The Perils of Human Genetics

Jerome E. Bickenbach

The Human Genome Project (HGP), the best funded scientific venture in human history, has already delivered on its promise to uncover the genetic antecedents of human disease and disorder. Daily, we hear of the discovery of genetic markers for yet another disease, or new ways to predict the appearance of late onset physical or psychological conditions. Somewhat muted in the background, however, have been calls for caution and concern. Many disability activists has wondered about the social consequences of research in human genetics for people with disabilities: Will our health policies and income supports be altered? Will people with disabilities face new forms of discrimination and marginalization? Although there are undoubtedly benefits flowing from research into human genetics, what are the perils?

Dr. Marcia Rioux of the Roeher Institute in Toronto, Ontario, with Dr. Jerome E. Bickenbach of the Developmental Consulting Program at Queen's University, Kingston, Ontario and Dr. Daune MacGregor of the Hospital for Sick Children in Toronto are engaged in a two year project to investigate the social policy consequences of the HGP for people with intellectual disabilities. Will our new discoveries and powers of prediction and control mold our law and social policy in ways that will prejudice the rights and welfare of people with mental disabilities? And if so, how can these detrimental social consequences be averted?

The project focuses on legal and social policy in two, salient, areas: health care and income security. Using Canadian social policy, legislation, and practice as heuristics models, the researchers are surveying existing law and policy to determine the present impact of human genetic research, with an eye to identifying specific areas of concern. Supported by key informant interviewing, mail out surveys and focus group sessions bringing together policy makers, professionals and consumers, the researchers will formulate ethical and legal guidelines for the future development of science and technology policy with regard to human genetic science. These guidelines will provide, for the areas of health care and income security, the basis for ensuring that people with intellectual disabilities will continue to benefit from genetic research and technology and that their rights to full citizenship and participation will not be compromised.

But why should we be concerned about the effects of human genetic research on social policy for people with disabilities?
The reason for concern goes to the heart of genetic research. Everyone agrees that the product of human genetics research is genetic information about individuals and populations. The medical and epidemiological relevance of this information is obvious; but what about its social relevance?

Here we must be more careful since, at least potentially, genetic information can be the source for the most profound form of stigmatizing labelling people with disabilities has as yet experienced. For genetic information purports to tell us what someone is 'really like', thereby relieving us of the need to look for signs, symptoms or other overt characteristics. Human difference, when labelled genetically, opens the door to the most profound forms of stigmatization.

But is this possible consequence very likely to become actual? The research believe that a prudent concern is justified, since there are very powerful social forces which, if not checked, could increase the likelihood that genetic information will be sought and relied on in ways that are detrimental to the interests of people with disabilities.

In times of perceived restraint on social resources, policy makers will be driven to seek ways of predicting future costs. Genetic information is optimal for these purposes. If a health care policy analyst could have at her disposal accurate information about the prevalence of a variety of mental and physical conditions in the population, then precise cost and resource projections could be made. If a specialist in income security policy could predict with great accuracy the number of people who will need income supports in the next fifty years, she would be able to integrate this policy into the general supply-side labor policy, with considerable savings.

Generally speaking, in social policy development, the ability to plan allows for overall cost reduction and rational resource allocation. People with disabilities, especially those with severe intellectual disabilities, have always been perceived to constitute a greater burden on social programs than others. In the absence of accommodation at the workplace, this perception is true, since without the prospect of meaningful employment, people with disabilities are forced to seek other sources of income.

Because of this feature of social policy, a more accurate, population-wide, predictor of the number of people who can be deemed "unemployable" would be welcome by policy makers. With the increased availability of genetic information, these same policy makers will be pressured to improve the validity of their projection by encouraging more far-reaching genetic screening and testing. The more this information is used, the more entrenched it will become as the basis for identifying and classifying people, and the more likely people will be viewed in light of their inherent disabilities, rather than the actual abilities.

As well, the perceived need for more strictly applied eligibility criteria for disability benefits -- income support, assistive devices, and special needs -- could create a demand for genetic determinants of disability. Genetic testing could then join means testing as the de facto qualification for social supports. All of this demand will lead to the proliferation of genetic information.

