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In-depth interviews exploring everyday functional difficulties among adults with intellectual and developmental disabilities to inform questionnaire design

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INTRODUCTION

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This report summarizes findings from a qualitative in-depth interview study with adults with intellectual and developmental disabilities (IDD) to provide foundational information for the design of supplemental functional disability indicators in clinical, point-of-care settings. The study was conducted by the National Center for Health Statistics' (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) using in-depth interviewing methodology. It was carried out as part of a larger project, "Engaging People with Intellectual and Developmental Disabilities to Enhance Functional Disability Representation in Point of Care Settings," funded by the Department of Health and Human Services Patient-Centered Outcomes Research Trust Fund and co-led by CDC's National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability (NCBDDD) and National Center for Health Statistics, Division of Analysis and Epidemiology. This study received both Office of Management and Budget and NCHS/CDC Human Subjects approval.

In this study, people with IDD refers to the combined populations of people who have either intellectual disability (ID) (1, 2) and/or developmental disability (DD), as defined by the DD Act (3). Respondents were self-selected according to their perceived or self-assessed disability status. Clinical, medical, or legal assessments were not obtained.

Qualitative in-depth interviews were used to help gain a greater understanding of the life circumstances and experiences of people with IDD to inform and enhance standard sets of functional disability indicators to be administered in point-of-care settings. A "point-of-care" setting refers to a place where medical care is received and where people with disabilities may present for services or supports, e.g., medical clinics or education programs.

The intent of the study was to provide information useful for the design of indicators, supplemental to the standard set of questions, to improve the representation of people with disabilities in healthcare and service data, including people with IDD. As such, it is important that people with IDD, and their support community, are directly included in the research, to ensure that the indicators developed are reflective of their experiences.

This report includes a description of the methodology followed by findings. The findings section includes a description of factors that affect how respondents perceive their difficulties, a description of how respondents framed the discussions about their difficulties, and finally, specific topic areas, or domains, that respondents found important to them when describing their day-to-day difficulties.

BACKGROUND

Consistent representation in healthcare and service data is necessary for improving services and outcomes for people with IDD. To fulfil this objective, questions that include people with IDD in disability measures are needed at point-of-care settings. Functional disability status was recently added as a United States Core Data for Interoperability (USCDI) v3 data element based on the current Department of Health and Human Services standard for identifying disability status in federal surveys (4). This standard includes the seven functional disability domains as included by the combined American Community Survey (ACS) and the Washington Group Short Set on Functioning (WG-SS) (5, 6): vision, hearing, cognition, mobility, self-care, communication, and independent living. However, there may be additional domains, or question topic areas, that specifically address any difficulties experienced by adults with IDD. Furthermore, the standard disability questions were designed for use in household surveys and have not been adapted for use in clinical settings.

To explore how respondents with IDD understand and perceive their difficulties and, further, what other constructs may need to be added to standard disability question sets as key indicators of IDD in point-of-care settings, a series of one-on-one unstructured, ethnographic interviews were conducted with participants with IDD and their close contacts from across the United States. The importance of including those with a disability directly in any research about them is well documented in the literature (7, 8). This applies equally to those with IDD, who may present with a wide variety of health conditions and impairments (9, 10).

METHODOLOGY

This study identified salient domains of functional difficulties experienced in the day-to-day life of adults with IDD using in-depth, or ethnographic, interviews. An in-depth interview can be considered as a form of guided conversation, with the interviewer using a “topic guide” (see Appendix 1) to set out the key topics and issues to be covered but letting the conversation progress in an unstructured manner (11). The aim was for the interviewer to guide, but not lead, the conversation, and explore, in-depth, factors that are most salient to the participant, within the context of their own life experiences. The interviewer kept the conversation focused on the topic of interest, but the participant defined the content of the discussion.

The outcomes of the in-depth interviews were detailed narratives, including stories of the respondents’ lives. These did not represent entire life stories, but rather key “biographical fragments” of each person’s story were recounted to better understand the “lives of people who often have exceptional difficulty getting heard” (12, p. 215).

Sample

Between June 2024 and January 2025, researchers from CCQDER interviewed a total of 31 adult participants (age 18 and older): 20 adults with IDD and 11 close personal contacts, all of whom were either

the birth or adoptive mothers of participants with IDD, to form 11 dyad pairs and 9 non-paired respondents with IDD.

A purposive sample of participants was selected for interview. With a purposive, non-random sample, the characteristics of the individual are used as the basis for sample selection. Adults with IDD and, where appropriate, a close personal contact, were recruited mainly through disability organizations, such as Special Olympics, that support people with IDD, including people with a diagnosis of ID, autism spectrum disorder, and cerebral palsy. Disability organizations agreed to send the study advertisement to their members, such that recruitment efforts were targeted to the population of interest. The inclusion of people with these diagnoses, or a combination of diagnoses, in the sample helped to ensure that a range of conditions associated with IDD were covered by the research. Additionally, a few participants were recruited from advertisements placed in Craigslist and CCQDER's respondent database, as well as through word-of-mouth. A particular effort was made to include some participants in the sample of people interviewed who used Alternative and Augmentative Communication (AAC) supports, such as using an electronic typed text to speech device or using a letterboard in conjunction with a communication partner.

Screening and Scheduling

CCQDER reached out to people who expressed an interest in taking part and administered a set of screening questions. Effort was made to draw a purposive sample that included participants with a range of basic demographic characteristics, such as age, sex, and race and ethnicity. Additionally, to ensure the sample included respondents with a range of support needs, initial support needs questions were administered during screening. Potential respondents or their close contacts answered "None," "Some," or "A lot," to two support needs questions: "How much help do you need to do daily tasks like washing all over, dressing, and cooking food?" and "How much help do you need to do daily activities like making appointments, using money, or shopping?" Potential close contacts were asked the same questions but answered about the person under their care rather than themselves. The recruiter used these responses to indicate an initial estimate of low, medium, or high support needs for each potential respondent before scheduled interviews. For respondents and close contacts who completed interviews, the interviewer then conducted a post-interview, follow-up support needs assessment (see Appendix 2)

Whether or not a selected participant used any special communication aids or hearing aids was ascertained during the scheduling procedures. Close personal contacts of participants with IDD, were also invited to participate in their own interview as one half of a participating dyad. Both members of each dyad were interviewed separately.

Care was taken to recruit a sample with a range of demographic and geographic characteristics, to the extent possible. The sample included participants from several geographically-dispersed states, including rural, suburban, and urban areas. The table below shows the overall achieved sample distribution by key characteristics.

Table 1: Sample characteristics

Demographics	Self-report (n=20)	Close contact (n=11)	Total (n=31)
Age-group in years			
18-29	11	0	11
30-49	8	2	10
50-64	0	5	5
65 or over	1	4	5
Sex			
Female	11	11	22
Male	9	0	9
Race/Ethnicity			
Non-Hispanic			
Asian	1	0	1
Black or African American	4	1	5
White	14	10	24
Multiple race groups	1	0	1
Hispanic	0	0	0
Support Level			
Low	7	NA	7
Medium	6	NA	6
High	7	NA	7

Notes: NA = Not Applicable. The final support needs assessment was completed by the interviewer following each interview, based on the level of support respondents received with daily life activities (13, 14). The table used to aid this post-hoc support needs estimation is included as Appendix 2.

