

Title:

Contributions of mental and behavioral health conditions to health service utilization among people with intellectual and developmental disabilities in Massachusetts

Emily Lauer, Nassira D. Nicola, Kimberley Warsett, Rodrigo Monterrey

Corresponding Author:

Emily Lauer, MPH, Director

Email address: [Emily.Lauer@umassmed.edu](mailto:Emily.Lauer@umassmed.edu)

University of Massachusetts Medical School

Center for Developmental Disabilities Evaluation and Research (CDDER), Eunice Kennedy Shriver Center

55 Lake Avenue North, S3-301

Worcester, MA 01655 USA

Nassira D. Nicola, MA, Health and Disability Program Coordinator, Massachusetts Department of Public Health, Office of Health Equity (Health and Disability Program), Boston, MA, 02108, USA

Kimberley Warsett, MSW, Massachusetts Department of Public Health, Office of Health Equity (Health and Disability Program), Boston, MA, 02108, USA

Rodrigo Monterrey, MPA, Deputy Director, Massachusetts Department of Public Health, Office of Health Equity (Health and Disability Program), Boston, MA, 02108, USA

This publication was supported by Grant Number 1NU27DD000002, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

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*, Advance online publication, <http://aaid.org/publications/journals/articles-accepted-for-publication>

## Abstract

While existing evidence suggests an increased prevalence mental and behavioral health conditions for people with intellectual and developmental disabilities (IDD), little is known about health service utilization patterns related to these conditions. This study provides population-based data on hospital service utilization. Medicaid claims for people under 65 years of age in Massachusetts were used (years 2008-2013) to identify a cohort of people with IDD. Utilization of inpatient hospitalizations and outpatient Emergency Department (ED) was compared with the U.S. and MA general population through risk ratios. Findings suggest mental and behavioral health conditions were major contributors to increased utilization of inpatient and outpatient ED services and underscore the need for community-based service options that understand how to treat these conditions in people with IDD and address the myriad of related factors to identify, treat and minimize the potential adverse life impact of these conditions for people with IDD.

Contributions of Mental and Behavioral Health Conditions to Health Service Utilization among  
People with Intellectual and Developmental Disabilities in Massachusetts

Over the past decade, the American healthcare system has embraced the “triple aim” (Berwick, Nolan, & Whittington, 2008, p.759) of improving patient experience at the individual level, improving health outcomes at the population level, and improving healthcare costs at the system level. However, systems of care frequently fall short of all three aims for people with an intellectual or developmental disability (IDD) resulting in poorer quality of care (Lewis, Lewis, Leake, King & Lindemann, 2002; Havercamp & Scott, 2015) and poorer health outcomes (Office of the Surgeon General, 2005; Krahn & Fox, 2002), and potentially avoidable gaps or excesses in utilization patterns (McDermott, Royer, Mann & Armour, 2018b).

People with IDD tend to be disproportionately high users of healthcare services (Krahn Hammond & Turner, 2006; Shea et al., 2018), yet also experience limitations in access to essential components of primary healthcare (Lennox, 2015). In addition, they are more likely to have multiple chronic conditions and, given the etiology and nature of their disabilities, complex care needs (Krahn, Hammond & Turner, 2006). In order to better inform strategies to produce more optimal utilization patterns and improve patient outcomes for people with IDD, it is essential to better understand how people with IDD specifically access and use healthcare services such as outpatient Emergency Departments (ED) and inpatient hospital services. Understanding these utilization patterns can facilitate better strategic planning on a population level, elucidate potential methods to reduce unnecessary or suboptimal utilization and better inform the specific treatment needs of people with IDD.

In the U.S., utilization of ED services is on the rise, thought to be caused by a U.S. primary care system that “finds itself unable to meet the growing demand for care...” (NEHI,

2010). As a result of increasing utilization for non-emergent conditions, EDs are increasingly overcrowded, leading to high costs and drains on healthcare systems, as well as delays in care and negative patient experience and outcomes (Hoot & Aronsky, 2008). Among those in the general population who utilize high cost and urgent medical services, a subset exhibits high frequency utilization. Interestingly, these high utilizers in the general population are more likely to have unmet non-medical needs such as food and housing insecurity, and are more likely to have mental and behavioral health conditions including substance abuse disorders (Behr & Diaz, 2016; Kushel, Perry, Bangsberg, Clark & Moss, 2002; Niedzwiecki, 2018). Mental illness has emerged as a substantial driver of medical service utilization: almost half of the frequent ED utilizers in the general population have a mental health diagnosis (Behr & Diaz, 2016); and 80% of people with mental illness sought medical, rather than behavioral health services, for treatment of their mental illness (Kathol, Melek & Sargent, 2015). This misalignment of care has the potential for substantial consequences both to individuals and the medical service networks, as the ED has low efficacy for treating mental and behavioral health conditions with many patients leaving these encounters with their mental health needs untreated (Kathol et al., 2015). In addition, patients with mental illness with compounding social factors, such as having public insurance as their primary insurer, are most likely to experience longer periods in the ED than medically necessary before transfer to another medical setting or admission, where warranted, which in turn is “associated uniformly with negative effects” (Singer, Thode, Viccellio & Pines, 2011) at the patient level, including increased length of stay, morbidity, and mortality.

Given the substantial association of mental and behavioral health conditions with increased and suboptimal healthcare utilization in the general population, assessing the

association of these conditions with healthcare utilization patterns in people with IDD may be highly informative for improving outcomes and reducing utilization-related costs. Examining patterns of utilization associated with mental and behavioral health conditions specific to people with IDD is warranted for multiple reasons: 1) people with IDD have a higher prevalence of mental and behavioral health conditions than the general population (Werges, 2007), 2) the diagnosis and treatment of these conditions in people with IDD is frequently complex and requires specialized supports and 3) the ways in which people with IDD may access and interact with health services can differ from the general population given the nature of their disability and their related support needs.

