Looking to the Future: Intellectual and Developmental Disabilities in the Genetics Era

Matthew J. Stowe, H. Rutherford Turnbull, III, Suzanne Schrandt and Jennifer Rack

Abstract

The disability community needs to become more aware and more involved in human genetics issues. This article is intended to highlight and discuss this need as it exists in the United States-although the issues discussed are often universal concerns. We begin by providing the context for our discussion with a history of the human genome project, medical science, and disability. We then discuss the limited role of disability community members in research and advocacy on genetic issues. We elaborate on these issues in six categories: (1) Health and medical; (2) attitudes and perceptions; (3) autonomy and self-determination; (4) discrimination or equality; (5) designing lives and the public health; and (6) family and society. We also discuss some of the existing responses that, through policy and practice, attempt to limit the harms and foster the benefits of genetic research in the United States. We conclude with our own recommendations for disability community involvement in genetics issues.

The 20th century, and the beginning of the 21st, brought significant changes to the field of intellectual and developmental disabilities. In the United States, for example, the last five years alone have evinced changes in policy and practice that include the emergence of the private school voucher movement, adoption of a new "gold standard" for educational research, major amendments to the *Individuals with Disabilities Education Improvement Act* (IDEA), increased pressure to reduce Medicaid funding (as well as other funding streams), and an increased emphasis on individual and family participation in service and policy decisions. These trends may have far-reaching effects on the quality of life of individuals with disabilities and their families. But they also beg these questions: What factors, now on the

horizon, will most affect persons with intellectual and developmental disabilities in the coming decades? How should persons with disabilities, their families, their advocates, and professionals prepare for these changes?

In this paper, we discuss one of these factors – research on human genetics – and its potential for broadly and directly affecting the rights and services of individuals with disabilities and their families world-wide. Although human genetic research is certainly not the only influencing factor on the horizon, it arguably holds the greatest potential for changing the ways in which disability is understood, classified, and responded to by law, by service provision, and by society at-large. We discuss other factors, such as funding and health care reform, as they relate to and may be affected by human genetic research. While human genetics research will have global implications, this paper will focus on the situation in the United States as a point of discussion.

We conclude the paper by asking the leadership of the disability field to remember that, in fashioning a brave new world, they are compelled to take into account science, policy (both exceptionalistic and generic), history and its lessons, and ethics and its precepts.

The Human Genome Project

In 1990, the U.S. Department of Energy and the National Institutes of Health, in cooperation with private and international research institutes, began a scientific undertaking of enormous proportions: the Human Genome Project (HGP). This ambitious initiative sought to identify all the genes that make up human chromosomes, which in turn constitute human DNA. DNA is the substance that, together with environmental influences, determines what biological traits we possess, including our potential, health, appearance, abilities, and impairments. Genes, the basic physical and functional units of DNA, carry information needed by our cells to make the proteins that carry out the necessary functions of cells, tissues, and organs of our bodies. In short, genes are the fundamental biological units that create life and contribute to our unique biological characteristics. They are also the primary unit of reproduction, the mechanism by which we transmit our biological traits to our offspring.

What does identifying human genes have to do with intellectual and developmental disability? The sequencing, or mapping, of the human genome has allowed, and will increasingly allow, scientists to identify genes that contribute to or even directly cause impairments. By identifying the

genetic factors influencing or causing disability, scientists may be able to create better ways to identify, classify, treat and ameliorate, prevent, or even cure some biological causes of intellectual or developmental impairment.

Yet the Human Genome Project also generates concerns about genetic discrimination, eugenic interventions, violations of privacy, decreasing social supports, unsound legal responses, and other ethical, legal, or social consequences that may directly or indirectly diminish the quality of life of persons with disabilities and their families.

Some genetic technologies, such as those that deal with genetic testing and screening, are increasingly becoming a part of regular medical practice. Techniques such as genetic therapy are just beginning to offer practical responses to genetically based impairments. Similarly, public and private responses to the use of such technologies are evolving. Laws have been passed in several states limiting the use of genetic information (Hall and Rich, 2000), and employers and insurers have begun to consider using, and some now do use, information from the research on human genetics to make decisions about employment and coverage (AMA Survey, 1999). The potential for the human genome project to broadly affect society, and particularly, members of the disability community – for good or for ill – is both profound and uncertain. The history of medical science sounds both a hopeful and cautionary note in this regard.

The Bright and Dark History of Medical Progress

The science of medicine has made astounding progress in the medical treatment of diseases and impairments in the last century. Since 1900, medical science has almost eliminated the incidence of some diseases, provided effective treatments for others, extended our lifespans, and reduced the functional impact of disease and impairment on our bodies. Modern medicine has given hope for life in the face of historically fatal conditions and reduced infant mortality. It has provided us with the means to reduce pain, anxiety, and monitor the conditions of our bodies. Rickets, diphtheria, small pox, whooping cough, measles, and polio – each at one time reaching epidemic proportions – are now rare or absent wherever there is access to modern medical facilities and services. The development of modern anesthesia, antibiotics, vaccines, surgical techniques, and modern pharmaceuticals have forever changed modern medicine by creating new options for preventing or treating disease and impairment and for ameliorating the pain and limitations that often accompany it.

But as bright as these accomplishments shine, the history of medical science also contains dark chapters in which scientific endeavours have resulted in violations of human rights and dignity. It is important to celebrate the accomplishments of medical science and continue to support research that may well provide medical benefits to persons with disabilities, but it is equally important to learn from the history of maltreatment of persons with disabilities as such research moves forward. In other words, we must endeavor to learn from the mistakes as well as celebrate the successes of medical science. Unfortunately, as a society, we have not effectively done so.

The blotches on the record of medical accomplishment are rarely acknowledged and are all too often glossed over as "bad science" conducted by a few, isolated "bad people." Such a casual dismissal of these events represents a serious injustice to those who suffered through them and presents a serious danger to those who may be subjected to similar treatment in the future. We must acknowledge the fact that human experimentation, widespread use of harmful treatments, involuntary and unnecessary institutionalization, and abuse and neglect in the care of individuals with disabilities, are also part of the history of medical science. Thus, before moving on to discuss the implications of genetic research, we provide some examples of maltreatment of persons with disabilities in the 20th century in each of the categories mentioned.

Human experimentation.

- From 1963 to 1966, the now infamous Willowbrook experiments were conducted. The Willowbrook experiments involved the injection of hepatitis into children with intellectual disabilities at the Willowbrook institution in New York to further the search for a vaccine (Krugman, 1986).
- 1932 marked the beginning of the Tuskegee Syphilis Study. In the Tuskegee study, 399 African American men, the majority of whom were illiterate sharecroppers, were diagnosed with late-stage syphilis, but were never told of their illness or provided any treatment, all so that researchers could track the progression of the disease. The experiment lasted almost 40 years (White, 2005a; White, 2005b; Rockewell, Yobs, & Moore, 1964).

Widespread use of harmful treatments.

- The frontal lobotomy (severing of the frontal lobes from the rest of the brain) was developed by Dr. Egas Moniz in 1936. Having gained widespread acceptance in the 1940s, the lobotomy was used

indiscriminately by many physicians without any surgical training and even by non-physicians on tens of thousands of individuals with mental illness between 1940 and 1951. Walter Freeman, a neuroscientist without any surgical training who popularized a modified form of the procedure, performed over 3,000 lobotomies – largely on people diagnosed with affective disorders (i.e., depression or anxiety). Side-effects related to the procedure included unresponsiveness, decreased attention span, blunted or inappropriate affect, disinhibition, postoperative seizure disorders, infections, and death. Dr. Moniz received the Nobel Prize for developing the procedure in 1949 (Mashour, Walker, & Martuza, 2005). While scientists eventually exposed the dubious efficacy of the lobotomy, its use did not end until after chlorpromazine was introduced in the 1950s.

Isolation, abuse, and neglect.

- In the U.S., by 1926, the number of individuals with intellectual and developmental disabilities involuntarily committed into overcrowded institutions "for their own good" or "for the good of society" reached 55,466. By 1967, that number had swelled to 200,000 (Lakin, 1979). Indiscriminate use of restraints and seclusion, forced labor, as well as other forms of exploitation, abuse and neglect, were common in such facilities during this period as smooth institutional operation and economic self-sufficiency supplanted treatment and education of the patients as the dominant priority. Widespread use of institutions as the de facto vehicle for "treatment" of disability did not decline until the deinstitutionalization movement gained significant momentum in the 1980s, and was due as much to concerns about the rising expense of institutional care as to the public exposure of widespread abuse and neglect of persons in institutions.

Eugenics and sterilization.

- The widespread acceptance of the flawed science of Eugenics in the early 20th century led to the involuntary sterilization of 60,000 American individuals suspected of having disabilities to prevent proliferation of genetically-programmed deviance (Allen, 2001). Eugenics theory during this period broadly attributed social harms, defined to include crime, poverty, laziness, mental illness, and disability, to the reproduction of the "unfit." Heredity and genetics allegedly were the root of all deviance and, thus, as susceptible to

> reproductive control as they were resistant to treatment. Eugenics proponents argued that the fit of society should not shoulder the burden of the unfit and that preventing the unfit from reproducing and simultaneously encouraging reproduction of the fit would alleviate most, if not all, social ills. This ideologically driven mandate was carried to the extreme in Nazi Germany when thousands of children and adults with disabilities were euthanized during World War II (Aly, Chroust & Pross, 1994; Friedlander, 1995). While revelations of the scientific bankruptcy of eugenics during the late 1920s and early 30s, and of Nazi genocide, brought an end to popular support for eugenics in the U.S. and elsewhere, eugenic policies and practices (i.e., involuntary sterilization) continued in the U.S. and Canada until the 1970s (Quinn, 2003).

The eugenics movement, arguably the most egregious example of how science can lead to maltreatment of individuals with disabilities, is particularly relevant to our discussion. While we should be cautious not to overstate the potential for genetic research to resurrect the flawed and inhumane laws and practice of the eugenics era, we must also be aware that eugenics and genetics grow from the same roots – the importance and effect of genes in determining the characteristics of persons and populations and the desire to develop technologies that will use this new knowledge to improve the lives of individuals and society.

Undoubtedly, the improvement of the lives of individuals and society is itself a laudable and altruistic goal, but, as the saying goes, the "devil is in the details." Clearly, the above examples of historic maltreatment demonstrate that altruistic intentions toward individuals with disabilities do not always translate into benefits for them and may even result in harm (or death) to their persons or their basic rights as human beings. The desire to improve society is even more suspect, as it also may result in the sacrifice of individual rights and well-being for prospective or hypothetical benefits to society at-large or the "normal" majority.

Fortunately, most harms (and unfortunately, most benefits) of human genetic research are still, at this point, a matter of speculation. But the speculative nature of such benefits and harms should not prevent us from anticipating the effects of such research. If individuals with disabilities, their families, their representatives, service providers, and policy-makers are to be prepared for the changes that human genetic research may bring, careful examination of the potential implications of human genetic research must be examined in advance of their impact.

The ELSI Project and the Public Dialogue on the Implications of Genetics

In 1990, the uncertain but compelling potential of human genetic research led the U.S. Congress to create and fund an initiative to investigate the *ethical, legal, and social implications* of the human genome project and to inform and educate stakeholders and the public about genetics and genetic issues. This project, dubbed ELSI, is tied into the funding of genetic research and serves as an ethical counterpoint to the human genome project. The ELSI project focuses on identifying the implications of scientific research before such implications become reality and fostering a dialog on those implications.

This proactive approach to the non-scientific implications of genetic research is unique in the history of science. Historically, both ethical and legal responses to new scientific discovery and innovation have been pursued retroactively, largely in response to problems and issues raised by the existence of particular technologies and associated or alleged harms and misuse of such technologies. By contrast, ELSI research aims to identify and examine social and individual effects of the Human Genome Project before they arise, so that responses to address such effects may be developed to prevent the harms and foster the benefits of the research.

Consider the opportunities presented by such a revolutionary approach to scientific inquiry. By calling for the ethical, legal, and social implications of scientific inquiry to be investigated, Congress provides an impetus for increased scrutiny of scientific findings by promoting a public discussion about research outside, as well as inside, the scientific community. This heightened attention is likely to foster increased questioning of the function and purpose of particular research efforts. What benefit does the research provide and for whom? What purpose does it ultimately serve? What interventions will it lead to and how will they be used?

Furthermore, the ELSI project demands that the implications for persons and society be examined broadly, not just with respect to health and physical well-being. It requires us to examine genetic research with an eye to equality and access, personal autonomy and responsibility, and the attitudes and perceptions of human worth that we as a society adopt and support. In short, the ELSI project challenges us to engage in a discussion, a public dialogue informed by specific research, on what we value as individuals and as a society, and to posit those values in a context of an emerging science.

The comprehensive potential of the human genome project – both to benefit or harm various sectors of society – brings with it the responsibility to ensure that the public dialogue is informed by a broad array of stakeholders and interest groups. Arguably, the most important groups to include in this discussion are those who have the most to gain from genetic research and those who are the most at risk from misuse of such research. As the above discussion of the history of medical science makes clear, persons with disabilities and their families fit into both of these categories. But despite the potential impact of genetic technologies on persons with disabilities, individuals with disabilities are not strongly represented in the dialogue about, or in studies of, the implications of genetic research.

To date, the disability community's engagement in public discussion over genetics has been limited to the following:

- The Arc, and a few other traditional disability rights and advocacy organizations, have initiated genetics education efforts and a discussion about genetics with their own membership (Davis, 1997). The Arc also has participated in the public debate when major federal legislation regarding genetics is proposed such as the Genetic Information Nondiscrimination Act of 2005.
- Disability organizations focused on medical advocacy and some disability-specific organizations – particularly those related to a known genetically-caused disability such as the Down Syndrome Guild – have been active in the public debate. The number of grassroots disability advocacy organizations represented in genetics advocacy groups, such as the Genetic Alliance, has increased, as have their advocacy efforts. Generally, these groups have focused on four concerns: (1) continued or increased support for the research, (2) genetic privacy (3) prohibition of genetic discrimination, and (4) availability of safe and effective genetic tests.
- Some ELSI research has reflected the views of some in the disability community. The Hastings Center, pursuant to a grant from the National Human Genome Research Institute, convened a group of representatives of the disability community and other HGP-stakeholder groups to discuss the disability rights critique of prenatal genetic testing. The Hastings Center project attempted to collect and find consensus among the stakeholder groups on the use of prenatal genetic screening technologies (Parens & Asch, 2003).
- Other ELSI research is currently being conducted at the Beach Center on Disability in Kansas. Its purpose is to identify the concerns and expectations of disability community members. The

> research is based on a theory of *vox populi*: the voice of the people most likely to be directly affected by policy and practice should emerge from peer-reviewed research methodologies. The Beach Center project is designed to broadly collect the perspectives of members of the disability community, including individuals with disabilities, their families, and their representatives, on the ethical, legal, and social implications of the human genome project. Additionally, the project examines the sources/origins, situations/contexts, timing, and potential impacts associated with each hope and each concern, and identifies possible responses – legal, social, education, or best practices – that might be used to facilitate the benefits and prevent possible harms of genetic research and technology development.

