

BRIDGING THE DIVIDE

DISABILITY RIGHTS AND REPRODUCTIVE RIGHTS AND JUSTICE ADVOCATES DISCUSSING GENETIC TECHNOLOGIES

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ABOUT GENERATIONS AHEAD

Generations Ahead brings diverse communities together to expand the public debate and promote policies on genetic technologies that protect human rights and affirm our shared humanity.

By looking at the benefits and risks of these technologies for different communities we promote policies that ensure full respect and human rights for all people. We work to increase the public awareness of the many social implications of genetics and build the capacity of organizations and leaders to develop more informed positions. By facilitating critical conversations between multiple stakeholders we have increased the number of perspectives and voices involved in the national discussions on human genetic technologies.

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EXECUTIVE SUMMARY

Recent developments in reproductive and genetic technologies—increased prenatal testing, screening and selection, as well as pre-implantation genetic diagnosis—are forcibly inserting disability rights issues into reproductive rights agendas, and reproductive rights issues into disability rights agendas. Events such as the introduction of legislation and initiatives in many states to make fertilized eggs or embryos “persons” with full legal rights, and the media attention to 2008 vice presidential candidate Sarah Palin’s son with Down syndrome all point to the increasing intersections between issues related to disability and reproduction and the need for dialogue to build the capacity of both movements to work in support of each other’s goals.

Since February 2007, Generations Ahead has hosted five Roundtable discussions with disability rights and reproductive rights and justice advocates working in the San Francisco Bay Area and Los Angeles. These Roundtables brought together seventeen advocates to discuss genetic selection technologies, caregiving, and working with the Right as core areas of tension and common ground between the two movements. They worked to develop a shared analysis of genetic technologies across movements with the goal of creating common ground and advancing coordinated solutions and policies. This report describes a first attempt by Generations Ahead to further dialogue between the two communities and to construct a basis for cross-movement alliance building and shared advocacy.

The disability rights and reproductive rights communities have often been at odds when it comes to the issues of abortion and increasingly available reproductive technologies, particularly genetic testing technologies. For disability advocates, concerned with challenging structural oppression facing people with disabilities and advocating for their increased social access, genetic testing has proved worrisome in its potential for selecting out fetuses based on disability. For reproductive rights advocates, the affirmation of reproductive autonomy is paramount, and genetic technologies are generally supported for increasing reproductive options for women and families.

Advocates worked to develop a shared analysis of genetic technologies across movements with the goal of creating common ground and advancing coordinated solutions and policies.

Key areas of discord between the two movements include different perspectives on “fetal anomaly” as justification for abortion, and differing notions of personhood. While reproductive rights advocates have supported the idea of “fetal anomalies” as an argument for abortion rights, disability rights advocates

have argued that this reinforces negative views of disability. And while the reproductive rights movement is fighting to restrict the legal definition of personhood to protect abortion, the disability rights movement is fighting to expand a perceptual definition of personhood to increase the social inclusion of people with disabilities. While these two goals are not necessarily in opposition to each other, the different approaches to addressing the definition of personhood have led to some tension and difficulties in working together across movements.

The plan of action that developed during the Roundtables rested on the following principles and values that emerged:

- Reproductive autonomy should include support for people making the choice to have children, including children with disabilities, and support to raise their children with dignity.
- All women who choose to parent should be valued as parents and all children should be valued as human beings, including children with disabilities.
- Policy advocacy should focus on providing social and material supports to women, families and communities, not on when life begins, whose life is more valued, or who can be a parent.
- Both movements should broaden their agendas to fight to improve the social, political, physical and economic contexts within which women and people with disabilities make decisions about their lives. The focus should be on changing society, not on individual decision-making.

Areas of common ground that were discovered and developed included working toward recognition and support of people's right to independent decision-making, resources that allow them to control their own lives, and respectful and dignified treatment. Furthermore, the basis for a shared vision was cultivated through the overlapping social analysis between those in the disability rights movement who use a social model of disability (the notion that it is the negative social attitudes toward disability rather than the disability itself that are the source of oppression for those with disabilities) and those in the reproductive rights movement who use a reproductive justice framework (the understanding that multiple, intersecting structural factors influence both women's ability to not have, but also to have children and parent them with dignity).

The Roundtables also resulted in a model for effective cross-movement work that included the need to learn more about each other's movements; utilizing a good process to hold the difficult conversations; building trust throughout the process; and working with people who come to the conversations with a willingness to be changed by the cross-movement work. The ultimate goal of doing effective cross-movement work is to identify shared values that can be used as the basis for collaborative and coordinated policy advocacy.

INTRODUCTION

Since February 2007, Generations Ahead has hosted five Roundtable discussions with disability rights and reproductive rights and justice advocates working in the San Francisco Bay Area and Los Angeles. These Roundtables brought together a total of seventeen advocates to discuss areas of tension between the two movements, and develop a shared analysis of genetic technologies across movements with the goal of advancing solutions and policies that reflect shared values and language.

Recent developments in reproductive and genetic technologies—increased prenatal testing, screening and selection, as well as pre-implantation genetic diagnosis—are forcibly inserting disability rights issues into reproductive rights agendas, and reproductive rights issues into disability rights agendas.

Events such as the introduction of legislation and initiatives in many states to make fertilized eggs or embryos “persons” with full legal rights, the media attention to 2008 vice presidential candidate Sarah Palin's son with Down syndrome, and the case of Ashley X¹ all point to the increasing intersections between issues related to disability and reproduction and the need for dialogue to build the capacity of both movements to work in support of each other's goals.

Prenatal testing and now pre-pregnancy testing (in which embryos from in vitro fertilization are screened for genetic conditions before implantation) raise difficult questions about how to simultaneously ensure reproductive autonomy while valuing people with disabilities. In this age of ever increasing reproductive genetic technologies it

becomes imperative that disability rights and reproductive rights advocates speak to each other and to each other's issues. New advances in these technologies pose complex challenges that, if only addressed on an issue-by-issue basis, have the potential to divide progressive movements.

