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The Importance of Attitudes Toward and Understanding of Disability and Science in the Age of Genetics

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This article reports concerns among disability community members that the implications of genetic research will be driven by mistaken beliefs about genetics and negative attitudes toward disability as identified in a qualitative study funded by the National Human Genome Research Institute. In addition to reporting the nature and the context of disability community concerns related to perceptions of disability and of human genetics, the authors discuss the historic role of attitudes toward disability and science in popularizing eugenics in early 20th century America as evidence of the seriousness of these concerns.

DESCRIPTORS: genetics, qualitative research, eugenics

Background

Human genetic research has the potential to revolutionize medicine and to transform society. By identifying the "building blocks" of human beings, the Human Genome Project has provided the basis for research to identify, to understand, to measure, and to manipulate human genetics. Yet, increased understanding and control over human genetics holds peril as well as promise (Andrews, 2001).

For persons with disabilities and their families, this dual potential of human genetic research—to either help or harm—is particularly acute (Stowe, Turnbull, Schrandt, & Rack, 2007). Genetic research promises better identification and diagnosis of disability and more effective treatments for the amelioration and the prevention of biological impairment. But persons with disabilities and their families must also be concerned about genetic discrimination, violations of privacy, eugenics, decreased social supports, and other direct and indirect effects of genetic research that may reduce their quality of life (Stowe et al., 2007).

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Indeed, the history of medical science lends credence to both the hopes and the fears about genetics and disability. The application of medical research to persons with disabilities includes both bright and dark chapters. Medical science has greatly improved diagnoses, all but eliminated some diseases, provided treatments for others, extended the human lifespan, reduced infant mortality, ameliorated functional effects of impairment, and provided us with the means to reduce pain, to reduce anxiety, and to monitor the conditions of our bodies. But it is equally true that medical science has engaged in human experimentation (Krugman, 1986; White, Meunier, & SteelFisher, 2005), fostered widespread use of harmful treatments (Mashour, Walker, & Martuza, 2005), and played a role in the mass institutionalization of persons with disabilities (Lakin, 1979). Eugenics, the application of scientific understanding of human genetics to "improve" the human gene pool, is perhaps the most egregious example of science leading to the mistreatment of individuals with disabilities and certainly the most relevant to discussions of modern genetics.

In the early 20th Century, the eugenics movement resulted in horrific crimes against persons perceived to be genetically inferior (Black, 2003; McGee & Magnus, 2000). At the height of the eugenics movement, countries around the world (including the United States) implemented various eugenic policies and programs including forced abortion policies, mandatory sterilization laws, restrictions on marriage, segregation and isolation policies, and—in Nazi Germany—a policy of genocide (Adams, 1990; Broberg & Roll-Hansen, 2005).

The United States was the first country to use compulsory sterilization for eugenic purposes (Lombardo, 2001). Involuntary sterilization laws were enacted in 33 states. Over 60,000 people with disabilities, or who were inaccurately identified as having disabilities, were involuntarily sterilized. The Supreme Court in Buck v. Bell (1927) held that compulsory state sterilization laws for eugenic purposes were constitutional. Revelations of the scientific bankruptcy of eugenics during the late 1920s and the early 1930s, and of Nazi genocide before and during World War II, eventually brought an end to popular support for eugenics in the United States and elsewhere—although involuntary sterilization in the

United States continued to be performed until the 1970s (Lombardo, 2001).

If we as a nation are to foster the promise and address potential harms as we enter the new era of genetic science, we must learn from the history of eugenics and of other dark chapters in the history of medical science. Typically, the eugenics movement is framed as merely the actions of "bad people" or the result of "bad science," but these oversimplifications are contrary to the historical evidence and are potentially dangerous. Prominent Americans such as George Bernard Shaw, Gifford Pinchot, Charles Lindbergh, and even Presidents Woodrow Wilson and Theodore Roosevelt supported eugenics. Social reformers such as Margaret Sanger, known for her founding of Planned Parenthood, and Alexander Graham Bell, were members of the American Eugenics Society (Pickens, 1968). Many more eugenics proponents were simply well-meaning and ordinary citizens. Furthermore, to dismiss eugenics as simply "bad science" is to suggest that involuntary sterilization of people with disabilities would be justified if it actually reduced the occurrence of disabilities—and invites contemporary researchers to correct their forebears' mistakes by providing a sound scientific basis for future discrimination.

Learning from the past requires us to recognize the truth obscured by these myths; that the eugenics movement resulted from something far more disturbing than evil intention or scientific failures: It resulted from the convergence of widespread beliefs about degeneracy, individual worth, societal responsibilities, and nature of disability around emerging scientific discoveries (Carlson, 2001). In other words, the eugenics movement can be seen as resulting from genetic science emerging in an atmosphere of disability stigma that in turn drove understanding and implementation of the science. This attribution is not limited to Eugenics. Arguably, stigma provided the foundation for many of the "dark" chapters in medical history—shock treatments, the Tuskegee Syphilis Study, frontal lobotomies, the Willowbrook experiments, etc. (Stowe et al., 2007).

Although some might correctly point out that eugenics was also focused on immigrants and was involved in the discrimination against others who did not have disabilities—these groups were labeled genetically "unfit" largely because they were inaccurately believed to have innate genetic characteristics that predisposed them and their offspring to degeneracy and disability. Science has, to a large extent, addressed this misclassification issue, but what about the underlying stigma of the disability label? How have attitudes and perceptions of persons with disabilities changed? Has the disability's rights movement and laws protecting persons with disabilities from discrimination sufficiently changed attitudes toward disability so that we can enter into the new age of genetics confident in the belief that disability is commonly recognized as "a natural and normal part of the human experience" (Americans With Disabilities Act, 1990)?

In light of the history and of the dual potential of genetics to help or to harm, we initiated a qualitative study, funded by the National Human Genome Research Institute, to broadly examine disability community perspectives on human genetic research. The study proposed to identify and to examine a full range of hopes and fears of persons with disabilities and their families regarding human genetic research across disability categories with both "grassroots" members of the disability community and disability community leaders. In this article, we report on one particularly notable concern identified in the study: the fear that the implications of genetic research are or will be driven by negative attitudes toward disability and mistaken beliefs about genetics. In short, this article reports on themes from the study related to attitudes and perceptions of disability and on genetics in light of the historic role of attitudes and perceptions in popularizing eugenics in early 20th century America.

Literature Review

Despite the historic role of disability stigma in scientific malfeasance and the potential impact of genetic research on persons with disabilities and their families, the disability community's involvement in dialogues about the implications of genetics has been limited (Stowe et al., 2007). This is particularly true with regard to research on the perspectives of persons with disabilities.

Significant research has been conducted on the perspectives of consumers of genetic services (Chapman, 2002; Lapham, Kozma, & Weiss, 1996; Peterson, 2006; Wertz, 1999), but although genetic consumer populations may include some persons with disabilities, the two groups are significantly distinct. That is so because disability community membership is defined by the socially created consequences of having an impairment—by the historic vulnerability to invidious treatment that members share—not merely a need for medical services (Krugman, 1986; Lakin, 1979). Although the perspectives of patients and consumers, defined by the action of seeking medical services, are inarguably valuable contributions to ethical, legal, and social implications dialogues, they should not be considered equivalent to the perspectives of disability community members who have historically experienced invidious treatment as an underserved and underrepresented minority population. Persons with disabilities are likely to be profoundly affected by advances in genetics regardless of their need for genetic services (Stowe et al., 2007).

A few studies have investigated disability community—rather than consumer—perspectives on human genetic research. The foundational, and still preeminent, study was conducted at the Hastings Center and resulted in what is commonly referred to as the disability rights critique of prenatal genetic testing (Parens & Asch, 1999). The disability rights critique highlighted the potentially coercive nature of offering prenatal genetic

tests by promoting "normalization" and the potential for a new era of "elective eugenics" to emerge based on prenatal screening and selective termination of pregnancies that test positive for disabilities (Parens & Asch, 1999).

As with the Hastings Center project, most studies examining the perspectives of persons with disabilities or their families have focused on specific genetic conditions such as cystic fibrosis (Henneman et al., 2001), Marfan syndrome (Peters, Kong, Hanslo, & Biesecker, 2002), Fragile X (Skinner, Sparkman, & Bailey, 2003), and achondroplasia (Gollust, Thompson, Gooding, & Beisecker, 2003). They are also often focused on attitudes toward the use of specific genetic technologies such as genetic testing or screening (Gollust et al., 2003; Middleton & Biegert, 2005; Parens & Asch, 2003; Skinner et al., 2003).

Although no study has broadly examined cross-disability perspectives toward genetics in the United States, evidence from the abovementioned studies has suggested a potential relationship between experience with particular congenital disabilities and attitudes toward the use of genetic technologies—particularly genetic testing and termination.

