

Disability, identity and the “expressivist objection”

S D Edwards

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The practice of prenatal screening for disability is sometimes objected to because of the hurt and offence such practices may cause to people currently living with disabilities. This objection is commonly termed “the expressivist objection”. In response to the objection it is standardly claimed that disabilities are analogous to illnesses. And just as it would be implausible to suppose reduction of the incidence of illnesses such as flu sends a negative message to ill people, so it is not plausible to suppose prevention of disability sends a negative message to disabled people. The expressivist objection hinges, however, upon a view of the relationship between disability and self identity which sees disability as part of the identity of the disabled person, in a way in which illnesses such as flu cannot be. This possibility is generally not considered in critiques of the expressivist objection. In this paper, an “identity claim” to the effect that disabilities can be identity constituting is accepted and the force of the expressivist argument is reconsidered in the light of its acceptance. It is concluded that even when such an identity claim is accepted, the expressivist objection is still not morally compelling.

A particular kind of objection is sometimes raised against the practice of prenatal screening for genetic anomalies associated with disabilities. According to the objection, such practices cannot be morally justified. The grounds given in support of that conclusion are that such practices cause offence and hurt to people currently living with the kinds of conditions screened for.

Thus, consider a person currently living with cystic fibrosis. Such a person might hold the view that prenatal screening for cystic fibrosis, with a view to termination on grounds of the presence of cystic fibrosis in the fetus, sends a negative message to the person to the effect that it would have been better had he not been born. Also, such a person might feel hurt or otherwise harmed as a consequence of that practice.

This view is, apparently, commonly held.^{1 2} It is sometimes termed “the expressivist argument”, or as it will be described here, the expressivist objection.³ The expressivist objection is the objection that prenatal screening (with consequent termination of pregnancy on grounds of disability) sends a negative message to currently living disabled people, and is therefore morally unjustified.

It is plausible to claim that the expressivist objection is based on a view of the relationship between disability and identity which holds that disabling traits or disabilities can be identity constituting, can be part of one’s very identity. This “identity claim” is rarely taken seriously in critiques of the expressivist objection. In his arguments in support of prenatal screening for genetic anomalies associated with disabilities, for example, Professor John Harris offers the following observation. He writes:

I just do not believe that attempts to remove or pre-empt dysfunction or disability constitute discrimination against the disabled as a group, anymore than medical treatment of disease discriminates against the sick as a group (p 96).⁴

It is interesting to juxtapose this remark with an earlier claim from Harris in his book *The Value of Life*:

...anyone who thinks that the detection of handicap in the fetus is a good reason for abortion, must accept that such an individual is, or will become, less valuable than one without such a handicap, less valuable because less worth saving or less entitled to life.

Many people with disabilities hold the view, however, that selective abortion on grounds of disability does convey a message, or otherwise imply, that it would have been better had they not been born. The Disabled Peoples International (DPI) statement on “the new genetics” claims—for example, that:

“The underlying reason for prenatal screening and testing is the elimination of the impaired fetus. This sends a discriminatory message to say that disabled people’s lives are not worth living or worthy of support (Parens,¹ p 8).

This statement of the expressivist objection amounts to the view that prenatal screening and termination on grounds of disability is morally wrong. Its wrongness stems at least in part from the harm done to existing people with disabilities by the practice of such screening.

Against the expressivist objection a view exactly like that put forward by Harris is typically advanced. As seen, this is that reducing the incidence of disabling traits no more sends a negative message to disabled people than reducing the incidence of flu sends a negative message to flu sufferers.

One commentator, Baily, a woman who underwent amniocentesis, says of the expressivist objection that it “only makes sense if people with disabilities are their disabilities” (p 68).⁶ It is this observation which goes to the heart of the matter in my view. For Baily sees that the coherence of the objection rests upon acceptance of an identity claim to the effect that disabilities can be (at least partly) identity constituting.

Commentators who cannot see the force of the expressivist objection see no relevant difference between reduction of the incidence of disability and reduction of the incidence of any disease. Thus just as reducing the incidence of flu can only be a desirable end, so too must reducing the incidence of a condition such as Down’s syndrome or cystic fibrosis.

For, in the eyes of such commentators (not implausibly) just as there is no question of a person being defined as a “flu sufferer”, there is no question of a person being defined in terms of their disability (p 32).⁷ In philosophical terms such commentators take illnesses such as flu to be contingent to a person’s identity, reasonably enough. And they extend this “contingency” view to disabilities.