More worrisome, though, is the pressure that has always existed in policy development to prevent costs where possible. "Costs" in this case are people, people with disabilities. With increasing availability of, and reliance upon, genetic information, we should see increased calls for "prevention" through genetic pre-selection. Genetically-based determinations of "low quality of life" already have an impact on the decisions of pregnant women whether to continue the gestation of "defective fetuses."
more genetic testing and screening available -- even in the form of over-the-counter, self-testing kits -- the more likely that pregnant women will be subtly pressured, through public opinion and professional advice, to decide to 'prevent' a child with genetically-identifiable disabilities.

Given that there are legitimate concerns and fears about the effects of human genetic research on the wider domain of social policy, research is crucial in this area. The momentum of the HGP is, of course, unstoppable. What is needed is clear evidence of the effects of scientific research and technological developments in human genetics has had, and will likely have on social policy that directly affects the lives of people with disabilities (and indirectly affects the lives of all of us).

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Asylum:
Institutional & Community Violence

Dick Sobsey and Wade Randall

Research suggests that children with intellectual disabilities are about twice as likely to be abused as other children and adults with intellectual disabilities are at least three times as likely to be victims of violence as other adults. This article summarizes some of the major points made in a discussion of the relative risks of institutional and community living that took place during Summer, 1995 on the International Coalition on Abuse & Disability (ICAD) electronic mailing list, an information and discussion group that involves about two hundred people in ten countries.

Horror Stories

The discussion was sparked by the report of the murder of twenty-two year old William Paige by three roommates in Greenfield, MA. Paige who was described as "mildly retarded" and "epileptic" had been chained, gagged, beaten, and tortured with electric shocks and burns for months before finally being killed. This report was followed by similar accounts of murders of young men with intellectual disabilities that occurred recently in New York, Oklahoma, and Alberta.

Some list members participating in the discussion responded, voicing concern that too much focus on community violence provided a rationale for institutionalization. They suggested that violence is more common in institutions and provided grim examples of alleged and confirmed abuse in a number of institutions. Some suggested that violence legitimatized as "treatment" is particularly offensive. For example, quotes from the Criminal Justice Commission's Report on an inquiry into allegations of official misconduct at the Basil Stafford Centre (1995) documented pervasive violence and neglect including the beatings with "behavior modification sticks" that were actually golf clubs, cricket bats, and baseball bats.

Research

A few research studies were cited comparing institutional and community violence (see Sobsey, 1994). While these studies
generally suggested that violence is about twice as frequent in residential care as it is in natural families, discussants agreed that available studies are inadequate to draw any firm conclusions. The complexity of controlling for many potentially confounding factors and the difficulties of categorizing a wide spectrum of living situations into simplistic and somewhat artificial categories of institutional or community living creates significant difficulty in interpreting such studies.

Conclusions

While many of the discussants believe that community living is safer than institutional living, all agreed that violence is a serious risk for people with intellectual disabilities in both settings. Discussants also agreed that the defining institutionalization in terms of sizes of buildings or numbers of residents is misleading. Attitudes about and relationships of caregivers to people with intellectual disabilities are more important predictors of risk. Small group homes in the middle of towns and cities can be as isolated and "institutional" as large rural institutions. Discussants also identified the need to develop appropriate safeguards against violence in decentralized, residential care facilities that may require different strategies than those suitable for large institutions.

References


ICAD subscription information is available on the World Wide Web at http://gpu.srv.ualberta.ca/~ddc/ICAD.html

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Dependency and Marriage for Mentally Retarded South Asians

M. Miles

Formal mental retardation work in South Asia began in 1918 when a special school opened at Kurseong. At Indiana Independence (1947) there were still very few such services. Mildly retarded children were casually integrated in village life. In towns, some attended ordinary schools. People with severe retardation were tolerated at the margins of society.

