Community Mental Health Journal
https://doi.org/10.1007/s10597-023-01091-4

ORIGINAL PAPER

Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities

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Received: 14 October 2022 / Accepted: 22 January 2023

Abstract

People with intellectual and developmental disabilities (IDD) have higher incidences of mental health conditions and behavioral support needs than people without IDD but may not receive needed care from community providers. We examined rates of co-occurring conditions in a representative sample of adults with IDD who use state funded services in Virginia. Using data from two datasets, we identified four categories of mental health and behavioral conditions. We used these categories to examine differences in individual- and system-level factors in people with and without co-occurring conditions. We found high rates of co-occurring conditions in our sample. We found important disability factors and system-level characteristics that were associated with having a diagnosed mental health condition or behavioral support needs. Differing patterns of diagnosis and treatment for co-occurring conditions suggests more work needs to be done to support people with IDD and co-occurring mental health conditions living in the community.

Keywords Intellectual and developmental disabilities · Mental health · Behavioral support

Introduction

Intellectual disability (ID) and developmental disability (DD) refer to distinct, but overlapping conditions. While intellectual disability refers to a significant limitation in intellectual functioning and adaptive behavior which begins prior to the age of 18, a developmental disability is a disability that occurs during the developmental period which may or may not include an intellectual disability (Schalock et al., 2019). While using precise language is vital, ID and DD are frequently referenced together in literature and in the provision of services. Schalock et al. (2019) suggest that the field of intellectual and developmental disabilities (IDD) is increasingly integrated, noting that ID and DD both emphasize limitations in human functioning, the rights of people with disabilities, and the need for individualized supports and community based environments. In this article, we will primarily use the term "IDD", with more specific language where appropriate.

Until relatively recently, clinicians and researchers believed that people with IDD could not have co-occurring mental health conditions (Gómez et al., 2021; Mazza et al., 2020). Under this early conceptualization, challenging behaviors, defined as culturally abnormal behaviors that posed a risk to the individual's safety or ability to interact with the community (Poppes et al., 2010), were attributed directly to a person's disability (Mazza et al., 2020). Recently, terminology has shifted away from labeling behavior as challenging or problematic in recognition that norms are culturally situated and that behavior often serves as communication (Friedman, 2021; García-Domínguez et al, 2022). We will primarily use the term "behavioral support

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Published online: 05 February 2023

needs" to reflect the language used in the data sources for this study.

Research has increasingly suggested that people with IDD can have a co-occurring mental health condition and may, in fact, have higher rates of mental health problems than people without IDD (Gómez et al., 2021; Ricciardi, 2013). This new understanding led to a debate in the field about the relationships between behavioral support needs and mental health conditions in people with IDD (Baudewijns et al., 2018; Gómez et al., 2021; McCarthy et al., 2010; Painter et al., 2018). Ongoing research is needed to disaggregate the interrelated presentations of mental health conditions and behavioral support needs to ensure that people with IDD and co-occurring conditions receive the proper diagnoses and support.

Mental Health Conditions and IDD

Literature suggests that people with IDD have higher incidences of mental health conditions than people without IDD, though the exact rates differ significantly based on the data source, population, and diagnostic criteria (Ricciardi, 2013). An analysis of Medicaid data from 2016 found that 59% of beneficiaries with IDD had at least one mental health condition (Reichard et al., 2019). Comparatively, a meta-analysis of articles published from 1985 to 2018 found a somewhat lower prevalence of 33.6% (Mazza et al., 2020). Studies using the National Core Indicators-In Person Survey (NCI-IPS), which uses representative samples of people with IDD who use state-funded services in the U.S. and is a key data source for this study, found rates of IDD with co-occurring mental health conditions ranging from 36.6% in 2009–2010 (Scott & Havercamp, 2014) to 44.8% in 2012–2013 (Esler et al., 2019). In contrast, approximately 21% of adults in the U.S. had a diagnosable mental health condition in 2020 (NAMI, 2022).

Despite the prevalence of mental health conditions, research suggests that people with IDD may not be receiving adequate mental health care in the community. Compared to people without IDD, people with IDD appear more likely to seek care in the emergency room for mood and anxiety disorders and to be hospitalized for mood and psychotic disorders (Lauer et al., 2019). Additionally, Lunsky and Balogh (2010) found that patients with IDD were more likely to have multiple hospitalizations related to the presence of mental health challenges compared to people without disabilities. Both mental health practitioners and people with IDD have expressed difficulties when they access mental health care, including inadequately prepared practitioners, poor service quality, and limited understanding of IDD (Whittle et al., 2017). Similar results have been found to be true in subsets of the IDD population, including autistic adults (Maddox et al., 2019).

Behavioral Support Needs and IDD

As with mental health conditions, the rates of behavioral support needs in people with IDD vary by study. An analysis of adults with intellectual disabilities in the United Kingdom reported that 18.1% of respondents had behavioral support needs (Bowring et al., 2017). In the United States, a study using NCI-IPS data found that nearly 45% of respondents with IDD needed some degree of support for self-injurious, destructive, or disruptive behavior. (Scott & Havercamp, 2014). More specifically, an investigation using 2015–2016 NCI-IPS data found that 23.2% of respondents needed some degree of support specifically for self-injurious behavior (SIB) and that SIB was associated with other behavioral support needs (Bradley et al., 2018).

