

## The Effects of Pre-natal Genetic Diagnostic Programmes and Selective Termination on Society's Relationship with the Disabled Community.

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The late twentieth century has seen the explosion of knowledge in a new field of science and medicine: that of molecular genetics. Genetic technology has begun to change the way in which we perceive *normality* and *abnormality* (Lippman, 1994a). Genetic technology, and especially pre-natal diagnosis, has an enormous potential for shaping society in ways already heavily influenced by other social factors, such as class, race and inherent ability (Lippman, 1994a). So what of the danger to people in our society who are already inherently disadvantaged by existing social conventions: people with disabilities? The question being asked by many sceptics is whether the technology will end up in increasing the discrimination and stigmatisation experienced by people with disabilities.

The *Human Rights Act* (1993) under section 21 states that discrimination on the grounds of disability is prohibited. Right Two of the 'Code of Health and Disability Services Consumers' Rights' (1996) also precludes discrimination on the grounds of disability.

However, it is necessary to define exactly what *disability* is. The traditional, medicalised view of disability is based on a norm of function, both mental and physical (Asch, 1995). Any problems that disabled people face are presumed to stem from their diagnosed physiological impairments (Asch, 1995). It is argued that underlying these 'medical' judgements is an inherent 'ableist' bias (Mosoff, 1993).

The overlooking of social factors that contribute to suffering from disease and disability within the medical model is noted by disability advocates, and it is argued that the sense of suffering associated with disability is primarily the consequence of social isolation due to discriminatory attitudes and practices (Asch, 1995, Mosoff, 1993 and Saxton, 1996). This is the social model of disability.

### Discrimination Against People with Disabilities?

Gillam (1999) identifies two possible arguments for why selective abortion may lead to discrimination against people with disabilities.

The 'slippery slope' argument is grounded on a number of potential causes for the increase in discrimination experienced by people currently living with disability (Gillam, 1999): the decreased number of people with disability, a deterioration in social attitudes towards these people, and an associated decrease in self esteem.

The claim that pre-natal testing leads to a drop in the numbers of people with a disability is based on evidence that most women choose termination on diagnosis of moderate to severe abnormality (Gillam, 1999). However, a drop in numbers due to pre-natal testing and subsequent termination is by no means still inevitable. This is because most disability is caused by accidents and old age, not genetic disorders (Gillam, 1999). Less than half of the cases in the United States of people with I.Q.s under 50 are caused by genetic factors (WHO, 1995).

Also, even with an increase in the numbers of selective terminations there may not be a decrease in the number of babies born with the conditions being screened for. The example given by Gillam (1999) is that of Down's Syndrome. The effects of the increase in screening and the trend of increasing maternal age may merely cancel each other out (Gillam, 1999). Indeed, in New Zealand there has been an increase in the rate of Down's syndrome, despite an increase in the uptake of pre-natal screening for the condition (Public Health Commission, 1995). A decrease in numbers is by no means inevitable (WHO, 1995).

However, for argument's sake, say the numbers of people with disability does decrease. A decrease in numbers

alone cannot cause an increase in discrimination, another process is required (Gillam, 1999). According to Gillam this is that 'smaller numbers will lead to disproportionately reduced funding for disability services' (Gillam, 1999). However, there will be no sudden decrease in total numbers, only a gradual drop-off as the birth incidence decreases. Without a sudden drop-off in the rates the government could not easily justify any cuts (Gillam, 1999, and WHO, 1995). In Greece an increase in per capita funding was associated with their thalassaemia carrier screening programme (Buchanan, 1996). A more credible theory is that the smaller numbers will lead to a smaller lobbying presence (Gillam, 1999), with a subsequent loss of funding. This could be offset by the fact that the total number of people with disability is unlikely to change and the sense of solidarity shared amongst the diverse disabled community (Asch, 1995) could help maintain services.

What of the propagation of hostile social attitudes, or at least a sense of stigmatisation? This will be discussed further later in the paper. For now it is enough to say that the 'slippery slope' argument does not provide a definitive answer as to whether the result of widespread pre-natal diagnosis will be an increase in discrimination (Gillam, 1999).

