

A DISABILITY RIGHTS ANALYSIS OF GENETIC TECHNOLOGIES

REPORT ON A NATIONAL CONVENING OF DISABILITY RIGHTS LEADERS
March 29-31, 2009 | Chicago IL

Convened by **Generations Ahead**. Co-sponsored by American Association of People with Disabilities, Center for Ethics at Yeshiva University, and Disability Rights Education and Defense Fund

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PARTICIPANTS

Marca Bristo | Access Living

Julia Epstein | Disability Rights Education and Defense Fund

Anne Finger | Writer, Activist

Andy Imparato | American Association of People with Disabilities

Alison Kafer | Southwestern University and Board of Generations Ahead

Mia Mingus | SPARK Reproductive Justice Now!

Ari Ne’eman | Autistic Self-Advocacy Network

Judy Panko Reis | Rehabilitation Institute of Chicago, Women with Disabilities Center

Rahnee Patrick | Access Living

Paul Preston | Through the Looking Glass

Howard Rosenblum | National Association of the Deaf

Marsha Saxton | World Institute on Disability

Amber Smock | Access Living, FRIDA, and ADAPT

Lauren Spiro | National Coalition of Mental Health Consumer/Survivor Organizations

Joe Stramondo | Little People of America and Michigan State University Department of Philosophy

David Tolleson | National Down Syndrome Congress

Betty Williams | Self Advocates Becoming Empowered

Gary Wunder | National Federation of the Blind

Planning Committee:

Adrienne Asch | Center for Ethics at Yeshiva University

Sujatha Jesudason | Generations Ahead

Jessica Lehman | Generations Ahead

Anne Sommers | formerly with American Association of People with Disabilities

Silvia Yee | Disability Rights Education and Defense Fund



EXECUTIVE SUMMARY

Every day, the media describe genetic technologies that promise to transform the lives of people with and without disabilities. Prenatal tests are now available for hundreds of conditions, from deafness to dwarfism to hemophilia, and women are encouraged to get tested for the assumed advantage of preventing disability in a future child. Some people with disabilities eagerly await news of stem cell research and clinical trials for gene therapy to mitigate or cure their disabilities. But many people in the disability rights movement are concerned that the increasing use of genetic technologies in this context reflects and reinforces societal assumptions that disability is always harmful and should be prevented, eliminated, or mitigated.

In March 2009, the National Convening on Disability Rights and Genetic Technologies was hosted by Generations Ahead, in collaboration with the American Association of People with Disabilities (AAPD), Disability Rights Education and Defense Fund (DREDF), and the Center for Ethics at Yeshiva University. Generations Ahead saw a critical need to

bring together disability rights leaders—people with disabilities themselves—for an informed debate on the issues by those directly affected. At the Chicago meeting, 21 disability rights leaders discussed the impact of genetic technologies on the disability community and strategized together about how the disability rights movement can address these concerns. Participants talked about how to honor and affirm the diversity that disability brings to the world,

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in the face of genetic technologies that could eliminate or prevent disability. In their conversations about disability and genetic technologies, these leaders addressed critical questions about human worth and the value of diversity. This report documents the key

discussions from the two days of meetings, analyzes complex issues of disability rights and genetic technologies, and summarizes actions for moving forward.

One of the key themes that arose at the National Convening was how the disability rights movement should address the search for cures for disability. Participants held a range of perspectives about how disability relates to their identity and in turn how

cures and selection may or may not threaten individual identity and disability community. Considering that many people with disabilities—who may not consider themselves part of the disability community at all—are strongly committed to curing or preventing disability, the group agreed that the disability rights movement must honor all views and not take a public stance against cures or prevention.

The convening also addressed questions of partnerships and inclusion in the disability rights movement.

Participants agreed unanimously that the movement must be inclusive to people with any disability, race, class, and sexual orientation, and working cross-movement was suggested as one way to do that. Many leaders were committed to finding common ground with a broad range of potential partners, though participants debated whether the disability rights movement can and should take a position on abortion and whether the movement will benefit or be harmed by working with organizations on the right.

SHARED VALUES

Convening participants affirmed this set of values that can guide future work on genetic technologies and disability rights.

- Finding common ground (with a variety of individuals and groups)
- Working cross-movement and cross-disability
- Making the disability community an inclusive community
- People with disabilities speaking for themselves (ourselves) and leading the work
- People having control of their own bodies, making their own informed choices
- Ending discrimination
- Respecting every human life—with or without a disability

PROPOSED ACTIONS ON DISABILITY RIGHTS AND GENETIC TECHNOLOGIES

- Public Education and Media Campaigns on Disability and Genetics
- Curriculum for Health Professionals
- Implementation of the Prenatally and Postnatally Diagnosed Conditions Awareness Act (Kennedy-Brownback)
- Bi-Partisan Congressional Task Force on Consumer Protection, Non-Discrimination and Genetic Technologies
- Disability Rights / Reproductive Rights and Justice Conversation
- Balancing Research Dollars (between cure/prevention and quality of life)
- Ensuring a Disability Rights Perspective on the President's Council on Bioethics

The disability rights leaders at the convening affirmed a shared set of values and principles to guide work on genetic technologies and disability rights. These encompass a broad range of commitments including finding common ground, leadership by people with disabilities, and making informed choices. These values provide guidance for the disability rights movement and allies in taking action on genetic technologies. Convening participants came up with a strong list of potential campaigns to address the impact of genetic technologies on people with disabilities and society as a whole.