Although these steps are significant, many advocacy organizations are not yet actively engaged in the genetics debate. Research into human genetics and the development of genetic technologies has continued to move forward since the completion of the final draft of the human genome in 2003, but it seems to move forward without strong input from the disability community. This fact might reflect the perception that genetics is a medical rather than disability issue or that many of the benefits or potential harms have yet to materialize. It might also reflect the difficulty of educating and building consensus on the broad range of issues that genetic research raises.

While, generally speaking, persons with disabilities and their families are unlikely to know much about genetic research and its implications (there have been no comprehensive studies of the extent and nature of genetic knowledge among disability community members), what persons with disabilities, their families, and their advocates do know brings mixed responses. In a survey conducted in Great Britain, 53% of disability community members reported mixed feelings (hopes and fears) about genetic research and technology development; 73% believed that genetics would bring both benefits and problems; and an astonishingly high 94% believed that genetic technologies should be more tightly regulated (Fletcher, 1999).

In any case, failing to engage in the dialogue and to develop the *vox populi* of the disability community increases the likelihood that individuals with disabilities will disproportionately bear the burdens and experience harms from the development of genetic technologies while receiving little of the benefits.

Implications of Genetic Research for Persons With Disabilities

What, then, are the implications of genetic research and the human genome project for persons with disabilities and their families? What benefits may result from the research and what possible harms and misuse must be prevented? Although the research and emergence of the *vox populi* of disability community perspectives are limited, as we discussed above, some conclusions can be drawn about what some of those implications may be and what might be done to address them so as to facilitate the benefits and prevent potential harms from occurring. We address these questions below by first outlining implications identified through research, discussing possible responses to address these implications, and by then discussing the underlying issues in the context of genetics and other foreseeable societal changes.

Generally, we discuss the implications of genetic research and technology development for persons with disabilities in six parts: Health and medical implications; evolving attitudes and perceptions; effects on autonomy and self-determination; cultivating discrimination or equality; designing lives and the public health; and effect on the family and society.

The Health and Medical Implications of Genetics

Perhaps the best place to begin a discussion of the implications of genetic research is with the real and potential health and medical benefits coming out of the research. While such benefits and potential benefits are more regularly covered in news stories than other implications, the vast scope of such benefits are difficult for even the well-informed to fully appreciate. Consider the ways in which genetic research and technology development may eventually improve health care and medicine in the following four broad categories:

Diagnosis.

- Genetic tests and knowledge of the genetic roots of health, disease, and disability will allow early and better identification of health conditions. Genetic tests and increased knowledge of the genetic factors that contribute to diseases and disability may improve the ability of doctors to classify, diagnose, and identify particular impairments, including presently unknown diseases, unidentified genetic causes of disability conditions, and unidentified variations among existing disability classifications (Bobrow & Grimbaldeston,

2000). Genetic research has the potential to reduce mistakes in diagnosis by providing objective genetic tests for diseases and disorders that currently must be diagnosed through subjective observation of clinical symptoms.

Treatment.

- New knowledge of genetic components of disability and disease also fosters new methods of treating disease and disability, including the development of new, more effective drugs, improved methods of applying dietary, lifestyle, surgical, medicinal, and educational interventions, and even new methods of treatment such as gene therapy (Insel, 2003). Genetic research and technology development may even lead to ways to eliminate, correct, or reverse some existing diseases and disabilities and their effects (Gentry, 2000). It may even allow for such curative actions to be taken *in utero* – before the child is born (Walsh, 1994).

Individualization.

- In addition to helping develop new drugs and treatments, genetic research will allow the types and doses of drugs and other treatments to be tailored for each person and each condition. The use of individualized drugs or therapies could eliminate the need for a "shotgun" approach to treatment, namely, using drug cocktails and any and all available treatments to minimize symptoms without regard to the particular genetic characteristics of the individual (Buchannan, et al., 2002; Senituli, 2002). The current practice of providing treatments for a particular “disease” or “disability” would, thus, be replaced by an individualized approach that focuses on treating the “person” and the manifestation of the disease or disability within that person. This new approach would make it easier to anticipate and prevent negative reactions to particular treatments, drugs, or interventions and to choose interventions that are better calculated to provide substantial benefits to the individual (Patenaude, Guttmacher & Collins, 2002; Sharp & Foster, 2000).

Prevention and wellness.

- Understanding our genetic health risks will allow each of us to anticipate, prepare for, and sometimes avoid or reduce those risks. Personal health may benefit as the effect of various toxins and the interaction between genetic and environmental factors contributing to disease and disability are better understood (Sharp & Barrett,

> 2000). This new information about our genetic predispositions and early diagnosis of diseases and disabilities may provide new opportunities to employ preventive or ameliorative interventions (Davidson et al., 2000; Gridley, 2001). By identifying our risks for future health conditions, genetic research may allow us to employ lifestyle changes tailored to effectively reduce our personal risk of disease or disability (Jones, 1999).

In short, genetic research and technology development has enormous potential to improve health, reduce pain and suffering, ameliorate the biological effects of impairment, prevent disability, and improve the overall effectiveness of health care and other disability services. Other, less direct benefits to health may also result, such as a reduction of stress in persons experiencing disability or in the parents of a person with disability brought about by increased knowledge of the nature of a disease or disability. Genetic research may also foster increased understanding of environmental and other non-genetic causes of impairment by eliminating biological causes as potentially confounding factors in research on environmental causes of disability.

Finally, improved diagnosis, treatment, individualization, and prevention may provide substantial cost-savings that may, in turn, have a cascading effect upon health care – reducing the average cost of health care, thus reducing insurance rates, and thus, in the U.S., allowing greater enrollment in health insurance plans and broader coverage for those who already have insurance (Caperna & Curley, 2003). On the other hand, such cost savings and subsequent effects on health care coverage must be weighed with the concomitant potential for genetic research to increase health care costs (see below).

The potential for genetic research to provide real health and medical benefits is undeniable and many benefits are already beginning to emerge. Genetic research has already identified and created tests for genes that cause many common disabilities, such as fragile X (the most common inherited genetic cause of intellectual disabilities) and cystic fibrosis (the most common fatal genetic disease). More than 900 genetic tests already are in use (U.S. Department of Energy, 2005a).

While research has not yet developed treatments for these and other genetic conditions, early identification of genes for some conditions provides opportunities for the use of preventive interventions. For example, children diagnosed with phenylketonuria (PKU) receive significant benefits from

dietary changes – and in fact may even experience no deleterious effects from PKU if the congenital disability is identified early enough in development (U.S. Department of Energy, 2005a). For the vast majority of other conditions, early identification through genetic testing may mean more timely use of educational and supportive services to reduce the impact on a child's development (Wolery & Bailey, 2002).

Furthermore, new treatments are on the horizon for many genetic diseases. Gene therapy clinical trials are currently underway for such diseases as Alzheimer's (Seppa, 2005), cancer, Severe combined immunodeficiency (SCID), and HIV/AIDS (U.S. National Institutes of Health, 2005), although none have yet been approved outside of clinical research settings. Progress has also been made in identifying genes that cause adverse reactions to some drugs (U.S. Department of Energy, 2005b), an early step in the eventual individualization of treatment based on genetic traits.

It is these potential benefits to health and medicine that provide the primary motivation for continued pursuit of genetic research. But even as we acknowledge the positive potential for genetics to improve health and health care, we should also be aware of ways in which genetic research might actually cause harm or reduce health – so that such outcomes may be avoided. There are several dangers that should be highlighted, some that involve direct harms and some that create barriers to the actualization of the potential benefits promised by genetic research. These dangers relate to the conduct and sufficiency of the research, translation of the research into practice, and individual and public understanding and reaction to genetic research and technologies.

Conduct of the research. Research on human subjects or human biological material raises, and has always raised, issues of human subjects protection. These issues are neither new nor unique to genetic research, but are perhaps enhanced by the nature of genetic research and technologies. After all, genetic research involves the "building blocks" of our biology and sometimes, such as in the case of gene therapy, involves the manipulation of those fundamental biological units. Thus, the same qualities that provide genetic research its potential for positive change create an equally high potential for harm if human subject protection measures are not carefully followed.

Such was the case in a stage one clinical trial on gene therapy conducted at the University of Pennsylvania's Institute of Human Gene Therapy in Philadelphia in which one participant actually died (Thompson, 2000). The

tragedy of his death was compounded by the fact that neither he, nor any of the other participants, stood to benefit from the therapy they received as part of the trial – although some participants were apparently misled into believing they would. From the history of medical science, we know that such incidents are not unheard of, and persons with disabilities and those with significant medical needs are often the most vulnerable to unethical and harmful experimentation.

We should also consider the chilling effect that this widely publicized death may have on others who may have previously been willing to participate in genetic research. Poor human subject protection is likely to reduce trust in the scientific and medical communities and prevent individuals from participating in genetic research or even seeking or accepting beneficial genetic services. The result could be slowed progress in achieving the benefits of genetic research and a reduction in the public health benefits that such research may engender if integrated into routine medical care.

Sufficiency of the research. For human genetic research to fulfill its potential to provide health and medical benefits, the research – consistent with principles for scientific inquiry – must be valid, reliable, and sufficient in its scope. Increasing pressure for genetic research to show results may undermine these basic research principles. Some concerns about the quality of research samples have already been voiced, including a lack of sufficient diversity (particularly minority participation), limited cell lineages, and the effect of real or imagined consequences of participation on sampling (non-selection bias). Concerns also exist with regard to methodological errors and the lack of longitudinal studies to identify the long-term effects and side-effects of genetic technologies before they are approved for use. Still others have voiced concerns about genetic research conducted without consideration of the utility of the results (Berry, 2003; Kenen & Smith, 1995). Heritability studies, for example, have been criticized for not providing any actionable data – unless promotion of the importance of genetic research is the intended outcome of such research. In practice, flaws in the research may result in the use of genetic tests with low predictive value or a high rate of false positives/negatives, a lack of knowledge on long-term effects of gene therapy and other genetic treatments, or the proliferation of fraudulent or unsubstantiated tests and treatments.

Despite these concerns, perhaps the most prevalent fear about the sufficiency of the research is that it is not progressing quickly enough and that public or religious opposition based on other concerns (such as trust in the medical and scientific communities) will inhibit the realization of

benefits from human genetic research. This concern is particularly acute in the area of stem cell research since public opposition to stem cell research threatens to spill over into genetic research – whether or not a particular genetic research has any relation to stem cells – because of the public misperception that they are the same thing.

Translation of the research to practice. When genetic research does result in knowledge and technologies that may improve the health and medical care of persons with disabilities, such technologies and knowledge must be integrated into health care; these must be used by doctors and other health care providers. This translation of the research to practice includes its own challenges. Some fear that those who provide health care services, recommend medical treatment, or create policy will not be adequately informed about genetic technologies, genetic issues, disability, or cultural and religious beliefs to appropriately and competently diagnose, treat, educate, and counsel individuals seeking their expertise or create policy to regulate the provision of such services (Gentry, 2000). Adequate understanding of the effective use of genetic technologies, their risks and limitations, are necessary if they are to provide real benefits to consumers. Inadequate knowledge on the part of providers could result in inappropriate uses and undermine effective medical decision making (Roberts, Parrish, & Stough, 2002). Specifically, genetic tests or screenings may be performed without regard to the availability of treatment and intervention, or for the welfare of the person. Similarly, well-marketed genetic technologies may be used to treat diseases or disabilities in situations where using more effective, safer, and inexpensive non-genetic treatments would be more appropriate and beneficial to the consumer.

These concerns also relate strongly to another aspect of the economics of health care. Do we have sufficient resources to ensure that genetic knowledge and technologies are properly used by knowledgeable health care professionals?

Understanding and reaction to the research. Consumers of medical services are, in western health care systems, partners in medical decision making. Patients, or in the case of children their parents, must provide consent to recommended medical interventions before those interventions are provided. Thus, many of the potential benefits of genetic research are dependent upon consumer acceptance of genetic technologies as safe and effective. The same can be said of non-genetic interventions which may be sought less often, even when safer and more effective than genetic treatments, if consumer belief in genetic technologies surpasses the reality

of their efficacy. Furthermore, little is known about how people will react to increased knowledge of their own genetic predispositions and potentials. The choices people make in response to such knowledge, including lifestyle choices as well as medical decisions, could have a profound effect on individual and public health. Thus, several concerns exist with respect to how individuals understand and react to genetic research.

- The complexity of genetic knowledge and technologies makes understanding of their significance, limitations, attendant risks, and potential benefits difficult for the average consumer and creates the concern that people will make health care and reproductive decisions based on inaccurate, incomplete, or misleading information or preconceptions (Suter, 2002).
- Genetic testing and screening may create anxiety, stress, and/or fear in individuals, families, and the general public with regard to the effect(s) that the results will have on their lives (Chadwick, 1999; Kass, 2002).
- Individuals may pay less attention and/or assume less personal responsibility for their health due to the identification of the existence or non-existence of genetic risk factors. Wellness activities may be reduced as more emphasis is placed on the importance of genetic factors in health (Knoppers & Chadwick, 2005).
- Underlying distrust and fear with regard to genetics or scientific and medical professionals may lead some individuals to not seek medical care, not inform relations about known genetic risks, and avoid the use of genetic technologies that might otherwise provide them a health benefit (Anderlik & Rothstein, 2002; Andrews, 1995).
- An overemphasis on genetic causes of disease and disability may result in too little attention paid to environmental causes of disease and impairment such as toxic substances (i.e., lead, mercury, etc.) (Mowat, 2002). Genetic testing, for instance, could overshadow research on fetal development, injury, and maternal wellness as factors related to infant health. Hospitalization, drugs, and other medical treatments may become the *de facto* method for addressing impairment and the availability and research on other interventions such as counseling, physical therapy, behaviour modification, and educational interventions may significantly decline.

Finally, it is worth noting that genetic research is largely funded by public tax dollars through research grants to individual scientists and public and

private research institutions. As with all activities supported by public funds, genetic research is subject to public perceptions and political pressures. How the public, consumers, and individuals with disabilities react to genetic research, and the extent to which they understand it are, thus, important factors determining the direction and continuation of such research and in its ultimate translation to health benefits for individuals with disabilities.

Evolving Attitudes and Perceptions

It is hard to understate the importance of attitudes and perceptions when it comes to the creation of policies and practices affecting persons with disabilities and their families. Attitudes, perceptions, communication, and understanding are natural antecedents to societal actions. We act, as a society, according to what we – or at least the majority – believe, communicate, and understand. In other words, what people know, think, and communicate forms the basis for what society, government, and the people in general do.

It is also inarguable, when one looks at history, that scientific discovery can have a profound effect on the beliefs, values, perceptions, and attitudes of a culture or society. Consider, for example, the effect that the development of birth control has had upon the role of women in American society or that transportation technologies have had on the extended family. Genetic technologies hold similar potential for changing the way we view ourselves and, particularly, the ways we view persons with disabilities.

How genetic research and technology development affects our attitudes and perceptions is largely dependent on how we perceive and understand genetics. Two common misperceptions of genetics may pose particular problems: genetic reductionism and genetic determinism.

Genetic reductionism.

