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# A Threat To Disabled Persons? On the Genetics Approach to Developmental Disabilities<sup>1</sup>

by Hans S. Reinders

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*This essay explores the claim that the genetics approach to intellectual disability does not imply a negative evaluation of disabled persons because there is a distinction between the person and the condition. Opponents of this claim deny the validity of the distinction. After identifying the presuppositions of the debate, the author discusses positive versions of the argument based on this distinction and suggests defenders of this distinction have committed the fallacy of genetization, which reduces personal identity to its biological basis.*

## The Issue of Negative Evaluation

Those who oppose the rapid proliferation of gene technology in medicine are suspicious about its use. Does using this technology imply a negative evaluation of persons with genetically-based positions and reinforce the marginalized position of disabled persons in society? Those who support the medical use of gene technology instead underline opportunities the "new genetics" provide to eliminate the causes of suffering for disabled persons and their families. They argue that no such negative evaluations are implied in using this technology.

In this paper I will discuss one argument that is offered by those who defend the use of technologies to identify genetic "defects," but who reject the charge of negative evaluation. Put briefly, this argument is that the aim of using gene technology in the field of developmental disability is to eliminate the causes of genetically based disabilities, not the persons who have those disabilities. Underlying this argument is a crucial distinction between the person and the person's condition. The objective of this paper is to show that this argument is flawed.

While people from the medical profession are right to reject the charge that they are making

negative evaluations of disabled persons, they nevertheless are wrong in thinking that they can make their case by distinguishing the person from the person's disabling condition.

## Disease and Disability

At first glance, the issue of negative evaluation when linking the person with his genetic condition seems to turn on a distinction between two types of medical conditions: those that allow a fulfilling life, and those that make such a life impossible. Critics of the genetics approach to disability argue that it characterizes people as people with diseases caused by medical conditions, who need to be cured, repaired or — in case no such intervention is possible — prevented. But as these critics claim, disabilities are not diseases. Disabilities, instead, are conditions that people can learn to cope with in order to achieve meaningful lives with their families when society provides them with the means to do this. Take, for example, people born deaf. People in the deaf community have learned to value their existence, not in spite of, but with their disability.

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There are other types of medical conditions, however, that rule out this view. For example, in the case of Duchenne's muscular dystrophy. The opportunity to live a life of human fulfillment is diminished by profound and progressive deterioration of all muscular functions. Life with Duchenne's disease appears to be a prospect of life with significant suffering, both for the child and for the parents.<sup>2</sup> Consequently, the distinction between a disability and a disease collapses.

Certainly Duchenne's muscular dystrophy is a disease as well as a disability. However, we must distinguish medical conditions (diseases) that express themselves in psycho-somatic functioning from medical conditions (developmental disabilities)<sup>3</sup> that express themselves in social functioning. As the examples of deafness and Duchenne's muscular dystrophy suggest, these different types of functioning are correlated in weaker or stronger ways.

Diseases can be distinguished from disabilities by focusing on the consequences. Persons with Down's syndrome typically have problems with social functioning due to limitations in cognitive performance. Aside from certain medical complications at birth and other health problems at a later age, such persons may suffer from all sorts of things — just like anybody else — but they don't suffer from the condition of Down's syndrome. Here, the correlation between the medical condition and the disability is a weak one, or at least much weaker in most cases than this same correlation in the case of Duchenne's muscular dystrophy.

This implies that using gene technology to diagnose and prevent the birth of a child with Down's syndrome is different from using the same technology to prevent the birth of a child that will develop Duchenne's disease. In the latter case the justification is a desire for a healthy child, or at least one whose life will not be burdened by the prospect of suffering and death at an early age. In the former case, the justification is a desire for a "normal" child or at least one whose possibilities in life will not be limited by a developmental disability. They differ in that one

is perceived as impairment combined with suffering, while the other is perceived as "abnormality" combined with limitation. Using gene technology to prevent a disease that causes suffering is very different from using this technology to prevent a disability that causes "abnormality." In both cases — Down's syndrome and Duchenne's disease — there is a necessary correlation between the medical condition and the disability. But as this correlation varies in strength, it implies different moral meanings. In some cases, for example, those involving deafness and Down's syndrome, the objection that a disability is not a disease makes sense. In other cases, for example, Huntington's chorea and Duchenne's muscular dystrophy, this objection does not have the same force.