### **Prevalence and Risk of Adverse Mental Health in People with IDD**

An exact estimate of the prevalence of mental health conditions in people with IDD has been difficult to attain (Kerker, Owens, Zigler & Horwitz, 2004); one estimate suggests that between 32%-40% of people with an intellectual disability have psychiatric disorders (Aggarwal, Guanci, & Appareddy, 2013). Numerous risk factors increase the likelihood that people with IDD will develop a mental illness across their lifetime. Biologically, genetic conditions associated with the etiology of their disability may augment the risk of developing mental illnesses, such as those related to shared neurodevelopmental origins (Owen, 2012; Trollor, 2014). Additionally, side effects of certain treatment regimens, such as prescribed pharmacological medications including psychotropics, may increase the likelihood of developing adverse psychological symptoms or behaviors (Trollor, 2014; Valdovinos, Caruso, Roberts, Kim & Kennedy, 2005).

Many psychological risk factors may also exacerbate the vulnerability of people with IDD for developing mental health conditions. On an individual level, many people with IDD do

not receive appropriate supports to build or augment coping and executive functioning skills which, particularly in high stress environments, can increase the likelihood of stress and related psychological disorders (Trollor, 2014) for people with IDD. On an interpersonal level, the environments within which people with IDD live often provide fewer opportunities to engage in many life choices leading to lower autonomy and self-determination. Stressors in close interpersonal circles such as parental divorce and lack of appropriate family supports have been shown to increase risk for depression in this population (Schmucke, Schmolz & Lindert, 2017). Additionally, fear of novel situations, exposure to violence, and neglect or exploitation, which people with IDD are more vulnerable to without appropriate supports, have been shown to be associated with depression (Schmucke, Schmolz & Lindert, 2017; Smiley et al., 2007). Conversely, people with IDD are less likely to have access to protective interpersonal factors such as social networks (Trollor, 2014) and access to peer interactions or other natural supports (Kerker, Owens, Zigler & Horwitz, 2004). In a cohort of 363 adults with ID, the relative percent of unmet needs in social relationships was found to be 22.2% (Schützwohl et al., 2016; Salvador-Carulla & Symonds, 2016).

Economic and interpersonal factors as well as systemic inequities experienced by people with IDD also contribute to their risk of adverse mental health. It has been suggested that poorer living conditions of people with IDD, rather than the impairment itself, may contribute to the poor mental health in this population (Hatton, Emerson, Robertson & Baines, 2017). Abuse and having a hyperstimulating or hypostimulating environment can lead directly to psychological distress, for example (Surjus & Campos, 2014). Poverty as well as an increased likelihood of experience with the criminal justice system may also increase the probability of mental health needs (Trollor, 2014).

Even people with IDD without formally diagnosed mental illness are more likely to experience adverse mental health. Lauer and Lauer (2019) found that people with a cognitive disability, which includes people with an intellectual disability as well as people with other cognitive disabilities, reported “non-specific psychological distress” at seven times that of people without a cognitive disability. Moderate to high levels of psychological distress are associated with mental health conditions, and even low levels of this type of distress may warrant preventive intervention (Kessler et al., 2002).

### **Difficulty Diagnosing People with IDD with Mental and Behavioral Health Disorders**

The diagnosis and treatment of mental and behavioral health conditions for people with IDD is complex due to a myriad of factors. The symptoms of mental health conditions may present differently in people with IDD, making accurate diagnosis challenging (Aggarwal, Guanci, & Appareddy, 2013). Additionally, people with IDD experience a range of physical and psychological symptoms related to the etiology of their disability. Some symptoms may be attributable to comorbid mental health conditions while some behaviors, particularly those with low social desirability, may be falsely determined to relate to mental health diagnoses.

People with IDD also have a range of communication abilities and ways in which they may interact with other people and their environment. While some people with IDD may be able to articulate themselves well verbally, others may use a combination of signs, gestures, auditory signs and behaviors to communicate that may not be well understood by other people. Attempts to communicate pain or discomfort, for example, may be mistaken by others as behavioral or mental health symptoms (Charlot, Abend, Ravin, Mastis, Hunt & Deutsch, 2011; Carr & Owen-Deschryver, 2007). “Diagnostic overshadowing” may contribute to presenting symptoms being ascribed to the person’s IDD rather than a physical or mental health condition (Reiss, Levitan &

Szysko, 1982). For example, numerous health conditions that cause physical pain or discomfort have been shown to be associated with “causing or worsening behavior problems” in people with IDD, such as “ear infections, premenstrual pain, sleep disturbances,... allergies, ...dental pain, seizures, and GI distress....[F]eeling ill, in pain or generally distressed because of a physical problem (i.e. constipation, dental pain, UTIs or urinary tract infections)” may increase the likelihood that someone with IDD, particularly those that cannot express themselves well verbally may react with a change in behavior (Charlot et al., 2011, p.200). Mental health conditions are particularly challenging to accurately diagnose in people with limited verbal communication skills and higher levels of intellectual impairments (Woods, 2011; Myrbakk & von Tetzchner, 2008). Adverse behavioral symptoms may result in health care encounters, where distinguishing between mental and behavioral health conditions and other reasons for behavioral-based communication is essential to accurate and high-quality treatment.

