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What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness?

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The understanding that people can be dually diagnosed with intellectual disability (ID) and mental illness is relatively recent. Up until the last 30 to 40 years, it was assumed that people with ID could not also have a mental illness,¹ and behavioral challenges were seen as a consequence of cognitive limitations rather than possible symptoms of underlying psychiatric conditions. This view shifted as people with ID increasingly resided in and received supports in the community, as they exercised their rights in communicating and representing themselves, and as realization grew about the widespread and long-term impacts of trauma and abuse on health, mood, and behavior.

The understanding of how to provide services and supports to people who are dual diagnosed continues to deepen and expand. In this data brief we examine National Core Indicators[™] (NCI[™]) data from 2017-2018 to explore the characteristics and outcomes of people with dual diagnoses with the hope that it will add to a growing body of knowledge.

Background

Prior to the 1980s and 1990s, it was assumed that people with intellectual disabilities could not also have a mental illness,² and behavioral challenges were seen as a consequence of cognitive limitations. At the time, restraints, medication, and punishment were meted out to control behavior, with medications viewed as a means to restrain rather than as treatment for a condition.

These assumptions began to change in the latter part of the 20th century as a consequence of the movement of people out of institutions—a reform fueled by the community mental health movement, litigation regarding the rights of people with disabilities, and major landmark federal legislation including the Developmental Disabilities Act. This shift required the development of community capacity to support people with multiple physical, social, emotional and mental health needs and the growing knowledge of the role of trauma and abuse as precipitants of behavior issues became better understood. In 2007, the National Association for the Dually Diagnosed (NADD) in association with the American Psychiatric Association (APA) published the Diagnostic Manual – Intellectual Disability (DM-ID) as a resource to help with diagnosis for people with co-occurring ID and mental health conditions. And our understanding of the role of trauma and abuse as precipitants of behavior continues to evolve today.

The exact prevalence of mental illness among people with intellectual disabilities is a matter of some debate among researchers. According to Campbell & Malone (1991), estimates range from 14% to 70%.³ More recently, NADD has estimated that the prevalence is somewhere between 30% and 40%.⁴ Cooper et al (2007) also reported wide variation in the prevalence, citing the need for consistency in methodology of both clinical diagnosis and identification.⁵ All of this is in comparison to a well-documented estimate of 15% to 19% prevalence of mental illness within the general population.⁶ The one common factor among discussions of prevalence is the crucial and immediate need to identify the range of supports needed to maintain people with dual diagnosis in the community.

Identifying appropriate services and treatment for people with ID who have a mental health diagnosis is complicated by the fact that it requires collaboration between two separate public systems: mental health and I/DD. Each service system within a state's larger human service system has distinct administrative rules and regulations, making it difficult to navigate by service coordinators, families, and providers. Each step—from access, eligibility and treatment planning to authorization and payment for services—is complex. VanderShie-Bezyak (2003) identified several consequences of this bifurcation, including inaccessible and nonexistent services for the dually diagnosed, discontinuity of care (e.g., passing from one service element to the other), separate support systems unwilling to collaborate, people with challenging behaviors being regarded as undesirable, confusion of primary versus secondary disorders, and lack of professional training.⁷

There has been recent federal attention to the needs of people with dual diagnosis as part of the 21st Century Cures Act (Public Law 114-255). The Act addresses the needs of people with serious and persistent mental illness and identifies the need for states and community programs to: “provide for an organized community-based system of care for individuals with mental illness, and ... individuals with co-occurring disorders” (section 8008 (b)(5)(A)ii). Most recently, the National Association of State Mental Health Program Directors (NASMHPD) has put forth several resources to support the clinical diagnosis and treatment of this population, including a

white paper published in 2017 entitled “*The Vital Role of Specialized Approaches: Persons with Intellectual and Developmental Disabilities in the Mental Health System.*”^a

The understanding of how to provide services and supports to people who are dual diagnosed continues to deepen and expand. The intention of this data brief is to provide some insights, using NCI data from 2017-18, into the characteristics and outcomes of people with dual diagnoses with the hope that it will add to a growing body of knowledge.

