



Curtin University





Recruitment: it's challenging

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Background

- Original research was designed to explore citizenship from the perspective of young adults with intellectual disability.
- Significant recruitment difficulty over several months rendered this project incomplete and stalled in data collection phase.
- A subsequent literature review indicated significant discussion and difficulty surrounding recruitment of people with intellectual disability in research studies.
- Design of new project to explore recruitment of people with intellectual disability from the perspective of academic researchers

Aim

- To understand how people with intellectual disability are recruited to be active participants in research by seeking conversation with academic researchers published in the area.

Methodology

- Inductive qualitative enquiry, informed by grounded theory - in the form of a semi-structured interview.
- 12 researchers met the inclusion criteria and consented to take part - with an average of 20 years research experience each, total 513 articles published.

Methodology cont'd

- Data analysis was completed in four phases.
- Transcripts were member checked and rigour was built into the research design.
- Ethics were granted by Curtin University HREC (approval HR224/2015).

Recruitment: Its difficult

- Differentiation of intellectual disability as a research population
- Lived experience of researchers
- Gatekeeping
- Ethical considerations
- Research Design
- Collaboration
- Rapport / Credibility / Trust

Recruitment: Its difficult

- Differentiation of intellectual disability as a research population
- *“If you really want to include and empower people with intellectual impairments you need to think very carefully about the methods you’re going to use, that will allow them to share their experiences and knowledge...”*

Recruitment: Its difficult

- Lived experience of researchers
- *“But the challenges, it's just, as everyone would tell you, just enormously time consuming. So the time to recruit...in the hope that you might get just a handful of people with [intellectual] disability, is a big, big, big investment in time.”*

Recruitment: Its difficult

- Gatekeeping

“So I think gatekeepers are a bit of a double-edged sword there around, obviously, trying to protect the rights of the person, but also then making their own decision about whether they will let you get past first base of the person or not.”

Recruitment: Its difficult

- Ethical considerations
- *“...is it therefore, okay, to exclude some people from research because they can't consent, and therefore we don't ever understand more about their world, and that's a complicated one, that's way beyond the ethics committees usually, too, that we run the risk of isolating people, isolating their experiences, because they can't respond in the usual sorts of ways that have been deemed ethical, because it's a one size fits all.”*

Recruitment: Its difficult

- Collaboration

The main factors discussed included; collaborating at early stages, organisations are useful for recruiting, nurturing partnerships, negotiating research design, establishing key contacts, building a shared understanding and disseminating information.

Recruitment: Its difficult

- Research Design
- *“...[It’s] often ridiculous the layers and yet another layer of “management” that has to be consulted and so – you know, it gets to the point where it’s just not viable to spend months and months and months chasing that particular group and you just get up and go somewhere else.”*

Recruitment: Its difficult

- Rapport / Credibility / Trust

the importance of building rapport with both gatekeepers and potential participants as soon as practicable in the research process, citing the positive impact this has on the project and their recruitment processes.

Discussion

- Original work in the field - to our knowledge, no previous study has directly approached recruitment for this population.
- Understanding this issue and its depth is essential if PWID are to be more actively involved in research. If experts within the field of intellectual disability have difficulty in recruiting participants, challenges may be amplified for general population studies wishing to be inclusive of PWID.
- Serves as a foundation to improve research activity and provide tangible concepts for further investigation.

Discussion

- Increasingly conservative decisions by HRECs.
- Gatekeeping
- Juxtaposition of protection vs involvement in research, to the degree that PWID were able to provide consent or assent to participate and demonstrate behaviour consistent with this decision or agreement.
- Serves as a foundation to improve research activity and provide tangible concepts for further investigation.

Final Thoughts

- The intention of this research is to open a dialog surrounding the issue of recruitment for PWID.
- This research has the potential to provide a foundation for future investigation and further development of strategies to improve recruitment.
- Through recruitment we will directly hear the voice of people with intellectual disability within research.



Thank you

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