

# Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 2. Policy and Systems Considerations

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Individuals with intellectual and developmental disabilities (IDD) are at high risk of co-occurring mental health conditions, including major depressive disorder, bipolar disorder, psychotic disorders, anxiety disorders, impulse control disorders, and others. Because of symptoms associated with these illnesses and with the disabilities themselves, these individuals are often served in a mental health service system framework. In this second of two articles on care for persons with IDD in the mental health system, the authors focus on policy and systems considerations to assist practitioners and administrators to provide high-quality mental health services for these individuals by recognizing existing infrastructures of support. The authors describe historical factors, including legislation and case law, that have led to greater inclusion of persons with IDD in mainstream

settings; systemic barriers to integrating services for persons with IDD and Medicaid waivers and provisions of the Affordable Care Act designed to overcome such barriers; and considerations for treating persons with IDD in various settings, such as emergency departments and forensic settings. They propose approaches to developing the workforce, such as by training direct service professionals and utilizing the services of board-certified behavioral analysts. A robust continuum of care and service delivery system that is increasingly sophisticated in working with persons with IDD, with and without co-occurring mental illness, is critical to maximize the autonomy and community inclusion of these individuals.

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Comprehensive mental health service systems provide an array of treatment modalities and recovery supports. The continuum of care is of critical importance for effective responses to people with varying levels of need, including persons with intellectual and developmental disabilities (IDD) with and without co-occurring mental illnesses, who often receive services in the mental health system. With evolving standards, funding streams, and expectations of families, advocates, and others, community-based care that delivers all elements of the continuum is an essential priority. The systems that support persons with IDD and persons with mental illness developed in tandem. Rules related to the Affordable Care Act (ACA) may compromise certain aspects of support for persons with IDD, and forensic settings often are ill prepared and inappropriate for this population. This is the second of two articles originally conceptualized by the National Association of State Mental Health Program Directors in collaboration with the Substance Abuse and Mental Health Services Administration in an effort to identify and rectify some of the problematic aspects of delivering services for persons with IDD who cross into the mental health system. In part 1, we described diagnostic and treatment considerations for persons

with IDD, including those pertaining to co-occurring mental illness (1). In part 2, we focus on systems and policies within and beyond the psychiatric hospital structure to explain aspects of the continuum of care for individuals with IDD and to increase understanding of the opportunities and challenges in delivering appropriate supports to this population.

## HIGHLIGHTS

- Individuals with intellectual and developmental disabilities (IDD) who have co-occurring mental health conditions must often seek treatment for these conditions by crossing over to the mental health system from the developmental disabilities system, where they are typically served.
- Mental health and developmental disabilities systems have distinct legal, regulatory, policy, and practice protocols, which places the burden of care integration on the individual rather than on the systems.
- Systems and policy changes can further integrate care for persons with IDD who have mental health conditions, and further efforts are needed to create a robust continuum of care for this population.

## INTRODUCTION TO THE ISSUES

State mental health authorities (SMHAs) traditionally have a mandate to represent and provide for the needs of youths with serious emotional disturbances and adults with serious mental illness—the latter typically defined as disorders of thought and mood (such as bipolar illness, schizophrenia, schizoaffective disorder, psychotic illnesses, and major depression, among others) that significantly affect psychosocial functioning. Substantial subpopulations are often faced with the fact that their needs may not be as readily addressed as a priority area.

In most states, the state developmental disability administration is separate from the SMHA, although in a few states they remain integrated. Psychiatric hospital inpatient services are primarily designed and focused on providing for individuals with mental illness, as are residential and community supports that are designed and funded via the SMHA through use of Medicaid and state general funds. Although it is now well established that persons with IDD have a higher rate of mental illness, including serious mental illness, compared with the general population, few acute psychiatric services are well designed to serve persons with psychiatric conditions that co-occur with autism spectrum disorder (ASD) or IDD.