The two-day convening launched an array of questions and clarified a number of conversations that will be useful for the disability rights movement to have—about cures, partnerships, and inclusion. The meeting confirmed that disability rights advocates are ready to take action on genetic technologies. New campaigns on these issues may allow the movement to broaden its base, diversify its leadership, and play a vital role in shaping society's views on disability and humanity.

INTRODUCTION

The language of disability is not always included in discussion of genetic technologies. A New York Post writer describes parents seeking “defect-free babies.” Who wouldn't want a defect-free baby? Stem cell research addresses people's fears of someday being diagnosed with Parkinson's or Alzheimer's disease—conditions people often do not recognize as disabilities but may be considered as such. New

genetic technologies seem far from disability; a puppy is cloned or tests are conducted for athleticism in children. However, all these genetic technologies are ultimately about what kind of human being we want to be and what kind of human bodies we value. Disability lies at the heart of these quandaries. People with disabilities—whether physical or sensory, intellectual or emotional—present to society a

THE MEDICAL MODEL vs. SOCIAL MODEL OF DISABILITY

Under the medical model of disability, disability has for centuries been thought of as a medical problem that should be eliminated or mitigated to the greatest extent possible. People with disabilities have historically been avoided, segregated, or pitied. Disability rights advocates now propose a new social model of disability, in which disability is not inherently harmful, negative, deviant, or defective. While the medical model dictates that the problem lies in the individual, the social model of disability pinpoints the problem in society's inability to accept and accommodate disability. In the social model of disability, a disability is not a medical problem that requires fixing, but rather a social problem. If society were to change prevailing views on disability, make the environment accessible to all, and find effective ways to more fully integrate people with disabilities into society, then disability would simply be another way of living.

PRENATAL TESTING CONCERNS

Screening and testing for genetic disabilities or diseases has become a regular part of prenatal care, with a large majority of pregnant women now choosing to test for Down syndrome and other conditions. A study from the Centers for Disease Control and Prevention documented a decrease in births of children with Down syndrome, possibly due to an increase in prenatal genetic testing and subsequent abortion. Parents of children with Down syndrome and many people with disabilities are concerned that pregnant women and their partners are not getting complete information about what it means to have a child with a disability.¹ Some parents fear that with fewer children being born with disabilities, policymakers will not see the need to provide and fund programs and services for people with disabilities. A decline in visibility could also affect people's attitudes about disability and understanding of the civil rights of people with disabilities.

PRE-IMPLANTATION GENETIC DIAGNOSIS (PGD)

Used in conjunction with in vitro fertilization, in PGD, a single cell biopsy and analysis is done on fertilized eggs before they are transferred to the uterus to test for specific genetic conditions. Prospective parents can then choose to implant embryos with or without specific traits, particularly disability-related impairments.

SEX SELECTION

For disabilities or conditions that are genetically carried on the X chromosome, prospective parents can use sex selection as a way to avoid having a child with a particular disability. For example, families with a high number of boys with hemophilia or with certain types of muscular dystrophy may choose to use sperm sorting or other sex selective technologies to ensure that future children will be girls, who cannot inherit these disabilities.

STEM CELL THERAPIES

Stem cell therapies may offer an opportunity for people with disabilities to mitigate their impairments. Many people would welcome the opportunity to live without pain, halt the progression of their disabilities, or continue activities they have loved. However, some people with disabilities are concerned that a rush to cure all disease and disability would reinforce the ideal that all disability is inherently harmful and should be avoided at all costs.

1. Harmon, A. (2007, May 9). Prenatal Test Puts Down Syndrome in Hard Focus. New York Times.

deviation from the norm and a reminder of what can happen when we allow our bodies to stray from the ideal.

Genetic technologies promise to ultimately alter the trajectory of society by making disability obsolete. Some scientists, medical professionals and ethicists envision a world in which medical technologies prevent the birth of children with disabilities, respond to and cure disease or injury that comes after birth, and alter genes so that future generations come closer and closer to the idealized “perfect” body. Not surprisingly, members of the disability rights movement are concerned. They talk about pride in their disabilities and the diversity that disability brings to the world, which would be lost if genetic technologies achieve their promise of eliminating disability. The disability rights movement asserts that society will not be better off without disabled people; what is needed, they argue, are changes in societal structures and practices. Disability rights advocates and social justice advocates envision a world in which we appreciate and celebrate diversity of ability, race, class, sexuality, and other characteristics, in which our differences enrich our lives and experiences. But some genetic technologies can be used to undercut those values, eliminating people with disabilities rather than barriers to their full inclusion.