- Genetic reductionism occurs when – because of individual or public misunderstanding of the nature, role, and limitations of genetics – we equate our genetic traits with who we are as persons. In effect, people believe that "we are our genes." This fallacious belief, if adopted by society, would redefine personal and social identity as a matter of genetic test results rather than relationships, experience, and self-definition. Of relevance to this discussion, the current tendency for persons with disabilities to be equated with their disability – without regard to their other characteristics or inherent worth as persons – may be aggravated by genetic research

that describes the genome as a blueprint of the person (Elias & Annas, 1992; Greely, 1998; Parens & Asch, 2003; Senituli, 2002).

Genetic determinism.

- Genetic determinism involves the fallacious belief that genetics more or less pre-determines the course and quality of our lives. As genetic technologies allow us to know more about our genetic traits, people may come to believe that success in any particular endeavor depends primarily on genetic predispositions, or that personal health over one's lifetime is primarily a function of an individual's genetic characteristics. In short, there is a danger that people will believe that your genes determines your future. You will be good at math if you have "good math" genes; violent if you have "violent" genes; and live long if you have "longevity genes" – and *only* if you have those genes (Allen, 1999; Shannon, 1999).

When such reductionist and deterministic beliefs are adopted it becomes easy to make value judgments based on genetics. The over-importance of genetics inherent in these beliefs translates into stigmatized genetic characteristics, stigmatized persons, and even stigmatized families, since biological relations share genetic traits (Kissell, 2002; Phelan, 2002; Wertz, 1998). This stigma is particularly likely when the person manifests genetic characteristics in obvious ways, such as with a developmental or intellectual disability. Consider the thought processes that such beliefs engender:

- Individuals have disabilities because of genetic traits.
- Those traits make them who they are – disabled persons.
- Those unalterable traits predetermine the limitations on their abilities and potential.
- Since the cause is genetic, non-genetic interventions are fruitless attempts to change who they inherently are.
- Thus, it is a waste of limited societal resources to provide special education, assistive technology, and rehabilitation services to such individuals.
- Thus, such resources would be better spent in efforts to reduce the incidence of disability through control over transmission of genetic disease (reproduction).

While these attitudes may seem far-fetched to some in a modern world, they were some of the attitudes and perceptions that fueled eugenics era policies, and while the flawed science of eugenics has been exposed, there is little

indication that the unjust stigma attached to having "bad genes" has been as effectively eliminated. Disability stigma in the age of genetics may take a variety of new forms, or invigorate the old:

- People may increasingly ignore positive characteristics of individuals with disabilities, as part of the reductionist tendency to equate individuals with their disability or devalued genetic traits.
- People may increasingly assume that persons with disabilities who fall into broadly defined categories (such as developmental or intellectual disability) cannot learn, work, or live independently – they are, from a genetically deterministic perspective, inherently unable to do so.
- Belief in the immutability of disability may cause people to increasingly believe that the quality of lives of persons with disabilities can never be raised to a "normal" level, and that the lives of persons with disabilities are less worthy or not worth living at all.
- As genetic traits are identified as contributing to certain behaviours, genetic determinism and reductionism may result in the redefinition of social ills – such as poverty, crime, unemployment, and teen pregnancy – as problems with the genetics of individuals or groups within the population.
- Greater knowledge about, and the ability to affect, our own and our children's genetic characteristics may foster the belief that people are responsible and to blame for "bad" genetic traits or disability. Parents of children with disabilities may be stigmatized for having a child with a disability (e.g., perceived as having chosen to have a child with a disability) and persons with disabilities may be stigmatized for not having their disability "cured" (whether or not a cure is actually available).

Genetic research and technology have the potential to exert a powerful influence over how disability and persons with disability are viewed by both disabled and non-disabled member of society. Even religious and philosophical beliefs, and moral and ethical standards, may be affected by inappropriate searches for genetic answers to non-genetic problems, such as questions about the instrumental versus intrinsic value of life (Phelan, 2002).

But the idea that genetic research inherently must foster negative attitudes and perceptions is as false an assumption as genetic determinism. Genetic research may foster positive attitudes, for example:

- Greater understanding of the universal nature of "carrier status" and predispositions to one or more impairments may reduce stigma as more people understand that everyone has abilities and impairments, and that impairment is experienced to a greater or lesser extent by everyone. A more universal understanding of genetic difference among individuals may result in each person being respected for their capacities and offered opportunities corresponding with their strengths rather than just their needs (Elliott, 2001).
- Better understanding of the importance of the social and environmental factors that interact with genetic factors to effect health and inhibit or facilitate success in one's endeavours (Jones, 1999).
- Realization of the important role of genetics in disability may reduce the extent to which parents, schools, and others are blamed for the existence or persistence of disability (i.e., the all too typical attitude that the parents' child-rearing practices caused and/or perpetuate the child's disability) (Phelan, 2002).
- The public dialogue about genetics may help eliminate or reduce the fear and stigma through which persons with disability are perceived by the non-disabled by increasing public and professional understanding of the lives of persons with disabilities (Wilson, 2002).

In short, genetic research also provides opportunities for advocating for a more accepting, respectful, inclusive, and universal perspective on the disability experience. Which will come to pass, the negative or positive attitudes and perceptions, is difficult, if not impossible, to completely predict – but much depends upon what we do to affect the development of such beliefs.

Finally, it is worth noting that as genetic research expands our knowledge of genetic predispositions and genetic disease, the very definition of disability itself may change. The definition of what is and is not a disability may expand to include many diseases, disorders, medical conditions, or even common human traits that do not affect function and may even include typical and natural variations in ability or health among individuals. In a society that places a high value on quality, an unachievable and narrowly defined vision of human perfection may continually push the disability label on to more and more characteristics deemed less than desirable.

Effects on Autonomy and Self-Determination

As the history of medicine demonstrates, the desire to implement new methods for improving health can sometimes result in misplaced desires to make decisions for persons with disabilities "for their own good" or "for the good of society." This paternalistic approach to addressing disability has haunted the history of medical treatment and continues to affect the provision of services even as disability advocacy groups argue for greater individual and family control over decision-making.

The promised health benefits of genetic research may reinvigorate the old arguments for paternalism and undermine the self-determination of individuals with disabilities and their families – or that of persons without disabilities. Whenever there is a means through which public health may be improved, there are those who advocate for its mandatory application to all; such advocacy can lead to the possibility that otherwise autonomous decision-making will be tainted by coercive social pressures. Thus, several concerns exist with regard to the implications of genetic research for personal autonomy in health care, reproduction, and service decision-making – some related to direct limitations on choice and others related to the nature and adequacy of information provided to inform personal decision-making.

Specifically, several possibilities exist that would place limits on the rights and opportunities for persons with disabilities to participate in service decisions:

Mandatory testing and treatment.

- Genetic screening programs or even genetic treatment programs may even become mandatory in order to advance public health objectives or achieve cost savings in education and health care. Furthermore, employers or insurance companies may require testing or treatment as a precursor to employment or coverage – hiring and covering (in their insurance benefits package) only those whose genetic profiles do not implicate a likelihood of high medical costs in the future (Andrews, 1995; Johnston, 2005; Wertz, 1992).

Testing and treatment without consent.

- Real choice requires an opportunity for decision-making. Integrating genetic information and technologies into standard medical practice may lead to reduced opportunities for individuals to make decisions about things that affect their lives, such as

whether to consent to or refuse genetic testing or treatment. Genetic tests may be inserted into routine screening panels for which specific consent to each test is not sought (Andrews, 1995). Tissue samples, DNA, or genetic information collected and stored for one purpose (assumedly a legitimate purpose) may be kept and stored for future uses for which consent will not be sought (Elias & Annas, 1992; Greely, 1998).

Even if opportunities are provided for individuals with disabilities to make decisions with regard to genetic tests and treatments, such choices may not be sufficiently supported or free of outside influence:

Consumer understanding.

- Real choice requires, in addition to the opportunity to make a decision, adequate information upon which to base a decision. The complexity of genetic information and technologies makes understanding of their significance, limitations, attendant risks, and potential benefits difficult for the average consumer and creates the concern that people will make health care and reproductive decisions based on inaccurate, incomplete, or misleading information or preconceptions (Andrews, 1997; Suter, 2002). It also creates a greater potential for individuals to be misled by companies offering unproven or even fraudulent genetic testing and treatment services.

Coercion.

- Professional, economic, and social pressures may undermine individual decision-making and coerce a particular testing or treatment decision. The influence of health care professionals who suggest that only one choice is the right one and the social stigma of disability may create significant pressure for individuals to consent to particular genetic tests or treatments (Suter, 2002). Insurance companies and social programs may even use coverage limitations and eligibility requirements to force individuals to make decisions that provide cost-effective outcomes regardless of actual risks, potential benefits, and quality of life outcomes for available options. The issue of coercion is particularly troubling with respect to reproductive decision-making. Prospective parents, particularly those who already have a child with a disability, may be pressured to consent to having their own genetics tested or to pre-natal testing, and, in the event of test results indicating a high risk of disability, pressured to avoid procreation or terminate a pregnancy

> (Davidson et al., 2000; Walsh, 1994). Some insurance companies already provide coverage for abortion if (and only if) prenatal tests indicate a high probability of a congenital disability. Research revealing that an estimated 80 percent of women terminate their pregnancies following a prenatal diagnosis of Down syndrome and that health care provider communications may play a strong role in those decisions lends significant credence to these concerns (Kramer et al., 1998).

Given the amount of influence, physicians, genetic counselors, and other health professionals have over their patient's decisions, if the information on disability and genetics provided to parents is biased or incomplete, or if the advice that health professionals provide is directive, the right of parents to reproductive decision-making may become largely illusory. Some disabilities rights advocates have argued that pre-natal genetic screening is inherently coercive because it suggests that some action must be taken in response to a "positive" finding of disability. In the absence of any treatment options (there are currently no pre-natal treatments to prevent or cure disability), the only "action" that can be taken is termination of the pregnancy.

Simply put, genetic research, and particularly the availability of pre-natal genetic testing, may have the result of pressuring prospective parents to abort fetuses identified as having a high risk of disability for the good of the family, the good of society, or ironically, the good of the child.

Finally, it is worth noting that increased disability stigma and the perception of genetically-linked disabilities as transmissible (though reproduction) may engender increased support for restrictions on the personal liberty of individuals with disabilities, such as through institutionalization or quarantine, in the name of public or individual health. Institutionalization, mandatory or coerced sterilization, or quarantine might be used to prevent an imagined epidemic of genetic disease or simply to reduce the incidence of unvalued characteristics by preventing those found to have such characteristics from having access to potential reproductive partners (Holland & Clare, 2003).

Yet such outcomes are not what is envisioned by most genetic researchers and are far from certain. In fact, genetic research and technology has the potential to increase opportunities for exercising choice by increasing the number of testing and treatment options available. In some cases, genetic research and technology may provide health care options where previously there were few or none at all. Certainly an increase in such options provides

increased opportunities for individuals and families to take control of their health and health care – but only if they are given the opportunity to make such decisions, are reasonably free of outside pressures, and have sufficient information to make their decisions.

Cultivating Discrimination or Equality

With increased availability and use of genetic technologies to identify an individual's predispositions to health and disability (and potential for having a child with a disability) comes the concern about what is done with that information. Employers, insurers, adoption agencies, and others might use such information to deny employment, insurance and other benefits, eligibility, or to otherwise discriminate against individuals and families based on their genetic information (Caperna & Curley, 2003).

Genetic testing and technology use can serve legitimate medical purposes for individuals and their families. So even if the fear of mandatory testing, discussed above, is addressed, the genetic information on individuals with and without disabilities and their families is likely to be collected. There is, therefore, a rational concern among disability rights advocates that provisions are made to keep such information confidential. Several challenges exist to ensuring confidentiality of genetic information:

Ubiquitous genetic samples.

- The genetic information of individuals or families may be acquired through testing of genetic material that was not collected through consensual sampling. Individuals who are deceased (but genetically related to living persons) or sloughed skin and hair provide non-consensual opportunities to collect genetic material. As part of the natural course of cell death we drop material everywhere we go. A trip to the barber's shop alone involves leaving enough genetic material for hundreds of genetic tests on the floor as we leave. What prevents the barber from selling such material for genetic research? What about trace genetic material we leave at work, or in the homes of others? It is difficult, if not impossible, to ensure that samples of our genetic material are not in the possession of others (Caperna & Curley, 2003).

Information of biological relations.

- Your genetics are not entirely your own – you derived them from a combination of your parents' genetics (although mutation also

provides some variance) and so did your siblings. This interrelation of genetic information among family members means that disclosure of your genetic information also provides genetic information on your biologically related family members. Privacy of individual family members may be compromised by genetic testing of their relations (Anderlik & Rothstein, 2001). Families or individuals may ultimately be denied employment or insurance coverage due to genetic information derived from genetic tests of one or more relatives or from family histories (Senituli, 2002). This also raises a concern about whether a physician has a duty to warn individuals about the implications of genetic test results of their biological relations. If, for instance, your sibling is found to have a gene that creates a significantly increased probability of Alzheimer's and as a sibling you have a 50% chance of carrying that same gene, should the doctor warn you of the possibility or keep the information completely confidential?

Genetic databases.

- Compounding the issues involved in keeping genetic information confidential is the proliferation of genetic databases by public and private entities. These genetic databases are generally formed for a specific purpose such as to identify criminals, establish parentage, or examine genetic characteristics of populations. Yet the storage of genetic information creates concerns over who has access to such information (including security concerns), the extent to which the information can be specifically attributed to individuals, and the protections that are or should be in place to ensure that the information is used only for the legitimate purposes for which it was collected (Elias & Annas, 1992; Greely, 1998; Knoppers &Chadwick, 2005).

Required disclosures.

- Even assuming you have the right to consent to or refuse genetic tests or treatment, do you also have the corresponding right to keep confidential the results of genetic tests when you consent to their use? Insurance companies, employers and others, even if prohibited from requiring genetic tests, may require individuals to disclose the results of any genetic test he or she has had performed, either explicitly or by making eligibility, employment, or needed services contingent on "voluntary" disclosure.

If genetic privacy is not ensured, individuals with particular genetic traits may experience discrimination similar to that experienced by individuals with disabilities, even though they do not presently experience any form of impairment. Individuals labeled with "carrier" status, those who have a family member with a genetically-linked disability, those who have genetic traits that create the possibility of future disability, or those whose genetic traits create a susceptibility to certain environmental hazards all may face discrimination (Davidson et al., 2000; Gridley 2001).

Public and private entities may establish eligibility criteria or make programmatic decisions that discriminate against individuals or families with particular genetic characteristics in a wide variety of contexts:

Insurance discrimination.

- Genetic research and technology, as aptly put by Senator Clinton, may create the "mother of all pre-existing conditions," (Clinton, 2005) as people with undesirable genetic test results, family histories, and genetic propensities may be denied insurance, charged higher premiums, or be required to accept coverage limitations related to their genetic propensities to illness or disability or the likelihood that a family member or future child will have a disability (Caperna & Curley, 2003; Wexler, 1990).

Employment discrimination.