The second argument, the *conceptual argument*, asks whether the values underpinning pre-natal diagnosis, that is quality-of-life judgements concerning both the affected individuals and their families, are in themselves discriminatory against those with disabilities (Gillam, 1999). Gillam (1999) argues that the negative quality-of-life assessments made cannot be discriminatory as they are applied to foetuses, not living people. If foetuses were living people then abortion would be illegal, but it is not, because of the widely held (if not universal) view

that the foetus has a lower moral value than a person (Gillam, 1999). The logical extension therefore cannot be made from moral decisions about foetuses to persons, according to Gillam.

Are these quality-of-life assessments in themselves discriminatory? Gillam says no. Extremely hurtful and possibly degrading to those existing with the same condition, yes, but not discriminatory (Gillam, 1999). Being offended is not the same as being discriminated against.

However, even though these assessments may not be morally discriminatory, they still hold very personal implications for many with disabilities under the spotlight (Gillam, 1999). Someone prying into one's life to draw the conclusion 'better off dead than alive' must be very demoralising. However, Gillam points out that even if a practice is offensive to a particular group, it is not necessarily morally unjustifiable, as this offence needs to be weighed up against possible gain, such as increased reproductive autonomy and the future wellbeing of members of society (Gillam, 1999). The warning bells, however, have been sounded.

### **An Oppressive Force Against People with Disabilities?**

A prominent disability advocate, Christopher Newell, notes that Gillam makes a strong case for the fact that pre-natal diagnosis is not intrinsically discriminatory towards those with disability (Newell, 1999). He emphasises, however, that the question at hand is rather whether this technology is oppressive. Newell, himself a person with a disability, argues that a better understanding of the dimensions of the debate can be gained if the genetic technology is understood as a tool of 'oppression and control which serves to devalue the lives of people identified as having disabilities' (Newell, 1999). Hence the question becomes wider than merely whether this technology is discriminatory. Newell joins with Asch (1995) and Mosoff (1993) in highlighting the fact that most of medicine uses 'disease labels to identify disability states and quality of life' (Newell, 1999). These descriptions have the unfortunate property of largely ignoring the experiences of people with disabilities themselves, even though quality-of-life is a very subjective experience (Kaplan, 1993).

Newell does not contest that pre-natal diagnosis can be meritorious in situations where the child-to-be faces likely death or severe pain and suffering (Newell, 1999). He does however question the lack of acknowledgement of the social and political nature of these decisions, and especially the nature of oppression experienced by those with disabilities (Newell, 1999). It is very important that we recognise whose knowledge we are utilising, and whose we are ignoring, and a balanced argument can only come out once this realisation has been acknowledged and acted on (Newell, 1999).

### **An 'Expressive Force' Against People with Disabilities?**

Let us return to the argument that pre-natal diagnosis expresses negative messages towards people with disability. Thomas Murray makes the observation:

By its very nature, pre-natal diagnosis cannot remain neutral about disability. At a minimum it conveys the message that society believes that living with a disability, or raising a child with a disability, is such a grave burden that it is morally permissible and medically appropriate to take expensive measures to ensure that such children are not born. (Murray, 1996)

This is part of what Allen Buchanan identifies as the 'expressive force' argument against the use of pre-natal diagnosis (Buchanan, 1996).

How are abortions with 'negative expressive force' separated from those without? As Nelson points out, a line seems to be drawn between some abortions, which are acceptable, private events, and others which are not (Nelson, 1998). Presumably because the objectionable character of some makes a case for some restriction, or further education on the part of the parents. As, however, many disability advocates are by no means anti-abortion, how do they distinguish selective termination after pre-natal diagnosis from other terminations, which they think of as just (Nelson, 1998)?

If a woman decides to abort due to the already large size of her family, or the fact that she is poor, then it could be argued these foetuses then stand for the concepts of the 'large family' and 'poverty', much the same as the abnormal foetus stands for 'disability' (Nelson, 1998). Does this mean these mothers hold objectionable attitudes towards large families and poverty

and should have special counselling and education before their decision is made?

