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Abstract

The author includes in her definition of New Reproductive Technology: abortion, contraception, amniocentesis, genetic screening, cloning, in vitro fertilisation, alternative insemination, sperm banks and storage of frozen sperm, genetic engineering, artificial wombs and techniques for determining the sex of the fetus. She maintains that the claims of the advocates for this technology i.e that it opens up a range of reproductive choices available to women and decreases the incidence of disorders in society, overshadow the implications for women's gender equality rights, and women's and men's disability equality rights.

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Reproductive Technology: A Rights issue

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New reproductive technology (NRT) refers to a range of medical interventions in the human reproductive process. It includes abortion, contraception, amniocentesis, genetic screening, cloning, in vitro fertilisation, alternative insemination by spouse or donor, sperm banks, storage of frozen sperm, genetic engineering, artificial wombs, and techniques for predetermining the sex of a foetus. Presented as a triumph of modern science, advocates of the new reproductive technologies make claims that this technology opens up the range of reproductive choices available to women and decreases the incidence of disability in society. These claims for the potential of new reproductive technology have overshadowed the implications for women's sex equality rights and for women's and men's disability equality rights.

The technological agenda in the area of new reproductive technologies risks the ethical and social transformation of these technological advances from a central concern for the well-being and potential of all people into an imperative to reduce or eliminate birth disability from the population. The stake and interest of people with disabilities in the issue is founded in the discriminatory attitudes and practices that have circumscribed their social and economic participation. This is what has led people with disabilities and particularly women with disabilities to approach the discussion with much less enthusiasm than is found in the scientific community. The issue for them is an issue of rights and

ethics not scientific accomplishment and social benefit.

The arguments in favour of rethinking the underlying premises of genetic engineering and genetic screening include three critical factors. First the fallacy of its potential to reduce disability. Second, the fundamental misunderstanding of handicap as a biological condition rather than a social construct and the consequent benefits claimed for its elimination. And third, the potential to undermine individual choice and the legal protection of autonomy.

The Fallacy of the Potential of NRT to Reduce Disability

New reproductive technology, particularly genetic engineering and genetic screening and selective abortion are premised on a narrow and deterministic perspective on disability. This perspective assumes that disability is principally the result of an undesirable genetically-pre-determined condition. In other words, disability is accounted for by an individual's genetic make-up. This is a false premise. At the outset, this is based on a false presumption. Even if genetic diagnosis were perfected so it could be carried out early and non-invasively it could never be effective in eliminating disability. For example, 85 percent of adult disability is caused after the age of 13 and more than ninety percent of infant disability is due to social and not genetic causes.

What is really troubling about this over-medicalisation and geneticisation of disability, besides its injustice, is

that it obscures the basic socio-economic contributors to disability (including malnutrition, physical abuse, stress, exhaustion, and toxicity from environmental pollution) - all risk factors which are preventable. By obscuring other causes in over-emphasising genetic causes, social attention and resources are deflected into medical technology and professional salaries rather than into providing the nutrition and social support and other low-tech, non-medical measures designed to minimise avoidable risk of infant disability and to counter its impact. The vision of technological utopia offered by new reproductive technologies is therefore unfounded, even if it were socially beneficial, a claim I cannot support.

The second part of this deterministic perspective on disability is that disability is an undesirable trait. Proponents of the new reproductive technology promise to reduce the incidence of 'defect' (equated with undesirable) in the population and insure the production of 'perfect' babies. The underlying assumption of this is that there is some social consensus or agreement about what constitutes a 'perfect' baby. Who decides who is appropriately fit to bring into the world and who has the capacity to make those decisions are left unanswered. The idea of ensuring the perfectly able-bodied able-minded human is both an irrational and a dangerously eugenic premise.

Handicap as a Social Construct

This simplistic equation of disability and individual genetic composition thus obscures the enormously complex

set of factors that result in disability and handicap. Handicap is a social construct. If prevention is the real agenda then an understanding of material conditions that cause handicap must be taken into account and seriously addressed. Unfortunately these are not issues that fall within the traditional sphere of the science of biology so they are ignored by the biorevolutionaries. The experience of most people with disabilities is that the disability itself is a minimal barrier. The real obstacles they face are a consequence of discriminatory attitudes, policies, laws and programs that both presume people with disabilities are social burdens and make that the reality.

The prevention of handicap and its corollary the promotion of the well being of people with disabilities involves reducing the risks associated with disability. Those risks include poverty, abuse, discrimination, unemployment and other social disadvantage. If people with disabilities are a social burden in terms of cost, implementing social and economic policies designed to include rather than exclude their participation in social and economic structures can reduce those costs. They do not have to be reduced by eliminating genetically based conditions.

