



# A REPRODUCTIVE JUSTICE ANALYSIS OF GENETIC TECHNOLOGIES

## REPORT ON A NATIONAL CONVENING OF WOMEN OF COLOR AND INDIGENOUS WOMEN

September 14-16, 2008 | Philadelphia, PA

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Convened by **Generations Ahead**. Co-sponsored by Asian Communities for Reproductive Justice, Black Women's Health Imperative, California Latinas for Reproductive Justice, Indigenous Peoples Council on Biocolonialism, National Asian Pacific American Women's Forum, National Latina Institute for Reproductive Health, and SisterSong Women of Color Reproductive Health Collective

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## ABOUT GENERATIONS AHEAD

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

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## EXECUTIVE SUMMARY

Reproductive and genetic technologies are critical social justice issues that can have lasting effects on how individual identity, family relations, and community connections are defined. Many reproductive genetic technologies offer enormous potential for treating infertility and allowing men and women, who in the past were not able to have biologically related children, to now do so with the use of these technologies.

At the same time, these very technologies can be used in ways that are potentially harmful to communities with the least amount of power and resources. Women of color reproductive rights and justice advocates and Indigenous peoples' rights advocates have expressed specific concerns about the relationships between genetic technologies and their communities. Core to their perspective has been identifying and naming the complex social forces and power relationships embedded in any decision to develop, use, or regulate genetic technologies.

To include the leadership and voices of those historically marginalized in reproductive health and rights debates, Generations Ahead convened a group of twenty-one women of color and Indigenous women leaders from across the U.S. for two days in September 2008. Given the many ways in which structural inequality and racism shape the reproductive decisions of all women, many advocates are concerned that women of color and Indigenous women will either be systematically excluded from the benefits of assisted reproductive technologies, or that these technologies might be used to “design” babies, further deepening racial bias against certain physical features. The

voices, values, and perspectives of women of color and Indigenous women are critical for a robust public debate. Their involvement can ensure that the many uses of genetic technologies benefit all women, their families, and communities, rather than cause harm or deepen existing social inequalities for some.

By the end of this two-day convening the participants generated a specific analysis and distinct set of values to guide the development and use of genetic and reproductive technologies. These values, emerging out of a discussion using a reproductive justice methodology, form the beginning of an alternative framework. This framework is based on notions of collective human dignity rather than the individual right to privacy and profit; the valuing of all human beings; respect for all types of families and all communities; and decision-making by those most impacted.

In addition, by using a reproductive justice framework, they identified important principles to help guide work in this area:

- Address underlying factors and root causes of social injustice.
- Include community involvement in solutions.
- Use a social justice and intersectional framework.
- Understand the role of oppression and power inequalities.

Taken together, the values and principles articulated at this meeting offer a radically different paradigm than the one currently shaping the development and use of genetic

The participants affirmed this list of values, values that are rooted in the history and culture of the participant's respective communities, in addition to being shared across groups:

- Place human beings, not profits, at the center.
- Believe that individuals, families, and communities are socially, culturally, and politically determined—not by biology, physical features, or genes.
- Advocate for impacted people and communities to be a part of the decision-making process.
- Prioritize the needs of the collective rather than the private needs of select individuals.
- Acknowledge the intersectionality of lived experience and the need for long-term solutions.
- Integrate a holistic approach that includes hearts, minds, and spirits.
- Recognize that we all live interdependently and are responsible for each other.

technologies, which is driven by profit, privatization, and individualism. The women at the convening addressed genetic technologies as an extension of existing social justice concerns and generated a compelling perspective that both argues for the importance of analyzing the impacts of these technologies from multiple, intersecting perspectives and emphasizes the need to analyze power dynamics and structural inequalities to ensure socially-just perspectives.

If genetic technologies are to be used to benefit rather than harm communities, the perspectives articulated here must be taken into account by researchers, policymakers, and

society as a whole. In a time when so many areas of life are dominated by a focus on genetics, the analysis put forward by women of color and Indigenous women offers a new framework that affirms interdependence and community well-being, not just individual benefits. The participants pointed to the kinds of principles and values they discussed during the convening as a possible foundation for proactive, inclusive policy work, as well as frame-shifting and message-reframing communications and campaign work.

Reproductive justice theory and methodology provide a critical framework within which to analyze the potential impacts of reproductive and genetic technologies on women of color, Indigenous women, young women and girls, economically vulnerable women, women with disabilities, lesbians, bisexual women, and transgender people. The potential benefits and risks lie at the intersection of multiple social and political forces. The reproductive justice movement fights for the rights of all women to decide to have children as well as not to have children, and to parent with dignity and respect. Reproductive and genetic technologies raise complex and difficult questions at a time when women have the potential to decide what type of children they want to have. Reproductive justice offers a vision of justice for all women in reproductive decision-making—justice that includes balancing individual desires with collective needs, human rights, and shared responsibility, and includes multiple stakeholders in the decision-making. The reproductive justice leaders at this event elaborated on that basic vision and extrapolated their perspective of justice into emerging uses of genetic technologies, providing clear guidelines and guideposts for future debate and decision-making for the movement.