These Roundtables are not the first instance of structured dialogue taking place between these two movements. In the early 1980s, disability rights and reproductive rights advocates hashed out tensions at multiple conferences and meetings, and in published writings.

The Roundtables were intended to build upon those earlier conversations and to possibly mobilize a group of advocates around a shared agenda. The first discussion in February 2007 was intended to focus on selection technologies, specifically pre-implantation genetic diagnosis, with the hope of avoiding the complexities of an abortion debate. However, it quickly became clear that there was a much broader list of topics that needed to be discussed before meaningful discussion of any one technology could occur. The group generated a list of broader topics for future discussion at that meeting. Participants prioritized two topics to discuss over the next three Roundtables: personhood (two

discussions) and caregiving. In June and September 2007, the group examined how personhood status is defined as well as the different realms in which the two movements address this concept. In March 2008, participants discussed the gendered nature of caregiving,

the context in which women make decisions about whether to have a child with a disability, and the class and race dynamics of paid caregiving for adults with disabilities. The group decided to focus the last discussion, in August 2008, on political alliances with the Right because of the divisive nature of anti-choice

efforts. They discussed the co-optation of progressive language and alliances between uncommon partners.

One of the critical challenges of our times is to re-examine and re-formulate progressive positions on technology, particularly human biotechnology, given all the complex and contradictory dilemmas its uses can pose. These Roundtable discussions offered a way to think more broadly about the intersections between disability rights and reproductive rights and justice, to talk longer, go deeper and develop better language to shape this policy field.

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1. Ashley X was born with a severe brain impairment in 1997 in Seattle. When she was 6, her parents petitioned the ethics committee at Seattle Children's Hospital to conduct experimental treatment to stop her growth, expressing the desire to make caring for her easier as she got older. The treatment, which was approved, involved removing her uterus, appendix, and breasts buds, and treating her with high doses of estrogen. The public first learned of the treatment in 2006 when doctors involved with the case advocated its use in an article in Archives in Pediatric and Adolescent Medicine. Although some commentators and medical professionals supported the treatment, the hospital's actions were widely condemned by disability rights activists; the hospital eventually admitted it had violated state law in failing to obtain a court order for the procedure. Ashley X's parents, who started a blog to explain their situation, similarly found themselves subject to criticism from some groups and support by others.



BACKGROUND

In the history of the disability rights and reproductive rights movements, two areas of tension between the movements emerged early on and continue to create discord. The primary tensions include different perspectives on “fetal anomaly” as justification for abortion and differing notions of personhood.

“FETAL ANOMALY” AS JUSTIFICATION FOR ABORTION

The reproductive rights movement, for the most part, has not questioned broad public support for abortion in cases of “fetal anomalies” or “fetal defects” and has, in fact, often used “fetal anomaly” as an argument for abortion rights. Disability rights advocates are concerned that this argument reinforces negative views of disability by including disability as an unchallengeable justification for abortion along the lines of rape and incest. Furthermore, the Right’s introduction of bills in several states to ban abortion in all cases has led reproductive rights advocates to emphasize “fetal anomalies” as one of the key exemptions necessary if such laws pass. In the often desperate battle to protect abortion rights, some reproductive rights advocates have strategically argued for the need for abortion in the cases of rape, incest and disability as a way to undermine their opposition and win undecided voters to their side.

NOTION OF PERSONHOOD

While the reproductive rights movement is fighting to restrict the legal definition of personhood, the disability rights movement is fighting to expand a perceptual definition of personhood. Reproductive rights organizations oppose policies that would grant a fetus

“personhood” status with full constitutional rights, drawing attention to the problematic nature of treating embryos and fetuses as separate from pregnant women or intended mothers. The disability rights movement is challenging a societal definition of personhood that defines a person based on one’s mental or physical capacities. While these two goals are not necessarily in opposition to each other, the different approaches to addressing the definition of personhood have led to some rancor and difficulties in working together across movements.

An important force in both of these areas of tension is the highly organized and well-funded anti-choice movement. Pro-life organizations court disability rights groups by focusing on “unborn children,” including those who have been/would be born with disabilities. The Right’s strategy to make fertilized eggs and fetuses “persons” with full legal rights can seem complementary to disability rights efforts to challenge the devaluation of those living with disabilities or those who might be born with disabilities. Some disability rights organizations have strategically chosen to not take a position on abortion so that they can work with both pro-life and pro-choice organizations to further their agenda.

The anti-choice movement’s continuous attack on abortion rights has kept the reproductive rights movement in a defensive position to retain access to abortion. The anti-choice movement’s tactics of courting disability rights organizations, attempting to personify embryos and fetuses, and proposing blanket abortion bans have fostered divisions between disability rights and reproductive rights communities. The advent of new technologies, not only prenatal, but also pre-pregnancy, that allow parents to avoid having a child with a disability has opened up another opportunity for discord.

BRIDGING FRAMEWORKS

However, while the disability rights and reproductive rights movements are focused on different goals, strategies and stakeholders, both movements share common ground in working toward recognition and support of people's right to independent decision-making, resources that allow them to control their own lives, and respectful and dignified treatment. In particular, advocates who use a reproductive justice framework and disability rights advocates who use a social model of disability share a recognition of the complex social, economic and political factors that affect people's choices and decisions. Both recognize the relationship of individual lives to larger social, political, and economic factors, and the intersectional and contextual nature of individual and family decision-making. They appreciate that the difficult decisions that women and people with disabilities make must be understood in terms of structural and pervasive inequality, mistreatment and bias.

A traditional reproductive rights framework is grounded in a civil rights model and depends on the legal system as the vehicle for change. Reproductive justice, on the other hand, uses an intersectional analysis that recognizes the multiple factors that affect people's lives and offers an understanding of the intersectional nature of economic, social and political forces that shape the lives of women, their families and communities. In contrast to the traditional strategies used by the reproductive rights movement, reproductive justice organizing has centralized the voices and concerns of marginalized communities, particularly women of color and low-income women. Reproductive

justice organizing goes beyond securing abortion rights to advocating for a more comprehensive agenda that includes the right to have children and parent those children with dignity and respect. Involving reproductive justice advocates and incorporating a reproductive justice framework into the Roundtable discussions created an important bridge, broadening the scope of a traditional reproductive rights approach and more easily allowing an integration of disability rights concerns into a comprehensive agenda.