These differing perceptions of disease and disability, respectively, trigger the moral debate on whether using gene technology implies negative evaluations regarding the lives of disabled persons. From the point of view of a disabled person, preventing the birth of children with developmental disabilities because they will suffer from serious limitations is not necessarily rational. One can instead choose to change — or at least to criticize — the social conditions that turn such limitations into "disabilities" and make "normality" imperative. People in the fields of developmental studies and special education are likely to agree with this view.

### **Gene Technology and Abortion on Demand**

Modern gene technology provides diagnostic techniques to confirm or deny predictions of this type: "person A is, or will be, affected by condition X." If genetic information about one's offspring can be used to decide whether or not to have a child with condition X, does this also imply a negative evaluation of living people who have the same condition? In other words, does using gene technology for such purposes constitute a form of discrimination?

This question has gained prominence due to the availability of abortion on demand: fetuses likely to develop a disability later in life can be

aborted legally. When in an overwhelming majority of cases fetuses diagnosed with Down's syndrome are terminated, this sends a clear message: having Down's syndrome reduces your child's and your own quality of life considerably.

Compare this situation with checking the cardiac function of a fetus by listening to its heart tones. A regular procedure in prenatal care, this normally would raise no moral doubts. But imagine that a prognosis of cardiac arrhythmia could be presented as sufficient reason for terminating the life of a fetus. No one takes this position because we have a variety of therapeutic means to combat cardiac dysfunction. Therefore, no one thinks that using cardiology techniques in prenatal care implies a negative evaluation of persons with cardiac dysfunction. By the same token, this issue *does* arise in the case of conditions such as Down's syndrome because that condition cannot be treated using therapeutic means. One's options are either to accept the child with the condition, or not to have the child at all. Due to the combined social practices of prenatal diagnosis and abortion on demand, the issue of discrimination becomes prominent. General access to abortion on demand adds to the plausibility of the discrimination issue.

### **Persons and Conditions**

The discrimination issue, now, seems to depend on the identification of the disabled person with her disabling condition. The genetics approach to disability cannot imply a negative evaluation of the disabled person's life unless one accepts that, for example, a person A with the fragile X syndrome is characterized by this syndrome. If one accepts this, then one will also accept that *if* the fragile X syndrome is terrible to live with, *then* a person with that condition will lead a terrible life. If one accepts this judgment as sufficient justification for preventing an occurrence of the fragile X syndrome, then as a practical consequence, persons with this syndrome ought not be born. Given this argument, it is clear that preventing people with fragile X syndrome from being born implies a negative evaluation of the lives of these persons.

But why accept this identification of the person with the person's condition in the first place? For medical conditions, we generally do make such distinctions between persons and their conditions. In this respect, genetically based conditions are equivalent to other medical conditions. Although we fight cancer, we do not try to eliminate persons who suffer from that disease. Like other diagnostic and therapeutic interventions, gene technology aims at the condition, not at the person.<sup>4</sup> There is no reason to single out, for example, the chromosomal abnormality that causes Down's syndrome from other medical conditions. We use diagnostic tests to detect cancer, but no one takes this to imply that in using these techniques, we are devaluating the lives of persons with cancer. Why not apply the same distinction to Down's syndrome?

### **Actual and Future People**

This "Distinction between the Person and the Condition" (DPC) argument plays an important role in defending the genetics approach to disability, particularly from the point of view of the medical profession. Doctors, including those working in genetics, say they fight diseases, not people. In doing genetic research and developing diagnostic tools and therapies, they claim to be dedicated to alleviating suffering and feel the charge of negative evaluation is unjustified, being based upon a false identification of persons with their conditions.

There is an obvious rejoinder to this argument: cancer and Down's syndrome are very different. We use diagnostic tests in oncology to detect and combat cancer, but killing a lethal tumor with chemotherapy is not the same as killing a fetus with Down's syndrome. The former is a malignancy, the latter a potential human being. The distinction between the person and the condition needs further justification if the DPC argument is going to work.

One way to justify the DPC argument would be to distinguish "future people" from "actual people." Doctors involved in genetics help people decide about future children. Because these

children do not yet exist, using gene technology to rationalize *preventing* them from coming into existence will not affect the lives of these children. Hence, living persons with disabilities are not affected by genetics technology. Decisions about whether to prevent the birth of a child are decisions about "admittance" to life; they are not decisions about living people. Therefore, a decision to terminate a fetus with *trisomy 21* in the second trimester of pregnancy will have no implication for living children with Down's syndrome. Nothing follows from such decisions regarding whether these children should be "mainstreamed" in education, whether they should have special working and housing facilities, or whether they should have full citizenship.

