

## In the Hot Tub: The Praxis of Building New Alliances for Reprogenetics

**T**he world's first test-tube baby, Louise Brown, was born in England in 1978. This unprecedented event generated some of the earliest feminist writings about the potential promises and dangers of reproductive technologies and reprogenetics, that is, human biotechnologies that involve the creation, use, manipulation, selection, or storage of gametes or embryos. Opinions were divided between feminists who supported the use of reprogenetics because it augmented reproductive options and choices for women, on the one hand, and those feminists who warned against the increased medicalization of reproduction, the potential commercialization of women's bodies and fertility, and the patriarchal technologizing of childbirth, on the other (see Raymond 1993; Boling 1995; Purdy 1996). Social scientists sounded alarms about the potential eugenic applications of these technologies, drawing attention to the ways in which they could be used to screen, eliminate, or prevent the birth of any fetus regarded as defective (Duster 2003).

In 2001 almost forty-one thousand children were born as a result of in vitro fertilization (IVF), six thousand from donated eggs and almost six hundred in surrogates or borrowed wombs, having been conceived in 411 fertility clinics in the United States (Spar 2006). As the use of IVF has expanded in the United States, scholars and bioethicists continue to voice their concerns (Thompson 2005). Unfortunately, these concerns have often been overshadowed by the vitriolic abortion debates in the United States, and they have largely remained outside the realm of social justice organizing and movement building. While some social justice ad-

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vocates are concerned about the potentially eugenic and exploitative abuses of reprognetics, at a policy level this issue presents some difficult-to-resolve contradictions between progressive movements. These differences are often not acknowledged in progressive calls for regulating reprognetics, yet they present significant barriers to social justice advocates' participation and organizing.

Present and pressing social, political, and economic problems have made it difficult to engage social justice leaders in debates about the future implications of technologies. The abortion debates and current culture wars have discouraged both policy makers and activists from wading into the treacherous waters of embryo politics, stem-cell research, and same-sex conception (terminology used by the Right to denote cloning). At a time when most people feel as though they are barely keeping up with the information and electronic revolutions, meaningful participation in reprognetic debates requires developing a basic and, for some, a new understanding of biotechnology, biomedicine, genetics, and biology.

Current debates about whether and how to regulate reproductive and genetic technologies in the United States range across a spectrum of options. The President's Council on Bioethics issued an extensive report in 2004 stating that its members still lacked sufficient data and information to make a strong proposal. Some scholars, like John Robertson, support the maintenance of the current status quo of patchwork regulation through existing agencies like the Food and Drug Administration, professional self-regulation, and our current nonsystem system (Robertson 2007). Others, like James W. Fossett, argue for decentralized governance at the state level, where policies are fought over and implemented on a state-by-state basis (Fossett 2007). Still others, including George Annas, advocate for international treaties and global governance, arguing that governance cannot be done on a country-by-country level (Annas 2006).

A fourth option has been to borrow from regulatory models in countries like the United Kingdom and Canada that employ comprehensive regulation of reprognetics (Annas 2006). In their recent report, *Beyond Bioethics*, Francis Fukuyama and Franco Furger (2007) propose regulation that consists of a set of ethical guiding principles, a series of prohibited and regulated activities, and a new regulatory institution. Erik Parens and Lori Knowles, in a 2003 Hastings Center Report, make three recommendations: bring embryo research into the light of public deliberation, create a commission to develop public oversight recommendations for Congress, and create a standing federal entity to facilitate systematic public and policy deliberation. In all, advocacy for comprehensive regulation tends to hinge on creating a federal regulatory agency.

In these proposals, and intentionally so, the role of social justice and feminist values, principles, and advocacy is opaque. They address how regulation should be structured, not who should be involved in the decision making. However, if social justice and feminist advocates are not organized and ready to participate in these discussions, these regulatory structures will be established in such a way as to disadvantage their concerns and voices. This, after all, is how politics operates. As Alta Charo notes in "Realbioethik," for as much time as we spend debating the ethics and technologies of reprogenetics, "in the end, it is the politics we are debating more often" (Charo 2005, 13).

When we survey this political domain, we see that the biotechnology industry is relatively well organized, the scientific and medical communities have their organizations and credibility to move their agenda, and certainly some factions of the conservative Right are ready to engage in this political fight. Are social justice and feminist advocates ready and able to engage? Do they have the information, knowledge, capacity, and resources to ensure that their perspectives and concerns are included? Are they tracking these issues, prioritizing their concerns, organizing their networks, developing their values and policy positions in preparation to engage? Clearly the stakes are high: reproductive autonomy for women, the valuation of children, the geneticization of race and difference, access to the technologies, and in some cases, the very survival of certain people. Yet while feminist scholars continue to warn us of the dangers of reprogenetics, they have most often been mute about how to engage in this debate and in the related policy-making process.

At the heart of all this work are several key contradictions between movements that need to be resolved as social justice advocates participate in this arena. These contradictions create deeply uneasy internal conflicts within and between movements—conflicts that are often at the core of why social justice advocates have not systematically addressed these issues. Simply figuring out the best policy framework and advocating for it is not the solution to this problem. The problem more often lies in the social and political challenges posed by the use of these technologies. Mobilizing social justice movements to participate in the debates and policy-making process on these issues is not enough; these movements also need to develop and advocate for a collective agenda.

