



# Increasing Caregiver Awareness: Helping Identify Anxiety and Depression in Individuals with Down Syndrome

## Mental Health Issues in Individuals with Down Syndrome

Down syndrome occurs in approximately 1 in 700 infants in the United States<sup>1</sup>. Down syndrome is a developmental disorder that occurs when an individual receives either a full or partial extra copy of the 21<sup>st</sup> chromosome<sup>1,7</sup>. This extra chromosome alters the developmental course of the individual, which can cause delays in intelligence and brain function<sup>1</sup>. Because of these delays, individuals with Down syndrome often have unique stressors that negatively impact their mental health<sup>6</sup>. Roughly half of the population of people with Down syndrome experience a mental health issue in their lifetime<sup>6</sup>. Because of this, it is important to be able to recognize mental health issues in individuals with Down syndrome. This is especially true for caregivers and family members of individuals with Down syndrome as they can help improve quality of life, across the lifespan, by helping identify mental health issues earlier.

## Mental Health Across the Lifespan in People with Down Syndrome

The following table provides a summary of the most common mental health issues that occur based on the age of an individual with Down syndrome. It is important to remember that this is not an exhaustive list but is instead a starting point for identification of mental health issues for caregivers of individuals with Down syndrome. If you suspect someone is experiencing a mental health issue, seek help from a trained mental health professional.

| Developmental age                          | Mental health issue   |
|--|---|
| Young children (age 12 and younger).       | <ul style="list-style-type: none"> <li>• ADHD</li> <li>• Oppositional disorder</li> <li>• OCD</li> <li>• Anxiety<sup>6</sup></li> </ul> |
| Adolescents to young adults (age 13 to 35) | <ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> <li>• OCD<sup>6,5</sup></li> </ul>                          |
| Adults and older adults (age 35 and older) | <ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> <li>• Dementia<sup>6,5</sup></li> </ul>                     |

## Identifying Anxiety and Depression in Individuals with Down Syndrome

As noted by the table above, anxiety and depression are the most common mental health issues an individual with Down syndrome will face throughout their lifetime. Accordingly, it is important for caregivers to be able to quickly and accurately identify these mental health issues in an individual with Down syndrome to help increase access to treatment. Because it can be challenging to verbally express internal feelings, there may be difficulties in accurately identifying depression and anxiety using traditional conversational techniques<sup>4,8</sup>. The *Diagnostic Manual for Intellectual Disabilities 2* (DM-ID-2) suggests one way to identify mental health issues in an individual with intellectual disabilities is to focus on behaviors rather than verbal communication<sup>4</sup>. By focusing on the behaviors of the individual with Down syndrome, caregivers and community members may be able to more accurately identify symptoms of mental health issues—specifically

anxiety and depression<sup>2</sup>.

The process of identifying anxiety or depression in an individual with Down syndrome can be done by examining their current behavior and asking, “Is this behavior normal or common for them?”<sup>6,7</sup>. Changes in an individual’s common behavior can be an important indicator that anxiety or depression is present.

Many behaviors that are used to identify anxiety or depression in the general population can be used to identify symptoms of anxiety or depression in an individual with Down syndrome. The following table lists some important behavioral cues that can help identify anxiety or depression in individuals with Down syndrome across the lifespan.

| Developmental Age  | Behavioral Cues: Anxiety   | Behavioral Cues: Depression   |
|--|--|---|
| Young children 12 and younger  | <ul style="list-style-type: none"> <li>• Excessive worry</li> <li>• Acting out (new behavior)</li> <li>• Increase in maladaptive behaviors that were not present before</li> </ul> | <ul style="list-style-type: none"> <li>• Social withdrawal</li> <li>• Isolation from other children</li> <li>• A decrease in play</li> <li>• Sadness</li> <li>• Loss of interest/joy in former fun activities</li> </ul>  |
| Adolescents—young adults ages 13-35  | <ul style="list-style-type: none"> <li>• Disruptive behavior</li> <li>• Acting out</li> <li>• Being aggressive</li> <li>• Fidgety</li> </ul>                                       | <ul style="list-style-type: none"> <li>• Not participating in social activities</li> <li>• Isolation</li> <li>• Sadness</li> <li>• Loss of interest/joy in former fun activities</li> </ul>   |
| Adults and older adults ages 35 and older (Depression tends to become more common than anxiety at this age.) | <ul style="list-style-type: none"> <li>• Anxious actions</li> <li>• Aggression</li> <li>• Repetitive behavior</li> </ul>   | <ul style="list-style-type: none"> <li>• Crying</li> <li>• Depressed appearance</li> <li>• Severe disinterest in activities</li> <li>• Weight loss</li> <li>• Insomnia</li> <li>• Fatigue</li> <li>• A lack of self-care</li> <li>• Social withdrawal</li> <li>• Isolation</li> </ul> |