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To summarize, this version of the DPC argument runs as follows: The genetics approach to disability doesn't imply a negative evaluation of the lives of persons with disabilities because it aims to prevent genetically-based medical conditions in people who do not yet exist, and who, therefore, cannot be harmed. In addition, existing people with such conditions cannot, by definition, be prevented.

### **Judging Other People's Lives**

What this version of the DPC argument overlooks is how reasons to prevent Down's syndrome actually arise. We need some basis to argue that one would rather not be a person with Down's syndrome, or to have a child with that syndrome. An obvious basis is to ask what life with Down's syndrome is like, or, what life with a child having

this syndrome is like. The next step is to ask: where do these images come from? Unless one is satisfied to rely on myth and prejudice, there is no other way to ground one's view than to look and see what life with Down's syndrome is actually like. In other words, the only rational way to proceed is to try to verify one's image of that kind of life. This implies that the most rational way to proceed is to evaluate the lives of people with Down's syndrome and ask whether one would want to have, or to be part of that kind of life. The revised version of the DPC argument continues to imply a negative evaluation of people with Down's syndrome: We want to prevent the illness, and the people who will have it, because we negatively assess the lives of people who are actually living this kind of life.

A second line of defense for the revised version of the DPC argument would be to point out that people can only judge their lives from an internal point of view. People are mistaken in grounding their judgment on their perception of what other people's lives are like, because they cannot possibly know what the lives of other people mean for these people themselves. Evaluations of this kind must take place in the first-person. Reasons for preventing a life, therefore, should be based on what people think about their own lives. They cannot — *logically* cannot, that is — be based upon other people's lives.

I do not believe this line of defense holds because it supposes that judging other people's lives requires a "view from nowhere." That is to say, in order to judge the life of *A*, I should be able to step outside my own point of view and then see what the life of *A* is like for herself. But this step is not required. First of all, I do not need to know what the life of *A* means to her, but only what a life like hers would mean to *me*. In judging the life of *A*, I am not judging that life from her own perspective, nor I am I trying to assess it from anybody's point of view in an objective manner. I am judging what the things I know about *A*'s life would mean to me in case they were part of my life. So the relevant distinction is between what I now judge my present life to be, and what I now

judge my future life would be were it to share some of the features of the life of *A*. I can identify these features only on the assumption that it is *my* life — in a possible future state — that is under consideration. If true, this implies a negative evaluation on my part that is the basis for judgment not to want a life with *A*'s medical condition or to have a child with that condition.

### The Human Person as a Body

The distinction between the person and the condition may reappear in a different form, which is best explained in terms of an example. Fragile X syndrome is a genetic deficiency that causes severe developmental disabilities. The genetic location of the deficiency is well known. While there is no genetic therapy available for it yet, such therapy is theoretically possible. If the genetic material that produces the wrong protein could be removed and the appropriate material inserted so that the right protein is produced in the right amount, then that would count as a genetic therapy. If we had such a therapy, our options would no longer be limited to accepting a child with the fragile X syndrome or to having the fetus aborted. Instead, there would be the possibility of having the same child — genetically speaking — but without the syndrome. Who would not desire that kind of result?

A third version of the DPC argument, then, amounts to this: even if measures taken to prevent the birth of fetuses with certain genetic "defects" is a way of killing potential people with disabilities, this is due only to the need to resort to abortion. When scientists are successful in the development of a gene therapy, the situation will change dramatically and the analogy with other diseases, such as cancer, will at that stage hold true. We then can claim to be eliminating medical conditions without eliminating persons.

There is at least a partial response to this. It turns on a conception of personal identity as constituted by bodily existence.<sup>5</sup> My bodily existence provides a 'context' within which my personal identity develops from the moment that I was born. From that moment onward, the social

meanings out of which my identity is constructed have been produced by interactions between me as bodily existence and my environment. Suppose that James now is a man with fragile X syndrome and someone puts the following question to his parents: "Wouldn't you have wanted James without, rather than with, fragile X?" What would there be for James' parents to say? The only logical answer for his parents would be to say that James is what he now is *because* of his condition. James' personal identity cannot be distinguished from his bodily existence characterized by fragile X. Therefore, it is mistaken to suggest that there could be a choice between James with or James without this syndrome. Confronted with the above question, his parents could make a choice — logically, that is — between having James with the condition of fragile X or having a healthy child, *whoever that child might turn out to be*. To suggest that James, as his parents now know him, would be the same as the genetically identical child without fragile X is to be guilty of a fallacy of geneticization. Whom I understand my son to be has very little to do with his genetic disposition, which is not to deny that his genetic dispositions determine his potentialities. The fallacy of geneticization lies in reducing my son's identity to his genetic disposition, which, in other words, is reducing personal identity to its biological basis.