NCI Data on People with Dual Diagnosis

To explore the characteristics and outcomes of people who are dual diagnosed with mental illness and intellectual disability, we analyzed NCI In-Person Survey data that was collected in 2017-18 by 35 states and the District of Columbia. For the following analysis, respondents who were reported to have both an ID diagnosis and at least one of the following diagnoses were included in the dually diagnosed cohort:

- Mood disorder
- Anxiety disorder
- Psychotic disorder
- Other mental health diagnosis

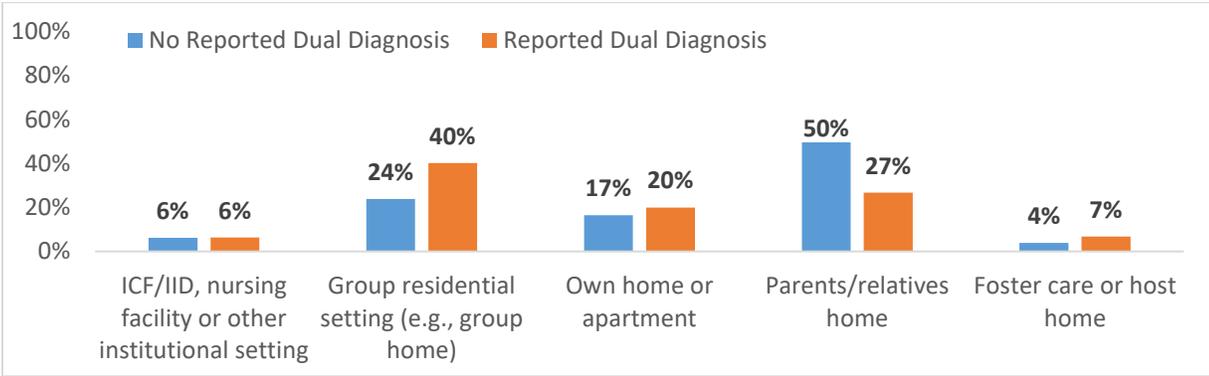
Of the 22,513 survey respondents, 10,729 (approximately 48%) met the criteria.^b The percentage of state respondents for whom a dual diagnosis was reported ranged from 34% to 64%.

In this brief, we include only those data that show a significance level of $p \leq .000$.^c Data are not weighted.

Demographics

Age. Those with a dual diagnosis have an average age of 44, compared to an average age of 42 among those without a dual diagnosis. Respondents age 40 and over were significantly more likely to have a dual diagnosis than those younger than 40 (51% vs. 44%). (N=22,456)

Residence Type. As shown below, people with dual diagnosis are significantly less likely to live at home with parents and significantly more likely to live in a group residential setting. (N=22,018)