- Genetic research and technology may also foster discriminatory treatment in employment, and particularly in hiring. Employers are the primary provider of health insurance coverage and their rates are often subject to the costs of health care for their employees. Furthermore, illness and disability can cause absence from work and other economic impacts upon employers. Thus, employers are generally motivated to hire those who are less likely to experience health problems or disability. The availability of genetic information may provide employers with a new means to screen prospective employees to ensure that individuals with disabilities and their families do not affect the “bottom line” (Buchannan et al., 2002; Kissell, 2002).

Other contexts for discrimination.

- Discrimination can also occur in adoption, criminal investigations and prosecutions, and in education, and can involve a broad spectrum of discriminatory treatment other than just eligibility.

> Preference may be given to parents who wish to adopt if they show a genetic predisposition to health and long life. Genetic information related to anti-social behaviour might be used in place of actual motive in criminal prosecutions. Prosecutors might thus claim, "He did it because his genetics create a propensity to unpredictable violent behaviour." On the other hand, criminal behaviour might be defended on the grounds that an individual's genetic proclivity for a behaviour renders him incapable of the requisite control or intent to break the law. In education, genetic classifications might form the basis for exclusionary placements, especially if accompanied by the belief that a genetically affected characteristic is largely immutable (as discussed under attitudes and perceptions). For example, if disruptive behaviour is perceived as a matter of genetics alone (or primarily), behaviour interventions may be regarded as generally useless and thus removals and segregated settings may become the de facto means of "managing" behaviour problems.

While concerns about widespread genetic discrimination are still somewhat speculative, anecdotal evidence and preliminary investigation into the topic has already identified situations in which genetic discrimination has occurred (Joint Government Report, 1998).

In addition to adding genetic characteristics to the roster of attributes vulnerable to discrimination, genetic research and technology may also aggravate existing discrimination against persons with disabilities and their families in two ways:

Unequal access/benefits.

- Disability discrimination and the cultural, ethnic, socio-economic, and gender discrimination that commonly co-occur with disability discrimination may be aggravated by unequal distribution of the benefits of public services, health care resources, and genetic technologies. Economically challenged groups may not be able to afford genetic technologies or health care. Indeed, it may well be that only the rich or upper middle class will be able to afford many of the benefits of research that has been funded, in part, by public funds (Elias & Annas, 1992). Genetic services may not be delivered in ways that are responsive to cultural differences. Resources drained by genetic research may not be available for individuals whose conditions are not genetic or whose conditions are too rare to attract fiscally motivated private entities to develop appropriate health care services.

Discriminatory use of genetic research and technologies.

- Knowledge about human genetics and new genetic technologies may also provide additional fuel for existing discrimination against women, people with disabilities, or individuals of diverse cultural, ethnic, or socio-economic status. Ethnic profiling based on genetics or the over-representation of minority groups in genetic databases may create disparities in criminal investigations, prosecution, and sentencing. Race-based or gender-based genetic research may be used to defend discriminatory treatment in public and private programs, based on an alleged genetic characteristic commonly occurring or not commonly occurring within a particular gender or ethnic group (Sharp & Foster, 2000). Claims by Lawrence Summers, president of Harvard University, that genetic aptitude might explain why fewer women than men earned top scores in high school math and science tests provides a recent example of such thinking (Bombardieri, 2005; Summers, 2005). Finally, genetic technologies may be used to select for "preferred" ethnicities or gender in childbirth – a practice that has been observed with a fair amount of regularity in other countries (Robertson, 2003).

Yet, the potential for discrimination created by genetic research is accompanied by possibilities for greater equality. As with its effect on attitudes and perceptions and with the evolution of autonomy and self-determination, genetic research can be used to forward or reverse the course of discrimination toward individuals with disabilities and others. In addition to generally changing discriminatory attitudes (discussed above) and improving function and opportunities through improved treatment (e.g., normalization), genetic research may reduce discrimination by increasing understanding and acceptance of human variation among individuals and cultural or ethnic groups – thus eliminating stigmatizing and demeaning stereotypes attached to such groups.

Genetic research may also focus on the investigation of diseases and complications that disproportionately affect minority groups because of differences in genetic predispositions to disease, drug metabolism, and genetic risks or vulnerabilities to environmental factors. For example, the National Human Genome Research Institute has, in the past, released several grant programs with this specific purpose in mind and continues to support pre-doctoral and post-doctoral grants to minority students to increase minority representation in genetic research activities (National Human Genome Research Institute, 2006).

Public Health, Designing Lives, and Eugenics

For those in the field of public health, genetic research and technology development provides the most potentially fertile method for general improvements in societal health since the invention of the vaccine. The revolutionary improvements in diagnosis and treatment that genetic research promises to provide could usher in a new age of biological well-being in which individuals, made cognizant of their genetic health risks, change their lifestyles and receive preventive treatments that minimize the occurrence of genetically-related disease and disability. Of course, this assumes that people will actually take advantage of the new technologies and change their behaviours to minimize genetic risks. This is a somewhat uncertain assumption given, for example, that research has shown increasing obesity and decreasing activity levels among Americans, despite common knowledge that a moderate diet and regular exercise will improve health and longevity.

Yet, even if Americans do not always change their behaviours to maximize health, they do, generally, avail themselves of medical technologies and pharmaceutical interventions to treat health conditions, and genetic science certainly has potential for improving existing drug treatments and providing new, genetically-based treatments. One of the most promising of such genetic technologies, one that potentially could be used to cure any congenital disability, is genetic therapy. If the occurrence of a particular gene mutation causes a genetic disease, gene therapy may “simply” may be able to repair or replace that gene with a "normal" one.

But, as exciting as the possibility of such a broad ranging cure is to some, public health efforts generally focus on prevention. Thus, a particular type of genetic therapy, called germ-line engineering is, from a public health perspective, the holy grail of genetic technologies. Germ-line genetic engineering involves changing the genetics in the reproductive cells of the subject so that undesired genetic traits are not inherited by any children the subject might have after the procedure.

While genetic engineering is currently still more science fiction than science fact, recent strides in genetic technologies remind us that it is just a matter of time before the fiction becomes reality. Prenatal genetic tests already allow us to identify many of a prospective child's genetic traits. How long will it be before we can effectively choose some of the genetic traits of our children? Fifty years? Maybe twenty? Parents conceiving through in-vitro fertilization already have some opportunities to "choose" their child's biological characteristics by choosing which fertilized eggs are transplanted and which are not based on the results of genetic testing.

Our knowledge and ability to select or alter genetic traits will continue to grow and we will eventually be able to substantially influence the genetic traits of our children and even alter our own. But, for many, these technologies present the most troubling ethical issues in genetic research. The ability, as individuals and as a society, to select the genetic characteristics of our children and maybe even alter our own seems, to some, uncomfortably close to playing God. Such awesome power to shape our own biological selves begs the question: should we? And, if so, for what (and whose) purposes? Before genetic engineering technologies come into their own, we as a society would be wise to find some answers to these questions.

So, to begin, let's suspend our disbelief for the moment and delve into some of the most speculative concerns regarding genetic research and technology:

Pandora's Box.

- Many believe abuse of genetic engineering technologies is inevitable, that no matter how we try to limit the use of such technologies, people will find a way to use them in ways that are entirely unethical (even assuming a clear line between ethical and unethical uses of such technology can ever be drawn and agreed upon in the first place). The range of possible abuses of genetic technologies is as broad as the human imagination and ranges from the use of genetic enhancement for personal vanity, to designer babies, to the creation of human-animal hybrids. Some might argue that the popularity of plastic surgery, the desire to give our children every advantage, and the actual creation of various animal hybrids (such as the glowing rabbit created by a French artist/geneticist) (Kac, 2000), support these fears.

Under- and over-valued traits.

- What genetic traits we ultimately select in reproductive decision-making or target for genetic enhancement, reflect the characteristics that we value as individuals and as a society. Often traits such as athleticism and high intelligence are considered to be of "unarguably positive value" even though they show no correlation with higher quality of life for the individual. What they do provide is an advantage in obtaining what western society has determined to be the high marks of success for our children – excellence in sports and academics. Other characteristics, more unarguable in their benefit to the individual (such as increased resistance to disease), or arguably more beneficial to society (such as altruism), receive significantly less attention and are likely to be

undervalued. Offering another example, it has been noted that there is a certain correlation between some mental instabilities and artistic achievement, but will parents select their child to be the next Van Gogh if it means the child will have mental health issues as well as artistic ability?

Loss of individuality/identity.

- If we can select the genetic characteristics of our children and everyone selects from a menu of commonly accepted beneficial genes, the differences among individuals will narrow and individuality and personal identity will be undermined. Would we create a normalized or "vanilla" society that lacks diversity? Would art and music and creativity suffer? Would, for example, athletic competition be meaningless in a world where there is no shortage of Michael Jordans? (Shakespeare, 2003)

Having discussed the more speculative genetic concerns about the distant future, it seems appropriate to now discuss a concern about genetics with a far greater basis in history: eugenics.

Eugenics

Eugenics, which directly translated from its Greek roots means "good birth," was the name given to a scientific and political movement in the early 20th century that sought to improve society through controlled reproduction. As briefly discussed above in the review of the darker chapters in medical history, the eugenics movement justified its approach as being based on genetic science. But, while the science of genetics may have provided the spark for the eugenics movement, the impact of the eugenics movement far outlasted its scientific roots. Policies in favor of mandatory sterilization continued to be implemented until the 1970s. But why did the policies not evaporate when the science originally used to justify them was discredited? And could new genetic research bring a return to such policies?

While one might argue that many factors contributed to the continuation of eugenic policies into the latter half of the 20th century, a few factors, all of which involve attitudes and perceptions towards genetics, social responsibility, and impairment, seem almost inarguably preeminent. The history of eugenics is a political history that involved the application of scientific solutions to a wide range of social problems that were reframed as being the work of genetic factors (Allen, 1999). For example, crime, immigration, unemployment, and poverty were severe social problems that

eugenics advocates believed could be eliminated by encouraging births by "fit" parents and preventing births by the "unfit." The presumed certainty of scientific methods and the reputations of professional experts were an attractive combination for responding to social turmoil (Allen, 1999).

The self-proclaimed objectivity of science also provided a comfortable shelter from claims of bigotry, elitism, or discrimination in policies supporting eugenics. Eugenic proponents could claim that they were just recognizing the “facts,” fundamental truths exposed through scientific methods. Such thinking was not considered ideological, or favourable to particular groups or interests, or potentially harmful. Instead, calling on medical and scientific “expertise” was simply seen as common sense. To argue against this perspective was to risk the appearance of opposing progress, science, and both the present and future welfare of the human race.

American eugenicists popularized eugenic science by marketing the potential of eugenics as a revolutionary scientific theory and by stigmatizing the "unfit" (immigrants, persons with disabilities, the poor, unwed mothers, etc.). Eugenics proponents claimed that individuals with disabilities, immigrants, and others possessed inferior genes, that they were the root cause of societal ills such as poverty. They were to be feared for the harm they brought and pitied for their immutable and inferior lives. Eugenicists argued that fit members of society should not be compelled to indefinitely shoulder the burden of the unfit. As one eugenics advertisement complained, "some people are born to be a burden on the rest" (Mehler & Allen, 1977).

It was these historical, and tenacious, beliefs and attitudes that arguably supported the continuation of eugenics policies long after the science was discredited and which, for that matter, gave birth to such policies in the first place. It is also societal beliefs, attitudes, and perceptions that will likely determine whether eugenic policies and practices are reinstituted in our contemporary response to genetic research. Of course, it is unlikely that eugenics will reemerge in the same form as in the past (e.g., in laws providing for mandatory sterilization), but, the persistence of many of the beliefs and attitudes that historically supported eugenics policies suggest that concerns about what has been termed "elective eugenics" (the coerced aborting of fetuses with a high risk of disability), should be taken seriously. Eugenics programs have, in fact, been explicitly authorized in other countries (Gutterman, 2003), and in the case of prenatal diagnosis of Down syndrome (as discussed above, Kramer et al., 1998), are to a lesser extent already being implemented in America (although without the sanction or authority of the state).

Effects on the Family and on Society

The implications of the Human Genome Project and human genetic research are obviously not limited to the individual; genetic research may substantially impact the formation and structure of families and society. In fact, some genetic technologies are already impacting families in certain circumstances, such as in childbearing.

As we discussed previously, genetic testing is already being used for early identification of genetic diseases or disabilities and to allow earlier provision of services and interventions. Similarly, such tests may provide prospective parents with better information upon which to make reproductive decisions, such as the means chosen to bring children into the family (Chapman, 2002; O'Connor & Cappelli, 1999), and what preparations, tests, or treatments to consider (Carmichael, 2003; Davidson, 2000). Of course, these same technologies – particularly when administered prenatally – also create fears of coerced termination of pregnancy and of eugenic practices.

Other current uses of genetic technologies that may impact the family include the use of genetic tests to identify familial and genealogical connections among individuals, establish paternity (Gentry, 2000), identify human remains (such as in times of war, mass genocide and natural disaster) (Greely, 1998), ascertain racial/ethnic/cultural roots (Brodwin, 2005), or reunite separated families (such as those separated by Hurricane Katrina in 2005).

Elaborating upon the above genetic technologies, genetic research may provide specific benefits to the family:

- Alleviating fears about the use of adoption, surrogacy, or artificial insemination as means for bringing a child into a family and thus result in greater utilization of these methods. Parents may, someday, be provided with genetic information on adopted children which may help them to be diligent for symptoms, to seek interventions early, and, thus, to improve the health outcomes for the child. Information on the health and genetic profile of potential sperm or egg donors or surrogates may allow the prospective parents to eliminate any candidates who may be carriers of recessive alleles for diseases for which they too are carriers, thereby eliminating the possibility of a child being affected by the disease.
- Providing new options for prospective parents who wish to have a child. People who have trouble conceiving may be provided with new or improved procreative options. Genetic therapies may be

used to correct genetic traits that prevent prospective mothers from carrying a child to term or prevent prospective fathers from producing adequate amounts of sperm. Similarly, the efficacy of artificial and assisted forms of reproduction may be improved by identifying genetic characteristics in fertilized eggs that would result in fetal death before they are implanted.

But genetic research also creates the potential for several negative affects on family formation by:

- Encouraging parents to use genetic technologies to ensure their children are as "perfect" as possible. Genetic testing may result in increased abortion of fetuses even if no genetic disease or disability is indicated as parents become less accepting of what they perceive to be genetically undesirable traits (Kass 2002). Other concerns involve the selection of a potential child's genetic characteristics for the benefit of others, such as parents or another biological relation (Ashcroft, 2003; Kilner, 2002; Shannon, 1999; Sutton, 2002), or the potential harm that may result to potential children from genetic testing or treatment (Rosenow & Andrews, 2002).
- Promoting consideration of genetic compatibility in selecting a spouse or mate with which to have children. Although genetic considerations are unlikely to unseat more traditional factors used in selecting a mate (i.e., physical attraction, compatibility, love, etc.), genetic factors may someday play a common, or more prominent, role in marital decision making – particularly for persons who want children. Some researchers, as well as religious organizations, have voiced concerns that emphasis on genetic factors in marital decision-making could result in poor marriage choices and higher divorce rates since stable and lasting marriages are based on the relationship of the spouses to each other and not to their genetic compatibility as parents.
- Inhibiting adoption, particularly with respect to the adoption of children with undesirable genetic characteristics or adoption of children by parents with undesirable characteristics. Genetic testing may create a class of unadoptable children (Anderlik & Rothstein, 2001), or parents who are not considered genetically qualified to adopt due to their own genetic make-up or even, depending on the laws and regulations governing adoption criteria, an incompatibility between their genome and that of the child they wish to adopt. Further, interest in adoption might wane as better methods of assisted conception are developed and more and more

infertile couples are able to conceive or create offspring genetically related to one or both of them.