Existing literature suggests that behavioral support needs are related to, but distinct from mental health conditions for people with IDD (McCarthy et al., 2010). An analysis of people with IDD in England found that 53.7% of participants with challenging behavior did not have a formally diagnosed mental health condition (McCarthy et al., 2010). Furthermore, presence of a mental health condition did not predict challenging behavior in this sample (McCarthy et al., 2010).

Interactions Between IDD, Mental Health, and Behavioral Support Needs

Part of the challenge in determining rates of mental health conditions and behavioral support needs behavior among people with IDD is disentangling the complex relationships between these constructs. For example, higher levels of intellectual disability (severe or profound) were associated with higher rates of documented behavioral support needs (García-Domínguez et al, 2022; Kats et al., 2013; Scott & Havercamp, 2014) and lower rates of mental health diagnoses (Scott & Havercamp, 2014), compared with people with mild or moderate IDD. McCarthy et al. (2010) analyzed clinical assessments from a specialist mental health service and reported that more severe levels of ID positively predicted challenging behaviors while a mental health diagnosis did not. In contrast, Painter et al. (2018) found that both functional limitations and mental health conditions were associated with challenging behaviors, particularly for people with more significant intellectual disabilities.

Beyond one's level of intellectual disability, specific disability diagnoses may be related to mental health conditions and/or behavioral support needs. Esler et al. (2019) reported

that people with both autism and IDD were less likely to be diagnosed with mood or psychotic disorders than people with only IDD and more likely to be diagnosed with anxiety disorders and challenging behavior. Additionally, people with both autism and IDD were more likely to be prescribed psychotropic medication than people with IDD only, beyond what would be expected by differences in diagnosis (Esler et al., 2019; Kats et al., 2013).

At the IDD service system level, a prior analysis using NCI-IPS data found that mental health conditions and behavioral challenges were associated with a person's residence type (García-Domínguez et al, 2022; Scott & Havercamp, 2014). People with IDD who lived with their families had the lowest rates of mental health conditions compared to all other settings (Scott & Havercamp, 2014), though the causes for this relationship were undetermined. Similarly, behavioral challenges were lower for people with IDD who lived with family or independently compared to people residing in group homes or institutions (Scott & Havercamp, 2014). Notably, most previous authors did not include host homes (defined as a licensed service in which a "licensed provider agency contracts with individuals or couples to provide Medicaid HCBS waiver services in their own homes for up to two individuals with I/DD"; [Virginia Register of Regulations, 2019]) as a potential residence type. Though our previous research (Dinora et al., 2020) has indicated that host homes play an important role in promoting community inclusion for people with IDD, particularly with serious behavioral or medical support needs are present, state regulations vary from state to state, meaning that host homes may not operate in the same way in different locations.

Importance to Community Mental Health

Community mental health practitioners are often the first line of intervention for adults with IDD who are also experiencing mental health and/or behavioral challenges. Yet research has suggested that community mental health workers feel ill-prepared to meet the needs of people with IDD (Maddox et al., 2019; Whittle et al., 2017). Additionally, difficulty accessing mental health services may have been exacerbated since the onset of the COVID-19 pandemic (Lake et al., 2021). Understanding the presentation of mental health disorders and behavioral support needs among people with IDD, an understudied and underserved population in community mental health, may help practitioners better prepare for meeting the needs of this population.

Study Objectives

This study has one primary objective, supported from analyses of a representative sample of state-funded service users with IDD in Virginia.

(1) To explore and describe different patterns of mental health diagnosis and reported behavioral support needs based on demographic and disability characteristics, service usage, and assessed support needs.

Methods

Ethical Oversight

This study was reviewed and approved by the institutional review board at the authors' affiliated university.

Data Sources

Data for this study came from two sources, merged at the level of the individual using a unique identifier to form a single large dataset of Medicaid long term services and supports (LTSS) users with IDD from one U.S. state. To the authors' knowledge, this data merger process is novel, and responds to calls to use merged administrative datasets to better understand outcomes experienced by people with IDD (Havercamp et al., 2019; Wagner et al., 2019).

National Core Indicators In-Person Survey

The NCI-IPS is a collaborative project between the Human Service Research Institute (HSRI), the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and participating states to monitor quality of life outcomes for people with IDD over time and across states. Our study used data specifically from Virginia. Respondents are randomly selected from all Home and Community Based Services (HCBS) users of the participating state's Developmental Disability (DD) waiver. We used Virginia's data from the 2017 and 2018 NCI-IPS cohorts, as provided by the state's DD agency. Because participants in each cohort are randomly selected, chances of the same respondent appearing in both cohorts are minimal. The state randomly selects a cohort of about 800 HCBS users with IDD to complete the NCI-IPS each year.

The NCI-IPS is a face-to-face interview with adults 18 years or older who use at least one state-funded service in addition to case management. Data for this study came from the background section and Section II of the NCI-IPS.

The background section is answered using case files prior to the interview (typically by a case manager) and includes demographic information, data about specific diagnoses and medications, and basic information about services used by the person with IDD. Section II may be answered by the respondent with IDD or a proxy who knows them well in instances when the participant is not able to respond independently. Section II contains objective questions about outcomes in a number of domains, including community participation, rights, and personal choices.