### **Inequitable Access to Services and Need for Collaborative Care for People with IDD**

In the U.S. and internationally, there is evidence that people with IDD pervasively experience inequitable access to mental health services and higher unmet needs for mental and behavioral healthcare (Schützwohl et al., 2016; Salvador-Carulla & Symonds, 2016; Ervin, Hennen, Merrick & Morad, 2014). In the U.S. specifically, there are a number of challenges for people with IDD who need services for both their disability and their mental health. Accessing quality healthcare has continued to be problematic for this population in the U.S. As more people with disabilities live in their communities, people with IDD access healthcare increasingly from generic community-based clinicians, finding healthcare services, such as psychiatry services, that can appropriately diagnose and treat people with dual-diagnoses of IDD and mental health conditions is a particular challenge. These include “inaccessible and non-

existing services for the dually diagnosed [people with an intellectual disability and mental illness], discontinuity of care (e.g. passing from one service element to the other), separate support systems unwilling to collaborate, persons with challenging behaviors being regarded as undesirable, confusion of primary vs. secondary disorders, and lack of professional training” (Werges, 2007). Many of these challenges are driven by a public healthcare system that as a whole is not well-equipped to support people with IDD (Ervin, Hennen, Merrick & Morad, 2014); over 90% of psychiatrists, for example, report they feel they lacked training in treating and diagnosing problems in people with IDD (Werner, Stawski, Polakiewicz & Levav, 2012). When considering access to care, it is important to note that in the United States, people with IDD are largely covered by public insurance (Ervin, Hennen, Merrick & Morad, 2014) lending further emphasis to the need to assess and understand any overutilization of services, misdiagnosis, or a lack of integration leading to increased service costs.

Given the complexity of mental and behavioral health conditions in people with IDD, this paper analyzes the reasons people with IDD utilize health services, specifically medical hospitalizations and outpatient emergency department utilization, to understand the association of these conditions with health service utilization patterns. Utilizing a large cohort of people with IDD covered by publicly-funded Medicaid services, this paper will examine how utilization patterns for people with IDD compare to the general population in order to better inform strategies to optimize health service utilization and related outcomes for this population.

## **Methods**

### **Data Sources for Intellectual and Developmental Disabilities Cohort**

Data used to analyze patterns of health service utilization in people with IDD were accessed from the Massachusetts Medicaid Management Information System (MMIS), including

the Medicaid recipient's enrollment status and claims for service utilization (fee-for-service claims and managed care encounters) with associated ICD-9-CM diagnosis codes (ICD-9-CM, 2011). All data access was performed under a data usage approval with the state. SAS 9.4 (SAS Institute Inc., Cary, NC) was used to conduct analyses.

### **Identification of Medicaid Members with an Intellectual or Developmental Disability**

MMIS data was utilized to construct a cohort of people aged 0-64 years of age with IDD. Analyses were conducted using methodology from a multi-state project funded by the Centers for Disease Control and Prevention (CDC) to apply consistent methods across state Medicaid data sources for health surveillance for people with IDD (McDermott et al., 2018). The cohort definition was applied to ICD-9-CM codes associated with service utilization from 2008 to 2013. The cohort was restricted to members who were only covered by Medicaid (and not commercial insurance or Medicare) to avoid missing claims from other first payers of medical service claims. In this restriction, an upper age cutoff was applied because of age-based eligibility for Medicare starting at 65 years. To be included in the cohort, Medicaid members needed to have one inpatient claim or at least two other service claims associated with the algorithm's list of diagnoses associated with IDD; multiple outpatient claims were required to rule out utilization related to a suspected but unconfirmed diagnosis.

Because members could have service utilization related to multiple ICD-9-CM diagnostic codes within the intellectual and developmental disability subset, a hierarchy (McDermott et al., 2018) was used to assign each person to a single diagnostic subgroup beginning with the most specific diagnosis (e.g., genetic causes) to the least specific diagnosis (unspecified intellectual disability). Eight mutually exclusive diagnostic subgroups were identified: Down Syndrome / Trisomy / Autosomal Deletions; Other Genetic Conditions such as Lesch-Nyhan, Tuberous

Sclerosis, Fragile X Syndrome, and Prader-Willi Syndrome; Fetal Alcohol Syndrome; Cerebral Palsy; Autism or Pervasive Developmental Disorder; Intellectual Disability.

### **Demographic Variables**

Demographic variables obtained from MMIS include gender (male/female), age at first enrollment, insurance status, and average number of years enrolled in Medicaid during the 5-year study period. Because race and ethnicity are optional fields in the Massachusetts MMIS, information for these variables is incomplete and was therefore excluded. The cohort was grouped into children (ages 0 – 17 years) and adults (ages 18 years and older).

### **Health Service Utilization**

The focus of this analysis was inpatient hospital admissions and outpatient ED visit encounters during the calendar year of 2012. Therefore, the cohort was further restricted to people enrolled in Massachusetts Medicaid at least 11 months in 2012. To distinguish between inpatient and outpatient care, ED visits resulting in discharge from the ED were considered outpatient ED visits; both ED visits resulting in hospital admission from the ED and inpatient admissions that did not involve the ED were considered inpatient hospitalizations.

Diagnoses associated with inpatient admission and outpatient ED utilization were categorized based on the primary ICD-9-CM diagnostic code for the facility claim for the service. Diagnoses were further categorized using the Clinical Classifications Software (CCS), a system of standardized, clinically meaningful categories to organize diagnoses and procedures in ICD-9-CM, as developed by the Agency for Healthcare Research and Quality's (AHRQ) Healthcare Cost and Utilization Project (HCUP) (Elixhauser, Steiner & Palmer, 2015).

