

## Agreement between Parents and Teens on Anxiety for Autistic Teens with Intellectual Disability

### Plain Language Research Summary

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To understand anxiety in teens, it's important to ask teens and their parents for their perspective. For teens with intellectual disability, historically, teens were not always asked about their anxiety, and instead, parents were asked about the teens' anxiety. Thanks to scientists, we now have tools so that we can also ask teens with intellectual disability about their anxiety.

It's important to know both parents and teens' perspectives on a teen's anxiety, not just because it's helpful to have multiple perspectives, but also, because those perspectives can give clues to how helpful receiving therapy for anxiety might be. If teens disagree with their parents and don't feel they are anxious, they might feel less motivated to participate in therapy for anxiety and may not benefit as much. Same for parents.

Teens and parents don't always agree on how anxious a teen is. One main reason is that anxiety is an internal experience, meaning it's sometimes hard for other people to know someone is feeling anxious. Research has shown that some parents and teens may be more likely to agree about their anxiety. This includes teens with higher verbal abilities and adaptive, or self-care skills, teens that have fewer autistic traits, and parents that aren't as stressed.

The author of this summary, Dr. Liz Glenn, and the research study's main scientist, Dr. Audrey Blakeley-Smith, were interested in understanding which parents and teens in their anxiety therapy study were more likely to agree on their anxiety symptoms. 72 parents and teens, ages 12 – 18 were participating in a study at CU Anschutz where teens and their parents attended a therapy group for anxiety. The therapy group is called Facing Your Fears, which is a type of therapy called cognitive-behavioral therapy, that focuses on learning to be brave through facing fears. The therapy was adapted to be helpful to teens with intellectual disabilities.

Our research found that most teens (80%) were able to complete a survey on their anxiety. Teens with higher self-care skills, use of complex speech, and IQ scores, were more likely to complete the survey. Parents and teens generally didn't agree on how anxious the teen feels. If we were to rate the agreement on a scale of 0 to 10, it would be a 1. However, for about half of the parents and teens, on a scale of 0 to 10, their agreement would be rated a

6. Also, when only looking at how teens rated their physical symptoms of anxiety, like feeling hot/sweaty, a fast heartbeat, and having trouble sitting still, there tended to be better agreement. Parents who provided more verbal reassurance to their teens about their worries, and avoided more situations where teens felt anxious, tended to agree more with their teens on how anxious the teen felt, when only considering the teen’s physical anxiety symptoms. Teens’ self-care abilities or language abilities did not affect agreement.

We found that there is greater agreement between parents and teens on anxiety with more “observable” behaviors, like physical symptoms, and when parents have high levels of behavioral changes related to teens’ anxiety. One reason is that parents’ verbal reassurance, or avoidance of scary situations, could be a “shared language” for teens’ anxiety, especially given that teens with intellectual disability express their anxieties to others in different ways. We didn’t find teens’ verbal abilities or self-care abilities affected their agreement with parents on their anxiety ratings. We still need more research on if agreement affects which teens benefit from the adapted Facing Your Fears therapy groups. Since not all teens could complete the anxiety survey, we also still need more research to create tools that don’t require as many verbal or cognitive demands. For example, teens could sort pictures of situations and physical symptoms related to their anxiety into yes and no boxes, instead of answering written questions.

Disclaimer: This project was supported, in part, by the Health Resources and Services Administration (HRSA) under the Leadership Education in Neurodevelopmental Disabilities (LEND) Grant T73MC11044 and by the Administration on Intellectual and Developmental Disabilities (AIDD) under the University Center of Excellence in Developmental Disabilities (UCDEDD) Grant 90DDUC0106 of the U.S. Department of Health and Human Services (HHS). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.