The current treatment approach for persons with IDD stems from three trends. First, IDD was distinguished diagnostically from “pure” psychiatric disorders. Historically, psychiatric illness was conceptualized as resulting from intrapsychic conflict, and persons with IDD were thought to lack intellectual capacity to have an intrapsychic conflict and thus were thought unable to have psychiatric illness. These misconceptions partly resulted in a lack of development of psychiatric services to meet their needs. Add to this an evolving understanding of better treatment for persons with IDD, with an emphasis on nonpharmacological approaches, and combine it with historical trends toward overprescription of major tranquilizers to suppress behavior, and what evolved were distinct directions in state developmental disability policies. Finally, systems also evolved from advocacy in the 1970s civil rights movement that focused on the right to education and habilitation, which had strong separate constituencies for persons with IDD. These developments spawned related system reform litigation and promoted statutory, regulatory, budgetary, and organizational changes, typically along separate lines for persons with IDD, compared with those with primary mental illness or youths with serious emotional disturbances.

Beginning in the 1980s, home and community-based services (HCBS) waivers—a separate federal funding stream embedded within Medicaid—were created to provide long-term services and supports in the community to persons with IDD who meet eligibility criteria. HCBS are gaining increasing attention and are also specifically being discussed

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in the post-COVID-19 era with regard to potential new federal funding. Medicaid waivers are agreements between the state and federal governments that set aside certain federal rules, thus permitting states to provide particular services, target particular client groups, or select geographic areas of the state, as an encapsulated funded opportunity apart from generally available statewide Medicaid services. The HCBS waiver eligibility criteria necessitate that “but for” the habilitative services provided by the federal waiver in the community, the person with IDD would require an institutional level of care in an intermediate care facility for individuals with intellectual disability. The supports of the SMHA typically operate in isolation from the supports of the state developmental disabilities administration, because it was assumed that HCBS waivers would meet all the needs of persons with IDD, except for medical treatment, which would be provided through the general state Medicaid plan. Medicaid-eligible beneficiaries with IDD who do not meet federal Medicaid waiver criteria for the particular waiver must access all their psychiatric services through the services overseen and funded through SMHAs.

Despite the splits in organization structures, the overlap in populations of persons with IDD and those with mental illness has become an increasingly frequent topic of discussion because of the challenges in serving them. This is especially so because psychiatric hospitals increasingly focus on serving persons with serious mental illness and because SMHA-supported community-based mental health services are often challenged to provide access to all levels of mental health care for persons with IDD, as would be available for others without IDD. State hospital beds also have increasingly been utilized by patients in the forensic system, where persons with IDD are also overrepresented, even though the state hospitals have evolved to serve most adeptly persons with serious mental illness.

As the field expands its understanding of the complexities of the brain and behavior, it is challenged by an increasing number of individuals with multiple diagnoses who do not fit into preconceived service niches. When behaviors of persons with IDD or serious mental illness or both are difficult to support, individuals may be brought to the attention of the mental health system—either voluntarily through an emergency department (ED) or involuntarily by police to a hospital or even a jail. There they are at risk of disparate treatment because of the challenges they present. For example, having some type of IDD is often a significant risk factor for longer 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 may result in increased psychological stress on patients, overuse and misuse of ED resources, worsened ED crowding, and delays in providing needed mental health treatment—and they often culminate in a public health concern (2).

**LEGAL BACKGROUND AND CONTEXT**

Significant legislation has served as a basis for advocacy, reform, and standards and has furthered the changing landscape of inclusion of persons with disabilities in mainstream settings, moving away from historical practices of isolation and separation (3). Table 1 lists significant laws related to disability rights and summarizes major provisions of these laws that have shaped today’s framework. Significant laws include Section 504 of the Rehabilitation Act, the Civil Rights of Institutionalized Persons Act, the Fair Housing Amendments Act, the Americans With Disabilities Act (ADA), the Individuals With Disabilities Education Act (IDEA), and Rosa’s Law (4–10).

Case law evolving around these federal statutes has also pushed reform toward inclusion of persons with disabilities in integrated, not segregated, community settings. 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 appropriate (11). This case has produced two decades of activity, moving individuals from institutions to community placements, as well as debates and some litigation pertaining to questions of funding, reasonable accommodations, and least restrictive alternatives in individual cases.

A recent example of emerging legal doctrine refining the contours of rights for persons with IDD is *Andrew F. v. Douglas County School District* (12). In 2017, 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. Advocates 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 in meeting developmental and academic milestones (13). The impact on youths and future adults may indeed be tremendous, although time will tell how much the ruling will affect actual IEP development.