### **Benchmarks and Data Analyses**

Benchmarks of inpatient hospitalization and outpatient ED visits were applied from the general population using discharge data from the 2012 HCUP National Inpatient Sample (NIS, 2012) for inpatient admissions (excluding maternal stays), and the 2012 HCUP Nationwide Emergency Department Sample (NEDS, 2012) for outpatient ED discharges. Because the NIS and NEDS also both utilize CCS hierarchical categories, direct comparison of medical conditions associated with utilization was possible. State-level general population data was only available for Massachusetts for inpatient data from the NIS for 2012.

As a measure of association between the presence of an IDD and utilization of health services for specific conditions, relative risks were calculated. This measure maintains a robust ability to estimate association regardless of the frequency of the outcome and were therefore considered an appropriate measure for this analysis. Relative risks were calculated as ratios of the utilization rate of the cohort (numerator) and the utilization rate of the general population (denominator). For these comparisons, general population rates were also restricted to the age groups under comparison (e.g. children or adults). Confidence intervals and significance levels were calculated using a Poisson distribution.

## **Results**

Among children with IDD, the most prevalent disability group was Autism / Pervasive Developmental Disorder (41.9%), followed by intellectual disability (41%) mostly of an unspecified level (Table 1). Among adults, intellectual disability was the most common type of IDD (49.5%), followed by Autism / Pervasive Developmental Disorder (25.1%). The majority of children in the cohort tended to be of elementary and teenage ages, corresponding with the ages after which most diagnoses of IDD are made. Adults in the cohort were predominantly of

younger ages (under 34 years). Across both age groups, males were more prevalent than females. See Table 1 for additional information on the sample cohort.

When comparing inpatient hospitalization rates for people with IDD (see Table 2) to the general population, adults with IDD aged 18-64 on Medicaid had 4.4 times the rate of inpatient utilization (399 per thousand adults with IDD) compared to MA general adult population (91 per thousand). The rate was similarly elevated when compared to utilization in the U.S. adult general population (92.6 per thousand). Among the top 10 reasons for inpatient hospitalizations of adults with IDD, a portion of top ranked diagnoses requiring hospitalization in this population were for co-morbid conditions associated with IDD such as paralysis and congenital anomalies. Mental and behavioral health conditions were also among the most frequent contributors to inpatient utilization for adults with IDD. Mood disorders were the third-ranked most frequent reason for inpatient hospitalization, with a rate of 16.6 per thousand adults with IDD. Schizophrenia and other psychotic disorders was the fifth most frequent reason for inpatient utilization with a rate of 12.2 per thousand for adults with IDD. Adults with IDD showed significantly ( $p < 0.001$ ) increased utilization for mood disorders compared to MA (RR=3.5) and U.S. (RR=4.9) general adult populations, as well as for schizophrenia and other psychotic disorders (MA: RR=7.5, U.S.: RR=7.1).

Patterns of inpatient hospitalizations among children with IDD (see Table 2) were similar to adults in the frequency of contribution of IDD-related conditions. Children with IDD also demonstrated frequent utilization for mental and behavioral health conditions, but with some differences compared to adults with IDD. Mood disorders were the sixth-ranked most frequent reason for inpatient hospitalization for children with IDD, with a rate of 5.8 per thousand. The CCS grouping of ‘attention-deficit, conduct, and disruptive behavior disorders’ was the ninth-

ranked reason for inpatient hospitalizations among children with IDD at a rate of 3.8 per thousand. Like adults, inpatient hospitalizations for children with IDD related to mental and behavioral health conditions was significantly higher than for children in the general population: utilization for mood disorders was significantly higher ( $p < 0.001$ ) for children with IDD compared to children in MA (4.2) and the U.S. (RR=4.1), and utilization for ‘attention-deficit, conduct, and disruptive behavior disorders’ was also substantially elevated in comparison with the general population of children in MA (RR=19.8) and the U.S. (RR=24.4).

For outpatient ED visits (see Table 3), mental health conditions were highly prevalent for adults with IDD as top contributors to utilization in Massachusetts. Mood disorders were the most frequent reason for outpatient ED visits in adults with IDD at a rate of 76.6 visits per thousand, which was substantially higher than the U.S. adult general population (RR=22.4). Anxiety disorders were also a frequent contributing reason for outpatient ED visits among adults with IDD, ranking eighth among primary reasons for the encounters. The rate of 36.1 visits for anxiety disorders per thousand adults with IDD was 9 times higher than the rate of utilization for this diagnosis among adults in the general population. Additionally, schizophrenia and other psychotic disorders was the fifteenth most frequent cause of outpatient ED visits for adults with IDD, at a rate of 27.9 per thousand adults which was 16.8 times higher than for the general population of adults in the U.S.

For children, mental and behavioral health conditions did not appear among the top ten reasons for outpatient ED visits (see Table 3). However, utilization related to these conditions was still substantially higher for children with IDD compared to children in the general population. The most frequently contributing behavioral category of diagnoses for children with IDD was attention-deficit, conduct, and disruptive behavior disorders, which ranked eleventh

with a rate of 19.6 per thousand children with IDD. The outpatient ED utilization due to this cause was 21.5 times that of children in the general population.