A more important contribution to reducing handicap would be decreasing the discrimination against people with disabilities so that the penalties associated with disability are removed. This recognises that disability is a social, legal and political issue not simply a biological issue. The disability movement has faced an uphill battle in its attempts to become recognised as a disadvantaged group which deserves, even mandates, an

equal share of well being and social justice. To the already disproportionate liability that people with disabilities have had to bear, because of the lack of equitable resources and services to support their participation, new reproductive technologies add the further implication that technology ought to be developed which would encourage their elimination at the reproductive stages.

The contributions of people with disabilities have been unjustly undervalued or, worse, gone unnoticed because of their traditional segregation.

People with disabilities have, consequently, had difficulty justifying their claim to the rights normally accorded with citizenship. The assumption that people who do not share the characteristics of the majority are less valuable is unjustifiable. The social wellbeing of a society requires that people of all kinds are included and accepted as equals. It means finding ways of ensuring that everyone is a fully participating citizen, without being penalised because of race, sex, or physical or mental ability. The basis of technological research and development should be the integration and involvement of people with differences not their elimination. This would include the potential of research and development that makes advances in treating and curing medical conditions within an ethical context. Because people with disabilities have been the victims of widespread discrimination, even when that wasn't the articulated goal and even when the exact opposite was claimed to be the purpose of the research, there is a legal and moral imperative to closely monitor proposed research agendas. The inherent biases against people with disabilities requires scrutiny of the

design, purpose and funding of research in new reproductive technology

Individual Choice and Autonomy

The underlying assumption of the proponents of new reproductive technology that disability should be eliminated also limits both implicitly and explicitly, the individual choice and autonomy of women in reproductive decisions. Discrimination against people with disabilities is so pervasive and the availability of resources and support services to raise children with disabilities so limited that many women do not consider there is a real choice of not aborting a disabled foetus. The messages they receive both from the medical profession and from society is that, since disability is undesirable, is detectable through pre-natal screening and can be eliminated through abortion, then if a woman chooses to have the child it is her responsibility to meet the child's needs. The result is a set of medical, social and economic pressures to abort rather than make an uncoerced, informed decision issues central to the exercise of autonomy.

Informed decision-making is critically important in this context. It involves the knowledge of the potential of people with disabilities not a litany of the inabilities.

It involves an understanding that while discrimination may seriously undermine the way a person with a disability lives, many people with disabilities have productive, valued lives. It involves an understanding that there is not some absolute benefit and

reward to eliminating disability. It involves an understanding that the costs of disability have been created by social discrimination and thus they are a social responsibility. Unless women are provided with a real choice, with real self-determination people with disabilities will continue to bear the cost of the uncontrolled, unexamined flood of technology in this field.

Conclusion

There are some important principles that must underlie the funding and acceptance of research and development in new reproductive technology. First and foremost, all new reproductive technology practices must contribute to equality and the inclusion of all people and ought to reflect a reverence for humanity and diversity of peoples. Second, new reproductive technologies, if available, must be available to all persons regardless of disability, socio-economic status, marital status and sexual orientation for the purpose of enhancing fertility. Third, new reproductive technologies must not be promoted or applied as a passive form of eugenics. In other words, disability should not be the sole reason for eliminating foetuses, any more than we would accept sex or race as a reason for abortion. Fourth, the language used must promote respect and dignity for all persons with a disability. Fifth, in determining the distribution and allocation of limited resources for research, serious consideration must be given to questions of values, including questions about whose life is valuable and who decides such questions. Finally, women's right of self-determination including reproductive freedom is compatible with the equality interests of individuals who have a disability. Women, in

exercising their rights, will be in a better position to do so if they have: the right to refuse prenatal screening; the right to refuse abortion when disability has been identified; the right to information about disabilities that is not biased and incomplete; and the right to have appropriate supports to raise the child with a disability.

The unchecked development of new reproductive technologies has a disproportionate impact on people with disabilities and on women. The race for genetic knowledge has far-reaching implications, some of which, like the insurance industry's refusal to insure a mother who refused to abort a disabled foetus in the U.S., threaten the fundamental nature of equality and diversity in our societies. Science is not an objective exercise. It requires the same kind of critical social, legal and ethical scrutiny that other practices receive. Now is as good a time as any to stop burying our heads in the sand and to clearly differentiate the benefits and the harms of these endeavours.