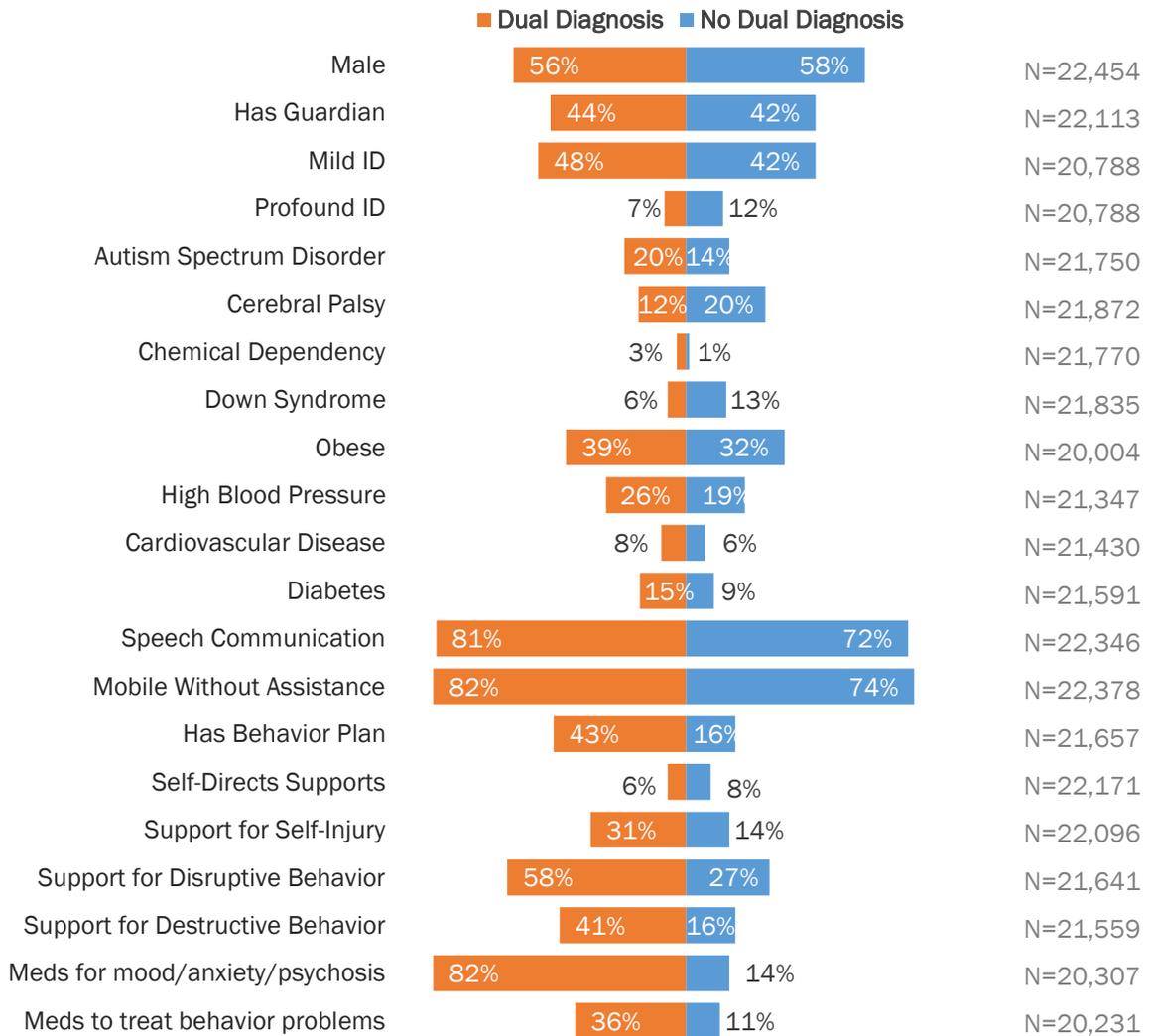


^a Available at https://www.nasmhpd.org/sites/default/files/TAC.Paper_.7.IDD_.Final_.pdf

^b “No,” “Don’t Know,” and missing responses to the questions on diagnosis of mental illness included in denominator.

^c Results from OR are excluded from this analysis.

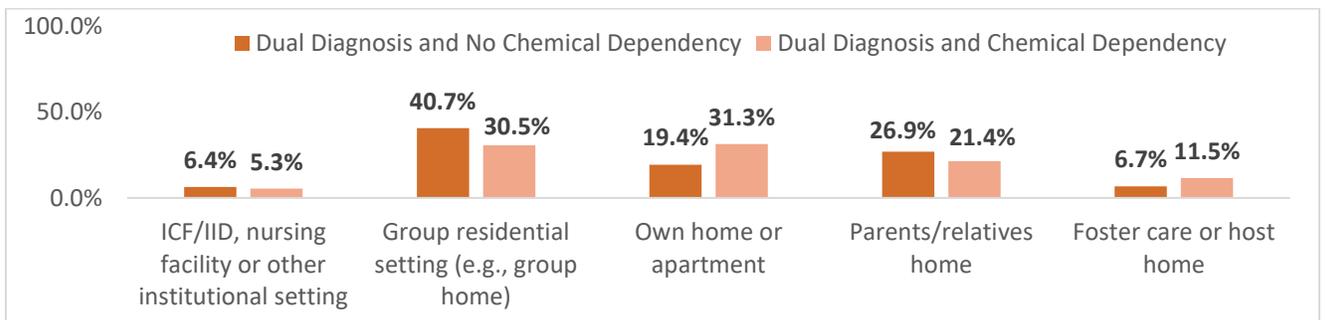
Additional Demographic Comparisons:



Further breakouts of some of these categories follow:

