

Psychological Assessment in Intellectual and Developmental Disabilities

Frequently Asked Questions

Introduction

This is an information sheet answering commonly asked questions about obtaining a psychological assessment when there is a suspected or confirmed intellectual or developmental disability, which includes autism spectrum disorder.

What are reasons to consider referring a person with an intellectual or developmental disability for psychological testing?

Reasons to consider referring a person for psychological testing include:

- ▶ **The person is not well understood by his or her support system:** He/she is not learning well, having difficulties coping, or family members/support persons need information on how to better understand and support them.
- ▶ **Change from an earlier assessment:** A reassessment may be helpful if there has been a long interval since the last testing, or no testing in adulthood as early results might be less stable and factors influencing the earlier testing might have changed.
- ▶ **Future planning needs:** Includes vocational, education, and housing directions. For example, can the person manage with a supported independent living arrangement? What are his or her current abilities and challenges? What are his or her support needs? If an adolescent is considering postsecondary education, note that most colleges (inclusive higher education program, community colleges and universities) require documentation within the past three years that shows a current disability diagnosis.
- ▶ **Before a psychiatric diagnosis:** It might be important to know the person's level of functioning in order to provide a context for presenting symptoms. Some aspects of IDD (e.g., a person functioning in the severe to profound range who is engaging in self-talk) might be developmentally appropriate for this level of functioning. This self-talk could be mistakenly interpreted as a symptom of psychosis by those who do not appreciate the effects of his or her functional level.
- ▶ Significant, unexplained change in the person's behavior (e.g., new onset withdrawal or aggression).
- ▶ A specific diagnosis might be needed for income support services. (In the United States, a documented diagnosis of intellectual disability is needed by age 18 or a documented diagnosis of developmental disability is needed by age 21 to qualify for federal or state disability supports).

What types of psychological testing are available?

- ▶ **Cognitive:** To identify the level of intellectual ability, strengths, and vulnerabilities.
- ▶ **Adaptive behavior:** To determine and describe how a person functions in day-to-day life.
- ▶ **Neuropsychological:** For issues such as dementia, stroke, head injury, and genetic disorders associated with cognitive decline (e.g., Down syndrome).
- ▶ **Personality and psychiatric type:** As an adjunct to psychiatric assessments (e.g., testing for depression, anxiety, or hyperactivity).

Do I need to find a psychologist with special training or expertise in IDD?

- ▶ For people whose cognitive functioning is likely in the borderline to mild range, any qualified psychologist can provide testing.
 - ▶ For people whose cognitive functioning is likely in the moderate, severe or profound ranges, a psychologist with experience and skills in testing such people is recommended.
-

How do I find a psychologist to do testing on an adult with IDD, or suspected IDD?

- ▶ For people under the age of 21 years who are still in school, the best route is usually through the school system.
 - ▶ For adults with IDD 21 years and older who need services and who are interested in employment and qualify for Vocational Rehabilitation, states' Vocational Rehabilitation offices may provide such assessments.
 - ▶ Alternatively, try contacting your state's professional psychological association to find a provider who has experience in disability evaluations or neurodevelopmental disabilities.
-

How long is the usual wait time?

- ▶ Services provided through schools vary in wait times. If a re-evaluation of a student with an Individualized Education Program is sought, states have between 25 and 90 days to complete the testing, depending on state law. If it's an initial evaluation of a student, a meeting must be held within 10 days of the parent request so that the team can discuss the request. Once the school receives consent for additional assessments, the team has 60 days.
 - ▶ Community service providers also vary in wait times between one to two months to about one year depending on the type of assessment and priority they give to the referral.
 - ▶ Private testing may be arranged, usually within weeks or months, if the person or his or her family have the financial resources to pay for it.
-

How much will this testing cost?

- ▶ **School District:** No cost. Given this, it is important to obtain testing while the person with IDD is still in school, so the costs will be covered. Records of past assessments can also be requested from the school, which might avoid the need to retest.
 - ▶ **Vocational Rehabilitation:** No cost.
 - ▶ **Private:** The typical cost for a full developmental assessment may vary from \$1,800 - \$5,000. Families/support persons should find out whether this fee would be covered, at least partly, by the individual's health care insurance.
-

Are there other free resources, or government or other funds to help pay for this testing?

- ▶ For people under the age of 21 and on Medicaid, Early and Periodic Screening, Diagnostic, and Treatment could cover psychological assessment services.
 - ▶ Check with your state's University Center for Excellence in Developmental Disabilities to see whether there are services or research projects offering psychological assessments as part of a study. (Check the Association of University Centers on Disabilities website, <https://www.aucd.org/directory/directory.cfm?program=UCEDD>).
-

What information does the psychologist need in the referral?

- ▶ **Developmental history:** Especially early development (e.g., when did the person begin to walk, talk, toilet independently).
- ▶ **Medical disorders:** Particularly those that can affect or interfere with cognition (e.g., epilepsy, attention-deficit hyperactivity disorder, adjustment disorder).
- ▶ **Medications:** Particularly those that can affect or interfere with cognition.
- ▶ **Relevant past assessments:** Psychological, occupational therapy, brain imaging.
- ▶ History of possible infections of the brain, traumatic brain injuries, or possible prenatal exposure to alcohol or other toxins.

What can be expected during the appointment for psychological testing?

- ▶ The person being assessed and his or her family/support person will be interviewed. This typically takes one to two hours.
 - ▶ Testing will be done one-on-one with the person being assessed. There might need to be one or more sessions of one-on-one testing, each of which will last one to four hours, depending on the type of testing.
 - ▶ Testing will be followed by a feedback session for the person being assessed and his or her family/support person. The psychologist will provide results of the testing, what they mean, and recommended actions or next steps. This generally takes about an hour.
 - ▶ The person and his or her family/support person will be asked to identify people and parties to whom they would like the report to be sent.
-

What information is likely to be included in a report?

- ▶ **Level of functioning:** Will include how the assessed person's cognitive functioning compares to others in his or her age group. It will also identify his or her relative strengths and vulnerabilities. The information might be expressed in various ways (e.g., IQ scores, Age Equivalent scores, percentile scores).
 - ▶ **Education/placement:** The report may recommend educational and skill development strategies to be used to help the person assessed to learn.
 - ▶ **Emotional disorders, personality:** The report will indicate how the person tested compares with others (e.g., with a similar level of intelligence or similar age) using various standardized scales (e.g., depression or anxiety scales).
 - ▶ **Behavioral management:** The report might recommend strategies for dealing with distressing behaviors that could challenge placements or supports.
 - ▶ **Other services:** The report might recommend various services (e.g., counseling, occupational therapy, applied behavior analysis, local programs).
-

Copyright

This document complements "Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines", published in *Canadian Family Physician*, Volume 64(4): April 2018, p254-279.

Originally published as: *Psychological Assessment in Intellectual and Developmental Disability: Frequently Asked Questions*. Temple, V., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019.

Modified with permission of the copyright owner, Surrey Place, Toronto, Canada. This tool was reviewed and adapted for U.S. use by Vanderbilt Kennedy Center, Toolkit Advisory Committee, including primary care providers, self-advocates, and family caregivers.

All rights reserved. The content of this tool may not be reproduced or stored in a retrieval system, or transmitted in any form or by any means without the prior written permission of the copyright owner. All content © Surrey Place, 2023. Contact the IDD Toolkit at iddtoolkit@vumc.org for permission to adapt information and tools to your local practice setting.