

CONF-9605357--SUMM.

Disability Rights in Dialogue with Clinical Genetics
Conference, May 31 to June 2, 1996

This report describes the goals and objectives, as well as the process, outcomes and plans for follow-up to the DOE/NIH ELSI funded conference entitled "Disability Rights in Dialogue with Clinical Genetics," which occurred May 31, through June 2, 1996 at the Rehabilitation Institute of Chicago.

Introduction to the Issues

The issue of prenatal diagnosis and selective abortion has been hotly debated in the medical, genetic counseling, feminist, parents, disability rights and bio-ethics literature, each of the various positions critiquing each other. People from the disability rights community in particular have begun to articulate a critical view of the practice of widespread prenatal diagnosis with intent to abort because the pregnancy might result in a child with a disability.

Unfortunately, people from the various disciplines and perspectives, such as bioethics, disability rights, feminism and so forth, by and large, have tended only to write for themselves and their colleagues. Few people have crossed disciplines try to talk to people with other views. The rapid advances of genome research have continued to produce new prenatal tests, raising many complex ethical questions regarding the applications of prenatal testing. But the widely disparate positions of the various factions has made it difficult to move toward formulation of public policy change necessary to encompass these new genetic technologies. Genetic counseling is in the front lines of the controversial social and ethical issues arising from prenatal diagnosis, in its interface between medical science and the consumer of services.

Initial Goals and Objectives

The primary intent of the conference was to invite and facilitate productive dialogue between individuals and groups of people who have traditionally not interacted as a result of their disparate views on these issues and to learn from this process, emphasizing the involvement of people with disabilities and people who work in clinical genetics.

In our initial proposal, we tentatively titled the conference "Seeking Common Ground: A Forum for People with Disabilities and Genetic Professionals." The proposed workshop was to be an educational forum for members of the disability community to meet together with genetic professionals and other key interested individuals, to discuss issues of mutual concern. These issues (and proposed sessions) could include:

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- civil liberties issues such as privacy and confidentiality, specifically as they affect individuals and families affected by a disabling genetic condition,
- programmatic and attitudinal accessibility of genetic services for disabled consumers,
- disability awareness training for genetic professionals, and the inclusion of disability issues (psycho-social, legal, and political) in genetic counseling and medical school training,
- the manifestation of eugenic attitudes towards disabled people, and subsequent discriminatory practices in genetic services,
- approaches to inclusion of people with genetic disease and disabilities and their family members in research and policy development in the Human Genome Initiative,
- issues of language and conceptualization of disability and illness, and how these may inform, restrict or distort communication about genetic technologies and services,
- career opportunity outreach to people with disabilities in the field of genetic services and applied science.

The intent of such a dialogue would be to open communication and provide a forum to educate both communities about each other's perspective. It would seek to challenge stereotyping, and enhance greater involvement of the disability community in the field of genetic services and technologies.

In our planning meetings, we quickly realized that the idea of a conference focussed on "public education" was premature. Given the disparity in the views of the various perspectives of participants, we decided on a research agenda for the conference, where we would focus on an analysis of the issues, identification of the social and ethical issues at stake, and exploration of relevant public policies. We wanted to document areas of consensus and disagreement and then to generate recommendations for research.

Our vision of this conference has been to create an atmosphere where the participants listen to each other at the deepest levels we can, so we can begin to appreciate and understand each other's views. This would include genetic professionals listening to people with disabilities about the history of the disability movement, "disability pride," and disability identity in relation to these issues, how patronizing medical treatment and attitudes directed at disabled people informs the debate about new reproductive technologies and genetic screening, and why people with disabilities might object philosophically to such technologies as prenatal diagnosis. We hoped to enlighten participants to enable them to appreciate how complex the issues are, for example, for disabled people who might elect to use screening technologies.

The conference would also include people within the disability rights community listening to genetic professionals about conceptions of disease and disability from the standpoint of medical

training, how and what medical professionals learn from experiences with patient/consumers, about concepts of cure, quality of life and alleviating suffering, and pressures on various professionals, (ie, doctors, genetic counselors, researchers) to utilize screening.)

We anticipated the scope and size of this workshop to be similar to that of the conference on "Reproductive Genetic Testing: Impact on Women", which took place in 1991, and was described in the American Journal of Human Genetics (52:1161-1163,1992).

The conference proposal received funding in late 1994 from both NIH and DOE as co-funders. NIH funds were channelled through DOE. The conference planning process was then postponed for a year due various factors related to the principal investigator's doctoral program and personal issues.