Middleton, Hewison, and Mueller (2001), in a large sample study on attitudes toward prenatal diagnosis of hereditary deafness among deaf, hard of hearing, and hearing participants, found that although 49% of hearing participants would consider prenatal diagnosis for deafness, only 21% of deaf and 39% of hard of hearing participants would likewise consider prenatal testing. Similarly, Brunger et al. (2000) found that although a majority of 96 parents of deaf children had positive attitudes toward genetic testing, none would use such information to terminate pregnancy.

A comparison of studies on attitudes toward termination in response to prenatal diagnosis of Down syndrome also illustrates the potential effect of disability experience on attitudes. Kramer et al. (1998) found that over 80% of women are willing to terminate pregnancies after receiving a prenatal diagnosis of Down syndrome. In contrast, a study focusing on women with siblings who have Down syndrome found only 33% willing to terminate in response to prenatal diagnosis (Bryant, Hewison, & Green, 2005).

Although there is far too little research to draw conclusions as to the source of these differences, one of the more likely explanations is that people who do not have personal experience with disability view it more negatively than those who do have personal experience with disability. This would be consistent with the social/psychological theory of prejudice formulated by Allport (1954) called the contact hypothesis. The contact hypothesis states that prejudice may be reduced by contact between members of majority and minority groups, particularly if equal status contact is sanctioned by institutional supports or if the nature of the contact is such that it increases perceptions of common interests and of common humanity (Allport, 1954).

The disability rights movement and the anti-discrimination laws have placed significant emphasis on inclusion and community-based services; however, have these efforts been sufficient to address fears of discrimination in an emerging era of genetic technologies? Are persons with disabilities and their families still concerned that discriminatory attitudes will drive genetic research and the implementation of genetics?

Methods

To examine these questions in the absence of significant foundational research, we proposed to collect in-depth perspectives on human genetics from as broad and diverse a sample of the disability community as possible and to identify concerns similarly held by members of the disability community with diverse disability experiences. That is, the purpose of the study was to identify hopes and concerns that were not specific to any one disability category, diagnosis, or role in the disability community, but rather ones that resonated broadly throughout the community—and to examine the basis, the context, and the quality of those hopes and concerns in some depth and detail. "Resonating broadly," however, should not be confused with generalizability of findings. This is a qualitative study and does not purport to generalize to all members of any population—let alone one as complex and difficult to define as the disability community. Rather, we aim for a high degree of transferability and hope that by broadly sampling, these results will ring true to a significant number of persons with disabilities and to their families.

The researchers selected this approach because of its relevancy to advocacy (where consensus matters) and because current research is insufficient for investigation into variance of perspectives within the disability community. Although this approach limits our examination of within and across group differences based on our data alone (because the sample is particularly small for narrowly defined groups), it allows us to identify promising topics for future study of variance and predictors of perspectives among differing disability populations.

We used a modified participatory action research (PAR) committee to engage the disability community in the research process (Reason & Bradbury, 2001). As usual with PAR committees, ours included participants representing the population sampled—three persons who either had disabilities or were parents of children with disabilities and three disability advocacy leaders. Additionally, we included four PAR members who were experts in various genetic and disability fields (a disability quality of life researcher, two genetic counselors, and a eugenics historian). PAR members participated in the research by referring us to important literature, by identifying local liaisons to aid in recruiting respondents,

and by making suggestions for conducting the research at each stage of the research process. The PAR committee met annually to guide the direction and the conduct of the study and to discuss the data and findings.

Our study used three qualitative methods of inquiry: multivocal synthesis (Ogawa & Malen, 1991) of the literature on ethical, legal, and social implications (centered on documents reflecting a disability community perspective), focus groups with grassroots members of the disability community, and interviews with key informants in the disability community. We outline the sampling and the procedures used for each of these approaches below and those used to integrate the data from all three approaches.

Multivocal Synthesis

As noted above, the research literature on the perspectives of disability community members is very thin. Indeed, the vast majority of existing evidence for disability community perspectives on genetics exists in social commentary, position statements, policy articles, and other nonempirical, declaratory examinations of the issues—typically written by a few or even a single author. This level of subjectivity in the basic literature would only be compounded by the application of narrative review—the traditional method for reviewing literature in research articles. The lack of systematic procedures in narrative review raises questions about its adequacy even when the literature includes significant empirical studies (Davies & Crombie, 2001; Wood, 2000). Such criticisms are even more applicable when the literature on a topic is more subjective and includes a wide range of differing approaches to the subject matter.

In contrast, a multivocal synthesis is particularly appropriate to this body of literature. A multivocal synthesis is a method for qualitative synthesis based on grounded theory intended to add systematic rigor to qualitative literature reviews (Ogawa & Malen, 1991). Yin (1991) argued that grounded theory already contains all the necessary procedures to support robust and rigorous synthesis—one simply needs to apply the same methods for attaining rigor in a qualitative study to qualitative synthesis (e.g., identification of emerging categories, iterative processes, triangulation, etc.). Multivocal synthesis of this kind is particularly appropriate when the literature is characterized by an abundance of diverse documents (Ogawa & Malen, 1991); and because it is based on grounded theory, it can be combined with focus groups and interviews with experts (Gersten & Baker, 2000)—as done in this study. To combine the synthesis with the focus groups and the interviews, the documents are simply treated as an additional data source for identification of themes and triangulation.

The sample for the multivocal synthesis included research articles (the few available), policy articles, books, position statements, and commentaries related to genetic research and technology implications that reflected or provided evidence of disability community perspectives on human genetics.

Articles were originally found through keyword searches of Internet and database sources (e.g., Google, PubMed, Lexis-Nexis, etc.); through PAR member identification; through review of the research portfolio for ethical, legal, and social implications research at National Human Genome Research Institute; and through cross-referencing of literature and citations. In our searches, we combined various keywords related to genetics (e.g., human genes or genome) or to specific human genetic technologies (e.g., screening, testing, engineering) with keywords related to disability identity (e.g., persons with disabilities, disability community) or to disability issues (e.g., discrimination, consent, stigma) to ensure that we comprehensively identified documents reflecting the perspectives of disability community members on human genetics.

After initial identification, two criteria for inclusion were used by the researchers to identify documents appropriate for the study. First, the documents had to discuss the implications of human genetics or to provide perspectives on human genetics issues. We excluded documents that primarily discussed embryonic stem cells or cloning as these topics are only tangentially related to the impact of genetic research on the disability community and would have been overly burdensome to examine. Second, to be included in the sample, the document had to reflect or to provide evidence of a disability community "voice" on the genetic issue discussed. This includes articles and commentaries written by persons with disabilities or by parents of persons with disabilities, position statements by disability organizations, and research on disability community perspectives.

Documents included in the study were then coded for both positive and negative implications (hopes and fears) using established methods for qualitative coding including (a) organization and reduction of raw data, (b) generation of categories and codes, and (c) interpretation of patterns and themes (Krueger & Casey, 2000; Lincoln & Guba, 1985; Patton, 1990). Two researchers independently coded each document and met to build a consensus on final themes. We used saturation—the failure to illicit additional codes/themes from new data collection—to determine when sufficient sampling had been completed (Krueger & Casey, 2000). Once saturation was achieved, we entered final codes into a Structured Query Language database for later integration and analysis alongside focus group and interview data.

The method used to code the documents is nearly identical to that used in the identification of themes from the focus groups and the interviews, but with two exceptions: First, there were no notes to analyze as with the focus groups and the interviews. Second, we coded almost all of the text from the focus group and the interview transcripts, but this was seen as excessive and time consuming with regard to the literature (particularly with

regard to books in the sample). Coding instead focused on identification of the major themes and on identification of key quotes manifesting the qualities of those themes in the documents.

The final results of the synthesis reflect a total of 67 documents identified as reflecting a disability community perspective from a total of 389 documents related to disability and to human genetics issues originally identified.

Focus Groups

We conducted 11 focus groups with members of the disability community in urban and rural areas around four cities (Kansas City, Baltimore, Raleigh-Durham, and New York City). We used purposive sampling for the focus groups to ensure broad representation of the diversity of disability experiences among members of the disability community. We required a minimum of 6 and a maximum of 12 individuals in each focus group consistent with established guidelines (Krueger, 1994).

According to Marin and Marin (1991), accessing hard-to-reach participants—such as the grassroots disability community members for the focus groups—requires an understanding of the communities in which they live. In order to access those respondents, Marin and Marin recommend two strategies: (a) collaborating with community leaders and (b) establishing legitimacy through sponsorship. Therefore, we recruited participants for all focus groups through liaisons employed by or volunteering for local nonprofit disability service organizations. We selected organizations and liaisons for their familiarity with and access to local target populations and for their ability to serve as trusted brokers in recruitment activities. The liaison initially identified and contacted each potential participant, set up the time and place for the focus group, and followed up with each willing participant to ensure a high attendance rate.