Supports Intensity Scale

Our second dataset, obtained from the state's DD agency, was the Supports Intensity Scale, Adult version (SIS-A; Thompson et al., 2015). The SIS-A is a nationally validated inventory that is administered in many U.S. states to assess the support needs of people with IDD. Results from the SIS-A are typically used for program planning and resource allocation by state agencies. The SIS-A assesses support needs in six general domains– Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, and Social Activities—as well as exceptional medical and behavioral support needs (Thompson et al., 2015). For this study, we used SIS data for all participants who had valid NCI-IPS and Medicaid claims on file for the years of interest in this study.

Variables

Mental Health and Behavioral Support Needs

We created four categories of participants to guide our analyses. Questions from the background section of the NCI-IPS were used to identify respondents with only mental health diagnoses, only behavioral support needs, neither mental health conditions nor behavioral support needs (hereafter referred to as "none"), and both a mental health diagnosis and behavioral support needs (hereafter referred to as "both"). The variables described here cover the extent of data about formal mental health diagnoses and documented behavioral support needs available in the background section of NCI-IPS.

Throughout this paper, these four categories (mental health only, behavioral support only, both, and none) will be referred to as our mental health/behavior categories. The mental health group included respondents who had a diagnosis of a mood disorder (depression, bipolar disorder, etc.), anxiety disorder (obsessive compulsive disorder, generalized anxiety, panic disorder, etc.), psychotic disorder (schizophrenia, hallucinations, etc.), and/or other mental health diagnosis. The behavioral support group included respondents who had diagnosed behavioral challenges (ADHD, aggression, self-injurious behavior, pica, etc.) or who needed support for self-injurious behavior (attempts to cause harm to one's own body), destructive behavior (externally directed, defiant behavior), and/or disruptive behavior (behavior that interferes with the activities of others). Respondents with both a formal mental health diagnosis and behavioral support needs were classified as "both" while respondents with no formal diagnoses or support needs documented in the NCI-IPS were classified as "neither".

The SIS-A uses a similar classification system for behavioral support needs and includes questions about externally directed destructiveness (assaults, emotional outbursts, property destruction, stealing), self-directed behavior (self-injury, suicide attempts, pica), sexual behavior, and other behavioral support. For this study, we used established criteria to identify participants with exceptional behavioral support needs.

Covariates

Independent variables also came from the background section of the NCI-IPS and included demographics, disability characteristics, and system level factors. Demographic variables included age, race, and gender. Disability characteristics included level of intellectual disability (mild, moderate, severe, and profound), mobility support needs (independent or requires assistance from mobility aids or another person), communication support needs (communicates using spoken language or another method), and overall level of support (SIS-A). System-level variables included residence type, guardianship status, and whether the individual with IDD had a behavior plan, took medication for behavior management (described as a "drug prescribed for a behavior modification purpose"), or took medication for a diagnosed mental health condition.

Analyses

Analyses for this study were conducted in R (R Core Team, 2013). First, we ran descriptive statistics and bivariate analyses to identify overall rates of mental health conditions and behavioral support needs in our sample and differences between the four mental health/behavioral categories in terms of covariates and personal opportunity outcomes. We then used the Chi-square test of association for assessing group differences on categorical variables and analysis of variance (ANOVA) for assessing group differences on continuous variables. The significance level for all analyses was set at $\alpha = 0.05$.

Results

Participants

Rates of specific mental health conditions and behavioral support needs are presented in Table 1. Approximately 33% ($n=532$) of the sample had at least one diagnosed mental health condition, with or without behavioral support needs. Mental health categories were not mutually exclusive, so some respondents reported more than one mental health diagnosis. Respondents were most likely to have a mood disorder (29.18%, $n=468$) or anxiety disorder (24.38%, $n=391$). Additionally, 57.29% ($n=919$) of the sample had documented behavioral support needs, with or without a diagnosed mental health condition. Respondents were most likely to need support for disruptive behavior (46.63%, $n=748$) or for unspecified behavioral challenges (34.16%, $n=548$).

Participant and system characteristics by mental health category are presented in Table 2. After merging the data sets, our total sample was 1604 service users with IDD. Overall, respondents were most likely to have mild (30.93%) or moderate (38.28%) intellectual disability. Respondents were generally male (60.60%) and White (62.28%) or Black (29.17%). A small number of respondents reported their race as Asian, Latinx, Native Hawaiian or Pacific Islander, or Native American. "Other" was offered as an option for gender but was not selected by any respondents. The mean age was 44.66 (SD = 16.07) with participants ranging from 18 to 98 years old. Slightly more than half of respondents took at least one medication for a psychiatric disorder (54.24%, $n=870$) and 28.43% ($n=456$) took medication to manage behavior. Notably, only 20.32% ($n=326$) of respondents had a formal behavior management plan.

Table 1 Rates of mental health conditions and behavioral support needs

	N (%)
Mental Health Conditions	
Mood Disorder	468 (29.18)
Anxiety Disorder	319 (24.38)
Psychotic Disorder	229 (14.28)
Other	139 (8.67)
Behavioral Support Needs	
Disruptive Behavior	748 (46.63)
Behavioral Condition	548 (34.16)
Destructive Behavior	509 (31.73)
Self-injurious Behavior	457 (28.49)

Mental Health Categories

Among respondents with a diagnosed mental health condition, 20.20% ($n=208$) did not have reported behavioral challenges and were classified as our "mental health condition" category, while 37.09% ($n=595$) had a diagnosed mental health condition and behavioral support needs and were classified as "both." Approximately 20% ($n=324$) of respondents only had behavioral support needs and were classified as our "behavioral support" category. Finally, 29.74% ($n=477$) of respondents had neither condition and were classified as "neither"."