Source: National Center for Health Statistics, Collaborating Center for Questionnaire Design and Evaluation Research, 2025.

Self-Report of Disability

The sample included participants with IDD who identified in the interviews as having a range of conditions associated with their IDD, including intellectual disability, autism spectrum disorder, cerebral palsy, fetal alcohol spectrum disorder, Down syndrome, epilepsy, apraxia, speech impediments, and blindness. Also, some respondents said they had a *"learning disability"* or that they were a *"special needs"* person. Some respondents who were aware of their IDD and medical diagnoses did not necessarily consider themselves to have a disability, per se, due to their positive outlook about their capabilities and independence. Notably, the sample included people who participated in the Special Olympics, a supportive organization which provides people with ID the opportunity to participate in athletic and social activities on a year-round basis.

In addition to IDD and related conditions, some respondents said they had co-occurring mental health conditions, such as bipolar disorder, anxiety, or schizophrenia, that contributed to their day-to-day difficulties. As one respondent explained, his ID, mental health condition, and communication difficulties

affected him in an interrelated way. He said, *"And, with that communication comes barriers and with barriers comes mental health and all that goes hand in hand."*

Alternative and Augmentative Communication (AAC)

To interview respondents who were reflective of the range of adults with IDD, people who had speech-related difficulties were purposely included. Respondents with speech difficulties, such that it impacted their ability to use their speech alone for their interviews, used different types of AAC supports, including AAC electronic devices, a letterboard in conjunction with a communication partner, and 'revoicing' with a communication partner (a technique in which the partner repeats the words spoken in a more clear and understandable way for an unfamiliar listener). Of the achieved sample of respondents with IDD, four used AAC supports, two of whom were part of dyad pairs.

Informed Consent

The interviews were conducted remotely via Zoom for Government. Each interview lasted up to 75 minutes to allow time for those who needed it the opportunity to fully express themselves. Each participant was paid $50 renumeration for taking part. All interviews were video recorded and transcribed using automatic transcription function in Zoom. Informed consent was obtained prior to the start of the interview.

At the beginning of each interview, before recording began, recruiters met respondents on the scheduled Zoom appointment. The recruiter made sure that the software was working properly, with clear video and audio, and that the respondent was ready for the interview. The recruiter than briefed respondents on the purpose of the study and the procedures that CCQDER routinely takes to protect human subjects, reviewing the consent form that was previously emailed to the respondent and reminding them of the renumeration procedure. In cases of lower literacy, the recruiter read the consent form out loud to the respondent, explaining each section.

If there was any indication of impaired consent capacity during the consent or interview process, staff were instructed to administer a formal assessment in the form of scripted and targeted questions adapted from published instruments measuring consent capacity (Question 1 to Question 4 below) (15, 16). Two additional questions were added by the CCCQDER team to provide respondents the opportunity to practice what they would actually say if they did not want to answer a question and also to check to ensure the respondent was not pressured to participate from another person. Where any doubt existed about the appropriateness of a response to any of the consent capacity assessment questions, staff were instructed to err on the side of caution and terminate the study session. For this study, the consent capacity questions were administered a few times during the consent process, and in those cases, respondents were able to affirm their understanding of their expectations and rights. No interviews ended early due to lack of consent.
Q1. Please tell me, in your own words, what you will be asked to do if you take part in this study?
Q2. When I say your taking part is completely voluntary, what does that mean to you?
Q3. Do you have to answer all of the questions in this study?
Q4. What can you do if you start the study but don't want to finish it?
Q5. What will you tell me if you don't want to answer a question?
Q6. If your [aide/caregiver/Legally Authorized Representative] wants you to take part, but you do not want to, are you still allowed to refuse?

Data Collection

In-depth interviews were respondent driven, in that interviewers focused on topics within the purview of the research focus that were most salient to each respondent. Interviewers first opened conversations with

respondents by asking them to introduce themselves and, in many cases, asked them about activities they enjoyed doing or social groups with which they participated. In that way, respondents and interviewers were able to start the conversations on a positive footing, before moving the conversation towards difficulties and barriers in their day-to-day lives. In cases where respondents were less expansive in their discussion or if they had expressive language difficulties as part of their IDD, interviewers utilized the topic guide to help discover topics the respondent was more interested in or comfortable discussing. Interviewers aimed to elicit narratives about day-to-day activities the respondent had difficulty performing, how much difficulty they had and why, any barriers to participation in their daily life, how much support they received or needed, and how they communicated. The topic guide utilized for interviews is included as Appendix 1.

In the case of close contact interviews, participants were asked to report about the person with IDD who they supported from their own experience and perspective. Interviewers opened the conversation with the general question "Tell me about [the respondent]," as means of an introduction and to get a sense of the close contact-respondent relationship. The focus of the close contact interviews was to gather contextual background information and detail to further inform their paired respondent interviews.

Data analysis and Reporting

A thematic framework was constructed and used to classify and organize data according to key themes, concepts and emergent categories (17, 18). Analysts first refamiliarized themselves with the qualitative data collected by examining the transcripts and video recordings of the interviews. They then developed a thematic framework by looking for main themes that ran across the data, as well as subthemes within those main themes. Analysts summarized and synthesized the data and charted the data within the framework created. Q-Notes software was used to help manage the data (19) and Excel was used to house the summary reports which were then examined across themes and sub-themes.

Self-reporting participants are referred to as "respondents" whereas "close contacts" refers to paired close personal contact participants. Where this report refers to verbatim statements, the accounts are italicized.

RESULTS

The findings of this study are presented below in three sections: 1) contextual factors that have implications for respondents' perception of their difficulties, 2) respondents' framing of their functional difficulties, and 3) salient difficulties in respondents' day-to-day lives that emerged across the interviews that were not already captured by the standard disability sets.

Contextual Factors

This section describes key contextual factors that could affect how respondents consider and answer questions about functional difficulties. These include perceptions and attitudes, both by respondents and also by others, as well as the role of technology in reducing the perceived difficulty of certain tasks and the burden on caregivers.

Self-Direction and Independence

Respondents and close contacts considered terms associated with self-direction and independence in inconsistent ways, which has implications for potential question design. For respondents, being "independent" did not necessarily refer to the capacity to do activities alone, without assistance. Respondents considered

themselves to be independent when they were able to participate fully in society the way they wanted to, when they had the agency and autonomy to direct the course of their lives, and when they were able to make important decisions about their daily and long-term plans.