### **Discussion**

Adults and children with IDD on Medicaid in Massachusetts demonstrate increased utilization of both inpatient hospitalizations and outpatient ED services compared with the general population. Unsurprisingly, many of the diagnoses driving this utilization are substantially related to the etiology of their disability (including congenital conditions and secondary conditions such as paralysis and epilepsy). However, this analysis contributes evidence that mental and behavioral health conditions are also substantial drivers of increased utilization across both adults and children with IDD on Medicaid in Massachusetts compared to people without IDD both within the state of Massachusetts and nationally. The conditions driving this increase of utilization fall within two specific areas within mental and behavioral health. The first is mood disorders, which were related to increased utilization across both adults and children with IDD in inpatient settings and in adults with IDD in outpatient ED settings. Relative to other mental health conditions such as schizophrenia, mood disorders may present at relative younger ages (in childhood) which is likely related to their impact on utilization across age groups. The second category of utilization within the CCS groupings are those containing some more generic groupings including those frequently related to presenting behaviors, such as ‘other psychotic disorders’ for adults and ‘conduct, and disruptive behavior disorders’ for children. While both of these categories within the CCS groupings do contain more specific diagnoses (schizophrenia in the first and attention-deficit disorder in the second), it is likely the more unspecified behaviorally-related diagnoses within these groupings are driving their increased use. The use of these diagnoses in increased frequency to the general population may

be associated with the challenges related to diagnosing mental and behavioral health conditions in people with IDD (Werner, Stawski, Polakiewicz & Levav, 2012) or utilization related to presenting behavioral needs without a formal mental health diagnosis. Given the lack of training for health care practitioners on mental and behavioral health in people with IDD and the need to apply one of the ICD-9-CM diagnostic codes to facilitate payment, it is possible that some of this coding, particularly the use of more generic codes could be subject to misclassification or at minimum, a tendency toward less specificity in diagnosis. Anxiety disorders is the other major mental health condition category that is a substantial driver of increased utilization in people with IDD, however, these patterns were specific to outpatient ED visits in adults with IDD. Other categories of mental health disorders such as depression and alcohol- and substance-use do not appear among the most frequent reasons for utilization in people with IDD illustrating a difference from patterns in the general population (Kathol et al., 2015).

The increased utilization demonstrated among both children and adults with IDD for mental and behavioral health conditions shows similarities to driving factors in the general population, but with important differences related to how mental and behavioral health conditions present and are optimally treated in people with IDD. As with the general population, effective strategies to reduce ED and inpatient utilization for these conditions likely lie in addressing the associated factors driving these encounters (Behr & Diaz, 2016). These findings lend evidence to the need to assess the adequacy and effectiveness of outpatient mental health treatment options and networks for people with these disabilities, as well as the influence of current and potential future policy interventions focused on access to treatment and building sustainable social networks (Behr & Diaz, 2016). The utilization of community-based support strategies that appropriately assess and treat people with IDD may offer solutions for reducing

inpatient and outpatient ED services, neither of which are optimal settings for the management of mental and behavioral health conditions. In addition, community-based support services tend to be better suited to address the economic, social and interpersonal factors that may present related service needs in order to address overall wellness needs for people with IDD. Community-based support services themselves may also have a direct influence on the decision-making pertaining to when and where to seek care for people with IDD who need greater levels of support, including accessible information and assistance communicating with others, to make decisions about accessing treatment.

### **Limitations**

The study is subject to several limitations. First, the primary source of information is insurance claims for medical services. Because the primary purpose of this data is for payment for services rendered, it may include artifacts related to this purpose including reasons for using certain diagnostic codes as primary reasons for service over others. However, this paper compares utilization between groups using the same types of data sources, which minimizes potential bias within the comparison of utilization patterns. Secondly, the cohort of people with IDD is limited to only those with Medicaid and no other insurance, and to people under 64 years which limits our ability to examine utilization across the lifespan. Because Medicaid may not be the first payer for medical services in dual-coverage scenarios, this limitation was necessary for the purposes of this study in order to analyze a complete profile of health service utilization for cohort members. However, because many adults with IDD are dually eligible for Medicaid and Medicare, our cohort of adults is particularly selective as seen in the biased distribution to younger age groups. Lastly, people with IDD on Medicaid in Massachusetts who did not receive any care during the inclusion period of 2008-2013 or whose care never included a diagnostic

code related to IDD may be excluded from the cohort. Strategies were employed in our methodology, including multi-year inclusion methods and use of claims over multiple providers and multiple types of services, to help minimize the potential for this sort of exclusion.

### **Conclusion**

By analyzing how mental and behavioral health needs relate to emergency and inpatient medical service use, as well as understanding the potential for misdiagnosis, researchers and public health professionals can better understand how to improve quality of care. Findings of this study clarify the extent to which mental and behavioral health needs are driving health service utilization for children and adults with IDD on Medicaid in Massachusetts. These suboptimal utilization patterns, particularly of the ED, for both adults and children with ID in need of care for mental and behavioral health conditions suggest unmet treatment needs for this population. Medical hospitals and particularly EDs are not ideal sources of care for mental and behavioral health conditions, especially for people with IDD who may have complex and specialized medical and behavioral health support needs. These patterns suggest the need for community-based services skilled in supporting and treating people with IDD which address mental health needs, as well as related underlying social factors such stability of basic resources and social networks which likely contribute to psychological distress and a lack of effective coping mechanisms. As people with IDD are increasingly reliant on the availability of community-based treatment resources, more work is needed to ensure professionals in the mental and behavioral health fields are trained to work with people with IDD. Proactive approaches to assessing and addressing mental and behavioral health needs are necessary as well as providing a wide-range of trained healthcare options (Solomon & Trollor, 2018).

Additionally, the disability service systems should ensure that best practices are applied in proactively assessing and seeking treatment for mental and behavioral health needs before they present as an emergent need or at a level requiring inpatient hospitalization. Examining the influence of policy within disability service systems – whether at the state or local levels - pertaining to the management and response of behavioral changes and reactions in people with IDD is also warranted to ensure these policies minimize any drivers of suboptimal health service utilization (such as ED visits). Given the unique mental and behavioral health needs for people with IDD as well as the changing landscape of community-based disability services, there is a need for financial support of innovation and piloting of strategies aimed to reduce suboptimal utilization patterns specifically for this population.

