constitution of the World Health Organization (WHO), 47th ed. Geneva, World Health Organization, 2009.

- WHO, Safe Abortion: Technical and Policy Guidance for Health Systems, 2nd ed. 92 (2012).
- 125 Jennifer Haberkorn, *How Zika Could Change the Politics of Late-Term Abortion*, Роцтко.сом (Aug. 22, 2016).
- See generally Leslie J. Reagan, Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America (2010) (providing a comprehensive history of rubella and its impacts on the reproductive rights and disability rights movements).
- ¹²⁷ Generations Ahead, Bridging the Divide, *supra* note 35, at 12 ("Both [disability rights and reproductive justice advocates] recognized that building and deepening a shared commitment to the dignity of all people would require intentional work on both sides. This intentional work would include trust and relationship building across movements in venues like these roundtables, learning more about each other's histories, perspectives and concerns, and a willingness to re-examine old perspectives and shift paradigms.").
- ¹²⁸ ADA, *supra* note 4, at § 12101.
- 129 CRPD, supra note 10, at art. 1.
- See also World Report on Disability, WHO and World Bank 3-5 (2011); Disability Language Style Guide, Nat'l Center on Disability and Journalism, available at www.ncdj.org/style-guide (last accessed on Nov. 23, 2016).
- ¹³¹ ADA, *supra* note 4, at § 12102.
- 132 CRPD, supra note 10, at preamble & art. 1.
- 133 Towards a Common Language for Functioning, Disability and Health, WHO 8 (2002).
- ¹³⁴ *Id.* at 9.
- ¹³⁵ See Michael Ashley Stein, Disability Human Rights, 95 Cal. L. Rev. 75, 93-94 (2007).
- ¹³⁶ What is a DPO?, DISABILITY RIGHTS FUND, http://www.disabilityrightsfund.org/faq/what-is-a-dpo/ (last accessed Nov. 23, 2016).
- 137 CRPD, supra note 10, at art. 2.
- ¹³⁸ ADA, *supra* note 4, at §§ 12112, 12132, 12182.
- 139 CRPD, supra note 10, at art. 2.
- ¹⁴⁰ ADA, *supra* note 4, at § 12111.

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