Some respondents also used the phrase *"self-directed"* to refer to having control over the types of support they receive and who provides that support. Receiving the necessary support and help to do certain tasks did not diminish their independence, but rather, it promoted their autonomy. For example, one respondent who lived in her parents' house and did not go outside her home without a support person said, *"I do have a sports coordinator and she's always with me when I go shopping* […] *she takes me out in public and we do stuff."* In describing her shopping needs she said, *"I do my own shopping because I have my own fridge…I have it up here, so I barely see my parents, because I have my own things.* […] *I'm very independent* […] *I do have a lot of confidence too."* Likewise, a respondent with cerebral palsy who needed high levels of support said, *"I have always been the type where my disability doesn't hold me back. I live independently, I have an able-bodied fiancé, I have been skydiving. So, there isn't much I don't do."*

Close contacts, by contrast, spoke more often about "independence" as referring to respondents doing things without their hands-on support, even if they had set up prior support structures for respondents, such as shared Google calendars to remind them of appointments, or auto pay for their bills. Like the term *"independent,"* the phrase *"living independently"* was used inconsistently across respondents and close contacts. Sometimes this referred to respondents living separately from their parents, though not always, and it could even refer to living without any disability supports. For example, one close contact referred to *"living independently"* to mean living truly alone. When talking about seeking a separate apartment for her daughter, she explained, *"I've talked to some people […] their adult child lives in an apartment. And there isn't that kind of supervision. That's just more independent living. I'm looking for something that's supervised."*

Finally, for some respondents and close contacts, disability awareness, advocacy, and receipt of the appropriate accommodations all supported respondent independence. One close contact talked about an advocacy program that her daughter had completed in the following way: *"they taught them all about advocating for themselves about independence, and you know it really made her grow as an individual."*

Attitudes of Others

Respondents and their close contacts often discussed the stigma they faced as people with disabilities. Additionally, they encountered assumptions about their capabilities, lack of empathy, and overall negative attitudes of other people that impacted their day-to-day lives and perceived levels of functional difficulty. As one respondent explained, *"My primary difficulty is when people, when people assume that I'm not capable* […] *I think we as a people should presume that people are confident and capable because, for the most part, they are."*

The negative attitudes of others emerged most often during interviews were when respondents and close contacts were speaking about trying to find work and getting medical care. Understanding the disability stigma respondents with IDD experience in professional settings is important for the purposes of this study, because the aim is to inform the design of questions to be administered at medical point-of-care settings. The social context within which respondents answer survey questions affects the response process (20).

Barriers to Employment: Having meaningful work was something many respondents and close contacts discussed. While many respondents did some paid or volunteer work, some of those who were looking for work talked about the difficulties of finding work with a disability. One respondent, who said his primary concern was finding a job, said, "*When people who have a disability want to find a job, like when you're trying to get paid or stuff, you have to be more confident* […] *or you need to* [have] *more practice of finding a job."* Another respondent said that she would love to work more hours than she does, but it is difficult to get hired

at a job that meets her needs: *"I don't have a wheelchair accessible vehicle, so I can't exactly go into the office. And then, for remote jobs people just don't hire me, frankly, because I'm disabled."*

Several respondents and close contacts spoke about the importance of having formal accommodations established and a good job coach, someone who understands the specific needs of the person with IDD, who can advocate for their accommodations, and who can interface with the employer directly. Several respondents had difficulties at their job due to different personalities and policies between managers. For example, one respondent, who was in the process of interviewing new job coaches, had been fired from a prior job when a new manager came onboard. The respondent had no legal recourse, because his accommodations had never been put into writing. During her close contact interview, his mother explained, *"The first manager did it just in the spirit of being a good person, right? We never had anything in writing that said they were accommodating him."* Similarly, another respondent had to find a new job when her fast-food employer did not provide accommodations consistently between managers. During her close contact interview, the respondent's mother explained that one manager was *"really great,"* but the other manager told her daughter, *"I really don't care if you have Down's Syndrome"* and refused to provide her accommodations, such as offering help when she was carrying heavy tubs of food.

Medical Neglect: Some respondents and close contacts discussed difficulties at medical appointments that were not related to confusion or access, but rather, to something one respondent referred to as *"medical neglect."* He said, *"they're treating me with less care than you would get as a person who can see or a person who is able-bodied."*

Some respondents and close contacts felt that health professionals lacked fundamental training and understanding about adults with disabilities. One respondent said that people in the medical field were afraid of what they did not know. She explained, *"A lot of the medical field hasn't kept up with the fact that people with disabilities are living longer, and they don't have the knowledge and experience."* In addition to those concerns, a close contact, whose interview focused primarily on her frustrations with health professionals, said that doctors treated her daughter like an overreacting child. She said, *"That's what's so frustrating about health care, is that they don't believe their pain is real."*

A few respondents who utilized AAC supports to communicate, and who did not have intellectual difficulties, further discussed their difficulties communicating with health professionals, in particular. One respondent said, "*Doctors have always been a struggle for me because, like most people, they think I have a cognitive impairment, because I have a speech impediment."* Likewise, another respondent who used a letterboard and communication partner as his AAC support said that going to the doctor was like, *"a very hard exam that you can't study for"* and that the doctors don't know what to do with him.

The Role of Technology

Technological supports and aids, including smart phones, reading applications, shared calendars, and associated artificial intelligence (AI) assistants, like Apple's Siri, were important, diverse tools utilized by some respondents to reduce the perceived severity of their functional difficulties. One close contact described the importance of smart phones to her son's daily life in the following way:
Honestly, I mean, if we lived 40 years ago, 35 years ago, he would be living at home in my basement, right? The reason he can be so successful is because of being able to watch the bus on his phone and being able to read a sign with his phone, and, you know, and me be able to track it where he is because of his phone. That kind of stuff.

Respondents who had low support needs, as well as some respondents with medium support needs, utilized their phones' speech to text capabilities for texting and emailing – both for sending messages and for reading received messages and emails. They also used AI assistants for a wide variety of purposes, including entering

events into their calendars, entering and receiving reminders, and saving their work calendars. One respondent also utilized *"tone analysis"* on his phone to help improve the readability of his texts and emails. These technological benefits lessened the difficulties and barriers they may have had due to their limited reading and writing skills, social skills, or memory capabilities. Additionally, they enabled respondents to have more autonomy in their day-to-day lives, lessening the amount of "hands on" support their family or care professionals needed to provide. For example, one respondent who could not read used the application "Speechify" to help him read the signs at bus stops, enabling him to use the public bus system to travel to new places without hands-on assistance from his family or support staff.

Technological supports and aids were not a widespread panacea for respondents' difficulties, however, particularly for situations involving spontaneous decision-making. For instance, when asked about "money management," respondents and close contacts considered a wide range of tasks and skills, depending on what was most salient to them, including the following: counting change, paying bills, and making financial decisions – both long- and short-term. Some, but not all, aspects of this varied set of tasks and skills could be supported through technology and automated systems. For example, some respondents and their close contacts talked about having set up bills with automatic payment schedules. Close contacts set up the initial payment system, and then respondents did not need to carry out that task themselves.

