

“You Can’t be Cold and Scientific”: Community Views on Ethical Issues in Intellectual Disability Research

Why did we do this project?



- In the past, people with intellectual disability have been treated badly during research studies.
- To help keep people with intellectual disability safe, they have sometimes been overprotected and not included in research studies.
- Now, some people want to see more people with intellectual disability be in research.
- Having more people in research may help us learn things to improve people’s lives.
- First we need to know what people from the community think about having adults with intellectual disability take part in research.

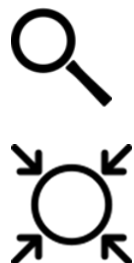
What did we do?



- We did focus groups (group interviews) with 57 people:
 - adults with intellectual disability,
 - people who provide social services to adults with intellectual disability and
 - family members and close friends of adults with intellectual disability
- We asked them:
 - What do you think about adults with intellectual disability being in research?
 - What good things can happen when adults with intellectual disability are in research?
 - What bad things can happen when adults with intellectual disability are in research?
 - And how can we keep people safe when they are in research?

What did we learn?

- Everyone thought adults with intellectual disability should be part of research studies because:
 - they should have equal rights to take part
 - they have been left out in the past
 - we might learn things that help make their lives better



- Some people were less excited about adults with intellectual disability being in research studies that might hurt them.
- Everyone thought good things might come out of adults with intellectual disability being in research studies:
 - They might feel good about themselves, get to speak for themselves, meet new people, and learn new things
 - They might get to show what they can do
 - They might feel like they are being treated like everyone else
 - Researchers and other people in the community might get to learn from adults with intellectual disability
- A lot of people talked about adults with intellectual disability having a hard time trusting others because of past experiences.
- Adults with intellectual disability said that it can be hard to decide whether a research project is real or a scam. Some service providers, family members and friends also weren't sure whether all adults with intellectual disability could figure out whether a research project is real or a scam.
- Everyone said it would hurt adults with intellectual disability if they are treated as a disability or a label, rather than as a person, by people who do research.
- Everyone talked about how to keep adults with intellectual disability safe in research studies.
- Adults with intellectual disability said that people who do research should treat them with respect. People who do research can do this by:
 - being truthful
 - seeing adults with intellectual disability as capable adults
 - using respectful words
 - asking for permission
 - and talking directly to adults with intellectual disability
- Everyone said that providing accommodations such as plain language, pictures and videos, examples, opportunities for questions and answers, time to respond, and helping people feel comfortable, can help people not get hurt and feel safer.



Why does this matter?

- People in the community agree that adults with intellectual disability should be a part of research.
- It is important that people who do research listen to people in the community.



Who did the work?

Katherine (Katie) McDonald, Nicole Schwartz, Colleen Gibbons, and Robert (Rob) Olick

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Want to learn more?

Check out our paper:

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<http://www.ncbi.nlm.nih.gov/pubmed/25769310>

Contact us:

(315) 443-5981

ProjectEthics@syr.edu

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