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The Expressivist Argument, Prenatal Diagnosis, and Selective Abortion: An Appeal to the Social Construction of Disability

Carolyn Gonter

As the ease of prenatal genetic testing increases alongside an increase in the number and variety of conditions testable, so does the general view, both in medical and social communities, that prenatal testing is a logical extension of good prenatal care with the goal of healthy babies. Presently though, prospective parents use positive prenatal test results primarily as the basis of a decision to abort fetuses that carry mutations associated with disease and/or disability. For many this is *not* simply a logical extension of the idea of good prenatal care.¹ The disability rights movement thereby suggests that we need to question the consequences of reproductive technologies and abortion policies for everyone with a disability.² The issue must be viewed in light of the history of our society's treatment of people with disabilities, according to which the disability rights movement regards such testing as potentially dangerous. This disability critique proceeds from the view that discrimination results when people in one group fail to imagine that people in some *other* group lead lives as rich and complex as their own and holds that the desire of prospective parents to avoid raising children with disabilities may depend on that failure.³ Though "[p]eople who make policy concerning the dissemination of genetic information have reached a consensus that the purpose of prenatal testing is to enhance reproductive choice for women and families – not to decrease the number of children with disabilities who are born", there is a definite tension between the goals of enhancing reproductive choice and preventing the births of children who would have disabilities.⁴

The disability critique proposes that selective abortion after prenatal diagnosis is morally problematic as it expresses negative or discriminatory attitudes, not merely about a disabling trait, but about those who carry it. This argument is called the *expressivist* argument. In what follows I hope to demonstrate the validity and applicability of this argument against the critiques of James Lindemann Nelson, as well as its foundations in and growth out of the view of disability as partially and detrimentally socially constructed. I will also summarize the parallel argument that the majority's view of disability is based on misinformation and that it is this misinformation that is the driving force for much of selective abortion after prenatal diagnosis. Central to this argument is the idea that living with disabling traits need not be detrimental either to an individual's prospects of leading a worthwhile life, to their families, or to society as a whole. In laying out these arguments I am not attempting to argue for a decisive threshold position regarding public policy or to express specific clear-cut practical conclusions regarding the topic; rather I hope to accurately and convincingly propose a view that should be acknowledged, and hopefully considered, concerning a decision of selective abortion.

The central claim of the expressionist argument, as stated by Adrienne Asch, is that the use of prenatal testing to select against disabling traits expresses a hurtful attitude about, and sends a hurtful message to, people who live with those same traits.⁵ Moreover, prenatal testing repeats and reinforces the same tendency toward letting the part, i.e., a single trait, stand in for the

¹ Parens, Erik, and Asch, Adrienne, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations" *Hastings Center Report*, 1999, September-October, 29(5): S1-S22, p.S1.

² Wendell, Susan, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge, New York, 1996) p.153.

³ Parens and Asch, p.S9.

⁴ Op. cit., p.S8.

⁵ Asch, Adrienne, as quoted in Parens and Asch, p.S2.

whole that many people with disabilities experience daily.⁶ That knowledge of a single trait is enough to warrant the abortion of an otherwise wanted fetus suggests that people are reducible to a single perceived-to-be-undesirable trait.⁷ In other words, the expressivist argument suggests that the greatest insult to people with disabilities, that some people are too flawed in their very DNA to exist, that they are unworthy of being born, lies at the heart of selective abortion. In Marsha Saxton's own words:

[F]ighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality – we are indeed worthy of being born, worth the help and expense, and we know it!⁸

Susan Wendell adds, along with her advocacy of the expressivist argument, not only that employing selective abortion to reduce the number of people born with disabilities sends a disparaging message to people with disabilities, but also that it strengthens the widely-held belief that life with a disability is not worth living, it might weaken efforts to increase accessibility and opportunities for people with disabilities (in appearing to reduce the social problems of people with disabilities by reducing the number of people with disabilities), and it could lead to even greater reluctance to commit resources to the medical treatment that makes the lives of people with incurable conditions more comfortable and rewarding.⁹ (While these are only empirical speculations, they are probable in light of our society's current treatment of people with disabilities.)