Without shared principles and agendas, reproductive rights advocates probably will not include disability or lesbian, gay, bisexual, transgender, and queer (LGBTQ) concerns; progressive civil rights advocates will not advocate for a precautionary principle approach to new technologies; and

racial justice and health advocates might not pay attention to the ways in which race can become reified and geneticized through biotechnologies.

This article examines the challenges, dilemmas, and strategies in advocacy and policy making on reprogenetics from a social justice and feminist perspective. It is not a theoretical analysis of the political, scientific, or social contradictions posed by reprogenetics. Instead, it is an accounting of the practical strategies that are currently being employed by one organization, Generations Ahead, to build the new alliances needed to ensure that reprogenetics are used in inclusive and just ways.

Generations Ahead ([www.generations-ahead.org](http://www.generations-ahead.org)) is a nonprofit social justice organization working to expand the public debate and policy-making process on genetic technologies. It works with a network of organizations around the country to look at the benefits and risks of these technologies to different communities and to ensure that diverse perspectives are included in public debates. Generations Ahead builds the capacity of organizations to take more informed positions and advocate for socially just policies. The mission of the organization is to bring together diverse communities to expand the public debate and promote policies on genetic technologies that protect human rights and affirm our shared humanity.

Generations Ahead's work is rooted in a cross-sector movement-building model that engages leaders from racial justice, reproductive rights, disability rights, and LGBTQ rights organizations to create a collective and proactive policy and advocacy agenda. At the core is a commitment to ensuring that historically marginalized communities will be at the center of these discussions, in large part because the eugenic potential of these technologies means that these communities have the most to lose. In the United States there has been a long and ugly history of science and modernity articulating eugenic agendas that include the sterilization, deselection, and incarceration of poor women, people of color, people with disabilities, and queer people.

While acknowledging the enormous potential for interesting and life-affirming scientific discoveries in human biotechnologies, Generations Ahead is committed to developing values-driven, solution-oriented, hopeful agendas that affirm the value of all human beings, all types of families, and all kinds of communities.

Generations Ahead grew out of the program on Gender, Justice and Human Genetics at the Center for Genetics and Society (CGS), a nonprofit information and public affairs organization working to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies. The Center for Genetics and Society

was established in 2000, and Generations Ahead became an independent organization in 2008 to complement CGS's use of an explicitly coalitional strategy.

The Center for Genetics and Society was organized by two founding directors, Richard Hayes and Marcy Darnovsky, in response to what they saw as a troubling resurgence in eugenic advocacy, in this case a market-based techno-eugenic ideology utilizing reprogenetic technologies. During their tracking of emerging technologies, they noticed a disturbing pattern of academic writings celebrating the potential of these technologies to redesign human beings, with little to no public challenge offered to this advocacy. In founding CGS, they envisioned organizing an effective response to the celebration of this kind of unfettered libertarian technological advocacy.

I joined CGS in 2004 and directed its program on Gender, Justice and Human Genetics. Coming from a professional background with an extensive history of organizing, advocacy, and research in a variety of social justice movements, I was troubled by social justice leaders' lack of preparedness to engage in debates that had the potential to reshape the reproductive rights and racial justice movements. For three years, my staff and I built this program to do outreach to social justice organizations and leaders, calling their attention to issues of reprogenetics, helping to build their understanding of and capacity to engage in public and policy debates, and building vehicles for social justice organizing and advocacy on reprogenetics. In January 2008, CGS helped to turn this program into Generations Ahead to more effectively focus on coalition building and developing shared policy positions with a broad network of social justice allies.

Since 2004 program staff in the both Gender, Justice and Human Genetics program and Generations Ahead have worked to increase awareness of the social and political implications of reprogenetics among social justice leaders and organizations and to build their capacity to engage meaningfully in the public and policy debates on these issues. Over the years we have reached out to more than two hundred social justice organizations and talked to hundreds of people in different movements about social justice concerns with regard to reprogenetics. In doing this work we had to overcome four main obstacles: the lack of bridging organizations and resources; the need for different frameworks for different movements; the lack of specific cross-movement dialogues to resolve tensions between movements; and, finally, the need for a new organization to structure and sustain new social justice alliances for responsible and just uses of reprogenetic technologies.

Central to this work has been the task of unearthing the complex social and ethical dilemmas reprognetics presents to different communities, developing strategies to acknowledge and work through differences, and building a coalition across movements for just uses of reprognetics. This article shares some of the strategies we are utilizing and the lessons we are learning as we build this work. In our vision, cross-movement coalition building is critical for truly just and responsible policies in this arena. Without a process for building alliances across movements, and without an organized vehicle through which to collectively work together and advocate, each movement will eventually mobilize itself to respond based on its own narrow interest. With these narrow responses, the different sectors of the social justice movement will find themselves at odds with one another, and the more powerful will advocate for policies that might benefit them at the expense of other interests.

However, if social justice movements begin working together early on, building trust and commitment, working through differences, and developing shared values upon which to craft policies, there is the hope that this kind of new social justice alliance can ensure that some do not benefit at the expense of others. Generations Ahead is building a national coalition representative of multiple social justice movements, rooted in a shared set of values that protect human rights, ensure inclusion and equity for diverse communities, and provide a model for just uses of these profoundly consequential technologies.

