

Why and how to involve people with learning disabilities in research

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Overview



What is a learning disability?

Who are ‘people with learning disabilities’?

Why involve people with learning disabilities?

How to involve people with learning disabilities – challenges and opportunities

What is a 'learning disability'?

Learning disability is

- A reduced intellectual ability (often taken as an IQ below 70); *and*
- Significant impairment of social or adaptive functioning; *which*
- Was present from birth or started during childhood

A learning disability is NOT

... the same as a 'specific learning difficulty' e.g. dyslexia, dyscalculia, dyspraxia

Basic facts and figures



- 1.5- 2% of the UK population have a learning disability
- They experience worse health outcomes (morbidity and mortality) than other people

Who are 'people with learning disabilities'?



Why involve people with learning disabilities in research?

Don't
ask why,
ask why
not...

Involve people with learning disabilities if you care about

- Equality & diversity
- Representative sampling of population
- Improving lives

How to involve people with learning disabilities in research?

Understand their needs and abilities



Mild learning disabilities



- 85% of all people with learning disabilities
- Will have attended mainstream school; may have been excluded
- Highly unlikely to receive specialist services

Mild learning disabilities

Research involvement



- Able to give informed consent
- Able to read and write if plain English is used

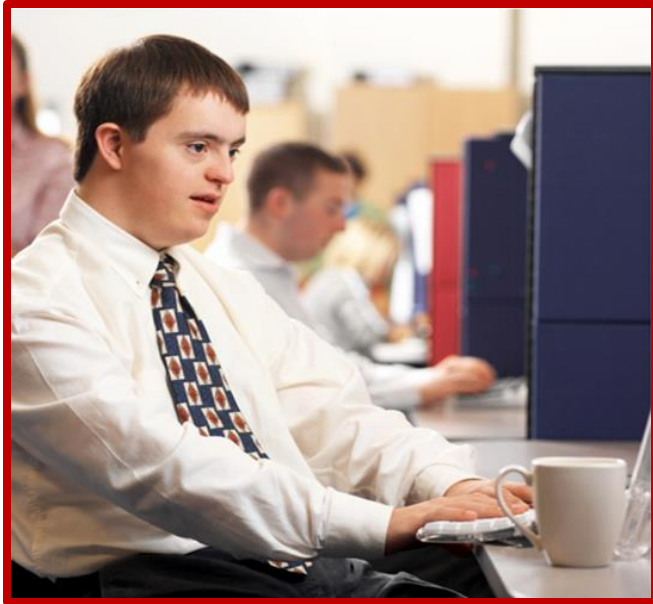
Moderate learning disabilities



- Around 10% of all people with learning disabilities
- Probably attended mainstream school, but in segregated classes
- May not meet local thresholds for specialist services

Moderate learning disabilities

Research involvement



- May be able to give informed consent
- May have limited literacy
- May need additional time and support to participate
- Suggestibility, acquiescence or confabulation may arise

Severe learning disabilities



- Around 5% of all people with learning disabilities
- Likely to have attended special school
- Likely to receive support from specialist health and/or social care services

Severe learning disabilities

Research involvement



- Consent likely to be tacit rather than explicit
- May have limited verbal communication
- Alternative modes of engagement may be needed

Profound and multiple learning disabilities



- Around 1% of all people with learning disabilities
- Will have attended special school
- Will need 24/7 care from family or from public services

Profound learning disabilities

Research involvement



- Unlikely to be able to give traditional informed consent
- Little or no verbal communication
- Participation may need to be mediated by a carer

Practical things to consider

Use simple language

- Avoid jargon
- Add pictures if possible
- Check the readability of your text
- Consider using alternative formats e.g. video

Be pro-active

- Pay people for their time
- Active recruitment
- Involve people on research steering groups
- Enable 'third party' participation i.e. via carers

Further sources of information

- NHS Digital: [Health & care of people with learning disabilities](#)
- NHS: [Learning from Lives and Deaths: People with a Learning Disability and autistic people \(LeDeR\)](#)
- Free online [readability test](#)
- NHS Health Research Authority: [Mental capacity](#)
- Change: [How to make information accessible](#)
- Mencap: [Involve Me](#)