As indicated, this is only a partial response because it leaves unanswered the question whether it is reasonable to assume that James' parents would rather have a healthy child than a child with fragile X, had there been a choice. Even if this assumption appears reasonable, it cannot save the DPC argument. In both questions, there is no real distinction between the person and the person's condition. As we saw, the real question would be: Would you rather have James than another child who also would have been another person? Or alternatively it would be: Would you have chosen a healthy child over a child with fragile X? Both questions make no distinction between the person and the condition. Instead, the first question makes a distinction between two different people, one known and one unknown. The

second question does the same, distinguishing a healthy child from a disabled one.

### Self-Respect and Public Esteem

What are the moral implications of what has been argued? If I would not want to live a life like James', this implies a negative evaluation of his life. Does my evaluation also, or does it not, constitute a form of discrimination? I will again argue from an example, in this case the condition of a neural tube defect, *spina bifida*.

When I make the kind of judgment stated above, I apply a standard for a valuable life. Let us refer to this standard as a standard for the good life. It is commonly believed in our society that people are entitled to their own standards for the good life. The question arises: Am I rightly accused of discriminating against people with *spina bifida* when I terminate my pregnancy of a fetus with that condition and justify this decision by saying that my personal standard for the good life excludes living with the consequences of *spina bifida*? Suppose I am on a public television panel discussion on gene technology and reproduction and I state this view on *spina bifida*. Would viewers who themselves live with that condition be justified in accusing me of discrimination?

The answer is both "Yes" and "No." It is clearly "yes" when we realize the importance self-respect holds for every member of society. Without self-respect, I cannot think of my life as worth living. Self-respect, however, is an interpersonal concept. The respect I have for myself is based on the fact that other people endorse it, not only in the moral sense that they owe me respect, but also in the factual sense that they respect me at least partly for the same reasons that ground my self-respect. Self-respect, in short, needs confirmation by others. Without confirmation by others, my reasons for self-respect are undermined. If a panelist tells me he does not want to live my kind of life because he does not consider it a worthwhile life, it offends me if I think positively of my life and expect to have that judgment confirmed by others. In fact, many persons with disabilities do share this expectation.

At the same time, the answer to the discrimination question must be negative because when a television panelist gives an opinion about life with *spina bifida*, he or she is talking about one's own life. How could he be discriminating against others in saying what life with *spina bifida* looks like from the perspective of his own, given his standard for the good life? This state of affairs occurs regularly; people who are reasonably content with their own lives are confronted with negative views about the life they are living, even by those who do not intend to offend.

The above argument warrants an additional conclusion with regard to members of the medical profession involved in gene technology, especially those who provide the means for using that technology for the goal of prevention. The affirmative part of the answer to the discrimination question implies that these scientists provide their clients with the means to carry out decisions that are based on negative evaluations of the lives of persons with disabilities. These means and the evaluations on which they are based are discriminatory when seen from the point of view of disabled persons. But at the same time, there are at least two reasons not to accuse members of the medical profession of participating in discriminatory practices.

The first reason follows from the earlier point about unintended offense. Doctors who engage in practices aiming at the prevention of developmental disabilities often feel that this accusation unjustly violates their moral integrity. This may be the case when these doctors are devoted to helping people by trying to prevent medical conditions that cause human suffering. Their intention, clearly, is not to offend.

No morally relevant description of what an agent does can ignore what the agent herself intends to be doing. A doctor who provides a pregnant woman with a prenatal test is doing various things. She is practicing her profession, doing an experiment, serving her client, earning a salary, helping to contain the cost of medical care for disabled persons, recognizing a woman's right to decide for herself, and so on. Clearly, some of

these descriptions are more relevant to moral evaluation than others, but the description of what the doctor *intends* to be doing cannot be discounted as irrelevant in this connection.