### **What's at stake?**

Genes and genetics play a powerful role in how many people define family and community and in how they understand themselves. Whereas in the past some people defined family and community by biology and “blood,” many are now using the language of genes and DNA. Family ties and connections are expressed in the language of sharing genes, behaviors and characteristics are defined by genetic inheritance, and presumptions about shared historical genes are used to delimit community boundaries. Unlike other technologies, genetics and reprognetics can shape how we relate to others and ourselves in fundamental and troubling ways.

There has been a long history of efforts to align lived experiences and structural inequalities with biological categories of difference, of trying to map social hierarchies onto genetic differences, of using scientific justifications for unequal treatment and abuse. This includes ugly chapters when science—in the forms of scientific racism and eugenics—tried to weigh in on sociopolitical debates about racial hierarchies. Many promising

advances and benefits in science and technology can have a shadow side. Now, as discoveries and innovations in reproductives develop rapidly, we are faced again with the challenge of ensuring that this science not be used to justify or promote structural discrimination and inequality, particularly on the basis of race, gender, sexuality, or ability.

In addition to these kinds of broad concerns, reproductives poses specific issues for different constituencies. These include concerns for women's health and rights advocates. Minimally, there are important concerns about the health and safety of selection techniques and the need for women's eggs. Conception and pregnancy are becoming more medicalized, and women are increasingly required to undergo genetic testing that can include genetic mutation carrier testing, preimplantation genetic testing, and prenatal genetic testing. These tests raise an array of ethical and social concerns: When is the testing used for informational purposes and when for deselecting undesirable traits or ascribing social significance to gene variations and genetic differences? What is the impact of the desire for "perfect" children on parents and children? What is the impact of the changing experience of pregnancy due to the testing? Reproductives allows some parents to choose the sex of their children and deselect those that will have disabilities. What does autonomous or ethical reproductive decision making for women look like when women are faced with increasing options for testing and intervention, often with very little information about the tests? Does reproductive liberty include the right of parents to select or "enhance" the characteristics of their children?

While the safety and accuracy of reproductives testing is critical, existing government oversight of these tests is limited and fragmented. According to the Genetics and Public Policy Center at Johns Hopkins University, "Without any central or comprehensive oversight, many if not most aspects of genetic testing occur without any government monitoring" (2004, 49). Who is publicly accountable for ensuring that the health, safety, and well-being of women, children, and families are considered and protected?

In addition, women's eggs are increasingly in demand for both fertility and research purposes. Women, particularly young women, are recruited by ads offering large payments (up to \$100,000) to "donate" their eggs for fertility purposes. Women are also recruited to provide eggs for research cloning, a type of stem cell research in the early stages of development. In both the fertility and research contexts, the process involves hormonal stimulation over several weeks to produce multiple eggs in one cycle (rather than the usual one egg) and surgery to suction the eggs out of their follicles. While there are some short-term health risks, there is no research data available on any of the long-term health impacts of hormonal

stimulation. Young women need accessible, comprehensive, and impartial information so they can make fully informed decisions about whether to go through the egg retrieval process or not. There are no uniform mechanisms in place to ensure this right, leaving only a patchwork of professional standards set by individual fertility clinics or egg brokers.

This kind of market for women's eggs is creating a new range of social and political challenges for women's health advocates. At a recent reproductive rights meeting on a women's college campus, all twenty women present admitted that they had either considered extracting their eggs for payment or knew of at least one woman who was either considering doing so or had done it. Other questions aside, not only did most of them not know what kinds of questions to ask in order to make a fully informed decision, but they also did not feel empowered to advocate on their own behalf in a medical context.

The reproductive rights movement has been hesitant to engage with the social and political challenges posed by reprogenetics, in large part due to the relentless attacks on abortion rights. Its members have avoided discussions about an affirmative role for government in regulation, protection, and oversight primarily because of fears that that role will extend to limiting access to abortion and other family-planning technologies. Additionally, the rhetoric of choice has so deeply penetrated the movement that it is now faced with, in the words of Rebecca Tuhus-Dubrow, a "messy overlap between reproductive rights and what could emerge as a neo-eugenics," where the fight for access to abortion and a woman's right to choose could segue into a fight for the right of parents to reprogenetically design their babies (2007, 1).

However, this is not the complete picture of the challenges posed to social justice movements by the use of reprogenetics. In the disability community, disability rights advocates are deeply concerned about the explicit intent of these technologies to deselect and eliminate people with disabilities. As Adrienne Asch asks, "Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities?" (Asch 2003, 315). Within the disability community, however, there are also many people organized in patient groups and cure advocacy groups who view the increasing development and use of reprogenetics as beneficial and necessary.

The LGBTQ liberation movement has its own complex relationship to reproductive and genetic technologies. These technologies are eagerly embraced for making genetically related children possible for LGBTQ



people. There are many, too, who hope for the identification of a gay gene to provide a scientific imprimatur of legitimacy to their sexual orientation. However, others fear the reductionist and potentially negative eugenic misuse of a gay gene and are concerned about the ways in which rerogenetics could reinforce and legitimize gender stereotypes and binaries. Still others are concerned that if there is any governmental oversight and regulation of the use of rerogenetics, LGBTQ people will either be regulated out of access to assisted reproductive technologies (ART) or see that use circumscribed by sexual orientation.