- Creating conflicting interests among relations. Issues such as when to tell and how much to tell potential relatives and spouses about genetic information gleaned from genetic testing (d'Agincourt-Canning, 2001; Davidson et al., 2000; Konrad, 2003), and issues surrounding the potential use of genetic technologies for reproduction, may create points of stress or contention within families (Kissel, 2002; Phelan, 2002; Rosenow & Andrews, 2002). Also at issue is a partner's right to consent, or refuse consent, to testing for the sake of reproductive decision-making, particularly if they do not want such information about their own health/disease status. Information derived from genetic tests may also change the way parents treat their children if the child tests positive for a genetic disease or disability. Parental reactions could range from being over-protective to withdrawing emotionally and/or financially from the child (Hoffman & Wulfsberg, 1995; Rosenow & Andrews, 2002; Wertz, 1998). In addition, the duty, or lack of duty, to warn relatives of the implication of individual genetic test results may undermine relationships.

Families are the fundamental units of a society. The cumulative effect of genetics on families, and on individuals within families, if substantial, may change society as a whole. In discussing the implications related to the potential of human genetics to improve health care and medicine, alter attitudes and perceptions, support or inhibit personal autonomy, foster or alleviate discrimination, and affect family relationships and childbearing, we have, to a certain extent, raised issues related to how society as a whole would change if the concerns or hopes related to genetic research and technology development were to be actualized.

What remains to be discussed is the potential effect that genetic research may have on the structure and foundational institutions of society. Specifically, genetic technologies have the potential to affect the size and diversity of the population, class structure, and religious institutions of society by:

- Reducing the randomness or chance process involved in reproduction and thus affecting the size and variation of a population. If genetic variation is substantially reduced in a population, it not only undermines competitive and creative endeavors (such as sports and art), but also the loss of those recessive alleles which provide disease protection to carriers (such

as the allele responsible for sickle cell anemia which provides protection against malaria) could make the populations vulnerable to a potentially devastating epidemic.

- Creating a class of people considered genetically unfit or even developing an entire class system based on genetics with the genetically enhanced on one end of the continuum and the genetically unfit on the other. If genetic information becomes a requisite for insurance, a class of the genetically uninsurable and unemployable may form, causing destabilization of the insurance market, a legion of unemployable yet capable and willing employees, and a lack of social cohesion (Anderlik & Rotherstein, 2001). Genetic profiling of individuals may even be used to reinvigorate claims about the uneducatability of some individuals, or groups of individuals, and/or cause the stratification of educational services based on efficiency and genetic merit (Sandel, 2004). A genetic-based class system could also affect family relationships if individuals or family status is determined by genetic characteristics that may differ, even among close relations (Tauer, 2001). Inflexible genetic classes would restrict the ability of an individual to advance in society despite personal merit or achievement (Freedman, 1998). Fears arise that the two genetic classes may arise, the "enhanced" and the "natural," and may become so genetically distinct, that they ostensibly become two subspecies of the human race (Sandel, 2004)
- Undermining traditional religious beliefs and stigmatizing those who hold to such beliefs in the face of scientific and genetic "evidence" to the contrary. Genetic research may break down or replace some culturally important religious and philosophical beliefs for some people and offend the beliefs of others. For instance, genetic research may threaten or offend beliefs in the universality of man and the equality of all people (Elliott, 2001), in the exalted place of humanity among other animals (Resnik, 2001; Shannon, 2001), about who we are as humans (Ames, 2001; Kass, 2002), in traditional medicine and healing (Sharp & Foster, 2000), and about humanity's place in the universe (Sandel, 2004).

On the other hand (and as should be fairly evident at this point) there are two sides to the genetic implications coin. For almost any potential harm a corresponding hope can be found – although not always with the same likelihood or equal potential. The above societal concerns are matched by three hopes related to the societal implications of genetics:

- The study of genetic epidemiology may actually help us study genetic diseases that are unique or prevalent to one population or ethnic group, thereby, helping us to identify and possibly prevent the loss of life or function and to promote the health, continuance, and expansion of endangered populations of people.
- Genetic research may provide greater opportunities for individuals to change their socio-economic status by removing genetic and impairment factors that limit an individual's opportunities to succeed.
- The goal of human genetic research to help and to heal may invigorate parallel religious, spiritual, and philosophical beliefs about our duty to our fellow persons and encourage people to become more spiritually and philosophically engaged as the complexity of human genetics is revealed and the wonder of creation is further illuminated.

Fostering Benefits and Addressing Concerns About Genetics

With such an extensive potential to affect individuals with and without disabilities, families, and society – for good or for ill – genetic research is bound to draw strong reactions. But what should be done to address the dangers and foster the benefits of genetic research? How should members of the disability community react to these emerging issues? By participating in public dialogue about the implications of genetic research? Yes, the disability community would be well served by taking better advantage of opportunities to voice their hopes and fears about genetic research. But, having been granted a seat at the table, so to speak, what should individuals with disabilities, their families, and their representatives recommend?

In order to address that question, it is first useful to outline what has already been done to address the implications of genetic research and technology. We therefore discuss what limited actions have been taken in law and research to address the concerns and foster the benefits of genetic research in four categories: support for genetic research and implementation, human subject protections, anti-discrimination and privacy laws, and regulation of genetic technologies.

Support for Genetic Research and Implementation

The human genome project has, since its inception, involved a cooperative (and sometimes competitive) effort among private and public scientists to

unlock the mysteries and potential of human genetics. As the draft sequence of the Human Genome Project was completed in 2003, funding for genetic research has continued to increase. Indeed, financial support for genetic research is a necessary element in any response to its implications if the potential benefits are to be achieved. So too is support for those mechanisms necessary for the ultimate implementation of such technologies. Many such mechanisms are in development or are already in place, such as genetics education programs for consumers and health care professionals, and laws authorizing and regulating genetic screening programs. Genetic counseling programs, both for training genetic counselors and for making genetic counseling available to those receiving genetic test results, continue to gain support and momentum.

But since the effectiveness of such programs to address concerns and facilitate expectations of genetic research depends upon how such programs are structured and conducted, it is important to consider the potential and mechanism for each approach.

Professional genetic education programs. Genetics education programs geared toward professionals vary in form and substance, depending on what sector of professionals comprise the audience. Instruction for clinical and medical geneticists, is obviously far more advanced than that for general allied health professionals. In the United States, to be considered a qualified medical or clinical geneticist, one must have a medical degree or a doctoral degree in a genetics program, and have completed a genetics fellowship in a program accredited by the American Board of Medical Genetics, or ABMG (University of Kansas Medical Center, 2006). Beyond clinical and medical genetics is the field of genetic counseling; over 20 colleges and universities in the United States offer fully accredited Masters in Human Genetics programs. Additionally, one can be trained as a genetics laboratory research assistant or a genetics laboratory technician by obtaining the appropriate education or certifications. The ABMG, mentioned above, is one of many professional genetics societies. There is also The American Board of Genetic Counseling, The American College of Medical Genetics, and The Association of Genetic Technologists, among others. These societies serve as governing boards and sources for the uniform standards to which these different professionals are held. While it is reassuring to know that those who work specifically in the field of genetics are trained and certified through standardized mechanisms, how comfortable can we be that general health professionals are being given adequate and consistent genetics training?

As research in human genetics advances, the use of genetic knowledge and technology in medicine will similarly advance. Broader utilization of this

knowledge and technology requires the concomitant training of all medical professionals; not just those classified as geneticists. The amount, and the complexity, of genetics education being provided across the different health profession disciplines is uncertain. However, the current aim of genetics organizations is to elevate and standardize the level of information being disseminated to all health professionals.

The Association of American Medical Colleges, or AAMC, produced a report in June of 2004, as part of their "Medical School Objectives Project," examining the potential for more comprehensive genetics education in general medical education (Association of American Medical Colleges, 2004). The authors of the report note not only the need for students to garner scientific genetic knowledge but, also, an understanding of the ethical and personal issues surrounding genetics (such as the particular need for privacy of genetic information). The report sets forth the recommended parameters of genetic knowledge that each graduating general practitioner requires, as well as the clinical techniques the student should have mastered during his or her medical education. As asserted by the authors, the task of this report is to give consideration to "the core competencies required" of the general physician, with regard to genetics (AAMC, 2004: 1).

Such guidelines for core competencies have similarly been suggested for other health providers by two American agencies, The National Coalition for Health Professional Education in Genetics, or NCHPEG, and The Association of Professors of Human and Medical Genetics/American Society of Human Genetics, or APHMG/ASHG. The NCHPEG created a core competencies guide in 2001, with a second edition in 2005, highlighting the suggested requisite knowledge, skills, and attitudes for all health professionals (including nurses, physicians' assistants, physical therapists, and others) (NCHPEG, 2005). In addition to producing these guidelines, the NCHPEG provides grant money for programs to educate "non-genetics healthcare professionals" about genetics (NCHPEG, 2006). Specifically for nursing faculty, The Cincinnati Children's Hospital Medical Center Genetics Program for Nursing Faculty, funded by an Ethical, Legal, and Social Issues (ELSI) grant provided by the National Human Genome Research Institute (NHGRI), is a highly acclaimed genetics education initiative (Cincinnati Children's Hospital Medical Center, 2006). The accompanying Web-Based Genetics Institute, or WBGI, is an internet alternative available to all nurses. Similar programs are being funded all over the United States, providing genetics education to nurses, physical therapists, and many other types of medical care providers, in an effort to increase the medical community's knowledge about genetic matters.

The genetic education initiatives aimed at general medical practitioners and allied health professionals come at a time when the medical community is being barraged with demands for integrating all of the newest, and most advanced, topics into medical education. Yet, considering the pervasive nature of genetics and the certain role genetic knowledge and technology will play in the future of medicine, a comprehensive understanding of genetic practices is indispensable. Furthermore, the use of genetic material and the potential implications of genetic technologies carry with them ramifications of more gravity than those previously seen among healthcare providers. Allied health professionals and physicians alike need an educational foundation for contemplating the matters presented by genetic practices, such as complicated privacy issues and ethical dilemmas. The scope and urgency of the curriculum additions proposed by genetics organizations are both reassuring and alarming. They show that many dedicated individuals are working toward a common goal of increasing genetics education among the medical community. Yet they also reveal that there currently exists a dearth of appropriate genetics education among the medical community. This is particularly alarming when we consider that the majority of genetic services will, at least initially, likely be recommended and provided by a physician who completed his or her medical training before genetics curriculum efforts gained significant momentum. Educating current physicians on the complexities of current and upcoming genetic research and technology is naturally more challenging than educating those who entered medical school after the completion of the human genome draft sequence.

Public genetics education programs. To be involved in the current dialogue regarding the ethics of genetic research and the potential abuses of genetic information, one must have at least a basic knowledge of genes, the role genes play in human function and human disease, and the possible uses of genetic therapies and genetic technologies. In a recent article describing the urgent need for public genetic education, author Susanne Haga of The Institute for Genome Sciences and Policy, explains that expanded genetic knowledge among the general public (as well as among teachers and health professionals) will not only help "improve the dialogue about these new tools and technologies, but will also help to prepare the next generation of scientists and ensure the appropriate use of genetic applications in medicine"(Haga, 2006).

As Haga explains in the article, adults are not the sole target audience for public genetic education. People of all ages need adequate and accurate genetic information. Because of its ubiquity, Haga identifies the internet as an excellent resource for disseminating genetic information to a wide array

of people. Indeed, many universities and colleges (such as The University of Kansas and The University of Arizona) offer on-line lesson plans for teachers wishing to introduce genetic topics to their classes (University of Kansas Medical Center, Genetics Education Center, 2006). In the United States, many of the main funding and governing bodies for genetic research (such as the Department of Energy and the National Human Genome Research Institute) also have very helpful and informative websites for public use.

The state of Washington launched a massive public genetic education campaign titled the Genetics Education Partnership, or GEP (GEP, 2006). The program was funded by a Dwight D. Eisenhower Professional Development grant in 1998 and consisted of a consortium of elementary, middle, and high school teachers along with genetic professionals who developed an "articulated framework for teaching genetics concepts" to students from kindergarten to grade 12. Through this project, the group was able to develop a guidebook for educating children about genetics topics and a website to distribute their information. Such projects seem to be an ideal way to promote greater knowledge of genetics among school-aged children and the general public.

Because public schools can often reach those populations that may not have access to internet technology, they have the potential to begin to bridge the digital divide between socioeconomic classes. It is crucial, as genetics is further integrated into medical practice, that all prospective stakeholders have credible and readily-available information about genetic research, practice, and technology. Expanding resources beyond the internet by utilizing public schools is one mechanism for providing genetic education to impoverished communities. Yet, we are faced again with a potential disparity of genetic knowledge and understanding – only children and adults with internet access will have ready and easy access to information and training on genetics. Those members of society without computer access and/or computer skills will be at a disadvantage. Furthermore, there is some question as to whether the implications of genetics for various societal groups, including persons with disabilities, are or will be adequately represented in these education programs.

Screening programs. Almost every state in the United States has a newborn screening or birth defects program. These programs frequently, though not always, include an educational and counseling component in addition to the application of the genetic test. This provides another avenue for some genetics education to potentially reach different aspects of the

population. In many states, newborn screenings are overseen by early intervention coordination councils, helping to ensure that any positive results of the screenings are immediately addressed through early intervention services. Yet some problems and concerns may actually be aggravated by these screening programs. For example, individual states mandate certain tests, the federal government also mandates certain tests, and many states conduct the testing in such a manner that parents assume these tests are mandatory. Although the information gathered as a result of the testing is guaranteed to be kept confidential, it is reported to a variety of people and agencies, per statute. The only typical escape from screening is a religious belief. A few states extend this exemption to include "other" reasons. Another troubling aspect of these screening programs is that the policy goal of disability prevention is emphasized many times over in the law and may foster directive attitudes toward counseling. More carefully worded statutes are needed here to avoid the unintended communications.

Autonomy concerns are greater in the arena of screening that is conducted prenatally. A few states, such as California, address prenatal screening in disease or public health statutes. California has even codified a statewide prenatal screening program for genetic conditions (CA H&S Code 125050, *et seq.*). While the statute mandates that participation in the program is voluntary, the same quandary exists here as in newborn screening programs: do the parents assume a constructive or apparent requirement? When a medical authority dictates that prenatal screening should be performed, it is not illogical to assume most individuals will comply. In prenatal screening, unlike newborn screening, however, the consequences can be more profound. Any person offered prenatal screening, particularly when within the construct of a state-funded or state-controlled program, should be counselled on the absolute freedom to decline such screening, with no adverse consequences.