**ORGANIZATIONAL STRUCTURES TO MEET MENTAL HEALTH NEEDS**

**Opportunities and Barriers**

Despite improvement over time in distinguishing mental health conditions and IDD and enhanced abilities to triage care

**TABLE 1. Examples of significant disability rights laws and major provisions**

Law	Year passed	Major provisions
Section 504 of the Rehabilitation Act	1973	Prohibits discrimination on the basis of disability for federal services or federally funded services (4).
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 (5).
The Fair Housing Amendments Act	1988	Prohibits discrimination against persons with disabilities, among others, in housing (6).
Americans With Disabilities Act (ADA)	1990 (amended in 2008)	Prohibits discrimination on the basis of disability in employment, government services, public accommodations, commercial facilities, transportation, and telecommunications (7, 8).
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 an individualized education program (IEP) for each child that is unique to the child’s specific needs (9).
Rosa’s Law	2010	Signed into U.S. public law by President Barack Obama in 2010. The law 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 (10).

for patients with IDD, barriers remain. Individuals with co-occurring IDD and mental health conditions need integrated multidisciplinary supports that, in the main, demand collaboration across services that are mandated, regulated, and financed by siloed offices, administrations, divisions, or departments of state governments. For more than a century, public institutions dominated state responses to treatment of persons with IDD and of persons with mental illnesses, and departments of mental health that operated both services were the norm. Reform legislation that heralded the era of community care was named the Mental Retardation and Community Mental Health Centers Construction Act of 1963 (14). As state agencies continued to operate with mandates to serve 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, greatly added to the work and budgets managed by state departments of mental health. In addition, community mental health agencies began to focus on development of community services for persons leaving state hospitals.

As community services grew, advocacy organizations dominated by “The Arcs” developed a major presence as providers dedicated to persons with intellectual developmental disorder and began advocating for separate departments responsible for administering the federal waivers providing services for persons with IDD. After decades of administrative restructuring, budget migration, and concomitant narrowing of eligibility criteria, state IDD and mental health authorities carry

out their responsibilities for financing, delivering, and monitoring publicly funded programs in ways that vary considerably from each other and from one state to another. Additional variation is imposed by the choices that states elect in the Medicaid program—the state plan elements, plan options, or waivers that best suit a state’s needs and interests. Despite the fact that people with IDD and co-occurring mental health conditions constitute an estimated one-third (32.9%) of the total number of persons served by IDD agencies, organizational structures, eligibility rules, clinical programs, and financing tactics are largely separate (15). The National Association of State Directors of Developmental Disabilities Services (NASDDDS) works diligently on behalf of state leaders to stay abreast of policy advances and challenges and coordinate training and information sharing. During the COVID-19 pandemic, for example, NASDDDS held regular webinars, group conversations, and other events to help leaders in disabilities services have the latest information and advocated for the needs of the populations served, as well as others, including system leaders, the direct service workforce, and other stakeholders. A recent overview found that of the 51 state authorities serving persons with IDD, only six are divisions that are still within departments of mental health, nine 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, or social services (16).

The more pervasive fragmentation of program authority and resource control that characterizes today’s bureaucratic landscape poses significant barriers for persons with IDD who may have a co-occurring mental disorder or those with ASD who may have a co-occurring mental disorder or intellectual developmental disorder. Guidelines for eligibility issued by state agencies, divisions, or offices are not clearly aligned across entities in many states; such alignment would 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 narrowed eligibility criteria to manage within tighter budgets, exacerbating the problem. In some states, persons with ASD, for example, were excluded from either the mental health or the 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, and program eligibility, waiver requirements, and coverage criteria limit flexibility in resource application. The eligibility challenges combined with the financing challenges are made more difficult to resolve by an absence in many jurisdictions of clear protocols for managing co-occurring conditions. High-level strategies to jointly solve problems related to resource allocation could ultimately benefit the individuals in need across systems.

The National Association for the Dually Diagnosed (NADD) is an association for persons with IDD and mental health needs that provides access to policy papers and practice guidelines that may be of assistance to states (17). In 2007, NADD collaborated with the American Psychiatric Association on the publication of the *Diagnostic Manual—*

*Intellectual Disability (DM-ID)*, a text guiding diagnosis of mental disorders among persons with IDD (18, 19). With the publication of *DSM-5*, NADD developed updated guidance for practitioners and a second edition, *DM-ID-2* (20, 21). Yet, even with this addition to the clinical armamentarium, willing clinicians are hampered in their treatment of this population by the lack of systemic infrastructure.