However, other aspects of money management, especially handling cash, making change, and making sound spending or saving decisions, were not things that respondents and close contacts could easily mitigate through automated systems or AI assistants. And, indeed, those tasks were commonly discussed difficulties that affected respondents' ability to perform certain jobs and go shopping without assistance or advice. For example, some close contacts spoke about the respondent's difficulties with impulse control. One close contact explained, *"If she's in like a spending environment, and she sees someone buy something, she wants to buy something too."* Similarly, another close contact said, *"She doesn't have access* [to her money] *because she doesn't have any impulse control. Plus, she would give anybody her money. That's back to that judgment issue."* Others, who did not have impulse control difficulties, still had a hard time understanding physical money and handling cash – in part due to the abstract association of bills and coins to monetary value and the overarching math skills required to handle cash. Some respondents spoke about their difficulties understanding cash and change as a barrier to employment or even as a barrier to moving to a different position at their work. One respondent, who worked at a grocery store explained why they could not fill the role of a cashier by saying, *"For the difficulties and my day-to-day life - like knowing change – counting change."*

Question designers targeting functional difficulties will need to be cognizant of the nuanced benefits of technological supports to daily life, some of which may reduce the perceived severity of difficulties respondents experience and the burden on caregivers to assist in certain tasks.

Framing of Difficulties

This section describes the way in which respondents talked about their day-to-day difficulties. The receipt of support, in the form of personal assistance, was something that all respondents across levels of support needs were willing and able to discuss to some degree. Respondents spoke about having *"help"* or needing help with a wide variety of tasks and activities, depending on their unique set of needs, even in cases where respondents did not use the word *"difficulty."* In that way, the "Receipt of Support" was a framework through which interviewers were able to discuss and understand the difficulties in respondent's day-to-day lives. For example, when talking about her difficulty using certain kitchen appliances and cooking from a recipe, one respondent said, *"I need help on some things. Things like if you just give me a paper tell me to make some food. I [...] need to know the ingredients, and how to make it, otherwise I don't know."*

Discussions about respondents' receipt of support were particularly important because some respondents,

especially people with positive outlooks on their lives who viewed themselves as independent, were focused on discussing their capabilities during the interviews. They did not speak about their difficulties or did not feel they had any difficulties in their day-to-day lives considering the help they received. For these respondents, living *"independently"* or doing a task *"without difficulty"* did not necessarily mean that they did those things alone, without help. Rather, it meant that they had the support they needed to have agency and feel empowered in their day-to-day lives.

Using the question phrases *"does somebody help you"* or *"do you need help,"* interviewers were able to discuss and understand whether respondents received or needed support to fully complete a wide variety of tasks. This was the case even for respondents who were focused on discussing their capabilities and achievements and those who reported having no difficulties with those same tasks with which they received help. These question phrases about *"help"* operated well, in that they were widely and consistently understandable, across both respondents and their close contacts. Questions about receipt or need of support would perform best if written in direct, literal, and specific language, as that is how respondents spoke about the help they received.

The following section describes receipt of support for respondents across support levels and needs as well as the two specific areas of communication support and support during medical appointments.

Receipt of Support

Across all levels of support needs, respondents were able to speak about receiving help with day-to-day activities, including whether they already received help or needed additional help, who helped them, and with what tasks they received or needed that help. The types of people who regularly helped respondents included family members, such as parents, siblings, children, spouses, and fiancés, and non-family support professionals as well. Support professionals were referred to by respondents and their close contacts in a variety of ways: aides, staff, personal care assistants (PCAs), counselors, direct support people (DSPs), job coaches, sports coordinators, and friends. In some cases, respondents' family members also filled the role of their paid support staff through certain Medicaid waiver programs.

Respondents with low support needs received help from family members and support professionals with routine tasks such as providing their transportation to and from work, including directly driving or setting up rides, setting up their schedules, making appointments, accompanying respondents to doctor's visits, helping with paperwork, liaising with job supervisors, and providing housing, either temporarily or long-term. This help that family and support professionals provided gave respondents the necessary structure for them to go about the routine of their day with relatively little additional hands-on assistance. For example, one respondent who lived in his own apartment and was able to drive himself to work, spoke about how his family helps *"sometimes"* with paperwork and forms, accompanying him at the doctor's office, or helping him buy groceries when he was low on money. He said, *"I mostly live on my own, but I need help with some issues with Section 8 housing."*

In addition to the support described above for those with low support needs, respondents who had medium support needs also received regular support with things such as money management, spending decisions, and advocacy and support in medical settings. For example, one respondent said that she always calls her mom before buying anything, to both make sure she can afford to buy the thing and also to check if it is a good decision to buy that thing.

Respondents with high support needs often needed help with the tasks described above plus, in some cases, they also required help with tasks of daily living, such as eating and going to the bathroom. Others needed help with most aspects of judgement and decision-making, including picking out weather-appropriate clothes and making safe decisions online and in the community. In those cases, the help respondents received was more frequent than people with low and medium support needs. For example, one close contact said that she

extensively supported her daughter through verbal cues and reminders, through setting boundaries and routines, and by driving her anywhere she needed to go. She explained that most areas of life she has some supervision. *"But, but for the most part, she'll get herself …I've already laid out pajamas, she gets them on. So, I mean, yeah, there's not much that she does without reminders."*

When their support needs were met, respondents often described themselves as being *"independent," "self-directed,"* or as having no difficulties in their day-to-day life, irrespective of how high their support needs were. As one respondent, who was living with her parents and had medium support needs, explained, *"I do my own shopping, because I have my own fridge…I have it up here, so I barely see my parents, because I have my own things* […] *I'm very independent."* Indeed, some respondents and their close contacts specified that having help and supports reliably in place allowed respondents to have fewer difficulties and more independence. For example, one respondent with high support needs, who needed help from her care assistants for a variety of activities, including eating and going to the bathroom, said, *"my main difficulties arise when my personal care assistants don't show up."* She described her independence in the following way: *"I have always been the type where my disability doesn't hold me back. I live independently, I have an able-bodied fiancé, I have been skydiving. So there isn't much I don't do."* Furthermore, one close contact said the following about putting in place the structure and skills for her son to live independently:
I don't expect to live forever. So, I try to get him as independent as possible, and then, you know, if I'm not here to do it or my husband is not here to do it, then you know just it's gonna make it easier for somebody else to step in and say, you know, he just needs oversight with this or that. So…and it works out. It works out."

Likewise, another close contact remarked how independent her son can be when his structure and routines are managed well. She said, *"We build the rollercoaster. I buckle him in and he's fine. He gets to the end."* This close contact's son said, when asked about difficulties in his life, that he had no difficulties in his day-to-day life that he could think of.

On the other hand, respondents who worried about getting enough or consistent help to meet their needs, or who did not yet have enough help, discussed that gap in support as a significant concern and vulnerability. For example, one respondent who used a letterboard as his AAC support did not yet have a consistent communication partner. He said that *"everything"* in his day-to-day life was difficult and that he could not do many things he wanted to do, including working, exercising at a gym, or going to a restaurant, because of this unmet need. Similarly, another respondent, who worried about relying on aging family members for her care, noted that finding care can be the biggest challenge.
I can be by myself for a little while, but essentially, I need 24-hour care. So, somebody's got to be with me at night. Finding care is the biggest thing and everything else can be worked out. But like, finding an experienced qualified safe caregiver that I'm comfortable with.