Since the 1970s, public awareness has grown. Some specialists have been trained, and more services developed. Earlier work was shaped by western advice and literature. Recently, some reaction began. Data are becoming available on South Asian communities living with intellectual disabilities through three millennia (Miles, 1995). There are calls for policies and services reflecting Asian cultural norms.
Independence as a Non-Asian Cultural Norm

Western debates on young disabled people's marriage prospects assume that young people normally become independent of their parents in late teens or early twenties. During that period they usually find their own intimate partner. The issue is whether intellectually disabled youths can live independently with adequate protection from exploitation and disease, and take responsibility of intimate relations and child-rearing. For most South Asians, such issues hardly arise. "Independence" is an alien abhorrent idea. Children are trained to respect and obey the grandparents, whether in minor or major matters. Only a small modern elite lead "independent" lives. The Asian pattern of extended-family relationships is richer than that of western nuclear or sub-nuclear families. Of course, there are some stresses and strains, but broadly South Asian families function well, against a background of economic poverty. The extended family mobilises its human resources for members perceived as needing special care, i.e. the very young, the elderly and the disabled. This is seen as decent, correct, caring behavior, rather than "paternalism."

A Different Problem

Problems expected in western countries for mentally retarded people courting, living together or marrying, are much reduced in South Asia, where marriage does not involve first competing to find a mate, then living as a separate household. The problem for Asian parents is to find another family willing to agree to a marriage, despite the young person's disability. Parents may have to make an arrangement with a family of lower status, darker skin, or other social handicap. Cultural pressures on families to arrange marriages for intellectually disabled children are as strong in South Asia as the contrary views in some western countries. The expectation that everyone should get married is sometimes reinforced by a belief that marriage may "cure" the disability.

Ethical Issues

Ethical issues can arise, over hygiene and eugenics. Menstrual hygiene is still a taboo of Indian women's lives. It is harder to conceal with disabled adolescent girls. Some mothers have used this as an argument for hysterectomy for their daughters (Balasundaram, 1994).

Mamoria, in an Indian sociology textbook (1981) repeated eugenic arguments from the 1920s, suggesting "ample justifications for selectively sterilizing the entire group of hereditary defectives... made compulsory by the State" (p. 450). He associated mental retardation with crime, prostitution, and risks to the "purity of racial stock" (p. 441). How widely such views are held is unknown, but Mamoria clearly did not see them as controversial. A former director of India's premier social science institute endorsed the book.

Concluding Remarks

There is something to be learned from societies with old and highly-evolved cultures, where practices now considered correct by westerners are found abhorrent and are confidently reversed. South Asian cultural practices with regard to intellectual disability are hardly those of a minority. Some Asian leaders may be willing to sign culturally-western declarations of human rights and modern aspirations; but "global ethics," in practice, remain an improbable goal until much
more inter-cultural exchange has taken place.

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Sexuality and Moral Management: Response to Case Studies

Herman P. Meininger

The two case studies in the first issue of *Ethics and Intellectual Disability* reflect the difficulty we have with accepting the fact that persons with mental retardation have sexual and relational needs of their own. The first case is - at least in my view - the simplest. The question is: should the woman who intends to have a sexual relationship (or her boyfriend) be moved to another facility or should the relationship be allowed to continue? If the relationship does not produce provable harm to one of the partners or both, there would be no moral reason to withhold them from having a (sexual) relationship. But there is in this case another, perhaps even more important, moral question: does a long-term-care facility have the right to move residents to another facility solely on the ground of having a sexual relationship with another resident? My answer would be negative. The institution has the responsibility to care for both partners and not to restrain but to guide and make room for their developing (sexual) relationship. This would include adequate sexual education, especially about methods of contraception, and clear practical arrangements in time and space, concerning the privacy of the couple. Restrictions or even a prohibition can only be justified when there are solid reasons to believe that such a relationship is or can become harmful for the mentally retarded persons involved or for others.

