

## WHAT'S THE HARM?

### HARMS IN RESEARCH WITH ADULTS WITH INTELLECTUAL DISABILITY

#### WHY DID WE DO THIS PROJECT?



- Having adults with intellectual disability be in research studies may help us find ways to improve their lives, but:
  - They are often excluded from research studies because some people worry that they can't make their own decisions or handle certain research experiences.
  - They may have a hard time trusting others due to having had negative experiences being in research studies or having been treated disrespectfully.
- It is important to keep people safe and respect people's wish to control what happens to them.
- We need to figure out what can hurt adults with intellectual disability when they are in research, and try to keep them safe.
- To do this, we need to learn what adults with intellectual disability think might be harmful.

#### WHAT DID WE DO?



**We surveyed 512 people** to learn about what might be harmful when adults with an intellectual disability are in research studies. 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 harmful or bad 13 experiences might be 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 potentially harmful or bad 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?



### How Harmful is it ...?

In general, all 5 groups agreed that each experience was harmful, with one exception: Adults with intellectual disability thought that *the researcher reporting information to the authorities* was more harmful than the other groups thought it was.

All groups agreed about how harmful it is when *adults with intellectual disability feel worried about what they will have to do* as a participant.

Adults with an intellectual disability and service providers believed that exclusion from research studies because *someone decided not to tell the adult with intellectual disability about the research study* was more harmful than family members, friends, and IRB members thought it was.

Adults with intellectual disability also thought that most of the psychosocial harms, such as *feeling upset or others getting upset about participation*, were less harmful than all other groups thought they were.

### Interest in Being in Research with each Harm

Overall, adults with an intellectual disability showed greater interest in being in research studies than all other groups thought they would, except *when someone else makes the decision about research participation*.

In general, adults with an intellectual disability had more interest in being in research where they might *feel upset, feel worried about what they will have to do, or they do not share their thoughts and experiences because someone else is with*

them than in research where researchers share their personal information with others without their permission, they feel labeled as a disability and not a person or treated like a child, feel pressured to participate, and if someone else makes the decision about research participation.



## WHAT DOES THIS MEAN?

Researchers should directly talk to adults with an intellectual disability about opportunities to be in research studies and also work to gain their trust. Respecting adults with an intellectual disability is very important.

Adults with intellectual disability may want to decide for themselves to tell the authorities if someone is hurting them.

Researchers should make sure that adults with an intellectual disability are making the decision to be in a research study, and find ways to help adults with an intellectual disability understand research so they can make good decisions for themselves.

Research policy and practice should reflect what adults with an intellectual disability think, and keep in mind that adults with an intellectual disability seem to be ok that some bad things may happen when they are in research studies. We should teach others about this.

**Want to learn more?** Check out our paper:

McDonald, K., Conroy, N. E., Olick, R. S., & Project ETHICS Expert Panel. (2017). What's the harm? Harms in research with adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 122, 78-92. doi: 10.1352/1944-7558-122.1.78

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