People with disabilities have much at stake in the development and use of such technologies. Against a historical backdrop of widespread eugenics practiced against people with disabilities, disability advocates are aware of the complex questions raised by the expanding uses of genetic technologies. Conversations about disability and genetic technologies address core questions about what it means to be human, who deserves to live and die, and how parents should make decisions for their children.

Within the disability community and disability rights movement there are many different sectors and

perspectives on disability and the use of genetic technologies. Some embrace the idea of cures and eliminating all disability, and others worry about how these technologies will impact social attitudes and values, increasingly marginalizing people with disabilities and narrowing the norm of what humans look like and do. The voices and perspectives of people with disabilities—not just advocates for people with disabilities, parents of people with disabilities, or medical professionals—are critical for a fully informed debate on who benefits from the uses of these technologies, who is at risk, and who decides when and how these technologies can and should be used.

The National Convening on Disability Rights and Genetic Technologies was intended to bring together those most impacted by these technologies and provide a forum for them to voice their specific concerns. Twenty-one disability rights leaders participated in the meeting, hosted by Generations Ahead, in collaboration with the American Association of People with Disabilities (AAPD), Disability Rights Education and Defense Fund (DREDF), and the Center for Ethics at Yeshiva University. At this convening, disability rights leaders from diverse sectors of the movement gathered together to develop their own analysis of the issues and determine guiding principles and strategies to take action. Major themes that arose were how to think and talk about cures and prevention, and how that relates to disability identity and disability community, as well as who should be considered as potential partners for the disability rights movement. More than providing answers, the National Convening was an important space for participants to work together, explore the difficult and differing perspectives on genetic technologies and the impact on people with disabilities, identify shared values from which to work across differences, and begin to strategize actions.



MAJOR THEME ONE: CURES, IDENTITY AND COMMUNITY

Disability rights leaders came to the convening asking, “Do we want to take a position on people trying to prevent, cure, or eliminate disability through genetic testing, treatment, and abortion?” At the core of this question lies a broader question, “Is it good or bad to try to cure, prevent, or eliminate disability at all?” The idea of being cured is inherently entwined with disability identity and disability community. Participants discussed how cures relate to the self-identity of people with disabilities, the potential discord between disability culture and cures, and the battle for resources between medical research and disability services.

Some participants drew a distinction between prevention and cures. A cure may change an individual’s identity, if disability is a piece of one’s identity, but if the disability is prevented in the first place, an individual will not experience an identity shift. However, implications for program funding, disability culture, and diversity hold true for both cures and prevention.

For someone who identifies strongly as a member of a disability community, talking about cures can sound like betraying one’s community. Some participants said they would feel guilty about accepting a cure if

one should someday exist. One woman asked, “Does this make me somehow a traitor to the disability rights movement, am I somehow undermining disability pride, if I defer future limitations?” A focus on finding cures, it was suggested, takes attention away from honoring the diversity of human beings. Another convening participant asked, “How is ameliorating disability not part of dismantling disability culture?” Even if a cure might appeal to someone on an individual level, the impact on the community must be considered.

“It may feel good politically to say I don’t like cures, but it doesn’t work for the whole community.”

Some convening participants said that their disabilities are central to their identity and that disability has made them who they are. One

participant said, “Disability is a core part of who I am, pretty central to who I am.” Others, while still not seeing their disability as a problem in their lives, said that it is not central to their identity. “If I hadn’t had a disability, maybe I’d be different, maybe I wouldn’t.”

For someone who does not consider disability to be central to one’s identity, cures may carry no individual threat. Some people said that they didn’t mind one way or the other if they had a disability now or in the future. “I find it strange that disability seems to be at the core of so much identity. I see [my disability] as a

significant factor in my life. Has it brought me good things? Some, yes. Has it brought me challenges? Yes, some. Am I sorry I have come down this road? Not at all. But I'm not sure there's any virtue in traveling down this road that I would have missed if someone had offered me a cure."

The question of cures and prevention is often seen as a dividing line between people who take pride in their disabilities and those who do not. Convening participants affirmed this divide, but with nuance. Those who consider disability to be a positive centerpiece of their identity felt that cures and selection against disability could threaten individual and group identity. Others who regard their disabilities as neutral did not feel threatened individually by cures, but some people in this category are concerned with the implications of cures and prevention. In using genetic technologies to select cures and non-disability as opposed to disability, some felt that people with disabilities would be less valued at a societal level.

The convening lacked the voices of people who do not self-identify as having a disability. The group in Chicago struggled with how to consider the experiences of people with hemophilia, diabetes, or arthritis, who may see themselves as having a chronic illness rather than a disability. Participants made no clear distinction between disease and disability. Some tried to distinguish based on whether disease is fatal and disability is not, or whether one is more severe than the other, but all attempts were found lacking. If there is no clear way to separate disease from disability, then perhaps people with diseases should

be considered part of the disability community.

What do cures mean for people with disabilities who do not consider themselves part of the disability community? Interestingly, convening participants were uncomfortable recognizing that many groups of people who identify as having a disease rather than a disability have made it their mission to eliminate disability. The importance of building community was seen as so vital that this issue keeps disability rights leaders from taking a public stance against cures. "For us to take a position that we're against cures or prevention doesn't honor

the diversity of our community," said one participant. "It may feel good politically to say I don't like cures, but it doesn't work for the whole community."

