This age in which we are living is characterized by rapidly increasing biotechnological knowledge; and revolutionary techniques involving assisted reproductive technologies, pre-natal diagnoses, genetics, and cloning. Significantly, these not only affect current humanity, but also provide choices about what types of humans will be born in the future. How “difference” is conceptualized within such a context must be subject to ongoing ethical and legal scrutiny; and the relationship between bioethics and people with intellectual disability exemplifies such a challenge. This discussion explores some initial observations of such a relationship.

Explorations thus far have revealed two significant contentions. First, people or potential people with intellectual disability are most likely to be rendered, even on biological determination alone, profoundly irrelevant or disqualified within bioethical conversations because they are deemed incapable of being rational, competent, independent beings (Clapton, 2000, 1999). Second, while recent scholarship and trends in disability studies have shifted under-
woes would soon be resolved! In this debate no one speaks of the elimination of people with disabilities, but, rather, of the elimination of “disability”, and the “suffering” with which it is assumed to be associated. Normally, this is taken, uncritically, to be positive, but is such a position sustainable? Without adopting some idealized notion of disability, what alternative perspectives might be proposed? Can advances in genetics ever benefit people with disabilities? These were some of the questions considered in invited and submitted presentations from geneticists, philosophers, social scientists, lawyers, representatives of groups for people with genetic “syndromes”, clinicians in services for people with intellectual disabilities, and researchers.

It soon became clear that the popular representations of the Human Genome Project far outstrip the reality. At the time of the meeting, the sequencing of the human genome was only in “draft form”, and not, as had been suggested in the press, complete. DNA sequences have been identified for only about 12,000 of the 30,000 to 35,000 genes that make up the coding sequences in the human genome (HG). While a target date for completion of the sequencing of the HG has been set for the end of 2002, this is only the beginning of main task. Only when the much longer term work of the investigation of the functional roles of each gene has been completed is it likely that there will be a conceptual advance in understanding.

Meanwhile, however, the process of identifying genes leading to specific syndromes associated with “disability” is a reality. What then about prenatal diagnosis and choice? As options increase, should choice be limited through the law, and if so, how? At present the assumption that a person’s life will necessarily include “suffering”, perhaps inevitably leads to a positive view of the opportunities that already exist as a result of the new genetics for the option of termination of pregnancy, as well as optimism about the new options that may soon be a reality with respect to “embryo preimplantation”. An alternative view is that there is no ineluctable link between suffering and a condition associated with a disability, such as Down Syndrome. Rather, suffering may simply be part of the human experience and the possession of three copies of chromosome 21 may, in some circumstances, play little role in this. Individual beliefs, in the context of societal attitudes, may be of more importance. Professor John Harris, the philosopher, argued strongly that we should seek offspring who, at least at the start of their lives, have no preventable disadvantage. Developing this argument further, he proposed that it is morally unjustifiable to make a free choice to have a baby with a disability: it is wrong to bring avoidable suffering into the world. This is not to deny choice; on the contrary, people are entitled to make their own decisions about their offspring. But for potential parents to choose not to prevent disability in their offspring, at present through genetic counseling and termination, would be similar to denying potential treatment to their son or daughter with congenital deafness. Rationally, we must prefer to avoid a “harmed condition”. The important issue for debate lies around what are, and are not, acceptable reproductive choices?

Other presentations examined the issues raised by John Harris in more detail, and from different perspectives. One view is that advances in genetics lead inevitably to a better understanding of disability and the potential for the suffering with which it is associated. However, while different interventions and treatments might be developed in the future, at present, prevention is the main option, and that should be a priority. From a more critical perspective, the construction of “disability” in a particular socio-historical contexts, the relationship between disability and individual identity, and the meaning of “suffering”, often conceptualized within a contentious framework of “tragedy” or “catastrophe”, were questioned. Men and women working in genetic research have to believe in their methods of classification, and in their models of understanding of intellect and behavior, as much as those who challenge the genetic deterministic perspective, have to believe in the “unconditionality of human relationships”.

We hope that the participants who attended this meeting came away enriched, not least by the opportunity to share time with others whose perspectives are so different from their own, but also in terms of what was decided and of the outcome - what was decided and what was the outcome is more difficult to answer. The styles of discourse, the knowledge bases of
different disciplines, personal experience and preconceptions, and the cultural contexts in which we work, are so different. How do we develop the arguments, and how do we share an understanding? Discussion and debate must be the way forward, but that will continue to be a challenge at a time when “sound-bites” are valued and reflection and complexity receives limited attention. And how can we involve people with intellectual disabilities themselves and their families, the “experts by experience”, in this debate?