A social model of disability broadens analysis, solutions and strategies for change beyond the individual level to comprehensive social change at the societal level.

Similarly, the social model of disability recognizes the impact of institutional oppression on people's lives. Unlike the medical model where disability is seen as an individual medical problem that

needs to be "fixed," in the social model of disability, the problem isn't the disability but rather negative social attitudes towards disability and the lack of supportive resources for people with disabilities. The medical model is a view of disability that claims that disability is a negative health problem that should be prevented, eliminated, or mitigated to the greatest extent possible. Under the medical model, the problem is with the individual person and the disability itself. The social model postulates that negative social attitudes and a lack of resources are the most significant barriers in the lives of people with disabilities, rather than the disability itself. Under the social model, disability is not inherently negative, and a person with a disability can live a full life with the appropriate resources and social opportunities. A social model of disability broadens analysis, solutions and strategies for change beyond the individual level to comprehensive social change at the societal level.



THREE THEMES AND SOME LESSONS

Three main themes emerged from the five Roundtable discussions. The first theme underscores the need for using a framework that recognizes both the intersectionality of people’s lived experiences and the need for long-term solutions that include changes in social relationships of power. In both the reproductive justice framework and the social model of disability, women’s reproductive decision-making is informed by multiple interlocking oppressions, including the exclusion of women of color, poor women and women with disabilities from full reproductive self-determination, and a legacy of disability oppression that fosters negative social perceptions of people with disabilities. All of these factors must be included in an analysis of the appropriate and ethical uses of reproductive genetic technologies. Long-term, comprehensive, intersectional policies that create structural changes in social inequality are needed for meaningful change in the lives of all women and all people with disabilities.

The second theme, building on the first theme of structural changes and intersectionality, focuses on fighting for dignity for all people – all women, all people with disabilities, all people of color, all classes, all lesbians, gays, bisexuals and transgender people. When groups are segmented and pitted against each other in terms of who is more oppressed, less valued, or more excluded, the focus shifts both to fighting for the rights and dignity of a few at the expense of others, and to keeping many groups in a

perpetual victim status. Any attachment to most oppressed/least valued status becomes a barrier to working together between groups, putting them in competition with each other and creating openings for others to play wedge politics and divide potential allies. When the discussion starts with which group feels/is more or less valued socially the discussion stays there, with little to no movement forward. By starting at the Roundtables from a

position that acknowledged the dignity and value of all people, the work became focused on learning about each other and figuring out shared values and policy agendas.

Third, working together on shared concerns related to genetic technologies is going to require both movements to broaden their agendas. This broadening of agendas is more than just

adding each other’s concerns to existing priorities, but will require a different analysis to reconfigure priorities and strategize an expansion of resources. The libertarian strain in both movements can often lead to a focus on individual independence, individual self-sufficiency, individual decision-making, and individual worthiness.

This focus on the individual includes the premise that one only wins at the expense of another. In the political arena, the assumption is that the pie is fixed and that the fight for resources for one group is at the expense of another group, or that the individual benefits at the expense of the community. The framing of difficult decisions need not be either individual OR community good, but rather

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individual AND community good together. Currently there are very few individual decisions that people make that are truly independent decisions. Often times, people are forced to choose between two bad options. The goal should be to increase good options for everybody – for women, for families, for people with disabilities, for children. By broadening the agenda and the range of options, people would not be forced to settle for a choice between two suboptimal options.

If both movements are to affirm the recognition and support of people's right to self-determination, resources that allow them to control their own lives, and respectful and dignified treatment, then individuals need to have more and better options. This means more collective responsibility and more support for children and families. Both movements can agree on shared principles of valuing women's authority over their reproductive decision-making and valuing the lives of people with disabilities. This means that they share a collective fight for securing the financial resources and social support to raise children and care for family members with disabilities. Caretaking and child-rearing, regardless of ability, must cease to be individual family issues with inadequate support from government and society. The fight needs to shift to fighting for a bigger pie, or a different pie, not how to divide up the existing inadequate resources for families and children.

In addition, these cross-movement Roundtables provided a model for how to do effective cross-movement work. Below are some key lessons learned doing this cross movement project.

a. Useful cross-movement work needs to include a good process for the conversation. That way, even if there isn't easy agreement or understanding, both sides will stay committed and involved. In the early phases of the conversation, worthwhile outcomes are hard to envision, but if both sides feel heard and valued through the process they will continue to work through the harder issues.

b. While trust is not necessary to start cross-movement work, it is essential to build it during the process. Trust is built through face-to-face conversations, by identifying and addressing areas of conflict and tension, and by concretely demonstrating solidarity for each other's issues (i.e., going to each other's events, reading about each other's issues, and speaking up for each other when the other is absent). Cross-movement work requires learning about each other's movements, sharing stories, and reading about each other's perspectives, analysis and priorities.

c. Authentic change can only occur when all sides are willing to be changed by the cross-movement relationship and work. This change requires a willingness to learn and integrate new information, and abandon a certain perspective or politic that might consist of a history of grievances or a victim-oppressor binary.

d. The core work of cross-movement work is to identify shared values to use as the basis for a shared advocacy agenda.

These themes emerged in different discussions throughout the five Roundtables. They are useful lessons that can be used by advocates working in reproductive and/or disability issues, as well as other social justice work, and can contribute to the development of analysis, language, strategy, and policy that integrate the needs and agendas of multiple movements.

Organized by topic, what follows is a synthesis of each Roundtable discussion. Each section begins with background information to contextualize the issue and ends with insights made in the discussion that contribute to these three themes and some lessons. The report concludes with suggestions for next steps and directions for future work and conversation.

