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J Med Ethics 2008; 34: 467-471

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Urh Groselj, Blaz Groselj (4 June 2008)

"Eugenics talk" and disabled – is it really just about emotions?

4 June
2008



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Groselj, et al.

Modern genetics differs crucially from the old eugenics, despite the sad fact that they coexisted for few decades in the respected countries like Sweden and Canada, where thousands of coercive sterilizations of mentally ill were taking place until early 1970s (1). Fortunately, the focus has shifted in the meantime from the genetic health of the population to that of an individual, and even more importantly - individual autonomy is now highly respected, with non-directiveness as a "dogma" of genetic counseling. But on the other hand, through accumulation of many private choices, the effects of the modern genetics could nevertheless be "genuinely" eugenic.

For instance, over 90% of pregnant women who are given a Down syndrome (DS) diagnosis choose to have an abortion, which is in consequence substantially decreasing the number of people with DS (2). Smaller community of people with DS (being less "heard") means not only less opportunities and services provided for them, but also decreased research interest in (improving) their condition. Furthermore, elimination of DS and other genetic "defects" slowly changes perception society has about disabled, being increasingly seen as something "abnormal", "preventable", their birth even as "irresponsible" (3). Diminishing opportunities for disabled, changed societal perceptions and its pressures, combined with the routinisation of genetic testing, prevent parents from making really autonomous choice. (Some disabled rights advocates even argue that it is unlikely that

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prenatal testing would be resourced to the existing degree only to provide more informed choice, which would mean that state has (financial) interests in diminishing number of disabled people.) The result is – arguably - a systematic bias against the birth of genetically disabled children. The costs of prenatal testing programs are sometimes compared to the financial savings in the reductions of individuals requiring extensive medical and social services (3). On one hand, this is quite usual thing to be done in a modern health care system. But on the other, it can further influence the attitude of modern genetics and society towards the disabilities (which could be seen primarily as a “cost”), and also impede parent’s autonomy (thinking that decision to keep disabled child is irresponsible).

Any pressures (e.g. societal, professional and financial) to limit individual’s choice in the issues of genetics and reproduction and giving up the non-directiveness of genetic counseling, meet not just emotional but also rational criteria to be qualified as eugenic.

Competing interests

None.

Literature

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