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Assessment #7

The Vital Role of Specialized Approaches: Persons with Intellectual and Developmental Disabilities in the Mental Health System

August 2017

Alexandria, Virginia

*Third in a Series of Ten Briefs Addressing: What Is the Inpatient Bed
Need if You Have a Best Practice Continuum of Care?*

This work was developed under Task 2.2 of NASMHPD's Technical Assistance Coalition contract/task order, HHSS2832012000211/HHS28342003T and funded by the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services through the National Association of State Mental Health Program Directors.

The Vital Role of Specialized Approaches: Persons with Intellectual and Developmental Disabilities in the Mental Health System

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August 2017

This work was supported by the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services.

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Executive Summary

Individuals with intellectual and developmental disabilities (persons with intellectual and developmental disabilities referred to as PWIDD or IDD henceforth)¹ are at high risk for co-occurring mental health conditions, with the incidence of psychiatric disorders—including illnesses such as major depressive disorder, bipolar disorder, anxiety disorders, impulse control disorders, major neurocognitive disorders, and stereotypic movement disorders—estimated to be more than three times higher in the IDD population compared to the general population.² One of the challenges in providing mental health services for these individuals in all age groups is in addressing their broader spectrum of unique needs.

A strong continuum and system of care across psychiatric services for persons with IDD, with and without co-occurring mental illness, is critical given the high incidence of psychiatric disorders in this population, as well as the national trends and societal values of maximizing living in natural environments in the community and social inclusion for persons with mental illness and IDD. The vulnerabilities faced by these individuals are pronounced and can lead to catastrophic consequences, including: pronounced rates of victimization, lack of access to appropriate treatment with multiple transitions in care that can create regression, the potential for criminalization of behavior as an unfortunate result of miscommunication, and other challenges.

Although persons with IDD are often seen in medical and psychiatric systems of care, “treatment as usual” for them has typically not been sufficiently nimble, knowledgeable, or adept. On the individual case level, a biopsychosocial formulation for assessment and treatment is necessary to approach a given situation when a person with IDD is in the mental health system. Cookie cutter approaches to the treatment of mental illness can lead to negative consequences and can fly in the face of the critical importance of planning care around individual need—so called person-centered care—and maximizing the ability of self-directed living unless reason and judgment are impaired to the point that health and safety are compromised.

This assessment provides a critical overview of highlighted areas for State Mental Health Authorities (SMHAs) and associated stakeholders to utilize in an effort to: 1) increase understanding of co-occurring disorders as a whole and develop a workforce better equipped to treat skillfully and help support affected individuals’ success; 2) identify current trends in effective supports that go beyond hospital beds, as well as areas in which improvements are needed; 3) understand pathways to resources to help support these individuals from early educational plans with individual supports pursuant to the Individuals with Disabilities Education Act (IDEA), where the expectation should be that an individual’s functioning can be improved with the right supports rather than accepting

¹ *Disclaimer: In this paper, references to antiquated terms for intellectual disability are offered solely for historical reference and to alert the reader to policy and statute that may still utilize terminology that today is considered derogatory and stigmatizing. Many jurisdictions have modified and updated terminology to comport with currently accepted language—something that the authors believe is an important step forward for consideration for all policy and legislation.*

² Harris J.C., *Intellectual Disability: Understanding Its Development, Causes, Classification, Evaluation, and Treatment*, Oxford University Press, New York, NY (2006).

the status quo; and 4) recommendations for policy makers and funders on how to best work with individuals with IDD across all developmental ages when they are within the mental health services system.

The importance of this population gaining equal access to treatments that others in the mental health and medical system are able to access cannot be overstated, along with the critical importance of recognizing their individual needs and maximizing their ability to live full and meaningful lives in society.

Case Example

“John” is a nonverbal man in his twenties with profound Intellectual Developmental Disorder. He has lived in group living environments since his early teens, after his father, who is his guardian, determined he could not care for him at home. John has had multiple housing placements in recent years due to issues with aggression and violence; staff members at his most recent support home now bring him to the Emergency Department (ED) due to “not being able to handle him anymore.” Staff members at the house are unclear about what precipitates his aggression, but have been giving him prescribed antipsychotics to “try to manage him” without noticeable changes to his behavior. They describe John hitting and kicking staff members, refusing to wear clothes, and smearing feces around the home. His underlying medical work-up shows nothing significant, but due to his behavior and because his residential program states they “can’t take him back” due to his behavioral issues, a determination is made that he must be admitted to the psychiatric inpatient unit at the hospital to see if an underlying psychiatric disorder could be contributing to his symptoms.

During John’s psychiatric admission, he continues to exhibit the same behaviors that prompted his admission, including aggressive and violent behavior toward staff and smearing feces and destroying property. He is placed in a quiet section of the unit designed for more intensive monitoring, and four staff are assigned to watch him at all times. Nursing staff, physicians and the entire multidisciplinary team admit they feel inadequately trained to effectively treat John on the inpatient unit, and wonder about next steps in treatment, support, and management.

Introduction to the Issues: Context, Legal and Structural Framework

Comprehensive mental health services systems provide an array of treatment modalities across a continuum, including inpatient, outpatient, crisis stabilization, longer-term supports and care, and residential. The continuum of care is of critical importance in tailoring effective responses to varying levels of need, and psychiatric beds should only reflect the very end of a spectrum of offered supports. With evolving standards, funding streams, and expectations of families, advocates, and others, community-based care with all forms of the continuum is an essential priority.

SMHAs traditionally have a mandate to represent and provide for the needs of youth with serious emotional disturbances (SED) and adults with serious mental illness (SMI), the latter typically defined as disorders of thought and mood (such as major psychotic and mood disorders) that significantly impact psychosocial functioning. General Fund appropriations directed to SMHAs are by necessity limited to such target populations. In some states, the state Developmental Disability Agency will be embedded within the same organization as the SMHA, but, as described below, they are more often separated. Psychiatric hospital inpatient services are primarily designed and focused on providing services for individuals with mental illness, just as are residential and community supports that are designed and funded by the SMHA. A separate line of community supports is set up for PWIDD, and the supports of one system typically operate in isolation from the supports of the other, although there may be overlap across acute psychiatric and emergency services.

With the continuum of care designed to focus on individuals with SMI as the priority patient group, subpopulations of significance are often faced with the fact that their needs may not be as readily addressed as a priority area. A growing example of this is in individuals with multiple challenges. A “co-occurring” disorder can refer to any two or more conditions that occur together within one person. In the SMHA context, mental illness combined with substance use disorders are increasingly labeled as “co-occurring disorders” as a shorthand way of invoking the idea that services should be designed to address both needs. Another population addressed by the term “co-occurring” includes individuals with mental illness and IDD.

The use in this context of “co-occurring” may not be ideal. It can be confusing as no one diagnosis is “primary”—rather, one condition’s manifestations may require supports over the other at any given time. Further, since the term “co-occurring” means different things, accurate dialogue requires a shared understanding of what conditions are being referenced. Additionally, although it is not a basis for the diagnosis of IDD, individuals with IDD and without mental illness can exhibit behavioral disruptions and challenges that in fact represent a communication strategy, but can appear as a primary mental illness either alone or in combination with the IDD. The case of John described above is illustrative.

When behaviors among persons with IDD, SMI, or both are difficult to support, individuals may be brought to the attention of the mental health system of care—either voluntarily through an emergency room or involuntarily by police transporting the individual to a hospital or even a jail. There, they are at risk for disparate treatment due to the challenges they present. Using need for psychiatric hospitalization as an example, having some type of IDD is often a significant risk factor for longer emergency department (ED) boarding and delayed access to needed care. ED boarding is the phenomenon whereby an individual waits in an ED for placement in a hospital bed after a determination is made that hospital level of care is needed; waits can last days to weeks,

and can result in increased psychological stress on patients, consume ED resources, worsen ED crowding, and delay needed mental health treatment.³

Traditional structures for ensuring that persons with IDD receive the supports they need have evolved in response to changes in values and knowledge. These changes—shaped in part by the establishment in the 1970s of civil rights—to education and habilitation and related system reform litigation, have in turn promoted statutory, regulatory, budgetary and organizational changes, as well as establishing new funding entitlements that provide for persons with IDD to receive an array of services and ongoing care as needed, shifting societal views of IDD as compared to mental illness.

One consequence of the organizational changes—the splitting of developmental disabilities and mental health authorities in state government bureaucracies—is that psychiatric hospitals now focus more exclusively on persons with SMI. Hospital beds run by SMHAs, although once developed for a variety of population types, are now designed to care mainly for individuals with mental illness, and often are not well-prepared to work with the populations of individuals with co-occurring IDD. Given the overlap in populations, this has become an increasingly frequent source of discussion, and especially so given the growing number of state hospital beds also utilized by patients in the justice system—the so-called “forensic patients” among whom persons with IDD are also over-represented. Community-based services provide critical aspects of a robust mental health system and therefore also should provide access for PWIDD to the same array of levels of mental health care as would be available for anyone else in the population without IDD.

In this paper, we review definitions and constructs related to supporting individuals with IDD, focusing on specific recommendations that look within and beyond the psychiatric hospital structure to ensure that proper services are in place across a continuum of care for individuals with IDD.

Recommendation for Policy Makers

Designated inpatient units for persons with intellectual and developmental disabilities offer the advantages of specialization but the disadvantages of potentially disparate, segregated treatment. Systems should review the balance between specialization and integration within psychiatric services and recognize that, even with integration, unique consultative supports may be needed for treating providers.

Legal Background and Context

Significant legislation has served as a basis for advocacy, reform, and standards and has thus furthered the changing landscape of inclusion of persons with disabilities into

³ Alleviating ED boarding of psychiatric patients. Quick Safety, an advisory on safety & quality issues. The Joint Commission, Division of Health Care Improvement. Issue 19; December 2015. https://www.jointcommission.org/assets/1/23/Quick_Safety_Issue_19_Dec_20151.pdf

mainstream settings designed to avoid isolation and separation.⁴ Table 1 below has a list of several significant laws relating to disability rights, as well as a summary of the major content of these laws that have shaped today’s framework.

Table 1: Summary Examples of Significant Disability Rights Laws

Significant Disability Rights Law	Year Passed	Major Content of Law
Section 504 of the Rehabilitation Act	1973	Prohibits discrimination on the basis of disability for Federal services or Federally funded services. ⁵
The Civil Rights of Institutionalized Persons Act (CRIPA)	1980	Sets out authorization to the U.S. Attorney to investigate conditions of confinement in certain institutions. ⁶
The Fair Housing Amendments Act	1988	Prohibits discrimination of persons with disabilities, among others, in housing. ⁷
Americans With Disabilities Act (ADA)	1990 (Amended in 2008)	Provides significant prohibitions against discrimination on the basis of disability in employment, government services, public accommodations, commercial facilities, transportation and telecommunications. ^{8, 9}
The Individuals with Disabilities Education Act (IDEA)	2004	Requires public schools to make available a free, appropriate public education in the least restrictive alternative to all eligible children with disabilities. Requires public schools to develop Individualized Education Programs (IEP’s) for each child that is unique to his/her specific needs. ¹⁰

⁴ *A Guide to Disability Rights Laws*, U.S. Department of Justice, Civil Rights Division, Disability Rights Section (July 2009), <https://www.ada.gov/cguide.htm#anchor63409>.

⁵ Rehabilitation Act of 1973, Pub. L. No. 93-112 (1973).

⁶ Civil Rights of Institutionalized Persons Act of 1980. Pub. L. No. 96-247 (1980).

⁷ Fair Housing Amendments Act of 1988. Pub. L. No. 100-430 (1988).

⁸ Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).

⁹ ADA Amendments Act of 2008. Pub. L. No. 110-325 (2008).

¹⁰ Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Significant case law evolving around these Federal statutes has also pushed the reform toward inclusion of persons with disabilities. Specifically, *Olmstead v. L.C.* is the 1999 U.S. Supreme Court case that held that persons with mental disabilities have the right to live in community settings, rather than institutions, if the “State’s treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”¹¹ This case has produced two decades of activity moving individuals from institutions to community placements, and sometimes litigation over questions of funding, reasonable accommodations, and least restrictive alternatives in individual cases.

Most recently, as an example of the emerging legal doctrine refining the contours of rights for PWIDD, in *Andrew F. v. Douglas County School District*, the U.S. Supreme Court unanimously found that under the IDEA a public school must utilize a higher standard (*i.e.*, a standard that is higher than “merely more than *de minimus*”) in crafting an Individualized Educational Program (IEP) that is tailored to enable a child to make progress specific to the child’s unique circumstances.¹² The case that led to this decision came about after the plaintiff’s parents, on behalf of their son with Autism Spectrum Disorder (ASD), argued their public school should pay for services that they ultimately received privately because his progress had stalled and the public school system had not done enough to support further progress.¹³ The decision led to an outpouring of enthusiasm among advocates, who tout the decision as one that will continue to push educational systems for supports and access to services to maximize the potential for individual students with disabilities to progress.¹⁴ The impact on youth and then adults of the future may indeed be significant, although time will tell how much the ruling will impact actual IEP development.

Organizational Structures to Meet Mental Health Needs: Opportunities and Barriers

Individuals with co-occurring IDD and mental health conditions need integrated multidisciplinary supports that demand collaboration of services that are mandated, regulated, and financed by siloed offices, agencies, divisions, and/or departments of state governments. Although once commonly integrated into single state departments, responsibility for persons with developmental disabilities and mental health conditions are rarely in the same state department today. In the more than a century during which public institutions dominated the state response to care for persons with developmental disabilities and treatment for persons with psychiatric disorders, departments of mental

¹¹ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

¹² *Andrew F. v. Douglas County School District*, 580 U.S. ___ (March 22, 2017).

¹³ *Ibid.*

¹⁴ McKenna, Laura. How a New Supreme Court Ruling Could Affect Special Education, *The Atlantic* (March 2017), <https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/>.

health that operated both services or departments of mental health and mental retardation were the norm.

