

Research involving d/Deaf people: challenges of methodology and method

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Context

- 9 million adults in the UK
- 1 per 1,000 – 2 per 1,000 through childhood
- 42% of 50+year olds
- 70% of 70+ year olds
- Between 50 and 100,000 BSL users

Context

- Not just a specialist interest
- Likely to be present in most social care research with adults – particularly older people

Many ways to BE deaf

- Traditional ways of trying to understand diversity:
- Age of ‘onset’
- Language used
- ‘degree’ of deafness
- Do these really tell us anything?

MARY – Deaf from a Deaf family. Fluent BSL user. Proud of her cultural heritage, doing a science degree

ALI: very good lipreader, bilingual in English and Urdu, recent cochlear implant, long term unemployed

GEORGE –, retired factory worker. Started losing his hearing in his early 60s. Uses spoken language, hates his hearing aid.

Being deaf

- All 3 have the same degree of hearing loss
- Does it tell us anything about their life circumstances? Their talents? Their histories?
- Does type of communication/language say anything about the consequences of that?

Why does this matter for research?

1. Problems for sampling, secondary data analysis and trustworthiness of data
2. Importance for research design
3. Consequences for research practice

Characterising samples

- Deafness as ethnicity
- Do you have a disability?
 - NO
- What is your ethnicity?
 - OTHER (Deaf)

Big D, little d distinctions

- What happens when fail to do so?
 - Purdham et al., 2008, meta-review of all major UK data sets concerning disability and equality.
- What happens when you do?
 - Not necessarily stable identity
 - Cohort problems
 - Hearing people can be Deaf too...

Characterising samples

- Official classifications
- ‘deaf with speech’ or ‘deaf without speech’
- Hearing impaired or speech impaired

Typical consequences

- Can you really carry out meaningful secondary data analysis?
- Meta analyses become unreliable
- Main effects models should not be trusted
- Don't forget proximal risk mechanisms

Influence of Models of Deafness on Research design

- Medical model(s)
- Social model(s)
- Cultural model(s)

Quality of life for older d/Deaf people in residential care (qualitative study)

Hearing aid
benefit and use

Hearing
perspective why
don't use?

Deaf perspective
why don't use

Social inclusion

Re-alignment of
identity in group
communication

Reinforcement of
social exclusion in
group
communication

Influence of
hearing
environment

Lack of awareness
and adaptation
creates additional
disability

Cultural
oppressions of
childhood revisited

Example of consequence for research practice

- Importance of emphasising language/communication preference
 - Reading does create barriers
 - Just because someone speaks does not mean that is their best way to express themselves
 - Lipreading is mostly guesswork
 - Cultural oppression to force a language choice

Example of solution

- Remote data capture
 - Select survey adaptation
 - Bilingual
 - Signing 'in' answers
- Multiples language and formats as standard, not as choice to be requested

Final thought