One of the central lessons urged by the disability rights movement is that much of the concept of disability is socially constructed. Disability cannot be defined purely in biomedical terms, as both biological and social aspects are interactive in creating *and* preventing it, just as feminist theorists hold that our idea of gender is largely socially constructed. The expressivist argument has this view at its foundations. Through an examination of the socially constructed aspects of disability (here, specifically in the writings of Susan Wendell in her *The Rejected Body: Feminist Philosophical Reflections on Disability*), the applicability of the expressivist argument is made much more apparent.

To begin, it becomes immediately clear when an attempt is made to come up with an adequate definition of disability that societal influence must be acknowledged. For example, even the United Nations' definitions of impairment, disability and handicap explicitly recognize the possibility that the primary causes of a disabled person's inability to do certain things may be social.¹⁰ Any standard of 'normal' structure, function and ability to perform an activity must depend to some degree on the society in which the standards of normality are generated. For example, in less technological societies, more people are considered disabled since the standards for normal ability and function are necessarily higher.¹¹ And when increases in the accepted pace of life in a society occur, there is a tendency for more people to become disabled, not only because of the physically damaging consequences of efforts to move faster, but also because fewer people can meet the expectations of 'normal' performance.¹² When a society provides few resources to allow people with disabilities to participate in its activities, all people with disabilities are marginalized, including the elderly. (Though many would not consider being elderly as a disability, most societies accordingly make it so.) Thereby in defining the

⁶ Ibid.

⁷ Parens and Asch, p.S2.

⁸ Saxton, Marsha, as quoted in Parens and Asch, p.S2.

⁹ Wendell, p.154-5.

¹⁰ Wendell, p.13.

¹¹ Op. cit., p.14.

¹² Op. cit., p.37.

appropriate roles of older people as very limited, societies disadvantage them.¹³ Similarly, in societies where a 'normal' woman is expected to lack strength, skills and range of movement, fewer women will be considered disabled (and more disability will go unrecognized) than in a society that does not hold these lower expectations for women. Or in other sexist societies, lack of opportunities and encouragement for women to develop bodily abilities, as well as constant objectification, threaten to deprive many women in these societies of their full physical potential.

¹⁴ Also, many social factors, such as high-risk working conditions, the abuse and neglect of children, and low public safety standards (to name just a few), which can damage people's bodies in ways that are disabling in their environments, "almost always affect some groups in a society more than others because of racism, sexism, heterosexism, ageism, and advantages of class background, wealth, and education."¹⁵ Accordingly, an appeal to biomedical typicality won't work for an attempted definition of disability, for even basic 'normal' abilities are relative to the environment in which they are performed. Further, the belief that 'the disabled' is merely a biological category masks the social functions and injustices that underlie the assignment of people to these groups.

For this reason, Susan Wendell proposes that any good definition of disability should recognize that normal physical structure and function, as well as normal ability to perform activities, depend, to some extent at least, on the physical, social, and cultural environment in which a person is living and are influenced by factors such as what activities are necessary to survival in that particular environment and what abilities that culture considers most essential.¹⁶ It would thus recognize that disability is contextual, i.e., in a given situation 'disability' is often *created* by the inability or unwillingness of others to adapt themselves or the environment to the physical or psychological reality of the person designated as 'disabled', while, at the same time, people with disabilities often regard their accommodations as ordinary, despite most people's insistence that they are unusually helpless or dependent.¹⁷ In this way, disability cannot be defined purely in biomedical terms, because social arrangements and expectations make essential contributions to disability *and* its absence.

Wendell's view of the social construction of disability can be divided into three general aspects, all of which are easy to recognize. First, social conditions, such as the availability of basic resources, the quality of medical care and practice, and the quality of one's living and working environment, affect people's bodies by creating or failing to prevent sickness and injury.¹⁸ Second, the assumed norm for pace of life in the social organization and physical structure of a society can marginalize people with disabilities, through its idealized expectations of performance:

Societies that are physically constructed and socially organized with the unacknowledged assumption that everyone is healthy, non-disabled, young but adult, shaped according to cultural ideals, and, often, male, create a great deal of disability through sheer neglect of what most people need in order to participate fully in them.¹⁹

In this way, disability is created even for those in a society who are not considered biologically disabled, such as pregnant women, parents with strollers, children, large people and the elderly. Third, disability is also socially constructed by the failure to give people the amount and kind of help they need to participate fully in all major aspects of life in a society, "the failure or

¹³ Op. cit., p.18.