Inadequate Reasons for Sterilization

The second case - 'a Mother's Request to Sterilize her Sexually-Active Daughter' - is more complicated. Although the title suggests a sexually active woman, the case description does not give us information about the woman's actual sexual behavior or her wish to have a sexual relationship. As far as I know, being "out-going" does not necessarily imply being "sexually active." Is this a case about an adequate method of contraception for an intellectually disabled and sexually active woman? Or is it a case about a mother who fears the consequences of possible sexual
abuse of her daughter? The point is relevant because I suspect that many requests for sterilization are neither based on the actual occurrence of sexual activity, nor on the wish to have a sexual relationship. It may not even be the case that such a wish exists, but only a general and rather vague fear of the danger for disabled women of being abused in non-voluntary sexual contact. Although I do not underestimate this danger, neither the fear of this danger, nor the other reasons the mother gives, would be a sufficient moral reason for the surgeon who is asked to perform the sterilization to act according to the mother's request.

Respecting Limited Competency and Taking Risks

The case description does not provide any information about the sexual education of the woman. What does she know about sexuality, about reproduction and about the benefits and the drawbacks of the available methods of contraception? To what extent is she able to make her own choice and to handle the practical consequences of this choice? As a matter of moral principle, the second question of the case study - 'should the woman be treated as an adult capable of making her own choices?' must be answered affirmatively. If her choices reasonably can be interpreted as the expression of authentic and durable wishes, and if they do not present a clearly harmful interference with her other interests or with the interests of others, I see no reason why her decisions should not be respected. In the same vein the question of whether the institution should try to have her declared incompetent so that a guardian can be appointed can be answered. This would only be justified when it is beyond any doubt that the woman is not able to make a responsible decision in any domain of life, whether it be health care or financial decisions, or decisions about housing and working conditions. Even if some kind of counseling or guidance may be appropriate in making some of these decisions, we should keep in mind that respecting the dignity of intellectually disabled persons may involve to accept some of the risks that all of us run.

The Role of Ethics Committees

The last question concerns the ethics committee. Should it insist to have a role in the deliberations regarding this case? The role of this committee obviously cannot be to sanction the institution's declared policy never to sterilize residents. If and when good moral reasons exist for a request to sterilize a disabled person - and such reasons may exist - this policy should be criticized. Categorically denying intellectually disabled persons the possibility of having a sterilization is as much a violation of their human rights as the legal obligation or social pressure to sterilize all of such persons. By not permitting the ethics committee to deliberate on this case because of an existing policy is to misunderstand the necessarily independent role of such committees. This is not to deny the administration its own responsibility and its right to reject the outcome of the committee's deliberation. If it does deny the ethics committee its legitimate role in the process, however, then the questions arises of whether 'moral management' is compatible with executing guidelines without questioning the moral implications of these guidelines in individual cases? I take the role of an ethics committee to be to formulate procedural arrangements that can warrant careful and responsible decisions about requests for sterilization.
and to discuss the compliance with these arrangements in individual cases. Moreover, ethics committees should stimulate and support administrations in developing programs for adequate sexual education of residents and training of staff-members in a balanced attitude towards the relational and sexual needs of their clients.

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An Anecdote
How to Handle a Sceptic

John is a mildly disabled man in his late forties who was interviewed in a documentary on the spiritual life of intellectually disabled persons. The interviewer, apparently a sceptic - probably on both counts, was trying to find out the difference between sending someone like John to Church or sending him to the zoo. As the conversation developed it turned towards prayer. This is how John handled the sceptic:

'Do you often pray John?'
'Yes I do.'
'What do you tell God, then?'
'Oh, just things. Things that worry me, sometimes.'
'And does it help you?'
'Oh, yes. It helps when I am sad.'
'So God does speak to you, then?'
'No. He never says anything.'
'How then can he comfort you?'
'He pats me on the shoulder.'

(For readers who are interested, there is a quite marvelous book on this theme: Brett Webb-Mitchell, God Plays the Piano Too - The Spiritual Lives of Disabled Children, Crossroad, New York, 1993).

Meetings
and Announcements

The Network on Ethics and Intellectual Disability has been invited to organize a workshop on the theme of 'Intellectual Disability, Genetics and the Value of Human Life.' The workshop is scheduled as a pre-congress workshop to the 10th World Congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID).

