The Scottish Government
University of Glasgow
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Scottish Learning Disabilities Observatory

Research Voices Citizens' Jury

Recommendations on Involving People with Learning Disabilities in Health Research

About this report

This report is for anyone who is interested in including people with learning disabilities in research.

We worked hard on this project and want to share our ideas with you.

The Research Voices Project Team helped us to write this report and share it with you.

We know that there is still lots of work to be done.

We hope that we can help you to think differently about research and ask questions about how to involve people with learning disabilities.

Introduction

In 2019, we joined the Research Voices Group and became a part of a Citizens' Jury of people with learning disabilities. Our Citizens' Jury was about health research.

We met up for 5 workshops between July 2019 and November 2019 to get to know each other and build our communication skills. We also learned about health research including why it is important and how it is done.

Our Citizens' Jury was 5 days long.

This report is about the recommendations that we have come up with to help people with learning disabilities be more involved in health research.

More information about the project is available on our website: https://www.sldo.ac.uk/inclusive-research/research-voices-project/

Why did we have a Citizens' Jury?

People with learning disabilities have worse health than other people. Sometimes this is because they do not get good quality health care. This is not fair.

Health research tries to find out about health and health care. Researchers want to understand what makes a difference to peoples' health. They also want to find out how to make health better for some people.

People with learning disabilities do not get many chances to be involved in health research.

The Citizens Jury was about hearing our voice.

The Jury question

A jury works together to answer a question. Usually, the people who organize the jury come up with the question. But our Citizens' Jury was different because we came up with our own question.

We came up with our own question by using ideas from two groups of people. We looked at ideas from health researchers who went to a roundtable discussion about our Citizens' Jury at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) conference. These researchers talked about the Jury and shared ideas for questions they would like to understand more about. We also looked at ideas the National Involvement Network (NIN) came up with when they thought about research. The NIN are a group of people with learning disabilities who help people with learning disabilities have a bigger say in the services that support them.

In small groups, we looked at all of the questions. We thought a lot of questions were not relevant to us, so we put them aside. Then we looked at what questions we thought would be interesting to answer and shared those with each other. Together, we looked at the most interesting questions from each group and voted on which one we thought was most important. Everyone got to vote. Once we chose our favourite question, we spent a long time changing the words and making sure we all understood it. We came up with this 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**

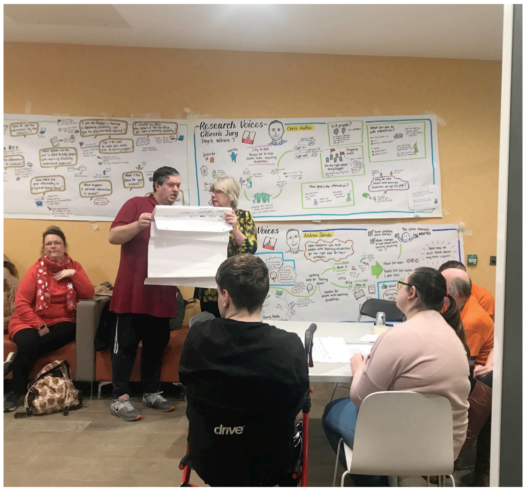
Expert Witnesses

We heard from seven expert witnesses in the Citizens' Jury. They were experts because they knew a lot about their topic, either because they had studied it for a long time or because they had personal experience. The expert witnesses used their experience and knowledge to speak to us, they spoke as people and did not try to represent their organisation.

We asked the experts to make an easy to understand presentation for us. We then asked them questions and decided what was important about their talk.

