

A QUANTITATIVE STUDY OF ATTITUDES TOWARD THE RESEARCH PARTICIPATION OF ADULTS WITH INTELLECTUAL DISABILITY: DO STAKEHOLDERS AGREE?

WHY DID WE DO THIS PROJECT?



- What people think about the research participation of adults with intellectual disability is important because those beliefs:
 - Inform research policy and practice.
 - Impact interest in and support for research participation.
- Research that includes adults with intellectual disability is important for understanding and promoting health.
- We do not know much about beliefs among community members and members of the scientific community about the research participation of adults with intellectual disability..

WHAT DID WE DO?

We surveyed 512 people to learn about what people think about the research participation of adults with an intellectual disability. Five groups of people took our survey:

- (1) Adults with intellectual disability
- (2) Close family members and friends of adults with intellectual disability
- (3) Disability social service providers
- (4) Researchers in the area of intellectual disability
- (5) Institutional Review Board (IRB) members



We asked them to rate (a) Their personal past research experiences, including how they feel about research in general and how much they trust researchers and (b) Their views on 6 different statements about the research participation of adults with intellectual disability.

We developed the survey from other research and working with an Expert Panel. We used graphic images, plain language and examples to improve accessibility of the survey.

WHAT DID WE LEARN?

Attitudes toward the Research Participation of Adults with Intellectual Disability



In general, all 5 groups held relatively positive views about the research participation of adults with intellectual disability, but there were important group differences.

Adults with intellectual disability were less likely to agree that *research about adults with an intellectual disability is very important* than service providers and researchers. Researchers indicated stronger agreement with this than family and friends and IRB members.

Adults with intellectual disability and IRB members were less likely to agree that *it is very important that adults with an intellectual disability take part in research studies* than were researchers.

Adults with intellectual disability were more likely to agree that *adults with an intellectual disability want to be in research studies* than all other groups. Researchers expressed stronger agreement with this item than IRB members.

Researchers were more likely to agree that *adults with intellectual disability **should be allowed to make up their own mind about being in research studies*** than family members, friends, and IRB members.

Adults with intellectual disability more strongly agreed that *adults with an intellectual disability **can make up their own mind*** than family members and friends and IRB members. IRB members less strongly agreed that *adults with an intellectual disability **can make up their own mind about being in research studies*** than service providers and researchers.

Adults with intellectual disability more strongly agreed that *adults with intellectual disability **need help from others to make up their mind about being in research studies*** than service providers.

Personal Characteristics and Comparisons of Experiences

Service providers involved in disability advocacy work more strongly believed that *adults with intellectual disability **can make up their own minds*** than other service providers.

IRB members involved in disability advocacy work more strongly *believed that it is very important that adults with an intellectual disability take part in research studies* and ***should be allowed to make up their own mind*** than IRB members who were not involved in disability advocacy work.

People that had a family member with an intellectual disability were more likely to believe that *adults with intellectual disability **need help making up their own minds about research participation*** than those who did not have a family member with intellectual disability.

Family members, friends, and disability service providers that supported adults with severe intellectual disability were significantly more likely to believe that *adults with an intellectual disability should be allowed to make up their own mind* than other family members, friends, and service providers.

For adults with intellectual disability, having a *positive view of research* in general and having *greater trust in researchers* were generally related to more positive attitudes about research with adults with intellectual disability.

Some participants also said that receiving help from others when making decisions about research participation should not mean that the adult with intellectual disability cannot or should not make up their own mind.

WHAT DOES THIS MEAN?

We found support for the importance of conducting research about adults with intellectual disability. But IRB members – and in some cases, adults with intellectual disability – seem to show somewhat less support than others.

However, safe and respectful inclusion of adults with intellectual disability in research is important for promoting health equity, and adults with intellectual disability expressed a strong interest in participating in research studies.

Efforts should be made to teach adults with intellectual disability, IRB members, and others about the potential benefits and importance of including adults with intellectual disability in research. We need to teach others about how to safely and respectfully include adults with intellectual disability in research.

Want to learn more? Check out our research article:

McDonald, K., Conroy, N. E., Olick, R. S., & Project ETHICS Expert Panel. (2018). A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree? *Disability and Health Journal*, *11*, 345-350. doi: <https://doi.org/10.1016/j.dhjo.2017.12.004>

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We received support for this research from the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health under Award Number R21HD075078. The content is solely ours and does not necessarily reflect the official views of the National Institutes of Health.

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