Factors Associated with Mental Health Category

Disability Characteristics

Bivariate analysis revealed several significant differences between the four mental health/behavior categories (mental health only, behavioral support only, both, neither). Significant differences are noted in Table 2. A person's status in our four-category conceptualization of mental health and behavior was associated with both level of ID (X^2 (9, $N=91.39$, $p<0.001$) and SIS-A (F (3, 1267) = 22.93, $p<0.001$). People who had only behavioral support needs were more likely to have severe or profound ID and higher overall SIS-A scores compared to respondents in the other three categories. Conversely, people with a formal mental health diagnosis, with or without behavioral support needs, tended to have mild or moderate ID and lower SIS-A scores. Mental health category was also associated with communication (X^2 (3) = 30.94, $p<0.001$), mobility (X^2 (3) = 24.92, $p<0.001$), and autism (X^2 (3) = 66.07, $p<0.001$). People who had a formal mental health diagnosis (with or without behavioral support needs) were more likely to communicate verbally and people in the "neither" category were less likely to need mobility support. People with only behavioral support needs were more likely to have an autism diagnosis.

System Factors

Importantly, we found congruence between two measures of behavioral support needs: the NCI-IPS and the SIS-A. Exceptional behavioral support needs, as measured by the SIS-A, was significantly associated with the mental health category (X^2 (3) = 24.69, $p<0.001$). People in the "both" category were more likely to have exceptional behavioral support indicated by the SIS-A while those in the "neither" category were significantly less likely to be identified as having high behavioral support needs.

Table 2 Mental health/behavior group differences

Characteristic	None ($N=477$)	Mental health ($N=208$)	Beh. support needs ($N=324$)	Both ($N=595$)	Total ($N=1604$)	df	X^2 or F
Gender (1599)						3	6.93
Male	279 (58.99%)	122 (58.65%)	217 (66.98%)	351 (59.09%)	969 (60.60%)		
Female	194 (41.01%)	86 (41.35%)	107 (33.02%)	243 (40.91%)	630 (39.40%)		
Age (1491)						3, 1487	18.48***
Mean (SD)	45.56 (16.94)	50.85 (16.49)	40.29 (14.93)	44.14 (15.09)	44.66 (16.07)		
Race (1604)							
White	263 (55.14%)	134 (64.42%)	212 (65.43%)	390 (65.55%)	999 (62.28%)	3	14.84*
Black	137 (28.72%)	67 (32.21%)	90 (27.78%)	174 (29.24%)	468 (29.18%)	3	1.28
Latino	7 (1.47%)	3 (1.44%)	10 (3.09%)	12 (2.02%)	32 (2.00%)	3	2.98
Asian	12 (2.52%)	0 (0.00%)	12 (3.70%)	11 (1.85%)	35 (2.18%)	3	8.7*[a]
Level of ID (1387)						9	91.39***
Mild	102 (27.57%)	79 (43.41%)	46 (16.20%)	202 (36.66%)	429 (30.93%)		
Moderate	123 (33.24%)	69 (37.91%)	113 (39.79%)	226 (41.02%)	531 (38.28%)		
Severe	71 (19.19%)	20 (10.99%)	65 (22.89%)	77 (13.97%)	233 (16.80%)		
Profound	74 (20.00%)	14 (7.69%)	60 (21.13%)	46 (8.35%)	194 (13.99%)		
Mobility (1604)						3	24.92***
Independent	362 (75.89%)	133 (63.94%)	205 (63.27%)	373 (62.69%)	1073 (66.90%)		
Assistance	115 (24.11%)	75 (36.06%)	119 (36.73%)	222 (37.31%)	531 (33.10%)		
Communication (1604)						3	13.63**
Speech	325 (68.13%)	118 (56.73%)	214 (66.05%)	353 (59.33%)	1010 (62.97%)		
Other	152 (31.87%)	90 (43.27%)	110 (33.95%)	242 (40.67%)	594 (37.03%)		
Autism (1604)						3	66.07***
No	432 (90.57%)	183 (87.98%)	219 (67.59%)	473 (79.50%)	1307 (81.48%)		
Yes	45 (9.43%)	25 (12.02%)	105 (32.41%)	122 (20.50%)	297 (18.52%)		
SIS-A (1271)						3, 1267	22.93***
Mean (SD)	0.02 (10.09)	-3.07 (9.68)	3.90 (7.499)	-0.28 (8.42)	.36 (9.14)		
Guardian (1576)						3	17.93***
No	278 (60.04%)	128 (62.75%)	149 (47.00%)	346 (58.45%)	901 (57.17%)		
Yes	185 (39.96%)	76 (37.25%)	168 (53.00%)	246 (41.55%)	675 (42.83%)		
Type of Home (1588)						18	151.50***
Group 2–3	25 (5.31%)	16 (7.69%)	23 (7.14%)	40 (6.81%)	104 (6.55%)		
Group 4–6	106 (22.51%)	62 (29.81%)	112 (34.78%)	245 (41.74%)	525 (33.06%)		
Group 7–15	17 (3.61%)	15 (7.21%)	12 (3.73%)	39 (6.64%)	83 (5.23%)		
Independent	29 (6.16%)	31 (14.90%)	14 (4.35%)	42 (7.16%)	116 (7.30%)		
Family	204 (43.31%)	51 (24.52%)	118 (36.65%)	121 (20.61%)	494 (31.11%)		
Host	40 (8.49%)	17 (8.17%)	34 (10.56%)	82 (13.97%)	173 (10.89%)		
Other	50 (10.62%)	16 (7.69%)	9 (2.80%)	18 (3.07%)	93 (5.86%)		
Medication for mental health condition (1604)						3	778.57***
No	430 (90.15%)	30 (14.42%)	214 (66.05%)	60 (10.08%)	734 (45.76%)		
Yes	47 (9.85%)	178 (85.58%)	110 (33.95%)	535 (89.92%)	870 (54.24%)		
Medication for behavior (1604)						3	324.41***
No	466 (97.69%)	181 (87.02%)	206 (63.58%)	295 (49.58%)	1148 (71.57%)		
Yes	11 (2.31%)	27 (12.98%)	118 (36.42%)	300 (50.42%)	456 (28.43%)		
Behavior plan (1604)						3	214.59***
No	461 (96.65%)	198 (95.19%)	239 (73.77%)	380 (63.87%)	1278 (79.68%)		
Yes	16 (3.35%)	10 (4.81%)	85 (26.23%)	215 (36.13%)	326 (20.32%)		