As far as I understand, however, the source of the objections to prenatal screening held by the DPI and bodies like it, such a “contingency” view of disabilities is rejected. For them, disabling traits are, in fact, at least partly identity constituting. Hence, a description of the identity conditions of at least some groups of disabled people would include reference to their disabilities.

The pattern of reasoning behind the response of groups such as the DPI would appear to run as follows.

- (a) Reduction in the incidence of condition C is viewed as morally desirable.
- (b) C is (at least partly) identity constituting for persons of type P.
- (c) Reduction of C necessarily entails the reduction of persons of type P.
- (d) Reduction in the numbers of persons of type P is considered morally desirable.
- (e) This is harmful to existing (and future) P-type people.
- (f) This is therefore morally wrong.

Let me explain this a little. In premise (a), obviously, conditions of type C are the kinds of states screened for in prenatal screening. It seems reasonable to suppose (a) is true since reduction in the numbers of births of neonates with disabling traits is generally considered a morally desirable end.

Premise (b) is the philosophically interesting claim concerning the relationship between disability and identity. That there could be an “identity constituting” relationship between disability and identity is something which those who dismiss the expressivist objection rarely consider. In the premise, obviously, persons of type P are disabled persons or some subset of them.

Premise (c) appears to follow if one accepts the identity claim.

Premise (d) seems to follow too, given acceptance of (a)–(c). Premise (e) is evidently true since, as the DPI statement shows, significant groups of disabled people are hurt and offended by the practice of prenatal screening and termination. The “message” conveyed by the practice of prenatal screening is that it is morally desirable that persons of a certain kind should not exist. This seems to presuppose that some human lives are less worth leading than others, and this is harmful to currently living disabled people since it expresses a view that their lives are not worth living. Finally, the conclusion, (e), is that given the harms endured by disabled people arising from the practice of prenatal screening, such practices are not morally justified.

As noted, whatever force the expressivist objection has appears to rely upon the identity claim asserted in premise (b). Otherwise the objections to the expressivist objection, rehearsed by Harris—that is, objections which equate disability and flu as far as identity is concerned seem to defeat it. What I propose to do now, contrary to Harris, is to grant the identity claim as advanced in premise (b). It will be seen, however, that the expressivist objection is not morally compelling even when such an identity claim is accepted.

ASSESSING THE MORAL FORCE OF THE EXPRESSIVIST OBJECTION

Recall that the main objection to the practice of prenatal screening from the perspective of the DPI is the discriminatory message such a practice conveys to the effect that “disabled people’s lives are not worth living or worthy of support”. In other words, the moral wrongness of the practice stems from the harmful effects it has. These harmful effects include, most saliently, the offence and hurt felt by people

currently living with the kinds of disabling traits screened for in the practice of prenatal screening.

But there are three grounds for resisting the expressivist objection, even if one allows that disabling traits can be identity constituting.

First, the wrong done by prenatal screening is that of the hurt or offence that practice conveys to existing disabled people (since abortion is not objectionable as such to members of the DPI). Of course, however, it does not follow from this that it is right to place the obligation not to harm others above the right to have one’s own reproductive autonomy respected. One is obliged to take into account consequences of one’s actions which might harm others but it does not follow that those harms count for more than the suppression of one’s free choice. One might choose to be a meat eater knowing this will offend vegetarians and lead to some harms to animals. It does not follow, however, that the harms to these other parties should “trump” one’s own autonomous choices. Or one may choose to have an abortion in the knowledge that this will offend prolife groups, but it does not follow that the offence caused to these groups outweighs one’s right to make such a choice. Exactly the same response can be made against the expressivist objection.

Moreover, one may judge, reasonably, that a decision to terminate a fetus on grounds of disability is justified due to the disruption and harms which one may judge, will beset one’s own current family.

So, from the moral perspective, accepting for the sake of argument the identity claim, the expressivist objection to prenatal screening is vulnerable to objection. It appears to require moral agents to place the obligations not to harm others above their wishes to enact their autonomous choices, and their choices to avoid avoidable harms. In this case, however, there is no reason why they should so place the interests of others above their own interests in having their reproductive autonomy respected.