Finally, respondents who had help, but were concerned about the long-term sustainability of that help, also talked about those concerns for the future as salient stressors. Some respondents heavily relied on a very small handful of people or even a single person to fulfill their support needs, leaving them exposed to risk if anything happened to their support person. One respondent, for example, who had high support needs, relied on her mother for all aspects of her care. However, her mother was in the process of beginning cancer treatment, and she did not know who could take care of the respondent during her ongoing treatments. That uncertainty was the respondent's primary concern. She explained her concerns about this in the following way: *"Getting people to help me – stay with me. Cause if mom is not here, I need somebody to stay with me, because [if] mom's going on the treatment. I need somebody else."*

Receiving Help with Medical Appointments: Most respondents and close contacts said that respondents needed personal support attending medical appointments. Some respondents simply received rides, whereas others also had support making the appointments and attending them, including completing necessary medical forms and speaking with health providers. For example, one respondent, with low support needs, said that he was

able to schedule and attend most appointments himself, but he always tells his mother about doctor's appointments. In her close contact interview, his mother explained, *"Now the doctor's office, I do go into the office, because they're talking about more health issues that he doesn't necessarily know or understand. So, I do that one. But other appointments, he could make his appointments. I just remind him."* Another respondent, with medium support needs, said that she found doctor's appointments to be *"confusing."* In her close contact interview, her mother said that her role often involved providing background information or as a clear sequence of events to the doctor, while also explaining the doctor's statements to her daughter: *"I have to interpret for both sides."*

Communication Supports: Respondents who used AAC supports faced unique communication concerns, compared to people who can rely on their speech alone to communicate, however, their experiences were applicable more broadly across the study sample. They highlighted both the complexities of having adequate support and accommodation for a range of situations, and also their experiences emphasized the ways in which difficulties in one functional area, communication for instance, may affect other areas of life such as social participation or learning.

Respondents who used AAC supports described difficulties getting adequate support for all communication situations they encountered, including personal and technological aides. And, due to the slower pace of communication using some AAC methods, respondents sometimes did not have adequate engagement from other people to have effective and meaningful conversations across social, professional, and medical settings. Even respondents with effective AAC supports in place found communication difficult, if their conversation partners could not hear them or if they were not engaged. One respondent explained her difficulty in the following way: *"Mostly, that I use this tablet to communicate. And I am slower, and maybe not so loud. Phone calls can be tough for me."*

Finding adequate support was difficult for respondents using AAC, particularly for respondents with a combination of functional difficulties. For instance, one respondent, who used revoicing to assist his speech during the interview, had a constellation of co-existing difficulties which made finding an effective AAC device challenging. During her close contact interview, his mother explained that he did have a device, *"but it's really difficult for him to use, because he's blind."* Devices designed for people with IDD relied on people being able to see, and devices designed for people who were blind did not account for people who have processing delay due to IDD. Another respondent, who used a letterboard to communicate, did not have a dedicated communication partner at all, and he relied on his mother to help him communicate with any third person. This limited his social participation, as his ability to do any activities outside the home relied on his mother being with him.

The pause between conversation turns using speech generating devices, meant that social interaction could be difficult and even isolating. As another respondent explained, she had a particularly difficult time in college. *"My so-called 'friends' would have full conversations with* [my care assistant] *while I would be sitting there. And professors would talk to her instead of me."*

Salient Difficulties

This section provides a detailed summary of specific areas of difficulty, or domains, described by respondents as important to them in their day-to-day lives. While not every domain was important to every respondent, these domains described below were broadly discussed across the sample. The domains are as follows: transportation, stress and anxiety, learning skills, money management, scheduling and planning, and judgement. These domains, in conjunction with the sections above on the context of respondents' difficulties and their framing of their difficulties may be beneficial for designing questions to enhance the standard disability question sets such that adults with IDD are more consistently included in disability measures.

Not included in the below section are domains already captured by the standard disability question sets.

Transportation

Getting from place to place without help was something that respondents described as aspirational – a goal that they strived towards to become more independent. Some respondents specifically mentioned their difficulties with their transportation, in that, the transportation options they had were limited or flawed in some way that formed a barrier for their participation in things like social events or employment. Most respondents did not have licenses to drive, though that fact alone did not necessarily make transportation a salient difficulty for them. Difficulties emerged more so from respondents feeling restricted, no matter the means they used. For example, one respondent explained that she was worried that not being able to get to a job in the future without driving. She relied on her mother for rides and did not yet have adequate training and experience with public transit. In terms of finding work, she said, *"The biggest barrier, for me, is being able to drive."* Whereas another respondent, for example, who was confident and experienced using public transit, talked about being able to go anywhere he wanted to go: *"I go with metro access, cause I have my metro access card with me and metro access is going to take me to places where I wanted to go."*

A few respondents and close contacts discussed the need for travel training to help improve respondents' ability to be more independent with their transportation, and to help them rely less on their close contacts or support professionals for rides. One respondent, who was both blind and had cerebral palsy said the following about travel training: *"I know I'm a home body, but even home bodies got to go out every now and again, explore the home, you know, you know, or the home area, I should say, you know, so for me, I, that would be one of my main difficulties"*

In some cases, respondents were concerned about the unreliability of the transportation available to them. They were frustrated that they were not able to be where they needed to be on time consistently. For example, one respondent said*, "they don't come like they supposed to because they're get me there early, sometimes they'll get me there late, or they might not come. So, I have to wait."* Similarly, another person, who said that the primary difficulties in her day-to-day life were communication and transportation, explained that her group home arranged rides for her. However, sometimes she had to wait longer than expected or that the ride did not come when expected: *"The timing can be tricky. I use the local paratransit system."*

Why Respondents Do Not Drive: Most respondents could not drive. Some directly said that they did not drive because of their disability. As one respondent said, *"Yeah, because I don't drive. Because I need my license. With my disability, we don't drive."* However, respondents did not always describe the reasons that they did not drive as something directly related to their disability. Some simply said, *"I don't drive"* or *"I can't drive."* A few referenced other people as the reason they did not drive: *"I don't trust people on the roads."*

In a few cases, slower pace of thought or reaction time was mentioned during discussions of driving, though most people did not describe their difficulties in that way. One respondent said, regarding driving, *"you know, that's gonna be hard because my brain works slowly."* Another respondent, who initially said that she did not drive due to her anxiety, explained, *"Reaction time, like I don't react in time like, like if I have to put on the brakes, I don't react in time. To put in on a breaks and stuff."*

Stress and Anxiety

Discussions of stress and anxiety in day-to-day life were common among respondents, across levels of support needs, and their close contacts, though the triggers for that stress and anxiety varied from person to person. The overarching triggers that caused respondents stress and anxiety included sensory stimuli like loud noise, bright lights, or large crowds, being reminded of past trauma or bad experiences, being pressured or rushed by

others, and fearing new people, new activities, or new schedules outside of their trusted routine. Additionally, some respondents reported having constant, underlying stress and anxiety about potentially losing their disability benefits, having difficulty finding a job, or the potential physical dangers around the kitchen or while driving. Some respondents also had been diagnosed with anxiety by a medical professional and, in a few cases, took medication for their condition.

