



states and found I/DD prevalence rates between 2.3% - 4.2% among Medicaid recipients (McDermott, et al., 2018).

One prevalence study of developmental disability drawn from National Health Interview Survey data from 2009 to 2017 found much higher rates, likely due to the inclusion of ADHD within this analysis. These researchers identified a prevalence rate for developmental disability of 16.93% of the population of children between 3 to 17. They noted a significant increase in the rate of developmental disability in the US between 2009 and 2017, with increases in ADHD, ASD, and intellectual disability accounting for most of this change (Zablotsky, et al., 2019).

There has been much attention to the increasing rates of ASD diagnosis over the past two decades. In 2020, 1 in 36 children were identified with ASD using data from the CDC’s Autism and Developmental Disabilities Monitoring Network. From 2000 to 2020, the rate increased from 6.7 children per 1000 to 27.6 children per 1000 (CDC, 2023). The increase in the number of children diagnosed with ASD may be due, in part, to increased awareness of and screening for ASD over the past two decades, as well as changes made to the diagnostic criteria under the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition (DSM-5), among other factors.

### I/DD and Behavioral Health Concerns

According to available survey data, people with I/DD report high rates of mental health conditions. The table below provides a comparison of Delaware and national behavioral health data from the 2017 – 2018 National Core Indicators Adult Consumer Survey. Among adults with I/DD who receive state services, Delaware respondents reported higher rates of some mental health conditions compared to the national sample (National Core Indicators, 2020).

<b>Condition</b>	<b>Delaware - NCI 2017-2018</b>	<b>US – NCI Average 2017-2018</b>
Mood Disorder	40%	30%
Anxiety Disorder	28%	27%
Behavior Challenges	40%	28%
Psychotic Disorder	17%	11%
Other Mental Illness / Psychiatric Diagnosis	10%	10%

Parents and guardians of adolescents with autism report that the children living in their homes experience high rates of depression and anxiety. Data from the National Survey of Children’s Health from 2016-2019 suggest that children diagnosed with both autism and ADHD have very high rates of depression and anxiety. Approximately 7 out of 10 adolescents with autism and ADHD are reported by parents and guardians to have anxiety, and nearly 4 out of 10 are reported to have depression (Accardo, Pontes & Pontes, 2022). A recent multi-state study of autistic adolescents found that by age 16 over half of the population had either a diagnosis of ADHD or anxiety. Suicidal ideation and behavior was noted for 16% of the population (Hughes, Shaw, & Patrick, 2023).

People with I/DD also appear to be at higher risk for suicide than people without disabilities (Marlow, et al., 2022; Moses, 2018), including higher rates of suicide attempts and death by suicide (Kolves, Fitzgerald, & Nordentoft, M, 2021; Kirby et al., 2019; Ludi et al., 2012). They also have higher rates of emergency department utilization than people without disabilities, in part because of emergency room visits for psychiatric conditions (Kalb, Stuart, & Vasa, 2019; Durbin, Balogh, Lin, Wilton, & Lunsy, 2018; Lunsy, et al., 2014). People with I/DD are also more likely to experience in-patient psychiatric hospitalization than individuals without I/DD (Righi, et al., 2018).<sup>1</sup>

### **Autism: Identity, Masking, Burnout**

Many individuals with autism prefer identify-first language – that is, referring to themselves as *autistic people*, rather than using person-first language, which is the preferred language for the greater disability community (Taboas, Doepke, & Zimmerman, 2022). Positive views of autistic identity are associated with better mental health outcomes (Cooper, Russell, Lei, & Smith, 2022; Price, 2022).

Autism *masking* or *camouflaging* is when a person attempts to hide features of their autism, for example, the desire to fidget or rock for self-calming purposes, not letting others know of focused interests, or hiding their sensory needs. Masking is associated with autistic burnout, which can lead to increased depression or anxiety (Cook, Hull, Crane, & Mandy, 2021; Price, 2022).