The Mental Retardation and Community Mental Health Centers Construction Act of 1963 heralded a new era of community care.¹⁵ As state agencies continued to operate for both populations, new community centers worked to serve both populations between the 1960s and 1980s. The rapid growth of community-based systems of care, combined with the demanding work of responding to multiple class action lawsuits on conditions at the state schools and state psychiatric hospitals, caused the amount of work under management at state departments of mental health to explode and stretched budgets to capacity. And community mental health agencies began to focus significantly on development of community services for persons leaving state hospitals.

Parallel to the growth of community services, advocacy organizations dominated by the “Arcs” developed a major presence as providers dedicated to persons with developmental disabilities and began advocating for separate departments of “mental retardation” or “developmental services.” Massachusetts, for example, split the Department of Mental Health (DMH) in 1984, creating a new Department of Mental Retardation (DMR), now the Department of Developmental Services (DDS). Nationally, state IDD and mental health (MH) authorities became responsible for funding and monitoring needed services, yet support and funding was uneven.

After decades of administrative restructuring, budget migration, and a concomitant narrowing of eligibility criteria, state IDD and MH authorities carry out their responsibilities for financing and monitoring publicly funded programs in ways that vary considerably from state to state. As will be discussed in a later section, additional variation is imposed by the choices each state elects under its Medicaid program with regard to the state plan elements, plan options, or waivers best suited to the state’s needs and interests. Despite the fact that people with co-occurring IDD and MH conditions comprise an estimated one-third (32.9 percent) of the total number persons served by IDD agencies, organizational structures, eligibility rules, clinical programs, and financing tactics are largely separate.¹⁶

Today, of the 51 state authorities serving PWIDD, only 6 are divisions that remain within departments of mental health, 9 are stand-alone departments of developmental disabilities, and 36 are offices or divisions within larger state executive offices, agencies, or departments of health, human services, and/or social services.¹⁷ This is a significant factor when addressing the needs of people with co-occurring conditions. Even when the functions were combined in a single state agency, eligibility, program, and financing rules inevitably fail to satisfy the needs of those persons with dual or complex conditions. However, with a single commissioner or director, one could bring divisions or offices in the department together to resolve challenging cases.

¹⁵ Mental Retardation Facilities Construction Act. Pub L. No. 88-164 (1963), <https://history.nih.gov/research/downloads/pl88-164.pdf>.

¹⁶ *National Core Indicators Adult Consumer Survey 2011–12 Final Report*, National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (2013), www.nationalcoreindicators.org.

¹⁷ NASDDDS (2017), <https://www.nasdds.org/>.

The pervasive fragmentation of program authority and resource control that characterizes the bureaucratic landscape of today poses significant barriers for those who may have a co-occurring intellectual disability and mental disorder or those who may have an autism spectrum disorder and co-occurring mental disorder. State agency, division, or office guidelines for eligibility are not clearly aligned across entities in many states to ensure that no one is excluded and that persons with co-occurring conditions are included.

Since the economic downturn of 2009, state agencies of all types have narrowed eligibility criteria to manage within tighter budgets, exacerbating the problem. In some states, autism spectrum disorders (ASD), for example, have been excluded from either the mental health or developmental disability agency guidelines. Recent advocacy in several states has pushed for more inclusion of services for individuals with ASD. Financing is further fragmented, however, with program eligibility, waiver requirements, and coverage criteria limiting flexibility in resource application. The eligibility challenges, combined with financing challenges, are made more difficult to resolve by an absence of clear protocols in many jurisdictions for managing co-occurring conditions.

NADD, an association for persons with developmental disabilities and mental health needs, provides access to policy papers and practice guidelines that may be of assistance to states.¹⁸ In 2007, NADD collaborated with the American Psychiatric Association (APA) on the publication of Diagnostic Manual – Intellectual Disability (DM_ID), a text guiding diagnosis of mental disorders in persons with intellectual disabilities.^{19, 20} With the publication of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), NADD developed updated guidance for practitioners.²¹

Beyond this initiative, the need for inter-system collaborative approaches to working across mental health services systems and those more specifically focused on serving PWIDD is well-recognized. As a starting principle, there needs to be acceptance that these individuals will and do appear in mental health services. From there, building more intersystem collaborative protocols is a needed next step, and some jurisdictions are more ahead than others in this endeavor. Guidelines that promote intra-system collaboration should take advantage of work already accomplished in this area, such as the strategic planning done for workforce development by the NADD, for example.²²

¹⁸ NADD: An Association for Persons with Developmental Disabilities and Mental Health Needs, <http://thenadd.org/>.

¹⁹ Fletcher R.J., Havercamp S.M., Ruedrich S.L., Benson B.A., Barnhill L.J., Cooper S.A. & Stavrakaki C.. Clinical Usefulness of the Diagnostic Manual-Intellectual Disability for Mental Disorders in Persons with Intellectual Disability: Results from a Brief Field Survey, *Journal of Clinical Psychiatry* 70(7), 967-974 (2009).

²⁰ Fletcher R.J., Loschen E., Stavrakaki C., and First M., *Diagnostic Manual—Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability*, NADD (2007).

²¹ Fletcher R.J., Barnhill J., McCarthy J. & Strydom A. From DSM to DM-ID, *Journal of Mental Health Research in Intellectual Disabilities* 9(3), 189-204 (2016),

²² <http://thenadd.org/products/accreditation-and-certification-programs/>.

Recommendation for Policy Makers

Policymakers should work to develop cross-agency guidelines for greater intersystem collaboration, recognizing that PWIDD will and do appear in the mental health service system. The development of these collaborative efforts should include input from a variety of stakeholders and examine collaboration across all ages, including persons served in the child/adolescent, adult, and older adult sectors. Perspectives of persons served, their families, and representative advocacy organizations will be critical in the development of guidelines.

Examples of important areas for these guidelines to address include:

- 1) Development of shared data to understand total numbers of individuals served across systems and those denied services because of overlap issues, and the development of planning based on those data**
- 2) Development of approaches to handle requests for services for people that do not neatly fit into administrative lines for particular services and the development of approaches for reviewing individual cases where overlapping needs are present but are not being met**
- 3) Fostering leadership to develop methods through blended and braided funding streams for continuum of care services that address the dual need populations**
- 4) Establishment of intersystem partnerships, such as with law enforcement and jail diversion programs, to include interventions for persons with both IDD and SMI**
- 5) Mutual workforce development**

Conceptualizing Intellectual and Developmental Disabilities (IDD): The Neurodevelopmental Disorders

Neurodevelopmental disorders are a category of disorders found in the DSM-5, one of the leading classification and diagnostic tool for psychiatric disorders.²³ This category of disorders includes a group of often co-occurring conditions with onset in the developmental period—usually manifesting before a child enters primary school—and is characterized by deficits in “personal, social, academic, or occupational functioning.”²⁴

²³ *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed., American Psychiatric Association; (2013).

²⁴ *Ibid.*

IDD, ASD, attention deficit hyperactivity disorder (ADHD), and other communication, motor, and learning disorders are included in this category. Neurodevelopmental disorders are distinct from the neurocognitive disorders, a separate category in the DSM-5 characterized by a loss in cognitive functioning from a prior level (e.g., Alzheimer's falls into this latter category). Intellectual functioning is often not impaired within the neurodevelopmental disorders, although it can be, and thus it is important to understand the total abilities of the individual being served to best address their needs.

Intellectual Developmental Disorder (IDD)

IDD is classified in the DSM-5 as a neurodevelopmental disorder. IDD underwent significant changes with the progression from DSM-IV to DSM-5. Many of these changes were in the context of a shifting public and political landscape on intellectual disabilities, a gradual transformation in perception that evolved throughout the last century. With regard to intellectual disabilities, terminology such as “feeble-minded” was employed professionally in the early 1900s as the generic term for all mental deficiencies, with expressions like “idiot” and “imbecile” as sub-degrees of this term.²⁵ Over time, these words have been seen as derogatory, and were replaced with the phrase “mental retardation”, which was introduced by the American Association on Mental Retardation in 1961.²⁶ This term also fell out of favor for similar reasons, as public and political sentiment changed and many advocacy, medical, and educational groups began using the term “intellectual disability” — including the American Association on Mental Retardation, which changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD) in 2007. Rosa’s Law, signed into United States public law by President Barack Obama in 2010, also removed references to “mental retardation” in Federal law and replaced them with “intellectual disability,” reflecting the changing landscape in diagnostic labels and efforts to use language that was less stigmatizing and demeaning.²⁷ As standards in diagnostic coding and references to these conditions in Federal statutes have shifted, states and organizations have similarly changed language. Policy and legislation that has not caught up with currently accepted terminology is problematic and SMHAs can help advocate for reform in this area.

Similarly, “intellectual disability (intellectual developmental disorder)” is used in the DSM-5,²⁸ replacing the term “mental retardation” used in the DSM-IV. According to the DSM-5, to meet criteria for this diagnosis, an individual needs to have deficits in intellectual functioning, deficits in adaptive functioning, and an onset of the deficits occurring in the developmental period.²⁹ While the DSM-IV focused on IQ scores as a cornerstone of the definition of mental retardation, in the DSM-5, the severity of the intellectual developmental disorder is classified as mild, moderate, severe, or profound,

²⁵ Doll Edgar, H.H. Goddard and the Hereditary Moron. *Science* Vol. 126, No. 3269, pp 343-344 (August 195).

²⁶ Harris J.C., New Terminology for Mental Retardation in DSM-5 and ICD-11, *Current Opinion in Psychiatry* 26:260–262 (2013).

²⁷ Public Law 111-256, § 2(b)(2), 5 October 2010, 124 Stat. 2643 (Rosa's Law).

²⁸ DSM-5.

²⁹ DSM-5.

based on adaptive functioning in conceptual, practical, and social domains. The focus on the use of IQ scores alone for diagnosis has been deemphasized.³⁰ In addition, with the DSM-5 removing a system of multi-axial assessments, intellectual and developmental disabilities have been moved in concept from Axis II of “underlying conditions” to conditions on equal par with other diagnoses.

The shift in thinking regarding an emphasis on adaptive functioning has reflected studies that have indicated that IQ test scores, while helpful as an approximation of domains in functioning, are inadequate to capture the full picture of deficits and strengths that together make up an individual’s adaptive functioning.³¹ This is of critical importance to distinguish in the public services context, as adaptive functioning is what often determines the level of support needed for the individual. Again related to current standards of focusing on strengths rather than deficits, the use of adaptive functioning provides a more comprehensive snapshot without resorting to reliance only upon a number or a score for an IQ test that can lead to stigmatization and labeling, or even an underestimation of the individual’s capabilities.

IQ testing in and of itself is not without its limits and challenges, as scores may shift over time for a population or an individual, as evidenced by the “Flynn effect,” the observed rise in standardized IQ scores over time.³² The Flynn effect is germane to intellectual disability, especially if an IQ score cut-off point is used as an integral part of a decision-making process for public services or in the legal system. The line-drawing seen with IQ testing can run significant risks in societal determinations, and increasingly the dangers of this line-drawing has been recognized in even high-stakes contexts.

In an extreme recent example, the United States Supreme Court reaffirmed in March 2017, in the case *Moore v. Texas*, that intellectual disability remains a constitutional barrier to the death penalty, but that current mental health standards must be applied in such cases.³³ The Court remanded the case of Bobby Moore back to a lower court after finding that Texas used a rigid IQ cutoff score to reject Mr. Moore’s claim to intellectual disability, despite his deficits in conceptual, social, and practical domains. The Court recommended taking into account the overall functioning of the individual when making the diagnosis of intellectual disability.³⁴ Although the legal case is a death penalty matter, the process and acknowledgment by the Court is an indication that the cutoff IQ score is insufficient to make complex decisions about a person’s needs and future.

Other diagnostic methodologies influenced the general definitions of intellectual developmental disorder used in the DSM-5. The AAIDD, which changed its name and adopted the terminology “intellectual disability” prior to even passage of Rosa’s Law or the publication of the DSM-5, defines intellectual disability by “significant limitations in

³⁰ DSM-5.

³¹ Yalon-Chamovitz S. & Greenspan S., Ability to Identify, Explain and Solve Problems in Everyday Tasks: Preliminary Validation of a Direct Video Measure of Practical Intelligence, *Research in Developmental Disabilities* 26(3):219–230 (2005).

³² Trahan L *et al.* The Flynn Effect: A Meta-Analysis, *Psychological Bulletin* Vol. 140(5), pp. 1332-1360 (September 2014).

³³ *Moore v. Texas*. 581 U. S. ____ (2017).

³⁴ *Ibid.*

both intellectual functioning and in adaptive behavior” that occurs before the age of 18.³⁵ Although the definition of “developmental disability” can vary from state to state, state definitions generally mirror the Federal definition of a “severe, chronic disability of an individual that...is attributable to a mental or physical impairment or combination of mental and physical impairments...is manifested before an individual attains age 22...is likely to continue indefinitely...and results in substantial functional limitations.”³⁶ The Federal definition lists several functional limitations, which include areas of adaptive functioning.³⁷ Adaptive functioning is defined by AAIDD, as it is in the DSM-5, as the assortment of conceptual, social, and practical skills that are learned and performed by an individual in their day-to-day life.

Table 2: Summary Examples of Adaptive Functioning Domains
Examples Summarized from DSM-5 and AAIDD Diagnostic Information

Domain	Difficulties With:
Conceptual Skills	<ul style="list-style-type: none"> - Reading, writing, language - Telling time - Handling money - Executive functioning (<i>i.e.</i>, planning, strategizing, setting priorities) - Memory
Practical Skills	<ul style="list-style-type: none"> - Activities of Daily Living (ADLs), such as bathing, toileting, and self-care - Instrumental Activities of Daily Living (IADLs) such as telephone use, paying bills, grocery shopping, and transportation - Skilled vocations - Legal decisions
Social Skills	<ul style="list-style-type: none"> - Interpersonal skills - Social responsibility and cues - Following rules - Understanding risk (level of wariness, naiveté, or gullibility) - Self-esteem

Thus, instead of emphasizing IQ, both the DSM-5 and the AAIDD consider IQ scores as only one measure among an array of other facets in arriving at a diagnosis of IDD. The AAIDD notes that, generally, an IQ score of 70 to 75 may indicate a limitation in

³⁵ American Association on Intellectual and Developmental Disabilities, <https://aaidd.org/intellectual-disability/definition#.WOEgMI61v-Y>.