TOPIC 1: SELECTION TECHNOLOGIES

BACKGROUND

Prenatal and pre-pregnancy selection technologies, such as ultrasound, amniocentesis, and pre-implantation genetic diagnosis, were developed to allow parents to avoid having a child with a disability. Disability rights advocates have argued that “de-selecting” for disability is detrimental to people with disabilities and to society. Whether de-selecting an embryo or fetus, selection based on disability reinforces the notion that disability and people with disabilities are a negative outcome, and therefore undesirable. Disability rights advocates worry that this kind of bias against disability can contribute to increased exclusion of people with disabilities, increased discrimination against those already living with disability and fewer resources for the disability community as a whole. While the disability rights advocates in the Roundtable discussion all identified as feminists who support abortion rights, they also challenged unquestioned acceptance of genetic testing technologies, arguing for the inclusion of a broader, more socially contextualized perspective in an individualized pro-choice position.

Reproductive rights advocates, on the other hand, have been concerned that any challenge to a woman’s individual choice is dangerous. Access to safe and legal abortions in the United States is premised on a legal argument for the right to individual privacy. Advocates argue that abortion is a complex, individual decision and that women should not have to justify their reasons for having an abortion. By extension, pro-choice advocates tend to argue that the use of selection technologies in a reproductive context falls within the same parameters of privacy and choice. Because access to abortion has been under relentless attack since *Roe v. Wade* in 1973, they argue that the politics of abortion cannot be separated out from any other reproductive decision-making. Engaging in conversation about selection technologies raises the question of how to ensure reproductive autonomy while simultaneously valuing the lives of people with disabilities.

DISCUSSION

Disability rights advocates talked about how perceptions of people with disabilities are profoundly distorted by pervasive and structural oppression against disability. The decisions people make to avoid having children with disabilities are often unquestioned and seen as “natural and common sense,” with no recognition of the systematic fear and bias against disability. These societal perceptions about people with disabilities inform women’s and families’ decisions about whether to bring a child with a disability into the world, often defining a child with a disability as an undue burden. Negative perceptions both reinforce an expectation that people should avoid having a child with a disability, and shape discriminatory attitudes toward those living with disability.

Engaging in conversation about selection technologies raises the question of how to ensure reproductive autonomy while simultaneously valuing the lives of people with disabilities.

Several disability rights advocates shared personal experiences to stress this point. One participant who became disabled in her 20s said that people regularly say to her, “If I were you, I’d kill myself,” or “If I had your disability, I would not want to live.” Another participant talked about how she would very likely

not have been born if prenatal genetic testing had been available when her mother was pregnant. A third advocate talked about the pride she has in the disability community and how the joy that her community brings into the world goes unrecognized. She asked why it is still acceptable for women who identify as feminists to point to people in the disability community and say, “That’s a reason not to continue with a pregnancy.”

A reproductive rights advocate said that many people believe that society can both work to decrease the incidence of disability and support people living with disabilities. The group discussed an article by Adrienne Asch², who argues that these two viewpoints are incompatible. De-selecting for disability as an undesirable condition is fundamentally incompatible with claims to fully include, value and treat

with dignity people with disabilities. Asch also argues that there should be no lines drawn about what conditions are acceptable to select for or against because as soon as the line is drawn some group or condition will always be on the other side of the line of acceptability. One participant agreed that fighting over whether to draw lines masks the issue of how to provide real choices for women so that it is not an individual “burden” to raise a child with a disability.

In the same way that our perceptions of disability are profoundly distorted by a history of discrimination against people with disabilities, sexism has distorted perceptions of pregnancy and motherhood. Applying a reproductive justice analysis further reveals how motherhood is not just linked to issues of gender and sexism, but intersects with class, race, citizenship status and sexuality. Hierarchies of power and privilege in society encourage parenting by some women and actively discourage other women. In the context of welfare, for example, policymakers feel justified in passing legislation that limits the reproductive decisions of poor women (mostly women of color), but not of privileged and educated (mostly white) women.

Social location (based on class, race, geography) affects people’s relationship to reproduction and to reproductive selection technologies. There is pressure on some women to reproduce and on others not to reproduce. As genetic technologies become more available, a new burden is being placed on women that is about only bringing a certain type of (non-disabled) child into this world. And definitions of who is a “good mother” are increasingly being linked to having children without disabilities, particularly as more and more information about embryos and fetuses is available before birth.

Advocates also talked about the history of the reproductive rights movement. The main goal of the early, professionalized feminist movement was abortion rights, focusing on women’s ability to choose not to have children. The newly emerging reproductive justice movement is shifting the debate. Now the fight is just as much about abortion and contraception as it is about the right to have children and to parent with dignity. This broader agenda allows for more common ground between reproductive justice and disability rights advocates as it acknowledges the multiple social, political and economic forces that shape the options available to different women. This framework contextualizes women’s decisions within structural inequalities that include disability oppression, racism, sexism, homophobia, classism, ageism and citizenship status, and focuses on fighting for the structural and social supports to have all kinds of children.

By acknowledging both disability oppression and reproductive oppression, these advocates were able to find common ground in a few areas.

By acknowledging both disability oppression and reproductive oppression, these advocates were able to find common ground in a few areas. They agreed that both movements could support providing pregnant women with comprehensive, unbiased and accurate information about prenatal and genetic tests, information that was biased neither against abortion nor against disability. They agreed that an agenda that supports all women and families in their decisions to have children and to parent with dignity would require many more social and economic supports for parenting. And they agreed that by including the effects of race, disability, class, sexual orientation and citizenship status in their analysis, both movements could more effectively acknowledge the lived reality of people and find more common ground, thereby building bridges across a larger number of social justice movements and creating more allies.

2. Asch, A. Disability Equality and Prenatal Testing: Contradictory or Compatible? Florida Law Journal, vol. 30, pp, 315-342, 2003.

TOPIC 2: NOTIONS OF PERSONHOOD

BACKGROUND

The concept of “personhood,” or how a person is defined, is a central area of tension between disability rights and reproductive rights advocates. Reproductive rights advocates are fighting to defend reproductive freedom by preventing the legal definition of personhood from being extended to fertilized eggs, fetuses and embryos. At the same time, people with disabilities have often been deemed “not persons” and denied basic human rights and acceptance as full persons, resulting in their efforts to expand perceptions of personhood and self-determination to include people with disabilities. As technologies develop that allow for extending and supporting life, manipulating embryos, and increasing the survivability of premature babies, definitions of when life begins and personhood are becoming more and more contested. Tensions over the issue of personhood surfaced in the case of Ashley X (2006), the 2007 Supreme Court decision to ban “partial-birth abortion,” and the personhood initiatives and legislative proposals in several states.