The Planning Process

The planning committee was created by Marsha Saxton and Beth Fine, both ELSI Working Group members. Marsha Saxton met Beth Fine through the ELSI Working Group, and they decided to work together, bringing in colleagues with relevant expertise. The planning committee included the following individuals:

Beth Fine, M.S. Northwestern University Genetic Counseling Program,

Carol Gill, Ph.D. Director, Chicago Institute of Disability Research,

Kristi Kirschner, M.D. Medical Director, Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago,

Judy Panko Reis, MA., MS., Administrative Director, The Health Resource Center for Women with Disabilities, Rehabilitation Institute of Chicago,

Marsha Saxton, Ph.D., Principal Investigator, Project on Women and Disability, and Suffolk University, Boston,

Judy Schiffman, M.S. Northwestern University Genetic Counseling Program

The planning committee held four conference calls and two face-to-face meetings in Chicago.

Selection of Participants

The planning committee members each proposed candidates for invitation to the conference, aiming at forty participants. Our criterion was to invite a range of individuals from relevant

disciplines and perspectives, who had some degree of familiarity with the literature, at least from within their own discipline, and would benefit from such a conference. An additional more subjective criterion was the personal qualification of our assessed ability to relaxedly and respectfully listen to divergent views on the topic. We sought diversity of perspective as well as race, disabled and non-disabled, gender, and geographic location. Our initial mailing list consisted of about sixty individuals to which forty were sent the first set of invitations. We received positive responses from thirty-three of these initial invitees which we interpreted to mean we had chosen well in our selection process. We then sent the second mailing of invitations in order to obtain the target number of forty individuals, anticipating that a few might have to cancel.

Individual responses to our outreach efforts revealed a great deal about participants differing perspectives. It was noted that a very large percentage of the non-disabled professionals made comments on the phone to Marsha Saxton, the Principal Investigator, along the lines of "I'm so flattered that you've invited me, and I'm really looking forward to this event," in contrast to comments from people who identified with the disability rights community, who's statements tended to run along the lines of "I'm really nervous about this event." or "I'm not sure this is a good idea." One disability activist said, "Disabled people's views are really unpopular with doctors; they don't want to hear what we have to say." The expression of these views reinforced the planning committee's perception of the need to emphasize respectful listening across differing perspectives. We wanted to create an agenda that would minimize arguing and debating, which would tend to stifle or obscure the real expression of deeply held views and opinions.

Location and Site

It was decided to hold the conference in Chicago, because Dr. Kristi Kirschner and Judy Panko Reis, members of the planning committee, were able to arrange for in-kind use of their agency, the Rehabilitation Institute of Chicago, as the site for the conference. This seemed to work well also because of Chicago's geographic centrality, and RIC's wheelchair accessibility and easy access to a local hotel with appropriate wheelchair accessibility.

Accommodation for Participants with Disabilities

Approximately half of the participants were people with a range of disabilities. This reflected the goal of involvement of individuals and perspectives which typically have not been included in discussions and other conferences about the ethical issues of genetic screening and prenatal diagnosis. Thus the conference was designed to be adequately accessible to persons with a range of disabilities, through provision of sign language interpreters and readings available on diskette (for blind individuals who have access to voiced computers) and the conference materials on tape. A resource person was enlisted to arrange for local wheelchair van service to and from the airport.

Conference Mission

The mission of the conference, as defined by the planning committee, was as follows:

To provide a forum to facilitate communication and mutual respect across the range of interested perspectives and disciplines, leading toward an appreciation of the complexity of disability issues raised within the context of genetic counseling and clinical genetic services, and to explore and document this range of perspectives.

Conference Format and Methodology

As a small but important step toward the creation of workable public policy, we wanted participants to understand that people's intellectual points of view arise from their life experience, and that listening respectfully to people articulate not only their ideas but pertinent personal factors from their lives and professions illuminate the issues and allow people to better understand and appreciate each other, and then to productively and creatively think together.

The planning committee posed the following questions as "broad themes" to address at the conference.

- 1.) How can we interestingly explore the range of views from clinical genetics and the disability rights community regarding prenatal diagnosis and selective abortion, with the help of ethics, sociology, feminism, economics, history, and the law?
- 2.) How might disability rights views help illuminate some of the social and ethical dilemmas that clinical genetics and research genetics face, ie, genetic discrimination and the Americans with Disabilities Act, allocation of resource, access to services for undeserved populations, and so forth.
- 3.) How can the disability community formulate a workable philosophic and political position regarding prenatal diagnosis and selective abortion, which raises awareness and fosters dynamic and productive dialogue with clinical genetics and other fields?
- 4.) How can the field of clinical genetics meaningfully encompass the disability rights perspectives into its education and practice?