³⁶ Federal Definition of Developmental Disability, in the Developmental Disabilities Assistance and Bill of Rights Act of 2000; Sec. 102. Definitions [42 USC § 15002].

³⁷ *Ibid.*

intellectual functioning. DSM-5, in the same way, considers scores of approximately two standard deviations or more below the population mean, +/- a 5-point margin for measurement error, as indicating a likely intellectual deficit. On tests with a standard deviation of 15 and a mean of 100, this involves a score of 65–75 (70 ± 5).³⁸

In order to best assess functioning, several tools are available, and some are being further promulgated. The AAIDD, for example, is in the process of developing a comprehensive standardized assessment of adaptive behavior, called the Diagnostic Adaptive Behavioral Scale.³⁹ AAIDD states the purpose of this scale is ruling in or ruling out a diagnosis of intellectual disability by providing information regarding the “cutoff point” where an individual 4- to 21-years-old is deemed to have significant limitations in adaptive behavior.⁴⁰ Having such a scale could have significant implications for determining an individual’s eligibility for services, benefits, and even treatment in legal contexts.

Overview of Population Prevalence: IDD, according to the DSM-5, has an overall general population prevalence of approximately 1 percent, with the prevalence of severe intellectual disability estimated at 0.006 percent.^{41, 42} Although estimates of the distribution of mild, moderate, severe, and profound IDD vary in the literature, some estimate that in the IDD population, 85 percent of individuals would be classified as mild, 10 percent would be classified as moderate, 4 percent would be classified as severe, and 1 to 2 percent would be classified as profound IDD.⁴³

Although there have not been consistent racial differences in the prevalence of IDD, there does appear to be a gender difference. Studies have shown males have a higher likelihood of being diagnosed with both mild and severe intellectual disability.⁴⁴ Looking at this data overall, however, we can see that the case of John (on page 5 of this paper) would probably represent someone who would be seen relatively rarely. On the other hand, persons with milder IDD would be much more commonly encountered. Overall, it is important to note that the heterogeneity of the population again raises red flags about over-generalizations.

Autism Spectrum Disorder (ASD)

ASD is a neurodevelopmental disorder with onset in the early developmental period. It is characterized by the presence of persistent deficits in social communication and social interaction in multiple contexts, as well as restricted and repetitive patterns of behavior,

³⁸ DSM-5.

³⁹ American Association on Intellectual and Developmental Disabilities, <https://aaidd.org/intellectual-disability/diagnostic-adaptive-behavior-scale>.

⁴⁰ AAIDD.

⁴¹ DSM-5.

⁴² Roeleveld N., Zielhuis G.A. & Gabreëls F., The Prevalence of Mental Retardation: A Critical Review of Recent Literature, *Developmental Medicine and Child Neurology* 39(2):125–132 (1997).

⁴³ King B.H., Toth K.E., Hodapp R.M. & Dykens E.M., Intellectual Disability in, *Comprehensive Textbook of Psychiatry, 9th Edition*, eds. Sadock B., Sadock V.A. & Ruiz P., Lippincott Williams & Wilkins, pp. 3444-3474 (2009).

⁴⁴ Einfeld S. & Emerson E., Intellectual Disability, in *Rutter's Child and Adolescent Psychiatry, Fifth Edition*, eds. Rutter M., Bishop D.V.M., Pine D.S., Scott S., Stevenson J., Taylor E. & Thapar A., Blackwell Publishing Ltd., Oxford, UK. (2008).

interests, or activities that cause clinically significant impairment in several areas of functioning, including personal, social, academic, or occupational.⁴⁵

Like IDD, the definition of ASD also underwent changes with the progression of the DSM-IV to the DSM-5. ASD is a new name that encompasses four separate disorders in the previous DSM-IV, including autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.⁴⁶ With the shift to DSM-5, there are restrictive behavioral patterns that are considered part of the diagnosis, while the social/communication criteria are collapsed into one section of the criteria set. These changes were based on research and expert opinion, with the hope that the diagnosis of ASD would be more specific, reliable, and valid.⁴⁷

As with intellectual developmental disorder, adaptive functioning is a key consideration in ASD. Some individuals with ASD exhibit marked deficits in socialization and communication that impairs their ability to function adaptively, highlighting the possible discrepancy between cognitive capabilities that can be measured via IQ and level of support an individual requires.⁴⁸

When screening for ASD, there are both developmental screenings and comprehensive evaluations that often occur. The American Academy of Pediatrics (AAP) recommends that all children be screened for developmental delays and disabilities during regular well-child doctor visits at 9 months, 18 months, and 24 months.⁴⁹ Screenings of children can be tied to funding streams such as Medicaid. This screening may involve questionnaires filled out by parents, discussions with caregivers, and professional observation of the child during the appointment. If a developmental screen is positive, a more comprehensive evaluation often follows, which can include in-depth neuropsychiatric testing and evaluation from a multidisciplinary team of speech and language pathologists, occupational therapists, pediatricians, psychiatrists, or more.

ASD Prevalence Overview: According to the DSM-5, in recent years the prevalence of ASD has been estimated at 1 percent of the population.⁵⁰ A 2009 study found that autism in 2006 seemed to affect ~1 in every 110 children,⁵¹ which was approximately a 66 percent increase in the incidence of ASD from even 4 years previously, when the

⁴⁵ DSM-5.

⁴⁶ *Highlights of Changes from DSM-IV-TR to DSM-5*, American Psychiatric Association (2013), [https://webcache.googleusercontent.com/search?q=cache:ZDGL1nozhlJ:https://www.psychiatry.org/File percent2520Library/Psychiatrists/Practice/DSM/APA DSM Changes from DSM-IV-TR - to DSM-5.pdf+%26hl=en&ct=clnk&gl=us](https://webcache.googleusercontent.com/search?q=cache:ZDGL1nozhlJ:https://www.psychiatry.org/File%20percent2520Library/Psychiatrists/Practice/DSM/APA%20DSM%20Changes%20from%20DSM-IV-TR%20to%20DSM-5.pdf+%26hl=en&ct=clnk&gl=us).

⁴⁷ *Updates to the APA in DSM-V – What Do the Changes Mean to Families Living with Autism?*, Autism Research Institute, https://www.autism.com/news_dsmV.

⁴⁸ Bolte S. & Poustka F., The Relation between General Cognitive Level and Adaptive Behavior Domains in Individuals with Autism With and Without Co-Morbid Mental Retardation, *Child Psychiatry and Human Development* 33(2), pp. 165–172 (2002).

⁴⁹ *Autism Spectrum Disorder: Screening and Diagnosis for Health Care Providers*, Centers for Disease Control and Prevention, <https://www.cdc.gov/ncbddd/autism/hcp-screening.html>.

⁵⁰ DSM-5.

⁵¹ Rice C., Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. *MMWR Surveillance Summaries* 58(10), pp. 1–20 (2009).

incidence was reported in similar studies to be 1 in 179 children.⁵² Even more recent 2012 Center for Disease Control and Prevention (CDC) data indicates the prevalence may be as high as 1 in 68 children.⁵³ There has been no clear answer as to why the prevalence rates for ASD seem to be increasing over time; some point to the changing diagnostic criteria for the disorder,⁵⁴ while others postulate that higher rates reflect increased awareness and early identification of this disorder or underestimation of the prevalence in the past.⁵⁵ The prevalence rates for ASD parallel—and by some measures, are higher than—those of illnesses such as schizophrenia.⁵⁶

Other Neurodevelopmental Disorders

Although not the focus of this paper, there are other neurodevelopmental disorders that include Attention Deficit Hyperactivity Disorder (ADHD) as well as the communication, motor, and specific learning disorders (*i.e.*, those impacting math and reading.) ADHD is another neurodevelopmental disorder characterized by persistent patterns of impairing levels of inattention, disorganization, and/or hyperactivity-impulsivity in multiple settings with onset in the early developmental period, with a requirement that several symptoms begin before the child reaches 12 years of age.⁵⁷ Although ADHD can be seen among people with IDD, generally this disorder alone does not require the level of support of other neurodevelopmental disorders.

Communication disorders include functional impairments in language, speech, and communication, and include disorders such as language disorder, speech sound disorder, childhood-onset fluency disorder (stuttering), and social (pragmatic) communication disorder.⁵⁸ Motor disorders include developmental coordination disorder, stereotypic movement disorder, and tics disorders (including Tourette Syndrome).⁵⁹

Co-Occurring Conditions, Prevalence, and their Manifestations

There are many conditions that co-occur within the neurodevelopmental disorders, ranging widely in psychiatric, neurodevelopmental, and physical domains. There was a general school of thought in the mid-1900s that individuals with a developmental disability could not also have mental illness, and that instead any behavioral issues were a

⁵² Manning S., Davin C., Barfield W., *et al.*, Early Diagnosis of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001-2005, *Pediatrics* 127(6) (2011), pp. 1043-1051.

⁵³ CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, <https://www.cdc.gov/ncbddd/autism/data.html>.

⁵⁴ Rutter, M., Incidence of Autism Spectrum Disorders: Changes Over Time and Their Meaning, *Acta Paediatrica* 94:2—15 2005.

⁵⁵ Manning *et al.*

⁵⁶ DSM-5.

⁵⁷ DSM-5.

⁵⁸ DSM-5.

⁵⁹ DSM-5.

result of intellectual disability.⁶⁰ However, research has shown the opposite to be true, and has instead suggested that the prevalence of mental illness in the developmentally disabled population is actually higher than in the general population.⁶¹ As stated in the executive summary, psychiatric disorders have been shown to be three to four times higher in individuals with IDD than individuals in the general population, and include illnesses such as major depressive disorder, bipolar disorders, anxiety disorders, impulse control disorders, major neurocognitive disorders, and stereotypic movement disorder.⁶²

Psychiatric disorders may manifest differently in individuals with intellectual disability compared to the general population. For example, a limited ability to verbally communicate anxiety, mood issues, or a psychotic thought or thought disorder may manifest in aggression or externalizing behaviors, which can often result in missed diagnoses and thus opportunities for treatment.

Other neurodevelopmental disorders, such as ASD and ADHD, are also frequently comorbid with IDD.⁶³ While numerous studies show that ASD and IDD co-occur, the actual prevalence rates of IDD in ASD vary widely in the literature, ranging from between 16.7 percent to 84 percent.⁶⁴ More recent studies, however, may put the co-occurring prevalence rates around or below 50 percent.^{65, 66} The close and often co-occurring relationship between IDD and ASD is also significant because an individual with IDD and ASD may have different needs and comorbidities when compared to individuals with either IDD or ASD alone. Individuals with comorbid ASD and IDD may have higher rates of repetitive, restrictive, or self-injurious behaviors, and may have a poorer prognosis.⁶⁷ In addition, studies have shown that greater a severity of one of these two disorders appears to have deleterious effects on the other.⁶⁸

ADHD, characterized by a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, in addition to ASD, is also a frequently comorbid neurodevelopmental disorder in individuals with IDD or in individuals with ASD alone. Some have even suggested that ADHD may be the most common co-occurring condition with IDD, with ASD being the second most common co-

⁶⁰ Putnam, C., *Guidelines for Understanding and Serving People with Intellectual Disabilities and Mental, Emotional, and Behavioral Disorders*. Human Systems and Outcomes, Inc. for the Florida Developmental Disabilities Council (2009).

⁶¹ *Ibid.*

⁶² Harris.

⁶³ Harris.

⁶⁴ Postorino *et al.*, Intellectual Disability in Autism Spectrum Disorder: Investigation of Prevalence in an Italian Sample of Children and Adolescents, *Research in Developmental Disabilities* 48, pp. 193–201 (2016).

⁶⁵ Postorino.

⁶⁶ Carlsson L.H., Norrelgen F., *et al.*, Coexisting Disorders and Problems in Preschool Children with Autism Spectrum Disorders. *Scientific World Journal*, p. 213979 (2013).

⁶⁷ Deb S. & Prasad K.B.G., The Prevalence of Autistic Disorder among Children with a Learning Disability. *British Journal of Psychiatry* 165, pp. 395–399 (1994).

⁶⁸ Matson J. & Shoemaker M., Intellectual Disability and Its Relationship to Autism Spectrum Disorders, *Research in Developmental Disabilities* 30(6), p. 1107-1114 (2009).

<http://dx.doi.org/10.1016/j.ridd.2009.06.003>.

occurring disorder.⁶⁹ In individuals with ASD, the most common co-occurring disorder in some studies was ADHD as well, with an estimated prevalence of 47.2 per 100 individuals.⁷⁰ Awareness of the possibility of co-occurring psychiatric and neurodevelopmental disorders in an individual with IDD is important, as it may be a target for interventions that can impact behaviors, functioning, and outcome.

Traumatic Brain Injury (TBI) can also be a co-occurring disorder. Consequences of TBI can include impaired thinking, memory, and cognitive function, decreased hearing or vision, or even personality changes or emotional symptoms such as depression, aggression, or impulse control issues.⁷¹

In addition, being aware of sensory deficits (visual, tactile, auditory) as often undetected co-existing issues is also helpful in providing data to develop a means to improve a PWIDD's quality of life. Sensory deficits are often found in greater numbers in the PWIDD population. While profound hearing loss is seen in about 1 in 1000 individuals in the general population, the prevalence of hearing impairment is at least 40 times higher in people with intellectual disability compared with the general population.⁷² These sensory deficits are not always recognized easily; one study found that 92 percent of people with severe and profound intellectual disability had visual impairment, but nearly two-thirds of those cases went unnoticed by caretakers.⁷³ There is therefore significant need for regular vision, ear, and hearing exams with appropriate interventions (*i.e.*, hearing aids) as necessary. Appropriate awareness of these as possible added challenges can dramatically open windows to more effective treatment interventions.