The Workshop Theme:
There appears to be growing scepticism among people working in the field of intellectual disability about the ethics of genetic screening and counseling. Whereas geneticists - as well as many of the ethicists who cooperate with them - approach the topic in terms of 'reproductive choice,' people in developmental studies, special education and related disciplines tend to see a devaluation of disabled lives as the basic ethical premise of medical genetics. The workshop focuses on the issue between both perspectives by raising the following question: does genetic screening on defects that cause intellectual disability presuppose a judgment on the 'value' of the lives of intellectually disabled persons and if so, what is the basis for such judgments?

The workshop is primarily intended as a forum for discussion and exchange between people from various disciplines. The format will be to start from brief introductory statements and short abstracts from selected papers. Participants will receive the text of these papers to be studied in advance. The workshop will be held July 8, 1996, 13.00-17.00, Finlandia Hall.

Call for Papers:
Participants are invited to send in summaries of proposed papers dealing with this question.

Closing Date: February 1, 1996.

Papers that are received on May 1, 1996, will be distributed to all participants of the workshop. Send summaries to, or contact for more information: J.S. Reinders, Dept. of Philosophy, Free University of Amsterdam, De Boelelaan 1105, 1081 HV Amsterdam, The Netherlands, telefax: +31-20-444-6635, e-mail: J.S. Reinders@esau.th.vu.nl.

**Ethical Issues in Developmental Disabilities**

A Book Review

Reviewed by Robert M. Veatch


In reading *Ethical Issues in Developmental Disabilities* one is plunked in the middle of a whole gaggle of behaviorists without a word of warning. The volume stems from a 1994 Nevada Conference on Ethics and Developmental Disabilities. Drawing primarily on University of Nevada affiliated people whose departmental affiliations are never made clear but who unmistakably live in the world of behaviorist psychology, the volume provides a fascinating glimpse into what such a group would take to be the ethical problems in providing support for persons with intellectual disabilities.

One senses immediately that ethics is a challenge for a group whose citations draw heavily on B. F. Skinner and other behaviorists—those who struggle with notions of human freedom and moral responsibility. This is, in large part, an academic book, for those with scholarly as well as clinical interests.

Large sections of the book, including the two opening essays along with their commentators, dwell on the perplexing problem of what ethics can mean in a Skinnerian world of stimulus and response. The result is some arcane discussion of pliancy, motivative and formative augmenting, and tracking that doesn't get to the developmentally disabled until the later chapters.

What is found there is an enlightening look at how behaviorists see ethics in the developmental disabilities world: a nice discussion of "over-helping" and "under-helping" from a developmental perspective; a discussion of competence that turns out to deal only with professional competence (not legal competence) of the developmentally disabled person or the surrogate; though in one of the most readable and provocative chapters, Stephen C. Moore shows remarkable possibilities in teaching adults competence in work skills; and a rich discussion of the rights of the client that oddly enough turn out to be exclusively rights of access to behaviorist therapies.

What is missing is a serious discussion of the ethical issues raised by those therapies and other problems in caring in this world. Aversive condition, for instance is not on the volume's agenda in site of the enormous controversy it has raised. Even on the right of access to therapy—certainly an important issue—some key questions are not pursued. The right to "the most effective treatment, for example, is at one point apparently equated with the right to "the least restrictive effective treatment." One wonders what these analysts would do with the philosopher's classical problem of a choice between the two. Presumably, a utilitarian would favor the most effective treatment even if restrictive while the liberal would favor the least restrictive effective treatment.

Alan Poling's chapter on Pharmacological Treatment of behavioral problems includes a nice discussion of proxy consent. This is a provocative beginning of a conversation about ethics across lines of discipline, schools of thought, and ethical stance.
Bibliography

The following are citations drawn from BIOETHICSLINE, a database produced at the Kennedy Institute of Ethics. For more information call the National Reference Center for Bioethics Literature at 202-687-3885; or 1-800-MED-ETHX; or medethx@gunet.georgetown.edu


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