Research study for adolescents with intellectual and developmental disabilities and their caregivers

What is the purpose of this study?

The goals of this research study are to understand the experiences and needs of adolescents with intellectual and developmental disabilities and their family in preparation to transition out of high school. We also want to understand how levels of self-determination (how much control a person has over their own life and can make their own decisions) and independence in ADLs (ADLs are everyday activities like bathing, dressing, cooking, etc.) impact adolescents and their family experience during the transition process.

Who can participate in this study?

- Caregivers:
  - Have a child with an intellectual and/or developmental disability who is between the ages of 15 and 18 years old
  - Willing to participate in either a survey about transitions and/or a 1–2-hour focus group (online or in-person)
- Adolescents:
  - Have a diagnosis of intellectual and/or developmental disability
  - Are between 15-18 years old
  - Cognitively able to participate in a short survey and/or a focus group
  - Willing to participate in a short survey and/or 1–2-hour focus group (online or in-person)

How will this study be completed?

If you agree to participate, you will be given a questionnaire to fill out including 1) questions regarding you and your family 2) questions regarding your child's performance of everyday activities and 3) questions about your child's self-determination. Next, focus groups will be held individually for adolescents and for caregivers. You will determine if you think your child is able to and would like to participate in the focus group. If you think they are able, your child will be given the option to participate in a focus group. Caregiver and adolescent focus groups will be held separately, but at the same time.

Each focus group will have 3-6 individuals, lasting 1–2-hours. Focus groups will be held in-person (at CCHMC) with an option to join online if you can't make it in-person (Zoom or Microsoft Teams). Focus groups will be led by occupational therapy students and an occupational therapist. They will be completed in an interview-like format to gather information about the transition process. Participation is voluntary and you or your child can withdrawal at any time. Focus groups will be audio-recorded, but names will be kept

anonymous. Information collected during the focus group will inform future therapy programs for adolescents with autism and their families.

What are the risks and/or benefits for participation?

There will not be any direct benefit from participation in this research study. However, by participating in this study, you may help other adolescents with intellectual and developmental disabilities and their families in the future. We plan to take the information learned during this study to create programs that can benefit adolescents and their families in the future.

There are no known risks to participation in this study. You will be assigned a numeric code that will link the information that we collect to you. Making sure that information about you remains private is important to us. To protect your privacy, your numeric code will be kept in a separate location from all your identifying information. In the event of any publication regarding this study, there will be no information specific enough to identify you. Electronic databases will be password protected and stored on a secure server at CCHMC. By participating in this study, you are giving permission for representatives of the CCHMC, the Investigator and CCHMC study staff including the Institutional Review Board and the Office for Research Compliance and Regulatory Affairs to review your answers to the survey.

Interested in participating? It is also OK if you only want to participate in part of the study, either the survey or the focus group. You don't have to participate in both.

Are you interested in participating in the survey online?

You can access the survey by going to: https://redcap.research.cchmc.org/surveys/ and enter the code: NED4FJK8F

Or you can scan the QR code

Are you interested in completing a paper copy of the survey? Or want to participate in the focus group?

Contact Karen Harpster at either Karen.harpster@cchmc.org or 513-803-3604.

Who do you call if you have questions about this study?

If you have any questions, please contact Dr. Karen Harpster, PhD, OTR/L at Karen.harpster@cchmc.org or 513-803-3604 (Principal Investigator).