Physically, more than 800 recognized syndromes listed in the Online Mendelian Inheritance in Man (OMIM) database are associated with intellectual disability, including the chromosomal abnormality trisomy 21, or Down syndrome, and the X-linked abnormality Fragile X Syndrome.⁷⁴ Other genetic disorders associated with intellectual disability include Klinefelter Syndrome, Williams Syndrome, and Tuberous Sclerosis. Although many think of genetic disorders as frequently associated with IDD, in reality, for most cases of intellectual disability, no specific genetic abnormalities are found.⁷⁵ Non-genomic associated conditions with IDD can be due to pre-term birth or perinatal in-utero exposures or teratogens (agents that impact the fetus), such as cigarette smoke or alcohol. Fetal Alcohol Syndrome (FAS) is a well-established condition that often results

⁶⁹ Stomme P., Diseth T.H., Prevalence of Psychiatric Diagnoses in Children with Mental Retardation: Data from a Population-Based Study, *Developmental Medicine and Child Neurology* 42, pp. 266–270 (2000).

⁷⁰ Kogan D., Blumberg S., Schieve L., *et al.*, Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder among Children in the U.S., 2007, *Pediatrics*, 124(5), pp. 1395–1403 (2009).

⁷¹ *Traumatic Brain Injury and Concussion: Basic Information*. Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Division of Unintentional Injury Prevention, https://www.cdc.gov/traumaticbraininjury/get_the_facts.html.

⁷² Carvill S., Sensory Impairment, Intellectual Disability and Psychiatry, *Journal of Intellectual Disability Research* 45, pp. 467–83 (2001).

⁷³ van den Broek E.G.C., Janssen C.G.C., van Ramshorst T., *et al.*, Visual Impairment in People with Severe and Profound Multiple Disability: An Inventory of Visual Functioning. *Journal of Intellectual Disability Research* 50, pp. 470–5 (2006).

⁷⁴ Zeldin A. & Bazzano A., *Intellectual Disability* (April 19, 2016), <http://emedicine.medscape.com/article/1180709>.

⁷⁵ *Ibid.*

in developmental disability and CDC studies have identified 0.2 to 1.5 infants with FAS for every 1,000 live births in certain areas of the United States.⁷⁶ Efforts at prevention of alcohol use during pregnancy should therefore be an active part of policy for approaches to supports among the adult populations. Should one of these co-occurring conditions exist, a provider may use the DSM-5 specifier “associated with a known medical or genetic condition or environmental factor” to note such factors, as this may affect an individual’s clinical course.⁷⁷

Recommendation for Practitioners

Co-occurring challenges such as psychiatric disorders, other neurodevelopmental disorders, hearing loss, and other sensory challenges, are important to take into account among the PWIDD population across the continuum of care and support services. There is much heterogeneity in the population, so generalizations and cookie-cutter approaches are risky.

PWIDD in the Mental Health System: Considerations and Challenges

Early Recognition

Case Example of “John”, Continued

As John’s behavior escalated, considerations and in-depth research evolved into a variety of plausible explanations for his shifting self-regulation. Specifically, his behavior could have been related to his unique communication of distress regarding the transition of a trusted caretaker, a trauma-reactive response to witnessing or experiencing victimization, or a triggering of manic symptoms due to a medication adjustment a few months prior, among other possibilities.

As noted above and as illustrated in the case example of John, one of the critical elements of working with individuals with IDD is to recognize that a person in services may have neurodevelopmental challenges, and that because there is tremendous heterogeneity within the IDD population as a whole, a cookie cutter approach does not work well. This applies to individuals seen in psychiatric services and to children in schools. Children in the mental health system with concomitant neurodevelopmental disorders should have a unique IEP that addresses both mental health issues and IDD. That applies equally to older adults appearing in emergency services, in nursing homes, or somewhere in the mental health system of care. If an individual seen in psychiatric services does have an

⁷⁶ Fetal Alcohol Syndrome-Alaska, Arizona, Colorado, and New York, 1995-1997, *Morbidity and Mortality Weekly Report*, Center for Disease Control and Prevention, 51(20), pp. 433-5 (2002).

⁷⁷ DSM-5.

IDD of some type, then clarification as to what those challenges mean for the person, in terms of abilities, as well as disabilities, will be key to working successfully with them.

However, an individual with IDD may not be the best historian of his or her own issues. Gathering collateral information about them when they are in care or a support setting will be important. Identifying whether the person has a guardian provides further information about the individual and the level of supports needed, as well as providing a pathway to help gain consents by the guardian for particular treatments. Mainstays of supportive interventions included consideration of habilitative options with behavioral supports, possible psychopharmacological approaches, and consideration of other types of interventions.

Trauma-Informed Care, Supports, and Systems

To provide Trauma-Informed Care (TIC) is to “understand the involvement and impact of violence and victimization on the lives of most consumers of mental health, substance abuse, and other services...also to apply that understanding in providing services ...to accommodate the requirements and vulnerabilities of trauma survivors and to facilitate their participation in treatment.”⁷⁸ Although considering the impact of trauma in an individual’s life is helpful when caring for anyone in the general population, it is especially important when caring for individuals with IDD. Research has indicated that individuals with IDD are more likely to be victimized, and that children with moderate to severe intellectual disabilities are more likely to be neglected, sexually abused, emotionally abused, and physically abused than children without such disabilities.⁷⁹ In addition, children with speech/language disorders also appear to be at increased risk for physical and emotional abuse, as well as neglect.⁸⁰ Because of a potentially reduced capacity to process information, including traumatic memories, those with IDD may be at higher risk of developing PTSD compared to the general population.⁸¹

Complicating this picture further is research that indicates exposure to environmental stressors may also be higher in the IDD population. For instance, exposure to poverty is higher in individuals with intellectual disability when compared to their non-disabled peers,⁸² as is violence in the family and social isolation,⁸³ which can in turn lead to reduced resilience in the face of other adverse life events and the compounding of negative effects on an individual’s life. Negative life events have been found to be

⁷⁸ Butler L., Critelli P. & Rinfrette E., Trauma-Informed Care and Mental Health. *Directions in Psychiatry* 31, pp. 197–209 (2011).

⁷⁹ Spencer N., Devereux E., Wallace A., Sundrum R., Shenoy M., Bacchus C. & Logan S., Disabling Conditions and Registration for Child Abuse and Neglect: A Population-Based Study, *Pediatrics* 116, pp. 609–613 (2005).

⁸⁰ *Ibid.*

⁸¹ Breslau N., Lucia V.C. & Alvarado, G.F., Intelligence and Other Predisposing Factors in Exposure to Trauma and Post-Traumatic Stress Disorder: A Follow-Up Study at Age 17 Years, *Archives of General Psychiatry* 63, pp. 1238–1245 (2005).

⁸² Emerson E. & Hatton C., Mental Health of Children and Adolescents with Intellectual Disabilities in Britain, *British Journal of Psychiatry* 191(6), pp. 493-499 (2007).

⁸³ Wigham S & Emerson E., Trauma and Life Events in Adults with Intellectual Disability, *Current Developmental Disorders Reports* 2(2), pp. 93-99 (2015).

significantly predictive of psychological trauma after six months in one study focusing specifically on individuals with intellectual disability.⁸⁴

For some with IDD, limited ability to communicate trauma, as well as limited knowledge or social skills, may result in difficulty integrating their perception of the traumatic event(s) and their emotional response,⁸⁵ resulting in sequela that can include affective aggression or behavioral dysregulation. In addition, there is often a perception that a PWIDD is not a reliable witness; one study found that jurors tend to perceive a child with IDD's witness statements as inherently unreliable.⁸⁶ This can lead to ongoing victimization if an individual is not believed to be a reliable historian and their statements are not taken seriously. Specialized interviewing techniques for investigators are important to ensure the best assessment of victimization. As seen in John's case, although challenging behavior in the IDD population is not uncommon, a subset of the externalizing behaviors may actually be a result of trauma.⁸⁷ Behavioral dysregulation is an important target for effective intervention, as behavioral dysregulation can lead to an individual's exclusion from a community or organizational supports, which can result in added social isolation for the individual. Being aware of trauma and the potential for PTSD as a cause of behavioral aggression can lead to more directed treatments and improvement of problematic behaviors.

Despite studies indicating that individuals with IDD experience trauma and negative life events at higher rates than the general population, there is still a lack of research on the integration of TIC in organizations and systems providing support for the IDD population.⁸⁸ At a systems level, providing TIC means operating with an awareness of the pervasiveness of trauma as well as its impact. This may require increased education and training on trauma for those staff caring for individuals with IDD, as well as encouragement of universal screening for trauma histories in all patients.⁸⁹ In addition, a goal of TIC should be to create an environment—whether it be in an inpatient setting, in adult foster care, or in an individual's home with caregivers—that fosters trust, a sense of safety, and the importance of an individual's choice through empowerment.⁹⁰

⁸⁴ Wigham S., Taylor J.L., Hatton C., A Prospective Study of the Relationship Between Adverse Life Events and Trauma in Adults with Mild to Moderate Intellectual Disabilities, *Journal of Intellectual Disability Research*, Vol. 58 No. 12, pp. 1131-1140 (December 2014)

⁸⁵ Keesler J., Trauma-Informed Day Services for Individuals with Intellectual/Developmental Disabilities: Exploring Staff Understanding and Perception Within an Innovative Programme. *Journal of Applied Research in Intellectual Disabilities*, Vol. 29, No. 5, pp. 481–492 (September 2016).

⁸⁶ Henry L., Ridley A., Perry J. & Crane L., Perceived Credibility and Eyewitness Testimony of Children with Intellectual Disabilities, *Journal of Intellectual Disabilities Research* 55(4), pp.385-91 (April 2011).

⁸⁷ Mevisen L., Lievegoed R., Seubert A. & De Jongh A., Do Persons with Intellectual Disability and Limited Verbal Capacities Respond to Trauma Treatment?, *Journal of Intellectual and Developmental Disability* 36:4, pp. 278-283 (2011).

⁸⁸ Keesler J., A Call for the Integration of Trauma-Informed Care Among Intellectual and Developmental Disability Organizations, *Journal of Policy and Practice in Intellectual Disabilities* 11, pp. 34–42 (2014).

⁸⁹ Butler

⁹⁰ Keesler (2014).

Recommendation for Policy Makers

Rates of trauma and victimization are alarmingly high in PWIDD. Safeguards, self-scrutiny, and monitoring are of ongoing critical importance.

Person-Centered Care, Self-Determination, and Decision-Making Supports

Person-centered care aims to shift thinking about an individual with IDD from their deficits and needs within a system, to focusing on their strengths, capabilities, and potential to contribute to their community. Person-centered care aims to develop collaborative supports with individuals with IDD focused on community presence and participation, positive relationships, respect, and competence.⁹¹

The concept of self-determination in the IDD population within this person-centered framework has been an area of significant focus in recent years. Self-determination is viewed by many as a fundamental human right—the right of an individual to manage his or her own life without unnecessary interference from others and to have more choice and control over life-impacting decisions.⁹² Individuals with IDD must have opportunities that enable them to exert control in their lives and be self-advocates,⁹³ because having those opportunities is a strong motivator of self-determination. Studies investigating the impact of self-determination on individuals with IDD have found that those who are more self-determined or receive more education on self-determination are more likely to be participatory and independent in performing community activities,⁹⁴ more likely to have a higher quality of life status,^{95, 96} and more likely to be working for pay at higher hourly wages.⁹⁷ Increased education on self-determination among individuals with IDD will

⁹¹ Claes C., Van Hove G., Vandeveldel S., van Loon J. & Schalock R.L., Person-Centered Planning: Analysis of Research and Effectiveness, *Intellectual and Developmental Disabilities*, Vol. 48, No. 6, pp. 432-453 (December 2010).

⁹² Wehmeyer M.L. & Palmer S., Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination. *Education and Training in Developmental Disabilities*, 38(2), pp. 131-144 (2003).

⁹³ AAIDD and The Arc Joint Position Statement on Self-Determination, Adopted August 18, 2008, <https://aaid.org/news-policy/policy/position-statements/self-determination#.WR2qhMm1v-Y>.

⁹⁴ Sowers J. & Powers L., Enhancing the Participation and Independence of Students with Severe Physical and Multiple Disabilities in Performing Community Activities, *Mental Retardation* 33, pp. 209-220 (1995).

⁹⁵ Wehmeyer M.L. & Schwartz, M., The Relationship between Self-Determination, Quality of Life, and Life Satisfaction for Adults with Mental Retardation, *Education and Training in Mental Retardation and Developmental Disabilities* 33, pp. 3-12 (1998).

⁹⁶ Lachapelle Y. et al. The Relationship between Quality of Life and Self-Determination: An International Study, *Journal of Intellectual Disabilities Research*, 49(Pt 10), pp. 740-4 (October 2005).

⁹⁷ Wehmeyer M.L. & Schwartz, M., Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities, *Exceptional Children* 63, pp. 245-255 (1997).

continue to be important, and includes, but is not limited to, decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, and self-awareness.⁹⁸

Issues of decision-making are also important to consider for individuals with intellectual or developmental disabilities, especially when considered in a person-centered care construct. In general, adults are presumed competent to make their own decisions unless there are specific concerns raised, and unless a court of law finds them to be incompetent. If someone is found incompetent, a next step could be guardianship, which is a legal process in which a court appoints an individual to make decisions in the best interests of the person who has been determined to lack the capacity. Decisions made by guardians can include some or all decisions about health care, living arrangements, property, and other personal life decisions.⁹⁹ Historically, the appointment of a guardian was and, for some, is still seen as a valuable approach to protecting an individual and his or her assets.¹⁰⁰

There is full guardianship, where a guardian has the authority to make all decisions for a person, but there are also alternatives to full guardianship. These alternatives include limited guardianship, where a guardian has legal authority to make decisions only in certain areas, such as finances or health care. But because guardianship is often considered to be the most restrictive option to protect a vulnerable person, other, less restrictive options prior to guardianship should also be considered. These include power of attorney, advanced directive, special needs trust, or special bank accounts with co-signers.¹⁰¹ The issue of decision-making capacity and guardianship is an important one for individuals with IDD, as intellectual disability is often used as grounds for guardianship. For example, in 2013, Texas had over 46,000 active guardianship appointments¹⁰² and, according to the Texas Office of Court Administration, 58 percent of these appointments were made due to the ward's intellectual incapacity.¹⁰³

Although guardianship is used routinely, it is important to realize that some individuals question the idea of guardianship and the notion of being granted decision-making powers over another person, and the effect it may have on the individual's autonomy and independence.¹⁰⁴ Recent disability research has moved toward an idea of supported decision-making, a process where, instead of assigning a guardian or substitute

⁹⁸ Browder D., Wood W.M., Test D.T., Algozzine B. & Karvonen M, A Map for Teachers to Follow in Reviewing Resources on Self-Determination, *Remedial and Special Education* 22, pp. 233-244 (2001).