Speaker	**Job role and Organisation**	**Presentation topic**
Laura Hughes McCormack	Research Associate, Scottish Learning Disabilities Observatory, The University of Glasgow	The physical and mental health of people with learning disabilities
Gillian Smith	Research Assistant, Scottish Learning Disabilities Observatory, The University of Glasgow	The physical and mental health of people with learning disabilities
Dr Thomas Kabir	Head of Public Involvement, The McPin Foundation	Research ethics and ethics committees
Professor Craig Melville	Professor of Intellectual Disabilities Psychiatry and Director of the Scottish Learning Disabilities Observatory, The University of Glasgow	Research funding – how projects get money
Ian Davies	Independent Self Advocate and Researcher (Northhamptonshire People First, The Open University)	My life as a researcher
Jenny Miller	Chief Executive, PAMIS	Including people with profound and multiple learning disabilities in health research
Professor Andrew Jahoda	Professor of Learning Disabilities, The University of Glasgow	How research can help people with learning disabilities get the right help for their problems
Professor Chris Hatton	Professor of Public Health, Disability Co-Director of Improving Health and Lives, the Public Health England Specialist Learning Disabilities Public Health Observatory, and Regional Co-Director of the NIHR Research Design Service North West, Lancaster University	Using information that health services collect about people with learning disabilities

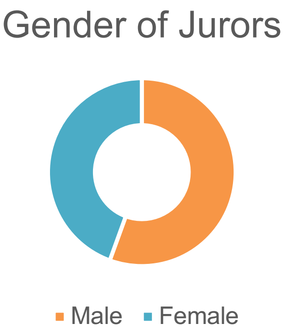
About us



- We are all individuals
- Some of us go to school
- Some of us go to work
- Some of us are parents
- We are lots of different ages
- We have worked really hard on our Citizens' Jury
- We found out a lot of research and new things
- We get along with each other and we support each other
- We work as a big team
- We have a big heart and feelings
- We have different experiences, and we use that to help each other
- We respect each other

The project team chose 12 people to take part in the Research Voices project from across Greater Glasgow and Clyde. They chose people from lots of different backgrounds. They tried to get people from different backgrounds so that they represented all the different groups of people with learning disabilities.The project team planned this by using information from Scotland's Census done in 2011 to decide how many females and males should be on the group. They also used this to decide the age groups of people in the Citizens' Jury.

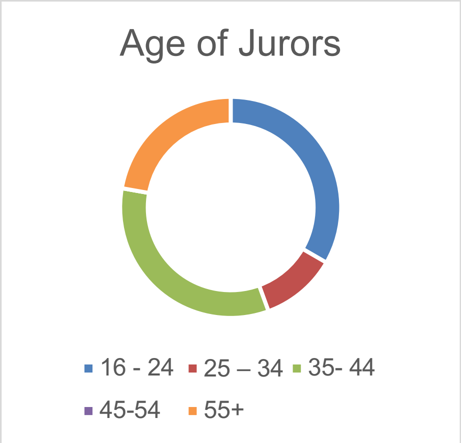
Age Group (years old)	Proposed group membership	Actual group membership
16-24	2	3
25-34	2	1
35-44	2	3
45-54	3	0
55 +	3	2
Totals	12	9



9 of the 12 people who joined the group were able to attend the Citizens' Jury.

Of the 9 members, 5 were men and 4 were women.

The jurors were lots of different ages, from 16 years old to 66 years old. There were no jurors in the 45-54 age range, which the project would have liked.



Many members of our group have health problems. Some members have illnesses like epilepsy and depression. We used our experience to help us in the jury.

Our recommendations

These recommendations are in our own words. The Research Voices team asked for some small changes to help make them easier to understand.

At the end of the jury, we voted on the most important recommendations and put these first in the report.

Recommendation 1: There needs to be more simple information made available about medication and treatments

This should be in the format of short and simple writing and drawings to show us

Why is this important?

- There is simply not enough information about medication and support out there
- Information about medicine and support can be life or death

> “They should offer more the therapy than the medication… we didn’t know about [health resources online].. doctors or surgeries should have told us” - Juror

Discussion:

Medication was an important theme throughout the Citizens’ Jury.

People with learning disabilities are more likely to take medication, but the group felt they were less likely to understand information about it.

Through talking to expert witnesses, the jurors learned about treatments and medicine they didn’t know existed.

Recommendation 2: More people with learning disabilities should be involved in health research as people who do research

People with learning disabilities who do research could work with other people without learning disabilities, or they could work on their own.