Within the racial justice and civil rights movements, references to past eugenic practices and the potential for rerogenetic neoeugenics reverberate with concerns about “designer babies” and the prenatal discovery and selection of skin tone genes. Racial justice organizing interest is slowly emerging at the convergence of DNA forensics, racial profiling, and the massive expansion of DNA databases and dragnets. Worries about new forms of prejudice and scientific racism are beginning to develop, especially since the case is being made for genetic definitions of race through the development of race-specific medications, ancestry tests, and genetically based racial health disparities (Harmon 2007). However, given the immediately pressing concerns of the aftermath of Hurricane Katrina, economic and health disparities, and criminal and education system reforms, rerogenetics and a fight against the reemergence of a discourse of scientific racism often slip to a lower priority.

Rerogenetics affects each of these communities in nuanced and complex ways. However, if we do not intentionally create cross-movement alliances, each movement could unintentionally position itself at odds with the others. For example, if the reproductive rights movement does not work with disability rights, LGBTQ rights, and racial justice advocates, it could support policies that devalue people with disabilities, that do not account for the needs of LGBTQ families, or that do not recognize the potential eugenic applications and outcomes of certain rerogenetic technologies. Similarly, disability rights advocates could press for their rights at the expense of women’s reproductive autonomy.

While there is much at stake for feminists as well as social justice advocates and movements, the political landscape of rerogenetics is often perceived as complex and unclear. This complexity exists independent of any political positioning on the part of the conservative Right. When religious and political conservatism is factored in, the landscape becomes a minefield of strange bedfellows and dogmatic defenses with limited opportunities for victory.

**Organizational resources and relationship building**

In 2004, CGS, in collaboration with Our Bodies Ourselves and the Committee on Women, Population, and the Environment, hosted a meeting of sixty-five feminists and activists to discuss the political, social, and ethical challenges of rerogenetics. This meeting, Gender and Justice in the Gene Age, was intentionally created by the three organizations to be an accessible space in which to engage feminist scholars and community-based social justice activists, including both newcomers and those knowledgeable about the issues.<sup>1</sup> Two days of discussion on feminist, eugenic, and disability concerns ended with a final session in which participants articulated their hopes and visions for charting a social justice and feminist pathway in governing rerogenetics. More significant than the discussion and vision was the commitment by the three organizations to continue to develop this work. The Committee on Women, Population, and the Environment organized a task force on Gender, Eugenics, and Biotechnology to work systematically on these issues. Our Bodies Ourselves increased coverage and visibility of rerogenetics in its book, and CGS created a full-time staffed program on Gender, Justice and Human Genetics.

This organizational commitment provided the structure, staff time, and financial resources to systematically do outreach and education to other feminist and social justice organizations, professional advocates, and activists. These organizations began to function as bridge structures between academics, feminist scholars, and bioethicists; they made public presentations accessible, developed constituent-specific materials, and created opportunities for advocates to gather together, clarify concerns, and begin systematically engaging in this public discussion.

The Gender, Justice and Human Genetics program of CGS and now also Generations Ahead are providing some of the resources needed to create a launching pad to move social justice and feminist advocates into more systematic and organized engagement.<sup>2</sup> Beginning in late 2004, staff have created a national network of social justice organizations and leaders aware of the feminist and eugenic concerns related to rerogenetics and

<sup>1</sup> For more information on this meeting, see <http://www.gjga.org>.

<sup>2</sup> The work described in the report "Gender and Justice in the Gene Age: A Feminist and Social Justice Meeting on New Reproductive and Genetic Technologies" (Center for Genetics and Society 2004) occurred between 2004 and 2008, a period when staff worked both under the auspices of the Gender, Justice and Human Genetics program of CGS and Generations Ahead. In order to avoid continually referencing both organizations, and because CGS and Generations Ahead employ the same strategy and staff, I will refer primarily to Generations Ahead as the organization leading this work.

created vehicles for them to increase their engagement. We have presented at conferences, participated in intimate briefings for boards and staff, met one-on-one with leaders, and hosted convenings of key leaders.

In 2005 we hosted our first cross-movement convening to address a broad range of social justice concerns around reprogenetics. This gathering was nicknamed the Hot Tub Meeting because participants were chosen for their willingness to frankly discuss their concerns with reprogenetics and the political challenges they raise, concerns that often felt difficult, risky, and politically incorrect to articulate. The invitees were selected based on a general criterion of “who do you want to sit in a hot tub with and talk about these issues?” Planned Parenthood Federation of America cohosted the meeting, and all invitees were midlevel leaders in their organizations. We decided not to invite executive directors of organizations because we wanted people to be able to engage in frank and difficult conversations without feeling obligated to represent their organizations’ position on the issues.

Over three days twenty participants got to know each other and discussed a process for how to engage their organizations and movements in a discussion about reprogenetics. The first half of the convening was spent in storytelling, where participants shared their personal histories and the forces that have shaped their lives. Hours were spent with participants walking along the beach, doing yoga, going for runs, and hanging out by the fireplace together. Participants clustered in groups of lesbians, black women, indigenous women, women with disabilities, women concerned about future generations, and two groups of women who identified as socially infertile (women who had postponed childbearing until later in life for social reasons). Each group reported on its unique perspective on reprogenetics, its members’ key challenges and struggles, and what they wanted other people to understand and respect about their experiences. Some of the lessons from this session included how intimately reprogenetics touches all our lives, the need to connect reprogenetics to broader social justice issues like universal health care and equality, how challenging it is to move from individual to community risks and benefits, and that we need to be very careful in the language we use to do so.

