

**Should Science Strive to Correct Human Imperfections?
A Moral, Ethical or Scientific Question
Commentary on Stowe et al., Journal on Developmental
Disabilities, 13(2), 2007**

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Stowe, Turnbull, Schrandt, and Rack (this issue) have raised issues that not only go to the heart of what it means to be "disabled," but their treatise also raises fundamental philosophical questions relevant to humanity itself. The authors have provided a most comprehensive examination of the potential threats, as well as benefits, of developments emerging from the human genome project.

Worldwide, there are serious concerns being expressed about the profound ethical issues surrounding the Pandora's Box that modern science and technology is opening. We certainly cannot leave the ethical implications to the scientists alone, many of whom hold the view that one should not put barriers in the way of scientific advancement. On the other hand, one must not take a hard-line Luddite approach as genetic discoveries certainly hold much promise for the good of humanity.

One area not addressed by the authors is the moral and theological controversy surrounding the use of embryonic stem cells in germline genetic engineering. To some in the community, this technology challenges the "sanctity of life." Those supporting the restrictions of this procedure are characterized as religious fanatics somewhat akin to those who prosecuted Galileo for his scientific propositions. Nevertheless, this issue does have implications for people with an intellectual disability. Those who hold these beliefs also have concerns about the growing societal view that a family who resists anti-natal screening or who chooses not to abort when the results indicate a foetus with impairments, is acting irresponsibly. This is a judgement that must be left to the family alone to decide.

In the context of the "designer baby" phenomenon, McKibben (2003) pointed out that we have had genetic engineering technology since 1978 when it was first used with animals. Only one mammal remains for which it has not been tried, and the only thing holding us back, asserted McKibben, "is the thin tissue of ethical guidelines, which some scientists and politicians are working hard to overturn" (2003, p. 10).

I have argued elsewhere (Parmenter, 2005) that the potential financial returns in the biotechnology field are seductive for pharmaceutical companies and governments that are anxious to capitalize on the potentially enormous profits to be made. Equally seductive is the neoliberal argument that individuals should be free to make choices, untrammelled by restrictive legislation. In this context, it is salutary to be reminded of the concept of "social capability" of the Nobel Prize winner in Economics, Amartya Sen (1992). This concept recognizes that personal well-being relies on more than the availability of material and social goods, for citizens must have the capacity to use those resources effectively for the common good. But it is the "cult of the individual" that is working against a more inclusive community milieu in which diversity is celebrated and not seen as a genetic aberration. At the same time, we are looking for a more caring and ethical community that supports each of its members in whatever situation they find themselves (Reinders, 2000).

The trouble with the concept of instrumental individualism is that it only values a person inasmuch as he or she contributes materially to society. It does not acknowledge the concept of distributive justice whereby a nation's wealth should support all of its members irrespective of their talents.

I would have liked a more detailed analysis of the impact disability studies have had upon the discussion of disability, bioethics, and human rights (for a detailed examination of this point see Asch (2003)). Much of this discussion has come from authors with a physical disability perspective, but aspects of the social constructivist position on disability can inform our position in the area of intellectual disability. This position, however, is not without its critics (Reinders, 2000; 2005).

Asch (2001) forcefully argued that the bioethics debate does not sufficiently question the traditional understandings of impairment, illness, or disability. It is a moot point to ask whether we would still experience disability if all impairments could be prevented or cured. Emerson (2004) pointed out that one of the strongest correlates of intellectual disability in the richest countries is poverty. Is this a cause or an effect? However, in the poorer nations it is certainly the case that it is environmental conditions and not genetic disorders that are the major cause of disabilities.

For a complementary discourse on the topic under discussion, the special issue of the *Journal of Intellectual Disability Research*, 47, October 2003, contains several papers presented to a meeting of the International Association for the Study of Intellectual Disabilities Special Interest

Research Group on Ethics, which met in Cambridge, U.K., in 2001, to discuss the topic of genetics. It also contains an extremely useful bibliography on the subject of genetics that expands the excellent coverage the present paper presents.

In conclusion, I reiterate an earlier comment (Parmenter, 2003) that, "The popular message, supported by the liberal society, is that the lives of people with disabilities are burdensome, together with the presumption of suffering... The concept that a disabled life can be an enriching factor for the family runs counter to society's perception of disability; that is invariably considered to be burdensome" (p. 563). This is a challenging concept for those who have expectations that the breakthrough in genetic discoveries will alleviate disability and suffering.

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