¹⁴ Op. cit., p.15, 17.

¹⁵ Op. cit., p.37.

¹⁶ Wendell, p.22.

¹⁷ Op. cit., p.30.

¹⁸ Op. cit., p.36-7.

¹⁹ Wendell, p.37-9.

unwillingness to create ability among people who do not fit the physical and mental profile of ‘paradigm’ citizens.’²⁰ Wendell is thereby not implying that social factors alone cause disability, rather that the social response to, and treatment of, biological *difference* (this idea will be further explored below) constructs disability from biological reality, determining both the nature and the severity of disability.²¹ This social response can be seen as a result of the problematic cultural habit of regarding the condition of a person, not the built environment or the social organization of activities, as the source of the problem of disability. This leads to the self-perpetuation of the social system’s construction of disability. In light of this view of the social construction of disability, the relevance of the expressivist argument becomes more apparent, as prenatal diagnosis followed by selective abortion can be viewed as reinforcing the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.

In his article, “Prenatal Diagnosis, Personal Identity, and Disability,” James Lindemann Nelson argues that the expressivist argument is inadequate for three reasons, 1) that, considered as a practice, abortions prompted by prenatal testing are “not semantically well-behaved enough to send any particular message,” for they do not function as signs in a rule-governed symbol system, 2) that, even granting the expressive power of testing and aborting, it would not be possible to distinguish between abortions undertaken because of beliefs about the potential disabling conditions of the future child and abortions undertaken for many other possible reasons, and 3) that the argument cannot, in general, distinguish successfully between abortion and gene therapy as responses to disability.²²

Nelson introduces his first criticism with Allen Buchanan’s argument that the claim that an action conveys a meaning is only correct when the agents involved meet two conditions. The first concerns the content of an agent’s beliefs: for an action to convey a certain meaning, he or she must hold the beliefs purportedly expressed by that action; the second is that those beliefs must play a certain role in the decision making, i.e., the agent’s decision either must be motivated by beliefs that disparage people with disabilities or cannot be a rational decision absent of the acceptance of such convictions. Nelson proposes that the case of selective abortion does not fit these conditions.²³ I believe he is wrong in the vast majority of cases. Though *in particular cases* the testing and termination of pregnancy can be considered rational without the attribution of such beliefs to the parent/s (as will be discussed below), generally, because of the numerous socially constructed aspects of disability, and particularly the common negative and misinformed stereotypes of people with disabilities (as will also be further discussed below), most people do, usually ignorantly, hold disparaging beliefs toward people with disabilities, which would most likely be the primary motivational force behind the decision to abort a potentially disabled fetus.

Nelson then suggests, though, that perhaps this argument rests on a conception of meaning that is too closely tied to the beliefs that people hold as they act. Accordingly he proposes that it is not so much the intentions of agents that do not send a disparaging message to people, rather that as social institutions, prenatal testing and selective abortion are “not governed by the kinds of rules that would be required to assign them a role in a symbol system.”²⁴ He summarizes Wittgenstein in saying that for some behavior to have semantic significance it must have a rule-governed role in publicly sharable system of symbols. Concerning language specifically, Wittgenstein believes that meaning something can be best conceived in terms of the sorts of counterfactuals that provide the criteria for judging whether a sign is meant in a certain

²⁰ Op. cit., p.40-41.

²¹ Op. cit., p.42.

²² Nelson, James Lindemann, “Prenatal Diagnosis, Personal Identity, and Disability” *Kennedy Institute of Ethics Journal*, 2000 September, 10(3): 213-228, p.213.

²³ Op. cit., p.216.