In small group exercises, participants shared their personal connections with and concerns about reprogenetics, concerns that included postponing having children until later in life due to financial and career pressures, stereotypes of black women as having too many children, worries about lesbians and gays not being able to access ART, and painful social messages targeting people with disabilities. Warm and trusting relationships between

leaders in reproductive rights, civil rights, racial justice, disability rights, environmental health, and human rights were intentionally built through personal sharing and storytelling.

Building alliances according to this model—beginning with individual relationship building and then moving from organizational relationship building to cross-movement relationship building—is a time- and staff-intensive way to start organizing. For CGS and now Generations Ahead, this has required a budget of several hundred thousand dollars and a staff of six people working almost full time to reach out to, connect with, and cultivate a network of 150 interested and engaged leaders in reproductive rights and justice, disability rights, civil rights, LGBTQ rights, human rights, racial justice, health disparities, and environmental justice organizations over four years. It has also required a stable organization able to support the work and invest in building staff capacity to understand the science and technology of rerogenetics, be effective and accessible communicators of the information, and build authentic relationships. Without this kind of a bridging program and these organizational resources, building interest and momentum in such a complex and future-oriented topic would be prohibitively challenging. One-on-one, personal cultivation and engagement have been necessary to build a national network of leaders and organizations interested and engaged in this area.

### **Specific framing for different movements**

The second component of the Generations Ahead model consists of a phase of inquiry and learning that goes both ways. As staff share information with movement leaders about rerogenetics and the related social justice concerns, they inquire into what about rerogenetics sparked these leaders' interest and how it connects to what they care about and work on. Interest is often kindled because the social justice concerns with rerogenetics resonate with an interest in science and technology, or deeply held values of equality and diversity, or an interest in grappling with ethical considerations. As this mutual process of learning and inquiry unfolds, Generations Ahead deepens its understanding of the rerogenetic concerns of different individuals, organizations, and movements. Through feminist practices of sharing, trust building, and consciousness raising, staff develop an analysis of the intersections and impacts of rerogenetics that is rooted in lived experiences of family and community and that openly acknowledges the tensions and challenges of building a new political perspective.

For example, it was only through multiple conversations with staff of

Choice USA, a young women's reproductive rights organization, that Generations Ahead staff began to track ads in college newspapers recruiting young women to donate eggs. As the dialogue deepened, an analysis began to emerge for both Generations Ahead and Choice USA about the context in which this recruitment occurs, how young women understand and internalize the messages about their bodies and money, and what kinds of informational and organizing campaigns might exist in connection with this issue. Thanks to this commitment to an intentional process of inquiry and learning, Generations Ahead staff were able to approach the issue without any undertones of judgment about young women's decisions and could strategize collaboratively with Choice USA about developing campus-based campaigns that are genuinely rooted in the complexities of young women's lives.

As Generations Ahead staff deepened their inquiry and learning about different movements, they found that they needed to frame the concerns related to reprogenetics differently for each community. Some, like disability rights advocates, had already been tracking all the ways in which reprogenetic technologies facilitate and encourage the unquestioning elimination of people with disabilities. Many advocates had a long history of writing and participating in these debates, dating back to the beginning of the second wave feminist movement. Other movements, like racial justice, immediately understood the eugenic implications of reprogenetics but hesitated to prioritize these issues, particularly in the aftermath of Hurricane Katrina, in the face of disparities in education and health care, and in the context of desperately needed criminal justice reforms. And others, like the reproductive rights movement, were extremely reluctant to begin considering these issues, given the bitter attacks on abortion and their current aversion to regulation.

For all of these movements, Generations Ahead has learned to develop an understanding of their priority issues and their current political landscape and has identified their key leaders and organizations in order to develop effective strategies for engaging their interest. To do this, staff had to immerse themselves in each movement. For example, to connect with the reproductive rights movement, program staff went to every important conference or meeting in the movement, became active members in national and regional reproductive rights coalitions, and served as board members and advisors for key organizations. This allowed them to build important and trusting relationships based on a genuine commitment to their concerns and issues outside the sphere of reprogenetics.

In addition to building trusting relationships, Generations Ahead frames all our discussions with allies around five inquiry questions. With

these questions we intentionally move away from predetermining how organizations should respond to the concerns raised. The goal is to engage people within a social justice framework and still leave open the discussion about specific values and policy priorities. As a social justice coalition-building organization, Generations Ahead is committed to a process of developing core values and policy priorities collectively. For example, with reproductive rights organizations, the five inquiry questions included: First, what are the risks and benefits of using ART? Who benefits? Who is at risk? Second, what is the balance to strive for between collective social justice and individual choices? Third, how do we prioritize resources and ensure the health and safety of all? What mechanism do we use to allocate resources, the government or the market? Fourth, who is making these decisions? Who should be included? Should they be made by democratic participation or expert decision makers? And finally, what are the values, and where is the voice, of the reproductive rights movement on reproductives?

This mode of inquiry and engagement on reproductives often exposed a core tension within the movement. The reproductive rights movement, particularly during George W. Bush's administration, has been struggling with the question of the role for government in reproductive rights. As late as 2008, government regulations were being used to curtail women's reproductive autonomy in the form of limiting access to abortion, contraception, and sexuality education. On the other hand, reproductive rights advocates, as progressives, have historically looked to the government for protection and access to services. There is no consensus in the movement about the government's role: should members be advocating for no state interference in reproductive rights or advocating for an affirmative role for the state in distributing reproductive health care resources, protecting vulnerable communities, and ensuring rights and access (Arons 2006)?