Stress and anxiety when faced with crowded places, extreme heat, and loud noises were more common among respondents with medium and high support needs and respondents with autism. They said they felt *"overwhelmed,"* or they *"shut down,"* for instance, in response to those sensory triggers. Some respondents had coping strategies to deal with these experiences, such as taking quiet time to themselves, taking deep breaths, journaling, or using devices like noise cancelling headphones.

Some respondents, who experienced stress and anxiety in their day-to-day life, described how it impacted their ability to do certain activities, such as work or learning to drive a car. For example, one respondent said that she had a hard time at her volunteer position when she felt overwhelmed and rushed: *"When so many people [are] telling you 'Have to do this too, and do that, and do this, also do that.' It makes my head hurt."* Another respondent worried about her ability to find a job that that allowed her to avoid her anxiety triggers. She said, *"I have a lot of food trauma, so it's hard to pick a job where there is not food."* Similar to finding employment, learning to drive a car was something respondents wanted to be able to do to gain more independence. However, some noted that they did not want to drive due to the anxiety they felt. For instance, one respondent said she was worried about *"crazy drivers out there."* Likewise, another respondent talked about driving in the following way: *"No, that's something I don't do. I used to have a permit. But that's…I couldn't do it because of my anxiety."*

In cases where respondents felt *"stressed out"* or anxious when they were pushed out of their set structures and plans, close contacts, rather than respondents, discussed the overall benefit of *"routines"* and *"structure"* as the remedies for such stresses. While one close contact remarked that an overreliance on routine was sometimes a difficulty in and of itself, she, and others, primarily spoke about the benefit of structure and routine to respondents' wellbeing. For the most part, routines and structured schedules were a strategy for success and *"thriving"* that close contacts supported and respondents felt was helpful. As one respondent said, his mother puts events into his calendar for him to follow: *"I look it up, and then I just go."* Another respondent said, *"Right in the beginning of the week, I ask what's happening."*

Respondents spoke more directly about their feelings in ways that close contacts could not, saying that they sometimes felt *"rushed"* or *"pushed"* by others. One respondent, who said that her disability caused her to have a slower reaction time, said she felt pressured at work to move more quickly than she was able. She said, *"Well, I have to move quickly in the morning to do my job. Or else they'll get mad at me […] Like I have to move quickly to do the garbage, and the all the carts, and recycle, and the bathrooms, or [they'll] still get mad at me if I take my time."*

Mental Health Conditions: Some respondents mentioned that they had diagnosed mental health conditions, and that these conditions were important and often difficult factors in their lives. Even when well-managed, the impact respondents described due to these conditions was distinct from the stress or anxiety that respondents without such conditions felt and described. In that, they tended to have long-term strategies for managing their conditions – with either medication, therapy, or a combination of treatments. For example, one respondent with schizophrenia said that avoiding triggers is an important part of avoiding a relapse: *"Well, I have an old friend group that I now have to avoid. And, I can't get stressed out because it makes me psychotic."* Another respondent spoke about attending regular therapy sessions to help manage his anger and behavioral condition.

Learning Skills

Difficulty learning skills and how to do certain tasks, in a broad sense, were discussed by many respondents and their close contacts. Those discussions focused on learning different types of skills and tasks, depending on what was most salient in the respondents' lives. For instance, respondents and their close contacts spoke about difficulty learning skills from school such as reading, writing, and math, and by extension, applied reading, writing, and math skills such as paying bills, writing checks, paying with cash, or counting change. Other specific skills respondents discussed learning included tasks for work and using household appliances.

Close contacts talked about respondents' difficulties learning from a broad, lifelong perspective. They tended to be able to describe what aspects of learning were difficult for the respondent – abstract thinking, memory difficulties, judgement, pace of thought, etc. As one close contact explained,
She needs many repetitions […] though a lot of trial and error we've discovered that she needs around like 900 to 1000 repetitions of something being the exact same way before she gets it, and if you change one factor in that scenario, then she starts over. She can't generalize to a different scenario.

Close contacts considered respondents' formal schooling, including individualized education plans and any special education classes taken, any post high school programs, such as transition or day programs, as well as the teaching that they themselves or other care assistants had undertaken to help the respondents learn various practical life skills, such as using household appliances, like the microwave or washer and dryer, riding the city bus, setting up and following a schedule, writing out and sending rent checks, and other such skills.

Respondents, unlike close contacts, did not spontaneously name "learning" as a difficulty, per se, though some affirmed they had learning difficulties when asked by the interviewer. Rather, they spoke about having difficulty with specific daily skills that were related to learning. For example, one respondent described her challenges with handling money and math in the following way when talking about work: *"Yeah, my boss told me 'You can't count money, because […] you don't know how to make change, you can't do that. So, a job coach will help you with that.'"* Likewise, another respondent who brought up her difficulties counting change, did so when asked an open-ended question about difficulties in her life. She said, *"For the difficulties and my day-to-day life – like knowing change. Counting change."* Another respondent said that sometimes she has difficulty with books, *"Because of the hard words that are in there."*

In addition to practical math and reading skills, several respondents with high support needs, and a few with medium support needs, spoke about *"cooking"* as a something with which they needed help. Oftentimes, respondents did have a set of meals they were able to make, and the difficulty they were referring to was the use of a specific appliance in the kitchen that they found hard to use consistently and safely, like the microwave or the stove. As one respondent, explained, typically her parents cooked for her. But, she said, *"I'm able to help make it, or they have like supervision on me while I make it. I think I make four meals by [myself] with them watching."* Similarly, another respondent said, *"I need help on some things. Things like if you just give me a paper tell me to make some food. I need a I need to know the ingredients, and how to make it, otherwise I don't know."* In her close contact interview, that respondent's mother said, *"She can't really do much in the kitchen without assistance. I was gonna say she can use the microwave, but she couldn't set it, because she doesn't understand the time. But, you can make a sandwich, you know, get out yogurt and granola."*

Some respondents connected their disability to their difficulties learning certain things. As one respondent said, *"my brain works slowly."* Another respondent said, *"Like I need a couple steps, a lot of steps….help me a lot before I'm able to do it on my own. Like, a lot of repeat."* However, other respondents said that they had "no difficulty" learning because they enjoyed learning or because they were ultimately able to learn skills, even if it took them longer than other people. Similarly, another respondent, who said he had no difficulties in his day-to-day life, said that he did not read or write. However, he used an application on his phone, Speechified, to help him, which reduced the impact of his reading difficulty in his day-to-day experiences.

The specificity with which respondents spoke about their difficulties learning indicates that clear, well-chosen examples embedded within a learning question would likely improve overall comprehension for respondents with IDD.

Money Management

For some respondents, across levels of support need, making decisions about money and managing their money – balancing saving and spending – was something they found difficult to do without the support of family members or close personal assistants. Various aspects of managing money were discussed during the interviews, including handling cash, understanding and counting change, paying bills, and deciding whether to buy something. These money management tasks were multifaceted, in that they required a combination of math, reading, and writing skills as well as decision-making abilities. For example, one respondent, who had low support needs and lived in his own apartment, received help from his mother with specific money management tasks. He said that she helped him write his rent check, since reading and writing were difficult for him. She also supported him by checking in on his bills regularly, to make sure each utility and bill was paid.