## INTRODUCTION

Reproductive and genetic technologies are critical social justice issues that can have lasting effects on how individual identity, family relations, and community connections are defined. Many reproductive genetic technologies offer enormous potential for treating infertility and allowing men and women, who in the past were not able to have biologically related children, to now do so with the use of these technologies. And, at the same time, these very technologies can be used in ways that are potentially harmful to some groups of people, particularly communities with the least amount of power and resources.

Given the many ways in which structural inequality and racism shape the reproductive decisions of all women, many advocates are concerned either that women of color and Indigenous women will be systematically excluded from the benefits of assisted reproductive technologies, or that these technologies might be used to “design” babies, further deepening racial bias against certain physical features. The voices, values, and perspectives of women of color and Indigenous women are not only critical for a robust public debate, but also to ensure that the many uses of genetic technologies benefit all women, their families, and communities, without causing harm or deepening existing social inequalities for some.

To include the leadership and voices of those historically marginalized in reproductive health and rights debates, Generations Ahead convened a group of twenty-one women of color and Indigenous women leaders from across the U.S. for two days in September 2008. The convening was co-sponsored by seven reproductive rights and justice organizations including Asian Communities for Reproductive Justice, Black Women’s Health Imperative, California Latinas for Reproductive Justice, Indigenous Peoples Council on Biocolonialism, National Asian Pacific American Women’s Forum, National Latina Institute for Reproductive Health, and SisterSong Women of Color Reproductive Health Collective. Participants included advocates who focus on reproductive justice, reproductive

rights, racial justice, and/or Indigenous peoples’ rights. The majority of leaders in the reproductive justice movement were present, as well as four leaders in the Indigenous peoples’ rights movement.

This report documents the two-day reproductive justice discussion of genetic technologies by women of color and Indigenous women leaders. In this new millennium, when technologies are being offered faster than policymakers and the average citizen can keep up, this group of leaders began a discussion about the social and ethical implications of using these technologies from the perspective of affirming the value of all human beings, all types of families, and a diverse range of communities.

## NEED FOR THE CONVENING

In the four years that Generations Ahead<sup>1</sup> has worked with social justice and reproductive health, rights, and justice organizations, it found that women of color reproductive rights and justice advocates and Indigenous peoples’ rights advocates express unique concerns about the relationships between genetic technologies and their communities. Core to their perspective has been identifying and naming the complex social forces and power relationships embedded in any decision to develop, use, or regulate genetic technologies. In addition, they identified some specific concerns, including:

- Higher rates of infertility among women of color but less access to reproductive technologies.
- Government attempts to control the reproductive rights of women of color and Indigenous women.
- The potential for eugenic applications of the technologies to breed “better” babies.
- The impact of genetic research on Indigenous peoples’ cultural responsibilities and values.
- Concern about the impact of biotechnologies on whole communities—not just women—and consequences for future generations.

- The resurgence of scientific racism and accompanying “geneticization” of social and environmental problems.
- Targeted advertisements for sex selection in Asian immigrant communities.

In previous conversations with these women of color and Indigenous women leaders, they often spoke of the diversity of histories, experiences and perspectives among different women of color groups and between women of color and Indigenous women. These histories can lead to varying experiences with genetic technologies. The variations between groups—African American, Latina, Asian, and Indigenous—are further complicated by factors such as class, ability, sexual orientation, gender identity, age, geography, and immigration status. This convening was deliberately designed to provide participants with the opportunity to share these distinctive and diverse perspectives and learn about each other’s experiences.

In addition, Generations Ahead wanted to use a reproductive justice methodology and perspective to document a different approach to genetic technologies. This approach starts with the voices of those who have the potential to be the most adversely impacted by these technologies and with a perspective of historically less powerful groups. A traditional reproductive rights framework is grounded in a civil rights model and relies primarily on legal and legislative strategies. Reproductive justice, on the other hand, uses an intersectional analysis that recognizes the multiple factors that impacts people’s lives. It contextualizes reproductive choices and decisions by including the intersecting economic, social, and political forces that shape the lives of women, their families, and

their communities. In contrast to the traditional strategies used by the reproductive rights movement, reproductive justice organizing centralizes the voices and concerns of marginalized communities, particularly women of color and low-income women. Reproductive justice organizing goes beyond securing abortion rights, to advocating for a more comprehensive agenda. By intentionally grounding the event in a reproductive justice framework, we expected that the discussion would be based in an inclusive intersectional analysis, thus leading to conclusions and strategies distinct from the individual rights-based perspective, which is dominant in the reproductive rights movement.

By the end of this convening the participants generated a specific analysis and distinct set of values to guide the development and use of genetic and reproductive technologies. These values form the beginning of an alternative framework, a framework based on notions of collective human dignity rather than the individual right to privacy and profit; the valuing of all human beings; respect for all types of families and all communities; and decision making by those most impacted.