Because the focus groups were intended to collect "lay" perspectives of disability community members rather than those of experts or of leaders in the disability community, we excluded participants who were active in disability advocacy at state or national levels and those with particular expertise related to genetics (e.g., medical professionals) from all focus groups. Persons under the age of 18 and persons without the legal capacity to consent to participation did not participate in the study. We used additional inclusion criteria specific to the type of focus group as discussed below.

Of the 11 focus groups, 7 were homogenously organized by disability service classifications—two intellectual/developmental disability (ID/DD) focus groups, two physical disability (PD) focus groups, two mental health (MH) focus groups, and one "other" disability focus group for those who did not fit into any of the other three classifications.

For the purpose of this study, intellectual/developmental disability was defined as a significant disability that occurs before age of 18 requiring continuous support (general definition from Developmental Disabilities Assistance and Bill of Rights Act) and affecting cognitive processes. Mental health disability was defined as including any one or a combination of more than one disorder listed in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (4th ed.). Physical disability included biological conditions affecting motor function, mobility, or sensory function. The "other" disabilities category included all other disabilities not fitting the other three categories such as cystic fibrosis and hemophilia.

Differing experiences, functional effects, and services related to different disability classifications are likely to support different perceptions of human genetic research and technologies. We conducted focus groups with each of the above classifications to ensure that the full range of hopes and fears were examined. Grouping together individuals with similarly classified disability experiences within a focus group also helped promote the comfort of participants and fueled the discussion (Stewart & Shamdasani, 1990). The above classifications were chosen because they are typically used to define the policy and the service streams through which members of the classification, and their families, are provided services and supports. To meet the criteria for inclusion in one of these focus groups, participants had to have either a disability or a child with a disability fitting the classification.

Of the 11 focus groups, 3 were conducted with persons who, in addition to either having a disability or being the parent of a person with a disability, self-identified as a member of a minority ethnic/racial group (e.g., Hispanic/Latino, African American). Disability classification was not part of the inclusion/exclusion criteria for these focus groups, but an effort was made to purposely sample for diversity of disability experience (cross-classification). These focus groups helped ensure that concerns likely to be specific to ethnic/racial minorities—such as genetic aggravation of existing racial discrimination, economic and benefit disparities among racial groups, and racially targeted eugenics—were sufficiently captured in the data and the perspectives of ethnic/racial minority members of the disability community were represented.

Finally, 1 of the 11 focus group was specifically limited to women in the disability community (women with disabilities and mothers of children with disabilities). Disability classification was not part of the inclusion/exclusion criteria for this focus group. Despite a high rate of participation by women in all of the focus groups, a focus group of only women was necessary to ensure that perspectives on reproductive issues related to genetic technologies particular to women in the disability community were also represented in the data. Geographic diversity of the focus groups is shown in Table 1, showing focus groups by research site.

Trained or experienced facilitators (research team members or liaisons) conducted each focus group. To prevent interference with the comfort level of respon-

Table 1
Focus Groups by Research Site

Research site	Kansas City	Raleigh-Durham	New York	Baltimore	All sites
Intellectual or developmental disability	X	X			2
Physical disability		X	X		2
Mental health disability		X		X	2
"Other" disability			X		1
Women with disabilities			X		1
Ethnicity & disability	XX	X			3
Total	3	4	3	1	11

dents to discuss sensitive issues of particular interest to others in that subpopulation (minority race/ethnicity or women), a member of the research team or a local liaison identified as part of the subpopulation facilitated each of these focus groups. A second researcher took notes and operated the recording equipment during focus group discussions.

IRB-approved consent forms were signed, and basic demographic data (e.g., gender, ethnicity, income status, individual with disability or parent with disability) were collected from each participant before beginning. No preliminary information on genetics or on eugenics history was given to participants, and the facilitator explained that he or she could not answer any questions related to the topic until after the focus group ended. We asked participants if any accommodations could be provided that would help them participate fully. The only accommodation provided was reading of consent forms to individuals with visual impairments in one focus group.

After an initial invitation for participant(s) to tell a little about themselves and the disability experience/role that qualified them for participation, the facilitator began with a general question about participants' knowledge of genetics—what experiences they might have had, what they had heard, or what they had read. The facilitator then asked open-ended questions regarding participants' hopes and fears about human genetic research and technology. Questions were asked recursively (so earlier answers shaped later questions) and moved from more general to more specific as the discussions progressed. Probes were used to request additional information from participants as needed to clarify or to provide detail about their answers (Krueger & Casey, 2000; Rubin & Rubin, 1995), such as: "Tell me more about that," "Could you give an example of what you mean?," and "How pressing is the need for a response to address this issue?" Specific probes also included those related to subject areas identified in the literature syntheses when needed to foster additional discussion, such as, "Do you have any specific concerns about genetic testing technologies?" Probes such as "Would anyone like to offer a different opinion?" were used to encourage focus group participants to voice viewpoints even if they disagreed with what had already been said. Facilitators attempted to avoid evaluative probes or responses that could bias the data (Krueger & Casey, 2000). Informal member checks were used during focus groups to enhance credibility of the data (Erlandson, Harris, Skipper, & Allen, 1993).

The researchers used the same established methods for identifying themes and for coding the interview transcripts as used with document synthesis, except that (as noted above) researcher notes were included in the analysis process and the coding involved identifying, to the maximum extent possible, the thematic nature and the significance of all the text in the transcripts. Final results of the coding were entered into the Structured Query Language database alongside, but differentiated from, the codes from the synthesis.

Final results of the focus groups reflect discussions involving a total of 97 participants in 11 focus groups.

Interviews

The researchers also conducted 10 interviews with key informants in four cities (Kansas City, Baltimore, Raleigh-Durham, and Madison). Because the purpose of the interviews was to collect expert perspectives on human genetics and disability issues, we limited participation in all interviews to individuals who were recognized as active state and national leaders in the disability community. Qualified individuals had to be both active in disability policy, advocacy, practice, or research and widely recognized for their contributions by their colleagues at the state or national level. We pursued this "leadership" approach to the in-depth interviews to ensure recruitment of respondents who would have an advanced level of knowledge of disability issues and of trends in their respective field.

To ensure that the breadth of the fields and of the perspectives was reflected in the sample, prospective respondents meeting the "expert" criteria were identified from three interest groups defined by their role or relationship within the disability community: (a) consumers of disability services, (b) providers of disability services, and (c) disability policy analysts or advocates. Inclusion criteria for "consumers" required participants to be currently receiving disability services or accommodations for their disability (or in the intellectual disabilities strand, a parent of a person receiving services). Inclusion as a "provider" was limited to persons

involved in direct services or support to individuals with disabilities or their families (e.g., independent living services, family support services, etc.). Inclusion as a "policy analyst or advocate" was limited to persons who play an active role in analyzing or in disseminating information about state or federal policies or to persons who advocate for systems change affecting individuals with disabilities or their families.

Additionally, having identified qualified respondents from each of these three interest groups, we selected one participant from each interest group whose expertise related to each of the three main disability classifications used in the focus groups: (a) intellectual/developmental disabilities, (b) mental health disabilities, and (c) physical disabilities. One consumer was also selected who represented the "other" disabilities category. The selection of interviewees based on these criteria (interest group/role and disability field) is displayed along with the geographic diversity among the respondents in Table 2.

The procedures for the interviews were similar to that for the focus groups (discussed above) except that interviews were in most cases (except two) conducted over the telephone rather than in-person. We also used the same process for identifying themes and for coding the interview transcripts as used with the focus groups and entered the results into the Structured Query Language database alongside, but differentiated from, data from the focus groups and synthesis.

Integration of Data

To integrate the data collected from the three methodologies, we re-examined and compared coding to identify equivalent patterns and themes across sources/methods (indicating appropriate combination of themes) and those that were significantly distinct (themes that could not be combined with those from other sources). This process was, as with initial identification of themes, first performed independently by multiple researchers who then met to come to consensus on the combination of the themes in the database.

This triangulation among data sources (literature, grassroots members, key informants), data collection methods (synthesis, focus groups, interviews), and multiple analysts (independent coding by multiple researchers) was done to reduce bias and to verify results independently of source, method, or analyst. To increase credibility of the data, we also used negative case analysis to more closely examine data that did not seem to fit the analytic patterns that emerged in the first round of coding (Lincoln & Guba, 1985).

The final sample for the study as a whole includes 67 documents in the synthesis and a combined total of 107 participants in the focus groups and the interviews. Breakdown of all participants by race/ethnicity and by gender is provided in Table 3.

Of the 107 participants, 47 identified themselves as White/Caucasian, 13 as Hispanic/Latino, 15 as Native American, 28 as African American, and 3 as part of more than one racial/ethnic group (1 participant declined to report ethnicity/race). Asians and Native Hawaiians were, unfortunately, not represented in the sample. Women comprised almost 75% of the participants (78 women in all).

Although the focus groups included participants representing the full range of socioeconomic status, 44 of the 97 focus group participants reported their status as low income—defined as eligibility for public assistance programs (e.g., cash assistance, food stamps, student lunch program, etc.). In contrast, none of the participants in the interviews were low income and several had particularly high incomes and SES status.

