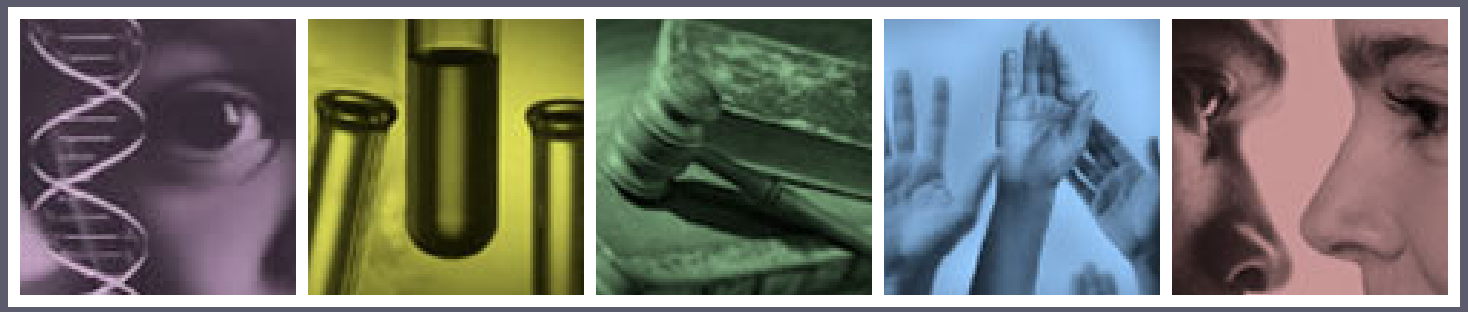
Building Movements: Disability, Race, Gender, Sexuality and Genetic Technologies



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Conference on Representing Disability:
Theory, Policy, Practice
Haverford College
November 9-11, 2006

Center for Genetics & Society

- "working to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies"
- Gender, Justice and Human Genetics
  - Reproductive Health and Human Rights
  - Race, Disability and Eugenics -- Patricia Berne
- Biotechnology in the Public Interest
  - Stem Cells in California
  - Stem Cells Nationally
- Not a Disability Rights organization

Our Work

- Reframe the Stem Cell Debate
  - Media & communications
  - Policy recommendations
- Social justice organizations & leaders
  - Outreach and education
  - Build their capacity and understanding to integrate & engage
  - Multi-movement engagement

Outline

- Broaden the questions
- Make the connections -- issues & technologies
- Strategies
- Lessons from our work

Questions

What are the implications of genetic testing for people with disabilities?

How can debates about the human genome project and about new technologies such as the cochlear implant more effectively incorporate the perspectives of those with disabilities?

Broader Questions

- What are the implications of genetic testing for people with disabilities, poor people, women, people of color and LGBTQ folks?
- How can debates about the human genome project and the new reproductive & genetic technologies more effectively incorporate the perspectives of people with disabilities, poor people, women, people of color and LGBTQ folks?
- How do we ensure that the debates about new genetic technologies take into account social justice principles of equity, diversity, democracy and human rights?

Reframe & Make Connections

- Disability as a social justice concerns inequality and eugenics (family eugenics, techno-eugenics, market-based eugenics)
- Disability & race – the geneticization of race & difference linked to the medical model
- Disability and reproductive health/rights – impact on and coercion of women
- Disability and Queerness –non-conforming gender and bodies

Technologies as social justice concerns

- genetic screening & de-selection - sex selection
- pre-implantation genetic diagnosis
- stem cells research & cures
- reproductive cloning
- human genetic engineering (inheritable and non-inheritable genetic modification)

Strategies

- Advisory Group
- Cross-movement conversations
- Multi-movement conversations

Disability Advisory Group

- What relationship does this sector want to have to these technologies? Nuanced positions
- Internal organizing & relationships – Moving forward as a disability rights movement
- What are the points of agreement/disagreement with patients' rights advocates?
- What analysis and contribution can disability rights make to social justice movements? Learn from the successes of ADA, living wage, coalition work

Cross-movement Conversations

- Never alone and all important: always disability AND race, gender, class, sexual orientation
- Disability always at the table of any discussion
- Understanding, not agreement
- Roundtable Discussions
  - Pre-implantation genetic diagnosis
  - Privacy and “choice”
  - Eugenics

Multi-movement Conversations

- Retreat at Asilomar
  - Reproductive Rights, Racial Justice, Economic Justice, Civil Rights, Disability, Queer Rights
  - Relationship Building
  - Safe spaces for complex & hard conversations
  - Personal Caucuses
  - Organizational Caucuses
  - Deal Breakers

Personal Caucuses

- Black Women
- Indigenous Women
- Women with Disabilities
- Queer Women
- “Socially Infertile”
- Concerns for Future Generations

Organizational Caucuses

- Reproductive Rights
- Civil Rights/Progressive Politics
- Environmental Justice
- Disability Rights
- Health Service Providers
- Human Rights
- Queer Rights
- Health Disparities

Deal Breakers

- Restrict abortion, post-implantation choice
- Restrict access to family formation technology
- “You can’t be a parent/have a family”
- Ban on any technologies -- bad guys ban, we don’t
- Precautionary principle
- Restrictions without sufficient/compelling scientific data
- Framed only as a medical model of disability
- Elevate the moral status of the embryo
- Jeopardize choice and autonomy for women

Outcomes

- All together, face-to-face completely changed the discussion
- Not abstract, but real conversation and debate
- Automatic shift from medical to social model
- Required listening and changing perspectives

- Commitment to Coalitional work to set the social justice agenda on Assisted Reproductive & Genetic Technologies

Lessons from the Field

- Make the social justice connections concretely in practice, not abstractly
- Build relationships, be in the room and at the table
- Create safe spaces to have the difficult conversations
- Make common cause – take on each other's issues
- Commit to working together