Genetic research will continue to advance, and there is the real potential for benefit, but this continues against a background of long-established fears of disability. Other contributions at the meeting reminded us that the forced sterilization, primarily of women, still takes place, that the goal of autonomy for adults remains problematic, and that the lived experience of people with disabilities and their families often remains one of disadvantage and exclusion.

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Genome

Tragedy and Catastrophe

standing of disablement from dominant medical perspectives about individual deficits, to social theories that focus upon the structures of an excluding society to those considered “not normal”, there has been little recognition of these changes in bioethics literature. Furthermore, one could readily claim that against this paradoxical backdrop, the contemporary biotechnological era is, in fact, facilitating the recolonization of the lives of people with disability by powerful disciplines such as medicine, science and the law, with the complicit support of moral philosophy.

That is because the complex relationship between bioethics and disability in Western society is predominantly constituted by conjoining two powerful relations: disability is perceived as personal tragedy; and ethics, especially bioethics, is predominantly practiced as traditional medical ethics. In this context, disability is viewed either as a distressing or disastrous situation or as an undesirable “problem” to be fixed or eliminated. The focus then, is on the alleviation of presumed unhappiness and suffering; Bioethics, as a discipline, is thus primarily committed to ameliorating the state of “not-good”, or preventing “not-right” ways of being human.

In deconstructing the conjunction of disability as personal tragedy and bioethics as traditional medical ethics, I contend that we need to explore the controlling discourses of tragedy and catastrophe in order to recognize inherent complexities about whose voices are being heard and whose agendas are being considered. In this context, tragedy can be defined as an unhappy event in real life with disastrous and sorrowful conclusions; catastrophe is a sudden disaster due to the disruption of the social order.

Identification of these discourses assists in differentiating between how dominant private and public concerns and agendas are conceived. For instance, tragedy is a discourse of the private arena, in which individual ethical choices are made in particular situations such as a clinical encounter. The presence of disability as a tragedy evokes personal, autonomous choices that are directed by such principles as beneficence and nonmaleficence, compassion, and mercy that seek to prevent or diminish the possibility of suffering and pain. Ultimately, it seems that the responses need to be determined by those who will be affected by such choices, and who will utilize forms of knowledge and information offered to them, most likely by “expert”, in order to make their personal decisions. In doing this, they juxtapose this input with their own past, present, and presumptions of future experiences to inform them in relation to assessing notions of unhappiness, suffering, dependency, and burden.

While a discourse of tragedy considers an explanation, a discourse of catastrophe seeks a cause, and thus shifts the focus to political and research actions to alleviate societal burden.

(Continued on page 4)
On the other hand, catastrophe is the discourse of the public arena with its context of social order. Therefore, ethical considerations are expanded from those of personal choice to societal concerns. The presence of disability, as a discourse of catastrophe, represents an intersection of moral, political and economic considerations; and anathema to what is considered “good” according to an established social order. While a discourse of tragedy considers an explanation, a discourse of catastrophe seeks a cause, and thus shifts the focus to political and research actions to alleviate societal burden.

This agenda is illuminated by Dreger, who interestingly highlights how the American political context has depicted the Human Genome Project as a “dramatic morality play.” In this “play,” she describes how scientists have been depicted as frontier explorers on journeys of discovery; with the territory then being claimed and mapped as a road map to good health; thus leading to subsequent claims that it would be immoral or unethical not to carry on with the Project and; then consequently using language and tropes of hunting the “bad” genes; and more recently, even to engaging in real estate practices of commodifying and trading the territory (Dreger, 2000). Such a construction presents some intriguing similarities to processes of colonization. It is pertinent to note these insights with Sibley’s description of how the history of colonialism, the rise of science, and the growth of capitalism have led to the “scaling of beings” by dominant groups, which subject presumed inferior beings to processes of exclusion or dispensability (Sibley 1995, p.27). The possible presence of intellectual disability, the inferior social status afforded to those affected, and the notion of societal burden seemingly underpin the promotion of prevention procedures such as pre-implantation or pre-natal testing and the...

... ethical considerations are expanded from those of personal choice to societal concerns.