Promising models require the participation of multiple service systems – including disability service systems, public health, primary care and hospital systems, and insurers, among others. There is a need for more collaborative and integrated care which addresses the needs of the whole person and “all major aspects of a person’s life” (Ervin, Hennen, Merrick & Morad, 2014, p.5). Collaboration is required particularly between physical and mental health providers to accurately assess and diagnose patients with IDD who may be presenting with behaviorally-related symptoms. Given the high rates of abuse (Byrne, 2018) experienced by people with IDD, integrated care models need to address the trauma and distress accompanying such events as well. A better professional pipeline is needed to increase access to clinicians skilled in treating people with IDD. On a state or regional level, a range of invested advocates may be influential in demonstrating and advocating for the need for trained and appropriate clinical services for this treatment.

Newer models of managing individual-level care, such as those provided by newer case management strategies and managed care models including partnerships with community providers have the potential to impact these patterns through the restructuring of traditional care pathways. Dissemination and replication of promising models will be essential to ensure comprehensive and equitable impact for people with IDD.

### References

- Aggarwal, R., Guanci, N., & Appareddy, V. L. (2013). Issues in treating patients with intellectual disabilities. *Psychiatric Times*, 30(8), 9-9.
- Behr, J. G., & Diaz, R. (2016). Emergency Department Frequent Utilization for Non-Emergent Presentments: Results from a Regional Urban Trauma Center Study. *PLoS One*, 11(1), e0147116.
- Berwick, D. M., Nolan, T. W., & Whittington J. (2008) The triple aim: care, health, and cost. *Health Affairs* (Millwood), 27, 759–769.
- Bipartisan Policy Center (2019, January). Integrating Clinical and Mental Health: Challenges and Opportunities. Retrieved from: <https://bipartisanpolicy.org/wp-content/uploads/2019/01/Integrating-Clinical-and-Mental-Health-Challenges-and-Opportunities.pdf>
- Brault, M.W. (2012). *Americans with disabilities: 2010. Current population reports*. Washington DC: U.S. Census Bureau.
- Byrne, G. (2018). Prevalence and psychological sequelae of sexual abuse among individuals with an intellectual disability: A review of the recent literature. *Journal of Intellectual Disabilities*, 22, 294-310.
- Carr, E. G., & Owen-DeSchryver, J. S. (2007). Physical illness, pain, and problem behavior in minimally verbal people with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37, 413-424.
- Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. (2011). Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *Journal of Intellectual Disability Research*, 55, 199-209.

- Ervin, D. A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. *Frontiers in public health*, 2, 83.
- Evans, E., Howlett, S., Kremser, T., Simpson, J., Kayess, R., & Trollor, J. (2012). Service development for intellectual disability mental health: A human rights approach. *Journal of Intellectual Disability Research*, 56, 1098-1109.
- Hatton, C., Emerson, E., Robertson, J., & Baines, S. (2017). The mental health of British adults with intellectual impairments living in general households. *Journal of Applied Research in Intellectual Disabilities*, 30, 188-197.
- Havercamp, S.M., & Scott, H.M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal*, 8, 165–172.
- Hoot, N. R., & Aronsky, D. (2008). Systematic review of emergency department crowding: Causes, effects, and solutions. *Annals of Emergency Medicine*, 52, 126-136.
- Elixhauser, A., Steiner, C., & Palmer, L. (2015) Clinical Classifications Software (CCS) for ICD-9-CM. Rockville, MD: AHRQ.
- International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). (2011) Atlanta, GA: CDC.
- Kathol, R. G., Melek, S., & Sargent, G. (2015). Mental health and substance use disorder services and professionals as a core part of health in clinically integrated networks. In: K. Yale, J. Bohn & C. Korschak (eds.), *Clinical Integration: Accountable Care & Population Health* (3rd ed). Virginia Beach, VA: Convergent Publishing.

- Kerker, B. D., Owens, P. L., Zigler, E., & Horwitz, S. M. (2004). Mental health disorders among individuals with mental retardation: challenges to accurate prevalence estimates. *Public Health Reports, 119*, 409-417.
- Kessler, R.C., Andrews, G., Colpe, L.J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T.,... & Zaslavsky, A. M. (2002). Screening scales of non-specific psychological distress. *Psychological Medicine, 32*, 959–976.
- Krahn, G. L., & Fox, M. (2014). Health disparities of people with intellectual disabilities: what do we know? What do we do? *Journal of Applied Research in Intellectual Disability, 27*, 431–446.
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 70-82.
- Kushel, M. B., Perry, S., Bangsberg, D., Clark, R., & Moss, A. R. (2002). Emergency department use among the homeless and marginally housed: results from a community-based study. *American Journal of Public Health, 92*, 778-784.
- Lauer, E.A., & Lauer, E. (2019) Assessing the association between mental health and disability indicators among adults living in the United States. *Disability and Health Journal, 12*, 98-105.
- Lennox, N. G., Van Driel, M. L., & van Dooren, K. (2015). Supporting primary healthcare professionals to care for people with intellectual disability: a research agenda. *Journal of Applied Research in Developmental Disabilities, 28*, 33–42.

Lewis, M. A., Lewis, C. E., Leake, B., King, B. H., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports, 117*, 174-184.

McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., ...Lauer E., ... Armour B.S. (2018). Using Medicaid data to characterize persons with intellectual and developmental disabilities in five US states. *American Journal of Intellectual and Developmental Disabilities, 123*, 371-381.