Section 1 of the report articulates the unique impact genetic technologies have on different communities, and the particular perspective each group brings to an analysis of the technologies. Section 2 documents some of the discussion about specific technologies through the analysis of five case studies. Section 3 documents the group’s recommendations for next steps, and Section 4 gives a concrete example of how this work of identifying shared values and principles was translated into concrete policy advocacy. Section 5 includes a conclusion to the report, and Section 6 lists the participants and their organizations.

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1. Founded in 2008, Generations Ahead operated from 2004-2007 as the Gender, Justice and Human Genetics Program of the Center of Genetics and Society, also in Oakland, California



## GENETIC TECHNOLOGIES IN DIFFERENT COMMUNITIES

To identify and acknowledge the different ways in which genetic technologies benefit and raise concerns in different communities, participants were asked to divide themselves into constituency-specific affinity groups to identify the perspectives of each group at the beginning of the convening. They divided into five affinity groups: Asian women, Latinas in the US, Indigenous women, women of African descent, and women with disabilities.

### INDIGENOUS WOMEN

While most of the participants were somewhat aware of the affects of genetic technologies on Asians, Latinas, and African American women, few knew anything about Indigenous peoples and genetic technologies. The only formal presentation at the convening was on the relationship between Indigenous peoples and biotechnologies, which was new to most of the women of color in the room.

The Indigenous women in the affinity group explained three terms that define the relationship of Indigenous peoples to genetic technologies: biocolonialism is a new form of colonization impacting Indigenous peoples that imposes foreign belief and legal systems and attempts to claim ownership over biological and genetic material; bioprospecting is the search for potentially profitable or useful genetic resources, including human, plant, animal, microorganisms, and associated traditional knowledge; and biopiracy is the theft of genetic resources and associated

traditional knowledge. The Indigenous women described experiences of exploitative and/or unethical research on Indigenous peoples in the areas of medical, behavioral, and anthropological genetics. Through these various examples, they identified the following common problems:

- The assumption of open access to Indigenous communities by researchers.
- Top-down and outside-in approaches to research in Indigenous communities, rather than working with Indigenous communities and leaders on community research priorities.
- Indigenous peoples bearing the risks but rarely, if ever, having access to the benefits of the research.
- Researchers making false promises of economic and non-economic benefit sharing with Indigenous communities.
- Lack of informed consent, particularly consent from tribal leaders for research done within the community.
- Widespread secondary uses of samples without additional consent.
- Unwillingness by researchers to repatriate misappropriated genetic material.

Based on these experiences, this affinity group explained that they had more concerns than confidence in the benefits of genetic technologies. They declared that the

scientific framework underpinning the development of these technologies is based on an “ideology of progress,” and undermines Indigenous peoples’ self-determination and sovereignty. The move toward industrializing childbirth and women’s reproduction fails to recognize women as the “first environment” and amounts to manipulating the natural process of reproduction. The group asserted that genes are not the cause of problems, and therefore, genetics is not the solution.

These Indigenous women stated that the full affects of genetic and reproductive technologies are unknown and therefore need further discussion among Indigenous peoples. They pointed to the technologies as intentional genocidal practices, undermining of tribal sovereignty, manipulating life, and affirming ownership of sacred property. They shared how scientific knowledge rejects and denies the existence of many other ways of knowing, including Indigenous creation histories and tribal stories of belonging and migration. Genetic ancestry testing can also be used to undermine tribal rights to determine community membership and sovereignty for Indigenous Nations by shifting to a biological/genetic definition of citizenship/membership rather than a social, political and cultural definition of community. They felt that the ideological framework and many uses of genetic technologies are counter to their long-held traditions.

Within their framework for addressing biocolonialism, Indigenous peoples have a comprehensive approach that does not distinguish between human and non-human (plant or animal) genetic technologies. Their cultural perspective is based on the following perspectives:

- Sacredness of the body and body parts
- Respect for life force

- Guardianship of community and the environment
- Sacredness of the ancestors
- Responsibility to future generations

Some of the unique perspectives that they shared, in their voices, include:

- “We have our own medicines, practices, and ceremonies regarding reproduction. These have always been there, and we’ve always used them. The new ways are counter to what we’ve done.

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**The scientific framework underpinning the development of these technologies is based on an “ideology of progress,” and undermines Indigenous peoples’ self-determination and sovereignty.**

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- “We are a cultural, social, spiritual, and political group, and this makes us different from the groups of women of color at the convening. Indigenous people are considered nations within a nation (in the US). This is based on a

colonial past.

- “Our rights are collective rights protected in international and national law. Our responsibilities are to the collective; we operate as a collective, and not as individuals who can make decisions for the whole group.
- “Biocolonialism is part of the ongoing colonization that is happening to all Indigenous people.”

The Indigenous women articulated a comprehensive perspective on community and the connection between plant, animal, and land, with stewardship and respect for all life as core values. The recognition of and respect for Indigenous peoples’ culturally based values, worldview, cultural responsibilities, and customary laws were identified as critical to their perspective on these technologies. The principle of the “Seventh Generation,” which teaches that one must take into consideration the impact of every decision and action on the seventh generation yet to come,



was identified as a guiding principle in decision making related to research, development, and utilization of genetic technologies.

