



The views of people with Down syndrome on the Non-Invasive Prenatal Test (NIPT)

Written by:

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Any views expressed in this report are the authors' own and not
those of the Nuffield Council on Bioethics or Mencap.



Summary

In the UK, screening is offered to all pregnant women from weeks 10-14 of pregnancy. If there is a high chance that the foetus has a genetic variation such as Edward, Down or Patau syndrome, the woman is offered an invasive diagnostic test, which has a risk of miscarriage.

The Department of Health recently announced that a new test, Non-Invasive Prenatal Test (NIPT), is likely to be offered to certain pregnant women via the NHS¹. The expansion of new technology has led to considerable debates surrounding the future direction of prenatal testing and the impact on society as a whole. The Nuffield Council on Bioethics carried out a consultation to consider the ethical implications of this proposed change in prenatal screening.

In August 2016 The Nuffield Council on Bioethics commissioned Mencap to lead on gaining the views of individuals with genetic variations and a learning disability. Mencap asked Dr Barbara Barter to act as lead facilitator for this piece of work, in light of her previous research in this field (Barter, Hastings, Williams and Huws 2016). Although the timescale for meaningful participation was very short it was considered crucial to include the perspectives of individuals with the genetic variations in question.

Nine people with Down syndrome agreed to take part in the consultation. Initially they attended information sessions to discuss the topic, and understand or clarify information. Seven individuals then took part in individual interviews in November and December 2016. The interviews were guided by particular questions and tailored to individual comfort with the topic. Interviews from six participants were transcribed verbatim and a process of thematic analysis was employed to analyse the data.

¹ <https://phescreening.blog.gov.uk/2016/11/03/addition-of-non-invasive-test-to-improve-screening-for-pregnant-women/>



Main findings

Participants spoke of negative discourses about disability and a lack of understanding and fear of Down syndrome.

Helen – The first thing people think of Down syndrome is it's sad and that it's scary. They don't know much about it.

This stood in stark contrast to their life experience and the life possibilities for anyone born with Down syndrome or disability.

Sophie – Am I a burden? Am I a risk? No, I'm a person with feelings... Because I have a friend... she may need more support but she is still precious. That's what I am trying to get across... people with Down syndrome should be loved for who they are, not what they achieve.

Participants agreed with testing as a means of preparation and as an opportunity for prospective parents to gain information.

Dylan – I think it's a good thing that they know... know what they are expecting. They know exactly what to do. How to treat the baby... They might not know, parents might now know what it'll be like.

Participants' views of termination varied from disagreeing to feeling unsure. Overall participants were saddened and expressed disappointment with termination following testing.

Dylan – That I guess I would be shocked... Because I think you would love the child...



At the same time, most agreed with a woman's decision to choose.

Helen – They are getting rid of it if they're finding out it's Down syndrome because they don't want that life for their baby or something. I mean it's a personal choice. I'm a pro-choice person. I believe what the woman wants she should get. If she doesn't want a baby with Down syndrome she doesn't have to... It's a woman's rights.

There was a consistent and strong call for balanced information, including the possibility to meet people with Down syndrome, as a means of supporting educated or informed choice for women and families.

Helen – Educate them. Mostly online at the moment... you can find out about many different disabilities... Educate themselves. They can research it... So they can have a more informed choice of whether or not to keep the baby. I think it's good to get more educated choice... but I think they should have more information for them.

Decisions to test and decisions taken following testing may have a direct or indirect impact on individuals on an emotional and practical level.

Sophie – It makes me feel like I'm not wanted in society. And no one loves us... [Speaks about how her family loves her]. But the government doesn't love me, because if they did love me they wouldn't do this.

Authors' conclusions and recommendations

1. Because both studies (this and Barter et al) were small and not representative of people with Down syndrome, further larger scale consultation is required to continue to build on this initial work.
2. People with Down syndrome and other disabilities should not be excluded from discussion about NIPT and similar issues.
3. Discussion with people with learning disabilities about complex and sensitive topics (such as NIPT) must be carried out in a thoughtful manner with preparation and support available, and adequate time for meaningful participation.
4. Individuals with Down syndrome may be aware of the issues around genetic testing, and clear information about the topic should be provided to them.
5. Further research is required to understand the diversity of living with any genetic variation.
6. Parents considering NIPT and its results should be offered opportunities to understand more about Down syndrome and the value of the lives of individuals with Down syndrome (e.g. through meeting people).



7. Given the perceived strength of the negative discourse surrounding Down syndrome, further work is required to understand what is needed to support informed choice.
8. Policy makers should take steps to mitigate the potential for the implementation and presentation of NIPT to be perceived by people with Down syndrome as questioning the value of their lives and themselves as 'wanted'.
9. As the technology, reach, and implementation of NIPT changes over time ongoing consultation with people with Down syndrome is necessary to capture the possibility of changing perspectives.