The need for intersystem collaborative approaches to working across mental health services systems and those systems more specifically focused on serving persons with IDD is well recognized. Acknowledgment that these individuals will and do appear in mental health services should, in principle, guide implementation of collaboration protocols and staging of clinical settings. Guidelines that promote cross-collaboration should take advantage of work in this area, such as strategic planning done for workforce development by the NADD (22). Intersystem collaborative efforts for persons with IDD should also take into account the confluence of race, structural racism, and social determinants of health in designing prevention, identification, and support options. This is an area that warrants further study.

### Financial Supports and Entitlements

Although there are differences in the legislative intent and management of state appropriations that flow to various agencies with discrete responsibilities for either persons with IDD or persons with mental health conditions, federal Medicaid funds to the states flow to persons with eligibility. Most persons with IDD with the co-occurring mental health conditions noted above are Medicaid eligible. However, as described above, most states finance HCBS through federal waivers available under the Section 1915(c) Medicaid waiver program and the 1915(i) state plan option that allow coverage of a wide array of community-based rehabilitative interventions and residential supports but that are typically not defined to target individuals with co-occurring conditions. For example, states that have expanded use of the provision for self-directed personal care through 1915(j) state plan services or 1915(k) Community First Choice personal care option can support individuals to live in their homes, but these provisions do not incorporate psychiatric care benefits. Psychiatric benefits must be accessed through the individual’s broader eligibility for Medicaid benefits (state plan Medicaid), with use of medical necessity criteria to determine the level of care provided. Moreover, the benefits are typically administered by different entities, with the waivers administered directly by either the state Medicaid program or the developmental disabilities administration, and the behavioral health benefits are often carved out to third-party management under the purview of the SMHA or the state Medicaid program. In addition, several state authorities have adopted Money Follows the Person and Balancing Incentive Payment programs; these programs provide increased federal financing for HCBS, but they do not integrate psychiatric care benefits.

Under the terms of the ACA, 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 (LTSS) for individuals with two or more chronic conditions. States may target health home services to individuals with IDD who have co-occurring mental health conditions. Arizona, Michigan, North Carolina, and Wisconsin, among others, operate managed LTSS for persons with IDD (17). 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, as has been planned for some Section 1115 waivers.

Another emerging opportunity is the activity in states to implement managed LTSS in the context of developing accountable care organizations (ACOs). According to the NADD report (23), several states, including Massachusetts, Maine, New York, Minnesota, and Oregon, were contemplating or had implemented Section 1115 waivers with provisions for ACOs and LTSS management. Over the past 30 years, states administered aspects of their Medicaid programs by using managed care organizations (MCOs), mainly to manage primary care and behavioral health specialty care under Section 1903(m) of the Social Security Act. Over the past decade, states have also tested the utility of MCOs for management of care for persons with IDD, with advocates urging continuation of tested provider networks and strong state oversight of the MCOs. As some states adopt new Section 1115 waivers and other ACA provisions noted above, they are leapfrogging over MCOs to implement ACOs and tie ACOs to LTSS provider networks to deliver better integrated and managed care to persons with IDD who need LTSS. This is occurring at the same time as Medicaid programs are forging similar partnerships between ACOs and behavioral health provider networks. This development poses new challenges and opportunities for the integration of care for persons with co-occurring conditions.

## **UNIQUE ASPECTS OF BEHAVIORAL HEALTH SERVICES FOR PERSONS WITH IDD IN PARTICULAR SETTINGS**

### **General Principles for Behavioral Health Services Across Settings**

Although mental health care settings vary in their missions—the correctional setting is a major outlier—approaches to supporting clinicians in the work of evaluating persons with IDD share some features across all treatment environments (22). EDs deserve special considerations, because the ED is where individuals who have experienced both treatment failures and environment support failures arrive to be assessed. Factors underlying these failures must be identified and remedies prescribed. As a result, the ED is where major conflicts arise, as the individual with IDD and in crisis meets a crisis system that is admittedly ill equipped to meet his or her needs. As noted, often neither the SMHA nor the state developmental disabilities administration understands the

basic underpinnings of the other's system, and the systems simply do not share enough of the same knowledge to make problem solving an easy process in the setting where the person is receiving services. The following sections are focused on what can be done to improve the capacity of mental health system providers to work with persons with IDD.