*$p<.05$, **$p<.01$, ***$p<.001$

[a]Chi-square may be inaccurate due to low cell count

A person's status in our four category classification was also associated with taking medication for behavioral support (X^2 (3) = 324.41, $p < 0.001$) and for a mental health condition (X^2 (3) = 778.57, $p < 0.001$). Respondents with diagnosed mental health conditions were more likely than those without a diagnosis to take psychotropic medication, especially if they had both a mental health condition and behavioral support needs. Similarly, people with reported behavioral support needs were more likely to take medication to manage behavior, especially if they also had a documented mental health condition. It should be noted that 33.95% ($N = 110$) of respondents with behavioral support needs only were taking medication for a mental health condition without an official diagnosis.

Mental health/behavior category was also associated with having a behavior plan (X^2 (3) = 214.59, $p < 0.001$); people with behavioral support needs, with or without a mental health diagnosis, were more likely to have a behavior plan. However, rates of medication use were higher than rates of having a behavior plan for both groups. While about one-third of respondents with behavioral support needs only took medication "for a mental health condition", only 26.23% ($N = 85$) had a behavior plan. For those with both behavioral support needs and a mental health diagnosis, 89.99% ($N = 535$) took psychotropic medication and 36.13% ($N = 215$) had a behavior plan.

Having behavioral support needs or both behavior support and a mental health diagnosis was significantly associated with having a legal guardian (X^2 (3) = 17.93, $p < 0.001$). Mental health category was also associated with a respondents' residence type (X^2 (18) = 151.50, $p < 0.001$). People with behavioral support needs or both were more likely to live in host homes, while people with no condition or only behavioral support needs were more likely to live with family. People with only mental health conditions were more likely to live independently.

Discussion

We found high rates of diagnosed mental health conditions and behavioral support needs in our randomly selected sample of people with IDD who used state-funded disability services in Virginia. The levels of reported mental health diagnoses and behavioral support needs reported in Table 2 are roughly consistent with levels reported previously by other researchers (Esler et al., 2019; Scott & Havercamp, 2014) and well above typically reported prevalence rates for people without IDD, also consistent with prior findings (National Alliance on Mental Illness [NAMI], 2022; Ricciardi, 2013). The rates of behavioral support needs in our sample were also roughly consistent with the work of other authors (Scott & Havercamp, 2014).

Our study found a complex web of associations between IDD-related factors, mental health, and behavioral support needs. Level of intellectual disability (mild, moderate, severe, profound) played a particularly important role in our analyses, sometimes in ways that we did not anticipate. For instance, people with severe and profound IDD tended to be more likely than their peers with mild or moderate IDD to only have identified behavioral support needs in the absence of any mental health diagnosis. Conversely, people with mild or moderate IDD showed a tendency toward having mental health diagnoses, either with or without behavioral support needs. These findings pointed to an interesting dichotomy, where it appears possible that case managers, community mental health professionals and service planners may have a tendency to identify and plan around mental health supports for people with mild or moderate IDD and around behavioral needs for people with severe or profound IDD. Though there could be many explanations for these observed relationships, one possibility is the presence of clinician bias. As other authors (Kildahi et al., 2020) have pointed out, if a clinician is not looking for a particular condition, they will not find it, opening the possibility that clinicians may not be looking for mental health conditions among people with severe and profound IDD.