²⁴ Nelson, p.216-17.

way.²⁵ By ‘rule following’, though, Wittgenstein is not referring to what *explains* a practice, rather the actual *behavior* of overtly using signs or symbols.²⁶ In this way, the existence of meaning requires the repeated use of rules, for our conception of grasping a rule at a particular time essentially involves the idea of applications of the rule over time. This is where Wittgenstein’s notion of ‘custom’ arises: “[A] person goes by a sign-post only in so far as there exists a regular use of sign-posts, a custom”; “I have been trained to react to this sign in a particular way, and now I do so react to it.”²⁷

Accordingly, as Nelson suggests, I agree that the hanging of a state or national flag would qualify as an established symbol according to such a system or custom. The standard job of hanging a flag at a capitol, for instance, is not merely to denote the state, but to express messages concerning a polity’s history and values.²⁸ But I disagree that as a social institution, prenatal screening followed by selective abortion does not have a similarly established role. As already demonstrated, ‘disability’ does actually have such a commonly acknowledged role in a publicly sharable system of symbols, which is what continues the (now “politically correct”) discrimination of people with disabilities. I believe it follows that selective abortion in order to avoid disability, with the foundation of this socially constructed negative symbol of disability, also has such an established symbolic role. Therefore, selective abortion of prenatally diagnosed fetuses *is* capable of sending disparaging messages to people with disabilities.

Nelson’s second criticism of the expressivist argument considers how it isolates a feature of selective abortion that distinguishes it as morally problematic from other assumed morally unproblematic abortions. He argues that abortion on the basis of, e.g., family size or poverty should also, according to the expressivist argument, send similarly disparaging messages to children and adults of large families or the poor.²⁹ Allowing that this would be an unfortunate, although unlikely, possibility, I believe it is irrelevant. The expressivist argument holds not only that disability involves socially constructed aspects leading to discrimination, but also that selective abortion on the basis of potential disability is a specific class of abortions, which involves a qualitative assessment of the particular inherent traits that are the biological aspects of disabilities. It is the subjective, as opposed to objective, rejection of a specific type of person, the rejection of a *particular* fetus, as opposed to the rejection of *any* fetus that happens to be potentially born into a particular objective situation (though that situation may still be socially constructed). When women abort for reasons of family size or income or their own health, etc., there is no similar change of mind involved as in selective abortion – they never wanted the fetus to become a child in the first place.³⁰ This idea of the importance of particularity is argued by Marsha Saxton’s belief that with prenatal diagnosis, as more generally with discrimination, a single trait stands in for the whole potential person and obliterates it. This tendency suggests that people are reducible to a single, perceived-to-be-undesirable, inherent trait. And accordingly, it sends the greatest insult to people with disabilities, that they are too flawed in their very chromosomal makeup to exist, to be worthy of being born.³¹

Important here is the view that *merely* the knowledge of a single trait is enough to warrant the abortion of an otherwise wanted fetus. Though this would be the case in such a situation as a disabled fetus being aborted because caring for a disabled child would impoverish the family, I believe that in such a circumstance, the expressivist argument would not hold for there is another central contributing factor to the decision of selective abortion, i.e., poverty. If, as I am assuming, the parents would not abort the fetus if they had more resources, the fetus is

²⁵ Wittgenstein, Ludwig, *Philosophical Investigations* (Blackwell Publishers, Ltd., Oxford, 2001) 186-188.

²⁶ McGinn, C., *Wittgenstein On Meaning* (B. Blackwell, Oxford, New York, 1984) p.36.

²⁷ Wittgenstein, 198.

²⁸ Nelson, p.217.

²⁹ Nelson, p.217.

³⁰ Asch, Adrienne, as quoted in Nelson, p.217-18.

³¹ Saxton, Marsha, as quoted in Parens and Asch, p.S2.

directly being rejected due to poverty, and only indirectly due to the potential disability. (I do believe, though, that this is a different and serious problem. I agree with Susan Wendell that adequate resources and accommodations should be provided to people with disabilities and their families in order to allow them to lead a fulfilling life, as they are capable of doing, with respect to the major aspects of life in a particular society.)³² Further, Nelson claims that many women who accept prenatal testing are at least somewhat ambiguous about continuing their pregnancies right from the start. I believe, though, that if they go through the effort of prenatal testing, this can only be construed as a result of their negative preconceptions of disability (misinformed or not) and its potential effects on them and the future child.