Our organizing experience in the disability rights movement has been different. Coming from a movement that is grossly underresourced, advocates often felt that they did not have the time or the means to work on these issues. Many of them felt discouraged and burned out on reproductives, given their long history of participation in these debates. It has taken a slow and steady process of relationship building to develop trust and elicit the engagement of key disability rights leaders. And after two years of solidifying relationships with disability rights scholars and advocates, we are developing strategies to begin outreach to patient advocacy and disease diagnosis organizations, for which we will need to develop an entirely different framework. This incipient work with the

patient advocacy sector of the disability movement highlights the tensions within this community, tensions between a social model of disability that focuses on challenging the social stigma attached to disability and advocating for the civil rights of people with disabilities, on the one hand, and a medical model of disability that interprets disability as a physiological problem to be fixed or cured, on the other.

Recently, we began engaging racial justice and civil rights advocates on the issue of DNA databases, forensics, and dragnets. Initially, we thought that a eugenics frame would be sufficient to inspire their increased participation. While they easily understand the eugenic implications and are deeply concerned about the ways in which genetic technologies can reify race into a genetic characteristic, their priorities have focused elsewhere. However, on the issue of the role of genetics and DNA in the criminal justice system, we have begun to develop some traction and momentum. Advocates worry that the same technology that is being used to exonerate many falsely accused people is going to be expanded into DNA data banks, racial profiling, and DNA dragnets. In January 2009, Proposition 69 went into effect in California, allowing law enforcement officials to take the DNA of any individual arrested (not convicted) for a felony offense. This raises serious concerns about privacy, genetic discrimination, the exacerbation of racial profiling of people of color, and the tendency for crime to be linked to race through genetics.

Racial justice and civil rights advocates are starting to engage. And as they become more involved, they are beginning to grapple with the contradictions genetic technologies pose, for example, the use of DNA forensics to exonerate innocent people of color at the risk of expanding DNA data banks, and the increasing use of race to measure health disparities at the risk of reifying race through race-based medicines like BiDil, the first drug marketed specifically for African Americans to treat heart disease. This new breed of race-specific drugs, with their dubious claims of efficacy, makes for a good marketing ploy, but it is bad science, lacking credibility in sound research and erroneously reinforcing the unproven idea that there are medically relevant genetic differences between racial groups.

And finally, interest among LGBTQ rights advocates has spread rapidly. Given the ways that ART has helped LGBTQ families have children, the awareness of ART was relatively high. Many LGBTQ advocates and organizations were already involved in setting legal precedent in relation to these technologies in their fights for LGBTQ family formation. In working with these advocates, we framed the social justice concerns as a caution against being unwitting proponents of reprogenetic policies that could

potentially harm the community. For all the benefits of ART, there are also potential dangers that include defining family only by genetic relationship and not acknowledging families-by-choice; using genes to identify and/or justify behavior (i.e., the “gay gene”); reifying a gender binary through technologies such as sex selection; and potentially exploiting vulnerable women through surrogacy and other family formation strategies. While many advocates are leery of any limits on access to ART, they were nonetheless willing to engage in the challenging conversations about how to prevent potential harm.

As Generations Ahead engages more social justice movements in discussions, it has confirmed that each movement or constituency faces a different set of concerns and challenges. And sometimes, even within movements, there is a range of concerns. For example, concerns expressed by most women of color were different from the perspectives represented by some white women in the reproductive rights movement, with women of color being more explicit about their concerns regarding the role of power and privilege in the use of and access to reprogenetics and being both more supportive of and more cautious about any regulatory role for the government.

We found that our messages about reprogenetics and social justice needed to be tailored to each movement, and staff had to demonstrate a commitment to broader allied agendas before they would be listened to seriously. While it is easy to talk about social justice and feminist concerns, staff learned that the realities of those concerns are often vastly different. These differences require various commitments, diverse strategies, references to different histories, and the use of varied frameworks. Staff have learned quickly the error of thinking that there is one unified social justice, human rights, or feminist agenda or one set of values, concerns, or goals in relation to reprogenetics. If we are to build new alliances on reprogenetics, the differences across the movements and between movements need to be mapped, acknowledged, and addressed.

### **Cross-movement tensions and dialogues**

The third component of the Generations Ahead model is rooted in practices that value and work with diversity and difference. In this component of the work, staff acknowledge the tensions between movements and how this affects relationships between groups, or the lack thereof. By identifying and naming differences (not pretending that they don’t exist) and appealing to broader values and visions, Generations Ahead encourages



leaders across movements to work together. As staff deepened their knowledge about the concerns and perspectives of different movements, they recognized the need to bring leaders across movements together to resolve tensions between movements, tensions that pertained specifically to historic differences.

Generations Ahead organized a series of roundtable dialogues to deepen understanding of the tensions related to reproductives. These discussions addressed a variety of topics of mutual interest: the dilemmas of privacy, preimplantation genetic diagnosis, and a dialogue among women of color. These roundtables were cohosted with other well-established organizations that were specifically interested in the topics. In these roundtables, advocates have struggled with the challenges of defining a role for government in regulation, the policing and protection of vulnerable communities, how to balance individual autonomy with collective responsibility, strategies for inclusion in a framework of scarce resources, what they needed to do to even start thinking about reproductives in the face of a multitude of pressing social concerns, and how to account for power and resource differentials in policy applications.