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However, there is another side to the story. If scientists working for the prevention of *spina bifida* imply by their work a negative evaluation of the lives of people with that condition, readers and writers of texts on ethics should carefully deliberate before we accuse them of participating in discriminatory activities. Who among us would want to live a life with that condition? To raise the question is to answer it. When thinking morally about the genetics approach to disability, it is difficult to maintain balance between negative and positive aspects. The field is fraught with moral ambiguity. Overlooking this ambiguity causes two types of problems. One is that we end up being hypocritical in criticizing the genetics approach. The other is that in endorsing this approach we may not want to see its potentially discriminatory effects upon persons with disabilities and their parents. Whereas intellectual honesty is primarily a virtue of the soul, solidarity is a virtue regarding particularly vulnerable human beings in our society.

### Conclusion

The distinction between the person and the condition is dear to members of the medical profession. Doctors strongly object to charges of negative evaluation. They seek the good of patients by fighting against conditions that cause patients to suffer. But in making this claim they are confirming, in a sense, what is held against them, namely, that they view certain variances in cognitive and psychological performance to be *diseases* rather than social phenomena. In doing so

they forget the limitations of their medical outlook and do not see what disabled persons and their families mean when they say that the "medical attitude" fails to do justice to their lives and experiences.

In many cases, medical conditions are a disability only when the environment limits the pursuit of certain goals. Being deaf limits one's ability to communicate only when the community in which one lives has not learned to use sign language. When one is unable to walk due to permanent paralysis, one still is able to go anywhere by wheelchair, provided one's environment is designed to be wheelchair accessible and, second, that the people in the environment treat that person with respect and dignity. Likewise, persons with Down's syndrome can learn if society provides adequate education. Disabled persons are persons with potential. The appropriate response to many disabilities is not *cure* or *prevention*, but rather *education* and *care*.

The issue is a difference between two disciplinary orientations, one medical, the other developmental and educational.<sup>6</sup> It is also a difference between people facing two types of questions. The first is whether they are at risk of having a disabled child, which is a question only doctors can answer. The other is whether parents will be able to cope with the needs of a disabled child and make the best of this child's life, relying upon help from, for example, professionals in special education and social workers.

From the point of view of the social sciences, the distinction between the person and the condition is not helpful. If Jean is a woman with *spina bifida*, all meaning attached to Jean's life is constituted by interpretations of that fact. There is no person "Jean" outside the life of the actual Jean. From the social scientist's point of view, the distinction between the person and the condition is contained within the presupposition that medical conditions are accidental. But Jean's *spina bifida* is not accidental to who Jean is, as was previously argued.

In many cases, the medical profession does *not*

make a distinction between the disabled person and their disabling conditions. If it did, developmentally disabled persons would be eligible for medical interventions. But this is often not the case. For example, persons with Down's syndrome may not have access to cardiac surgery or heart transplantations. Likewise, if a developmentally disabled woman has been involuntarily sterilized by blocking her fallopian tubes, she probably will not be eligible for artificial reproductive techniques such as *in vitro* fertilization. If doctors were consistent in distinguishing the person from the condition, we would expect doctors to spend at least as much time trying to ameliorate the lives of disabled persons as they now spend developing strategies to prevent children with disabling conditions. To date it does not seem that doctors adopting the genetics approach to developmental disabilities have done so.

## Endnotes

1. This paper is a philosophical account of one of the crucial points of debate in an international workshop on the ethical implications of the genetics approach to intellectual disability. The workshop was held as a preconference workshop on Ethics and Intellectual Disability preceding the Tenth World Congress of the International Association for the Scientific Study of Intellectual Disability (IASSID) held in Helsinki, Finland, July 8-13, 1996.
2. It should be added that there have been reports from people with Duchenne's disease who make claims similar to claims by people from the deaf community.
3. This term and its derivatives always refer to developmental disability in this text.
4. See Terrence R. Dolan and A. Buchanan. 1996. "Gene Therapy: Promises and Concerns." *Japanese Journal of Developmental Disabilities* XVII (\$): 243-260. The authors of this text suggest that a central tenet held by disability advocates is that the genetics approach entails a devaluation of persons with disabilities, and then claim that these advocates fail to distinguish between the individual and the condition.
5. I follow there an argument developed by Dr. Steven D. Edwards, PhD (Center for Philosophy and Health Care, University College Swansea, Swansea UK) at the international workshop mentioned previously, in his paper "Intellectual Disability, Genetics, and the Value of Human Life," pages 3-7.
6. Some of the evidence for the different orientations in the medical and the educational professions was provided at the preconference workshop by Dr. Jean Ware, PhD, in her paper "Life-Saving Treatment for Children with Severe Intellectual Disabilities: Do Professionals' Attitudes Indicate a Judgment on the Value of Children's Lives?"