McDermott, S., Royer, J., Mann, J. R., & Armour, B. S. (2018b). Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability. *Journal of Intellectual Disability Research, 62*, 165-178.

Myrbakk, E., & von Tetzchner, S. (2008). Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities, 29*, 316-332.

National Inpatient Sample (NIS). (2012) Rockville, MD: AHRQ, HCUP Retrieved from: [www.hcup-us.ahrq.gov/nisoverview.jsp](http://www.hcup-us.ahrq.gov/nisoverview.jsp).

Nationwide Emergency Department Sample (NEDS). (2012). Rockville, MD: AHRQ, HCUP; [www.hcup-us.ahrq.gov/nedsoverview.jsp](http://www.hcup-us.ahrq.gov/nedsoverview.jsp).

New England Healthcare Institute. (2010). *A Matter of Urgency: Reducing Emergency Department Overuse A NEHI Research Brief*. Retrieved from: [https://www.nehi.net/writable/publication\\_files/file/nehi\\_ed\\_overuse\\_issue\\_brief\\_032610\\_finaledits.pdf](https://www.nehi.net/writable/publication_files/file/nehi_ed_overuse_issue_brief_032610_finaledits.pdf)

- Niedzwiecki, M. J., Sharma, P. J., Kanzaria, H. K., et al. (2018). Factors Associated with Emergency Department Use by Patients with and without Mental Health Diagnoses. *JAMA Network Open*, 1, e183528.
- Nikolov, R. N., Bearss, K. E., Lettinga, J., Erickson, C., Rodowski, M., Aman, M. G., ... & Arnold, L. E. (2009). Gastrointestinal symptoms in a sample of children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 39, 405-413.
- Office of the Surgeon General, US Dept of Health and Human Services. (2005). The Surgeon General's call to action to improve the health and wellness of persons with disabilities. Washington, DC.
- Owen, M. J. (2012). Intellectual disability and major psychiatric disorders: a continuum of neurodevelopmental causality. *The British Journal of Psychiatry*, 200, 268-269.
- Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: diagnostic overshadowing. *American Journal of Mental Deficiency*, 86, 567-74.
- Salvador-Carulla, L., & Symonds, S. (2016). Health services use and costs in people with intellectual disability: building a context knowledge base for evidence-informed policy. *Current Opinion in Psychiatry*, 29, 89-94.
- Schmückle, D., Schmolz, G. K., & Lindert, J. (2017). "Mental health in adults with intellectual disabilities. Protective and risk factors for depression and anxiety"-a cross-sectional study. *Gesundheitswesen (Bundesverband der Ärzte des Öffentlichen Gesundheitsdienstes (Germany))*, 79, 415-418.
- Schützwohl, M., Koch, A., Koslowski, N., Puschner, B., Voß, E., Salize, H. J., ... & Vogel, A. (2016). Mental illness, problem behaviour, needs and service use in adults with intellectual disability. *Social Psychiatry and Psychiatric Epidemiology*, 51, 767-776.

Shea, L. L., Xie, M., Turcotte, P., Marcus, S., Field, R., Newschaffer, C., & Mandell, D. (2018).

Brief report: service use and associated expenditures among adolescents with Autism Spectrum Disorder transitioning to adulthood. *Journal of Autism Developmental Disorders*, 48, 3223-3227.

Singer, A. J., Thode Jr, H. C., Viccellio, P., & Pines, J. M. (2011). The association between length of emergency department boarding and mortality. *Academic Emergency Medicine*, 18, 1324-1329.

Smiley, E., Cooper, S. A., Finlayson, J., Jackson, A., Allan, L., Mantry, D., ... & Morrison, J. (2007). Incidence and predictors of mental ill-health in adults with intellectual disabilities: prospective study. *The British Journal of Psychiatry*, 191, 313-319.

Surjus, L.T. & Campos, R.T. (2014). Interface between intellectual disability and mental health: hermeneutic review. *Revista de Saude Publica*, 48, 532-40.

Trollor, J. (2014). Making mental health services accessible to people with an intellectual disability. *Australian & New Zealand Journal of Psychiatry*, 48, 395-398.

Valdovinos, M. G., Caruso, M., Roberts, C., Kim, G., & Kennedy, C. H. (2005). Medical and behavioral symptoms as potential medication side effects in adults with developmental disabilities. *American Journal on Mental Retardation*, 110, 164-170.

Werges, D. (2007). The Other Dual Diagnosis: Intellectual Disability and Mental Illness. *NAAD Bulletin X (5) Article 2*.

Werner S, Stawski M, Polakiewicz Y, Levav I. (2012). Psychiatrists' knowledge, training and attitudes regarding the care of individuals with intellectual disability. *Journal of Intellectual Disability Research*, 57, 774-82.

Woods, R. (2011). Behavioural concerns: assessment and management of people with intellectual disability. *Australian Family Physician*, 40, 198.

Table 1

*Demographics of Cohort with IDD*

	<b>Children</b>		<b>Adults</b>	
	N	%	N	%
<b>Disability Group</b>				
<b>Intellectual Disability</b>				
Mild ID	344	1.1	1,979	10.0
Moderate-to-Profound ID	114	0.4	1,003	5.1
Unspecified ID	12,271	39.5	6,820	34.4
<b>Developmental Disabilities</b>				
Down Syndrome/Trisomy/Autosomal Deletions	2,199	7.1	1,406	7.1
Other Genetic Conditions	659	2.1	589	3.0
Fetal Alcohol Syndrome	236	0.8	108	0.5
Cerebral Palsy	2,217	7.1	2,947	14.9
Autism / Pervasive Developmental Disorder	13,020	41.9	4,968	25.1
<b>Age Group</b>				
0 years	33	0.1		
1-2 years	1,573	5.1		
3-6 years	7,327	23.6		
7-12 years	13,637	43.9		
13-17 years	8,490	27.3		
18-24 years			11,452	57.8
25-34 years			3,994	20.2
35-44 years			1,772	8.9
45-54 years			1,473	7.4
55-64 years			1,129	5.7
<b>Gender</b>				
Male	21,383	68.8	11,460	57.8
Female	9,677	31.2	8,360	42.2
<b>Total Intellectual and Developmental Disabilities</b>	<b>31,060</b>		<b>19,820</b>	

