



Scottish

Learning Disabilities

Observatory



Research Voices Citizens' Jury

Our Ideas for Change

An easy read report

Who are the Research Voices group?



The Research Voices group is a group of people with learning disabilities in Scotland



The Research Voices group made a Citizens' Jury

A Citizens' Jury is a group of people who want to talk about an important issue

This Citizens' Jury talked about **Health Research**



The Citizens' Jury was made up of people with learning disabilities

There were 5 men and 4 women

- The youngest was 16
- The oldest was 66



People on the jury had different health problems

They used their stories to help them on the jury



Research can help us find out about lots of different things

Health Research helps us to find information out about peoples' health



Health research is important because

- it helps people with learning disabilities to get the best care possible
- people with learning disabilities have worse health than other people in Scotland

What did the Citizens' Jury do?



The jury came up with an important question

**How can people with learning disabilities influence health research?
Including influencing:**

- **What research is done to help people with learning disabilities**
- **How this research is done**

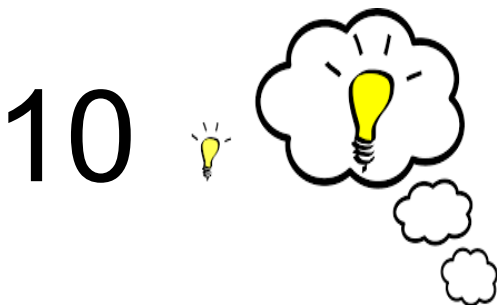


The Citizens' Jury met up for 6 months

They heard from people who know about health research called experts

They asked these experts questions

They thought about what should be different



The Citizens' Jury came up with 10 ideas for change

What are the ideas for change?



Idea 1

People with learning disabilities should get easy to understand information about:

- Medicine
- Treatments that can help them feel better

This information should use easy to understand words and pictures



Idea 2

People with learning disabilities can be researchers

- They can help find out information and understand why things happen
- They might need more time and help to be researchers



Idea 3

Some people have profound learning disabilities.

These people might need a lot of support and find it difficult to communicate

They might have these other disabilities as well, such as:

- Physical disabilities. This is a disability to do with the body (they might need a wheelchair)
- Sensory disabilities. This is when people find it difficult to see or hear
- Lots of health problems

People with profound learning disabilities should be involved in research

Their families should be involved too

Their stories are important

Health research organisation



Idea 4

It is too hard for people with learning disabilities to get involved in health research

There should be an organisation that helps people get involved

Experts and families should be part of this organisation



Idea 5

People with learning disabilities should help choose how money is given out to health research

They can help decide what type of research is done



Idea 6

People with learning disabilities should

- choose how their information is used in health research
- decide if they want their doctor to share their personal information with researchers
- understand how their information will be used

Some people do not want to be labelled

Let's talk about
our health



Idea 7

There should be a **campaign** around the health of people with learning disabilities

A **campaign** is a way of raising awareness

It can help other people understand health problems



Idea 8

There needs to be more support and help for people with learning disabilities to learn about health research

Health research is meant to help make peoples' health better

But is too hard for people with learning disabilities and their families to get information about health



Idea 9

People with learning disabilities should be involved in research **ethics committees**

Ethics committees are groups that get together to decide if research is safe or not safe

They can make changes to research to make it fair and safe for people

They can say no to research if it is not safe and good for the people involved



People with learning disabilities can help these groups understand what it is like to have a learning disability



Idea 10

In 3 years' time, the Research Voices group should meet again

The group can see if this report made a difference

The group can do another report

What happens next?

Scottish
Learning Disabilities
Observatory
TalkingMats

The Scottish Learning Disabilities Observatory and Talking Mats work together on this project



We will talk about these ideas for change

We will help people understand why they are important



Health research can help change peoples' lives

It is important that people with learning disabilities have a voice



Thank you for reading this report