Second, one can consistently hold two views: (a) prenatal screening is justified; and (b) disabled people should be supported, and certainly should not be abandoned on grounds of disability. Thus, the “loss of support” need not follow from the continued practice of prenatal screening.

Third, acceptance of the expressivist objection seems to lead to a *reductio ad absurdum* to be described now. On the face of it, it looks as though the objection implies that any means of reducing the incidence of C is objectionable. For of course any such reduction brings with it a reduction of P-type people.

This objection will apply in the case of disabilities which have a genetic origin (Down’s syndrome, cystic fibrosis etc). Also, however, perhaps counterintuitively, it will apply in cases where disability is caused in some other way—for example, by illness or physical trauma (as—for example, in the case of Christopher Reeve).

For in either of these types of cases, in removing the disability one thereby reduces the numbers of P-type persons, and “sends a message” to people who have the relevant disabling condition. This is so even if the person herself decides to have her disability removed—for example, by surgical intervention to remedy deafness, blindness or paraplegia and so on.

So the expressivist objection seems to have the implication that it is wrong both first, to seek to prevent any form of disability, and second, to cure or “put right” any existing disability.

If it is true that the objection has these implications, then some might justifiably regard the expressivist objection as vulnerable to criticism on the grounds that its acceptance leads to absurd consequences. Specifically, that its acceptance

leads to the consequence that it is wrong to rectify or even to seek to prevent the incidence of disabling conditions. Thus, even if an "identity claim" is accepted to the effect that disabling traits can be identity constituting, and thus are not analogous to flu and other illnesses, the wrongness of prenatal screening need not follow; or so it has been argued here.

Correspondence to: S D Edwards, Centre for Philosophy and Health care, School of Health Science, University of Wales Swansea, Swansea SA2 8PP, Wales; s.d.edwards@swansea.ac.uk

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ECHO

Pre-employment genetic screening



Please visit the *Journal of Medical Ethics* website [www.jmedethics.com] for a link to the full text of this article.

The complete analysis of the human genome raises the possibility of extensive use of genetic screening to assess future health risks for individuals. One application might be pre-employment screening. Such screening might have benefits and disadvantages for potential employees, employers, and society. For job applicants screening might reveal a genetic susceptibility to the health hazards of the job; the job may be avoided or special health precautions may be taken. Potential disadvantages of screening include inconvenience, anxiety, the uncovering of private information, refusal or loading of insurance, and reduced employment prospects. For employers the advantages of screening could include reduction in costs from employee ill-health, lower insurance costs, and the possibility of targeting of safety measures. The disadvantages could include the costs of screening, workforce unrest, the costs of turning down and replacing job applicants, and, in some countries, the possibility of legal suit for employment discrimination. For society screening might be beneficial by reducing occupational ill-health or disadvantageous by adding to costs. Genetic screening affects not only potential employees but also their families. Various national and international bodies have made recommendations about pre-employment genetic screening, mostly to the effect that genetic screening should not be a requirement unless it is clearly needed to assess safety or susceptibility to harm but that it may be offered when it might clearly benefit potential employees.

Quantification of the potential advantages and disadvantages of proposed screening programmes might help employers to decide whether to introduce screening and job applicants to decide whether to participate. Four measures are described in this paper: number needed to screen (NTS), number needed to exclude (NTE), expected incidence in those excluded (I_{exc}), and preventable fraction (PF). NTS is the number of job applicants who must be screened to prevent one having the given adverse outcome, NTE the number who must be turned down to prevent one case, I_{exc} the expected incidence of the adverse outcome in those turned down because of screening had they been accepted, and PF the proportion of adverse outcomes that could be prevented by the screening programme. The use of these measures is illustrated using data from a study of atopy and specific sensitisation to fungal amylase in bakers and algebraic formulae are given for the calculation of each of the measures when relative risk, the prevalence of the prognostic indicator (genotype in the case of genetic screening), and the overall cumulative incidence of the adverse outcome under consideration are known. Screening for a rare genotype would be associated with a low PF and high NTS and would most likely be considered not worthwhile. Similarly an uncommon adverse outcome would imply high values for NTS and NTE. The formulae could be enlarged to take account of financial and health costs for employees, employers, and society as a whole.

This paper describes statistical indices that might be useful in evaluating the potential costs and benefits of pre-employment genetic screening programmes. Such indices might help in reaching decisions about the ethical acceptability of individual programmes.

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