## ASIAN WOMEN

Keenly aware of the high cultural value placed on children and family, the group stated that many Asian women often feel pressured to use genetic technologies to have children or certain types of children, primarily sons. While these technologies are sometimes seen as an answer to the pressures of having to bear children, there is, at the same time, shame about having to use fertility treatment as the way to do so. Furthermore, the technologies are not socioeconomically

accessible to all women, an important consideration for this group. They described the ways in which access is constrained by language, culture, ethnicity, immigration status, and economics. In addition, they discussed the ways in

which the market for eggs from Asian donors also places them on the “supply side” of the spectrum in troubling ways.

The group highlighted concerns about the ways in which availability of genetic technologies not only allows but also can promote sex selection. They noted the disproportionate marketing of pre-pregnancy sex selection techniques to Asian communities and in Asian community media. They shared concern about the potential for selection of traits in the future, such as intelligence, and the impact this might have on Asian communities where intelligence is highly prized.

The group recognized international linkages, such as buying and selling reproductive services across country borders, (surrogacy, reproductive tourism, etc.) and the ways in which cultural norms, such as son preference in home countries, can be carried over to the United States.

Finally, the group explained that a respect for science in many Asian communities means that science is often not questioned.

Some of the unique perspectives that they shared, in their words:

- “‘Model minority’ stereotype of Asians can put pressure on women to ‘have it all,’ including a career and family.
- “Strong connections to home countries reinforce cultural values that disadvantage women and girls.
- “Asians are often more accustomed to prioritizing family and community needs in the face of individual

needs and rights, which can lead to acceptance of a broader perspective on genetic technologies, or more problematic policies like population control policies and the ‘one-child’ policy in China.”

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**‘Model minority’ stereotypes  
of Asians can put pressure on  
women to ‘have it all,’  
including a career and family.**

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These Asian women highlighted the diversity of perspectives and approaches to health in Asian communities, and suggested that traditional approaches to health and health care should be included in this discussion. They identified a need for disaggregating health data rather than lumping different ethnic communities together. And they discussed the importance of valuing differences in linguistic and cultural practices in health and wellness, along with being mindful of transnational connections and the ways in which cultural practices and values can travel globally.

## WOMEN OF AFRICAN DESCENT

These African American women decided to identify their group as women of African descent in recognition of the diasporic and mixed race experiences of Blacks in the United States. They expressed concern about the potential



for increased commodification and exploitation of Black women's bodies, given the long history of slavery and eugenics in the United States. They pointed to trends towards genetic determinism where families, intelligence, and inherent value could be based on one's genetics, not on one's humanity. The group explained that the technologies create an environment that equates parenthood with biology and challenges Black women's notions of family and community. The group emphasized that addressing the high rate of infertility among Black women means focusing on the causes of infertility, rather than an emphasis solely on access to the technologies to address or "fix" the environmental causes of infertility.

Some of the unique perspectives that they shared, in their words:

- "It takes a village' strategy places value on child rearing beyond biological connections (godchildren, extended family, grandparents, etc.)."
- "Connections to family, community and nation are more important than seeing oneself individually."
- "We have a healthy critique of these technologies based on our historical mistrust of the medical establishment and science."

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**They valued inclusiveness, a commitment to social and structural transformation, and gender equity in addressing concerns raised by genetic technologies.**

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- "We acknowledge linkages to other racial and ethnic groups: there is a feeling of community and inclusivity."
- "The current collection of DNA for criminal purposes is expressly linked to stereotypes of Black people as criminals (e.g. search for a "criminal gene")."

- "As Black people living in the U.S., we are less connected to land: if there were Africans here in the convening, they might place more of an emphasis on geography."

Women of African descent highlighted the importance of the value of mutual responsibility, and that individuals, families, and communities should be in a relationship of mutual responsibility. They valued inclusiveness, a commitment to social and structural transformation, and gender equity in addressing concerns raised by genetic technologies.

## WOMEN WITH DISABILITIES

Women with disabilities started by highlighting the historical abuses of women with disabilities, including coerced sterilization. They explained how the medical model<sup>2</sup> of disability supports a eugenic outlook, and that the increase in genetic testing could lead to more and more people being defined as disabled, accompanied by a

2. In the medical model, disability is seen as an individual medical problem that needs to be "fixed." In the social model of disability, the problem isn't the disability but rather negative social attitudes towards disability and the lack of accessible built environments for people with disabilities.

mentality of “personal responsibility,” which places the responsibility of living with disability on individuals absent any state or community responsibility. They identified the perspective of the (not possible) “extinction” of disability as a viewpoint that could encourage declining support for services and resources for people with disabilities, while further devaluing those with disabilities. The “benefits” of the technologies are based in a paternalistic paradigm that assumes people with disabilities need to be helped, and considers certain lives to be expendable.

They connected disability oppression with queer oppression in two ways: the normalization of non-disabled and heterosexual people, and the fact that both disability and queer communities are discouraged from reproducing. They observed a critical need to carefully examine the oppressive language around disability that is used when talking about genetic technologies (e.g., abnormality, fetal anomaly, and birth defects). And they reiterated the point made by several other groups, that with these technologies attention shifts to the biological roots of what are really social problems and conditions.