Here Nelson's view that selective termination does not *have* to be taken as an expression of negative attitudes has been put forward. However, he does concede that it *may* result in disrespectful messages (Nelson, 1998). The example that he uses is that although a woman who has decided to have a selective termination may believe that she has perfectly acceptable feelings towards people with disabilities, she may entertain *contingent* beliefs which affect her decision, of which she is not completely aware (Nelson, 1998). This is part of the complicated nature of the decision process. Nelson calls possible objectionable messages arising from pre-natal diagnosis and selective termination 'at worst a symptom, not the disease' (Nelson, 1998). Why should only prospective parents be counselled and educated, and possibly have their reproductive autonomy challenged, when it is the whole of society that has the problem? Surely it is society in general that needs to be educated in the issues (Nelson, 1998).

Nelson's (1998) conclusion is there is potential danger in the employment of the technology, but the way to overcome it is by attacking the area with the biggest potential for change, educating society, rather than compromising people's reproductive autonomy.

### **Worsening Stigmatisation of People with Disabilities?**

The following is a quote from the father of a child with a disability (Jamie):

The danger for children like Jamie does not lie in women's freedom to choose abortion; nor does it lie in pre-natal testing. The danger lies in the creation of a society that combines eugenics with enforced fiscal austerity. In such a society, it is quite conceivable that parents who 'choose' to bear disabled children will be seen as selfish or deluded. Among the many things I fear coming to pass in my children's lifetime, I fear this above all: that children like James will eventually be seen as 'luxuries' employers and insurance companies cannot afford, or as 'luxuries' the nation or the planet cannot afford (Bérubé, 1996 cited in Nelson, 1998).

The Nuffield Council on Bioethics report on genetic screening (1993) documents the worry that there exists within society a tension between the fact that society is both providing resources for the care and integra-

tion of people with disabilities into society, and then at the same time is providing a considerable amount of resources to try and prevent the birth of babies with the same conditions. The worry is that blame will be placed at the feet of the parents, and that society will direct its hostility at both the parents and the child (Nuffield, 1993).

A report on the European perspectives of genetic screening (Chadwick et al, 1998) notes that 'fears have been expressed about the long-term harm which could result from screening programmes if it becomes widely seen as part of parents' responsibility to see to it that the quality of their children is optimal', and that 'the ability to detect genetic disorders could lead to a decrease in respect for handicapped life' (Chadwick et al, 1998). The same fears are expressed by two other European reports in addition to Nuffield (Hoedemaekers et al, 1997). Such attitudes, which could see prospective parents as irresponsible if they do not have pre-natal testing, or decide to continue with an abnormal pregnancy, could spring from resentment as to the imposition of costs to the public for the care of the individual with a disability.

As to how to prevent the dangers of stigmatisation, the Nuffield report emphasises the importance of education and counselling (Nuffield, 1993). Asch backs this up in her article (1995) where she notes that higher levels of education lead to lower levels of negative sentiment towards those with disabilities.

This is the position that Gillam (1999) advocates. But she makes an important point that is built on to some degree by Nelson (1998). If stigmatisation is not to be the result of pre-natal screening programmes, then there is going to have to be a very concerted effort made

by the government and health providers to educate and promote positive ideas about the value of people with disabilities to the *general population* (Gillam, 1999). Gillam (1999) is not convinced that this can be done. She has some reason to be sceptical. During the  $\beta$ -thalassaemia screening programme in Cyprus, it has been shown that the comprehensive effort to educate the populace in the issues involved resulted in a directive and coercive message being passed on (Hoedemakers and ten Have, 1998). In this case the state and public health services' personal interests were being pushed, with little regard for non-directiveness, or a mix of positive and negative images of the disease being presented. It is difficult to promote an educational message about how it is worthwhile engaging in reproductive services to prevent the birth of people with inbuilt limitations and burdens, while simultaneously encouraging the integration of existing people, with the same conditions, into society (Hoedemakers and ten Have, 1998).

#### **So what can be concluded about the effects of pre-natal diagnosis and selective termination on people with disabilities?**

Although, as Gillam maintains, the technology may not be intrinsically discriminatory or, as Nelson maintains, does not necessarily have a negative expressive force, it still seems to be grounded on very shaky moral foundations. Yes, there is definitely a case for the use of the pre-natal technology in many situations. Yet it may not be the right course of action to restrict the reproductive autonomy of couples because *society* does not treat people with disabilities fairly. Since the potential for damage is very great, the most cautious of courses should be pursued.

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