## CONDUCTING INTERVIEWS WITH INDIVIDUALS LIVING WITH INTELLECTUAL DISABILITIES

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This check sheet explains why it is important to make research inclusive of those with an intellectual disability (ID) and reviews a number of considerations to keep in mind when conducting interviews with this population. The check sheet also provides suggestions and a guideline tool on how to ascertain whether participants with intellectual disabilities or related challenges have the capacity to consent to participate in research.

» **What is an intellectual disability?**

The American Association of Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, n.d.).

Limitations often present in the early years of life, and may lead to both intellectual (i.e., mental capacity, learning, problem solving) and adaptive (i.e., language, literacy, number concepts, interpersonal skills, self-esteem, occupational skills and daily living) difficulties. There are variations in scope and severity for those with intellectual disability.

The guidance below provides support to researchers who plan to engage participants that may have an intellectual disability or related challenges.

» **Why is it important to make research inclusive of those with intellectual disabilities?**

Studies on the prevalence of intellectual disability vary. A meta-analysis study by Maulik et al. (2011) considered the prevalence of intellectual disability. Specifically, they reviewed studies from 1980-2009, considered adults and youth, and translated studies in other languages. Their analysis indicated that the prevalence of intellectual disability is 10.37 out of 1,000 (Maulik et al., 2001). This equates to approximately 1% of the population that may have an intellectual disability. The highest prevalence was seen in low and middle income countries, where the rates were almost twice that in high income countries. Although a relatively low percentage of the population, this meta-analysis suggests there are tens of millions of people worldwide who have an intellectual disability.

The UN Convention on the Rights of Persons with Disabilities affirms "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices" and "Full and effective participation and inclusion in society" among its guiding principles (UN DESA, n.d.). From this rights framework, it is essential to engage people living with intellectual disabilities to better appreciate the range of their lived experiences. Indeed, persons with intellectual disability may have particular vulnerabilities or capacities that make them more or less resilient to a range of stressors.

During disasters or other large-scale emergencies it is important to consider how those with disabilities are affected. Horton and Paulus (2020) conducted a rapid study of the effect that the COVID-19 pandemic had on adults with disabilities, including those with intellectual disability. They conducted virtual interviews with participants living in the United States and Canada and utilized the guidance from this resource.

» **How is research involving people living with intellectual disability different?**

Engaging those with an intellectual disability for regular or rapid response research interviews may require additional tact and consideration, especially given that a number of barriers may exist. This includes appreciating differences in expectations and language use; difficulties with abstract thinking and recall; inclination to give socially desired answers; and insufficiency of written information (Frankena et al., 2015).

Some good practices for interviewing those with an intellectual disability include using visual images to show concepts or objects (sometimes called "talking mats"); focusing on concrete experiences; taking a dialogue approach; reading out loud if required; using accessible language with illustrations; and developing specific communication strategies with the person with ID (Frankena et al., 2015).

» **Important considerations when interviewing individuals with intellectual disabilities:**

Researchers interviewing those with an intellectual disability should consider the dynamics for making it a positive experience including:

1. Consider accommodation requirements at every stage of the research study. This includes ensuring the written material (e.g., study overview) and correspondence (e.g., emails) are written simply and clearly.

2. Engage the participant well before the interview to ensure they are prepared for and reminded about the upcoming interview.

3. Consider perceived power differences between the researcher and participant and encourage relationship building in advance and during the interview.

4. Ask the participant if there is anything you can do to enhance their participation.

5. Understand that capacity to provide consent diminishes over time for some. For instance, an individual who was previously able to give informed consent may lose the capacity to do so, and the researcher cannot simply assume that previous consent remains valid in such a case. Therefore, it is important to confirm consent both before and during the study and with each subsequent follow-up interview.

6. Seek consent from a legally authorized representative for those unable to provide informed consent, while being mindful of the ethical issues involved (Oruche, 2009).

7. Be patient and flexible when interacting with participants with cognitive and related disorders. This includes slowing down to a pace where the participant can better follow along, and potentially conducting two or more shorter interviews rather than one lengthy one.

8. Take pauses to ask a participant with an intellectual disability to demonstrate their understanding of questions and to affirm comprehension of participant responses.

» **A practical tool for ascertaining capacity to provide consent**

The Evaluation to Sign Consent (ESC) Tool is a reliable and valid tool that can be used to ascertain capacity to provide consent for individuals with possible cognitive challenges (Resnick et al., 2007). This brief tool consists of five items and takes less time to complete than other suggested tools. See Resnick et al. (2007) for the questions, acceptable answers, and instructions to administer the questionnaire. The questions in this tool are appropriate for an intervention where the person is being asked to do something—such as a physical task—and can also be applied to responding to an interview.

Horton and Paulus (2020) conducted rapid qualitative interviews online with people with an intellectual disability and adapted the ESC tool for this purpose. The following script was used, which may assist other researchers conducting similar rapid research, including interviews with those who have an intellectual disability or other related cognitive challenges:

*"I'd like to be sure you are comfortable with the procedures of the interview. (Briefly review the information form, which was also emailed to participants in advance of the interview.) I would now like to ask you four questions before we begin:*

*Q1. What are the potential risks of participating in this study?*

Appropriate answers are becoming upset; no risk.

*Q2. What is expected from you in this study?*

Appropriate answers are answering questions (about your experience and feelings).

*Q3. What if you don't want to continue?*

Appropriate answer is asking to stop.

*Q4. What if you don't feel comfortable?*

Appropriate answers include to say something, ask to stop.

Participants who provide appropriate responses to these four questions have demonstrated understanding and capacity to consent, and the research can then progress. With that said, and as noted above, it is important to regularly check in and to ensure re-consent during the research process.

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