People with learning disabilities might need more time, more help and more patience to do that.

Why is this important?

- We have more experience of learning disabilities than people who do not have learning disabilities
- Sometimes we might have a different understanding
- It will give us a chance to prove you wrong and stop you shutting us out
- People with learning disabilities might have different questions because we know what it is like to have learning disabilities
- It will make research better

> "If the person without learning disabilities is willing to listen, cooperate, they might share different ideas and perspectives" - Juror

Discussion:

The Citizens' Jury heard Ian Davies, an expert witness who is a researcher with learning disabilities.

This experience inspired them to think about having more people with learning disabilities involved as researchers and being involved in different parts of the research process.

The group discussed the partnership between people with learning disabilities and people without as co-researchers.

They heard that sometimes there is information that only one person can see, or that you need a certificate (or special permission) to see.

That means the person with disabilities cannot be part of looking at the information. But the Jury suggested that they could help to analyse the results of research even if they can't see the information.

Recommendation 3: People with profound learning disabilities and their families should be more involved in research

This includes research that uses information from health services.

The kind of researchers we need for this work are kind, caring and genuine.

Why?

- If no one gets involved in research, there will be no change. It will be the same old research.
- To find out what it is like for people with profound learning disabilities.

"We are a minority of a minority" – PAMIS Group Member

Discussion:

The Citizens' Jury heard from Jenny Miller from PAMIS, an organisation that supports people with profound and multiple learning disabilities.

The group felt that people with more profound learning disabilities and their families should have a voice, but that there were some things that might put families off, like the wrong researcher being chosen for research.

The group briefly talked about people with learning disabilities being researchers for this group, because they would have a connection due to their shared experience.

Recommendation 4: There should be an organisation that people with learning disabilities can go, to be involved in health research

The organisation should be new or could be part of an organisation that already exists.

It should be non-judgmental and should be made up of research experts and other people like families.

Why is this important?

- We are the experts and we are looking for answers.

> "For us to get involved in anything... the gap is too wide" – Juror

Discussion:

The Citizens' Jury felt that it may be difficult for people with learning disabilities to be part of the world of health research.

They said that people with learning disabilities might need help and support to be involved.

But they thought that people with learning disabilities would want to be involved, with the right help.

Recommendation 5: People with learning disabilities should influence how money is given out to health research

We can do this by:

1. Being actively involved in the decision-making process of what research is funded and where the money goes.
2. Being proactive and educating organisations that we should be involved in all stages of decision making.
3. Protest in order to have our voices heard and to be more involved in regulations and research.

Why is this important?

- Only people with learning disabilities can tell people how it feels.
- People with learning disabilities know what the priorities are.

"You can watch a football game but playing the game is totally different" - Juror

Discussion:

The Citizens' Jury heard from Professor Craig Melville about how research gets funding.

Once the jury understood how money is given to research projects, they felt that people with learning disabilities should be involved in the process because they know what topics are the most important.

However, the group also said that it is not enough to give money to research, it should also be given to make a difference and help make peoples' health better.

Recommendation 6: There should be information and choice about whether people with learning disabilities are ‘flagged’ or not

Why is this important?

- To keep our independence.
- It is our rights and we should have control over our decisions and personal health information.

“The word flagging, it’s so controversial” – Juror

“Maybe identified…or awareness” –
Juror response

Discussion:

The word ‘flagging’ or ‘flagged’ is used in this context to describe when a person with learning disabilities goes to the doctor and the doctor puts a note on their computer to say that they have learning disabilities.

Then, researchers can use information from all the people who have a ‘flag’ on their file to find out about their health. They can see whether lots of people with learning disabilities went to hospital or if people with learning disabilities had a flu jag.

There was a lot of debate in the Citizens’ Jury about flagging. Some jurors thought that it could help people get better care if they were ‘flagged’, because people would know they might need more help.

Some jurors did not want people using their information if they did not give permission and felt worried about being labelled. The group compromised and said everyone should have a choice in this.

Recommendation 7: There should be a campaign around the health of people with learning disabilities

This campaign should

- raise awareness of the poor health of people with learning disabilities.
- talk about how to make things simpler for us.
- change people's ideas about us.