Though more study is necessary in order to make causal claims, based on our results there is some indication that a person's communication method may be associated with the identification of mental health and behavioral concerns. In our study, having a mental health condition, either with or without behavioral support needs, was associated with mild or moderate IDD as well as communication via verbal speech. Conversely, study respondents with severe or profound IDD were more likely to have behavioral support needs (without mental health diagnosis) and were also more likely to communicate without using speech. This observation about the role of speech as one's primary form of communication may suggest the challenge with identifying mental health difficulties among people who do not communicate via speech, which would be logical the challenges of communicating the nuances of mental or emotional unease (Gómez et al., 2021). It may also point to the fact that professionals who support people with IDD may need to take more time to understand how people with more severe IDD communicate and express their mental and emotional state in the absence of speech (Gómez et al., 2021). It is worth noting that behavior in and of itself is often a form of communication, so understanding what a person with more severe IDD is attempting to communicate via their behavior is also important (Gómez et al., 2021).

The finding that behavior plans were associated with documented behavioral support needs is not surprising but is encouraging as it may suggest that these plans are being used as intended. However, at least in Virginia, the use of

behavior plans continues to lag far behind pharmacological interventions for behavioral support needs, to be described in more detail in the following section. Behavior plan usage was higher for people in the "both" category (36.13%) than for those with only behavioral support needs (26.23%). Additionally, having exceptional behavioral support needs indicated by the SIS-A was significantly associated with the "both" category, but not with the "behavioral support only" category. More research is needed to better understand if and why people with behavioral support needs without a mental health diagnosis are not receiving additional services, even though they may be useful. Though speculative, it is possible that the presence of an official diagnosis triggers the development of other formal supports in ways that the presence of behavioral support needs alone does not.

Clinical Implications

Our study descriptively analyzed patterns of psychotropic medication use in our sample. Consistent with the work of other researchers (Esler et al, 2019; García-Domínguez et al, 2022; Lunsky & Modi, 2018) we found widespread use of medications to manage mental health and behavioral conditions, even when formal diagnoses were not noted. We also found that NCI-IPS respondents were more likely to use medications to manage behavioral support needs than they were to have a behavior management plan on file. These findings may suggest a tendency by clinicians to prescribe medications for people with IDD without exploring other options for managing mental health conditions and behavior, such as talk therapy or referral for behavioral analysis (García-Domínguez et al, 2022). As Ramerman et al. (2018) noted, both the presence of behavioral support needs and a mental health condition and the use of psychotropic medications can have negative consequences for quality of life for people with IDD. Considering the potential short and long-term side effects of medication use and the consequences of behavioral and mental health challenges in tandem is critical for providing person-centered clinical care, with the goal of addressing an individual's underlying need, rather than merely extinguishing a behavior (Gómez et al., 2021). Furthermore, research suggests that appropriate staff training in positive behavior support can reduce behavioral support needs without pharmacological interventions (Friedman, 2021; McGill et al., 2018).

The relationships between a person's primary communication method, level of ID, and the presence of a mental health diagnosis also have important clinical implications for the treatment and management of mental health conditions in people with IDD. In our study, respondents with mild and moderate levels of ID who communicated verbally were more likely to have a formal diagnosis of a mental health condition. This relationship is reflected in research on non-pharmacological interventions for people with IDD and a mental health condition. Psychological therapy options for people with IDD remain under-researched, particularly for people with severe and profound IDD (Evans & Randle-Phillips, 2020; Gómez et al., 2021; Hamers et al., 2018). Literature suggests that they may be successful with the appropriate adaptations and attention to individual needs, but most studies have focused on people with mild and moderate levels of ID (Evans & Randle-Phillips, 2020; Gómez et al., 2021; Hamers et al., 2018). This lack of evidence-based treatment may leave community mental health providers unprepared to support people with mental health conditions and moderate or severe IDD, forcing them to default to pharmacological interventions (Gómez et al., 2021; Hamers et al., 2018).

Limitations and Future Research

While this study offers important insights on co-occurring mental health conditions and/or behavioral support needs in people with IDD, there are limitations that must be considered. Our sample consisted of adults with IDD in Virginia who use disability services. Literature suggests that only about 20% of people with IDD in the United States use state funded services (Larson et al., 2020). Additionally, state policies around medication management, behavior plans, and mental health treatment for people with IDD may vary considerably, so that results from this study may not be generalizable to other states or outside of the US.

Additionally, all analyses in this study are descriptive in nature and cannot be used to imply causation or anything more than speculative conclusions about relationships between more than two variables. More research is needed to better understand the relationships between mental health conditions, behavioral support needs, and services for people with IDD.

The role of pharmacological treatment among our study's participants was somewhat unclear. Medications were widely prescribed for both mental health and behavior management, but the effects of those medications in actually reducing the presentation of mental health symptoms and behavioral support needs is unclear and warrants more study. Additionally, we do not have data to support analyses related to the specific factors that led to prescription of psychiatric medications in the first place. Since the use of medication in our sample of people with IDD substantially outpaces observations from people without IDD (Brauer et al., 2021; Terlizzi & Norris, 2021), this question ultimately warrants further study.

Likewise, the role of formal behavioral management plans requires future research to illuminate whether they are

effective. A report to the Department of Justice found that Virginia lacked the needed behavioral specialists, limiting access to behavior support services, including behavior plans (Report of the Independent Reviewer, 2021). Furthermore, the programming that was in place did not meet established quality guidelines (Report of the Independent Reviewer, 2021) Given the evidence that appropriate staff training and support can reduce behavioral support needs for people with IDD (McGill et al., 2018), the use of formal behavior management plans has important implications at the individual- and system-levels and deserves additional study.