One of the most interesting, challenging, and informative cross-movement dialogues hosted by Generations Ahead has included advocates from disability rights and reproductive rights organizations. Significant tension between these two movements revolves around prenatal screening and selective implantation or termination. Given the challenges of this conversation, Generations Ahead decided to start small and explore a model of working across differences that incorporated our components of relationship building, storytelling, learning/inquiry, and sustained conversations. The program hosted four conversations with the same group of people over two years. In these four sessions they have built relationships with one another, created a safe space for hard conversations, and committed to working together to move the issue forward. While the initial focus of the meeting was to discuss preimplantation genetic diagnosis, throughout the first four-hour meeting it was not mentioned. Participants were more interested in working through the broader tensions between disability and reproductive rights.

Given the widespread lack of awareness about disability issues, staff facilitated a learning and discussion session on disability issues for the reproductive rights advocates before the joint meeting began. This session was a concrete demonstration of commitment to learning and sensitivity, and it ultimately changed the tone of the joint conversation. In the pre-session, able-bodied participants acknowledged their challenges around

disability and had a safe place to ask questions and learn more. Disability rights participants reported that the pre-session contributed significantly to their level of safety during the conversations.

During this series of dialogues, both sides agreed that there has been a long and complicated history of trying to resolve tensions, that they need to create safe spaces to listen to each other's stories and points of view, and that a broader, intersectional perspective moves the conversation forward faster for both sides. While participants recognized that there is a potentially rich discussion to be had on issues of parenting, caregiving, decision making, and individual responsibility for social outcomes, they decided that one of the core tensions was around the issue of personhood. The disability rights movement has worked to expand notions of personhood to include a wide range of people and abilities, and the reproductive rights movement has actively fought against giving an embryo or fetus the status of personhood. After two meetings, this group committed to working together to develop bridge language and methods for working in alliance on reproductives. While it is not clear how they will resolve the tension, all participants have learned from one another, are more invested in working together, and are slowly developing a commitment to one another and to one another's issues.

Some important lessons have emerged out of these cross-movement conversations for Generations Ahead and all the participants. First, the best way to advance alliance building across areas of difficult differences is to not expect consensus or agreement on all issues or values. Potential allies should not allow cross-movement alliances to be shaped by areas of disagreement but rather by areas of understanding and agreement, however limited they might be. For example, both movements agreed that women needed comprehensive, unbiased information about prenatal testing to make informed decisions in their reproductive lives, whether or not there was an agreement about how to define personhood or when life begins.

Second, when the conversation begins with an assumption of limited and scarce resources, alliance building and shared agendas are impossible because it always looks like one side will gain at the expense of the other. In these roundtable discussions, it served both groups to expand their agendas to include both advocating for resources for caregiving and parenting in a reproductive rights agenda and also adding concerns about reproductive health to the disability rights agenda. This way both benefited, and both served their constituents better.

A third lesson is that trust has to be built by concretely demonstrating a commitment to each other's values and work. This commitment cannot

be assumed, and the way to demonstrate it is through spending time with each other, working together, showing up at each other's events, learning about each other's histories, and speaking up for each other when the other is not present.

The work Generations Ahead has done through these roundtables is just the tip of the iceberg in terms of tensions between social justice movements on the issue of reproductives. At one multimovement event, Generations Ahead asked small groups of participants from different movements to report on their unique perspectives and challenges with reproductives and then to identify "deal breakers" for their movements. Participants defined deal breakers as values, principles, or strategies on which their respective movements would find it impossible to compromise. Some of the important and contradictory deal breakers that emerged included:

- Policies curtailing access to any ART (reproductive rights and LGBTQ rights)
- Any limits on women's reproductive autonomy (reproductive rights)
- Policies not based on the precautionary principle of proving no harm before utilizing any technology (environmental justice and indigenous people's rights)
- Any position that elevates the moral status of the embryo or fetus (reproductive rights)
- Any bans on using technology ("only bad people ban things") (political progressives and civil rights)
- Positions not substantiated with documented scientific evidence of adverse health impacts or proven safety risks, a position antithetical to a precautionary approach of proving no harm (political progressives)
- Policies that limit the definition of family to two heterosexuals or that fail to respect a variety of family formation strategies (LGBTQ rights)
- Any perspective that frames disability as a medical issue rather than a social or rights issue (disability rights)
- Any perspective that does not take into consideration the needs and rights of future generations and collective responsibility (racial justice and indigenous people's rights)

In learning about the political terrain for advocacy on reproductives, Generations Ahead has come to recognize the significant barriers to cross-movement alliance building even among a group of relatively like-minded social justice advocates. These deal breakers helped to clarify why there has not been more organized advocacy and policy response across move-

ments. For as theoretically important and obvious as it is for social justice groups to work together, there is much work to be done to build an alliance for just uses of reproductives.

From these cross-movement dialogues, Generations Ahead identified several important strategies and lessons for how to work in this area. First, there is a need to develop common language and messaging on these issues. Many participants from different movements misunderstood each other simply because they tended to talk about the concerns in different ways. For example, reproductive rights and racial justice advocates talk about quality of life as a group or community assessment that includes economic and social conditions such as living wages, civic participation, and cultural expression, whereas in a disability context it is usually applied in assessing the value of an individual's life and whether that specific life is considered by others to be worth living.