Although we did not ask participants for their or their child's diagnosis, discussion in the focus groups suggests that participant disabilities significantly varied in type and in severity and also represented a diverse range of possible genetic influence—from primarily genetic (e.g., Angelman's syndrome) to almost purely environmental (e.g., traumatic brain injury). Sixty-four participants in the focus groups and 3 of the 4 consumers interviewed were individuals with disabilities. Twenty-five focus group participants and 1 consumer were parents of children

Table 2
Interviews by Research Site

Research site	Kansas City	Raleigh-Durham	Madison	Wash. DC	All Sites
Consumers					4
Intellectual or developmental disability			X		1
Physical disability	X				1
Mental health disability				X	1
"Other" disability	X				1
Providers					3
Intellectual or developmental disability			X		1
Physical disability		X			1
Mental health disability		X			1
Policy experts/analyst					3
Intellectual or developmental disability		X			1
Physical disability				X	1
Mental health disability	X				1
10 Total	3	3	2	2	10

Table 3
Participant Demographics

Racial/ethnic categories	Sex/gender			
	Females	Males	Unknown	Total
Hispanic or Latino	7	6	0	13
American Indian/ Alaska Native	13	2	0	15
Asian	0	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0	0
Black or African American	21	6	1	28
White	35	12	0	47
More than one race	1	2	0	3
Unknown or not reported	1	0	0	1
Total of all subjects	78	28	1	107

with disabilities. Eight others (all in the focus groups) were identified as both persons with disabilities and parents of children with disabilities.

Results

When initially questioned, most of the participants in the focus groups, and some in the interviews, reported a low level of understanding of genetics, and that this understanding was based largely on media reports. Their self-reported level of understanding is consistent with the literature that identifies genetics as an area of emerging awareness and understanding (Singer, Corning, & Lamias, 1998; White, Meunier, & SteelFisher, 2005). Nevertheless, the participants demonstrated sufficient ability to discuss the ethical, the legal, and the social issues related to genetics in significant detail—even in the focus groups—and highlighted the specific hopes and concerns they had about human genetic research and genetic technologies.

Discussion of the implications of genetic research, both in the focus groups and in the interviews, ranged over a broad number of topics and themes. Twenty-five themes emerged from the data related to participants' concerns about human genetic research and 19 themes emerged related to participants' positive expectations or hopes. We organized the themes related to concerns and hopes into 7 categories—(1) information and beliefs, (2) equality and fairness, (3) health and safety, (4) autonomy and self-determination, (5) human genetic manipulation, (6) effects on the family, and (7) societal changes. In this article, we focus on the first of these categories: information and beliefs. The information and beliefs category consists of themes related to how persons with disabilities, how the nature of disability, and how the effect of disability upon a person's life are perceived and understood. It also includes themes related to how, and the extent to which, genetics and, more generally, science, are understood and perceived.

Although discussion of any one theme and the prominence of such discussions varied considerably among individual articles, focus groups, and interviews, there was remarkable agreement among data sources (disability voice literature, interviews, and focus groups) and across interview and focus group categories (physical disability, intellectual/developmental disability, mental health, other, minority/ethnicity, and women) on the importance of information and beliefs in determining the ultimate implications of human genetic research. Almost all of the focus groups and interviews on the implications of genetic research prominently included discussions about public and professional knowledge about genetics and beliefs about persons with disabilities. Information and beliefs about disability and genetics were consistently prominent themes in much of the disability voice literature (Kaplan & Sexton, 2005; Parens & Asch, 1999; Wilson, 2002).

Several patterns emerged from the data related to information and beliefs. First, and unsurprisingly, most participant comments and articles discussing information and beliefs were concerned (rather than hopeful) about the present state of information and beliefs about disabilities and genetics in the wake of human genetic research. Second, we identified four overarching themes related to concerns about information and beliefs: negative attitudes and perceptions of disability, lack of understanding and experience with disability, lack of understanding of genetics and science, and communication of attitudes toward disability and genetics. Third, each of these themes was supported by data from all three sources (literature, grassroots members, key informants) and all four disability classifications (intellectual/developmental, mental health, physical, and other) and by multiple interest groups in the interviews (consumer, professional, and analysts/advocates) and by both persons with disabilities and parents in the focus groups.

We detail each of these themes below. Because of the remarkable level of agreement across data sources and collection methods, we do not report findings for each method/source (focus groups, interviews, synthesis) independently. We do so because we do not believe it would add anything significant to the analysis and to avoid the redundancy of discussing each theme three times. Instead, we discuss the results of all three sources/methods together and provide examples from each. We avoid quantification of agreement (e.g., 5 of 9 focus groups or 3 of 10 interviews) on themes to avoid implying generalization of the results. Instead, we use commonly understood terms for the level of agreement (e.g., one, a few, many, most, and almost all). As these themes are, in many ways, interrelated and tend to overlap with others, we begin discussion of each theme with a concise statement relating its nature as discretely as possible before discussing the connections and the interrelations among the themes.

Negative Attitudes and Perceptions of Disability

Theme Description: Stereotypes and stigma related to disabilities are still prevalent and may fuel paternalistic attitudes or animus toward persons with disabilities and discriminatory genetic policies, practices, and individual decision making (e.g., such as with termination in response to prenatal test results).

One of the most common themes in the data related to information, beliefs, and genetic implications involved concerns that the public, the professionals', and the policy makers' views of persons with disabilities and their quality of life were based on stereotypes. Our respondents and the literature on present and on past experiences of persons with disabilities expressed the nearly uniform belief that there are widespread misperceptions of living with disability. Participants in both the interviews and the focus groups noted that typical perceptions of persons with disabilities solely concentrated on their disability and on their "suffering." As one focus group participant stated,

> There are conditions, disabilities, different things that happen where people are suffering, but the perception out there is that everyone across the board is suffering with a disability and that's not true. I mean there are people living day in/day out lives and being very productive and they're living with a disability. They're not suffering from a disability.

Participants were cautious not to generalize their own experiences to others, often either agreeing that some persons with disabilities did suffer because of their condition or qualifying their criticisms of disability-as-suffering perceptions by saying they were incorrect for many or most persons with disabilities. Other participants explicitly recognized disability as sometimes involving suffering and hoped that genetics would provide the means to treat or to cure disabilities so that "people in the future wouldn't have to suffer and the people who are suffering now could have all their pain and suffering removed."

Many participants discussed their own quality of life in reference to their hopes for genetic research. Some indicated that they would welcome a cure, whereas others felt that their quality of life with a disability was fine, that disability was part of their identity, or that disability had made them better or stronger persons. Yet a strong majority agreed that these were personal perspectives, and the choice to use or not to use genetic technologies to address disability was a personal decision. As noted above, almost all participants agreed that the overarching concern involved the extension of a single perception of disability to all persons with disabilities in an age of increasing availability and use of genetic tests and technologies.

Another concern related to overgeneralized perceptions of persons with disabilities involved reductionist attitudes toward disability. Participants believed that public perceptions of persons with disabilities were focused solely on their disability as the overwhelmingly dominant factor determining their identities, capabilities, and quality of life. Participants believed that such reductionist attitudes toward persons with disabilities were widespread and resulted in the unrecognized contribution of persons with disabilities to society:

> Once I was blind in my father's eyes, I was a useless child. He never said it, he didn't have to say it... within cultures, once a kid is disabled it is figured by the parents or the other family members, well, this kid is not going to be able to amount to anything....

Several participants were quite passionate about the reductionist myth that persons with disabilities could not work or otherwise contribute to society through their activities. They noted that history is full of examples of famous persons who made significant contributions to society and also had a disability (or what would be considered a disability today).

In addition to failing to recognize the abilities of persons with disabilities, many participants reported that the public viewed persons with disabilities as a burden on society because of their disability. A typical comment is from a focus group member: "People in... our society see people with disabilities as just a burden. It's just a drain of their time, their energy, and money." Some participants also expressed the belief that the general public blamed persons with disabilities for social problems (such as insurance cost). As one interview participant stated:

> ...everywhere we go the majority of the able-bodied public thinks that we are a big financial burden. We're just going to suck every bit of money out of the insurance system, out of Medicare. And then Medicaid, it's in bad shape because of us and we are just non-productive and we're never going to amount to anything. We're just going to have to be taken care of all of our lives...

Some participants even believed that persons with non-obvious or with "hidden" disabilities were often viewed with suspicion because they are seen as choosing to have or to maintain disability in order to gain benefits:

> Participant 1 (P1): This isn't a person's choice, which I think is a part of the dynamic; that people think the people with disabilities [could] choose to maybe not have a disability but choose to be [disabled]. Participant 2 (P2): To milk it for all it's worth. P1: Milk it for all it's worth, exactly. And

be manipulative and that's the issue of trust with people with disabilities confront too.