A extensive list of research questions in five topic categories, to be examined by five working groups, was developed which reflected these themes. (see Appendix for Working Group Research Questions.)

Group One: Medical Model v. Disability Minority View

Group Two. Feminism, Reproductive Rights

Group Three: Eugenics, Line Drawing and Autonomy

Group Four: Clinical Genetics; Professional and Training Issues

Group Five: Economics, Insurance and the Genetics Industry

A set of guidelines was developed to assist conference participants in their working groups. Facilitators were recruited in advance of the conference.

For the opening panel presentation, Friday afternoon, May 31, four keynote speakers each offered their discipline's or community's perspective on key historical and current factors on the social and ethical issues of prenatal diagnosis and selective abortion. The four speakers were: Carol Gill, Ph.D. addressing disability rights issues, Mary Mahowald, Ph.D. addressing women's and feminist issues, Lori Andrews, J.D. addressing bioethical and legal issues, and Eugene Pergament, M.D. addressing clinical genetics issues, (due to travel conflicts was unable to speak as originally planned; his presentation was read by Beth Fine.)

Following the panel presentations, a 30 minute question- answer, discussion period was conducted. A reception was then held for informal discussion and socializing.

On Saturday, morning, June 1, Diane Beeson, Ph.D. sociologist, presented a training exercise for participants designed to illuminate a key conference agenda: listening across disparate perspectives. Dr. Beeson described the exercise as "Narrative Ethics", a relatively newly defined tool within the field of ethics which seeks to grapple with ethical dilemmas by focusing on narration of individuals' psycho-social-political experiences in their individual lives. Marsha Saxton participated with Dr. Beeson in the demonstration of listening skills, and discussion of the content of the issues and the listening skills followed the demonstration.

The participants were then divided into small (eight to ten member) working groups for most of the rest of the conference, with periodic report backs and discussion from the groups throughout Saturday. The working groups were designed to be as diverse as possible in terms of representing a range of views. One optional meeting, offered Saturday lunchtime, gave participants the chance to meet for open discussion in "constituency" or "interest groups" with other participants from similar backgrounds or perspectives. Five groups met, including people with disabilities, genetic counselors, social scientists, parents and bioethicists.

Early on in the conference participants were forthcoming in their feedback about the conference methodology, describing the working group meetings with such words and phrases as "intense", "emotional", "amazing," "hard," "illuminating", "painful", "what I've been waiting for for years" and so forth. Interestingly, on Saturday evening, after a full day of working group meetings, the whole group met together for a feedback and discussion session, the group nearly unanimously requested an additional working group meeting session, which was added to the schedule for the final day, on Sunday morning. One participants stated "These groups have been so intense, we've bonded! We need at least one more meeting for closure."

Video Taping the Conference

Much of the conference was video taped, with the exception of a few of the small working groups, where the crew of five, working in pairs, with two cameras and one additional radio-quality audio tape recorder, were unable to tape all of the five concurrent group meetings.

Participants were asked to sign video release forms, with the proviso that at any time, any individual could request not to be taped. Several individuals did take that option before expressing very personal or controversial material. This of course meant we were not able to record everything that occurred at the conference. But this also meant that the conference itself was able to be made confidential and relatively "safe" for the expression of sensitive material.

There were a few comments that the cameras felt intrusive, but there were also a few other comments that the cameras were surprisingly non-disruptive. A few participants mentioned that the camera crew were sensitive and professional and may have actually enhanced the experience of the conference in lending the notion of extending this process beyond the confines of the conference room and into the wide world. Given the valuable record of the conference and the myriad potential uses of the footage, the conference conveners felt that the cameras' presence was well worth the degree of disruption they may have caused.

The final morning, Sunday, June 2, based on a range of feedback about key issues emerging from the working groups, an additional narrative ethics presentation was offered. Three mothers of children with genetic-related conditions, (Tay Sachs, Trisomy 18, and spina bifida) all who'd experienced some relationship to prenatal diagnosis, were present at the conference. The conference coordinator, Marsha Saxton, invited one mother up to the front of the conference to talk about her perspectives on prenatal technologies, and the experience of mothering a disabled child who died (at age 10 from medical complications) This particular woman was founder of a national support organization for Trisomy 18 families.