Table 2

*Inpatient Hospitalizations for People with IDD*

<b>Adults</b>									
<b>Rank</b>	<b>CCS Description</b>	<b>IDD Cohort</b>		<b>Risk Ratios*</b>					
		<b>N Visits</b>	<b>Rate (Visits per 1000 people)</b>	<b>RR</b>	<b>Compared to MA General Population</b>		<b>Compared to U.S. General Population</b>		
					<b>95% CI</b>		<b>RR</b>	<b>95% CI</b>	
1	Paralysis	1454	73.4	4577.1	3,570.1,	5868.2	2,989.4	2,819.2,	3,169.9
2	Epilepsy; convulsions	547	27.6	30.1	27.5,	32.9	33.6	30.9,	36.5
3	Mood disorders	329	16.6	3.5	3.1,	3.9	4.9	4.4,	5.4
4	Pneumonia	278	14.0	8.2	7.3,	9.2	8.4	7.5,	9.5
5	Schizophrenia and other psychotic disorders	242	12.2	7.5	6.6,	8.5	7.1	6.3,	8.1
6	Skin and subcutaneous tissue infections	221	11.2	5.0	4.4,	5.7	5.9	5.2,	6.7
7	Other hereditary and degenerative nervous system conditions	195	9.8	89.5	75.6,	105.9	115.3	100.1,	132.8
8	Other nervous system disorders	195	9.8	12.2	10.6,	14.1	14.2	12.3,	16.3
9	Septicemia (except in labor)	182	9.2	4.9	4.3,	5.7	4.1	3.5,	4.7
10	Nervous system congenital anomalies	170	8.6	476.5	362.2,	626.9	691.2	591.7,	807.4
<b>Children</b>									
1	Paralysis	615	19.8	428.8	329.6,	557.8	784.7	716.3,	859.5
2	Epilepsy; convulsions	353	11.4	10.8	9.6,	12.1	12.8	11.5,	14.2
3	Other hereditary and degenerative nervous system conditions	254	8.2	114.9	90.7,	145.6	132.0	116.4,	149.8
4	Other nutritional; endocrine; and metabolic disorders	229	7.4	28.6	24.2,	33.9	35.8	31.4,	40.8
5	Other congenital anomalies	206	6.6	9.9	8.5,	11.6	16.0	14.0,	18.4
6	Mood disorders	180	5.8	4.2	3.6,	4.9	4.1	3.6,	4.8
7	Other lower respiratory disease	135	4.3	28.1	22.6,	35.0	30.5	25.7,	36.1
8	Pneumonia (except that caused by tuberculosis or sexually transmitted disease)	129	4.2	3.1	2.6,	3.7	2.6	2.2,	3.1
9	Attention-deficit, conduct, and disruptive behavior disorders	117	3.8	19.8	15.9,	24.7	24.4	20.3,	29.3
10	Asthma	115	3.7	1.9	1.6,	2.3	2.4	2.0,	2.9

\*All Risk Ratios are significant to the p&lt;0.001 level.

Table 3

*Outpatient ED Visits for People with IDD*

<b>Adults</b>					
<b>Rank</b>	<b>CCS Description</b>	<b>IDD Cohort</b>		<b>Risk Ratios*</b>	
		<b>N Visits</b>	<b>Rate (Visits per 1000 people)</b>	<b>RR</b>	<b>Compared to U.S. General Population 95% CI</b>
1	Mood disorders	1519	76.6	22.4	21.3, 23.6
2	Abdominal pain	1309	66.0	3.0	2.9, 3.2
3	Superficial injury; contusion	1209	61.0	3.7	3.5, 3.9
4	Sprains and strains	904	45.6	2.0	1.8, 2.1
5	Epilepsy; convulsions	824	41.6	13.6	12.7, 14.5
6	Other injuries and conditions due to external causes	821	41.4	5.2	4.8, 5.5
7	Nonspecific chest pain	752	37.9	2.3	2.2, 2.5
8	Anxiety disorders	715	36.1	9.0	8.4, 9.7
9	Skin and subcutaneous tissue infections	686	34.6	3.1	2.9, 3.4
10	Other upper respiratory infections	654	33.0	2.7	2.5, 2.9
<b>Children</b>					
1	Other upper respiratory infections	1614	52.0	1.2	1.1, 1.3
2	Superficial injury; contusion	1217	39.2	1.7	1.6, 1.8
3	Fever of unknown origin	1090	35.1	2.1	2.0, 2.2
4	Other injuries and conditions due to external causes	1025	33.0	2.1	2.0, 2.3
5	Otitis media and related conditions	779	25.1	1.2	1.1, 1.3
6	Nausea and vomiting	731	23.5	2.4	2.2, 2.6
7	Sprains and strains	685	22.1	1.5	1.4, 1.6
8	Epilepsy; convulsions	679	21.9	6.8	6.3, 7.3
9	Abdominal pain	672	21.6	2.0	1.9, 2.2
10	Open wounds of head; neck; and trunk	657	21.2	1.4	1.3, 1.5

\*All Risk Ratios are significant to the  $p < 0.001$  level.