Nelson also argues that the intrinsic/extrinsic distinction is not relevant and that it “runs counter to” the disability rights movement’s central claim that disabilities are, in a very important measure, socially constructed.³³ As I already argued, I believe that it is, on the contrary, quite relevant. I also believe that it actually fits well with the social construction view. This view does not neglect the inherent biological aspects of particular disabilities; rather it claims that much of the negative and detrimental stereotyping of people with disabilities results from limiting societal arrangements and common misunderstandings. The choice and implementation of selective abortion does include the rejection of a particular fetus on the basis of an inherent genetic mutation. But it is also heavily swayed by the societal view of the influence of that particular trait on the life of the potential individual and his/her caregivers. For example, prenatal testing will diagnose a *third copy of chromosome 21*, but that fetus will generally, if it is rejected, be rejected as a result of how the parent/s view *Down’s Syndrome*. Though I acknowledge that poverty is also similarly socially constructed, the important point for the expressivist argument is the problematic circumstantial duality surrounding prenatal screening followed by selective abortion. Not only does it involve the rejection of a *particular* fetus, but it also has an established symbolic role in society, i.e. the discrimination of people with disabilities.

In his third and final critique of the expressivist argument, Nelson claims that, if expressivistic considerations pertain to abortion, they must also pertain to efforts to avoid the conception of a fetus facing such probabilities, or to therapeutic responses, i.e., gene therapy, that might eliminate the conditions that may result in the disability. He goes to great lengths to explain that the identity of the potentially disabled individual is eliminated by therapy, just as s/he would need to support a view that abortion in itself was morally problematic.³⁴ But, to begin, the expressivist argument is not applicable to the use of preventative measures prior to or during pregnancy, such as eating healthy, taking vitamins, and not smoking or drinking, as Nelson claims, because in employing them, a *particular* potential individual is not being rejected. And the heart of the expressivist argument, i.e., the potential discrimination, lies in this particularity of the rejection. And secondly, concerning gene therapy, I completely agree with Nelson and believe that others who advance the expressivist argument would as well, that there is no difference between selective abortion and gene therapy, regarding the applicability of the expressivist argument. Thus, as Nelson gives no reference to any objection to the view that gene therapy is just as problematic as selective abortion in the ‘disability community,’ he seems to be outright assuming that its members would hold the contrary in direct contradiction with some of its central propositions. Regardless, this critique is still Nelson’s strongest, and it stipulates further analysis. To conclude on the topic of Nelson’s critique of the expressivist argument, I hope to have responded adequately in order to more thoroughly show the relevance of the expressivist argument against selective abortion as a valid consideration.

³² Wendell, p.55-6.

³³ Nelson, p.218.

³⁴ Nelson, p. 219-20.

Before concluding, I wish to quickly summarize an argument parallel to the expressivist argument, as it runs hand-in-hand with it. The argument that prenatal genetic testing followed by selective abortion is driven by misinformation holds that it depends on a misunderstanding of what life with a disability is like for children with disabilities and their families: “if prospective parents could see that families with children who have disabilities fare much better than the myth would have it, [they] would be less enthusiastic about the technology.”³⁵ This argument also has its foundations in the view of the partial social construction of disability. According to Wendell, there is a lack of realistic cultural representations of people with disabilities, and as a result there is a widespread fear of being disabled, which is exacerbated by the assumption that disability means exclusion from the major aspects of a social life, such that life as a ‘disabled person’ is not worth living.³⁶ Such widespread ignorance and fear contribute to the desire to prevent disability by preventing difference (i.e., by means of selective abortion) from the ‘norms’ of society.³⁷ In this way, the common but inadequate understanding of what diagnoses of particular disabilities actually mean and of the quality of life of people with those disabilities puts the welfare, security and social acceptance of people with disabilities in jeopardy.³⁸