These subthemes related to burden and blame perceptions usually emerged from discussions about preventing persons with disabilities from being born, about mandatory testing and treatment, or about coercion to accept testing or treatment in clinical settings. Participants' concerns echoed those in the literature warning that blame for social problems and perceptions of persons with disabilities as a burden on society might increase as control over human genetics improves and disability is increasingly seen as avoidable or as a matter of choice (Andrews, 1995; Johnston, 2005; Marteau & Drake, 1995). Parens and Asch (2003) also clearly felt that pervasive negative attitudes would have a coercive effect on reproductive decision making based on prenatal screening results.

Lack of Understanding and Experience With Disability

Theme Description: Negative perceptions of persons with disabilities (stereotypes and stigma) stem from a general lack of experience with persons with disabilities in a personal or in a real-world context.

Many participants in both the focus groups and the interviews attributed negative perceptions of persons with disabilities (discussed above) to a lack of experience with persons with disabilities outside a clinical setting. Speaking about the general public's perceptions of disability, one focus group participant put it in these terms: "They have no frame of reference because they haven't lived with people with special needs. They haven't celebrated the joys and the happiness." In speaking about the perceptions of professionals, one interview participant specifically pointed at disability reductionism—equating the person with their disability—as the consequence of limited understanding of disability outside the medical context:

> And I think that's what I'm trying to get at. It's not looking at the whole person. Like the doctor... they know what they were taught, what they got from the textbooks. They know that kind of very clinical scientific part of it, but they don't know the human side of it.

These comments reflect the belief held by most participants that pervasive stigma and stereotypes of persons with disabilities (such as discussed above) are due to a lack of knowledge about the real lives of persons with disabilities. Participants largely agreed that people who lack real-world knowledge and experience with disability often believe the stereotypes and the myths about disabilities discussed above: That disability is the defining characteristic in a person's life, that all persons with disabilities "suffer" and could not have a high quality of life, and that persons with disabilities do not contribute to, and are a burden on, society. One focus group participant was particularly passionate in his concerns about the connection between inexperience and negative perceptions saying:

> It (disability) is seen as the end of, I mean,... there's the story of E.R., he's in an airport and a guy comes up to him and he said, if I were you, I'd kill myself. You know, and E.R. said to him,... you don't know what you're saying, you don't know what you'd do. People don't know what it is to be disabled but they see it as being the end of living. It's really horrible.

The few positive comments participants made about knowledge of disability related to the comparatively improved level of experience with disability due to both the inclusion of children with disabilities in regular education environments and the increasing presence of persons with disabilities served in community settings. Participants also suggested various ways in which inexperience with disability—and the resulting attitudes toward persons with disability—might be better addressed, such as through disability education for professionals (including genetic counselors and physicians), increased emphasis on parent-to-parent connections for information on disability quality of life, and written or multimedia information for prospective parents reflecting actual, real-world disability quality of life and family quality of life developed by persons with disabilities and their families (rather than health-related quality of life estimates designed and delivered by physicians).

As discussed in the Introduction, this corresponds to discussions of the contact hypothesis in the literature. It is interesting to note, however, that the literature was more critical of this lack of personal experience and understanding of disability—perhaps because of the emphasis on systems change in many such documents (Sensenbrenner, 2004).

Lack of Understanding of Science and Genetics

Theme Description: Myths about genetics (e.g., that genetics cause all disability or that genetic phenotypes are immutable) may reduce support for nonmedical interventions and accommodations and may foster discriminatory policies, practices, and decision making in pursuit of addressing the medical "problem" of disability.

Participants in the focus groups and the interviews discussed the reported misperceptions of and inexperience with persons with disability in response to questions about their concerns about genetic research, reflecting the belief that such attitudes and understanding would play an important role in determining the ultimate social, ethical, and legal implications of genetic research for persons with disabilities and their families. Similarly, a small number of participants in several different focus groups expressed concerns that misunderstandings and

lack of knowledge about genetics could also have deleterious implications for persons with disabilities and their families. These themes were not as common in the focus groups and in the interviews as concerns about attitudes and understanding of disability—likely because of the generally low level of understanding of genetics among participants—but what was stated was consistent and echoed by others in the focus groups after being introduced by a participant. These themes were discussed far more often and in more detail in the literature.

The literature specifically discusses multiple facets of public understanding of the limitations of genetics—knowledge of genotype—phenotype differences, knowledge about the accuracy of genetic tests, awareness of mutation as well as hereditary influences on health and impairment, and mutability of genetically influenced characteristics in response to environmental interventions (Beckwith, 2002; Freese, 2006; Hubbard & Wald, 1999; NIH Consensus Development Panel, 1997). Participants spoke in more general terms about public and professional understanding of genetics. The most common concern voiced by participants involved the concept of genetic determinism. The following comment by a focus group participant was typical and involved physicians and others treating genetics as if they determined the course and outcome of a person's life:

> ...Maybe with the result of the genetic testing... they say okay, this person is going to experience whatever it is. But they really don't know the full picture because there is such variability.... If the doctor thought... this is what you have and this is what it's going to mean and we can forecast this and yet they can't because... there is a lot of... interaction with your environment.... I think there's just a lot that is still not going to be known just because the genetics component of it becomes known...

An interviewee put this same concern a bit more concisely:

> I get that fear, you know, that we establish this deterministic, predetermined pattern for people based on what their gene shows us, when we know the environment plays a good part in a lot of development and success and capacity for people.

Participants in the focus groups and in the interviews also discussed some concerns related to the knowledge of patients (and science generally) with regard to the accuracy of genetic tests:

> P1: I had a friend who did have the amnio done and she was told that her child had Down's Syndrome. She got prepared for a child with Down's syndrome, and her baby was completely normal.... P2: ...we make those decisions based on that test, we don't really know what is the true accuracy.... I think you get into some sketchy science.

Another concept given significant treatment in the literature is the belief that genetics can provide universal solutions to the "problems" of disability. The literature discussed the "solution" issue as an aspect of scientism (Kliewer & Drake, 1998) or as the result of genotype (Hubbard & Wald, 1999) and geneticization (Hoedemaekers, 2001). Participants often implicitly discussed concerns about overreliance on genetic solutions in their discussions about genetic research as "playing god," as the limitations of medical approaches, and as the recognition of persons with disabilities as contributing to society and having a life worth living. Although the framing of these issues was different between participants and the literature, the general concern was largely equivalent.

Communication of Attitudes Toward Disability and Genetics

Theme Description: Communication of accurate knowledge about the disability quality of life and the limitations of genetics is currently inadequate to address the prevalence of stereotypes and myths, which are likely to become more, rather than less, prevalent due to ongoing inaccurate or negative portrayals in the media.

Many participants discussed concerns about attitudes toward disability and knowledge of genetics in relation to communicating knowledge about genetics and disability, specifically about the inability or failure of the health care and of the public service systems to improve knowledge and to dispel myths related to disability or genetics (or science in general).

A few participants expressed concerns about the difficulties in communicating sufficient and accurate knowledge of genetics to patients and to professionals. They noted the difficulties involved in disseminating scientific knowledge to professionals and the potentially disparate quality of care it creates:

> ...not all of the doctors in the whole wide world keep themselves abreast of the stuff that's going on and..., so while some specific doctors are presenting their patients with,... "you could decide to block this particular gene,"... it doesn't necessarily mean that the doctor in the next county over... is offering that same service....

But although there was some concern about dissemination of sufficient and of accurate information on genetics to patients and to professionals, there was also some sense that U.S. health care systems were fairly well set up to address such issues:

> I think I'd like to give credit to our country for the fact that we have the Food and Drug Administration, we have the National Institutes of Mental Health and

we have the National Institutes of Health and that we have a Surgeon General and,... we're all so organized in a way that our health care is carefully watched.

In contrast, most participants viewed issues related to communicating about disability as more serious concerns given the cultural pressure against discussing disability outside the medical context. One focus group participant illustrated what another participant phrased as "disability phobia," a cultural avoidance of the topic of disability, through a story that resonated with other members of the focus group:

P1: There was a friend of a family..., he had a burn on his back and it created a real odd pattern of skin texture on his back. And I was just a kid and I saw it, after I saw it, I couldn't help but say, "What's that?" I didn't know how to phrase it any other way. P2: Right. P1: And of course all the adults around were going, Shhhh.

Participants also expressed concerns about how public and professional communications propagated some of the myths and stereotypes related to disability. One participant noted that, in news reports, a person's disability is often mentioned prominently saying:

All people see is the anger and violence when there is some bad person who has a mental health disability on the news. They blame the mental health disability for the violence when it is just that the person is mean.

This comment echoes literature on the presumptive prominence and on the importance attributed to disability in media portrayals (Edney, 2004). As disability studies scholars have often pointed out, people with disabilities are portrayed as either heroes for overcoming their disabilities or victims of their disabilities. In either case, the disability is seen as both terrible and the defining characteristic of the person's life (Edney, 2004). Participants in the focus groups believed that popular media, TV, and movies tended to take a similarly reductionist and negative approach to disability.