Human Subject Protections

In the U.S. (and other western nations), the area of human subject protection has grown remarkably within the past 60 years, since the atrocities committed in Nazi Germany during World War II. Now, both federal and state laws guarantee a fair level of protection to any person involved in medical experimentation. However, the advent of genetic research and experimentation present somewhat novel concerns for human subject protection and, to date, only some American states have enacted laws specific to genetic research.

The U.S. federal law that regulates human subject protection, 45 C.F.R. Part 46, states that all research involving human subjects is covered under this regulation (45 C.F.R. 46.101). It also contains a separate section pertaining to pregnant women, "neonates," and human fetuses (45 C.F.R. 46.201). While there is currently no federal legislation that directly regulates genetic research, genetic research can be thought to fit under the above provisions for human subject protection because it is research involving human subjects or research pertaining to pregnant women, neonates, and human fetuses.

The federal human subjects protection regulations require the involvement of an Institutional Review Board, or "IRB," in all research with human subjects (45 C.F.R. 46.107-109). This means that more than just one person will be consulted on a given research project: several people from different disciplines will individually and collectively evaluate the research in order to approve the research plan. The use of an IRB guarantees that no single person's views or beliefs will dictate what research is deemed ethical, instead, that responsibility will be shared among a diverse group of people. This is of grave importance in genetic research, where, as we have outlined, the religious and ethical questions are many.

Another important theme in human subjects protection is that of informed consent. The human subjects protection regulation specifies the requirements for informed consent. These include:

- "A statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures which are experimental;
- A description of any reasonably foreseeable risks or discomforts to the subject;
- A description of any benefits to the subject or to others which may reasonably be expected from the research;
- A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject;
- A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;
- For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained;
- An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and

whom to contact in the event of a research-related injury to the subject; and

- A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled" (45 C.F.R. 46.116).

Because genetic research carries with it so many unchartered risks, the need for the researcher(s) to carefully explain any harms or benefits to potential subjects is even greater than the risk of other types of research. For example, if an individual elected to be involved in a drug trial that might permanently alter his or her DNA, the effects therein potentially extend much farther than his own body. His offspring, and the offspring of each generation beyond that, would be forever altered. The well-established difficulties inherent in garnering truly informed consent from human subjects is the chasm that exists between the researcher's extensive medical knowledge and the subject's lack thereof. In the complicated realm of genetic research, that chasm could widen further.

Anti-Discrimination and Privacy Laws

Of all of the concerns surrounding advancements in genetics, two are at the top of the list: unauthorized access to genetic information and genetic discrimination. The potential abuses of genetic information being used to discriminate among individuals and populations in health insurance, medical care, education, employment, adoption, and various others facets of life are vast.

Privacy in health care and employment. Federally, some actions have been taken to ensure the privacy of genetic information in the U.S. With the enactment of The Health Insurance Portability and Accountability Act (1996), or "HIPAA", medical information, including genetic information, was assured a great deal of security (P.L. 104-191). HIPAA does not solve the privacy problem, however, because the law itself does not prevent the collection of genetic information by insurers, nor does it bar insurers from requiring an individual to submit to a genetic test (NHGRI, Genetic Discrimination, 2006). HIPAA also fails to prevent insurers from disclosing genetic information about insured persons (NHGRI, 2006).

All but two states have enacted some form of health care or insurance legislation that contains genetic information privacy provisions. Some state laws are more comprehensive than others, however, significant gaps still exist.

Insurance laws.

- State laws governing insurance are inconsistent often varying in form and content but, as a general rule, they seek to prevent an insurer's acquisition of genetic information either from genetic testing or from responses to questions about genetic information. Some state laws go further and prevent insurers from asking questions about whether or not an individual has ever submitted to genetic testing (regardless of inquiring about the actual test results).

Health care laws.

- The genetic privacy provisions in state health care laws are even less consistent than those in state insurance laws. Some state health care laws guarantee the privacy of information contained in medical records. Many state laws also guarantee the anonymity of any information gathered for newborn screening or birth defect registries. These protections, however, are not universal across the country.

The internet is becoming more and more accessible, and therefore more vulnerable to abuse (i.e., "hacking"). As medical data, insurance documents, and other public records similarly become more computerized, the need to safeguard genetic information increases. While the existing (albeit assorted) state laws can play a role in preventing, or minimizing, misuse or disclosure of genetic information, the same amount of protection should be afforded genetic information equally in all states. Furthermore, as computer databases (such as criminal databases) become larger, and eventually possibly span the nation, the need for more comprehensive legislation to safeguard such information becomes critical.

The U.S. Congress is now considering several bills aimed at advancing various privacy protections necessary for the reduction and/or prevention of genetic discrimination. The Coordinated Environmental Health Network Act, the Identity Theft Protection Act, the Financial Institution Privacy Protection Act, the Equal Rights and Equal Dignity for Americans Act, and the Medical Information Protection and Research Enhancement Act all deal with different aspects of genetic privacy (NHGRI, Genetic Discrimination, 2006). Most recently, Congress proposed the Genetic Information Nondiscrimination Act of 2005 (H.R. 1227) which includes privacy and confidentiality requirements for health insurance providers, including public health insurance providers.

In reality, however, and in light of the nature of medical care, particularly newborn care, it is hard to predict exactly how many people will come in

contact with a medical record during just one visit to the doctor's office or the hospital. In order to be foolproof, a law would have to cover every possible breach of confidentiality in a hospital or doctor's office setting. Because would be difficult (if not impossible) to do, and because unauthorized disclosure could have devastating effects on one's ability to acquire health insurance, employment, or even housing, regulation regarding privacy of genetic information must be supplemented by regulation addressing the use of information, whether obtained with or without proper consent. In other words, to the extent that we cannot prevent some authorized disclosures from occurring, we need to ensure that genetic information is not used for discriminatory purposes.

Genetic discrimination in insurance and employment

While American federal and state laws exist to prohibit discrimination within these laws, significant gaps exist that may allow for discrimination against people based on their genetic characteristics. Consider, for example, the following limitations on the extension of two pieces of federal legislation, the Americans with Disabilities Act (42 U.S.C. §§ 12101 et seq.) and the Health Insurance Portability and Accountability Act Act of 1996 (42 U.S.C. § 300gg and 29 U.S.C § 1181 et seq.) (hereafter HIPPA) to the prevention of genetic discrimination.

Americans with Disabilities Act.

- The ADA, intended to prohibit discrimination solely on the basis of disability, does not contain language specific to genetic traits. The U.S. Supreme Court's decision in *Bragdon v. Abbott*, 1998, at first glance, does suggest that the ADA may provide some protection against genetic discrimination, even in the absence of an existing condition. Following this decision, an individual would have to be "regarded as" having a disability by the employer or insurer as a result of their genetic characteristic in order to receive protection under the ADA (524 U.S. 624, 1998). This threshold question is, however, more narrow than it first might appear. In other cases, such as *Sutton v. United Airlines (1999)*, *Murphy v. United Parcel Service (1999)*, and *Albertsons v. Kirkingburg (1999)*, the Supreme Court limited what is, and is not, a disability under the ADA and, generally, required that a disability be presently existing, not potentially or hypothetically existing, casting serious doubt about whether genetic discrimination would be covered by the ADA (527 U.S. 471; 22 F.3d 1186; 527 U.S. 555).

Health Insurance Portability and Accountability Act.

- HIPAA prevents group health insurers from using genetic information to make rules for insurance eligibility. It does not, however, prevent group health insurers from requiring or requesting genetic testing, nor from disclosing a person's genetic information without obtaining prior authorization to do so.

Of course, American state law also provides some protection against genetic discrimination. Nearly ever single state has some law pertaining to health insurance, employment, and/or healthcare that dictates that an insurer/employer, or medical provider shall not discriminate on the basis of genetic information. These laws are often ambiguous and leave much open for debate. It would be far more effective if each state codified a distinct provision for genetic discrimination instead of attempting to subsume this very important matter into other laws, such as those for health insurance. We may not even know at this point, all of the areas where discrimination might occur. Consequently, a better approach would be to simply eliminate, at the front end, the possibility for any and all discrimination.

Having state laws that thoroughly and effectively regulate the use of genetic information is clearly important. However, comprehensive federal legislation is still very necessary for three reasons:

- Typically, state laws vary greatly with regard to scope and coverage. Some existing state laws, such as those in California and New York, are as comprehensive or more comprehensive than the proposed federal legislation (CA INS CODE §1-16030, NY CLS INS §101-9901). Other states, such as Pennsylvania, have no provisions for genetic nondiscrimination, whatsoever. This means that citizens of one state may have significant protection while citizens of other states have none at all.
- Existing state laws have not carefully defined terms such as "employer", leaving questions as to whether employment agencies, labour organizations, and similar entities are equally affected by the law. Similarly, many state laws have not specifically indicated whether health insurance provisions cover group plans, individual plans, or state-run plans.
- Many existing state health insurance statutes already contain glaring gaps. For example, some prevent genetic discrimination based on genetic information, but allow genetic discrimination based on genetic conditions that are manifested. Often the wording of the legislation is tricky and could, potentially, lure some consumers into a false sense of security.

Adoption, Paternity, and Law Enforcement

While issues of genetic privacy and discrimination in health care and insurance get the most attention and are, perhaps, the most obvious areas for potential abuse of genetic information, other areas, such as adoption, paternity, and law enforcement also face new issues in this genetics age. Legal requirements to address some of these emerging issues are just beginning to be enacted, while others are more clearly established and reasonably consistent among jurisdictions.

The use of genetic information in adoption decisions has been sanctioned by many American state laws; these states guarantee that a person choosing to adopt a child is granted access to the complete medical history of the child, including any available genetic information (whether from genetic testing or from family history). For example, an Arkansas statute requires that all medical information, including genetic information, pertaining to a child being placed for adoption be made available (AR CODE 9-9-212(g)(2)). This practice is understandable; in western nations it is assumed to be the right of an adoptive parent to know the complete medical history of any child presented for adoption, and, in fact, that such knowledge is necessary in order to be able to parent the child safely, especially if any predisposition for a genetic condition exists.

One, seemingly obvious, drawback may well be that children with identified genetic conditions will be less frequently chosen by adoptive parents because of parents' concern over the potential implications of a genetic predisposition to disease. Adverse selection already occurs in the adoption of children with existing disabilities; the availability of genetic information simply increases the gamut of reasons for which certain children may not be chosen for adoption. This may explain why state laws endeavour to protect the privacy of the genetic information of the family relinquishing the child for adoption. The same Arkansas statute referred to above also requires that the genetic information of the adoptee be kept in a location separate from any other information that could be used to identify the biological family of the adoptee.

In some cases, state law requires the release of medically important genetic information, but does not directly express at what time in the adoption process this information must be released. The Oregon adoption statute, for example, states that the medical information of the adoptee "including a record of potentially inheritable genetic or physical traits or tendencies of the biological parents or their families (must) be provided to the court before

any judgment of adoption of a minor is entered (OR ST 109.342)." This wording suggests that the adopting parents may not have mandatory access to this information prior to choosing the child for adoption. This is a very complicated ethical issue. Using the example of a child with no manifested disability, but with a genetic pre-disposition, it balances the right of the adoptive parents to receive the information, with the interest (arguably a right) of the child to be given a "fair shot" at being adopted, and the right of the biological family to maintain the confidentiality of their genetic information. Currently many states have adoption laws guaranteeing access to the adoptee's genetic information, and within those, several also have provisions regarding the required anonymity of the biological family.

In contrast to the variable approach to adoption and genetic information, nearly all American states have enacted laws safeguarding the genetic information gathered in paternity testing. Aside from disclosure to the court hearing the proceeding, this information may be made accessible only to the subject of the testing and then should be destroyed within a set amount of time.

In the matter of criminal investigations and convictions, the privacy of one's genetic information again becomes more complicated. Numerous states have statutes dealing with DNA collection for individuals who commit specified crimes. These genetic samples containing the DNA are then stored at a designated facility, while the related genetic information is stored in a database for a limited amount of time. The genetic information collected from the DNA sample is not as worrisome in terms of discrimination as the sample material itself, since it only involves, so-called, "junk" DNA. Access to the information in the database would not provide the recipient of that information with any data about potential genetic conditions (assuming junk DNA is not discovered to be more important than currently believed). It is access to the genetic material itself that is worrisome, as it could then be tested for information about the individual's potential genetic health. This explains why some state laws articulate specific timelines and procedures for the storage and destruction of the material. In the 29 or so states without explicit limitations on the collection and use of genetic samples (Kimmelman, 2000), the subjects of the testing are at great risk of exposure and potential discrimination.

The wording in most state statutes, whether pertaining to employment/insurance or otherwise, is typically vague. This problem is, of course, not unique to genetic policy, but here the potential for ill effects is great. When one considers the balance of knowledge and how far the scale

is tipped against the average person in most federal or state laws, one may fairly conclude that having a vague genetics law is exceptionally dangerous and made worse because genetics, as a field, is highly technical and, thus, more difficult for the average citizen to understand. Furthermore, the consequences of such vagaries are harder to predict. These statutes need to be worded in precise but understandable language so that people know, and can advocate for, their rights.

Regulation of Genetic Technologies

Genetic technology refers to the vast array of methods, existing and potential, that facilitate the use of genetic research in diagnosis, as interventions, or for other purposes. Genetic testing is the most widely used genetic technology, and, as discussed above, is the one most often targeted for regulation. Gene therapy is another genetic technology that is gaining momentum. Gene therapy may potentially be used to replace "abnormal" genes with "normal" ones, repair genes that are not functioning correctly, or regulate a gene in a manner that will prevent expression of particular symptoms or conditions (Department of Energy, Gene Therapy, 2006). Some types of gene therapy involve using a virus as a mechanism of transportation in order to get a gene to where it needs to be in a person's body. Selecting certain traits through genetic technology is another practice that has been used in recent years. Pharmacogenomics, the practice of tailoring drugs to a person's particular immune response through a study of his or her genetic inheritance, is yet another area of genetic technology (Department of Energy, Pharmacogenomics, 2006).

American lawmakers are working toward greater regulation of genetic technology, but such regulation is in its infancy. Gene therapy and pharmacogenomics will likely be regulated by the American Federal Drug Administration (FDA). No human gene therapy product has yet been approved for sale or use by the FDA (Department of Energy, Gene Therapy, 2006). Already, however, drugs that are "genetically engineered" are being used to fight degenerative diseases. One class of these drugs is called biologic response modifiers (Food and Drug Administration, 2006). Although these drugs are genetically engineered, they carry the same connotations of "science fiction" as do many human gene therapy products and procedures. Many such drugs have been approved since the late 1990s (FDA, 2006), and are regulated under the same laws and regulations that govern all drugs and drug development.

Beyond such pharmaceutical regulation, very little genetic technology legislation exists. The patenting of genetic material and genetic discoveries has become a hot button topic with western bioethicists. The Patent and Trademark Office of the United States (USPTO) is the body that determines the patentability of an invention (Andrews, Mehlman & Rothstein, 2002). According to a genetics policy text, "raw products of nature are not patentable"; this means that human substances should typically not be granted patents (Andrews, et al., 2002: 161). However, when a gene product has been modified in some way to become a substance not commonly found in nature, a patent may be granted (Andrews, et al., 2002: 162). To receive a patent for genetic material, an inventor must do the following;

- Identify a novel genetic sequence
- Specify the sequence's product
- Specify how the product functions in nature (what the use of the product is), and
- Enable one skilled in the field to use the sequence for its stated purpose (Andrews, et al., 2002: 162).