### **Treatment Environment Considerations**

Clinicians should have a treatment environment that optimizes a therapeutic frame as well as safety for them and the person in crisis. Conducive treatment environments consider the physical environment of the treatment setting, the training and demeanor of the treatment staff, and advance knowledge of both treatment strategies and existing supports for people in this population (24, 25). Although 85% of persons with IDD have mild intellectual impairment, mild impairment does not necessarily translate to a need for fewer accommodations. Because of the heterogeneity of the population (25), the assessment of needed accommodation is determined on a person-by-person basis. Given the growing societal and legal expectation of full inclusion of persons with IDD, these preparations can no longer be viewed as optional (26). Environment triggers of undesirable behavior can result from intolerance of fluorescent lighting, small spaces, ambient noise, or overstimulating environments. Certainly, all treatment providers are limited by the architectural space provided to them, but steps can be taken to mitigate light and sound challenges within most environments. Involving self-advocates from the local developmental disabilities council may help treatment settings self-assess their environment and may provide an opportunity to interact with persons with IDD who are not in the midst of a health crisis. Having more integrated exchanges with self-advocates provides staff, who may see persons with IDD only in crisis, an opportunity to see the benefits of more optimized inclusion.

## **WORKFORCE DEVELOPMENT**

### **Clinicians**

Training of diverse frontline clinicians in both clinical and system strategies is necessary for improved care. It is not uncommon, however, for staff in the mental health and health care systems who have direct contact with the IDD population to feel unprepared to care for these individuals. Frontline staff along with mental health staff often have limited training to provide professional support and treatment interventions for persons with IDD. For example, the Accreditation Council for Graduate Medical Education (ACGME) requirements for board certification of general psychiatrists and ED physicians do not list a specific requirement for competency or clinical experience with this population (27, 28). Training requirements for pediatricians list clinical exposure in neurodevelopmental disabilities as an area that can be part of training, but such training is not absolutely mandated (29). In contrast, the ACGME board certification guidelines for child psychiatry require demonstrated competence and an “organized educational clinical experience”

in intellectual developmental disorder or developmental disorders (30). Despite these gaps, state mental health administrators often rely on evaluations by clinicians in the trenches to resolve system conflicts, although these very clinicians may not have a firm grip on parsing a complex presentation. Further, without proper training, these clinicians could direct large sums to be spent on providing the wrong treatment. Therefore, a better-trained workforce is needed to help support successful outcomes for individuals with IDD.

Training enhancements for workforce development could also be offered in important topical areas throughout a clinician's professional career. For example, one area of focus might include fostering patient engagement skills that are most likely to optimize efficient and effective assessment and information transfer. A recent online CME training on this topic, available through OptumHealth advocates and using the training acronym RAFT (respect, accommodation, follow-up, time), might be a beneficial beginning in raising awareness of how best patient engagement can occur with this population (31).

### **Direct Care, Board-Certified Behavior Analysts, and Administrative Leadership**

Although identifying and correctly treating co-occurring psychiatric and somatic illness is a significant contributor to long-term success, most parents and experts in the field will agree that for persons with IDD who require caretaker support, a more than substantial part of their quality of life is dependent on their caretakers (32). The term "direct service professionals" (DSPs) reflects this important professional role. This term also emphasizes the need for DSPs to have sufficient training and the necessary demeanor and deportment to provide quality service, although it is generally acknowledged that the pay scale offered for these positions often does not attract individuals with a career focus on becoming a DSP, which reflects another barrier that states are beginning to examine.

Ideally, critical training for DSPs includes understanding positive behavior supports (PBSs) and applied behavior analysis (ABA), as well as an emphasis on maximizing a positive environment. PBS has spread even to forensic psychiatric settings (33). PBS connotes an emphasis on choice and control for persons with IDD, who are supported by caretakers able to teach skills necessary to achieve communication goals to persons with IDD who are currently achieving their communication goal with nonadaptive behavior. A functional behavioral assessment and a behavioral plan developed with the specialized skills of an appropriately trained professional or board-certified behavioral analyst can create and augment an environment that supports PBS and that can be managed by DSPs.