...you were talking about the negative feeling about disability, it's very prevalent in our society... the two winners of the [2005] Academy Awards they were both movies about [suicide in response to disability], ... both the American Choice and the Foreign Choice.

Participants generally gave significant weight to media influences. Typical comments reflected criticisms of media-driven culture:

P1: Yeah, make a movie about it, and the people who are watching the movie, instead of looking, doing the research and the science, they will believe what you show them. That says something about us. P2: We're gullible.

Participants also voiced concerns about information communicated in the clinical setting, suggesting that the limited knowledge about and the experience of living with disability foster negative forecasts about what the life of a child diagnosed with a disability will be like:

I just wonder how much education parents get from doctors or who it's left to. Doctor's had given us the bleakest—and luckily she has not followed through on that path of having the worst possible scenario—but yes, that's what they gave us when she born. She wouldn't walk, she'd be in a wheelchair, we'd have to straight catheter her. Because I've heard many stories like that.

A few participants even voiced concerns about negative attitudes fueled by the very nature and context of the discussions surrounding genetics:

It seems to me there are two different receivers of the information; the individual who is faced with the knowledge of what they are carrying in the way of a child, for example, and the public, and I haven't really figured this out for myself..., and I won't say I am in favor of abortion, but as long as we keep on talking about the fact that we can get rid of the defective child, the public still sees disability as a terribly bad thing.

These participant concerns are similar to arguments in the literature that prenatal genetic screening inherently implies that something is "wrong" and must be addressed when a prenatal test is positive for a congenital disability (Parens & Asch, 1999).

Finally, some participants were concerned that scientists would focus public perceptions on the perceived "suffering" of persons with disabilities in order to foster support for genetic research:

If you're in this group of scientists and you want to do more study, you want to do more research in that direction,... You're going to march out a crippled or disabled, or handicap child, this is the people they're going to put out in front there.... They need us to use as their PR to further that research.

The Knowledge–Communication–Attitudes Model of Implications

Although the concerns related to negative attitudes, understanding, and communication were never fully brought together within the focus groups or the interviews, analysis

of the discussions around each subtheme strongly suggests a model for concerns about the implications of genetics in light of current, and likely future, knowledge and beliefs about genetics and disability. Discussions both within the focus groups and in the interviews reflected a belief among participants that attitudes, communication, and understanding are natural antecedents to individual and to societal actions. It is as though participants were saying "we act as individuals and as a society according to what we—or at least the majority—believe, communicate, and understand." Expectations and concerns related to what people know, think, and communicate are strong antecedents for what society, government, and individuals will ultimately do with regard to genetic research and persons with disabilities.

Analysis of these data showed that participant concerns about the implications of human genetic research are due in part to perceptions that incomplete knowledge of genetics and of negative views of disability will shape personal and societal decisions about the proper use and regulation of genetics. Participants feared that media and professional communications about disability would perpetuate the stigma and the discrimination already experienced by many persons with disabilities. Human genetic research, through this lens, promises to provide new tools to support old attitudes—those underlying discriminatory and invidious treatment against persons with disabilities.

Figure 1 visually depicts the logic of this concern in a model where knowledge of genetics and of disability is incompletely and inaccurately communicated (as represented by triangular "shards" of incomplete knowledge) to affect attitudes (whether newly formed or existing) toward genetic research and persons with disabilities that, in turn, influence decisions and actions that ultimately determine the implications of human genetic research for persons with disabilities and their families.

This model is, of course, an oversimplification of the complex factors that will ultimately determine what policies and practices society will adopt to guide the use of genetic technologies. Financial interests, active stakeholder groups (such as in the disability community), religious views, political efficacy, and a host of other factors will play a significant role in forging policy and practice the new era of genetic medicine. Nevertheless, this model may be more applicable to individual decision making with regard to genetics and to the concerns about "elective eugenics" voiced by Parens and Asch (1999)—termination of pregnancy in response to prenatal diagnosis of disability (or risk of disability) becoming increasingly widespread—although other factors such as religious beliefs will also play a role in reproductive decision making.

Discussion

The idea that what "we the people" say and think in a democratic society affects our actions as a society is neither new nor surprising, but only very limited research has examined whether attitudes about disability and genetics (such as those identified in this study) affect attitudes toward genetic policies or practices (Gollust et al., 2003). But as we showed in the Introduction, experience with disabilities—likely resulting in differing,

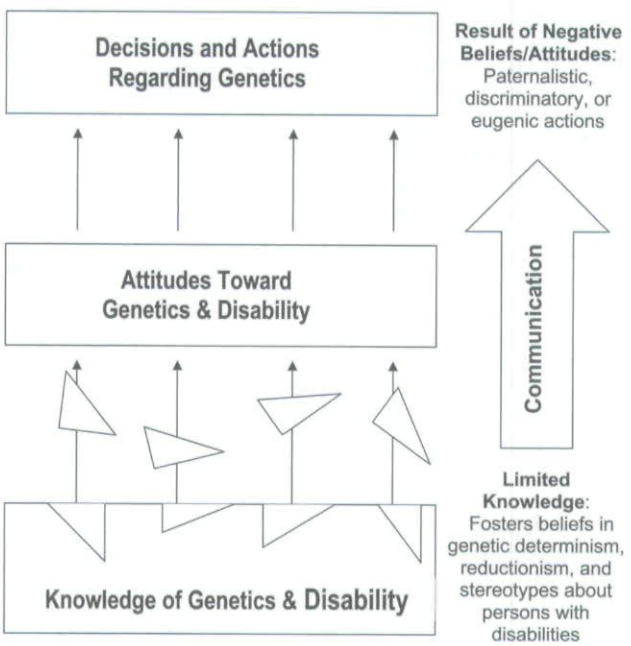

Figure 1. Knowledge–communication–attitudes model of implications.

and more accurate, perceptions of disability quality of life—have been shown to affect some individual reproductive decisions in light of genetic test results (Brunger et al., 2000; Middleton et al., 2001). These studies add credibility to the universal concern voiced by disability community members in this study about the effect of negative attitudes and perceptions of disability as genetic technologies become increasingly integrated into standard medical practice.

It is important to note here that the remarkable consensus in this study is only with regard to the problem that perceptions and attitudes toward persons with disabilities pose and the negative influence they may have on the use of genetic technologies. Participants and the literature are much more divided on which harms stemming from these attitudes are most likely to occur or most to be feared: discrimination in insurance and employment, reduced support for disability services or inclusion, prenatal screening and termination, or one of a host of others. But although concerns about harms differ, the apparent consensus in the disability community is that harms are likely to result if attitudes toward and perceptions of disability are not addressed.

An examination of the history of eugenics supports this conclusion, and the themes identified in this study related to knowledge and beliefs—negative attitudes and perceptions of disability, lack of understanding and experience with disability, lack of understanding of genetics and science, and communication of attitudes toward disability and genetics—are all reflected in the history of the eugenics movement.

A foundational principle of the eugenics movement was that fit members of society should not be compelled to shoulder the burden of the unfit. As one eugenics advertisement proclaimed, "some people are born to be a burden on the rest" (Black, 2003); or as a 1914 biology text explained, "they take from society, but they give nothing in return. They are true parasites" (Hunter, 1914). Disability was also portrayed by eugenics supporters as an overwhelming burden on both the individual and the family (Pernick, 1996). These views of persons with disabilities as suffering their own existence enabled eugenicists to argue that sterilization was humane because it prevented suffering in future generations by preventing children with disabilities from being born.

Together, these arguments proved to be effective and provided altruistic rationalizations for practices that, viewed from the "patient's" perspective, were inherently harmful. The negative perceptions of disability that fueled these arguments—fear/resentment toward and pity for persons with disabilities—although seemingly more severe than the stereotypes and the stigma identified in this study under the theme of negative attitudes and perceptions of disability, are qualitatively the same. Both focus on pity and fear, on burden, and on the unrecognized contributions and quality of life of persons with disabilities and their families.

Perhaps part of the severity of the negative perceptions of persons with disabilities in the eugenics era (as compared to today) was due—as hypothesized by many of our participants—to the low expectations for and experience with people living with disabilities (lack of understanding and experience with disability). The height of the eugenics movement predated the social model of disability, the civil rights movement, and inclusion. In short, the public had little experience with disability and had few opportunities to conceive of disability, in any terms other than medical (Braddock & Parish, 2001). Participants in our focus groups and interviews talked about the danger posed by the misperception of the actual quality of life and contribution of persons with disabilities. But in the early 20th Century, the stigma driving the eugenics movement reflected a misperception of potential quality of life; actual quality of life was probably low for many due to lack of services, supports, and higher expectations (Braddock & Parish, 2001).