One participant acknowledged that for people who are newly disabled, it is easy to understand how they

may desire to walk again, or to not have their disabilities. To support the entire disability community and respect a myriad of views, it is critical not to split the community by saying unilaterally that cures are wrong, for individuals or for society as a whole. The disability community needs to accommodate differing viewpoints and make room for individuals with disabilities to choose stem cell therapy or other emerging treatments while at the same time continuing to promote a social model of disability and a vision of a fully accessible society.

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MAJOR THEME TWO: DIVERSITY AND PARTNERSHIPS

Political positions on the issue of cures and prevention are unfortunately only one factor that may divide the disability community or the disability rights movement. Other possible divisions that need to be bridged, or not, included how to work across different types of disability; how to address race, class and sexual orientation; and whether to include pro-life/anti-abortion advocates. In addition, the group spent time discussing whether the disability rights movement should work with any and all other groups and movements, and whether disability rights groups should consider themselves part of a broader social justice movement.

These discussions were shaped by who was and was not in the room. With a commitment to raising the voices of diverse communities and those most impacted, Generations Ahead, AAPD, DREDF and Yeshiva University had decided to prioritize the participation of leaders with disabilities who work directly in their communities and represent a disability constituency. They invited leaders from disability rights groups, the most underrepresented disability perspective in these debates, rather than patient-advocacy or disease-specific groups, which are often led by health professionals, family members, and other advocates.

CROSS-DISABILITY

Convening participants placed a high value on working across different disability groups and including people with all disabilities, whether or not they identify as such. Attending the convening were people who are deaf, blind, short-statured, physically disabled, and autistic, along with people with mental health disabilities, intellectual disabilities (sometimes

called developmental disabilities) and brain injuries. One group not represented was people with chronic disabilities or illnesses, such as hemophilia or cystic fibrosis. The convening also included a few people without disabilities—a parent of a child with disabilities and a child of deaf adults, both of whom also work at major disability rights organizations.

“That’s what real inclusion is—not just cross-disability, other identities too.”

The disability rights movement has historically been dominated by wheelchair-users, and advocates see a need to broaden the movement in order to build power and make change, and to show the kind of inclusion within the movement that is encouraged in society. Inclusion has been a major goal for the disability rights movement, in terms of getting children and adults with disabilities included in schools, workplaces, and public accommodations. As one participant in Chicago expressed, “That’s what real inclusion is—not just cross-disability, other identities too.” If the disability rights movement wants society to accept people with disabilities broadly, and if movement leaders want social justice groups to consider disability an important issue, then perhaps disability advocates too must be open to working with all kinds of people.

RACE, CLASS, SEXUAL ORIENTATION, AND AGE

The discussions at the convening about the relationship between race, gender, sexuality, and

disability identities, and about discrimination and oppression, were affected by the people in the room. The planning committee struggled to assemble a group with racial and ethnic diversity. The final group of 21 leaders included only four people of color (three Asian-American and one African-American). Of nationally recognized disability rights organizations, the majority of leaders are white. The planning committee members did not want to reinforce the existing lack of representation of people of color in leadership roles in the disability rights work, built through years of racism and segregation in and out of the disability rights movement; however, they labored to identify people of color to invite from major disability rights organizations and felt a need to work with existing leadership.

As one participant stated, “We have to be careful about what it means to tell our stories. The independent living movement is an overwhelmingly white, middle-class movement. If we put our stories at the center, then we’re ignoring some other things.” It was a challenge for convening participants, and for disability rights leaders in general, to speak for the broadest group of people with disabilities, and to understand all perspectives, without having people from all backgrounds fully represented.

Convening participants generally agreed that the disability rights movement should be broadened to include larger numbers of people of color, youth, and others who face discrimination. A participant who identifies as a queer person of color said that she has historically not felt comfortable working in the disability rights movement, due to such little discussion around race and sexuality, and because “I didn’t see people who looked like me.” She suggested, “If we want more people of color in the disability movement, we have to do cross-movement work.” Working with groups doing racial justice, reproductive justice, or other work will bring disability rights in contact with people with disabilities who are LGBTQ, people of color, or people who hold another

identity also. “Doing cross-movement work helps us see parts of disability that we would never have seen.”

The discussions also lacked varying perspectives on class. In a conversation about the interplay between poverty and disability rights, a participant pointed out the middle-class make-up in the room: “Be conscious of who we are in this room right now.” Profit in the genetic technology industry came up several times, in

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terms of the money to be made through in-vitro fertilization and prenatal tests, whether embryos can be bought and sold, and the cost to society of a person living with a disability. Participants repeatedly talked about profit as a major factor in the growth of genetic technologies. But the group recognized its own inability to speculate on the impact of genetic technologies on poor people or working-class perspectives on this issue.

Overall, there was easy agreement that the disability rights movement should be broadened to include larger numbers of people of color, youth, and people with other identities.