⁹⁹ Rood C.E., Kanter A. & Causton J., Presumption of incompetence: The Systematic Assignment of Guardianship within the Transition Process. *Research and Practice for Persons with Severe Disabilities* 39, pp. 319-328 (2014).

¹⁰⁰ Kanter A., Guardianship for Young Adults with Disabilities as Contrary to the Language and Purpose of the Individuals with Disabilities Education Improvement Act, *Journal of International Aging, Law & Policy* Vol. 8, No. 1, (2015).

¹⁰¹ Rood.

¹⁰² *County-Level Courts: Probate and Mental Health Activity from September 1, 2012 to August 31, 2013*, (November 19, 2013), http://www.txcourts.gov/All_Archived_documents/JudicialInformation/pubs/AR2013/pgmh/1-ProbateAndMH-Detail.pdf.

¹⁰³ Slayton D., *Texas Guardianship Cases: Improving Court Processes and Monitoring Practices in Texas Courts*, Texas Office of Court Administration, Austin, TX (2015).

¹⁰⁴ Frolick L.A., Promoting Judicial Acceptance and Use of Limited Guardianship, *Stetson Law Review* 31, pp. 735-755 (2002).

decision-maker, an individual with IDD is supported in making decisions for him- or herself, allowing the person to retain his or her right to make decisions.¹⁰⁵

Article 12 of the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) states that persons with disabilities should enjoy legal capacity on an equal basis with others in all aspects of life, and that state parties should ensure that people with IDD are provided with the autonomy, freedom, and the tools to make their own decisions in order to exercise their legal capacity.¹⁰⁶ Supported decision-making has been defined to mean that the individual with IDD is the ultimate decision-maker, but is given support from one or more persons so that the individual with IDD is able to participate in society on an equal basis with others who make their own decisions.¹⁰⁷ Tools to help an individual with IDD with supported decision-making may include peer support, community services, personal “ombudspeople,” personal assistants, and/or good advanced planning.¹⁰⁸

Research on supported decision-making has suggested that the traditional legal concept of allowing an individual to make legal decisions only if he or she can demonstrate the ability to exercise such judgments independently may be outdated, and does not take into account that most people make decisions with supports within the context of the social environment in which they live.¹⁰⁹ Some suggestions about how to more fully implement supported decision-making include increasing education on decision-making skills in primary schools, providing more professional development, and educating families, judges, and the public on the abilities of individuals with IDD.¹¹⁰ In addition, providing individuals an opportunity to participate in the decision-making and planning process when transitioning from a child with IDD to an adult can also be important, and should be focused on the individual’s preferences, needs, strengths, and desires.^{111, 112}

Some critics of supported decision-making in lieu of legal guardianship argue that more research needs to be done to delineate just how similar and different supported decision-making and alternative surrogate decision-makers are before implementing wide scale, systemic changes.¹¹³ Others have called for more research to identify the most effective ways to develop and support self-determination and the autonomy of individuals with

¹⁰⁵ Kohn N.A., Blumenthal J.A, & Campbell A.T, Supported Decision-Making: A Viable Alternative to Guardianship?, *Penn State Law Review* 117, pp. 1111-1157 (2013).

¹⁰⁶ Article 12, United Nations Convention on the Rights of Persons with Disabilities (2006), <http://www.un.org.proxy.lib.umich.edu/disabilities/convention/conventionfull.shtml>.

¹⁰⁷ *Ibid.*

¹⁰⁸ *Article 12-Legal Capacity: Principles of Implementation*, CRPD Forum, International Disability Alliance (2010), <http://www.internationaldisabilityalliance.org/resources/article-12-legal-capacity-principles-implementation>.

¹⁰⁹ Arstein-Kerslake A., An Empowering Dependency: Exploring Support for the Exercise of Legal Capacity, *Scandinavian Journal of Disability Research* Vol 18, No. 1, pp. 77-92 (August 2014).

¹¹⁰ *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities: A Short Summary*, 2012 National Roundtable, American Bar Association (2012).

¹¹¹ Rood.

¹¹² Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446 (2004).

¹¹³ Parker M.H., Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making, *Journal of Bioethical Inquiry* (2016).

IDD within complex systems.¹¹⁴ Either way, decisional capacity deficits must be considered and addressed as individuals with IDD are seen within care systems.

Recommendation for Policy Makers

Prioritize the ability to develop self-directed and person-centered care planning, focusing on the PWIDD’s strengths, capabilities, and potential to contribute to their community. As in case law, understand that maximal self-direction and autonomy can be achieved with the right supports, except in circumstances where decisional capacity limitations are severe enough to warrant a guardian. Assessments should be regularly updated with the expectation of improvement over stagnation.

Treatment and Supports

Habilitative Services

The Centers for Medicare and Medicaid Services defines “habilitative services” as “Health care services that help a person keep, learn or improve skills and functioning for daily living...These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.”¹¹⁵ Several aspects of these supports are delineated below, but do not reflect the total array of supports that may be needed.

Behavioral Supports

Case Example of “John”, Continued

After several weeks on the inpatient unit, a specialized consultant is brought in, who helps the staff develop a plan that supports positive behavior and teaches staff how best to work with John. The consultant learns that John’s worsening behavior in the community relates to an episode of neglect and abuse of a fellow resident, and resultant staff turnover at the home.

Behavioral supports can play an integral role in working with persons exhibiting challenging behavior in individuals with IDD and concomitant disorders, and may significantly improve an individual’s quality of life and his or her ability to function in

¹¹⁴ Issue Brief: Self-Determination and Self-Advocacy by People with IDD, American Association on Intellectual and Developmental Disabilities, December 2015, <https://aaidd.org/docs/default-source/National-Goals/self-determination-and-self-advocacy-by-people-with-idd.pdf?sfvrsn=0>.

¹¹⁵ Glossary of Health Coverage and Medical Terms, Center for Medicare and Medicaid Services, OMB Control Numbers 1545-2229, 1210-0147, and 0938-1146, <https://www.cms.gov/ccio/resources/files/downloads/uniform-glossary-final.pdf>.

the community. Challenging behavior can present, for a multitude of reasons, as aggression towards others or the environment, impulsivity, self-injury, or other behaviors that are seen as socially unacceptable and may impact the individual's adaptive functioning in the community. Although the data varies, some have estimated that the prevalence of behavioral problems among persons with comorbid ASD and IDD is approximately 50 percent, and that levels of problem behavior severity can range from minor and time-limited to severe, chronic, and potentially life threatening.¹¹⁶

It should first and foremost be noted that all behavior reflects some type of communication. Bi-directional communication can be challenging with regard to the expression and reception of the same communication, particularly when the expressed communication is non-verbal. There may be miscommunication between the individual and the person receiving the communication, who may be assessing the first person's needs. Similarly, communications may not be received clearly by individuals for whom social cues, tone of voice, facial expressions, use of idiomatic expressions, and other common communication shortcuts are easily missed or misinterpreted. Thus, when looking at a communication or a behavior as something to better understand or even a "problem to address," it is better to ask what the communication or behavior is trying to achieve. In the case example, the communicative function of John's aggressive behavior should have been a focus; abuse, neglect, medical pain, comorbidities, or irritation at staff turnover in the home all should have been considered early in the process.

A biopsychosocial approach is an important first step toward understanding behavior. Symptomatic treatment using person-centered behavioral interventions should occur prior to pharmacological intervention.¹¹⁷ In the past, non-pharmacologic behavioral management to control challenging behaviors in the IDD population included more frequent use of restraints, electric shock, cold water sprays, or deprivations like withholding food or visitation with friends and family.¹¹⁸ Research has shown these interventions are not effective at reducing problem behaviors,¹¹⁹ and many were themselves traumatizing. Instead, behavioral supports should be culturally appropriate and designed for the individual and his or her own specific needs, with the goals of removing environmental precipitants for challenging behaviors, emphasizing the idea of choice, and focusing on social integration.¹²⁰

Behavioral interventions based on Applied Behavioral Analysis (ABA) are often used with ASD, but can be used in responding to other IDD issues. Over the years, additional models focused more on maximizing positive behaviors and incorporating the relationship with the individual have also been evolving, moving away from the

¹¹⁶ Doehring P. *et al.*, Behavioral Approaches to Managing Severe Problem Behaviors in Children with Autism Spectrum and Related Developmental Disorders, *Journal of Child and Adolescent Psychiatric Clinics of North America* Vol. 23, No. 1, pp. 25-40 (2014).

¹¹⁷ Ageranioti-Bélanger S. *et al.*, Behaviour Disorders in Children with an Intellectual Disability, *Paediatr Child Health* 17(2), pp. 84-88 (February 2012).

¹¹⁸ Position Statement on Behavioral Supports, Board of Directors, The Arc of the United States (Adopted August 23, 2010), <http://www.thearc.org/who-we-are/position-statements/life-in-the-community/behavioral-supports>.

¹¹⁹ The Arc.

¹²⁰ The Arc.

previously accepted use of aversive stimuli.¹²¹ Both ABA and Positive Behavioral Supportive (PBS) approaches examine behavior and help the individual to function better in their environment. The use of Positive Behavioral Interventions and Supports in public school systems now has also been extended to the IDD population and the population of persons with SMI in state hospitals and other segments of the mental health continuum of care. Such interventions are often described as either comprehensive—which includes early behavioral intervention at a young age for an extended period of time, often focusing on an extensive range of adaptive functioning skills—or problem-focused.¹²²

Utilizing a Functional Behavioral Analysis (FBA) to determine what functions the individual is attempting to achieve with his or her behaviors is an important first step. Completing an FBA helps determine the antecedent of the behaviors to find their purpose and cause—the antecedent, the behavior, and the consequence (the so-called ABCs). This helps understand the behavioral patterns and helps shape more positive behaviors.

The purpose is often a communication of some need, attention, escape, or a stereotypy that soothes. Often—estimated in some studies to be as often as in 60 percent to 75 percent of cases—problem behavior is reinforced by social consequences such as attention, access to preferred materials, and escape from instruction.^{123, 124, 125} Teaching an alternative, socially acceptable behavior to serve the same communicative function, and consistently rewarding and reinforcing the new, desired behavior, is advised.¹²⁶ Techniques such as differential reinforcement based strategies, antecedent intervention, functional communication training, and extinction are all methods that have been described in the literature with some success. In fact, in a review of over 100 studies involving young people with ASD/IDD and problem behaviors, behavioral interventions such as those described above resulted in more than 86 percent of individuals benefiting from treatment, with 65 percent being characterized as “responders” where their problem behavior was reduced by more than 80 percent.¹²⁷ In addition, using behavioral modification strategies with a consequence-based structure and clear limits (*i.e.*, withdrawal of privileges) along with the reinforcing of positive behaviors as already described, is often recommended.¹²⁸

¹²¹ Kappel B., Dufresne D. & Mayer M., *From Behavior Management to Positive Behavioral Supports: Post-World War II to Present*, March 2012, https://www.google.co.il/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0a_hUKewiR3PrUkbrVAhXBCBoKHUM4BuUQFggpMAA&url=https%3A%2F%2Fwww.fmn.gov%2Fmnddc%2Fpositive-behavior-supports%2Fpdf%2FFrom-Behavior-Management-to-Positive-Behavioral-Supports.pdf&usq=AFQjCNGoDARlc0hlJ0MqCkNa2jbjuvhwbw.

¹²² Doehring.

¹²³ Iwata B.A., Pace G.M., Dorsey M.F. *et al.*, The Functions of Self-Injurious Behavior: An Experimental Epidemiological Analysis, *Journal of Applied Behavioral Analysis* 27, pp. 215-240 (1994).

¹²⁴ Hanley G.P., Iwata B.A. & McCord B.E., Functional Analysis of Problem Behavior: A Review, *Journal of Applied Behavioral Analysis* 36, pp. 147-185 (2003).

¹²⁵ Hagopian L.P. *et al.*, Initial Functional Analysis Outcomes and Modifications in Pursuit of Differentiation: A Summary of 176 Inpatient Cases, *Journal of Applied Behavioral Analysis* 46: pp 88-100 (2013).

¹²⁶ Ageranioti-Bélanger.

¹²⁷ Doehring.

¹²⁸ Ageranioti-Bélanger.

Behavioral supports are important at all stages of life, though some have suggested that individuals in the 16- to 22-year-old age group show the greatest need for support when compared to the other age groups, suggesting this time period should be an important focus.¹²⁹ For youth with behavioral challenges, therapies such as Parent-Child Interaction Therapy can be helpful in developing positive communication early on—by teaching caretakers to help develop positive responses in their children.¹³⁰

Recommendation for Practitioners

All behavior reflects some type of communication. An individual’s limited ability to verbally communicate anxiety, mood issues, or a psychotic disorder may manifest in aggression or externalizing behaviors, which can often result in missed diagnoses or opportunities for treatment. Always ask, “What is the communication or behavior trying to achieve?”

Pharmacologic Supports

Case Example of “John”, Continued

Staff at John’s previous support home admitted they were giving him increasing doses of antipsychotics to try to “manage” his challenging behavior, without much success. Prior to a behavioral plan being put in place on the inpatient psychiatric unit, nursing staff frequently requested increased doses of medication in an effort to control his aggression, although it did not seem to be helping. After gathering the proper clinical history, it was determined that John’s heightened activity was largely related to adjustment reaction, frustration, and distress over changes in his caretakers. Ultimately, John improved with behavioral supports, although his medications were also readjusted.