Reproductive rights advocates dispute fetal personhood by arguing that fetuses don’t feel pain and don’t communicate. This representation of a person as somebody who is able to communicate and express pain can then be construed as excluding people with disabilities who don’t communicate (at least not in typical fashion) or whose pain seems incomprehensible or inexpressible. Anti-abortion advocates try to link the conversation about disability and abortion by framing the question as, “If you think that a severely disabled adult who can’t speak or care for himself or herself is a person deserving protection, then why isn’t a fetus equally a person deserving protection? They are functionally similar.”

The disability rights and reproductive rights movements have taken conflicting positions on issues related to personhood in several recent events. In the case of Terry Schiavo and the battle over disconnecting her from life-support systems, many disability rights organizations opposed the court decision that allowed her husband to remove her feeding tube. In contrast, reproductive rights organizations argued that end of life decisions are akin to beginning of life decisions and should be left to families without court or governmental interference.

DISCUSSION

The group acknowledged that systemic and institutionalized negative attitudes towards disability have played a role in discounting the human rights and full personhood of people with disabilities. Placing this discussion in a historical context, participants agreed that many groups throughout history have not been considered fully human with full human rights: enslaved Africans, Indigenous people, people of African descent, women, Japanese Americans during World War II, homeless people, people with mental illness or intellectual disabilities, young people, children, and prisoners. The denial of political and civil rights is fundamentally premised on the denial of personhood status.

In general, all participants agreed that there is no scientific answer to when life begins; it is not a scientific inquiry but a deeply personal, religious and spiritual matter. Within each movement there isn’t a monolithic notion of the concept of personhood. The term is used in multiple ways and has various meanings. Yet each movement tends to have a primary realm for addressing it. For the reproductive rights movement, the debate takes place in the legal realm; for disability rights advocates, the focus is the perceptual realm, or how people are perceived.

The kernel of all oppressions is the “othering” of people, people who are positioned as outside the norm of being “human.” The group discussed some of the characteristics society uses to define personhood and “normal:” productivity, citizenship, capacity to feel pain, rationality/decision-making, and autonomy/self-sufficiency. Currently, a person’s economic value and societal productivity are closely linked to personhood, with people’s earning capacity often determining the acknowledgment of their personhood and associated rights. Personhood as defined by productivity and economic values reinforces the perception that people with disabilities are an economic drain and an inherent burden on society.

The notion of “quality of life” as a measure of personhood was also discussed because a person enjoying a certain quality of life is often used as the yardstick to measure the value of a life. “Poor quality of life” is often used to justify euthanasia, de-selection, or diminishing resources for people with disabilities. The disability advocates rejected

this notion based on a history of using narrow definitions of quality of life to undermine and disregard the lives of many people with disabilities. In contrast, reproductive justice advocates talked about quality of life as a collective, community concept, not as an individual measure. They argued for using the term to measure the well-being of a whole community, not to determine the value of an individual life. As these advocates shared their different meanings of the same term, it became clear that understanding each other's language and meaning becomes a critical part of finding common ground.

While the reproductive rights movement had a comprehensive agenda and multi-faceted strategy pre-Roe v. Wade, after this Supreme Court decision the movement narrowed its focus to abortion issues using a legal and legislative strategy. This strategy developed largely in response to Right-wing legal and legislative attacks on abortion that began once Roe was passed. Currently, one tactic of the religious Right is to create a cultural and legal notion of personhood for fetuses and fertilized eggs by imbuing them with rights that are parallel to—and sometimes greater than—the rights of women. Granting legal personhood status to fetuses or fertilized eggs would separate their rights from the rights and self-determination of pregnant women, allowing for state intervention in a woman's pregnancy, for the limitation or removal of women's control over their bodies, and the limitation of women's reproductive decision-making authority.

Since the passage of the Americans with Disabilities Act, the principal focus of the disability rights movement has been on the *implementation* of laws and on shifting people's perceptions about people with disabilities. In a perceptual realm, the question is more about what makes a person, and is there a clear line that divides whether one is or is not a person? The question of rights still arises in the form of when is one accorded rights? Does one have to be sentient and self-directing? Is personhood based on some socially and politically constructed definition of "quality of life"?

The legal concept of personhood assumes a person with full choice and rights, and the norm is premised on an idealized definition of a sentient white male, not someone with a disability, a woman or a child -- as in the case of Ashley X, a child with a disability whose doctor said she had the sentience of a three month old. Her caregiver was given the legal right to make decisions for her, including authorizing experimental treatments to remove Ashley's uterus, appendix and breast buds to stunt growth and maturation for ease of care. In this case, disability rights advocates raised concerns about the welfare and human rights of Ashley X and challenged the notion that her caregivers had the right to authorize these treatments for their convenience, without her consent. Even with legal

rights, some with disabilities are not considered fully human because they are seen as lacking sentience or human value.

As disability rights and reproductive rights and justice advocates fight battles in different realms about who is recognized as a person, there is going to be a point at which the concept of personhood must be made compatible

in the law for both movements. Given that the legal definition of who is a person cannot be changed according to context, since the law is incapable of different linear or parallel recognitions, all Roundtable participants recognized the need for coordination, alignment and agreement in this area.

Where they found common ground was in shifting the focus to fight for the human rights and dignity of all people—all women, all people with disabilities, all people of color, all classes, and all lesbians, gays, bisexuals and transgender people. And rather than focusing on individual rights, attention needs to shift to the obligation to treat each other with dignity. More important than a monolithic definition of personhood is the need to determine how to advance language, frameworks, and advocacy that simultaneously ensure reproductive freedom and the valuing of lives of people with disabilities.