WORKING WITH THE PRO-LIFE OR PRO-CHOICE MOVEMENTS

Several participants noted the risk in working with certain allies, specifically pro-life groups. Of concern in working with pro-life/anti-abortion groups was that the larger, more visible movement might co-opt

or overtake disability language and messaging, making it appear that all disability rights groups were anti-choice. On the issue of prenatal genetic testing, people with disabilities can be seen as just a pawn in the pro-life movement, rather than having a unique and recognizable message.

Convening participants disagreed sharply on whether the disability rights movement can or should assert a pro-choice stance. Several people at the convening did not want to discuss abortion, and several saw this conversation as necessary for

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the disability rights movement in order to move forward. One participant said about his organization, “There have been attempts to drag us into the question of whether abortion is a good thing or a bad thing. We’ve tried very hard as an organization not to deal with that.” Frustrated that disability concerns with genetic technologies or assisted-suicide have often been latched onto by pro-life groups and have been connected to abortion without the consent of the disability groups involved, some asserted, “This is independent of the abortion debate. We have an obligation as a community to defend our right to live in this world.”

Some participants, particularly women who identified as feminists, seemed to feel that ignoring abortion in fact ignores their reality. A pro-choice position—or maybe even a willingness to discuss abortion—might be an example of a value so central to people’s identity that it must be shared in order for people or groups to work together.

Genetic technologies are forcing many disability organizations to talk about abortion for the first time, requiring difficult conversations that may help build a stronger and more inclusive disability rights movement.

There was strong interest among those at the convening in working with reproductive rights and reproductive justice advocates. Genetic technologies are of great interest and concern to reproductive rights and justice, as well as disability rights, and this common ground may provide an opportunity for these groups to collaborate. Some participants shared their experiences of spending years educating reproductive rights advocates about disability and working to insert disability into conversations about pregnancy and abortion. These individuals made significant progress in bridging the gap between these movements. With the expanding use of genetic technologies, these alliances may be ever more important.

Many participants said that disability rights advocates should work with different groups as necessary to reach specific goals, and that leaders should think broadly about who they can work with to win change. “I think we use a social justice framework where it’s useful, and use our connections with the Right or the pro-life community where it’s useful.” Participants shared success stories involving unlikely partnerships, including passing legislation for the rights of parents with disabilities in Idaho and Kansas, plus the partnership between Senate Republicans and Democrats that led to passage of a bill about education for pregnant women about disability. Some claimed that, “we have an obligation to our community to use all resources that are conducive to our community’s ends to advance our interests. Casting a broad tent, being inclusive about the coalitions we build, is only going to help us.” The critical factor in building unusual alliances, many claimed, is finding common ground or shared values—even just a little bit.

POWER AND JUSTICE

Everyone at the convening seemed to agree that the disability rights movement needs to build more power as a movement, and that this power could be built by joining with other groups. An unanswered question was whether to build more power by working with different groups at different times or by choosing long-term allies to work with exclusively.

It was pointed out that by using a broader social justice framework, in which disability oppression is seen as similar to other oppressions, there may be more opportunities for strong cross-movement work, on genetic technologies or on any issue. “If we can start to see that other people are feeling that same sort of depth and emotion that we are ... that’s where we can make a connection to other communities affected by genetic technologies in unjust ways. For me, the notion of a social justice framework becomes important, about recognizing larger systems of power, inequality and privilege that we’re all located in.”

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Disability justice may provide a strong framework for genetic technologies (see sidebar). The group labeled “the libertarian perspective” the notion that individuals and families should be able to use whatever technology they would like, regardless of how that action affects the larger community. While generally unspoken, convening participants seemed uncomfortable with people choosing pre-implantation genetic diagnosis, prenatal testing, or abortion, without any thought to the impact on the disability community or society as a whole. If disability rights leaders like the idea of disability

justice, does adopting a disability justice framework mean putting the disability advocacy world inside a larger social justice framework?

DISABILITY JUSTICE

Disability justice is a different way to frame disability work, with “rights” viewed as focusing on an individual’s rights and equality with the mainstream, and “justice” seen as examining the impact on the community. While disability rights may be about working for equality with the mainstream, disability justice is about “challenging what privilege means and saying what we want to be different.”

The concept can be compared to reproductive justice, which has grown out of reproductive rights. The reproductive rights movement uses a civil rights model, focusing on an individual’s right to abortion. Reproductive justice takes into account the intersectional factors—economic, social, and political—that affect the lives of women, their families, and communities as a whole. Just like reproductive rights and justice, disability rights and justice do not have to be mutually exclusive.

“Disability justice gets at a conceptualization of disability within all these other systems—class, race, sexuality, feminism, etc. It’s an exciting way to think about new directions in which we can take account of all the different ways in which disability is shaped by different circumstances.”

Ultimately, some participants liked the idea of working with social justice groups when goals converge, and many did not want to adopt a social justice framework that would exclude the possibility of working with groups with differing perspectives. They felt that if they are to represent the entire disability community, perhaps they could not take a stance that would not work for everyone. The disability rights movement, in order to fully incorporate and represent all people with

disabilities, of all backgrounds, may benefit most by not taking a clear position on cures, abortion, or any number of other issues. More importantly, however, it was clear that the disability rights movement needs to have these difficult conversations. The movement must allow people to be heard and must understand people's varying experiences, in order to gain power and move forward effectively on responding to genetic technologies.