Some of the unique perspectives that they shared, in their words:

- “Because many in our community depend on (health care) technology for survival, we hold both contradictions and complexities in our analysis. We can embrace the good in technology without the oppression and ensure that the technology is helpful.
- “It is hard for people with disabilities, who are political, to be part of the pro-choice and reproductive health community because of the controversial nature of abortion following genetic testing.
- “We bring a social critique of ableist systems, including a call for alternate institutions and models of support.

- “We recognize that everyone has to confront disability at some time in their lives.”

The women with disabilities emphasized the importance of critiquing systematic oppression, rather than individuals, and the importance of using a social model of disability. They affirmed the leadership of people with disabilities in these discussions as providing a critically need perspective and voice. And they recommended using a justice framework that integrates an ableist analysis to ensure the valuing of all bodies.

## LATINAS LIVING IN THE U.S.

These Latinas spoke about the need to examine their complex relationship to notions of fertility, particularly the myth of the hyper-fertile Latina woman, the lack of information and research about who uses assisted reproductive technologies in the Latino community, and how that intersects with class and immigration privilege. They shared anecdotal stories of Latinas who came to the U.S. to be surrogates for other families and were then able to obtain a green card, illustrating an intersection

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...with these technologies, attention shifts to the biological roots of what are really social problems and conditions

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between the technologies and immigration. The group discussion focused primarily on how much was still unknown about Latinas’ use of these technologies. They identified a strong need for more research to find out how women in their communities feel about fertility, assisted reproduction and genetic testing.

Even while they highlighted many values shared by other groups—including the importance of family, parenting, spirituality, and community—the Latinas mostly felt that this was just the beginning of this conversation for their community. They wanted a deeper conversation about fertility and family, and wanted that conversation to be more grounded in research and current data about community attitudes and uses of reproductive and genetic

Together, all the participants affirmed this list of values, values rooted in the history and culture of their respective communities, in addition to being shared across groups:

- Place human beings, not profits, at the center of these discussions and policies.
- Believe that individuals, families, and communities are socially, culturally, and politically determined—not by biology, physical features, or genes.
- Advocate for impacted people and communities to be a part of the decision-making process.
- Direct resources toward social and economic causes of inequality rather than emphasizing genetic and technical solutions.
- Use social justice values and principles as the foundation of policy work rather than individualism and commercialization.
- Acknowledge the intersectionality of lived experience and the need for long-term solutions.
- Integrate a holistic approach that includes hearts, minds, and spirits.

technologies. This group did not specifically share comments about their unique perspective with the other groups; their conversation focused primarily on the need for further research.

## IDENTIFYING SHARED VALUES AND PERSPECTIVES

Each affinity group identified specific values and perspectives that the group collectively affirmed as forming a nuanced and comprehensive picture of what is at stake for women of color and Indigenous women. Through further discussions, the whole group then worked to clarify an inclusive list of shared values across affinity groups. These shared values included an important valuing of interdependence and intersectionality with an intentional focus on community, rather than just the individual. All agreed that family was vital, even as they stated that family was not to be defined by genetics alone, but rather, by shared lived experiences.

In addition, both the Asian women and women with disabilities affinity groups affirmed a holistic approach to understanding bodies and wellness—beyond a Western medical model. The Latinas and women with disabilities also articulated the importance of spirituality as central to their perspectives.

No attempt was made to come to a consensus on the list of shared values. Rather, it was understood to be a preliminary and inclusive list for this group, although by no means exhaustive. There was a strong request for additional

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**Genetic technologies will affect different groups in different ways: economically, socially, politically, and culturally.**

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discussions and clarifications, since not everybody understood the values and principles in the same way. The participants recognized that not all values were equally important to everybody. The intent was to develop and offer an alternative set of values to the currently predominant ones of commercialization, privatization, exploitation, anti-disease, and anti-aging, mixed in with a strong belief that science and technology are not ideological but objective.

Overall, the participants agreed that the potential harms posed by these technologies are too critical to be ignored, and if society is to develop truly inclusive policies and practices for the uses of genetic technologies, all of these different perspectives need to be included in the deliberation and decision-making. Genetic technologies will affect different groups in different ways: economically, socially, politically, and culturally. As technologies are researched and used, and as policy is developed, not only must the perspectives articulated here be included, but the differences between communities must also be taken into consideration. Otherwise, policies will be established that disadvantage some groups, run counter to deeply held cultural values, or reflect only a narrow worldview.



## SPECIFIC USES OF GENETIC TECHNOLOGIES

In order to deepen their analysis and refine their perspectives, participants discussed a wide range of genetic technologies. This included assisted reproduction, prenatal genetic testing, race-specific medicine, and DNA collection for research and for criminal investigations. They discussed real-life case studies of these technologies and related trends like reproductive tourism (traveling to other countries for fertility treatment or to hire surrogates or egg donors) and genetic determinism (genes as explanation for a variety of conditions, identities, or human variation) to parse out the specific concerns that women of color and Indigenous women might have.

