



# Prenatal testing for Down syndrome: the real discussion

By Hans S. Reinders

Hans Reinders argues that if our society could achieve for people with a disability the things that we all value most deeply - love, friendship, intimacy - then life with a disability would be less bleak and feared; it would not be something to be avoided at all costs. If people with a disability were able to achieve this *good life* then the negativity surrounding disability would diminish and so would the debate over prenatal testing. The real question according to Hans is: How do we as a society make sure that it is possible for people with a disability to achieve a *good life*?

Whether or not there is a problem with prenatal testing for Down syndrome (referred to here as PTDS) depends on how we approach the question. In this article I will look at the ethical aspects of PTDS. Let me quickly describe two of the most prominent, and conflicting, positions when looking at the discussion around PTDS.

## The right to reproductive choice

Western societies generally accept PTDS as a morally legitimate practice that is justified by the right of parents to obtain information about the health of their unborn child. As such it is hard to see what can be said against PTDS. Matters are different, however, when this right is connected with a woman's right to abort an unwanted child, which in these societies is also generally recognised. Testing itself is not the problem, generally speaking, but one's position on PTDS may change when this practice is aimed at aborting children with Down syndrome as unwanted. For example, one may think it is wrong that the birth of people with Down syndrome is the object of prevention.

Within this argument for testing two positions can be taken. The practice of PTDS can be promoted by healthcare authorities, either to promote public health or to minimize healthcare costs. Our governments hardly ever take this position, because who are they to tell the community that people with Down syndrome should not exist? Many of these people live reasonably happy lives, and they are not manifestly expensive healthcare consumers, to use a current term. This is where the

second position kicks in. Whether or not individual citizens want to accept the birth of a child with Down syndrome is a question for them to decide. Since family issues are part of their private lives, they are entitled to reproductive choice. Not only do they have the right to choose when to have children, if at all, and with whom, and how many, the PTDS has also given them the option of deciding what kind of children they want. Democratic governments should stay away from deciding these issues for them. This means that people have a right to choose healthy babies. If they decide that children with Down syndrome do not qualify, then this decision falls within their right to reproductive choice.

## Rights of people with a disability

Squarely opposed to this individual rights position is the view of Down syndrome advocates. They will stress the argument that people with Down syndrome do not live inferior lives. Even when the condition comes with a number of above average health risks—such as congenital heart failure—it does not follow that Down syndrome is a disease, any more than an above average risk for breast cancer means that being female is a disease. Therefore the habit of looking at Down syndrome as falling within the area of healthcare is already problematic. The success of early intervention programs over the last decades have been quite spectacular, indicating that people with Down syndrome are capable of developing much better than was assumed in previous times. Many people with Down syndrome make valuable contributions to society: they are students, actors, photographers, writers or

athletes; films like *Yo, tambien* and *Le Huitieme Jour* that have persons with Down syndrome as leading actors are internationally acclaimed.

If we understand Down syndrome in the above way, we can argue that seeking to prevent the existence of people with Down syndrome is discriminatory, because the reasons for doing so are wrong. Others say that the right to reproductive choice should be controlled because prospective parents might not be well informed when making the decision about having a child with Down syndrome. Usually this view is defended by arguing for the rights of people with disabilities. People with Down syndrome should be treated as citizens with the same rights and opportunities to live the same sort of life that is enjoyed by others.

### Which right is right?

As important as these arguments for and against PTDS are, however, they are flawed in one respect. If one wants to claim the same right to equal opportunity to live a life of one's own for all people, then it is hard to see how people's right to decide family issues for themselves could be restricted in a justifiable way. The reason is that the two positions pro and con PTDS described above are in fact argued from a rights position: the *rights* claim that supports the *right to choice* argument also supports the right to equal opportunity argument.

### The good life

In my view, the real discussion about PTDS lies in our perception of what constitutes a *healthy* baby, and I would like to suggest another way to approach the discussion.

Without cultural understandings of what constitutes a healthy baby, we probably would never have known something like PTDS to begin with. Images of people with disabilities leading deplorable lives continue to be widely disseminated among the general population. Rights claims are not very effective in this respect. Whatever rights can do for people with disabilities, they cannot legislate how other people think about them. This is the essence of my argument: we need to change the way the community perceives disability and then the need for debate around PTDS will cease.