Still, though, it must be acknowledged that there is a plurality of disabling traits in addition to the plurality of attitudes toward prenatal diagnosis. For example, there are multiple genetic disorders that guarantee the death of an afflicted child by a very early age. Most parents would understandably like to spare themselves the experience of bearing a child who will soon die, beyond, of course, sparing the child of such pain and suffering. In cases such as these, though, I believe the expressivist argument would actually be by definition irrelevant, for no possible discrimination would result. In such cases, when carrier risk is known, novel reproductive technology even allows for preimplantation genetic diagnosis (PGD), in which in vitro fertilized eggs can be diagnosed prior to their implantation into the mother. Such in vitro screening and choice implantation is justified, I believe, when parental carrier risk for early fatal disorders, such as Tay-Sachs Disease or Trisomy 18, are identified (most likely due to a prior afflicted child). At the same time, though, I believe the expressivist argument holds against PGD beyond such extraordinary circumstances, for it still consists in the rejection of an embryo on the basis of a single, *particular*, inherent trait. Further, for certain individuals who possess different characters and aptitudes, the overall experience of raising even a non-fatally disabled child could be negative – they may be making an honest and informed acceptance of their own character and goals in deciding to abort a prenatally diagnosed fetus.³⁹

It is at this point that it must be remembered that both of the above arguments of the disability rights movement are not intended to justify absolute restrictions on prenatal testing for genetic disability. Instead, they are intended to make prospective parents pause and think about their choices and decisions, and to challenge professionals to help parents better examine the reality of their options and not simplify the facts; “[t]hey are intended to help make our decisions thoughtful and informed not thoughtless and automatic.”⁴⁰ In other words, though there is in general a powerful reason for not aborting a child on the grounds of prenatally diagnosed potential disability, the issue is complex, involving many more and important aspects beyond the potential discrimination of people with disabilities. Specifics of the disorder as well as familial circumstances must be addressed. It is for this reason that I qualified above that I am not attempting to argue for a decisive threshold position regarding public policy or to express specific clear-cut practical conclusions, rather I hope to be accurately and convincingly

³⁵ Parens and Asch, p.S7, S11.

³⁶ Wendell, p. 42, 47, 151.

³⁷ Op. cit., p. 82.

³⁸ Op. cit., p.151, 155.

³⁹ Parens and Asch, p.S11.

⁴⁰ Op. cit., p.S16.

proposing a view that should be acknowledged, and hopefully considered, concerning a decision of selective abortion.

In conclusion, I have summarized the two primary arguments of the disability rights movement against prenatal genetic testing followed by selective abortion, that it is morally problematic (the *expressivist* argument) and that it is driven by misinformation. I hope to have demonstrated in doing so, in showing both arguments' foundations in the view of disability as partially but detrimentally socially constructed, and in responding to Nelson's critiques of the expressivist argument, the validity, relevance and applicability of these arguments for the social well-being and the cultural bettering of society as a whole.

To reiterate, I find it ironic that the social factors that contribute to the seriousness of and suffering associated with any disorder or disease are often overlooked, while it can be argued that "the 'tragedy' and 'suffering' of 'the disabled' result primarily from the *isolation* of disabled people in society."⁴¹ A stereotyped vision of people with disabilities is often held by prospective parents undergoing prenatal diagnosis and considering selective abortion and is often fueled by their lack of exposure to people with disabilities. "Families with a disabled child, however, learn to appreciate the richness of their child's life, and to recognize how much quality of life depends on social support" – "it is discriminatory attitudes that make raising a disabled child much more difficult than the actual logistics of his or her unique care."⁴² Further, there will always be adults and children with disabilities due to reasons not preventable by genetic technological means. Therefore it is important to consider that not only does the widespread use of selective abortion to reduce the number of people born with disabilities send a message of rejection to children and adults with disabilities, that they are not valued and do not really belong, but it also strengthens the common belief that life with a disability is not worth living (ignoring that social improvements could make life with a disability much more worth living than it is now), could weaken efforts to increase accessibility and opportunities for people with disabilities, and could lead to even greater reluctance to commit resources to medical treatment of people with incurable conditions. Finally I agree with Susan Wendell's worries that the screening of fetuses and selective abortion, though they began as voluntary medical procedures, could fairly quickly become culturally mandatory, which could lead to the potential blaming of women if they do not undergo all the available medical procedures, and could also lead to increased tolerance of eugenic policies in general and expansion of eugenic efforts into other areas, a particular danger in our societies that are already engrained with cultural myths of control and perfection of the body.⁴³

⁴¹ Saxton, Marsha, (commentary) *Hastings Center Report*, 1996, 26(3): 22.

⁴² *Op. cit.*, p.22.

⁴³ Wendell, p.153-6.