The evocation of tragedy and catastrophe discourses in relation to intellectual disability and biotechnological advances such as the Human Genome Project is contentious in as much as these discourses fail to embrace what Hilde Lindemann Nelson (1995) refers to as “counterstories.” “Counterstories” of real lived and relational experiences with people with intellectual disability can offer both alternative understandings that challenge notions of inferiority, and ethical platforms from which to engage in critical discussions. I argue, then, that the challenge ahead will be to address some pertinent questions, such as “Can these counterstories be heard in such a biotechnological climate of science and industry” and “What currency will bioethics, as a discipline, give them against the very powerful and colonizing disciplines controlling the biotechnological revolution.” It seems that these are questions that urgently require addressing when considering disability, suffering, and moral status in the age of the Human Genome Project.

References

The Human Genome Project and Intellectual Disability

Dr. F. Lucy Raymond*

The aim of the Human Genome Project is to identify the linear sequence of DNA which constitutes the genetic material of a human being. The assumption is that having this knowledge will facilitate our understanding of the human condition both in its normal and diseased state and thus guide our efforts to identify and potentially ameliorate diseases. With respect to intellectual disability the project assumes a medical model of disability and so far has confined its study to identifying single genes that are likely to cause intellectual disability when abnormal in an individual. These genes are rare, but if found, have a high predictive value for its effect in an individual. Two overall strategies have been used to identify these genes which:

- Identify rare families where the intellectual disability alone runs in the family. Most of these have an X-linked pattern of inheritance where males are affected preferentially and carried through females who are either mildly affected or unaffected. The first of these conditions to be identified was fragile X syndrome and more recently seven more genes on the X chromosome have been identified that correlate with intellectual disability. All the single genes responsible for intellectual disability through this mechanism are rare and, even where a gene abnormality is detected, the extent of the disability is very variable.

- Focus on diseases or syndromes where affected individuals have a characteristic physical form and intellectual disability is only part of the overall clinical manifestations of the conditions. Examples are Prader-Willi, Williams, Smith Magenis, Coffin-Lowry and X-linked alpha thalassaemia syndromes. The identification of the genetic abnormality has been technically easier as samples from affected individuals with common clinical features can be grouped together experimentally and assumed to have a similar molecular abnormality. Again the presence of a genetic abnormality in these individuals strongly predicts intellectual disability although the extent of the disability varies among individuals with the same condition.

One can envisage potential benefits in identifying the genetic causes of learning disability in an individual in both clinical and research contexts.

- Molecular characterization of conditions associated with intellectual disability has enabled grouping of similarly affected individuals and has facilitated understanding of the specific disability associated with a condition. This has helped, and will increasingly help, in identifying specific educational and medical needs for certain groups of patients and accurate advice to affected individuals and their carers.

- Molecular genetic testing can provide an explanation as to the cause of intellectual disability in an individual. Parents frequently seek to find an explanation for why their child has problems. Identifying genetic abnormalities can
potentially reduce the burden for responsibility of causation that many parents feel, although, complex feelings of guilt about unknowingly handing on genes that lead to disease should not be underestimated.

- Accurate molecular information now ensures accurate advice about recurrence is now tailored to individual families. Previously only empirical recurrence risks were available from population-based observations. These are composite figures made from a few families where the recurrence is high and many more families were the recurrence is low due to a different disease causing mechanism.
- Prenatal testing becomes possible in a subsequent pregnancy where there is a recurrence risk. This choice becomes available to couples who previously had no choice. If the genetic abnormality is identified, the choice now in subsequent pregnancies is: a) prenatal testing early in pregnancy and a termination of pregnancy if the second child is affected; b) prenatal testing and preparation for the birth of a second affected child; and c) the choice to have no prenatal testing.
- Molecular genetics has the potential to provide understanding of some of the cellular mechanisms that underlie abnormalities in brain development and thus increase our knowledge of this complex process.

There are also perceived disadvantages of studying the molecular mechanisms underlying intellectual disability. Some of these concerns are:

- Identification of molecular genetic abnormalities that lead to intellectual disability reinforces a medical model of disability, which is unacceptable to many. It raises questions of when genetic variation is an abnormality and when it is a normal variant.
- It also reinforces many ideas of genetic determinism and easily becomes generalized inappropriately to all intellectual abilities.
- Identifying gene abnormalities may generate choices for parents with respect to prenatal testing. Previously if there was no choice then individuals did not have to enter the debate of the morals and ethics of termination of pregnancy for intellectual disability and the consequent effect on those individuals in society who were not terminated. This debate is qualitatively identical to that stimulated by prenatal testing for Down’s syndrome.