<sup>a</sup> Taken from Munir (2019) and Capone et al. (2011).

<sup>b</sup> Taken from Munir (2019); Määttä et al. (2006), and Capone et al. (2011).

*Note.* Individuals with Down syndrome are at a much higher risk of dementia than the general public (Coppus et al., 2006). Signs of dementia are mostly oriented around extreme decreases in cognitive ability.

*Note.* Transitions or large life changes have been seen to impact individuals with Down syndrome quite heavily, possibly leading to many depressive and anxiety related symptoms due to individuals with Down syndrome being emotionally sensitive to environmental triggers. It is important for caregivers to note that any environmental change may be highly impacting to an individual with Down syndrome throughout their lifetime (NDSS, 2019).

## Conclusion

This fact sheet provides the readers with two important skills. First, increasing caregiver awareness of the most common mental health issues that occur across the lifespan of an individual with Down syndrome: specifically, anxiety and depression. This skill can help increase early identification of mental health issues in individuals with Down syndrome by helping caregivers become more aware of the specific issues to assess. Second, by using the behavioral criteria and assessing the behavior of an individual with Down syndrome, a caregiver may be able to identify specific warning signs of anxiety or depression and then seek proper professional help and resources. It is important to note, however, that these behaviors do not equate to a diagnosis of any mental health issues. If a caregiver recognizes these signs in someone they know, it is important to seek help from a trained mental health professional who has experience working with individuals with Down syndrome experiencing mental health issues.

## Contributing Authors

Alfredo Araujo, B.S.  
Rylan Hellstern, B.S.  
Ty B. Aller, Ph.D., LMFT

## References

1. National Down Syndrome Society. (2019). *Down syndrome*. Retrieved from <https://www.ndss.org/about-down-syndrome/down-syndrome/>
2. Capone, G. T., Aidikoff, J. M., & Goyal, P. (2011). Adolescents and young adults with Down syndrome presenting to a medical clinic with depression: Phenomenology and characterization using the Reiss scales and Aberrant Behavior Checklist. *Journal of Mental Health Research in Intellectual Disabilities*, 4(4), 244-264.
3. Coppus, A. M. W. E. H., Evenhuis, H., Verberne, G. J., Visser, F., Van Gool, P., Eikelenboom, P., & Van Duijin, C. (2006). Dementia and mortality in persons with Down's syndrome. *Journal of Intellectual Disability Research*, 50(10), 768-777.
4. Fletcher, R. J., Barnhill, J., & Cooper, S. (2016). DM-ID-2: Diagnostic manual, intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston, NY: NADD Press.
5. Määttä, T., Tervo-Määttä, T., Taanila, A., Kaski, M., & Iivanainen, M. (2006). Mental health, behavior and intellectual abilities of people with Down syndrome. *Down Syndrome Research and Practice*, 11(1), 37-43. Retrieved from <https://library.down-syndrome.org/en-us/research-practice/11/1/mental-health-behaviour-intellectual-abilities-people-down-syndrome/>
6. Munir, K. (2019). *Mental health issues and Down syndrome*. Retrieved from <https://www.ndss.org/resources/mental-health-issues-syndrome/>
7. Smith, D. S. (2001). Health care management of adults with Down syndrome. *American Family Physician*, 64(6), 1031-1044. Retrieved from <https://www.globaldownsyndrome.org/wp-content/uploads/2011/08/11-2001-American-Family-Physician-Guidelines-For-Adults-with-DS.pdf>
8. Straccia, C., Baggio, S., & Barisnikov, K. (2014). Mental illness, behavior problems, and social behavior in adults with Down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*, 7(1), 74-90.

Check us out on social media!