Disability advocates advance inclusion through political means and use the language of individual rights, which in our society is seen as the most powerful weapon in politics. For reasons explained above however, it is doubtful that the community's perception of disability, which is shaped by fear and prejudice, is affected by arguments around individual rights.

I believe there is a growing awareness among disability advocates that the debate needs a broader perspective.

This broader perspective appears under the heading of *the good life*. *The good life* introduces the view that the primary question in ethics is what makes our lives worthwhile. Philosophers tell us that the answer we give to this question usually involves two kinds of *goods*. On the one hand there are goods that can be obtained and accumulated, such as education, jobs, a house, holidays, all kinds of possessions. On the other hand, however, there is a different kind of *good*, sometimes called *hyper goods*. These are the *goods* that cannot be obtained or accumulated: they are goods like health, friendship, love. The strength of these goods is that they add meaning to the first kind of goods. A well-paid job, a house of one's own, possessions: would we care as much about these things if we didn't share the joy of having them with a friend or loved one? Or are they as valuable if we lack sufficient health to enjoy them? The great ancient philosopher Aristotle thought that friendship was the true end of human existence, for even ill-health can be much more bearable in the company of a true friend or loved one.



### The good life and PTDS

How does this relate to the discussion about the ethics of PTDS? It does so in showing that the underlying issue is the question of what makes our lives truly worthwhile, and how disability fits into the answer we give. In many ways disability reduces the opportunities to obtain and accumulate the first kind of goods. So, in general, it is fair to say that disability limits one's options in life, but it does not necessarily limit the possibility of friendship and love. This explains why so many people who share their lives with a child with a disability or sibling will tell you that it has been difficult at times, but nonetheless a very rewarding experience that they would rather

not have missed. This is particularly true in the case of sharing one's life with a person with Down syndrome, as is widely reported.

In the last decades, disability advocacy has been wary of this kind of talk because it locates the issue of accepting people with disability in emotional terms, and in western societies emotional justification is politically less acceptable. Consequently, advocates have developed arguments for inclusion around rights. The politics of rights has been quite successful, as is reflected in the fact that the disability rights movement has been claimed *the last civil rights movement*. However, what was implied in the politics of rights is that inclusion came to mean equal opportunity. Rights open institutional space: they open the school system and enable you to become a student, or the housing market to become a tenant, or the job market to become an employee, and so on. But rights *cannot* open the area of hyper goods, particularly the areas of intimacy, love and friendship.

I have come to think about these things not necessarily in connection with moral arguments about PTD but more generally in connection with the inclusion debate. It has always struck me to hear from people with disability how friendship is the number one *good* they miss the most. This is particularly true of people with intellectual disabilities, including people with Down syndrome. Why then do we continue to discuss inclusion as if it is a rights issue, as if we didn't know that what people with a disability want most dearly has little to do with rights?

### Conclusion

If we shift the debate around prenatal testing for Down syndrome to how can we best ensure that people with disability can enjoy the good life, it will follow that public perception of disability will change so that the birth of a child with Down syndrome is not something undesirable or to be feared.

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The only ethically responsible benefit to prenatal testing for Down syndrome is to help parents and doctors discover if the baby has any other associated health risks, for example, heart defects, stomach/bowel malformations, and prepare themselves the best they can for any medical assistance the baby may require at delivery.

My husband and I were heavily pressured to consent to an amniocentesis test after an eighteen week ultrasound scan revealed our baby had a significant heart defect. Wanting to know more fully what other health risks our baby had, we did agree to the highly-invasive procedure, making it clear to the doctor that whatever the result, we were continuing with the pregnancy. When Down syndrome was diagnosed we were pressured on several occasions by the obstetrician to explain why on earth we were not willing to terminate the pregnancy. Largely for

this reason we feel doctors need to be far more impartial and respecting of parents' decisions. I worry that all too often a particularly inaccurate and gloomy picture is painted of life with a disabled child so parents get pushed into making a decision they may regret for the rest of their lives. I was told I would have to end my teaching career and that having any more children would be highly inadvisable. On both counts these *health* professionals were wrong and now we have three beautiful daughters and I teach four days a week. We need to hear more positive stories from people in the Down syndrome community and this would help to minimise negative information given to expectant parents by the medical profession.

**Kitty O'Sullivan**