Gene tests are patentable; but genes and gene fragments raise additional controversy. The USPTO offered interim guidelines for the patenting of gene fragments in 1999, though some patents for gene fragments had already been issued (Andrews, et al., 2002: 162-163). A search of the human genome information database yields no United States Code provisions governing gene commercialization or patenting, though this legislation is sure to come as more and more researchers seek patents (National Human Genome Research Institute Legislation Database, 2006). For now, existing genetic patenting guidelines provided by the USPTO and other general patent laws must suffice. As far as the future of genetic commercialization and patenting, this is yet another area where input from the bioethics and disability communities will be needed to assure that science does not go awry. There exist convincing arguments for allowing the patenting of genetic material, including the progression and advancement of medical technology. There also exist questions about the morality of making human substances a profitable commodity.

Conclusion

One thing is abundantly clear about present efforts in America to address the implications of genetics through law, policy, and practice, and it is that these responses are far from sufficient to cover the myriad of concerns and to

foster the potential benefits of human genetic research. Most often, in the world of medical advancements, legal and policy responses are just that – responses. Here in the U.S., the Human Genome Project and the ELSI program provide a unique and novel opportunity to create legislation or policy that will be proactive in nature. And, while researchers concerned with ELSI matters may not, at this point, be able to provide answers to all of the issues and implications of human genetic research, they can become more involved in the search for these answers by participating in public dialogue and conducting further research on the implications of genetics for persons with disabilities and their families.

That said, what recommendations can one now make for those who will begin, or continue, to discuss the implications of genetics for persons with disabilities and their families? At this point, a few general inter-related recommendations seem safe to make:

- *A unified effort to advocate for the disability perspective.* For people with disabilities, the most important facet of any advocacy efforts aimed at better genetics policy and legislation is a unified voice. Obviously, opinions among members of the disability community vary considerably – particularly between those who focus on scientific advocacy and those who focus on disability rights advocacy. But, although there may be a fundamental difference in the approaches and priorities each of these sections of the disability community takes in their efforts to improve the lives of persons with disabilities, they are not mutually exclusive. If the diverse members of the disability community can learn to respectfully disagree on some issues and come together to create comprehensive goals on other issues, it increases the likelihood that the voice of persons with disabilities and their families will be heard in the development of responses to genetics issues. Those who advocate on the medical side of disability want to ensure that genetic research and technology is fully supported and available to anyone who wants genetic services. Those who focus on the social model of disability want to ensure that no genetic interventions are forced upon anyone, that the public perceptions of people with disabilities are not adversely affected by the use of genetic practices, that support for non-genetic services continue, and that no one is negatively viewed (or punished) for electing not to receive genetic services. Both sets of aims can be achieved through a more unified approach to advocacy. Failure to work together means that both groups will have to accept the limited effectiveness that divided advocacy will have in bringing the perspective of individuals with disabilities into the public dialogue.

- *Addressing the importance of attitudes and perceptions.* One area that most, if not all, disability advocates typically agree on is that persons with disabilities should not be stigmatized, punished, or discriminated against merely because they have a disability or particular genetic characteristics. Given the importance of public and professional attitudes and perceptions of disability in ensuring people with disabilities are extended basic human rights and dignity, a united advocacy effort would be well served by focussing its initial efforts on expanding public knowledge and understanding of the intersection of genetics and the experience of disability. Many stereotypes exist with respect to persons with disabilities. Concurrently, many myths and misconceptions exist with regard to genetics. The perpetuation and expansion of such stereotypic and ill-conceived beliefs in this age of genetics might well create the darkest chapter yet in scientific and medical history. On the other hand, the use of genetic information and technology could ultimately bring about one of the brightest eras of science and medicine, if fueled by a more accurate and humane perception of persons with disabilities as whole persons, by respect for the right of all individuals to make their own medical decisions, by an understanding of both the potential and the limitations of genetic technologies, and by recognition of the universal nature of impairment. Creative, cooperative, and enduring efforts to meet these goals must be developed if this vision is to occur.

- *Support for genetic research and programs that benefit persons with disabilities.* Genetic research and programs offer significant potential benefits for individuals with disabilities and their families. While objections and concerns should be raised with respect to some of the above-mentioned potential uses of genetic research and technology development – uses that could do great harm to persons with disabilities and their families – it is as important to focus on achieving the "good" as preventing the "bad". Advocacy efforts often tend to focus on preventing harm. As with law and policy, advocacy is, by nature, a reactionary effort but the potential of the human genome project requires a more proactive approach. If members of the disability community are active only to prevent the harmful implications side of genetics advocacy, they will be sacrificing important opportunities to direct and nurture the positive growth and progress of helpful genetic research and technologies.

- *Support for protections against genetic discrimination and other initiatives.* In the area of genetic discrimination, American laws and

policies governing the collection and use of genetic information already exist but, collectively, they form an inefficient and insufficient patchwork of prohibitions, limitations, and exceptions that are likely difficult for individuals with disabilities to enforce. Furthermore, such protections have not been adequately extended beyond the more obvious areas of insurance and employment. As elaborated, this is an area requiring much work. In addition, disability community members should lend support to efforts to train individuals to provide non-directive genetic counselling and more accurate information on disabilities and family experiences of disability. A real gap exists between the perceptions of disability held by many health care professionals and the general public and the real-life experiences of individuals with disabilities and their families. Closing that gap may provide a significant step in preventing potential harms from the use of genetic technology based on inaccurate perceptions and understanding.

- *Bringing issues of genetics and other new technologies into health care reform discussions.* Finally, it is important that the issues of genetics be raised in the proper contexts. Research on brain development, imaging technologies, information technologies, and mounting pressures for cost control in health care all may significantly impact disability rights and services. Some of the same issues raised with genetic technologies may equally apply to other medical and scientific technologies currently being researched (for example, brain development and imaging technologies). Furthermore, solutions to some of the genetic issues may relate to the use of other technologies or may be complicated by them (for example, information technologies). Even issues related to economic pressures might suggest "new" solutions (good or bad) to future genetics implications as, for example, society begins to question whether the underlying risk-sharing purpose of health insurance is being fulfilled and whether society should continue to consider it acceptable to adjust insurance rates and determine eligibility based on biological conditions and factors over which an individual has little or no control and that provide no preventive or cost reduction incentives. Thus, issues surrounding genetic research and technologies should be considered, in light of these other factors, under the broad umbrella of health care reform.

The Brave New World and Slippery Slopes

When George Orwell wrote 1984, in 1949, he envisioned a brave new world, but he also condemned that world. In Oceana, his imagined future state, Big Brother used language and the science of linguistics for mind control. The original meaning of words was perverted, and the ideas behind the words were obliterated and changed to meet the state's purpose. Big Brother also used various forms of behaviour modification to control even the most intimate of a citizen's behaviour, and, by controlling behaviour, Big Brother attempted (largely successfully) to control how citizens think. Control over language, behaviour, and thought were the essential ingredients of Oceana, and the source of this trio of controls was science.

We are by no means at the point that Orwell imagined. But we might be, someday. That is both the threat and the promise of human genetics, as we have pointed out above.

That Orwell's imagination and our potential reality have run parallel to each other should surprise no one in the field of disability. Just as scientific breakthroughs in the understanding of intelligence and adaptive behaviour have played major roles in how policy makers and the public generally define and regard disability (particularly intellectual/cognitive disability and related developmental disabilities), and just as chemistry has contributed greatly to how policy makers and the public generally define and regard other types of disability (particularly mental/emotional disabilities), so the science of the human genome will drive policy leaders, practitioners, and the public in their understanding of the human condition generally and of the specialized version of the human condition known as "disability".

The correlation of science with policy, practice, "regardedness" and the social construct of disability is indisputable. Will a person's genetic constitution become a basis, much less the dispositive basis, for policy, practitioner, and social responses? History teaches us that such an outcome is not unlikely.

That prospect is sobering. It will affect those who now have widely recognized disabilities and, therefore, it belongs to the arena known as disability policy. But that prospect may also affect those who are not now widely recognized as having disabilities; it therefore belongs not to an exceptionalistic, specialized subfield of policy but, instead, to the universalistic, generic field of policy.

This is not to say, merely, that the slippery slope that disability advocates fear may result from the Human Genome Project is likely to be made even slicker, though that is a possibility. It is, instead, a warning that the slope that exists for those with disabilities may someday also carry those who now are free of that often (always?) stigmatizing trait.

Similarly, the benefits that the human genome project offer to the current disability community may be extended to those who do not now seem to have, or are "regarded" as having, disabilities. If the Human Genome Project can carry upward along a slope those with disabilities, it can do likewise for those without them (as understood by the current criteria of "disability").

All of which is to say that, as we consider the future of disability policy, we must do so by focussing singularly on the emerging sciences (human genome, brain functioning, and others). We must do so, not by isolating traditional disability and non-disability concerns and constituents, but by convening them into a single channel for public dialogue (in which there will great disagreement, of course). And we must be especially congnizant of history's lessons and of the potential that some of them may be repeated.

The brave new world that we might fashion, then, is a mixture of science, disability and generic policy alike, and history. But it must consist of yet more: the developed capacity for empathetic reciprocity. That is, we dare not maximize nor minimize the value of any given individual simply because of that person's inherent or altered traits; we must accord ultimate value to every person, and we must be able to see ourselves in the other's image, to be able to reciprocate, both in our mind's eye and in our behaviours, with those of us who seem to be different than others of us.

Thus, the challenge of the brave new world depends on how we will use science, policy, history, and ethics. It may be trite to say, "'Twas ever thus," but trite is truthful and that truth – that we must combine science, policy, history, and ethics – is precisely accurate for the future and precisely the focus of the ELSI project.

What may be uniquely useful in adhering to the truth and the ELSI formulation of it is the opportunity – which we consider a duty – to solicit, hear, and heed the vox populi. Our democratic tradition of participatory decision-making demands no less, and our public policy ("disability is a natural part of the human condition") compels us to do so.

References

Albertson v. Kirkingburg, 527 U.S. 555 (1999).

Allen, G. (1999). Genetics, eugenics and the medicalization of social behavior: Lessons from the past. *Endeavour, 23*(1), 10-19.

Allen, G. (2001). Is a New Eugenics Afoot? *Science 294*, 59-61.

Aly, G., Chroust, P., & Pross, C. (1994). *Cleansing the fatherland: Nazi medicine and racial hygiene* (B. Cooper, trans.). Baltimore and London: The Johns Hopokins University Press.

AMA Survey on Workplace Testing (1999). *Medical Testing: Summary of Key Findings*. Retrieved June, 2002, from http://www.amanet.org/research/medico/index.htm

Americans With Disabilities Act of 1990, 42 U.S. Code §§ 12101 et seq., Chapter 126. *Equal Opportunity For Individuals With Disabilities.*

Ames, D. A. (2001). Eugenic danger or genetic promise: A revolution for the millenium. *Cross Currents, 51*(3), 293.

Anderlik, M. R., & Rothstein, M. A. (2001). Privacy and confidentiality of genetic information: What rules for the new science? *Annual Review of Genomics and Human Genetics, 2*, 401-433.

Andrews, L. B., Mehlman, M. J., & Rothstein, M. A. (2002). *Genetics: Ethics, law, and policy.* St. Paul, MN: West Group.

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

Andrews, L. B. (1997). Compromised consent: Deficiencies in the consent process for genetic testing. *Journal of American Medical Womens Association, 52*(1), 39-42.

Arkansas Code, Section 9-9-212(G)(2). Title 9. Subtitle 2. Chapter 9. Subchapter 2. *Revised Uniform Adoption Act*.

Ashcroft, R. E. (2003). Back to the future. Response to: Extending preimplantation genetic diagnosis: Medical and non-medical uses. *Journal of Medical Ethics, 29*(4), 217-219.

Berry, R. M. (2003). Genetic information and research: Emerging legal issues. *Healthcare Ethics Committee Forum, 15*(1), 70-99.

Bobrow, M., & Grimbaldeston, A. H. (2000). Medical genetics, the human genome project and public health. *Journal of Epidemiology and Community Health, 54*, 645-649.

Bombardieri, M. (2005). *Summers' remarks on women draw fire*. The Boston Globe. Retrieved, January 17, 2005, from http://www.boston.com/news/education/higher/articles/2005 /01/17/summers_remarks_on

Bragdon v. Abbott (1998), 118 S.Ct. 2196, 524 U.S. 624.

Brodwin, P. (2005). `Bioethics in action` and human population genetics research. *Culture, Medicine and Psychiatry, 29*(2), 145-178.

Buchanan, A., Califano, A., Kahn, J., McPherson, E., Robertson, J., & Brody, B. (2002). Pharmacogenetics: Ethical issues and policy options. *Kennedy Institute of Ethics Journal, 12*(1), 1-15.

California Health & Safety Code, Division 106. Personal Health Care (Including Maternal, Child, And Adolescent) Part 5. Hereditary Diseases/Congenital Defects Chapter 1. Genetic Prevention Services Article 4. Prenatal Testing, Section 125050 et seq.

California Insurance Code, Section 1- 16030, New York Consolidated Legal Service, Insurance Law, Section 101-9901.

Caperna, L. M., & Curley, R. A., Jr. (2003). The brave new world is here: privacy and the HGP: governments and courts must step in to provide protections and regulations for the use of individuals' genetic testing results. *Defense Counsel Journal, 70*(1), 22-35.

Carmichael, B. (2003). The Human Genome Project – threat or promise? *Journal of Intellectual Disability Research, 47*(7), 505-514.

Chadwick, R. (1999). Genetics, choice and responsibility. *Health, Risk and Society, 1*(3), 293-300.

Chapman, E. (October 2002). Ethical dilemmas in testing for late onset conditions: Reactions to testing and perceived impact on other family members. *Journal of Genetic Counseling, 11*(5), 351-366.

Cinncinati Children's Hospital Medical Center. (2006). *Genetics education programs for nurses*. Retrieved February 1, 2006 from http://www.cincinnatichildrens.org/ed/clinical/gpnf/default.htm

Code of Federal Regulations, 42 C.F.R. Section 201 et seq. Subtitle A. Subchapter A. Part 46 Subpart B, *Additional Protections for Pregnant Women, Human Fetuses and Neonates Involved In Research*.

Code of Federal Regulations. 45 C.F.R Section 101 et seq. Subtitle A, Subchapter A, Part 46 Subpart A, *Basic HHS Policy For Protection Of Human Research Subjects*.

Code of Federal Regulations. 45 C.F.R Sections 107-109. Subtitle A, Subchapter A, Part 46, Subpart A, *Basic HHS Policy For Protection Of Human Research Subjects*.

Cohen, J. (2002). Fetal fortunes: New technologies offer a window on the genetic fate of the unborn. The consequences: More successful pregnancies, healthier babies – and some gut-wrenching ethical choices. *Technology Review, 105*(8), 54-60.

d'Agincourt-Canning, L. (2001). Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics, 15*(3), 231-247.