Counting change and understanding how to handle cash was a common difficulty for respondents. Some said they avoided cash entirely in order to mitigate their difficulties understanding physical money. One close contact, for instance, said that her son did not handle cash, since he did not understand math well or the concept of receiving change back: "*he has been known to give a $20 bill for a hot dog and a coke at a ball game and walk away."* Likewise, a respondent said that she uses a card to pay for things because she found coins and bills difficult.

Some respondents, particularly those with low and medium support needs, had protocols to help them with spending decisions. For example, one respondent said that she calls her mom whenever she wants to buy something, to make sure she can afford it, and that it was a good purchase decision. Similarly, one close contact explained her son's strategy. She said, *"He knows, if a price tag has 3 numbers on it, meaning it's $9.99 or lower, he doesn't have to call and check in. If it's higher, he calls and checks with me if it's okay to buy it."* Another respondent helped to decrease spending mistakes by only taking out $20 from the ATM at one time.

Respondents with high support needs who had difficulties with money tended to have more structured support from their parents or professional assistants for banking and savings actions. As one respondent said, *"Since I started getting money, mom has told me to save up money. And every time I do that, I feel sad, because I only get a little bit of money."* Similarly, another respondent said, "*My mom put my money in the saving account for me."* Finally, one close contact explained the need to put restrictions on her daughter's access to money in the following way: *"She doesn't have access, because she doesn't have any impulse control. Plus, she would give anybody her money."*

When speaking about difficulties with money management, some respondents specifically spoke about having a hard time understanding cash and *"counting change,"* which was discussed above in "Learning Skills."

Scheduling and Planning

Many respondents had help managing their schedules (see above section on Receipt of Support), in that they received help with some or all the following: making appointments, entering events and appointments into a calendar (digital or otherwise), and providing reminders or cues. Additionally, some respondents with high support needs also had help with their eating and sleeping schedules. Overall, the type and degree of assistance that respondents' family members or support professionals provided depended on each respondent's need. For example, some respondents were able to manage their own work schedules, but they needed help coordinating

medical care and other occasional appointments.

The use of shared phone calendars and other sharable calendar technology helped close respondents' aides support their schedule management even when respondents lived separately from their family.

Concept of time: Respondents tended to thrive under more structured routines and had more difficulty fitting in and remembering non-routine, situational events into their schedules. For example, one respondent described himself as *"very routine dependent."* He further described his difficulty in the following way: *"Things that are sudden and like off the unexpected or being able to remember that I've planned something and not double booking. Those are the sort of things that I have trouble with. I usually have to be reminded."* Likewise, the close contact for this respondent said, *"Not so much time management, because he can do that with established routines. But, the concept of time."*

When describing respondents' difficulties with time and planning, some close contacts noted that the difficulties were not "time management" issues, in terms of procrastinating or wasting time. Rather, the difficulties were more related to understanding time more conceptually. For example, one respondent said that she had difficulty giving herself enough time to get ready before she is picked up. Similarly, a close contact said that she was working on helping her daughter function *"in time."* She explained, *"Okay if you spend 25 minutes making this breakfast, you're not gonna have time to eat it, because you have all this other stuff to do."*

Respondents more often described such challenges in terms of the help they needed, rather than as a specific difficulty. When talking about keeping her weekly schedule, one respondent said, *"Yeah I definitely need help. I Can't do it on my own yet."*

Judgement

Some respondents had difficulties with good decision making and forming opinions when interacting with other people, either malicious or not. For instance, when asked an open-ended question about difficulties in daily life, one respondent gave the example of having a hard time choosing what to order at a restaurant. She said, *"I don't know when I like go to a restaurant, I don't know what I want to order and stuff, so a lot of times when I go to a restaurant my mom makes me order first, so I don't order the same thing as her."* Typically, the types of decision-making difficulties respondents and close contacts spoke about were more serious, however, such as, what to do in an emergency. As one close contact explained, *"I'd be very concerned with, you know, the 'what ifs'* […] *like even when it came time to leaving her home alone* […] *What happens in the state of an emergency and what happens if you're at home and there's a fire, you know, what are you gonna do?"*

Respondents and their close contacts most often discussed having difficulty with judgement when meeting new people either online, on the phone, or in person. One close contact for a respondent with cognitive delays explicitly used the term "*judgement"* to describe her daughter's impulsiveness when meeting new people and socializing online.

Respondents tended to speak about difficulties in judgement in terms of what they were restricted from doing, even when they did not expand on the reasonings for that restriction, or they spoke about times they needed supervision. For example, one respondent said, *"I'm working on with* [my mom] *being able to go outside of the school by myself, with friends. And being able to like go somewhere* […] *without having someone watching me."* She also spoke about online restrictions in the following way: *"It's hard to. Not have social media when all my friends do, but I understand, you know, my mom and dad's perspective… about how dangerous, dangerous it can be."* Another respondent said, *"I can't do… being alone by myself being alone, because if I answered the door, mom will be like really mad at me for answering the door for people."*

Close contacts spoke about judgment in terms of *"social skills"* and *"safety."* One close contact, who said that *"judgement"* was her daughter's most significant difficulty, felt that her daughter would always need some sort of supervision, for her own security. She said, *"If she were living alone* […] *I think she, you know, anybody that would come to her door would be your best friend."* Another close contact said that her daughter lacked *"stranger danger,"* and the resulting vulnerability was limiting for her.

IV. Conclusion

This in-depth interview study serves to provide foundational information to develop supplemental functional disability indicators for adults with IDD to be administered at point-of-care settings alongside the standard disability question sets. The study findings explored factors that affect how respondents perceive their difficulties, how respondents frame and discuss their difficulties, and finally, the domains that respondents highlighted as important to them, which differed from those already included in standard sets of disability questions. Six domains emerged: transportation, stress and anxiety, learning skills, money management, scheduling and planning, and judgement.

In addition to exploring which day-to-day difficulties were most salient, the interviews revealed the language respondents and their close contacts used when discussing their difficulties, thus providing foundational information about optimal approaches to elicit discussion and collect information about their lived experiences. These qualitative interviews therefore provide a basis for the development of questions that would include adults with IDD in disability measures.

Using the question phrases *"does somebody help you"* or *"do you need help,"* interviewers were able to elicit whether respondents received help or needed help to complete a wide variety of tasks. Indeed the "Receipt of Support" was a framework through which interviewers were able to discuss and understand the difficulties in respondent's day-to-day lives, even in cases where respondents and close contacts who were focused on discussing and highlighting capabilities. These question phrases about *"help"* operated well, in that they were widely and consistently understandable, across both respondents and their close contacts. All respondents, regardless of specific circumstance, were able to talk about whether they had help doing a given task. Questions about receipt or need of support would perform best if written in direct, literal, and specific language, as that is how respondents spoke about the help they received – in specific and direct ways.