SHARED VALUES

Participants agreed that shared values are important for any partnership, inside the disability rights movement or beyond. Whether allies share one specific value or an overall set of beliefs, some common ground is necessary for an effective relationship. The group in Chicago came up with a set of values and principles to guide future work on genetic technologies and disability rights. Given the diversity of perspectives in the room and the short amount of time together, there was not an attempt to reach full consensus; however, strong convergence on values was identified.

WORKING WITH DIFFERENT INDIVIDUALS AND GROUPS

Reflecting the perceived need to identify shared values and common ground in order to build relationships with various groups, almost all participants agreed on finding common ground as a core value. However, participants reiterated concerns that disability rights groups might not want to work with everyone; sometimes they might want to build something new and not worry about who they alienate. Reservations were also raised about whether this might exclude voices not traditionally in power in the disability rights movement. To begin to address these concerns, the group added the following corollaries to the value of finding common ground: being strategic in our decision-making and setting ground rules with allies.

Similarly, the group affirmed a strong commitment to working cross-movement and cross-disability. As one

“When people with disabilities are devalued, all humans are implicated. When any community is devalued it affects the disability community.”

participant explained, “When people with disabilities are devalued, all humans are implicated. When any community is devalued it affects the disability community.” This value showed up in earlier discussions about the importance of working with all disability groups, whether or not they currently identify as part of the disability community. Some convening participants worried about whether some might use a difference in values to refuse to work with certain people. The group debated whether the value of working cross-movement and cross-disability should be considered separately, but one participant pointed out that for people with disabilities who identify as part of a community of color or LGBTQ community, the lines are blurred between cross-disability and cross-movement work.

The group strongly agreed that the disability community should be an inclusive community.

Participants had earlier recognized that the disability community is not currently welcoming of people of all races, sexual identities, and classes, or even all disabilities and diseases. There was immediate consensus that all should be included in the community and all voices should be heard.

SELF-DETERMINATION AND LEADERSHIP

Convening participants agreed unanimously that people with disabilities should speak for themselves (ourselves) and lead the work. Included in this ideal were putting disability stories in the center, leadership by self-advocates, leadership and power structure by those most impacted, and self-determination. Given the concern raised about the lack of racial and class diversity within the mainstream disability rights movement and at the convening, one participant reminded the group that putting “our” stories in the center can exclude the perspectives of those who are not yet in the circle. Communication and sharing knowledge were raised as important ways to welcome more voices into the work and to share power beyond those who have traditionally held it.

On discussions of abortion throughout the convening, there was vast disagreement among participants about whether disability rights advocates should take a position or even discuss it. These questions resurfaced in a discussion of a proposed value: People having control of their own bodies, making their own informed choices. The group overwhelmingly supported this value. However, concerns were raised about how this value might be interpreted. In particular, several people worried that it might be construed as support for assisted suicide. Reservations also came from one person who earlier had said that disability rights as a movement should not take a position on abortion, both because not all people with disabilities agree, and because disability rights groups might work with both pro-choice and pro-life entities. Interestingly, several people had agreed that disability rights should not take a position on abortion but were willing to independently support

the value of people having control over their bodies—presumably a situation in which private views differ from public stances. One person also commented, “if we are saying that one of our core principles is that we are pro-choice, I’d like us to be more explicit about it,” suggesting that further conversation is needed on whether disability rights can and should take a position on abortion as a movement.

Throughout the convening, participants agreed on the importance of informed choices. Many people expressed unease that pregnant women are forced to make decisions about whether to undergo prenatal testing and whether to abort, without comprehensive information about what disability would actually

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mean for a fetus, child, and family. However, one participant questioned “the notion that having as much information as possible is always good.” With the rise of prenatal testing, it has often been assumed that the more testing—and the more information—the better. Disability rights advocates at the convening pointed out that it may sometimes be better, for an individual and for the larger community, not to know everything. While not intentionally keeping information from someone, this could mean that people should be given better information in order to decide whether to proceed with every prenatal test, and it might argue against putting resources into creating more genetic tests.

RESPECT AND NON-DISCRIMINATION

Very little discussion was needed to agree on the value of ending discrimination. Included in this value were equity and access, and a commitment to challenging oppression, privilege, and abuse of power. The group also agreed that the disability rights movement should strive to understand the larger social, political and economic context, in reference to people with disabilities and genetic technologies. While the timeframe of the convening did not allow for a comprehensive discussion of how this would happen, this value demonstrates agreement among a broad group of disability rights leaders that in their work, it is important to seek ways to include new voices, consider the impact of differing political and economic perspectives, and challenge existing power structures both within the disability rights movement and beyond.

The group also agreed with the value of respecting every human life—with or without a disability. Much discussion arose, however, on the specific applications of this value. “Biodiversity” or “human diversity” was proposed as a corollary. While participants disagreed on what term to use, they generally agreed that having a diversity of people in our society, with and without disabilities and other characteristics, is good for all.

