

IS SAFETY IN THE EYE OF THE BEHOLDER? SAFEGUARDS IN RESEARCH WITH ADULTS WITH INTELLECTUAL DISABILITY

WHY DID WE DO THIS PROJECT?



- When we do scientific research, it is important to keep people who take part in the research safe.
- In the past, some people with an intellectual disability have been in research that was harmful, and that was not likely to help them. They also were sometimes not asked to make their own decision about being in the research study.
- It is important to remember that many people with an intellectual disability experience less control over their lives and have less experience making decisions.
- Since people with an intellectual disability have more rights and opportunities today, we need to look again at how to best keep people safe when they are in research.
- Not everyone agrees on how to keep people with an intellectual disability safe, and we rarely ask people with an intellectual disability what they think.
- It is important to balance protection and freedom of people with intellectual disability. To do this, we need to learn about how a lot of people feel about safety in research, especially adults with intellectual disability and people who provide them support.

WHAT DID WE DO?



We surveyed 512 people to learn about how to safely do research with adults with intellectual disability. Five groups of people took our survey:

- (1) Adults with an intellectual disability
- (2) Family members and close friends of adults with intellectual disability
- (3) Disability service providers
- (4) Researchers in the area of intellectual disability
- (5) Institutional Review Board (IRB) members (who make sure that people who take part in research are treated well)

We asked people who took the survey to rate (a) How safe each of 17 safeguards is for adults with an intellectual disability and (b) How likely adults with an intellectual disability would be to participate in research that had each of the 17 safeguards.

We developed the survey from other research and working with an Expert Panel. The Expert Panel included 7 people with an intellectual disability, and two members from each of the other 4 groups. We used graphic images, plain language and examples to improve accessibility of the survey.

WHAT DID WE LEARN?



Major Findings about Views on Safety

The 5 groups thought differently about some of the safeguards.

The groups disagreed most about the safety of different ways to recruit. Compared to other groups, adults with an intellectual disability thought it was safer to be recruited by service providers, researchers, people with disabilities, and someone they are comfortable with.

Service providers thought *researchers giving adults with intellectual disability time to think about whether or not to participate* was safer than family, friends, and IRB members thought it was.

Service providers also thought *adults with intellectual disability having the choice to have someone they are comfortable with at the study and researchers learning how to interact with adults with intellectual disability* were safer than IRB members thought.

In general, adults with an intellectual disability think *being directly involved in recruitment and making their own decisions* were the safest safeguards.

All 5 groups agreed that *researchers talking to others before the adult with intellectual disability* was less safe than most other safeguards.

Major Findings about Likelihood to Participate in Research

Adults with an intellectual disability were more likely to want to be in research when *researchers learn how to interact with adults with intellectual disability* or when they are *recruited by a service provider* than if they were recruited by a family member.

Adults with an intellectual disability were least likely to want to be in research if others are talked to before them.

WHAT DOES THIS MEAN?



Ways of recruiting people with intellectual disability in research should feel safe to adults with an intellectual disability.

People who do research should directly talk to adults with an intellectual disability about opportunities to be in research, but also work with those trusted by people with an intellectual disability like service providers.

People who do research should keep personal information private and know how to make sure that adults with an intellectual disability understand the research study so they can make a decision that is right for them.

People who do research and IRB members should learn how to respectfully work with adults with an intellectual disability, and how to work with people who provide support to adults with an intellectual disability in ways preferred by adults with an intellectual disability.

WANT TO LEARN MORE?

Check out our paper:

McDonald, K., Conroy, N. E., Olick, R. S., Kim, C. I., LoBraico, E. J., Prather, E. M., & Project ETHICS Expert Panel. (2016). Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability. *Journal of Empirical Research on Human Research Ethics*. doi: 10.1177/1556264616651182

Members of the Project ETHICS Expert Panel include Anna Carroll, Marty Cuddy, Micah Fialka-Feldman, Dan Flanigan, Pat Fratangelo, Lance Gonzalez, Michael Kennedy, Kathleen King, Chris Mansfield, Deb McGowan, Rachel Romer, Margaret Turk, Shquria Velez, Pamela Walker, and Priscilla Worrall.

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