In small groups they examined the ethical and social questions raised in different situations and the particular implications for women of color and/or Indigenous women, families and communities in five case studies. In each case study, the participants identified critical concerns to include in any decision-making and made recommendations for how to approach addressing the complex issues presented. Each group used a reproductive justice framework in their discussion and analysis, a framework that allowed them to highlight the contextual nature of the analysis and the intersecting social and political forces at play. By using reproductive justice as a tool for deeper understanding, they were able to place women of color and Indigenous women – along with their families and communities – at the center of the analysis, rather than as an afterthought.

What follows is a brief description of each case study and the recommendations, concerns and comments that were

noted in each of the small group discussions.

**Prenatal testing:** Expanded medical recommendation that all pregnant women be offered screening for Down syndrome with a recognition that possibly up to 90% of women who receive a positive result choose to terminate the pregnancy.

- In using a social rather than biological or medical approach to this issue, attention must be paid to ensure that all women have the resources to make the best decision for themselves and their families. This includes creating the social and economic conditions to support women's decisions, whether they choose to abort or carry the pregnancy to term.
- Respect and appreciate the diversity of all life by rejecting the politics of appearance that reinforce negative attitudes towards people with disabilities.
- Use a justice framework with an intersectional analysis that understands the contexts in which women are making choices rather than an individual choice framework. Promote communal responsibility rather than placing an onus on individual women and families.

**Reproductive tourism: hiring surrogates in India:** Americans and Europeans hire surrogates in India for a fraction of what it would cost in their home countries.

- Find real solutions to poverty: most Indian surrogates have limited options and surrogacy is not a solution to poverty.

- Protect human rights: surrogacy can create a system of servitude based on the idea that one can purchase a womb. These women can be seen as commodities and intensely monitored in this arrangement for another's benefit.

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**...most Indian surrogates have limited options and surrogacy is not a solution to poverty.**

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- Ensure reproductive autonomy: how do we distinguish between informed consent and coercion based on financial need and poverty. Are these women exercising their rights or being exploited?
- Ensure access to health care and social protections against stigmatization for being a surrogate.
- Pay attention to long-term health consequences.
- Recognize the imbalance of money and power: these Indian women are paid less than those who are providing the same service in the US.

**Genetic determinism: African American women and breast cancer:** The high rates of mortality among African American women with breast cancer even though they have lower incidence of the disease.

- Assess the real benefits of genetic research for marginalized communities by examining the links between environmental toxins and cancer, and the way toxins can cause biological changes in genes that are then explained only as genetic conditions.

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**Those most impacted must be involved in the process, strategy and solutions.**

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- Articulate immediate versus long-term needs and solutions to address health disparities in communities of color and Indigenous communities.
- Those most impacted must be involved in the process, strategy and solutions.

- Build alliances with environmental health and justice movements locally and nationally.
- The attention to genetics perpetuates the notion that race is biological destiny and an individual's own burden.
- More data and resources are needed to address other theories that explain health disparities other than genetics.

**DNA collection for research: The Genographic Project:**

National Geographic Society's project to collect DNA samples from 100,000 Indigenous people around the world to study ancient human migration. This group identified the following concerns with this project and advocated a boycott of the Genographic Project.

- The project undermines Indigenous peoples' cultural, social and political approach to identity, community, and origins. It promotes the non-Indigenous collection and ownership of oral histories related to creation stories, migration, family histories, and languages.
- It treats Indigenous people, their genes and their ancestral remains as historic artifacts to be collected on genetic "safaris" in the name of honoring them.
- The project was created without community input and buy-in.
- It reinforces corporatization and privatization of genetic research.

**DNA collection for forensics:** The use of DNA dragnets in solving crime.

- Dragnets involve coercive pressures that promote fear, violate privacy, and diminish informed consent.
- Articulate an analysis of violence that recognizes the complexity of underlying social and political factors and the intersections of race, class, gender, immigration, and sexuality.
- Promote means to address violence grounded in a social justice framework, including community involvement and solutions to violence.

## SIGNIFICANCE OF THE CASE STUDIES

The small group discussions on these five topics illuminated the intersections between genetic technologies and a variety of pressing issues: disability oppression; globalization, commodification and exploitation; scientific racism and environmental justice; biocolonialism; and criminal justice and racial profiling. While some technologies or practices directly affect only one community, their implications can be far-reaching. Biocolonialism opens the door to genetic exploitation of communities of color, such as the creation of DNA databases through ancestry testing. Allocating research dollars to determine the genetic link to breast cancer among African American women diverts resources away from addressing environmental impacts on all low-income communities of color who are most impacted by exposure to toxins. Outsourcing surrogacy to women in India may normalize the exploitation of women of color for reproductive services. Clear agreement emerged through these discussions that understanding the relationship of the use of genetic technologies to discrimination and inequality is critical for developing a progressive social and political agenda.

In the case study exercise, some principles in common emerged across multiple groups, whether in relation to prenatal testing, reproductive tourism, genetic determinism, or DNA collection. These principles that can be more broadly applied to addressing concerns raised by other genetic technologies issues, including:

- Address underlying factors and root causes of social injustice.
- Include community involvement in solutions.
- Use a social justice and intersectional framework.
- Understand the role of oppression and power inequalities.