Although medications are at times used in an attempt to manage challenging behavior in individuals with IDD and comorbid disorders, the evidence base for psychopharmacology in this population is limited. Often, clinicians are faced with making decisions about medication management on an individual basis, based on a specific situation. The risk of polypharmacy leading to complex drug-drug interactions and the potential demise of the individual have been discussed extensively within the mental health population policies and protocols, and the need for this dialogue is especially true for PWIDD who are at risk of having medications prescribed on top of medications, without the needed exploration of the individual issues that might be at play. Given the limited guidance on helpful medication strategies in the literature, psychopharmacology should be driven by data rather than anecdote, such as behavioral tracking sheets and evidence and comprehensive

¹²⁹ Shogren K.A., Seo H., Wehmeyer M., Thompson J. & Little T., Impact of Protection and Advocacy Subscale on the Factorial Validity of the Supports Intensity Scale – Adult Version. *American Journal on Intellectual and Developmental Disabilities* 121, pp. 48–64 (2016).

¹³⁰ Parent-Child Interaction Therapy, <http://www.pcit.org/>.

contextual data for the specific individual. As noted previously, problem behaviors are often driven by a desire for communication, so understanding that prior to using a medication is very important.

Treating recognized psychiatric disorders that are comorbid with IDD is a reasonable use of psychopharmacology in this population. As previously noted, quality and quantity of research on this subject is limited, but low dose antipsychotics such as risperidone are the most commonly used pharmacologic interventions, followed by antidepressants and mood stabilizers.¹³¹ However, a thorough investigation of environmental precipitants and an attempt to modify these precipitants should precede the use of medication, if indicated, in conjunction with non-pharmacologic strategies to address symptoms that may lead to problematic behavior.

Many of the studies about pharmacologic or biological interventions are performed in adults, yet the use of medications in children with IDD is seen fairly commonly. A recent meta-analysis indicated that antipsychotic medications such as aripiprazole or risperidone may be effective for reducing challenging behaviors in children with intellectual disabilities in the short-term, but they carry a risk of significant side effects, including elevated prolactin levels and weight gain. In addition, their long-term effectiveness has not yet been thoroughly studied.¹³² It is also of note that many of the medications investigated in studies on this topic are being used outside of their approved FDA indication, which is consistent with evidence that indicates that off-label prescribing may be as high as 46 percent among individuals with intellectual disabilities.¹³³ The most frequently cited off-label indications in this population include reduction of aggression, arousal, and behavioral disturbance, as well as mood stabilization.¹³⁴

The National Core Indicators published a report in 2012 looking at the use of medications in public IDD systems and the relationship of medication use to health and wellness. The final data set included 8,390 adults, and 53 percent of the individuals with intellectual and developmental disabilities in the data set were taking medication to address one of three mental health conditions (mood, anxiety, or psychosis) or behavioral challenges--or a combination of those issues.¹³⁵ Those using medications were found demographically to be slightly older than those not taking medications, more likely to be white, more likely to live in group homes, more likely to be in poorer health and use tobacco products, and more likely to also have ASD.¹³⁶

¹³¹ Deb S., Psychopharmacology, Chapter 19 of *Handbook of Psychopathology in Intellectual Disability: Research, Practice, and Policy*, Eds. Tsakanikos E. & McCarthy J., Autism and Child Psychopathology Series, Springer Science + Business Media, New York, pp. 307–324 (2013).

¹³² McQuire C. *et al.*, Pharmacological Interventions for Challenging Behavior in Children with Intellectual Disabilities: A Systematic Review and Meta-Analysis, *BMC Psychiatry* 15:303 (November 2015).

¹³³ Haw C. & Stubbs J., A Survey of Off-Label Prescribing for In-Patients with Mild Intellectual Disability and Mental illness, *Journal of Intellectual Disabilities Research* 49, pp. 858–64 (2005).

¹³⁴ *Ibid.*

¹³⁵ NCI Core Indicators. What does NCI tell us about adults with intellectual and developmental disabilities who are taking prescribed medications for anxiety, behavior challenges, mood disorders or psychotic disorders? NCI Data Brief, Issue 6 (December 2012).

¹³⁶ *Ibid.*

Given the complexity of prescribing medications for this population, whether those medications were actually indicated is difficult to know—a difficulty that highlights the challenging balance of prescribing medications in this population—namely, the risk of undertreating an actual, comorbid psychiatric disorder vs. inappropriately medicating a behavioral issue.

Environmental Supports

Recommendation for Practitioners

Given the limited guidance on helpful medication strategies for PWIDD in the literature, the evidence for psychopharmacology should be case-specific, data-informed rather than anecdotal, coming from behavioral evidence and comprehensive contextual information (e.g., behavior tracking reports) for the specific individual.

Large intermediate care facilities (ICFs) and long-term wards of state psychiatric hospitals are no longer the mainstay of services for PWIDD. At the end of the day, optimal and wide-ranging community integration opportunities for PWIDD depends on optimal behavioral and somatic health. Although identifying and correctly treating psychiatric and somatic illness is important, most parents and experts in the field will agree that, for PWIDD requiring caretaker support, a more than substantial part of their quality of life is dependent on their caretakers.¹³⁷

For that reason, there has been a shift in the field from describing professional caretakers as “direct service workers” (DSWs) to “direct service professionals” (DSPs). This change emphasizes the need for DSPs to have sufficient training and the necessary demeanor and deportment to provide quality service. It is generally acknowledged that the pay scale offered for these positions often does not attract individuals with a career focus. It is often found that a caretaking position is a second job used to make ends meet.

Ideally, critical training for DSPs should include a full understanding of PBS, which is provided in an ABA context with greater emphasis on a positive environment. PBS has spread even to forensic psychiatric settings.¹³⁸ While always remembering that behavior can be a non-verbal communication of a need, desire, or distress, PBS connotes an emphasis on choice and control for the PWIDD, while supported by caretakers able to teach the PWIDD engaged in non-adaptive behaviors the skills necessary to achieve those goals. Though a functional behavioral analysis and the development of a behavioral plan requires the specialized skills of an appropriately trained professional or Board Certified Behavioral Analyst, DSPs can create an environment that supports PBS. The concept of

¹³⁷ Moseley C., *Picking up the Pieces of Our Own Mistakes: Supporting People with Co-Occurring Conditions*. National Association of State Directors of Developmental Disabilities Services (February 2004), <http://www.nasddds.org/resource-library/behavioral-challenges/program-design/picking-up-the-pieces-of-our-own-mistakes/>.

¹³⁸ Tolisano P., Sondik T.M. & Dike C.C., A Positive Behavioral Approach for Aggression in Forensic Settings, *Journal of the American Academy of Psychiatry and the Law* 45, pp. 31-39 (March 2017).

Person-Centered Tiered Supports communicates the essential components most succinctly.¹³⁹

Trauma-Informed Care is also critical training for DSPs, because the severe, out of proportion, affective dysregulation resulting from a trauma history often confounds positive relationships with caretakers and therefore the provision of PBS. Too often, emergency departments and mental health clinicians are called to be the solution when environmental supports have broken down. Even more frustrating to clinicians in those emergency, urgent, and non-urgent settings is the inability to see into those environments through a report of the PWIDD's perspective. Counterproductive polypharmacy and placement standoffs are the result.

Recommendation for Practitioners

Gather information from all sources, especially direct service professionals, who can provide a wealth of information to inform program and planning. Peer partners, provider treatment networks, and an emphasis on environmental precipitants to behavioral challenges should be helpful.

Financial Supports and Entitlements

Case Example of “John”; Continued

As John's stay on the inpatient unit continued, the unit's physical damages totaled over \$20,000 and three staff took leaves of absence due to injury in the workplace. Eventually, the county intervened and, with the help of county resources, a new placement was identified for John. His services were funded under a Medicaid waiver, and he was able to have a review of his support plan with modifications to his plan of service that will hopefully result in longer-term stabilization.

Individuals with co-occurring IDD and mental health conditions face, as referenced previously, a fragmented response to their needs that is driven by fragmentation in public policies, clinical programs, bureaucratic structures, and the financing of care. Efforts to effectively coordinate care to improve outcomes for people with co-occurring conditions are often stymied by the structure and rules associated with the respective financing of developmental disabilities services and mental health services. While there are differences in the legislative intent and operating management of state appropriations flowing to different agencies with discreet responsibilities for either IDD or MH, Federal Medicaid funds to the states flow to those with eligibility. The majority of persons with the aforementioned co-occurring conditions are Medicaid eligible.

However, the entitlements are typically stronger for persons with developmental disabilities, as not all persons with psychiatric conditions have the diagnosis, disability

¹³⁹ Diagrammed at <http://dmh.mo.gov/docs/dd/tie-dyedtrianglegraphic.pdf>.

and duration of condition that qualify them for Medicaid benefits. Most states finance home and community-based services available under the § 1915(c) Medicaid waiver program and the § 1915(i) state plan option, which allow coverage of a wide array of community-based treatments and residential supports. However, the terms of the waivers and state plan options are typically written with a primary client population in mind, rather than targeted to those with co-occurring conditions.

States that have expanded the provision of self-directed personal care through § 1915(j) state plan services or the § 1915(k) Community First Choice personal care option can support people who live in their homes, but these provisions do not automatically incorporate access to acute psychiatric care benefits. Moreover, the benefits are typically administered by different entities, with the waivers administered directly by either the Medicaid or DD authority in the state and the behavioral health benefits often carved out to third party management. Several state authorities have also adopted Money Follows the Person (MFP) and Balancing Incentive Payment (BIP) programs which, while providing increased Federal financing for home and community-based services, do not, again, align with psychiatric care benefits.

Under the terms of the Affordable Care Act, new emphasis was placed on the coordination and integration of care for populations with complex needs. For example, Health Homes are an optional state plan service designed to improve care coordination across primary, acute, behavioral health, and long-term services and supports for individuals with two or more chronic conditions. States need to target Health Home services to individuals with co-occurring IDD/MH conditions.

Arizona, Michigan, North Carolina, and Wisconsin, among other states, operate managed long-term services and supports for persons with IDD, according to a 2016 report from NADD, the association for persons with developmental disabilities and mental health needs.¹⁴⁰ Some states have or are in the process of expanding the role of carve-out managed behavioral health organizations to manage care for persons with IDD, a development that presents the opportunity to better coordinate and integrate care for those with co-occurring conditions. Another emerging opportunity is the activity in states to implement managed long term services and supports (LTSS) in the context of developing accountable care organizations (ACOs). According to the above-cited NADD report, several states, including Massachusetts, Maine, New York, Minnesota, Oregon are implementing § 1115 Medicaid waivers with provisions for ACOs and LTSS management.

Over the last 30 years, states administered aspects of their Medicaid programs using managed care organizations (MCOs), mainly to manage primary care and behavioral health specialty care under § 1903(m) of the Social Security Act. As states have, during the last decade, tested the utility of MCOs for management of IDD care, advocates have urged continuation of tested provider networks and strong state oversight of the MCOs. As some states adopt new § 1115 waivers and other ACA models for integrating care, they are leapfrogging over existing MCOs to implement ACOs and tie ACOs to LTSS provider networks to deliver better-integrated and managed care to persons with LTSS. This is occurring at the same time as Medicaid programs are forging similar partnerships

¹⁴⁰ Fletcher R.J., Baker D., St. Croix J. & Cheplic M., editors, *Mental Health Approaches to Intellectual/Developmental Disability: A Resource for Trainers*, NADD, Kingston, NY (2016).

between ACOs and BH provider networks. This development poses new challenges for the integration of care for persons with co-occurring conditions.

Recommendations for State Executive Offices of Health and Human Services (EOHHS)

Devise a targeted health management framework for intersystem collaboration to ensure the health of the population of persons with IDD and MH conditions. Within that framework:

- 1) Identify population parameters, characteristics, care use patterns, and emerging risk indicators and build these data points into the state’s care management information systems;**
- 2) Define a covered continuum of evidence based care and best practices that are responsive to the population of persons with IDD and MH conditions and can be delivered in a mix targeted to their unique service needs through an individualized plan of care;**
- 3) Structure sufficient financial and performance incentives to focus care interventions on protecting this population’s health and managing emerging risk;**
- 4) Establish guidance for multidisciplinary care management teams and services coordination teams with defined accountability for population outcomes;**
- 5) Build collaborative, integrated care across governmental sectors including EOHHS, Education and Criminal Justice/Public Safety secretariats; and**
- 6) Focus routine data inquiries on quality and emergent risk indicators, using results for continuous quality improvement.**

Recommendation for State IDD and MH Authorities

Strengthen and specify interdepartmental/interagency service coordination teams with authority to solve fragmentation in eligibility, service delivery, and care financing affecting persons with co-occurring conditions.

Recommendation for State Medicaid Agencies

Establish clear performance measures and payment incentives in MCO or ACO contracts to ensure that persons with co-occurring IDD and MH conditions are accorded access to competent treatment and recovery support services delivered through an individualized plan of care in a mix targeted to their unique service needs. Direct the MCOs and ACOs to employ multidisciplinary care management teams to carry out population health studies, review data system reports, manage emerging risk, and direct integrated service delivery solutions.

Recommendation for Practitioners

Secure access to current policy and regulatory guidance in your state governing the provision of services to persons with co-occurring IDD and MH conditions. The guidance would include coverage and reimbursement guidelines, as well as criteria for case reconciliation carried out by interagency health and human services bodies designed to parse eligibility, and clinical and financial responsibility, for complex cases crossing multiple agency lines.

Unique Aspects of Behavioral Health Services for PWIDD in Particular Settings

General Principles in Providing Behavioral Health Services to PWIDD across Settings

The following section can be applied to numerous settings, including EDs, acute inpatient units, state hospital units, forensic settings, and correctional settings. Although each of these settings vary in their mission—with the correctional setting being the major outlier—evaluating PWIDD across each of these environments has some similarities.¹⁴¹

Although the method described here is similar in all of these treatment areas, EDs deserve special considerations because this is where both treatment failures and environmental support failures arrive to be addressed. As result, this is where major conflicts arise as the individual in crisis meets a crisis system that is admittedly ill-equipped to meet the individual's needs.