TAKING POSITIONS

One area of contention was around whether disability rights should have our own unique position as a movement. The proposed value arose out of concerns about having disability rights messaging appropriated by pro-choice or pro-life entities. For example, if a self-advocate group expresses concern that a future test for autism may result in the abortion of fetuses determined to have a gene for autism, then pro-life groups may swallow up the group’s message and say that they are against abortion. Mainstream media and general society may never understand the distinct message of this group. However, several participants

thought it might be unlikely or undesirable to come up with a distinct disability rights position on any given topic, based on the diversity of the disability community and the push for integration of people with disabilities in broader society.

Similar to taking a unique position was a proposed value for taking no hard stance against cures and prevention, and to create a positive stance of what the movement stands for instead. Through earlier discussion, the group reached consensus that taking a stance against cures excludes many people and practical realities from the disability rights movement. However, one participant said that specific disability groups may have reason to take a public anti-cure perspective. For the autistic community, he said, many self-advocates lean toward an anti-cure perspective and “cures or prevention are not appropriate paradigms.” Is it possible for a specific disability group to take a strong position that is at odds with those of other disability groups, while still building a broad and inclusive movement? As far as taking a positive stance, all agreed that while it is important to stand up against egregious affronts, the disability community is too good at being reactive, whether on genetic technologies or discrimination. A positive stance can give energy to the disability rights movement and bring people together around a hopeful vision.

ACTING ON SHARED VALUES

These values, generally agreed upon by all convening participants, provide an idea of the values important to the disability community. Consensus was reached that shared values are generally important, so understanding these values can help disability organizations work with each other and can guide other groups, such as reproductive rights and justice, in working with the disability community. As difficult as it may be to figure out how to address genetic technologies, these values provide some guidelines—a reminder of what principles to keep in mind as the movement proceeds with next steps and takes action.



TAKING ACTION

At the convening, it was clear from the beginning that these leaders were ready and eager to take action on genetic technologies. Convening participants brainstormed and prioritized six possible projects or campaigns, building on shared values and responding to a need to make the topic of genetic technologies accessible to people with disabilities on a grassroots level.

1. PUBLIC EDUCATION AND MEDIA CAMPAIGNS ON DISABILITY AND GENETICS

A small working group proposed to educate the public about disability and genetic technologies, especially through the media. Education would focus on what it means to have a disability or have a child with a disability, as well as the history of eugenics. The project would support individual disability organizations by providing education and media materials to the grassroots disability community as well as offering media trainings. It would allow individuals and organizations to get involved—reaching out to local media, placing op-eds and news articles in local and national publications, taking advantage of social media (such as Facebook and blogs), and finding new ways to raise public awareness of disability rights

and genetic technologies.

2. CURRICULUM FOR HEALTH PROFESSIONALS

A second working group envisioned a campaign to improve curriculum on disability and genetic testing in medical schools and schools for genetic counselors and other health professionals, addressing concerns that health professionals pass on their own negative assumptions about disability to families considering genetic testing. Disability organizations would provide general education on disability in the context of prenatal testing. Training of medical professionals could involve interacting with people with different disabilities in the community, as well as reading scholarly articles with a disability perspective. Since the convening, directors of several genetic counseling schools as well as leaders of the National Society of Genetic Counselors have expressed strong interest in working with disability rights advocates to improve disability education for genetic counselors. This project might help to build new partnerships (involving collaboration with reproductive rights and justice groups) and make issues of genetic technologies accessible to people with disabilities on a grassroots level by offering a variety of disability rights advocates a chance to speak up on genetic technologies.

3. KENNEDY-BROWNBACK IMPLEMENTATION

The Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008 was the product of an unusual collaboration between Senators Kennedy (pro-choice) and Brownback (pro-life). The Act is intended to provide more comprehensive information and support to pregnant women and new mothers whose fetus or newborn is diagnosed with Down syndrome or another condition. Collaborating with the Genetic Alliance, who was awarded funding for the project, disability rights organizations will help to implement the Act and develop informational materials.

4. BI-PARTISAN CONGRESSIONAL TASK FORCE ON CONSUMER PROTECTION, NON-DISCRIMINATION AND GENETIC TECHNOLOGIES

Another working group suggested developing a Congressional Task Force to look at a variety of genetic technologies and their implications, drawing members of Congress into the issues and actively involving community members. This Congressional Task Force could travel around the country seeking community input on genetic technologies from the perspective of consumer protection and non-discrimination in the use and impact of genetic technologies. Issues to be considered include direct-to-consumer genetic testing, stem cell research, the use of race in genetic research and biomedicines, newborn screening, biobanks in health research, DNA forensic databases, and genetic testing. This bi-partisan Congressional task force would explicitly include people with disabilities, people of color, women, LGBTQ people and children in its public consultation process.