Taken together, the values and principles articulated in the small groups and the affinity groups offer a radically different paradigm than the one currently shaping the

development and use of genetic technologies, which is driven by profit, privatization, and individualism. The women at the convening addressed genetic technologies as an extension of existing social justice concerns. They generated a compelling perspective that argues for the importance of analyzing the impacts of these technologies from multiple, intersecting perspectives and that emphasizes the need to analyze power dynamics and structural inequalities to ensure socially-just perspectives.

If genetic technologies are to be used to benefit rather than harm communities, the perspectives articulated here must be taken into account by researchers, policymakers, advocates, and society as a whole. In a time when so many areas of life are dominated by a focus on genetics, the analysis put forward by women of color and Indigenous women offers a new framework that affirms interdependence and community well-being, not just individual benefits.

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**The women at the convening addressed genetic technologies as an extension of existing social justice concerns.**

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## NEXT STEPS

The women at this convening identified several next steps for advancing a women-of-color and Indigenous-women's reproductive justice approach to genetic technologies, including community-based educational tools, more research in these communities, and more cross-movement dialogues on cross-cutting issues.

Community-based education on these issues was identified several times as a much-needed next step for community groups. Most of the leaders felt they lacked the knowledge, resources and time to develop the kinds of popular education tools that they could take to their grassroots membership. And until their members started identifying genetic technologies as a high priority issue, most of these organizations would not be able to engage more robustly in the public debates and policy-making. They asked for public education materials related to ancestry testing, DNA forensics, reproductive technologies and fertility/infertility in culturally specific context for Latinas, Asian Pacific Islander and African American women.

Several participants stated that they needed to see more research on these issues for their communities to deepen their own knowledge on these issues. Participants wanted more information about comparative policies in other countries, international standards, and opposition research

on the Right with regards to genetic technologies. They also wanted more community-based research that included qualitative and quantitative questions about knowledge, beliefs, attitudes, and usage rates of genetic technologies in different communities.

Given the way this convening was set up to both identify specific community perspectives and shared values, many participants expressed a strong interest in intersectional

and cross-movement discussions and dialogues, particularly dialogue within the reproductive rights and justice movements on abortion as it relates to reproductive genetic technologies. Participants also thought that deeper

conversations with the LGBTQ movement, environmental justice, and Indigenous people's rights movement would be helpful.

Ultimately the participants highlighted the importance of using a reproductive justice and movement-building approach in policy advocacy and messaging. They reiterated the value of utilizing pro-active (as opposed to reactive or defensive) strategies to reshape any debate on abortion and reproductive genetic technologies. They pointed again to the kinds of principles and values they discussed during the convening as a possible foundation for proactive, inclusive, frame-shifting, and message-reframing work.

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## APPLICATION OF ANALYSIS AND STRATEGY: POLICY AND MOVEMENT-BUILDING RESPONSE TO FEDERAL LEGISLATION

Congressional Representative Trent Franks (R-AZ) introduced a bill that would ban abortions for sex selection and what he termed “race selection.”<sup>3</sup> The language of the bill and accompanying press conference required a rapid response. At the convening, the group had discussed this bill, recognizing it as a strategy to limit access to abortion and limit some (Asian and African American) women’s decision-making

authority about their reproductive health. They saw it as an attempt to divide communities and be a wedge between like-minded groups—including feminist, pro-choice, Asian, and Black communities. The bill targeted Asian women without naming them, using language about son preference “within certain segments of the United States population, primarily those segments tracing their ethnic or cultural origins to countries where sex-selection abortion is prevalent.”

When the bill was introduced one week after the convening, Generations Ahead, SisterSong, and the National Asian Pacific American Women’s Forum (NAPAWF) reached out to other movement leaders in reproductive rights and justice, domestic violence, racial justice, and Asian communities to host a conference call and form an alliance to craft a different kind of message to respond to this bill. Using the kind of contextual and intersectional analysis that they refined at the convening, allies on the conference call highlighted the double standard embedded in the issue of sex selection in the United States. While Asian Diaspora communities are

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condemned for practicing sex selection, non-Asian individuals and couples using sex selection for “family balancing” or “gender variety” are free from this judgment. They discussed the underlying factors of sexism, son preference, and reproductive autonomy, and actively engaged South Asian and Asian domestic violence prevention leaders in the discussion.

Rather than respond with a traditional defense of abortion as an individual choice premised on privacy, the group wrote an opposition letter to Congress incorporating the values and principles that had been identified earlier at the convening of women of color and Indigenous

women on genetic technologies. They reiterated a commitment to social justice and intersectionality, and pivoted to a call for a deeper commitment to racial and gender equality in this situation with a focus on eliminating health disparities without limiting access to abortion. Instead of leading with a message of individualized decision-making devoid of a broader, complex lived reality, they called for a more community oriented and community led solution. The group made a commitment that women of color leaders (particularly from the Asian and South Asian anti-violence movement) would be the most visible spokespeople and messengers. Mainstream reproductive rights groups made a strategic decision to support the leadership and messaging of this organized group of women of color leaders who approached this issue with clear values and principles to guide the discussion, response, and messaging.