ASD. About half (54%) of people under 40 with autism have dual diagnosis and 64% of people over 40 with autism have dual diagnosis. Of those with ASD overall, 57% have a dual diagnosis; in comparison, 46% of those without ASD have a dual diagnosis. (N=21,750)

Chemical Dependency. As shown below, people with dual diagnosis and chemical dependency are more likely to live independently; people with dual diagnosis without chemical dependency are more likely to live in a parent or relative’s home. (N=10,221)



Outcomes

Choice

Of those not living in a parent or relatives' home, 58% of those with a dual diagnosis chose or had input in choosing their home, compared to 54% of those without a dual diagnosis. (N=12,417)

Of those with a dual diagnosis:

- 86% chose or had input in choosing their daily schedule, compared to 82% of those without a dual diagnosis. (N=21,914)
- 93% chose or had input into what to do during their free time, compared to 90% of those without a dual diagnosis. (N=21,941)
- 57% chose or had input into their day activity, compared to 55% of those without a dual diagnosis. (N=13,772)
- 89% chose or had input into what to buy with their spending money, compared to 83% among those without a dual diagnosis. (N=21,795)

Rights

More respondents (36%) with a dual diagnosis reported there are rules about having friends or visitors in their home than those without a dual diagnosis (33%). (N=12,494)

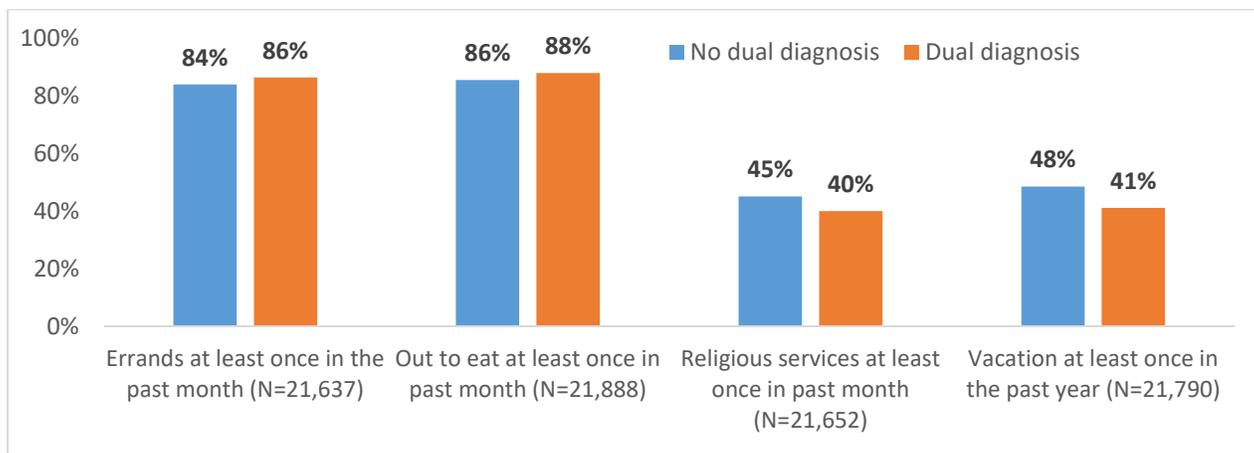
Fewer respondents (92%) with a dual diagnosis report that staff treat them with respect than those without a dual diagnosis (95%). (N=12,886)

Social Life

Regarding the friendships and relationships of those with and without dual diagnosis:

- 77% of those with a dual diagnosis report having friends other than staff or family, compared to 79% of those without a dual diagnosis report. (N=14,669)
- 47% of those with a dual diagnosis report wanting more help to contact friends, compared to 40% of those without a dual diagnosis. (N=13,945)
- 79% of those with a dual diagnosis report being able to see friends when they want, compared to 83% of those without a dual diagnosis. (N=12,653)
- 13% of those with a dual diagnosis report feeling often lonely, compared to 8% of those without a dual diagnosis. (N=14,214)

Community Inclusion



Regarding opinions of community activities, 87% of those without a dual diagnosis and 83% of those with a dual diagnosis report being able to go out and do the things they like to do (N=14,410). Similarly, 82% of those without a dual diagnosis and 77% of those with a dual diagnosis report being able to go out enough to do the things they like to do (N=13,493). Regarding leisure time at home, 87% of those without a dual diagnosis and 82% of those with a dual diagnosis report having enough things to do at home (N=14,545).

