

UCEDD Directors Meeting

February 17th, 2022 3-5pm ET

Breakout Room Notes

Breakout Room Title: Having People with IDD in Meaningful Roles of Research Projects

Facilitator: Ilka Riddle

Notetaker: Aryana Jones

- What practices or strategies have you found successful for including individuals with disabilities in the research process with the goal of them serving as collaborators and co-investigators?
- What challenges or barriers have directors faced to work towards this goal?
- What types of support have been given and how have UCEDDs navigated university requirements?

Notes:

- What new research projects can we do at the UCEDD? Less chart data.
- Researchers want consent forms to be at too high of a reading level and makes the research inaccessible.
- Successful practice: offering the researchers to create our own templates in an accessible format at a lower reading level.
- Clear language summaries have been found to be useful to a lot of people even without disabilities
- Putting a focus on young researchers in a “disability research lab”
- How do we help the hospital understand the value of having researchers with less experience or different experience because of their disability?
- Reconciling the past to change the future of research
- Not just about plain language but having meaningful engagement with people with lived experiences
- Telehealth can be a benefit to increasing meaningful engagement
- You can have roles in research other than being a “subject”
- Research ethics training is often not accessible
- Can electric consent forms be more accessible?
- <https://centerforstartservices.org/Truth-and-Reconciliation-Project>



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- What can be done at the federal level to support inclusive research?
- Federal grants should require “clear or plain language” so the UCEDDS have better leverage when talking to researchers
- Requiring better tracking of disability status and race and ethnicity.
- Disability identity needs to be more at the forefront.
- Table 1 in every research paper should include a disability demo section
- Are UCEDDs educating their members on IRB (professional development)
- We need more training on how to get people with disabilities to participate in research studies
- We are very much at the beginning of breaking down the barriers that keep people with disabilities away from the research process
- One new person on an IRB can implode all previous good work that had been done
- It’s hard to participate in research as researchers and training on this would improve the process for everyone at all levels.
- Losing some of the jargon will encourage people with disabilities to participate
- Offering more focus groups
- Engaging the community to explain what is research
- Researchers can benefit from not having a narrow lens
- Representation at all levels will encourage people to participate. People want to see others who like them in the research process
- Non-traditional spaces to learn about the research process will bring more diversity
- Focus on young advocates with disabilities
- What supports are needed to have people with disabilities in the research process
- Group informed consent: breaking down what consent means to the entire group in an engaging format has been found to be enjoyable and helpful. Allows higher-level language to be more easily absorbed
- CITI training with IRB is inaccessible
- IRB should be group informed to allow participants a chance to ask questions and help others. Allows facilitator to translate in plain language in real time to the entire group.



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