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Both movements can join together to challenge the notion that birthing a child with a disability is a negative outcome on the one hand and the Right's "pro-life" rhetoric that seeks to elevate supposed fetal rights above women's rights on the other.

Both sides 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.



TOPIC 3: CAREGIVING, REPRODUCTION AND DISABILITY

BACKGROUND

Caregiving in our society is a gendered activity, with women occupying the primary role of caregivers in families and society. Women and people with disabilities are affected by similar systems of structural inequality when it comes to caregiving, both in terms of women's assumed responsibility to care for their children, and the stigma placed upon people with disabilities who require care. In the past, some feminists have claimed that children and adults with disabilities are burdensome to the women caring for them, rather than acknowledging the systems and institutions that fail to provide the needed resources and supports. Public debate continues about whether caregiving should be a private family matter, in which families handle all decisions and provide care themselves, or if caregiving should be a public issue, in which resources are allocated by the state from public funds.

Women are the primary caretakers of children and of people with disabilities, either as mothers and family members or as paid attendants, health care workers and childcare workers. Most women make the decision about whether or not to parent, particularly to parent a child with a disability, based on multiple intersecting factors -- whether they can afford to stay home from work, whether they have the resources to provide the care that their child or family member needs, and whether

they have sufficient social support. In addition, with an aging population, more attention is being paid to caregiving, who does it, how much it costs, and within what kind of social and familial relationships. The topic of caregiving, specifically the gendered nature of it, creates an opportunity for the disability rights and reproductive rights and justice movements to find common ground with models for promoting equitable, just and compassionate approaches.

DISCUSSION

All participants acknowledged that women face multiple challenges in deciding whether to have a child with a disability, or in caring for children or other family members with disabilities. These challenges include both a lack of information about what it is like raising a child with a particular disability and a terrible deficit of social and financial support to raise a child with a disability. Social attitudes about caregiving play an important role in women's decisions about continuing or terminating a pregnancy following a prenatal diagnosis of disability. On the one hand, women may be considered irresponsible for giving birth to a child with a disability. And, on the other hand, when women adopt children with disabilities and take on their care, they are told

that they are “saints” for assuming such a “terrible burden.” These responses represent two ends of the same spectrum, in which there is no room for women’s real experiences of choosing or not choosing to raise a child with a disability.

Women face disproportionate responsibility when making a decision about whether or not to have a child with a disability, in large part because they are the primary caregiver in most families. Participants talked about how pregnant women are generally given little information about what it means to raise a child with a disability. Disability rights advocates explained that women and their families do not always have accurate information about the reality of caring for a child with a disability, including accurate information about the disability and the resources needed to raise that child.

A reproductive justice framework takes into consideration the multiple factors in women’s reproductive decision-making, not just their right to make their own decisions. The Roundtable participants discussed the many pressures women face—social, political, economic and ethical—in making decisions related to pregnancy, childbearing and caregiving. They acknowledged that women might make different decisions if other supports or options were available, including prenatal care, childcare, general health care and education. In particular, the lack of financial resources for families to raise children with disabilities and the attached stigma create a culture that actively discourages families from having and raising children with disabilities. Both the disability rights and reproductive rights movements are invested in all women having access to more social and financial support systems in caring for families and parenting with dignity. However, securing the resources and social supports necessary are often seen as an individualized family issue, with inadequate support from government and society. Whether raising a child with a disability or without, women and families are receiving less and less financial and social support. These advocates acknowledged that this could be one area for creating common ground between the two movements, pivoting away from fighting over the same small slice of resources and advocating for more resources for all.

Disability rights and reproductive rights and justice advocates can forge a new public agenda around caregiving built on an analysis of the gendered character of caregiving, promoting social and financial support to raise children and care for adults with disabilities, and addressing class and race privilege.

In addition, while the reproductive rights and justice movement focuses on women as care providers, the disability rights movement focuses on caregiving from the perspective of the disabled person receiving care. Historically, people with disabilities requiring physical assistance have been put in institutions where they lose much of their decision-making power. As a result, the disability rights movement has fought hard for people with disabilities to direct their own care. The new model of caregiving is for people with disabilities to pay caregivers, with caregiving viewed as a legitimate profession. However, this model sets up an employer-employee relationship, giving power to the

disabled employer but not always to the caregiving employee. Roundtable participants discussed how paid caregivers are predominantly people of color and immigrants. Caregiving relationships mirror societal power dynamics of race and class, with people of color providing care to a disproportionately white aging population. Groups are pitted against each other in political struggles,

and government agencies and health care companies often dictate the terms of employment with little input from the person with a disability or the caregiver. Home care workers are often exploited by long hours with low pay, just as people with disabilities struggle to have their care needs met in a dignified and affordable manner. These connections are rarely recognized.

Working together across movements, disability rights and reproductive rights and justice advocates can forge a new public agenda around caregiving built on an analysis of the gendered character of caregiving, promoting social and financial support to raise children and care for adults with disabilities, and addressing class and race privilege. By incorporating the value of interdependence, both movements can emphasize the ways in which all people depend on each other to meet various needs, including the need for physical care. Caregiving should and can be a socially valued activity that is both widely available and given adequate financial compensation.

TOPIC 4: PERCEPTIONS AND REALITY OF BEING ALIGNED WITH THE RIGHT

BACKGROUND

Issues of genetic technologies are highly polarized in the U.S., with religious conservatives generally taking positions in opposition to the use of these technologies and progressives in support with a “full speed ahead” attitude. Yet many progressive disability rights advocates have voiced alarm that genetic technologies may lead to a reduced number of children born with disabilities, dwindling resources available for people with disabilities, and increased discrimination against those living with disabilities. Some reproductive rights organizations have also raised concern about genetic technologies—the increased medicalization of reproduction, commercialization of women’s bodies and inattention to women’s health and safety. When progressive advocates critique how technologies are used, the Right often takes this to be an indication of support for their position. In several instances, the Right has co-opted women’s health language to support their own positions. Segments of the pro-choice community have at times been accused by others of being “in bed with the Right,” failing to see that the underlying values, goals and methods are clearly distinct from those of the Right. At the same time, disability rights leaders have sometimes intentionally chosen to work with the Right in an effort to achieve their goals. Opponents of abortion rights have also appealed directly to people with disabilities to work together to defend the rights of the disability community.