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<sup>1</sup> It is important to note that differences in these rates are not fundamentally associated with having an I/DD but may be related to the challenges and barriers that individuals frequently face.

There is limited research on substance use within the I/DD population. One review of existing literature suggests that while prevalence of substance use tends to be lower than that of the general population, the I/DD population is more susceptible to substance use disorders (SUD). Having a co-occurring psychiatric diagnosis is associated with an increased risk of developing an SUD within this population (Fulda et al., 2023). One analysis of data from the 2018 National Survey on Drug Use and Health found that people with cognitive disabilities have more than three times the odds of having a drug use disorder and two times the odds of alcohol use disorder compared to adults who do not have disabilities (Aram, Slopen, Arria, Liu, & Dallal, 2023). An analysis of Medicaid SUD treatment claims between 2008 and 2012 estimated an overall prevalence rate for SUD for people with intellectual disability and / or ASD as approximately 1% -2%, which was less than the rates for the general population. However, they noted increased SUD treatment claims for individuals with ASD during that time period (Roux, Tao, Marcus, Lushin, & Shea, 2022). Data suggests that while people with I/DD experience substance use disorders they may under-utilize treatment resources.

Researchers from the Netherlands have noted that I/DD status is typically not identified in treatment data (as is also the case in the US). To address this challenge, VanDerNagel and colleagues have used several methods to ascertain the prevalence of people with I/DD who use treatment services, including surveying key stakeholders, interviews, IQ tests, and examination of medical records with the conclusion that SUD is seen as a major concern among stakeholders, despite difficulties in determining a prevalence rate within this population (VanDerNagel, Duijvenbode, Ruedrich, Ay, & Schellekens; Sizoon, et al., 2010; VanDerNagel, et al., 2014). This research also demonstrates that the number of people with I/DD who receive SUD treatment services is likely undercounted.

## Trauma-Informed Care

Trauma is associated with greater risk for physical and behavioral health concerns (Trauma Matters Delaware, n.d.). Adverse childhood experiences (ACEs) are traumas that occur early in a person's life and can have a long-lasting impact on health and wellbeing. Studies show that people with I/DD have higher rates of ACEs compared to the general population. One survey of adults with I/DD in Pennsylvania that live in campus-based residences found higher rates of ACEs among this group than the general population, and childhood adversity was associated with chronic medical conditions in adulthood (Santoro, 2018). A 2018 literature review of ACEs and children with ASD found that this population is more likely to experience bullying, have divorced parents, and live in households with income insufficiency than the general population of children (Hoover, & Kaufman, 2018).

People with I/DD also experience higher rates of crime victimization. Data from the National Crime Victimization Survey (2017-2019) show that people with disabilities have rates of violent victimizations nearly four times that of people without disabilities. The rate for rape/sexual assault was more than four times that of the age-adjusted rate of people without disabilities. Violent victimization is highest for people with cognitive disabilities (83.3 per 1,000 versus 12.3 per 1,000 people without disabilities), yet it is less likely to be reported to police by people with disabilities than by people without disabilities (Harrell, 2021 – BJS report). Experiencing violence can put people at risk of developing behavioral health conditions, such as post-traumatic stress disorder, depression, or anxiety.

Given that individuals with I/DD are exposed to trauma throughout the lifespan, trauma-informed care is critical for this population. Behavioral health providers should screen for trauma and be aware of the ways in which it can contribute to depression, anxiety, and substance use disorder among other behavioral health concerns.

## Conclusion

Although the research is limited, what is available indicates that individuals with I/DD experience high rates of behavioral health concerns. There is a need for greater screening for I/DD and greater screening for behavioral health conditions among people with I/DD. Public health systems should consider these unique needs, identify ways to increase access and inclusion for behavioral health services, and provide evidence-based, trauma-informed approaches that best support the wide spectrum of needs for this population.

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