Employment/Volunteering

Around one-fifth (19%) of those without a dual diagnosis and 17% of those with a dual diagnosis report having a paid job in the community (N=21,953).

Health

- 71% of those without a dual diagnosis and 65% of those with a dual diagnosis reported being in excellent or very good health. (N=22,013)
- 85% of those without a dual diagnosis and 89% of those with a dual diagnosis reported having had a physical exam in the past year. (N=21,261)
- 79% of those without a dual diagnosis and 82% of those with a dual diagnosis reported having a dentist visit in the past year. (N=20,135)
- 60% of those without a dual diagnosis and 54% of those with a dual diagnosis reported having a vision exam in the past year. (N=18,381)
- 52% of those without a dual diagnosis and 56% of those with a dual diagnosis reported having a hearing test in the past 5 years. (N=14,375)

Summary

Respondents with dual diagnosis in the NCI sample were:

- Considerably more likely to need some or extensive support for both self-injurious behavior and disruptive behavior.
- More likely to take medications for a co-occurring mental health condition, but also more likely to report taking medications for a behavioral challenge.
- More likely to report wanting additional assistance to stay in touch with friends.
- More likely to report feeling lonely.

What Are the Policy Implications?

This data brief reveals what many anecdotal stories suggest: People with co-occurring intellectual or developmental disabilities and mental health conditions have unique needs that require complex supports in order to access their community in the same manner and to the same degree as those without co-occurring conditions.

With respect to medications, it is not uncommon for state I/DD systems to have regulations or policies prohibiting or significantly limiting the use of medications for controlling behavior. However, the NCI data reported here show a significant number of people taking medications for self-injurious, disruptive or destructive behavior. This data may suggest a need for further exploration of diagnoses to ensure that behavioral challenges are not inaccurately attributed to mental health conditions. It is crucial that accurate diagnostics be supported and aligned with accurate prescribing of medications—including the clear delineation of the purpose and desired results. Such nuanced distinction between medications to treat a mental health condition and those for behavioral purposes is difficult for skilled clinicians; for direct support professionals without a clinical background, the distinction may be lost completely. It is not unusual, for example, for primary care physicians to prescribe psychoactive medications to assist with insomnia or sleepwalking, which may actually be an unrecognized symptom of bipolar disorder. This area of practice requires significant effort among the state, private provider, service coordinators and health providers with both systems.

People with co-occurring I/DD and mental illness diagnoses are frequently admitted to emergency departments for intervention when a person's symptoms become sufficiently intense that families or service providers fear for the physical health or safety of the individual. It is not unusual for people to end up caught in an emergency department for several days.

State Promising Practices

NYSTART is one approach used to provide supports and services to people with a dual diagnosis in New York. START stands for Systemic, Therapeutic, Assessment, Resources and Treatment. The NYSTART Model provides prevention and intervention services to individuals with developmental disabilities (DD) and complex behavioral health needs through crisis response, training, consultation, and therapeutic supports. The goal is to create a support network that is able to respond to crisis needs at the community level. Providing supports that enable an individual to remain in their home or community placement is the first priority. NYSTART does not replace existing services in the community but provides training and technical assistance to enhance the ability of the community to support individuals with DD and co-occurring mental illness/complex behavioral needs.

Delaware has implemented the ACIST (Assertive Community Integration and Support Team) model. ACIST is an intensive support program that offers behavioral health, case management and psychiatric supports in a community-based holistic approach. People with dual diagnosis and supported by the Delaware Department of Developmental Disability Services receive crisis intervention, intensive case management, behavior analysis, psychiatric supports and monitoring of medical conditions in a multi-disciplinary model. Early results of the approach have proven promising as it has already shown a decline in ED utilization for people in the ACIST program.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit www.nationalcoreindicators.org.

We welcome your feedback and questions. If you want to discuss this report or have questions about NCI, please contact Dorothy Hiersteiner, NCI Coordinator, at dhiersteiner@hsri.org

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