

What some people with Down syndrome said about the new Non-Invasive Prenatal Test

What is the new Non-Invasive Prenatal Test?



When a woman is pregnant, she can choose to have a test called screening.



Screening can help a woman or couple to find out more about the foetus.

A foetus is what a baby is called before it is born.



Some foetuses might have Down syndrome.

Screening can help a woman or a couple find out if their child has Down syndrome.



There is a new test called the Non-Invasive Prenatal Test (NIPT).

This test is done by taking blood from the woman to help find out more about a foetus.



This will make it easier for a woman or couple to find out if a foetus has Down syndrome, or other genetic differences.



The government has said that more people will be able to have the new Non-Invasive Prenatal Test.

This will probably start in 2018 or 2019.

Finding out what people think about the Non-Invasive Prenatal Test



The Nuffield Council on Bioethics have asked a lot of people what they think about the Non-Invasive Prenatal Test.



The Nuffield Council on Bioethics have written a report about the Non-Invasive Prenatal Test.



The Nuffield Council on Bioethics asked Mencap to help them find out what people with Down syndrome say about the Non-Invasive Prenatal Test.



Barbara Barter talked to six people with Down syndrome.

Barbara has written down what they said in a report.

What did the people with Down syndrome say about the Non-Invasive Prenatal Test?



The people with Down syndrome said that other people are scared of Down syndrome.

They said that people think Down syndrome is sad.



The people with Down syndrome talked about lots of positive things in their lives and don't think that Down syndrome is sad or scary.



They thought screening for Down syndrome helped parents to know more about their baby and what to expect.



Most of them felt sad that some people might not want to have a baby if it had Down syndrome. Some people said it made them feel like they weren't wanted.



Most people thought that a woman should have a choice whether they wanted to have a baby with Down syndrome or not.



They said people should have more information about Down syndrome.

They had lots of ideas about giving this information like meeting people with Down syndrome and hearing about their lives and all of the things they do and enjoy.

What does the report say? It says:



That it was very valuable to speak to people with Down syndrome about NIPT.



That the Nuffield Council on Bioethics have been told what these people with Down syndrome said.



That this was a small group of people with Down syndrome and we should find out what lots of other people think or want to say.



That people with Down syndrome should be able to talk about NIPT. People with Down syndrome don't have to talk about NIPT if they don't want to.



That some people might have heard about NIPT but might not understand it. People should have more information about screening if they want it.



That people should have more information about Down syndrome.

That parents should have more information about Down syndrome.



It says that people who write the policy about NIPT should know that screening can make people with Down syndrome feel sad and unwanted



That what people with Down syndrome say about NIPT might change in the future and we should keep thinking about people with Down syndrome.

We should keep asking what people with Down syndrome think or have to say about NIPT.