Often, neither the SMHA nor the state IDD administration understands the basic underpinnings of the other's system and they simply do not share enough of the same knowledge to make problem-solving an easy process. While SMHA decision-making is usually driven by medical necessity criteria and is an **entitlement** process, access to home- and community-based services waiver services for PWIDD is driven by an **eligibility** process that often caps participant numbers and individual budgets.

In addition, once the IDD administration has implemented an HCBS waiver, it must ensure the health and safety of all waiver participants. If a waiver participant is engaging in unsafe behavior in a community setting, either because of a lack of appropriate environmental supports or because the environmental supports provided are not sufficient in the face of a psychiatric crisis, the provider relies on the SMHA and the ED to act together as a safety net. The service lines of state IDD administrations strive to “de-medicalize” the community supports of the PWIDD, leaving a wide communication gap between the service providers in a setting where all budgets are strained (and frustration is high).

¹⁴¹ Bakken T.L & Sageng H., Mental Health Nursing of Adults With Intellectual Disabilities and Mental Illness: A Review of Empirical Studies 1994–2013, *Archives of Psychiatric Nursing* 30(2), pp. 286-91 (April 2016).

State administrators often rely on the evaluation of clinicians in the trenches to resolve these conflicts. However, without a workforce that has a firm grip on parsing a complex presentation and the ability to explain their thought process, large sums of money can be spent on providing the wrong treatment. Without a doubt, the foundation for the most cost-effective intervention is an accurate understanding of the individual in crisis. The use of a biopsychosocial model is critical to not only establishing a correct diagnosis, but to also formulate the best intervention. To begin the diagnostic process, a safe, conducive treatment environment must also be provided.

The successful triage and treatment of a PWIDD in any acute or routine treatment setting is dependent on adequate preparation of that environment. Major elements to be considered are: the treatment setting, the training of the treatment staff, and advance knowledge of both treatment strategies and of existing supports for people in the sub-population.^{142, 143} While 85 percent of PWIDD have mild intellectual impairment,¹⁴⁴ mild impairment does not necessarily translate to accommodation because of the heterogeneity of the population. The assessment of needed accommodation should be determined on a person-by-person basis; given the growing societal and legal expectation of full inclusion of PWIDD, these preparations can no longer be viewed as optional.¹⁴⁵

The treatment area needs to be viewed with a critical eye. Awareness of issues associated with PWIDD should prompt the clinician to quiz the caretaker on environmental triggers of undesirable behavior, such as an intolerance to fluorescent lighting, small spaces, or overstimulating environments. Certainly, all treatment providers are limited by the architectural space provided to them, but it is well worth the time to consider this issue, for the benefit of staff and patient alike.

Ensuring treatment providers have the appropriate skill set in advance of encounters serves to circumvent the frustration of trying to assess an individual with no clear idea of what treatment plan is possible. Training should include the patient engagement skills that are most likely to optimize efficient information transfer. A recent online continuing medical education training on this topic, available through OptumHealth, advocates using the training acronym R.A.F.T. (Respect, Accommodation, Follow-up, Time) in raising awareness of how to best engage this patient sub-population.

Involving self-advocates from the local Developmental Disabilities Council is another strategy for assessing treatment settings, and provides an opportunity to interact with PWIDD who are not in the midst of a health crisis. Having more integrated exchanges with self-advocates provides staff, who may only see PWIDD in crisis, an opportunity to see how to achieve optimized inclusion.

¹⁴² Hovermale L.S., Paclawskyj T., Simpson D. & Samstad, E. The Evaluation of Intellectual and Developmental Disabilities, in eds. Chanmugam A., Triplett P. & Kelen B., *Emergency Psychiatry*, Cambridge University Press (2013).

¹⁴³ Bradley E., *Guidelines for Managing the Client with Intellectual Disabilities in the Emergency Room*, Centre for Addiction and Mental Health. University of Toronto, Surrey Place Centre (2002).

¹⁴⁴ King.

¹⁴⁵ Rosenbaum S., Using the Courts to Shape Medicaid Policy: *Olmstead v. L.C. by Zimring* and Its Community Integration Legacy, *Journal of Health Politics, Policy and Law* 41(4), pp. 585-97 (August 2016).

As to effective strategies for the actual evaluation, the biopsychosocial model previously embodied in the DSM Axis System starts with what was previously known as Axis V (i.e., optimal and current functioning or Baseline) and working up through Axis IV (Psychosocial Stressors), Axis III (Medical Conditions contributing to the current presentation), and Axis II (Trademark Personality and Communication Style, *i.e.*, Behavioral Communication), before considering what used to be called an Axis I diagnosis of psychiatric illness.

During the first encounter in an emergency, urgent, or non-acute setting, a critical task is to get an understanding of the PWIDD's baseline. Such encounters tend to be problem-focused, and being presented with an individual with multiple issues tends to lead clinicians to assume that all of them are chronic. The extent of the current problem cannot be understood until the long-term baseline is understood. The initial focus must be on changes in functional adaptive behavior over time. Subsequent clinical inquiry should investigate psychosocial changes, symptoms, behavioral changes indicative of medical issues, trademark behaviors and their function, history of trauma, and finally the evidence that may support the assignment of a psychiatric diagnosis or substance use disorder determination.

Psychosocial stressors tend to be undervalued in this population. In the case example of John referenced throughout this paper, it is possible that all of John's distress could be attributed to psychosocial stressors, but it is unlikely that he is exhibiting this level of intensity to such a change for the first time in his life. Knowing if he has reacted to similar stressors in an equivalent way in the past builds an understanding of his behavioral topography.

Medical conditions are often overlooked in individuals not well equipped to localize pain, describe symptoms, or assist the clinician in other ways to uncover a somatic diagnosis.^{146, 147} Aggression and property destruction/disruptions, as well as self-injurious behavior, can be a method of expressing pain/distress that has a medical cause. Impacted wisdom teeth, migraine headaches, severe PMS, peptic ulcer disease, and gastroesophageal reflux disease (GRD) all represent common medical conditions that can be very painful and/or distressing and do not manifest outwardly, even to observant treatment providers.

Gaining a sense of the PWIDD's usual temperament and personality style helps to filter the possibilities. A typically shy person who has rather suddenly become more outgoing might show up in the ED after eloping repeatedly. His or her presentation might not seem all that remarkable unless the treatment provider understands what a departure the action represents. Trauma and its impact on personality and temperament in this sub-population is even more challenging than in the more neuro-typical and often confounds pharmacologic treatments. In this situation, clinicians tend to chase symptoms with

¹⁴⁶ Clements P., Focht-New G. & Faulkner M.J., Grief in the Shadows: Exploring Loss and Bereavement in People with Developmental Disabilities, *Issues in Mental Health Nursing* 25(8), pp. 799-808 (July 2004).

¹⁴⁷ Cooper S.A., Morrison J., Melville C., Finlayson J., Allan L., Martin G. *et al.*, Improving the Health of People with Intellectual Disabilities: Outcomes of a Health Screening Programme After 1 Year, *Journal of Intellectual Disability Research* 50, pp. 667-77 (2006).

medications without acknowledging that the target issue, usually affective dysregulation, is only going to be mitigated by medication and successful treatment can only be accomplished with environmental manipulation in combination with medication.

This scenario underscores the necessity of understanding the PWIDD's baseline, given that the affective dysregulation of a trauma history tends to be a long-term circumstance and the trauma history and behavioral topography can be uncovered in the personal health records that may accompany the PWIDD.

Arriving at a psychiatric diagnosis depends greatly on accurate data transfer from the home environment, whether it be group home, family home, or some other supported living arrangement. Sleep data viewed over a 24-hour period and in the context of the baseline can be an excellent clue indicating psychiatric illness if it has not been obscured by other pharmacologic interventions. Changes in weight and appetite may also be helpful, but can be obscured by other factors. Family history and caretaker reports are even more critical in this sub-population than with more neuro-typical patients with mood disorders. Remembering that psychiatric illness tends to be more episodic in nature while IDD is chronic can provide clues and alert the clinician to the need to look for patterns.

In the end, any major departure from baseline which cannot be attributed to other factors may deserve at least an empiric trial of a psychotropic expected to address an identified target symptoms. This is best done with the support of a behavioral plan that has been developed and with a review of data on behavioral targets thought to be impacted by medication. Most often these behavioral targets are physical aggression, property destruction/disruption, verbal aggression/disruption, elopement, and sexually inappropriate behavior. All of these behaviors tend to carry significant emotional valence for caretakers, underscoring the need for data rather than anecdotal reports. Data reveals behavioral trends that are difficult to deduce from non-data driven reporting.

Effective treatment of psychiatric illness does not often result in immediate symptom cessation. Rather, symptoms tend to melt away. It is incumbent on any prescribing clinician to not prescribe medication as a part of an overarching and ongoing treatment plan to simply and solely suppress behavior. Utilizing a biopsychosocial method to sort presentations into those that may truly represent psychiatric illness should be the initial goal, followed by empiric medication trials using data-driven feedback. It is critical for the clinician to maintain an open mind that permits constant reassessment of the information at hand. Medications can be associated with significant risk and adverse outcomes; PWIDD should not be unnecessarily exposed to these risks.

Recommendations for Policy Makers

Systemic data collection must be done to better identify population prevalence and needs across systems.

Recommendations for Practitioners

Current practitioners should be encouraged to update their skills in working with PWIDD through continuing education activities. Trainees must be instructed in best practices in the appropriate biopsychosocial approach to psychiatric diagnosis and treatment of PWIDD.

Criminal Justice and Forensic Settings

Adults and juveniles with IDD are over-represented in justice and forensic settings, often stemming from tragic circumstances and at times leading to tragic outcomes. Although much attention is paid to the over-representation of persons with mental illness in the justice system, historically less focus has been on PWIDD in these same juvenile and adult criminal justice settings. However, the population is getting increasing notice, and serious concerns have been raised regarding over-arrest, use of force, conditions of confinement, and access to appropriate services within the criminal justice systems. One oft-cited study points to the higher prevalence of individuals with IDD in justice settings, citing they represented 4 to 10 percent of the population within one prison system, which was more than twice the prevalence in the community.¹⁴⁸ An earlier study put the prevalence at about 2 percent, but then noted that was likely an underestimate.¹⁴⁹ Data from the Bureau of Justice Statistics found that among prisoners and jail inmates, cognitive disabilities stood out as the most commonly reported disability, with about 20 percent of prisoners and 30 percent of jail inmates reporting this type of disability.¹⁵⁰

When an individual with IDD is in the justice system, there are several areas of concern. The American Association on Intellectual and Developmental Disabilities, in partnership with The ARC, has crafted a position statement articulating the importance of persons with IDD being treated fairly within the justice system and having access to necessary accommodations and supports to realize justice in proceedings. In the background to the statement, they note the risks of victimization, failure to recognize the unique abilities and needs of persons with IDD, denial of due process, as well as risks of discrimination in sentencing, release, confinement, and other outcomes.¹⁵¹

As noted earlier, rates of victimization and trauma are already high among persons with IDD, and their involvement in the juvenile and criminal justice system can compound some of those traumatic experiences. Conditions of confinement can create further challenges. Their understanding of their legal rights when facing criminal charges, as well as their understanding of rules in correctional settings, can be limited—leading to further difficulties. A review of the literature notes several studies showing that individuals with IDD can be at risk of being uniquely exploited and victimized in correctional settings.¹⁵²

Self-injury—such as head-banging, regressive acts, or other behavioral manifestations of distress—are not uncommon among detainees and inmates with IDD. Behavior that is

¹⁴⁸ Petersilia J., *Doing Justice? Criminal Offenders with Developmental Disabilities*, California Policy Research Center (CPRC) Brief 12(4), CPRC, University of California (August 2000).

¹⁴⁹ Nobel J.H. & Conley R.W., Toward an Epidemiology of Relevant Attributes in eds. Conley R.W., Luckasson R & Bouthilet G.N., *The Criminal Justice System And Mental Retardation: Defendants And Victims*, Paul H. Brookes, Baltimore (1992).

¹⁵⁰ Bronson J. & Maruschak L., *Disabilities among Prison and Jail Inmates, 2011–12*, U.S. Department of Justice Office of Justice Programs Bureau of Justice Statistics Special Report, RTI International (December 2015).

¹⁵¹ *Criminal Justice System: Joint Position Statement of AAIDD and The Arc*, <https://aaid.org/news-policy/policy/position-statements/criminal-justice#.WWBcrYjyuUk>.

¹⁵² McDermott B.E., *Developmental Disabilities*, in eds. Trestman R., Appelbaum K., & Metzner J., *Oxford Textbook of Correctional Psychiatry*, Oxford University Press (2015).

difficult to manage in corrections can result in periods of confinement in segregation units. Specialized supportive units or programs with habilitative services are unlikely to be available for most inmates with IDD, although current formal data on the frequency that those programs and services exist within correctional systems is limited.

PWIDD are also frequently encountered within forensic populations (primarily those found incompetent to stand trial or not guilty by reason of insanity) traditionally managed through state mental health services. Jail detainee waitlists for admission to state hospitals of incompetent to stand trial defendants include individuals with IDD. Once admitted to a competence to stand trial restoration program, efforts to restore these individual's competence are labor intensive and can incur additional costs. Data indicates that restoration to competence is feasible for some individuals with IDD,¹⁵³ although time to restoration may take years compared to the more traditional months on average required for persons with mental illness.¹⁵⁴

This lengthy period to restoration can, of course, impact bed occupancy. What's more, by being hospitalized through the competency route, issues can surface with an individual with IDD who might not clinically require hospital level of care or might fare worse in an institutional setting designed more to help persons with SMI. IDD has been a focus of discussion in recent years among the members of the National Association of State Mental Health Program Directors' Forensic Division.

Advocacy groups such as The Arc have developed strategies for system reform and attention to the unique needs of the population, through the establishment of their National Center on Criminal Justice and Disability.¹⁵⁵ The on-line publication *The Impact*¹⁵⁶ provides useful information regarding better policing, risk of victimization (including sexual victimization) in correctional settings, prevalence of fetal alcohol syndrome, the importance of recognition by judges and other justice professionals, and crisis intervention techniques all geared to the IDD population.