3. Representative Franks claimed that the high rate of abortions among African American women amounts to “race selection,” disregarding the root causes leading to unintended pregnancies and disparities in abortion rates.

The growing awareness of shared commitments identified at the Generations Ahead convening was the starting point for a longer discussion to develop deeper strategies to reach out to other movements, including disability rights and LGBTQ rights, and create an advocacy plan that includes more community participation. Their goal was not simply to defeat this legislation, but to use it as a movement-building opportunity led by those who would be most impacted by the bill.

Based on the leadership of women of color that was affirmed at the convening, Generations Ahead, SisterSong, and NAPAWF held a day-long strategy meeting on December 8, 2008, with reproductive rights and justice organizations and South Asian domestic violence prevention organizations to build awareness and organize

momentum on this issue. Twenty-seven organizational leaders came together to deepen their understanding of the complexities of sex selection and contextualize “race” selective abortions. This meeting was an important gathering of both mainstream reproductive rights organizations, such as the Center for Reproductive Rights, American Civil Liberties Union, Planned Parenthood, and leading reproductive justice organizations like National Latina Institute for Reproductive Health and the Black Women’s Health Imperative. Workgroups formed at this meeting are continuing to work in several areas, including development of a legislative packet educating Congressional leadership on issues of sex selection and the way this particular bill seeks to drive a wedge between Asian and African American groups and reproductive rights groups.

## CONCLUSION

Several important successes emerged from this convening of women of color and Indigenous women addressing genetic technologies. Now more than twenty organizations appreciate the benefits and dangers of emerging genetic technologies. They have a political framework in which to locate and analyze the issues, which no longer appear as a concern of only affluent white women seeking fertility services. Based on the values and principles they identified, they are better equipped to engage in public debates and respond to policy proposals, in ways that are in alignment with their core values and strategies.

In addition, they are now part of a network of allied organizations and leaders shaping a social justice response to these issues, and have had a successful experience putting their learning into action with the proposed sex selection and “race selection” abortion ban. While genetic technology is still not at the top of the priority list for their organizations, they are now prepared and able to engage when necessary. They will be seen as the early leaders on this issue, potentially shaping future debates and policy advocacy.

## AN ALTERNATIVE PARADIGM

Generations Ahead believes that genetic technologies will affect different communities in different ways, shadowing the multiple and complex ways in which science and technology have benefited some and disadvantaged others. The primary strategy has been to position the issues of genetic technologies as an extension of existing social justice concerns—to find a way to manage the benefits and risks of genetic technologies responsibly, protect human rights, and ensure just uses for all women and all communities. This will require that the work is informed by the alternative paradigms that communities have been fighting for, as articulated by the women at the convening:

- Place human beings, not profits, at the center.
- Believe that individuals, families, and communities are socially, culturally, and politically determined—not by our biologies, physical features, or genes.
- Advocate for impacted people and communities to be a part of the decision-making process.
- Prioritize the needs of the collective rather than the

private needs of select individuals.

- Acknowledge the intersectionality of lived experience and the need for long-term solutions.
- Integrate a holistic approach that includes hearts, minds and spirits.
- Recognize that we all live interdependently and are responsible for each other.

In addition, these leaders identified important principles to guide work in this area:

- Address underlying factors and root causes of social injustice.
- Include community involvement in solutions.
- Use a social justice and intersectional framework.
- Understand the role of oppression and power inequalities.

While this inclusive paradigm and these values and principles are not new, in relationship to genetic technologies they needed to be collectively identified and historically documented. The marvels of genetic science and the new world of possibilities suggest that we need new ideas, theories or paradigms to understand and govern them. However, as this gathering and discussion demonstrates, it is more likely that we need to remind ourselves of our historically held values. These values and principles orient us towards unity, collaboration, mutual responsibility, shared purpose, and for the prioritization of human beings, in all our diversity, over profits. These women envision a world in which those impacted have a

seat at the decision-making table, and in which policies governing responsible uses of genetic technologies integrate a complex and interdependent understanding of social life.

Reproductive justice theory and methodology provide a critical framework within which to analyze the potential impacts of reproductive and genetic technologies on women of color, Indigenous women, young women and girls, economically vulnerable women, women with disabilities, lesbians, bisexual women, and transgender people. The potential benefits and risks lie at the

intersection of multiple social and political forces. The reproductive justice movement fights for the rights of all women to decide to have children as well as not to have children, and to parent with dignity and respect. Reproductive and genetic technologies raise complex and difficult

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questions at a time when women have the potential to decide what type of children they want to have. Reproductive justice offers a vision of justice for all women in reproductive decision-making—justice that includes balancing individual desires with collective needs, human rights and shared responsibility, and including multiple stakeholders in the decision-making. The reproductive justice leaders at this event elaborated on that basic vision and extrapolated their perspective of justice into emerging uses of genetic technologies, providing clear guidelines and guideposts for future debate and decision-making for the movement.



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