This final presentation appeared to have a profound impact on the whole group. As the mother of this child described what she experienced as the positive impact her disabled daughter (nonverbal and unable to walk) had had on the family, and then went on to describe the child's final illness and eventual death, the group of 40 participants became intensely engaged in this story. The mother told the group of her daughter's last moment; "I said goodbye to my greatest teacher." Several people were openly crying. There have been many comments about this session and the impact it had on participant's appreciation of the complexity of the issues.

During the closing evaluation session, participants were invited to respond to the questions, "What was difficult about this conference, and what useful or important to you?" Many of the responses were passionate and forthright. Most were recorded on video, so they will eventually be transcribed as part of the permanent record of the conference.

Evaluation Forms and Correspondence

Evaluation questionnaires were included in the conference packets.

Below are questions stated on the questionnaire, followed by a few representative comments (in italics) taken from the twenty-four filled out evaluation forms:

1. What were your hopes or expectations of this conference?

- to be able to understand the issues of disability as they relate to reproductive prenatal testing; to be able to start a productive dialogue.*
- to focus on the issues of genetics from a disability rights perspective.*
- I hoped for a dialogue and found it; but did find some patronizing views.*
- To learn, to think, to feel- all met! I loved this experience and appreciated the chance to meet so many interesting people.*
- To have a true dialogue between communities with various perspective and vested interests. I felt these were largely met-though I would want to include basic scientists and OB/GYN's.*
- Broaden the dialogue. The conference more than met my high expectations. We needed more time though.*

2. What did you most like about the conference?

- I think the discussion format was great, way better than paper presentations!*
- the group, the process, everything!*
- the profound shared experience we all had, and the fact that although we are diverse we also are so much alike.*
- the best part of the conference was the Narrative Ethics, clearly presented and demonstrated.*
- I wanted to be heard and I was!*

3. What would you change?

- include more primary care physicians*
- representation of OB/GYNs*
- get people from ELSI, DOE, NIH to come*
- Send a detailed agenda before the conference*
- more conceptual thinking*
- there were no developmentally disabled people who are greatly affected by the technology. It was a predominantly white group and few disabled men.*
- No cameras next time?*
- more time -- but considering how busy people are, that's hard.*
- I would have had one shared dinner and had the conference go on into the evenings.*
- Too intense for my taste, though I learned a lot. Maybe more breaks.*

4. Please rate and comment on the following components of the conference.

Question 4 asked participants to rate on a scale of one (poor) to five (excellent) nine different components of the conference (opening comments, plenary panel, receptions and meals, Narrative Ethics demonstration, working groups, constituency groups, reportback/discussion sessions, session of the conference process, summary/closing) plus an overall conference rating.

A tally of the responses for this question is included below. Not all of the participants rated every conference component listed on the evaluation form, so the ratings are not "statistically" meaningful. However, the high number of the "good" and "excellent" ratings indicated that the majority of participants rated the various conference components, as well as the overall conference, very favorably.

	1 Poor	2 Fair	3 Average	4 Good	5 Excellent
Opening Comments			4	18	
Plenary panel	4	14		6	
Reception, breakfast and lunch	8	6		10	
Working groups	2	8		12	
Constituency or interest groups		7		12	
Reportback/discussion sessions		11		6	
Reflections on the conference	6	7		7	
Process session					
Summary/closing	2	6		10	
Overall conference evaluation	1	8		14	

5. List one or two things from this conference you will take back to your work.

-This reinforced the need for more placements and curriculum [for genetic counselors] that addresses familiarity with individuals with disabilities

-renewed commitment to advocacy. Need to explore if the sickle cell community considers themselves "disabled".

-Let's require genetic counseling students to take part in rotations with ARC centers, (Association of Retarded Citizens) independent living centers, rehab centers, infant stimulation programs, etc.

-importance of interaction with individuals with diverse perspectives, especially disabilities.

-the knowledge that this issue is, in many ways, a crisis for those of us with disabilities. My

feminism has been altered, and my views on pro-choice have changed.

-- a clearer appreciation of the difficulties of communicating disability views and views critical of genetic technologies to clinical geneticists -- the need to reframe the issues.

-greater understanding of disability perspective and what their lives are like, and realization that some disability rights people have great misunderstanding of genetic and people who work in the field.