As SMHAs are responsible for state hospitals that are increasingly occupied by individuals with forensic histories, and are increasingly involved in the development of specialized justice diversion services, greater interagency collaboration between SMHAs and DD agencies is critical to maximizing coordination, efficiency, and common ground regarding philosophy of approaches for diverting individuals with mental illness and/or IDD out of the justice system and into supportive environments of care.

¹⁵³ Wall B.W., Christopher P.P.J., A Training Program for Defendants with Intellectual Disabilities Who are Found Incompetent to Stand Trial, *American Academy of Psychiatry and the Law* 40(3), pp. 366-73 (2012).

¹⁵⁴ Pinals D.A., Where Two Roads Meet: Competence to Stand Trial Restoration from a Clinical Perspective, *New England Journal of Civil and Criminal Confinement* 31, pp. 81-108 (2005).

¹⁵⁵ <http://www.thearc.org/NCCJD>.

¹⁵⁶ <https://ici.umn.edu/products/impact/301/#Cover>.

Recommendation for Policy Makers

Given the overrepresentation of PWIDD in justice and forensic systems, SMHAs should partner with IDD agencies overseeing services for these persons, and together there should be interagency outreach and collaboration with law enforcement, courts, and corrections to provide skilled de-escalation, diversion approaches, cross-discipline education, and linkages to services and guidance in developing greater supports to accommodate persons with disabilities in justice and forensic systems, as well as build bridges to programs reflecting alternatives to incarceration. SMHAs should partner in cross-agency activities and policy development to strengthen appropriate services for the IDD population within corrections and offer strategies to advance improved conditions of confinement targeting this sub-population’s needs.

Workforce Development

As noted in the case example of John, it is not uncommon for staff within the mental health and health care systems who have direct contact with the IDD population to not feel prepared to care for such individuals. Many psychiatric or ED personnel, community support providers, and others across the continuum have not had adequate training to provide professional support and maximize functioning of the individuals served. For example, the Accreditation Council for Graduate Medical Education (ACGME) requirements for board certification of general psychiatrists and ED physicians does not have a specific requirement listed to have competency or a clinical experience with this population.^{157, 158}

Among other specialties that would have likely exposure to PWIDD, training requirements for pediatricians lists clinical exposure in neurodevelopmental disabilities as an area that can be part of the training requirements, but that training is not mandated.¹⁵⁹ In contrast, the ACGME board certification guidelines specifically for Child Psychiatry require demonstrated competence and an “organized educational clinical

¹⁵⁷ ACGME Program Requirements for Graduate Medical Education in Emergency Medicine, ACGME-approved focused revision: February 6, 2017, effective July 1, 2017. Revised Common Program Requirements effective July 1, 2017,

http://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/110_emergency_medicine_2017-07-01.pdf.

¹⁵⁸ ACGME Program Requirements for Graduate Medical Education in Psychiatry, ACGME-approved focused revision: February 6, 2017, effective July 1, 2017. Revised Common Program Requirements effective: July 1, 2017,

http://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/400_psychiatry_2017-07-01.pdf.

¹⁵⁹ ACGME Program Requirements for Graduate Medical Education in Pediatrics. ACGME-approved focused revision: February 6, 2017, effective July 1, 2017. Revised Common Program Requirements effective: July 1, 2017,

https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/320_pediatrics_2017-07-01.pdf.

experience” in intellectual developmental disorder or developmental disorders.¹⁶⁰ There is a need, then, to develop a better-trained workforce to help support the success of individuals with IDD. In addition to psychiatrists, ED physicians, and pediatricians, there are countless other disciplines that work with PWIDDs; increasing their baseline knowledge and training in serving this sub-population is important.

To that end, some progress in workforce development for those supporting PWIDD is being made. ABA is one approach appropriate for some individuals with IDD, and board-certified behavior analyst (BCBA) training is a part of a relatively new initiative that grew out of ABA.¹⁶¹ Yet there is still work to be done.

The NADD has a comprehensive workforce development program through its Accreditation and Certification programs, developed in collaboration with the National Association of State Directors of Developmental Disabilities Services (NASDDs). The competency-based workforce development program emphasizes a comprehensive biopsychosocial model, and provides opportunities for professional work to be reviewed and certified through a peer review process that includes the review of sample case conceptualization.¹⁶²

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs operate through university systems, and work to advance workforce capacity by preparing trainees from multidisciplinary professional paths to assume leadership roles in their respective fields, encouraging high levels of interdisciplinary clinical competence related to work with the IDD population.¹⁶³ LEND programs provide “long-term, graduate level interdisciplinary training, as well as interdisciplinary services and care,” with the goal of improving the health of infants, children, and adolescents with disabilities.¹⁶⁴

In addition, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 mandated the creation of University Centers for Excellence in Developmental Disabilities (UCEDDs), which are components of a university system or public/not-for-profit entities associated with universities that provide interdisciplinary training to students and professionals intended to direct services and supports to people with disabilities of all ages and their families.¹⁶⁵

¹⁶⁰ ACGME Program Requirements for Graduate Medical Education in Child and Adolescent Psychiatry. Revised Common Program Requirements effective July 1, 2017, http://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_child_and_adolescent_psyh_2017-07-01.pdf.

¹⁶¹ Board-Certified Behavior Analysis, <https://bacb.com/bcba/>.

¹⁶² <http://thenadd.org/products/accreditation-and-certification-programs/>.

¹⁶³ Association of University Centers on Disabilities (AUCD), *About LEND* (2011), <https://www.aucd.org/template/page.cfm?id=473>.

¹⁶⁴ *Ibid.*

¹⁶⁵ Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402 (October 30, 2000).

Through these programs, knowledge and skills of professionals working with the PWIDD population can improve, ultimately improving health care delivery systems for individuals with disabilities.

Recommendation for Policy Makers

Workforce development in the community must include attention to biopsychosocial frameworks, the role of personal supports, behavioral support approaches such as ABA and PBS, and the requisite training, as well as salaries that support the challenging work to minimize disruptions in treatment. Policy-makers should encourage advocacy and planning for a workforce across mental health and other healthcare systems that can work with PWIDD by developing training models and early exposure in training through approaches such as targeted clinical rotations and field placements.

Table 3: Summary of Recommendations

<p>Psychiatric Treatment</p>	<p>Designated inpatient units offer advantages of specialization and disadvantages of potential disparate, segregated treatment. Systems should review the balance between specialization and integration within psychiatric services, and recognize that even with integration, unique consultative supports may be needed for the treatment providers.</p>
<p>Organizational Structures to Meet Mental Health Needs</p>	<p>Policy-makers should work to develop cross-agency guidelines for greater intersystem collaboration, recognizing that PWIDD will and do appear in the mental health service system. The development of these collaborative efforts should include input from a variety of stakeholders and examine collaboration across all ages, including persons served in the child/adolescent, adult and older adult sectors. Perspectives of persons served, their families, and representative advocacy organizations will be critical in the development of the guidelines. Important areas for guidelines include:</p> <ol style="list-style-type: none"> 1) Development of shared data to understand and develop planning for the total numbers of individuals served across systems, and those denied services because of overlap issues 2) Development of approaches to handling requests for services for people that do not neatly fit into administrative lines for particular services, as well as approaches for reviewing individual cases where overlapping needs are present but not met 3) Fostering leadership to develop methods through blended and braided funding streams for continuum of care services that address the dual need populations 4) Establishment of intersystem partnerships, such as work with law enforcement and jail diversion programs to include interventions for those with both IDD and SMI 5) Mutual workforce development

<p>Co-Occurring Conditions and Accurate Parsing of Contributing Biopsychosocial Factors</p>	<p>Co-occurring challenges such as psychiatric disorders, other neurodevelopmental disorders, hearing loss, and other sensory challenges, as well as psychosocial and medical factors, are important to take into account among the PWIDD population across the continuum of care and support services. There is much heterogeneity in this population, so generalizations and cookie-cutter approaches are risky.</p>
<p>Trauma-Informed Care</p>	<p>Rates of trauma and victimization are alarmingly high in PWIDD. Safeguards, self-scrutiny, and monitoring are of ongoing critical importance.</p>
<p>Person-Centered Care</p>	<p>Prioritize the ability to develop self-directed and person-centered care planning, focusing on a PWIDD’s strengths, capabilities, and potential to contribute to their community. Understand that maximal self-direction and autonomy can be achieved with the right supports; assessments should be regularly updated with the expectation of improvement over stagnation.</p>
<p>Behavioral Supports</p>	<p>All behavior reflects some type of communication. A PWIDD’s limited ability to verbally communicate anxiety, mood issues, or a thought disorder may manifest in aggression or externalizing behaviors, which can often result in missed diagnoses or opportunities for treatment. Always ask, “What is the PWIDD’s communication or behavior trying to achieve?”</p>
<p>Pharmacologic Supports</p>	<p>Given the limited guidance on helpful medication strategies for PWIDD in the literature, the evidence for psychopharmacology should be case-specific, data-informed rather than anecdotal, and come from behavioral evidence and comprehensive contextual information and behavior tracking reports for the specific individual being treated.</p>

<p>Environmental Supports</p>	<p>Gather information from all sources, especially direct service professionals, who can provide a wealth of information to inform program and planning. Peer partners, provider treatment networks, and a recognition of environmental precipitants to behavioral challenges can be helpful.</p>
<p>Financial Supports and Entitlements</p>	<p><u>Recommendation for State Executive Offices of Health and Human Services (EOHHS):</u> Devise a targeted health management framework for intersystem collaboration to ensure the health of the population of persons with IDD and MH conditions. Within that framework:</p> <ol style="list-style-type: none"> 1) Identify population parameters, characteristics, care use patterns, and emerging risk indicators and build these data points into the state’s care management information systems; 2) Define a covered continuum of evidence based care and best practices that are responsive to the population of persons with IDD and MH conditions, that can be delivered in a mix targeted to their unique service needs through an individualized plan of care; 3) Structure sufficient financial and performance incentives to focus care interventions on protecting this sub-population’s health and managing emerging risk; 4) Establish guidance for multidisciplinary care management teams and services coordination teams with defined accountability for population outcomes; 5) Build collaborative, integrated care across governmental sectors; and 6) Focus routine data inquiries on quality and emergent risk indicators, using results for continuous quality improvement. <p><u>Recommendation for State I/DD and MH Authorities:</u> Strengthen and specify inter-departmental/interagency services coordination teams with authority to solve fragmentation in</p>

	<p>eligibility, service delivery, and care financing affecting persons with co-occurring conditions.</p> <p><u>Recommendation for State Medicaid Agencies:</u> Establish clear performance measures and payment incentives in MCO or ACO contracts to ensure that persons with co-occurring IDD and MH conditions are accorded access to competent treatment and recovery support services delivered through an individualized plan of care in a mix targeted to their unique service needs. Direct the MCOs and ACOs to employ multidisciplinary care management teams to carry out population health studies, review data system reports, manage emerging risk, and direct integrated service delivery.</p> <p><u>Recommendation for Practitioners:</u> Secure access to current policy and regulatory guidance in the state governing provision of services to persons with co-occurring IDD and MH conditions. The guidance should include coverage and reimbursement guidelines, as well as criteria for case reconciliation carried out by interagency health and human services bodies that is designed to parse eligibility, clinical, and financial responsibility for complex cases across multiple agency lines.</p>
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<p>General Principles to Behavioral Health Services Across Settings</p>	<p><u>Recommendations for Policy Makers:</u> Systemic data collection must be done to better identify population prevalence and needs across systems.</p> <p><u>Recommendations for Practitioners:</u> Current practitioners should be encouraged to update their skills in working with PWIDD through continuing education activities. Trainees must be instructed in best practices for the appropriate biopsychosocial approach to psychiatric diagnosis and treatment of PWIDD.</p>
<p>Forensic System</p>	<p>Given the overrepresentation of individuals with IDD in justice and forensic systems, SMHAs should partner with agencies overseeing services for these persons. Together there should be interagency outreach and collaboration with law enforcement, courts, and corrections to provide skilled de-escalation, diversion approaches, cross-discipline education, linkages to services, and guidance in developing greater supports in justice system routine to accommodate persons with disabilities, as well as bridges to programs reflecting alternatives to incarceration.</p> <p>SMHAs should partner on cross-agency activities and policy development to strengthen appropriate services for the IDD population within corrections and offer strategies to advance improved conditions of confinement targeting this sub-population’s needs.</p>
<p>Workforce Development</p>	<p>Workforce development in the community must include attention to personal support, behavioral supports, techniques such as ABA, an understanding of biopsychosocial issues, and the requisite training, as well as salaries that support the challenging work to minimize disruptions in treatment. Encourage advocacy and planning for a workforce that can work with PWIDD by developing training models and early exposure to PWIDD in training and clinical rotations.</p>

Conclusion

Individuals with IDD within the mental health system have unique needs and can pose particular challenges at times, so that attention to this population is critical. Often psychiatric beds are called upon to support individuals with IDD. Although inpatient psychiatric hospitalization can be a needed response, a robust continuum of care and service delivery system that is increasingly sophisticated in working with this population is critical to maximizing the autonomy and community inclusion of these persons.

It is important to identify individuals with IDD and their conditions that require special supports and treatments, including a focus on critical areas such as trauma-informed services, person-centered approaches, and environmental supports. This assessment outlines several recommendations for consideration, summarized in Table 3.

Individuals with IDD will seek services in EDs, medical hospitals, acute psychiatric hospitals or come to the attention of the adult and juvenile justice systems. Services designed to support these individuals can themselves be fractured or siloed and when stressors challenge the supports, there can be real shifts in behavior and need. Attention to unique needs in particular settings is vital. Financing and policy alignment, as well as interagency cooperation and cross-training, will each be critical to maximally leveraging supports and services to best help individuals across populations.

State Mental Health Authorities have a unique vantage point that requires a willingness to support individuals with serious mental illness along with the multiple comorbid conditions accompanying and compounded by mental illness. It is hoped that the information and recommendations in this assessment helps SMHAs to realize the potential to improve practice in serving PWIDDs with dual diagnoses in the various settings in which they might present.