In an unusual finding of common ground, Senator Sam Brownback, a staunch pro-life advocate, forged an alliance with pro-choice Senator Ted Kennedy and prominent disability groups to pass the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008. The legislation is intended to provide better information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with a disability. The Act received

the support of both reproductive rights and disability rights advocates. However, this kind of shared agenda is the exception rather than the norm, with anti-abortion advocates often advocating for the broadest definition of personhood, opposing the right to die, and using pro-life language to appeal to disability communities.

DISCUSSION

The group discussed several situations that illustrate the challenges that arise when advocates work to strategically build alliances for short-term wins. In 2004, California’s ballot included an initiative to provide \$3 billion in public funding for stem cell research. Some pro-choice advocates expressed concerns about women’s health in providing eggs for research cloning, a type of stem cell research that requires fresh eggs from women. They attempted to raise concerns with liberal stem-cell supporters who assumed

that all progressives would support funding for stem cell research. Two years later, a Missouri ballot included an initiative in favor of research cloning. An anti-choice organization that opposed stem cell research put out a brochure opposing the initiative citing the dangers of egg harvesting for women and quoting women’s health advocates—without their permission—who had raised pro-choice concerns

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in the California case.

Roundtable participants addressed how the Right is co-opting women’s health and disability language to their own advantage to advance an anti-choice agenda. To challenge this co-optation, the group asserted that social justice advocates have to expose the Right’s underlying intention to limit abortion access, as well as their lack of

attention to anti-discrimination issues in many other areas.

Some disability rights organizations have chosen to work with anti-choice as well as pro-choice groups and legislators. In the case of the Prenatally and Postnatally Diagnosed Conditions Awareness Act, disability rights advocates worked with Republican Senator Brownback, as well as Democratic Senator Kennedy, to ensure that pregnant women receive comprehensive information on a disability diagnosis for their fetus or newborn. Senator Brownback was honest in his intention to reduce the number of abortions. He was quoted as saying the bill was “a chance to advance the cause and have fewer children killed.” Yet because the bill was initially co-sponsored by Senator Kennedy, a pro-choice legislator, it contained no anti-abortion language and was not opposed by the pro-choice community. One reproductive rights advocate at the Roundtable said the bill could have been one of “common ground” between the two movements, yet Brownback’s comment and anti-abortion record made pro-choice groups leery of working with him. At the same time, this advocate thought the bill could be part of advancing a policy agenda that supports families that are raising kids with Down syndrome, and supports motherhood and parenting more generally.

People with disabilities at the Roundtable were divided over whether the disability rights movement should work with everyone, or whether the movement needs to choose sides and ally itself with the Left. One roundtable participant suggested that both sides of the political spectrum need to come together in order to move forward

while pointing out that people with disabilities come from all communities and hold a range of political views. However, one advocate raised the question of whether working with the Right precludes opportunities to work with social justice organizations and therefore has a long-term negative impact. Participants stated that it is important for organizations to have a clear, consistent message about their values. Some expressed concern that working on both sides can muddle this message.

Roundtable participants identified a libertarian strain in both the reproductive rights and disability rights movements, manifested in an emphasis on individual choice and self-reliance. Pro-choice advocates appeal to the American public’s interest in individual decision-making. Disability rights advocates use arguments of self-sufficiency to get personal assistant services or employment opportunities. Major disability rights laws, notably the Americans with Disabilities Act, have received bi-partisan support and have been signed by Republican presidents. The language of these laws appeals to conservative rhetoric, using talk of self-sufficiency in efforts to win physical access or employment opportunities.

The group, however, feared that this libertarian strain may feed into conservative values and have negative consequences in the long run. Reinforcing people’s ideas of individualism may be inconsistent with a greater vision of an interdependent world. In this way, using the language of the Right may hinder the long-term goals of the disability rights and reproductive rights and justice movements.





SHARED VALUES AND PRINCIPLES

Despite a tense and sometimes painful history of disagreement between the two movements, these Roundtables suggested some clear directions for addressing the multiple and complex challenges raised by genetic technologies within and across both movements. Across the five Roundtable discussions, a set of shared values and principles emerged, principles that can create the foundation for both movements to continue to work together to advance a shared agenda. These principles can be synthesized as follows:

These principles can be synthesized as follows:

- Reproductive autonomy should include support for people making the choice to have children, including children with disabilities, and support to raise their children with dignity.
- All women who choose to parent should be valued as parents and all children should be valued as human beings, including children with disabilities.

- Policy advocacy should focus on providing social and material supports to women, families and communities, not on when life begins, whose life is more valued, or who can be a parent.
- Both movements should broaden their agendas to fight to improve the social, political, physical and economic contexts within which women and people with disabilities are making decisions about their lives. The focus should be on changing society, not on individual decision-making.

Taken together, these shared principles suggest a need to reframe the issues—a framing away from the right not to have children to a right to have children, and a framing away from creating a self-sufficient, productive individual to re-shaping society to provide for the needs of all people, regardless of gender, race, ability, sexual orientation, citizenship status and class. In pivoting away from more narrow agendas and principles to broader, more inclusive values, new political opportunities and new alliances are possible.

THE CROSS-MOVEMENT ROUNDTABLE PROCESS

Over the course of the Roundtables, participants continually expressed their appreciation for the opportunity to be in these conversations with each other. Most of them had decided to participate because they recognized that the challenges posed by this complex intersection of reproduction and disability would only emerge more and more. A few noted that the deeper understanding that they had gained from listening to each other across movements had already led to more thoughtful, informed, and coordinated responses to reproductive technology questions. A reproductive rights advocate reported that, based on these conversations, she was intentionally changing the way her

organization talks about disability. Several advocates said that learning more about the theoretical underpinnings and paradigms of the other movement has been the most helpful part of the process; that learning about the theory helped make sense of the politics.