Finally, this study tells us little about how either mental health conditions or behavioral challenges relate to important life outcomes such as employment, physical health, social inclusion, or community participation. Additional study to understand such relationships would be very helpful to the IDD and community mental health fields.

Conclusions

Though limited by the scope of the datasets and the analyses employed, this study provides new insight into the presentation of mental health and behavioral support needs of people with IDD, an understudied population in the community mental health field. We found interesting associations between level of IDD, communication style, and the presentation of mental health and behavioral support needs, with useful implications for community mental health workers. More study is necessary and can help us develop a more nuanced understanding of how people with IDD present mental health and their behavioral support needs.

Funding This work was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research [Grant Number 901FRE0015-02-0].

References

Baudewijns, L., Ronsse, E., Verstraete, V., Sabbe, B., Morrens, M., & Bertelli, M. O. (2018). Problem behaviours and major depressive disorder in adults with intellectual disability and autism. *Psychiatry Research, 270*, 769–774. https://doi.org/10.1016/j.psychres.2018.10.039

Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & Griffith, G. M. (2017). Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. *British Journal of Clinical Psychology, 56*(1), 16–32. https://doi.org/10.1111/bjc.12118

Bradley, V., Hiersteiner, D., Rotholz, D., Maloney, J., Li, H., Bonardi, A., & Bershadsky, J. (2018). Personal characteristics and outcomes of individuals with developmental disabilities who need support for self-injurious behaviour. *Journal of Intellectual Disability Research, 62*(12), 1043–1057. https://doi.org/10.1111/jir.12518

Brauer, R., Alfageh, B., Blais, J., Chan, E., Chui, C., Hayes, J., Man, K., Lau, W., Yan, N., Beykloo, M., Wang, Z., Wei, L., & Wong, I. (2021). Psychotropic medicine consumption in 65 countries and regions, 2008–19: A longitudinal study. *The Lancet Psychiatry, 8*(12), 1071–1082. https://doi.org/10.1016/S2215-0366(21)00292-3

Dinora, P., Bogenschutz, M., & Broda, M. (2020). Identifying predictors for enhanced outcomes for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 58*(2), 139–157. https://doi.org/10.1352/1934-9556-58.2.139

Esler, A., Hewitt, A., Hall-Lande, J., Pettingell, S. L., & Houseworth, J. (2019). Psychotropic medication use for adults with autism spectrum disorder who receive services and supports through adult developmental disability services in the United States. *Journal of Autism and Developmental Disorders, 49*(6), 2291–2303. https://doi.org/10.1007/s10803-019-03903-7

Evans, L., & Randle-Phillips, C. (2020). People with intellectual disabilities' experiences of psychological therapy: A systematic review and meta-ethnography. *Journal of Intellectual Disabilities, 24*(2), 233–252. https://doi.org/10.1177/1744629518784359

Friedman, C. (2021). Reducing 'challenging' behavior by training support staff to promote dignity and respect. *Journal of Developmental and Physical Disabilities, 33*(3), 449–458. https://doi.org/10.1007/s10882-020-09757-7

García-Domínguez, L., Navas, P., Verdugo, M. Á., Arias, V. B., & Gómez, L. E. (2022). Psychotropic drugs intake in people aging with intellectual disability: Prevalence and predictors. *Journal of Applied Research in Intellectual Disabilities, 35*(5), 1109–1118. https://doi.org/10.1111/jar.12996

Gómez, L. G., Navas, P., Verdugo, M. Á., & Tassé, M. J. (2021). Empirically supported psychological treatments: The challenges of comorbid psychiatric and behavioral disorders in people with intellectual disability. *World Journal of Psychiatry, 11*(11), 1039–1052. https://doi.org/10.5498/wjp.v11.i11.1039

Hamers, P. C. M., Festen, D. A. M., & Hermans, H. (2018). Non-pharmacological interventions for adults with intellectual disabilities and depression: A systematic review. *Journal of Intellectual Disability Research, 62*(8), 684–700. https://doi.org/10.1111/jir.12502

Havercamp, S. M., Krahn, G. L., Larson, S. A., Fujiura, G., Goode, T. D., Kornblau, B. L., National Health Surveillance for IDD Workgroup. (2019). Identifying people with intellectual and developmental disabilities in national population surveys. *Intellectual and Developmental Disabilities, 57*(5), 376–389. https://doi.org/10.1352/1934-9556-57.5.376

Kats, D., Payne, L., Parlier, M., & Piven, J. (2013). Prevalence of selected clinical problems in older adults with autism and intellectual disability. *Journal of Neurodevelopmental Disorders, 5*(1), 27. https://doi.org/10.1186/1866-1955-5-27

Kildahi, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. (2020). "If we do not look for it, we do not see it": Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 33*(5), 1119–1132. https://doi.org/10.1111/jar.12734

Lake, J. K., Jachyra, P., Volpe, T., Lunsky, Y., Magnacca, C., Marcinkiewicz, A., & Hamradi, Y. (2021). The wellbeing and mental health care experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities, 14*(3), 285–300. https://doi.org/10.1080/19315864.2021.1892890

Larson, S. A., Eschenbacher, H. J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M. L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. University of

Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Lauer, E., Nicola, N. D., Warsett, K., & Monterrey, R. (2019). Contributions of mental and behavioral health conditions to health service utilization among people with intellectual and developmental disabilities in Massachusetts. *Inclusion, 7*(3), 188–201. https://doi.org/10.1352/2326-6988-7.3.188

Lunsky, Y., & Balogh, R. (2010). Dual diagnosis: A national study of psychiatric hospitalization patterns of people with developmental disability. *The Canadian Journal of Psychiatry, 55*(11), 721–728. https://doi.org/10.1177/070674371005501106

Lunsky, Y., & Modi, M. (2018). Predictors of psychotropic polypharmacy among outpatients with psychiatric disorders and intellectual disability. *Psychiatric Services, 69*(2), 242–246. https://doi.org/10.1176/appi.ps.201700032

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2019). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism, 24*(4), 919–930. https://doi.org/10.1177/1362361319882227

Mazza, M. G., Rossetti, A., Crespi, G., & Clerici, M. (2020). Prevalence of co-occurring psychiatric disorders in adults and adolescents with intellectual disability: A systematic review and meta-analysis. *Journal of Applied Research in Intellectual Disabilities, 33*(2), 126–138. https://doi.org/10.1111/jar.12654

McCarthy, J., Hemmings, C., Kravariti, E., Dworzynski, K., Holt, G., Bouras, N., & Tsakanikos, E. (2010). Challenging behavior and co-morbid psychopathology in adults with intellectual disability and autism spectrum disorders. *Research in Developmental Disabilities, 31*(2), 362–366. https://doi.org/10.1016/j.ridd.2009.10.009

McGill, P., Vanono, L., Clover, W., Smyth, E., Cooper, V., Hopkins, L., Barratt, N., Joyce, C., Henderson, K., Sekasi, S., Davis, S., & Deveau, R. (2018). Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support. *Research in Developmental Disabilities, 81*, 143–154. https://doi.org/10.1016/j.ridd.2018.04.020

National Alliance on Mental Illness [NAMI]. (2022). Mental health by the numbers. Retrieved from https://www.nami.org/mhstats

Painter, J., Hastings, R., Ingham, B., Trevithick, L., & Roy, A. (2018). Associations between mental health problems and challenging behavior in adults with intellectual disabilities: A test of the behavioral equivalents hypothesis. *Journal of Mental Health Research in Intellectual Disabilities, 11*(2), 157–172. https://doi.org/10.1080/19315864.2018.1431747

Poppes, P., Van der Putten, A., & Vlaskamp, C. (2010). Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities. *Research in Developmental Disabilities, 31*(6), 1269–1275. https://doi.org/10.1016/j.ridd.2010.07.017

R Core Team. (2013). *R: A language and environment for statistical computing*. R Foundation for Statistical Computing.

Ramerman, L., Hoekstra, P. J., & de Kuijper, G. (2018). Health-related quality of life in people with intellectual disability who use long-term antipsychotic drugs for challenging behaviour. *Research in Developmental Disabilities, 75*, 49–58. https://doi.org/10.1016/j.ridd.2018.02.011

Reichard, A., Haile, E., & Morris, A. (2019). Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. *Intellectual and Developmental Disabilities, 57*(5), 405–420. https://doi.org/10.1352/1934-9556-57.5.405

Report of the Independent Reviewer. (2021). Report of the independent reviewer on compliance with the settlement agreement United States v. Commonwealth of Virginia. Retrieved from https://dbhds.virginia.gov/assets/doc/settlement/indreview/211213-final-19th-report-to-the-court.pdf

Ricciardi, J. N. (2013). Co-occurring psychiatric disorders in individuals with intellectual disability. In D. D. Reed, D. F. DiGennaro Reed, & J. K. Luiselli (Eds.), *Handbook of crisis intervention and developmental disabilities* (pp. 213–243). Springer.

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2019). The contemporary view of intellectual and developmental disabilities: Implications for psychologists. *Psicothema*. https://doi.org/10.7334/psicothema2019.119

Scott, H. M., & Havercamp, S. M. (2014). Mental health for people with intellectual disability: The impact of stress and social support. *American Journal on Intellectual and Developmental Disabilities, 119*(6), 552–564. https://doi.org/10.1352/1944-7558-119.6.552

Terlizzi, E. P., & Norris, T. (2021). Mental health treatment among adults: United States, 2020. *NCHS Dara Brief, 419*. Retrieved from https://www.cdc.gov/nchs/products/databriefs/db419.htm.

Thompson, J. R., Bryant, B., Schalock, R. L., Shogren, K. A., Tassé, M. J., Wehmeyer, M. L., Campbell, E. M., Craig, E. M., Hughes, C., & Rotholz, D. A. (2015). *Supports intensity scale—Adult version: User's manual*. American Association on Intellectual and Developmental Disabilities.

Virginia Register of Regulations. (2019). Title 12. Health: Department of Medical Assistance Services, Chapter 122. Virginia Register of Regulations, 35 (12). Retrieved from http://register.dls.virginia.gov/details.aspx?id=7347.

Wagner, J. B., Kim, M., & Tassé, M. J. (2019). Technology tools: Increasing our reach in national surveillance of intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 57*(5), 463–475. https://doi.org/10.1352/1934-9556-57.5.463

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2017). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities, 11*(1), 69–102. https://doi.org/10.1080/19315864.2017.1408724