Darnovsky, M. (2001). Human germline manipulation and cloning as women's issues. *GeneWatch, 14*(4), 1;13-14.

Davidson, M. E., Weingarten, K., Pollin, T., Wilson, M. A., Wilker, N., Hsu, N., et al. (2000). Consumer perspectives on genetic testing: Implications for building family-centered public policies. *Families, Systems, and Health, 18*(2), 217-235.

Davis, S. (1997). *The Human Genome Project: Examining the ARC's concerns regarding the project's ethical, legal, and social implications.* Speech at the DOE human genome program contractor-grantee workshop IV. Washington, D.C.

Department of Energy Human Genome Project Information. (2006). *Gene Therapy.* Retrieved February 1st, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetherapy.html

Department of Energy Human Genome Project Information. (2006). *Pharmacogenomics.* February 1, 2006, from http://www.ornl.gov/sci/techresources/Human_Genome/medicine/pharma.html

D'Souza, D., & Bailey, R. (2001). Our biotech future – An exchange (opposing opinions on genetic engineering of children). *National Review, 53*(4).

Elias, S., & Annas, G. J. (1992). Social policy issues raised by the Human Genome Project. *The Genetic Resource, 6*(2), 32-37.

Elliott, C. (2003). Adventures in the gene pool. *The Wilson Quarterly, 27*(1), 12-21.

Elliott, E. D. (2001). The genome and the law: Should increased genetic knowledge change the law? *Harvard Journal of Law & Public Policy, 25*(1), 61-70.

Fletcher, R. (1999). Telehealth rescues isolated patients. *Health Management Technology, 20*(11), 52-3.

Food and Drug Administration. (2006). *Arthritis: Timely treatments for an ageless disease.* Retrieved February 1, 2006, from http://www.fda.gov/fdac/features/2000/300_arth.html

Freedman, T. G. (1998). Genetic susceptibility testing: ethical and social quandaries. *Health and Social Work, 23*(3), 214-222.

Friedlander, H. (1995). *The origins of Nazi genocide: From euthanasia to the final solution.* Chapel Hill, NC: The University of North Carolina Press.

Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Congress (2005).

Gentry, D. B. (2000). Genetic technology and family conflict. *Mediation Quarterly, 18*(1), 5-17.

Glannon, W. (1998). Genes, embryos, and future people. *Bioethics, 12*(3), 187-211.

Greely, H. T. (1998). Legal, ethical, and social issues in human genome research. *Annual Review of Anthropology, 27*, 473-502.

Gridley, D. (2001). Genetic testing under the ADA: A case for protection from employment discrimination. *Georgetown Law Journal, 89*(4), 973-99.

Guterman, L. (2003). Choosing eugenics: How far will nations go to eliminate a genetic disease? *Chronicle of Higher Education, 49*(34), A22-A26.

Haga, S. B. (2004). *Teaching resources for genetics.* Nature Publishing Group. Nature Reviews, Genetics.

Hall, M. A., & Rich, S. S. (2000). Genetic privacy laws and patients' fear of discrimination by health insurers: The view from genetic counselors. *Journal of Law, Medicine, and Ethics, 28*(3), 245-57.

Harman, L. B. (2003). Attitudes toward genetic testing: Gender, role and discipline. *Topics in Health Information Management, 24*(1), 50-58.

Health Insurance Portability and Accountability Act of 1996, 42 U.S. Code § 300gg and 29 U.S. Code, §1181 et seq.

Hoffman, D. E. & Wulfsberg, E. A. (1995). Testing children for genetic predispositions: Is it in their best interest?. *Journal of Law, Medicine, & Ethics, 23*(4), 331-344.

Holland, A. & Clare, I. C. (2003). The Human Genome Project: Considerations for people with intellectual disabilities. *Journal of Intellectual Disability Research, 47*(7), 515-25.

Insel, T. R. (2003). Psychiatry in the genomics era. *American Journal of Psychiatry, 160*(4), 616-620.

Jallinoja, P., Hakonen, A., Aro, A. R., Niemela, P., Hietala, M., Lönnqvist, J., et al. (1998). Attitudes towards genetic testing: Analysis of contradictions. *Social Science and Medicine, 46*, 1367-1374.

Johnston, T. (2005). In one`s own image: Ethics and the reproduction of deafness. *Journal of Deaf Studies and Deaf Education, 10*(4), 426-441.

Joint Government Report (1998). *Genetic Information and the Workplace.* Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission, Department of Justice.

Jones, J. (1999). Mapping the human genome: The genetics revolution. (The impact of new technologies in medicine). *British Medical Journal, 319*(7220), 1282.

Kac, E. (2000). GFP Bunny. In P. T. Dobrila & A. Kostic, (Eds.), *Telepresence, biotelematics, and transgenic art* (pp. 101-131). Maribor, Slovenia: Kibla.

Kass, L. R. (2002). The age of genetic technology arrives. *American Spectator, 35*(6), 40-46.

Kenen, R. H. & Smith, A. C. M. (1995). Genetic counseling for the next 25 years: Models for the future. *Journal of Genetic Counseling, 4*(2), 115-124.

Kilner, J. F. (2002). *Commentary: The ends don't justify the genes.* The Center for Bioethics and Human Dignity: Bannockburn, IL.

Kissell, J. L. (2002). The human genome project: A Pandora's Box. *Journal of Systemic Therapies, 21*(2), 19-29.

Knoppers, B. M., & Chadwick, R. (2005) Human genetic research: Emerging trends in ethics. *Nature Reviews Genetics, 6*(1), 75-79.

Konrad, M. (2003). From the secrets of life to the life of secrets: Tracing genetic knowledge as genealogical ethics in biomedical Britain. *Journal of the Royal Anthropological Institute, 9*(2), 339-358.

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.

Krugman, S. (1986). The Willowbrook hepatitis studies revisited: ethical aspects. *Review of Infectious Diseases, 8*(1),157-62.

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

Mashour, G. A., Walker, E. E., & Martuza, R. L. (2005). Psychosurgery: Past, present, and future. *Brain Research, Brain Research Reviews, 48*(3), 409-19.

McMahan, J. (2005). The morality of screening for disability. *Reproductive BioMedicine Online, 10*, 129-132.

Medical Schools Objectives Project. (2004). *Report VI, Contemporary issues in medicine: Genetics education.* Washington: American Association of Medical Colleges.

Mehler, B., & Allen, G. E. (1977). Sources in the study of eugenics #1: Inventory of the American Eugenics Society papers. *The Mendel Newsletter: Archival Resources for the History of Genetics & Allied Sciences. 14*, http://www.ferris.edu/isar/archives/sources /aes.htm

Middleton, C., & Biegert, M. E. (2005). Planning for the age of genetics: A Denver-based system makes ethical, theoretical, and practical decisions about genetic medicine. *Health Progress, 86*(1), 35-40.

Mowat, D. (2002). Ethical, legal and social issues surrounding the Human Genome Project. *Internal Medicine Journal, 32*, 89-90.

Murphy v. United Parcel Service. 527 U.S. 516 (1999).

National Coalition for Health Professional Education in Genetics. (2005). Retrieved February 1, 2006, from http://www.nchpeg.org

National Coalition for Health Professional Education in Genetics. (2006). *Contracts and Grants.* Retrieved February 1, 2006, from http://www.nchpeg.org/ContractsGrants.html

National Human Genome Research Institute. (2006a). *Funding Opportunities For Minority and Special Populations.* Retrieved February 17, 2006, from http://www.genome.gov/10000985

National Human Genome Research Institute. (2006b). *Genetic Discrimination.* Retrieved February 1, 2006, from http://www.genome.gov/10002077

National Human Genome Research Institute Legislative Database. Retrieved March, 2006, from http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm

O'Connor, B. V., & Cappelli, M. (1999). Health beliefs and the intent to use predictive genetic testing for cystic fibrosis carrier status. *Psychology, Health, and Medicine, 4*(2), 157-168.

Oregon Statute, Section 109.342. Volume 3, Chapter 109, Medical history of child and biological parents required; content; delivery to adoptive parent and to adoptee on majority.

Orwell, G. (1949). *Nineteen-eighty four.* London: Secker & Warburg.

Parens, E., & Asch, A. (2003). Disability rights critique of prenatal genetic testing: Reflections and recommendations. *Mental Retardation and Developmental Disabilities Research Reviews, 9*(1), 40-7.

Patenaude, A. F., Guttmacher, A. E., & Collins, F. S. 2002). Genetic testing and psychology: New roles, new responsibilities. *American Psychologist, 57*(4), 271-282.

Phelan, J.C. (2002). Genetic bases of mental illness – a cure for stigma? *Trends in Neuroscience, 25*(8), 430-431.

Quinn, P. (2003). Race cleansing in America: A nationwide gene-purity movement promoted methods that eventually were adopted by the Third Reich, and everyone from John D. Rockefeller to W.E.B. Du Bois supported. *American Heritage, 54*(1), 34-43.

Resnik, D. B. (2001). DNA patents and human dignity. *Journal of Law, Medicine, and Ethics, 29*(1), 152.

Richards, M. (1998). Annotation: Genetic research, family life, and clinical practice. *Journal of Child Psychology and Psychiatry, 39*(3), 291-305.

Roberts, C. D., Parrish, L. H., & Stough, L. M. (2002). The role of genetic counseling in the elective termination of pregnancies involving fetuses with disabilities. *Journal of Special Education, 36*(1), 48-56.

Robertson, J. A. (2003). Extending preimplantation genetic diagnosis: Medical and non-medical uses. *Journal of Medical Ethics, 29*(4), 213-216.

Rockwell, D. H., Yobs, A. R., & Moore, M. B., Jr. (1964). The Tuskegee study of untreated syphilis; The 30th year of observation. *Archives of Internal Medicine, 114*, 792-8.

Rosenow, L. & Andrews, L. B. (2002). How the fruits of the human genome project may impact marriage and family relationships. *Journal of Systemic Therapies, 21*(2), 4-18.

Sandel, M. J. (2004). The case against perfection. What's wrong with designer children, bionic athletes, and genetic engineering? *The Atlantic Monthly, 293*(3), 51-62.

Senituli, L. (2002). The gene hunters: When an Australian biotech firm went bioprospecting in Tonga, Lopeti Senituli was part of the welcoming committee. *New Internationalist, 349*, 13-15.

Seppa, N. (2005). Neuron savers: Gene therapy slows Alzheimer's disease. Retrieved August 30, 2005, from http://www.sciencenews.org/articles/20050430/fob1.asp. *Science News Online 167*(18), 275.

Shakespeare, T. (2003). *2053 AD: After Disability?* Retrieved February 14, 2006, from http://www.bbc.co.uk/ouch/closeup/2053/index.shtml

Shannon, T. A. (1999). Ethical issues in genetics. *Theological Studies, 60*(1), 111.

Shannon, T. A. (2001). The Human Genome Project: Now the hard work and the hard questions – ethical issues related to the human genome project. *Commonwealth, 128*(6), 9.

Sharp, R. R., & Barrett, J. C. (2000). The environmental genome project: Ethical, legal, and social implications. Retrieved August 30, 2005, from http://www.mindfully.org/GE/Environmental-Genome-Project.htm. *Environmental Health Perspectives, 108* (4), 279-281.

Sharp, R. R., & Foster, M. W. (2000). Involving the study populations in the review of genetic research. *Journal of Law, Medicine & Ethics, 28*(1), 41-51.

Stolba, C. (2002). Overcoming motherhood: Pushing the limits of reproductive choice. *Policy Review, (Dec.)* 31-41.

Strauss, R. P. (2002). Beyond the easy answers: Prenatal diagnosis and counseling during pregnancy. *Cleft Palate-Craniofacial Journal, 39*(2), 164-168.

Summers, L. (2005). Remarks at NBER Conference on Diversifying the Science & Engineering Workforce. Retrieved January, 2005, from http://www.president.harvard.edu/speeches/2005/nber.html

Suter, S. M. (2002). The genetics revoultion: Conflicts, challenges and conundra: The routinization of prenatal testing. *American Journal of Law & Medicine, 28*(2&3), 233-270.

Sutton v. United Airlines, 527 U.S. 471, (1999). Ct. 2139.

Sutton, A. M. (2002). *Commentary: Designer genes. When having a child to save a child causes some children to die*. The Center for Bioethics and Human Dignity: Bannockburn, IL.

Tauer, J. E. (2001). International protection of genetic information: The progression of the Human Genome Project and the current framework of human rights doctrines. *Denver Journal of International Law and Policy, 29*(3), 209-237.

Thompson, L. (2000). Human gene therapy: Harsh lessons, high hopes. *FDA Consumer, 34*(5).

U.S. Department of Energy Office of Science. (2005a). *Gene testing.* Retrieved September 1, 2005, http://www.genome.gov/10001754

U.S. Department of Energy Office of Science. (2005b). *Pharmacogenomics*. Retrieved September 1, 2005, from http://www.ornl.gov/sci/techresources/Human_Genome/medicine/pharma.shtml

U.S. National Institutes of Health. (2005). *Gene therapy*. Retrieved August 30, 2005, from http://clinicaltrials.gov/search/intervention=%22gene+therapy%22&recruiting=true

University of Kansas Medical Center. (2006). *Genetics Education Center*. Retrieved February 1, 2006, http://www.kumc.edu/gec/prof/career/html

Walsh, J. (1994). Reproductive rights and the human genome project. Southern California *Review of Law and Women's Studies, 4*(1), 145-181.

Washington State Genetics Outreach Education Programs (2006). *Genetics Education Partnership.* Retrieved Febrary 1, 2006, from http://genetics-educationpartnership.mbt.washington.edu/guide/programs.html

Wertz, D. C. (1992). Ethical and legal implications of the new genetics: Issues for discussion. *Social Science & Medicine, 35*(4), 495-505.

Wertz, D.C. (1998). Ethical issues in pediatric genetics: Views of geneticists, parents and primary care physicians. *Health Law Journal, 6*, 3-42.

Wetz, D.C. (1992). Ethical and legal implications of the new genetics: Issues for discussion. *Social Science and Medicine, 35*(1), 495-505.

Wexler, N. S. (1990). Presymptomatic testing for Huntington`s disease: Harbinger of the new genetics. In Z. Bankowski & A.M. Capron (Eds.), *Genetics, ethics and human values: Human genome mapping, genetic screening and gene therapy*. Proceedings of the XXIVth CIOMS Round Table Conference. Hereditary Disease Foundation:Tokyo and Inuyama City, Japan.

White, R. M. (2005a). Misinformation and misbeliefs in the Tuskegee Study of Untreated Syphilis fuel mistrust in the healthcare system. *Journal of the National Medical Association, 97*(11), 1566-1573.

White, R. M. (2005b). Misrepresentations of the Tuskegee study of untreated syphilis. *Journal of the National Medical Association, 97*(12), 1729-1731.

Wolery, M., & Bailey, D. B., Jr. (2002). Early childhood special education research. *Journal of Early Intervention, 25*(2), 88-99.

Correspondence

Matt Stowe
matstowe@ku.edu

Rud Turnbull
rud@ku.edu

Beach Center on Disability
University of Kansas
Haworth Hall, Room 3136
1200 Sunnyside Avenue
Lawrence, KS
66045-7534
U.S.A.