5. DISABILITY RIGHTS / REPRODUCTIVE RIGHTS AND JUSTICE CONVERSATION

A working group of feminist disability rights advocates was interested in continuing conversations

about intersections and tensions between the reproductive rights and disability rights movements, particularly since most mainstream disability organizations avoid taking a position on reproductive choice and abortion, and most reproductive rights organizations leave disability perspectives out of their work. Conversation is needed about how to address concerns about genetic testing and disability rights while at the same time supporting women's reproductive autonomy. A broader conversation could also explore issues of involuntary sterilization that threaten both disability rights and reproductive rights.

6. BALANCING RESEARCH DOLLARS

Convening participants also discussed the need to establish parity in the federal disability research agenda between basic scientific research on the cause of disabling conditions and quality of life and participation-based research involving people with disabilities. This campaign might involve seeking coordination between federal research agencies and support for research on quality of life and participation of people with disabilities.

7. ENSURING A DISABILITY RIGHTS PERSPECTIVE ON THE PRESIDENT'S COUNCIL ON BIOETHICS

A small lunchtime group strategized about ways to ensure a disability rights perspective on any newly re-constituted Presidential Commission for the Study of Bioethical Issues. Several names and strategies were suggested, including proposing a list of academic and community experts for the next Council.



CONCLUSION

Disability rights activists have commented that the most important way to alter how people think about genetic technologies in relation to disability is to change general societal perceptions of disability. Unfortunately, social change on that level will take decades, if not centuries, and genetic technologies are changing and expanding in use every day. An opportunity presents itself—to talk about these issues with people with disabilities and with the larger community, and to take action. As the National Convening

demonstrated, the disability rights movement may accomplish the most by being open to varying perspectives on cures, prevention, and the value or harm of disability. Leaders will need to work with a

variety of groups yet not be afraid to take a stand. Disability rights advocates have identified many different possibilities for action, depending on a

group's size, capacity, and mode of action. New campaigns around genetic technologies may provide an opportunity to consider disability justice and to broaden the disability rights movement to include stronger leadership by people of color, LGBTQ people, and other groups. Rather than being threatened by changing and expanding genetic technologies, the disability rights

movement can take these changes as an opportunity to grow and build the movement, work with a wide variety of people and groups, and alter society's views of bodies, perfection, and humanity.

Rather than being threatened by changing and expanding genetic technologies, the disability rights movement can take these changes as an opportunity to grow and build the movement, work with a wide variety of people and groups, and alter society's views of bodies, perfection, and humanity.

APPENDIX: READINGS FOR THE NATIONAL CONVENING ON DISABILITY RIGHTS AND GENETIC TECHNOLOGIES

Patricia E. Bauer, "What's Lost in Prenatal Testing: Why Encourage Testing for Down Syndrome," Washington Post 14 January 2007: B7.

Adrienne Asch, "A Disability Equality Critique of Routine Testing and Embryo or Fetus Elimination Based on Disabling Traits," Political Environments (2007): 43-47, 78.

Tom Shakespeare, "Arguing about genetics and disability," Interaction 13.3 (2000): 11-14.

Laura Mingos, "Will Stem Cell Research Help or Harm the Disabled?" LA Times 04 August 2001: B19.

Jennifer Ross, "Perspectives of Hemophilia Carriers," Treatment of Hemophilia 8 (2004).

Deborah Kent, "Somewhere a Mockingbird," Prenatal Testing and Disability Rights, ed. Erik Parens and Adrienne Asch (Washington: Georgetown University Press, 2000) 57-63.

Generations Ahead, "Information Sheet: The Prenatally and Postnatally Diagnosed Conditions Awareness Act," 16 October 2008.

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.

ACKNOWLEDGMENTS

Our deep appreciation goes to the co-sponsors of the National Convening on Disability Rights and Genetic Technologies: American Association of People with Disabilities, Center for Ethics at Yeshiva University, and Disability Rights Education and Defense Fund. We thank Access Living for hosting the event, assisting with accommodations and logistics, and kindly providing a tour of the building and its art. We are grateful to those who funded the event: Jessie Smith Noyes Foundation, Appleton Foundation, General Services Foundation, Ms. Foundation, Tides Foundation, Ford Foundation, and an anonymous donor; and thanks to Embassy Suites for a generous discount for our stay. We sincerely thank all those who came to the event and made it a success. Report written by Jessica Lehman, with assistance from Sujatha Jesudason and Alison Kafer.

GENERATIONS AHEAD STAFF

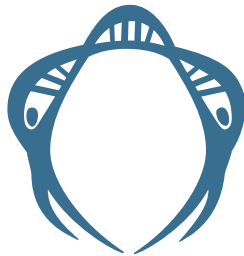
Sujatha Jesudason, Executive Director

Marina Ortega, Associate Director

Susannah Baruch, Policy Director, Consultant

Jessica Lehman, Project Director

Victoria Quevedo, Administrative Associate



GENERATIONS
A H E A D

405 14TH STREET, SUITE 605, OAKLAND, CA 94612

EMAIL: INFO@GENERATIONS-AHEAD.ORG | PHONE: (510) 832-0852 | FAX: (510) 832-2548

WWW.GENERATIONS-AHEAD.ORG