Second, if people are to work together across movements, they need to develop clear goals and objectives. Organizations will not be interested in working together on such tough issues without clear objectives and end points. Any attempt to work across movements needs to clarify hoped-for accomplishments early; otherwise it will be hard to attract leaders and organizations to the cause.

Third, many dialogue participants said that they needed more information and education on these issues and that they needed the tools to promote education and discussion within their organizations. They felt that because their organizational leadership knew little about these issues, they were reluctant to engage or prioritize them. A lot of internal education and dialogue needed to happen before external dialogue and action could occur.

Fourth, we need time to work together, to engage in discussions, and to change how we work internally within organizations and externally with one another. When we have a good process for working together, even if different sides do not agree about the outcome, they will stay in the room. In the beginning, cross-movement work is so tender it is impossible to predict the outcome beforehand. The best we can do is construct good ways of working together to get us through to a new, unpredictable result.

And fifth, developing policies on reproductives requires nuanced perspectives and positions. Framing the issues as either/or (good or bad, right or wrong, government or market, or, most importantly, between individual or collective good) does not serve us and does not advance fruitful discussions. For example, inquiries framed politically as a choice between individual or collective good do not reflect reality. There are few

individual decisions that people make that are truly choices they want to make. Usually they are choosing between two bad options. Our social justice goal should be to increase good options for everybody around reproductives so that people are not forced to settle for a bad choice between poor options.

As the difficult conversations proceed and contradictory deal breakers are identified and addressed, more social justice leaders are becoming active in the Generations Ahead network. The process of acknowledging differences and then participating in conversations to try to resolve them is deepening people's commitment to working on this issue. As an example, several reproductive rights leaders have increased their commitment to understanding and integrating disability rights issues into their analysis and language. Because of these dialogues, a statewide reproductive rights coalition has committed to a series of internal conversations on disability. This intentional work of building cross-movement relationships, discussions, and strategies has become a key component of Generations Ahead's work and success.

#### **Leadership for building a new alliance**

After four years of relationship building, learning and inquiry, and cross-movement discussions, Generations Ahead is beginning to build a national cross-movement coalition. Leaders from organizations representing reproductive rights, disability rights, youth advocacy, progressive politics, progressive religious congregations, economic justice, and LGBTQ rights participated in the first strategy discussions in 2007. After acknowledging the advantages and disadvantages of coalition work, leaders from eight organizations committed staff time and resources to creating a new coalition. In conjunction with Generations Ahead, these eight leaders articulated a vision for working on reproductives that includes developing shared principles, values, and guidelines to inform their decision making, policies, and advocacy on reproductives. They want to create a coalition that is a safe space, like some of the cross-movement dialogues, where organizations and leaders can get to know each other, hear about each others' work and histories, learn from each other, and work through differences in goals, objectives, tactics, and strategies. Through the coalition, they want to work to increase awareness and public participation in debates on reproductives, bring multicomunity perspectives into the discussions, develop a socially just policy agenda, create a hopeful vision for the future of reproductives, proactively advocate for policies, and implement a sophisticated media strategy that uses diverse voices on this

issue. Their ultimate goal is to build a national-level coalition—informed by local, grassroots, and global concerns—that works nationally and, when strategic and necessary, on state-level policies and politics around reprognetics.

This coalition is in the early stages of development, with much yet to be determined. A core group of leaders and organizations is committed to building and sustaining it. To them, this vision of social justice organizations working together, joined by shared principles and advocating proactively for a collective policy agenda on reprognetics, is compelling. They are honest about the deal breakers and realize the amount of political goodwill needed to develop strategies to work through them. In many cases, they cannot even imagine what these shared principles might be, but they trust the process of working together, committed to a bigger vision, with strong incentives to work through differences. They acknowledge that they may not be able to resolve the core tensions between some movements, but they believe that through this process they can work together despite their differences. They want their social justice commitments and relationships on this issue to be defined by the areas on which they agree, not by their disagreements.

The demand for this national coalition was the impetus for the Gender, Justice and Human Genetics program of CGS to reformulate itself as Generations Ahead. This kind of coalition requires an organizational structure that initiates the process without predetermined policy positions. The CGS program has now morphed into a different kind of bridge organization. Instead of being a bridge between academic and scientific writings on reprognetics and social justice organizations, it will become an organizational bridge between movements. It is an organization that intentionally builds the capacity and resources for multiple social justice movements to work together in addressing reprognetics.

### **Conclusion**

Whether this new alliance across movements is viable is yet to be determined. Clearly the need for new alliances across movements is strong, but alliances like this don't just happen. Intellectual and practical work needs to be done, and is being done, to make it happen. This work consists of forging connections between leaders and organizations, developing frameworks that resonate in different movements, creating safe spaces for difficult dialogues between movements, and maintaining the support and resources needed to build and sustain new alliances.

However, the linchpin of this work is developing a set of guiding prin-

ciples and values related to just uses of reprogenetics. These principles and values will determine the kinds of policies developed and advocated for; they will capture the hopes and visions for the future and will establish the frameworks within which social justice and feminist organizations, leaders, and activists will work together. To develop these guiding principles requires building relationships and trust across movements, engaging in difficult conversations, and honestly acknowledging differences and working to resolve them. Perhaps, more than anything, this is the praxis of building new alliances: the practical work of bringing people together to work together. In the case of reprogenetics, while the challenges are clear, so too are emerging strategies for building the necessary new alliances for just uses of these technologies.

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