

Attachment 2: History and development of the interview topic guide

The topic guide for the in-depth, exploratory ethnographic interviews was designed by the project principal investigators to address the research aims for this specific project: identify any functional difficulties or barriers to participation in day-to-day activities that participants experience, associated with ID/DD, that are outside the domains covered by standard disability question sets, such as the Washington Group Short Set of questions. The findings from these ethnographic interviews will then contribute to the future design of a set of functional disability questions that may be used to identify adults with a disability, including adults with ID/DD. When designing the topic guide, the principal investigators drew upon findings and lessons learned from a prior question evaluation project of functional difficulty questions for adults with ID/DD conducted on behalf of the Association for Community Living. Data collection on that prior project took place from 2019-2022¹.

Each section of the topic guide touches on aspects of a respondent's life with the goal of eliciting a rich, descriptive narrative of that person's day-to-day functioning and where they may have limitations, barriers, or difficulties. The ethnographic interviews are designed to be respondent-driven. While the topic guide serves as an aide for the interviews, it is not a structured list of questions. Rather, aspects of daily life that the respondents themselves find important will dictate the flow of the discussion.

¹ Validity Study of IDD Questions: Rounds 1 & 2 (OMB No. 0920-0222, Exp. Date 01/31/2026)