Question designers may need to take particular care when invoking complex concepts such as independence, independent living, self-direction, or even the technological aides that support independence, as those concepts may be interpreted by respondents in varied, inconsistent ways. Also, any support or technical aides used may affect the way respondents perceive their own functioning. For instance, respondents in this study reported that they lived independently, even when requiring high levels of hands-on daily support, since they exerted agency over the care they received and the activities they participated in during the course of their day.

These findings are relevant for question design. The information obtained through these interviews can be used to better understand respondent considerations of their functional difficulties and their support needs. Furthermore, the findings underscore the importance of considering how different groups of respondents perceive their disability and their day-to-day difficulties, including what functional difficulties and needs are most important to them, so that respondents may consistently understand questions about those difficulties and needs.

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Appendix 1: Topic guide

Development of questions to include adults with Intellectual and Developmental Disabilities (IDD) in point of care settings

Qualitative exploratory research: Interviewer's guide. (Virtual interview)

Research Aim

To identify any additional functional difficulties or barriers to participation in day-to-day activities associated with IDD but not captured by domains of the standard set of functional disability domains used on surveys.

Research objectives

- To elicit a conversation to identify functioning that individuals with IDD could be identified from.

Exploring:

- Day-to-day activities person with IDD has difficulty performing, level of difficulty & why.
- Barriers to participation in daily life and life opportunities.
- Level of support received and whether that support is sufficient.

This is a guide. Not all topics will be covered during the interview. The interview is respondent driven.

1. **Introduction and consent**
   - Introduce self and NCHS
   - Explain/Reiterate:
     - Purpose of research
     - Nature and length of discussion
     - Voluntary and confidential nature of research
     - Maintaining privacy
     - Transcription
     - Video and audio recording
   - Obtain verbal consent to take part and record
2. **Opening discussion**
   - [Close contact only] Tell me a bit about [respondent]
   - [Close contact only] Relationship to respondent
   - Describe what's fun/enjoy/easy/hobby/likes/feel good
   - *If needed,* what do you do for fun?
   - Current/past member of club, organization, group
   - *If needed*, describe your typical day.
3. **Difficulties /challenges in life**
   - Challenges/problems/dislikes/feel bad
   - Current /past difficulties or challenges in day-to-day activities
   - Level of difficulty/changes over time
   - Barriers to overcoming difficulty/problem
   - Impact on life/daily living
   - Comparison with others
4. **Disability / impairment**

- Knowledge/perception of disability/how describe
- Type of disability, if known
- Primary diagnosis, if known
- Age of onset/ongoing difficulty

5. **Household composition**
   - Living arrangements
6. **Environment**
   - Urban/Suburban/Rural

Specific domains

7. **Independent living**
   - Level of independence
   - Help and support with day-to-day activities (aide or caretaker / special equipment)
   - Ability to do errands alone
   - What aspects does person need help with? (Physical/mental/emotional)
   - Enough help? More help? Less help?
   - Barriers to independent living
8. **Access to transportation (Mobility)**
   - Ability to drive / use public transportation
   - Barriers to transportation use
9. **Communication**
   - Establish any difficulties with communication (understanding or being understood)
   - Establish communication style preference
   - Internet access/use
10. **Learning**
    - Academic vs. non-academic learning
    - Adult vs. childhood learning
    - Barriers to learning
    - Ability to process information
    - Adapting to change / learning new things
11. **Form of thought / pace of thought**
    - Following a process / doing things in the right order
    - Processing speed
12. **Focused attention**
    - Easily distracted / difficulty concentrating
    - Mental fatigue
    - Sensory overload
13. **Organizing, planning and time management**
    - Managing schedule
    - Planning ahead
14. **Economic life**
    - Basic transactions – paying for things in grocery store, conceptualizing amounts
    - Complex transactions – managing bank account, managing finances/paying bills
15. **Employment opportunities**

- Employment current/past
- Barriers to employment (remuneration/volunteering)
- Feelings about jobs
- Employment support (e.g. job coach/training)

16. Interaction with others

- Interactions within and without disability community
- Barriers to interacting with other people
- Self-confidence
- Attitudes
    - Nervous of strangers / untrusting of strangers / fearful of other people
    - Attitudes of other people
- Self-expression
    - Ability to express feelings/needs to others
    - Receptiveness of others to feelings/needs of person with disability

17. Handling stress

- Feeling overwhelmed
- Completing paperwork
- Feelings of frustration

18. Communication

- Communication style and preference
- Any difficulties with speech and being understood
- Internet use/access
- Use of symbols and graphics

19. Changes over time

- Difficulties progressing/decreasing
- Future outlook and goals

20. Ideas and suggestions – summary thoughts

- Most significant difficulty and why

21. Closing

- Signpost: discussion will be ending in 5 minutes
- End on a positive
- Invite participant to raise any other issues/share anything else/ provide suggestions/ask any questions
- End interview discussion

Appendix 2: Estimation tool for respondents' level of support needs

The table below draws primarily on the Tassé et al. (2019) article (13) as recommended by subject matter experts and project collaborators at NCBDDD. Following each interview, the interviewer used the information learned about the respondent's life experience and support needs and compared that interview data to the table below to form a best-fit estimated level of support need. Additional columns titled "AAIDD support needed" and "DSM-5 practical domains" draw from the NASEM (2015) report, Table 9.1 (14).

Support Level	Indicators in adulthood					
	Self-care	Travel	Money	Employment	AAIDD support needed	DSM-5 Practical domain (IDD)
Low	-Many learn to live and work independently	-Use transit with minimal help, many can drive	-Manage simple aspects of banking -Need support for complex banking (paying bills)	-Many can earn part- or full-time competitive wages (support at work depends on complexity of work)	-Intermittent support needed during transitions or periods of uncertainty	-Typically, independent in self-care –Needs support with health care and legal decisions, and with grocery, transportation, food prep, money management
Medium	-Most are safe around the home -Need support with some aspects of self-care	-Most not traveling independently to new places -Need support to be safe in the community	-Understand concept of money, but struggle to make change or budgeting	-Can tell time independently -Need substantial support for employment (finding and keeping)	-Limited support needed in daily situations	-Extended period of teaching needed for independence in self-care tasks, reminders needed often, more supports needed for work
High	-Need some supports for basic hygiene and self-care	-Need substantial support to do any independent travel or shopping	-Need substantial support to do banking of any kind	-Need significant supports to be engaged in paid employment	-Extensive support needed for daily activities	-Support for all areas of self-care, not able to make responsible decisions for wellbeing -Long-term teaching and ongoing support needed for new skills
Profound (not in study)	-Needs supervision with self-care and being safe at home	-Need substantial support to be safe and healthy in community and at home	-N/A -Need substantial support to know days of the week and time of day	-Limited vocational skills -Engagement in employment would necessitate structure and support	-Pervasive support needed for every aspect of daily routines	

Notes: NCBDDD = National Center for Birth Defects and Developmental Disabilities. AAIDD = American Association on Intellectual and Developmental Disabilities. DSM = Diagnostic and Statistical Manual of Mental Disorders. NASEM = National Academies of Sciences, Engineering, and Medicine.