We should tell the government what we are saying. We can make posters and do a petition and get attention for the issue.

Why is this important?

- The media do not do enough. There is not enough information about health. We have to do it ourselves.

Discussion:

The Citizens' Jury felt that there needed to be more action to help the government and members of the public understand the poor health of people with learning disabilities.

By leading their own campaign, they felt that they could challenge assumptions. But the group also discussed that being part of a campaign is hard because there are always "closed doors… people have like totally given up on trying to voice their opinion"

> "Don't give up. Keep going, keep going" - Juror

Recommendation 8: There needs to be more support and guidance for people with learning disabilities and the people who help them to learn about health and health research

We should be able to find out about health research in a way that is easy to understand. Information could be pictures, writing or adverts on the TV and radio.

Some people might need help and support to get information. There should be information for important people like mums, dads, carers, teachers, headmasters, doctors, nurses, hospital staff

There should be easy to understand information in important places like schools, clubs, GP practices and hospitals.

Why is this important?

- If people with learning disabilities understand more about health problems, we will know what help we can get
- More awareness will help people with learning disabilities to be treated better and with kindness
- Some people with learning disabilities cannot talk, so they cannot tell us when something does not work. So we need to make sure that the people who support them (like families or support workers) know more
- There will always be people with disabilities
- People get older and health needs change
- People need information about their condition

"Doctors don't listen to you…but they're the ones with all the information" - Juror

Discussion:

The Citizens' Jury heard from expert witnesses Laura Hughes-McCormack and Gillian Smith that people with learning disabilities have worse health than other people.

They felt like there was a problem with information. Information might not be getting to the right place, or it might not be easy enough to understand.

The group had a very in-depth discussion about how health advice like "just exercise" might not be enough, because people with learning disabilities may have more physical barriers to exercise and may also be worried about bullying and abuse while out in the community.

Recommendation 9: People with learning disabilities should be involved in research ethics committees

We can tell the people in the committee what it is like to have a learning disability. We should speak to people who regulate ethics committees and change the rules.

Why?

- People with learning disabilities should be involved because it will give ethics people more of an idea what it is like living with a disability.

Recommendation 9a: People with learning disabilities could become part of the committee

Why?

- Because people with learning disabilities can be part of committees and would have an important voice

"[we] need to prove it!"

Recommendation 9b: People with learning disabilities might need advocates to help them

Discussion:

The Citizens' Jury heard from Dr. Thomas Kabir who explained what ethics is.

Ethics was a complicated subject, but the group focused on why people with learning disabilities are not part of ethics committees.

The group had heard some of the barriers, and their recommendations are about trying to overcome those barriers.

Some members of the group felt that people with learning disabilities will need extra help to understand ethics.

Why?

To help your confidence and to talk up more and use easy read and other ways of communicating like Braille and signing

Recommendation 9c: Ethics people should find the best way to pay or recognise the contribution of people with learning disabilities who are part of committees

Why?

People should be paid but it might affect benefits and make people afraid to be part of it. Some people might want to volunteer.

"I've got a way… say someone sends you a massive pile of paper about ethics, instead of a big stack of papers you send 10-15 papers in simple English. if blind or deaf have a brail or translator"

Recommendation 10: In 3 years' time, we should meet again to do another report and see if this report made a difference

Discussion:

Throughout the Citizens' Jury, there was a lot of discussion about accountability and making sure work always had an impact. This extends to the Jury's own work.

A message from the Research Voices Team

This project was delivered in partnership between the Scottish Learning Disabilities Observatory and Talking Mats and funded by the Wellcome Trust.

We were overwhelmed by the quality of contribution made by the Research Voices Citizens' Jury and believe that they have provided extremely valuable recommendations for the future of learning disability health research.

The recommendations made in this report call on action from all stakeholders in research. Some of these recommendations have wide reaching implications, and may need to be explored in more depth.

The Scottish Learning Disabilities Observatory is dedicated to supporting the research community to respond.

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Thank you!