

IS IT WORTH IT? BENEFITS IN RESEARCH WITH ADULTS WITH INTELLECTUAL DISABILITY

WHY DID WE DO THIS PROJECT?



- Research studies can help us learn new things to make life better for people with an intellectual disability.
- Many good things can come from people with an intellectual disability being in research studies. Good things might happen for the person who is in the study. For example, people might learn something, get to do something new, or meet new people. They might also feel good from getting to do something for others.
- Good things might also happen for other people with an intellectual disability down the road.
- We need to learn what more people with an intellectual disability think about the good things about being in research studies, and learn how their ideas compare to others (such as their family members and friends, disability service providers, researchers, and IRB members)

WHAT DID WE DO?



We surveyed 512 people to learn about what good things might happen when we do research studies with adults with 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) How important or good 11 things are for adults with an intellectual disability and (b) How likely adults with an intellectual disability would be to be in research that had each of the 11 potentially good things.

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?



The Importance of Benefits

The 5 groups had different views about how important the 8 benefits to people with intellectual disability who are in research studies were. In general, adults with intellectual disability thought that these benefits were more important than other groups thought they were.

Adults with intellectual disability thought *feeling like you are helping others, learning new things, meeting people, doing something new, and receiving incentives* were more important than other groups thought.

Adults with intellectual disability thought *feeling valued or worthwhile, feeling in control and making own choices, and sharing thoughts and experiences* were less important than other groups thought.

The 5 groups also had different views about how important the 3 benefits to people with intellectual disability that might happen down the road were.

Adults with intellectual disability thought that *research improving the lives of adults with intellectual disability* was more important than family, friends, service providers, and IRB members thought it was. IRB members thought that *research improving the lives of adults with intellectual disability* was less important than all other groups thought it was.

Adults with intellectual disability thought that all types of benefits were important. The other groups generally thought that benefits down the road were more important than benefits to adults with intellectual disability who are in the research study.

Interest in Being in Research with each Benefit

Adults with intellectual disability were more likely to be interested in being in research where they *felt like they were helping others, could learn new things, meet people, do something new, and receive incentives* than other groups thought they would be.

WHAT DOES THIS MEAN?

Adults with an intellectual disability think that it is very important that good things happen when they are in research studies, and they are very interested in being in research when good things might happen.



Adults with an intellectual disability want to help other people by being in research studies.

Other groups may not understand how important being in research studies is to adults with an intellectual disability, or how good things can happen to them when they are in research studies.

People who do research studies should do research studies that lead to good things happening, and make sure to tell people the good things that might happen if they are in a research study.

People who do research studies and IRB members should learn about community views and consider those views when deciding how to do research studies.

Want to learn more? Check out our paper:

McDonald, K., Conroy, N. E., Olick, R. S., & Project ETHICS Expert Panel. (2016). Is it worth it? Benefits in research with adults with intellectual disability. *Intellectual and Developmental Disabilities, 54*, 440-453. doi: 10.1352/1934-9556-54.6.440

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