-You did a divine job! I was expecting to confront narrow-minded disability-phobic genetics professionals--what a surprise to meet [so many professionals] who turned my stereotypes around. As a mom with a disability I was especially impressed with the receptivity many genetic professionals expressed to my concerns.

6. Your suggestions for next steps.

-continue conferences like this, enlarging on these themes.

-Make this group a working group and continue the dialogue we started here.

-ASGC requirement to participate in this format.

-writing for popular press as well as scholarly publications.

-further opportunities to brainstorm about effective political steps to keep genetic technologies from hurting people

-invite geneticists to talk about fetal therapy and gene therapy and future prospects; also need representative from NIH or DOE who can talk about why money should continue to be channeled into the Human Genome project and its impact on society as a whole.

-include people with intellectual disabilities.

7. Where should the final report (proceedings, outcomes, video) be distributed?

-published in its entire form in the American Journal of Genetic Counseling and the American Journal of Human Genetics.

-National Society of Genetic Counselors

-a variety of professional journals. Use video in training genetics professionals, medical/nursing students/ ELSI/ NICHD, ACOG, ASHG

-Alliance of Genetic Support Groups, Council of Regional Networks

-to scientists, professors of ethics and technology, to genetic counselors while in training, to people with disabilities, to women considering these technologies, or just considering having children.

-to women's groups, the media

-schools of social work, legislators, directors of genetic testing programs

-grassroots activists groups

-The Hastings Center Report

Another form of feedback came from letters participants wrote to the conveners after the conference. Here are a few excerpts from these letters.

You provided a kind and gentle forum to discuss a very passionate and energy filled subject. It is still hard to completely explain the feeling I'm leaving with . . . but I am hopeful you will have met the goals for the conference and beyond.

(Kris Holladay, parent and president of Support Organization for Trisomy 18)

I would like to take this opportunity to thank you for inviting me to participate in such an incredible experience. I still am "reeling", in a sense, from the impact that the conference had on my understanding of the issues discussed. I want to add that I was also very impressed by the sensitivity and intelligence with which you led the proceedings.

(Meredith Margolis, Ph.D. Psychologist and parent of child with Tay Sachs)

Thanks again for doing such a wonderful job in putting the conference together. I was so pleased that the comfortable atmosphere allowed us as a group to be open with one another, sharing personal experiences and thoughts. . . . I think that there was at least an implied consensus, that by our very presence at the conference, it indicated that we all wanted to work together and learn from each other. . . . We've gotten off to a great start.

(Lisa Chen, M.S. genetic counselor, UCLA)

I wanted to tell you how very much the conference meant to me. It was a profound and altering experience and a wonderful demonstration of the difference between thinking about issues intellectually and getting to also experience them viscerally. I also want to tell you what I have been telling all sort of other people, and that is what a masterful job I think you did in creating a safe and honest atmosphere for the whole meeting; that what made the meeting succeed. I have never seen anything quite like it and I can't stress enough how impressed I was and how much credit I think you deserve.

(Nancy Press, Ph.D. sociologist, UCLA)

Outcomes and Follow-up to the Conference

The outcomes and products of the conference will include the following:

1.) **Participants' experience:** the impact of the conference experience on the individual participants, and whatever changes or influences the conference may have inspired in the professional lives of these individuals, such as the ones listed in the evaluation section above.

2.) **Articles:** the writing and publishing of articles about the conference and its innovative methodologies (narrative ethics, listening across differing perspectives, emphasis on small working groups, and so forth) by the planning committee and participants.

The four plenary presentations and the narrative ethics presentation are, with minor revisions,

publishable pieces. Planning committee members are discussing possible publishers for articles about the conference.

3.) Video tapes. We have begun reviewing the video tapes and have found them to be potentially of tremendous value as training and educational material for students and professionals in a range of related fields, as well as public broadcasting material for general viewers. We must now begin the process of developing funds to produce such materials. The planning committee and the video producer are exploring options to produce a sample reel, a short "rough cut" of the footage, which can be shown to potential funders.

4.) Follow-up activities: At the National Society of Genetic Counselors annual meeting in October in San Francisco, plans are underway to present a plenary workshop, convened by Beth Fine, with the same title as the conference, focusing on similar issues, and utilizing an innovative approach to enable the 700 participants to experience and confront the issues beyond a didactic lecture approach.

Several participants have suggested an annual conference on the topic to enable a long range focus on the issues, with an eye to developing consensus and eventually public policy recommendations. The planning committee will invite participants to share ideas for funding, coordination and outreach.