With the progress of the Human Genome Project there are concerns that if all genetic abnormalities could be detected we would inevitably slide into an era of designer babies without realizing it. This is a real concern and needs to be considered. However, the ability to predict the level of intellectual disability from genetic information is limited to a few genes, that when abnormal, cause profound intellectual disability. These gene abnormalities are rare in the population but highly significant in the few affected families. Even in these families there is considerable heterogeneity and range of disability, which is thought to be due to influences both by the external environment and by internal influence of other genes within that individual. In general, most genes and genetic variation are poor predictors of disease and would never be useful in predicting the level of intellectual disability in an individual except in these rare cases. I would therefore argue that, apart from identifying the rare, highly penetrant genes where a medical model of disability would seem more acceptable, genetic testing of low-penetrant genes, which are a poor predictor of intellectual disability, would neither be accurate, or desirable. It is encouraging that this is also the view of the general public in surveys of UK attitudes to genetics.

The Human Genome Project and the identification of genes involved in intellectual ability continues. We have the opportunity to understand some of the molecular mechanisms of learning disability in individuals and provide insights into the behavioral characteristics of these conditions. As this knowledge emerges over the next few years, it is imperative that it is used appropriately for the benefit of those with intellectual disability so that their lives are enriched by this knowledge rather than simply excluded.

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In Memoriam

Stanley S. Herr 1945-2001

Stanley Herr, professor of law at the University of Maryland, died Sept. 24, 2001, of cancer. Professor Herr had served as president of the American Association on Mental Retardation. He litigated landmark legal cases on behalf of citizens with mental retardation establishing their right to public education in the District of Columbia and a ban on the execution of retarded criminals in Maryland. He also litigated actions against Willowbrook, the New York institution responsible for inhumane treatment of persons with mental disabilities.

At the University of Maryland he taught courses on disability rights and civil rights. He was a Kennedy Fellow at the White House during the Clinton administration, a Rockefeller fellow for human rights at Columbia University, a Kennedy fellow at Balliol College, Oxford, and a Fulbright senior research scholar at Tel Aviv University and Hebrew University of Jerusalem. He studied law at Yale and received a doctorate from Oxford University. He was the author of Rights and Advocacy for Retarded People and Legal Rights and Mental Health Care. He is survived by his wife, Raquel Schuster-Herr and three children.

Gunnar Dybwad 1909-2001

Gunnar Dybwad, a leading authority in the developmental disabilities field, who championed the rights of children with disabilities to receive a public school education, died in Needham, Mass on September 13.

He held positions including executive director of the National Association for Retarded Children and professor of human development at Brandeis University where he was the founding director of the Starr Center for Mental Retardation at the Heller School for Social Policy and Management.

Another Supreme Court Case to be Heard on the Death Penalty and the Mentally Retarded

Susan Poland

On September 25, 2001, the U.S. Supreme Court chose to review in the capital murder case of Atkins v. Virginia. Daryl Atkins, age 18 at the time, along with William Jones, abducted Langley Air Force Base airman Eric Nesbitt, age 21, at gunpoint late at night outside a convenience store, robbed him of $60 in his wallet before forcing him to withdraw $200 from an automated teller machine, and then drove to a remote road, where Atkins fatally shot Nesbitt eight times. Atkins has an I.Q. of 59 and the mental age of a 9-12 year old. Testimony by the two forensic clinical psychologists conflicted as to whether Atkins was mildly mentally retarded or at least average in intelligence; both experts, however, agreed that Atkins had the ability both to understand his criminal conduct and to act in accordance with the law. The Supreme Court of Virginia found it significant that the diagnosis of mental retardation involves more than the determination of I.Q. and that it involves consideration of "adaptive functioning," the ability to live independently. Although a jury twice sentenced Atkins to death for the crime, two of the five state supreme court judges dissented on assigning the death penalty to mentally retarded defendants. The U.S. Supreme Court will hear oral argument on the Atkins case in spring 2002 and decide the case later in the term before July.

Institute of Ethics. Many can be found on PubMed by searching either mental retardation or intellectual disability, limiting the search to the subsets bioethics, human, and English language.


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