In this difference between the past and the present lies potential hope for the future. We have obviously come a long way in recognizing and in protecting the rights of persons with disabilities, integrating persons with disabilities into our schools, workplaces, and communities, and we have reduced the prevalence and the severity of the stigma attached to persons with disabilities. The efforts of advocates have made an enormous difference. Recognition of rights and integration has had a substantial impact. But as our study shows, significant doubt remains. Persons with disabilities and parents of persons with disabilities are skeptical about whether we have made enough progress to prevent future discriminatory action in the research and in the implementation of genetic technologies.

Similarly, we have made enormous progress in our knowledge of genetics. Science has shown that few impairments have a simple genetic cause (i.e., Mendelian traits). Most biological impairments involve both multiple genes and complex interactions with various environmental factors (Hubbard & Wald, 1999). We also know that some genes may cause disease or impairment in one form (e.g., different alleles) but provide a benefit in another form—such as malaria protection for persons with the heterozygous form of the gene for sickle cell anemia (Howe, 2005). The list goes on and many of the assumptions and arguments of eugenics proponents have been put to rest by sound scientific methodologies.

Yet, the self-proclaimed objectivity of science—which provided a comfortable shelter from claims of bigotry, elitism, or discrimination in policies supporting eugenics—has not changed (Hubbard & Wald, 1999). Although maximizing objectivity is a staple of scientific rigor, it can also provide a scientific rationalization for social prejudice; eugenicists were just recognizing the facts, fundamental truths exposed through scientific methods. Science can and sometimes does still overreach. The methods of eugenic science were flawed, yes, but the real impact of

eugenics resulted from scientific beliefs that overreached the methods used and were seen by some as an answer to problems that are decidedly subjective and value-based—such as whether one believes in an intrinsic value to human life regardless of disability. Concerns about scientism in the literature, and implied throughout the focus groups and the interviews, suggest that overconfidence in scientific objectivity, reporting results that overreach the methods used, and pushing scientific answers for value-based questions were not washed away with the bad science of eugenics.

To a great extent, public attitudes and understanding of genetics and of disability are about communication. Eugenics began as a scientific endeavor, but eugenic beliefs were transmitted to the public through film (e.g., "The Black Stork”), science and biology textbooks, popular literature, college courses on eugenics, "fitter family" contests at state fairs, eugenic church sermons, news about eugenic science, and direct advocacy by a variety of groups dedicated to the goals of eugenics (Hasian, 1996; Rosen, 2004; Selden, 2000). During the 1920s–1930s eugenics, ideologies permeated U.S. media and culture. The participant comments and the literature show that media depictions, professional communications, educational institutions, and other methods of knowledge dissemination continue to support some stereotypes and misperceptions. Although such communications are less overt than in the past, they have not sufficiently changed to address concerns about the communication of myths and stereotypes about science and disability that can fuel stigma and discriminatory attitudes and actions.

Limitations and Recommendations for Further Study

There are several limitations to this study that must be acknowledged. First and foremost, it should be remembered that this is a qualitative study and even with the broad sampling and triangulation used by the researchers, the results cannot be generalized to the disability community as a whole or even any subgroup within the disability community. Second, the sample is likely to be biased toward self-advocates and family advocates because of our recruitment sources. Third, most of the parents involved in the study were in the intellectual/developmental group (19 of 25), although only 1 of the 8 persons identifying as both a parent and a person with a disability was in the intellectual/developmental group. Thus, the intellectual/developmental group was dominated by parents, whereas the other groups were largely dominated by individuals with disabilities. Finally, although one of the focus groups (ID/DD) was entirely parents and two focus groups were entirely persons with disabilities (one MH and one PD)—we did not specifically design the study to conduct focus groups specifically for individual and parent perspectives.

Another limitation of the study involves the groupings we did choose. We have not, as of yet, discussed between-group and within-group variation. We have deferred that discussion until now because (a) the data in the area of attitudes and beliefs toward genetics and disability showed a strong consensus across the methods, demographics, and classifications shown in the study and (b) the differences in perspective that did appear were not consistent among any of the classifications we have used. It is unclear to us whether this is due to the complexity and to the diversity of the within-group and between-group samples or other factors.

But although the groupings used in this study, and expected to result in differing perspectives on attitudes and beliefs—parent/individual, disability classification, race, gender, and interest group—did not do so consistently, some other possible factors were identified from analysis of notes taken during interviews and focus groups that seemed to have a greater effect on participant perspectives. Additional confirmation of the potential importance of these factors was also found in a subsequent search of the literature. These included the cultural competence component of trust (Metlay, 1999), the belief in the naturalness or in the wrongness of genetics (Sjoberg, 2004), disability identity (Hahn & Belt, 2004), and the quality and severity of disability experienced (Gollust et al., 2003).

In other words, trust in institutional structures, in stakeholder influence, and in leadership may reduce concerns about the impact of attitudes and beliefs. Belief in the wrongness or in the unnaturalness of genetics may increase fears and may promote negative predictions in all related areas. Greater self-identification of an individual as a person with a disability and as a part of the disability community may increase concerns about perceived threats to that identity or to members of that community. Finally, both the quality and the quantity of functional limitation, pain, social difficulty, and other reductions to the person's quality of life associated with the person's disability experience may effect perceptions of genetics and of medical science generally.

The researchers recommend that these factors be examined more closely in subsequent research to identify the quality and the significance of their effects on genetic perspectives among disability populations.

Conclusion

Scientific understanding of genetics has significantly improved since the eugenics era, but many of the beliefs that supported the popularization of eugenics remain. Attitudes toward science and disability have changed somewhat; but as our research shows, it is not enough for persons with disabilities to feel confident that their rights, dignity, and worth will be recognized and respected in the upcoming age of genetics.

Although the results of our study cannot be generalized to the disability community as a whole, it seems clear

that societal efforts to foster the benefits and to prevent the harms of genetic research must do more than simply educate the professionals, the public, and the disability community about genetic technology in order to calm their fears about the potential dangers of genetics. Genetics education efforts should also address the myths and misperceptions about disability and the limitations of science generally. Furthermore, the perspectives of persons with disabilities should be increasingly voiced and heard in the public dialog about genetics. Although the risks of a resurrected eugenics movement should not be overestimated, neither should it be ignored; nor is eugenics the only harm that could result from negative attitudes toward persons with disabilities. Neglect, human experimentation, harmful treatments, involuntary and unnecessary institutionalization, and abuse in the care of individuals with disabilities are also part of the history of medical science (Stowe et al., 2007).

As genetic technologies are increasingly integrated into health care (and other efforts to address societal problems), public and professional attitudes toward those vulnerable to discrimination and to invidious treatment become increasingly important. For these reasons, additional research to examine professional and public attitudes toward persons with disabilities and genetics should be pursued and programs to address common myths and misperceptions about disabilities should be created, enhanced, or otherwise supported—particularly those targeting genetic professionals, consumers of genetic services, and genetic policy makers.

References

Adams, M. (Ed.). (1990). *The Wellborn Science: Eugenics in Germany, France, Brazil, and Russia*. New York: Oxford University Press.

Allport, G. (1954). *The nature of prejudice*. New York: Addison Wesley.

Americans With Disabilities Act, Pub. L. No. 101–336, U.S. Code Title 42 (1990). The Public Health and Welfare, Chapter 126. Equal Opportunity For Individuals With Disabilities.

Andrews, L. (1995). Prenatal screening and the culture of motherhood. *Hastings Law Journal, 47*, 967–1006.

Andrews, L. (2001). *Future perfect: Confronting decisions about genetics*. New York: Columbia University Press.

Beckwith, J. (2002). *Making genes, making waves*. Cambridge, MA: Harvard University Press.

Black, E. (2003). *War against the weak: Eugenics and America's campaign to create a master race*. New York: Four Walls Eight Windows.

Braddock, D., & Parish, S. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 11–68). Thousand Oaks, CA: Sage.

Broberg, G., & Roll-Hansen, N. (Eds.). (2005). *Eugenics and the welfare state: Sterilization policy in Denmark, Sweden, Norway, and Finland*. Lansing, MI: Michigan State University Press.

Brunger, J., Murray, G., O'Riordan, M., Matthews, A., Smith, R., & Robin, N. (2000). Parental attitudes toward genetic testing for pediatric deafness. *American Journal of Human Genetics, 67*, 1621–1625.

Bryant, L., Hewison, J., & Green, J. (2005). Attitudes towards prenatal diagnosis and termination in women who have a sibling with Down's syndrome. *Journal of Reproductive and Infant Psychology, 23*, 181–198.

Buck v. Bell, 274 U.S. 200 (1927).

Carlson, E. (2001). *The unfit: A history of a bad idea*. Cold Springs Harbor, NY: Cold Springs Harbor Laboratory Press.

Chapman, E. (2002). The social and ethical implications of changing medical technologies: The views of people living with genetic conditions. *Journal of Health Psychology, 7*, 195–206.

Davies, H., & Crombie, I. (2001). *What is a systemative review?* Retrieved August 1, 2003, from http://www.evidence-based-medicine.co.uk/ebmfiles/WhatisSystreview.pdf.