All of them expressed appreciation for the process of the conversations. They felt that many of the shifts in perspectives and changes in understandings came not from attending one meeting, but from being in multiple meetings with the same people. This was the first series of cross-movement conversations that Generations Ahead

hosted. Through the process the organization learned about several different components that helped to increase the success of the conversations, and they developed a model for doing effective cross-movement work.

One component of the model is getting the right people in the room. Critical to having successful cross-movement conversations is inviting people who are willing to be changed by the work that happens in the discussions. Authentic change can only occur when all sides are willing to re-examine their ideas and beliefs and be open to the possibility of changing their deeply held perspectives. The goal of the conversations is to create change. And change requires difficult conversations and a willingness to learn and integrate new information, and in this case, a willingness to abandon a certain perspective or politic. Changing one's perspective is not a requirement of participating, but a willingness to change in the face of new information and new relationships is necessary.

Changing deeply held perspectives can often feel dangerous and risky, which leads to another important component – building trust in and through the discussions. While trust between participants and across movements was not necessary to start cross-movement work, it was essential to build it during the process. Trust was created in this process through face-to-face conversations, by identifying and addressing areas of conflict and tension, and by concretely demonstrating solidarity for each other's issues. Intentionally learning more about each other's histories, priorities and perspectives was an important part of building trust. Before each Roundtable, articles important to each movement were sent to all participants, and significant time was spent before each discussion in socializing, sharing meals and telling personal stories.

Prior to the first Roundtable meeting, Generations Ahead held a “Disability 101 workshop” with the reproductive rights and justice advocates because most of them had had little or no experience with disability rights issues. The workshop provided participants with an opportunity to examine their own attitudes and learn about disability rights. It also helped build a foundation of trust in the room when the disability rights advocates arrived, because they knew the reproductive rights advocates had engaged in self-examination and education.

In addition, conflicts between the movements were intentionally and respectfully identified and addressed. The relationships and trust in the group were built on the full recognition that there were conflicts between movements

and that their work together was to address those tensions. The expectation was never that the group would come to a consensus, but rather that each side would deepen their understanding of the other's perspective. Not expecting to come to consensus, just more understanding, allowed for people to be less defensive and dogmatic in the meetings, since there was no push for agreement. Often the conflict between the movements was based on different understandings of language. For example, personhood in the reproductive rights context meant a legal definition while in the disability context alluded to a perceptual definition. “Quality of life” for disability advocates had strong anti-disability connotations, while the same term for reproductive justice advocates was seen as an affirming way to measure the well-being of a community. Only through conversations that were at times painful were both groups able to understand these different perspectives and feel the possibility of building common ground.

An important part of trust-building in the group depended on having a good process for the group to go through. In this case, even though the process was basic – agreeing to talk about one area of tension, readings ahead of time, a meal and socializing before the discussion, and a couple hours of discussion that was respectful of different perspectives—there was ongoing commitment to staying involved, even when the conversations felt difficult or painful. That way, even if there wasn't easy agreement or understanding, both sides stayed committed and involved. In the early phases of the conversation, worthwhile outcomes are hard to envision, but if both sides feel heard and valued through the process, they will continue to work through the hard conversations.

And finally, the core of cross-movement work is to identify values to use as the basis for a shared advocacy agenda. While participants broached each discussion topic from different perspectives and histories, where they most often found common ground was in agreement about values, such as supporting women as parents and parenting with dignity, and autonomy and self-determination in decision-making for women and people with disabilities. While they might have disagreed in their political analysis or strategies, these participants were able to acknowledge that they cared about the same social issues and were able to begin discussing what a shared advocacy agenda might look like. This identifying of shared values and principles became one of the most important and hopeful aspects of the cross-movement conversations, creating the possibility of collaborating together and building stronger alliances.

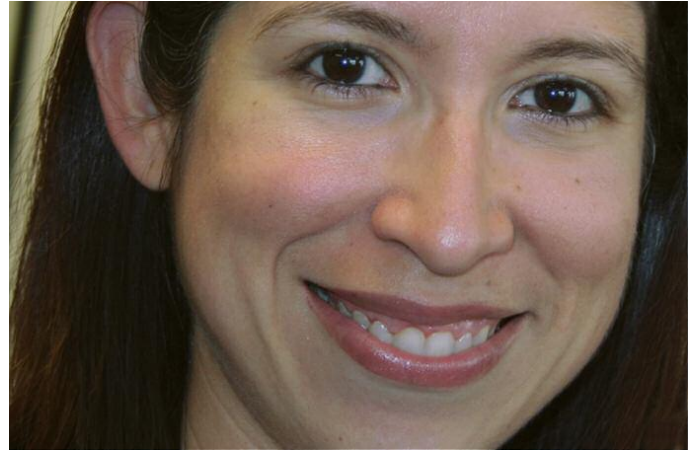
NEXT STEPS

All participants acknowledged that these Roundtable discussions were just the beginning of a longer process of creating concrete alliances on specific issues between the two movements. The conversations were the first steps in openly acknowledging and understanding the tensions, both historic and current, between the disability rights and reproductive rights and justice movements. While these movements share some values, that has not always provided enough impetus to work together and make common cause.

In order to expand the work of the Roundtable discussions to move toward building a shared policy agenda based on the values, principles and visions articulated above, several next steps are needed:

1. Continue information-sharing, trust-building, and openly discussing areas of conflict between the movements. While this work can continue at the regional level for deeper insights, more importantly this work needs to begin at the national level, with national leaders and national organizations.
2. Apply these identified shared values and principles to policymaking and communications on current events: develop an informal national network of both movements to respond to proposed legislation and media coverage, and proactively develop policy proposals.
3. Continue the smaller regional conversations to develop the leadership of those already invested in supporting the national work.

The process of cross-movement work is not easy, and these are complex topics to grapple with. Yet the Roundtables have shown that engaging in these hard conversations among those with the commitment to work together can lead to important and paradigm-shifting analysis, insights, and recommendations. Together the disability rights and the reproductive rights and justice movements can forge a powerful alliance and a shared policy agenda on genetic technologies that challenges inequality, discrimination, and limited opportunities on multiple levels.





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