Edney, D. R. (2004). *Mass median and mental illness: A literature review*. Retrieved July 10, 2005, from http://www.ontario.cmha.ca/content/about-mental-illness/mass-media.asp.

Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA: Sage Publications.

Freese, J. (2006). Commentary: The analysis of variance and the social complexities of genetic causation. *International Journal of Epidemiology, 35*, 536–537.

Gersten, R., & Baker, S. (2000). The professional knowledge base on instructional strategies that support cognitive growth for English-language learners. In R. Gersten, E. P. Shiller, & S. Vaughn (Eds.), *Contemporary special education research: Synthesis of the knowledge base on critical instructional issues* (pp. 31–79). Mahwah, NJ: Lawrence Erlbaum Associates.

Gollust, S., Thompson, R., Gooding, H., & Beisecker, B. (2003). Living with achondroplasia: Attitudes toward population screening and correlation with quality of life. *Prenatal Diagnosis, 23*, 1003–1008.

Hahn, H., & Belt, T. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior, 45*, 453–464.

Hasian, M. (1996). *The rhetoric of eugenics in Anglo-American thought*. Athens, GA: University of Georgia Press.

Henneman, L., Bramsen, I., Van Os, A., Reuling, I., Heyerman, H., Van der Laag, J., et al. (2001). Attitudes towards reproductive issues and carrier testing among adult patient and parents of children with cystic fibrosis (CF). *Prenatal Diagnosis, 21*, 1–9.

Hoedemaekers, R. (2001). Geneticization. In R. Chadwick (Ed.), *The concise encyclopedia of the ethics of new technology* (pp. 157–164). San Diego, CA: Academic Press.

Howe, E. (2005). *Untangling sickle-cell anemia and the discovery of the heterozygote protection*. Retrieved October 2006 from http://www.ihpst2005.leeds.ac.uk/papers/Howe.pdf.

Hubbard, R., & Wald, H. (1999). *Exploding the gene myth*. Boston, MA: Beacon Press.

Hunter, G. (1914). *A civic biology: Presented in problems*. New York: American Book Co.

Johnston, T. (2005). In one's own image: Ethics and the reproduction of deafness. *Journal of Deaf Studies and Deaf Education, 10*, 426–441.

Kaplan, D., & Sexton M. (2005). Disability community and identity: Perceptions of prenatal screening. Original publication in *GeneWatch, 14*, 6–8. Retrieved from http://www.ourbodiesourselves.org/book/companion.asp?id=31&compID=43#4.

Kliewer, C., & Drake, S. (1998). Disability, eugenics and the current ideology of segregation: A modern moral tale. *Disability and Society, 13*, 95–111.

Kramer, R., Jarve, R., Yaron, Y., Johnson, M., Lampinen, J., Kasperski, S., et al. (1998). Determinants of parental decisions after the prenatal diagnosis of Down syndrome. *American Journal of Medical Genetics, 79*, 172–174.

Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks: Sage.

Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Krugman, S. (1986). The Willowbrook hepatitis studies revisited: Ethical aspects. *Reviews of Infectious Diseases, 8*, 157–162.

Lakin, K. C. (1979). *Demographic studies of residential facilities for mentally retarded people: A historical review of methodologies and findings* (p. 8). Minneapolis, MN: University of Minnesota, Center for Residential and Community Services.

Lapham, E. V., Kozma, C., & Weiss, J. O. (1996). Genetic discrimination: Perspectives of consumers. *Science, 274*, 621–624.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lombardo, P. (2001). Eugenic sterilization laws. *Image Archive on the American Eugenics Movement.* Dolan DNA Learning Center, Cold Springs Harbor. Retrieved September 2006 from http://www.eugenicsarchive.org/html/eugenics/essay8text.html.

Marin, G., & Marin, B. (1991). *Research with Hispanic populations.* Newbury Park, CA: Sage Publications.

Marteau, T., & Drake, H. (1995). Attributions for disability: The influence of genetic screening. *Social Science & Medicine, 40*, 1127–1132.

Mashour, G. A., Walker, E. E., & Martuza, R. L. (2005). Psychosurgery: Past, present, and future. *Brain Research Review, 48*, 409–419.

McGee, G., & Magnus, D. (2000). Eugenics, ethics. In T. Murry & M. Mehlman (Eds.), *Encyclopedia of ethical, legal, and policy issues in biotechnology* (pp. 199–204). Hoboken, NJ: John Wiley & Sons.

Metlay, D. (1999). Institutional trust and confidence: A journey into a conceptual quagmire. In G. T. Cvetkovich & R. E. Lofstedt (Eds.), *Social trust and the management of risk* (pp. 100–116). London: Earthscan.

Middleton, A., Hewison, J., & Mueller, R. (2001). Prenatal diagnosis for inherited deafness—What is the potential demand? *Journal of Genetic Counseling, 10*, 121–131.

Middleton, C., & Biegert, M. (2005). Planning for the age of genetics: A Denver-based system makes ethical, theoretical, and practical decisions about genetic medicine. *Health Progress, 86*, 35–40.

NIH Consensus Development Panel (1997). Genetic testing for cystic fibrosis. *NIH Consensus Statement Online, 15*, 1–37. Retrieved September 2006 from http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat4.chapter.17667.

Ogawa, R. T., & Malen, B. (1991). Towards rigor in reviews of multivocal literatures: Applying the exploratory case study method. *Review of Educational Research, 61*, 265–286.

Parens, E., & Asch, A. (1999). The disability rights critique of prenatal genetic testing. *Hastings Center Report, 29*, S1–S22.

Parens, E., & Asch, A. (2003). Disability rights critique of prenatal genetic testing: Reflections and recommendations. *Mental Retardation and Developmental Disabilities Research Reviews, 9*, 40–47.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Pernick, M. S. (1996). *The Black Stork: Eugenics and the death of "defective" babies in American medicine and motion pictures since 1915.* Oxford: Oxford University Press.

Peters, K., Kong, F., Hanslo, M., & Biesecker, B. (2002). Living with Marfan syndrome III: Quality of life and reproductive planning. *Clinical Genetics, 62*, 110–120.

Peterson, A. (2006). The best experts: The narratives of those who have a genetic condition. *Social Science & Medicine, 63*, 32–42.

Pickens, D. (1968). *Eugenics and the progressives.* Nashville, TN: Vanderbilt University Press.

Reason, P., & Bradbury, H. (2001). *Action research: Participative inquiry & practice.* London: Sage.

Rosen, C. (2004). *Preaching eugenics.* New York: Oxford University Press.

Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data.* Newbury, CA: Sage.

Selden, S. (2000). Eugenics popularization. *Image Archive on the American Eugenics Movement.* Dolan DNA Learning Center, Cold Springs Harbor. Retrieved September 2006 from http://www.eugenicsarchive.org/eugenics/list3.pl.

Sensenbrenner, C. (2004). *Testimony on prenatal genetic testing technology.* Washington, DC: U.S. Senate Committee on Commerce, Science and Transportation Subcommittee on Science.

Singer, E., Corning, A., & Lamias, M. (1998). The polls-trends: Genetic testing, engineering, and therapy awareness and attitudes. *Public Opinion Quarterly, 62*, 633–664.

Sjoberg, L. (2004). Principles of risk perception applied to gene technology [Special issue]. *EMBO Reports, 5*, S47–S51.

Skinner, D., Sparkman, K., & Bailey, D. (2003). Screening for Fragile X syndrome: Parent attitudes and perspectives. *Genetics in Medicine, 5*, 378–384.

Stewart, D. W., & Shamdasani, P. N. (1990). *Focus groups: Theory and practice.* Newbury Park: Sage.

Stowe, M., Turnbull, R., Schrandt, M., & Rack, J. (2007). Looking to the future: Intellectual and developmental disabilities in the genetics era. *Journal of Developmental Disabilities, 3*, 1–64.

Wertz, D. C. (1999). Patients' and professionals' views on autonomy, disability, and "discrimination": Results of a 36-nation survey. In B. Williams-Jones & T. Caulfield (Eds.), *The commercialization of genetic research.* New York: Plenum.

White, C., Meunier, J., & SteelFisher, G. (2005). Public perception of genomics/genetic testing: CGAT survey results. *PharmaWeek.* Retrieved June 2006 from http://www.pharmaweek.com/Exclusive-Content/11-4.asp.

Wilson, J. (2002). (Re)writing the genetic body-text: Disability, textuality, and the Human Genome Project. *Cultural Critique, 50*, 23–39.

Wood, P. (2000). Meta-analysis. In G. M. Breakwell, S. Hammond, & C. Fifeschaw (Eds.), *Research methods in psychology* (2nd ed., pp. 414–425). London: Sage.

Yin, R. (1991). Advancing rigorous methodologies: A review of "Towards rigor in reviews of multivocal literatures...." *Review of Educational Research, 61*, 299–305.

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