Trauma-informed care is also a critical training element for DSPs, because the severe, out-of-proportion, affective dysregulation resulting from a trauma history often confounds positive relationships with caretakers and thus the provision of PBS. Too often, EDs and mental health clinicians are called to be the solution when environment supports have broken down. Counterproductive polypharmacy and placement standoffs can easily develop when an individual's behavior is

poorly understood, which then can be played out in acute treatment settings. Well-trained DSPs able to convey relevant data to clinicians are more likely to avoid these confounds.

Progress in workforce development for those supporting persons with IDD includes formal training in ABA and signifies an advancement in the field (33, 34). Examples of additional efforts to help expand the skills of this workforce include several national programs. The NADD has a comprehensive workforce development program through its accreditation and certification programs, developed in collaboration with the NASDDDS, which includes opportunities for professional work to be reviewed and certified through a peer-review process (22). START (systemic, therapeutic, assessment, resources, and treatment) is a research-based comprehensive model of services utilized in many states and recognized as evidence-informed and a best practice (35). START uses an apprenticeship model and national database to support caretakers while also incorporating a systems linkage approach to service provision. The Center for START Services is based at the University of New Hampshire Institute on Disability/University Center for Excellence in Disability. Offerings from the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) continue to advance workforce capacity (36). LEND programs provide "long-term, graduate level, interdisciplinary training," with a goal of improving the health of infants, children, and adolescents with disabilities. LEND programs operate through university systems and aim for trainees to assume leadership roles in their careers. In addition, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 mandated the creation of University Centers for Excellence in Developmental Disabilities, which are components of a university system or public, not-for-profit entities associated with universities that provide interdisciplinary training to students and professionals with the goal of directing services and supports to people with disabilities of all ages and their families (37).

### **CRIMINAL JUSTICE AND FORENSIC SETTINGS**

Adults and juveniles with IDD are overrepresented in justice and forensic settings, often stemming from tragic circumstances and at times leading to tragic outcomes. Although much attention is paid to the overrepresentation of persons with mental illness, the IDD population is also increasing in these settings, and serious concerns have been raised regarding overarrest, use of force, conditions of confinement, and access to appropriate services in the context of juvenile and criminal justice systems. For example, the American Association on Intellectual and Developmental Disabilities, in partnership with The Arc, crafted a position statement articulating the importance of fair treatment of persons with IDD in the justice system and of access to necessary accommodations and supports to realize justice in proceedings. In the background to the statement, the authors noted the risks of victimization, failure to recognize the unique abilities and needs of persons with IDD, denial of due process, and risks of discrimination in sentencing, confinement, release, and other outcomes, to

name a few (38). One oft-cited study points to the overrepresentation of individuals with IDD in justice settings, noting that they are estimated to account for 2%–3% of the general population but 4%–10% of the prison population (39). More data are needed to further understand these findings with a diversity lens focused on race and ethnicity for persons with IDD within these criminal-legal contexts.

As noted earlier, rates of victimization and trauma are already high among persons with IDD, and their involvement in the juvenile and criminal justice systems can compound some of those traumatic experiences. A review of the literature noted several studies showing that some individuals with IDD are at risk of being uniquely exploited and victimized in correctional settings (40). 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 difficult to manage in correctional settings can result in periods of confinement in segregation units or other challenging conditions. Specialized supportive units or programs with rehabilitative services are not commonly available for inmates with IDD, although current formal data on the frequency that those programs and services exist within correctional systems are limited.

Individuals with IDD are also commonly encountered in forensic populations (primarily those found incompetent to stand trial or not guilty by reason of insanity), which are traditionally managed through state mental health services. Waitlists for admission to state hospitals of jail detainees deemed incompetent to stand trial also include individuals with IDD (41). Data indicate that restoration or remediation to competence is feasible for some individuals with IDD (42, 43). Of note, time to restoration may take years, compared with the more traditional average of weeks or months required for persons with mental illness. In addition, the restoration process has traditionally consigned persons with IDD to long-term institutional living, often in state hospitals not designed to meet their needs, which can further affect bed occupancy and capacity for those with serious mental illness.

In recent years, the National Association of State Mental Health Program Directors' Forensic Division has taken up the matter of persons with IDD. 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 its National Center on Criminal Justice and Disability (44). Production of *Impact*, through the University of Minnesota, for example, provided useful information and resource material to support better policing and to address risk of victimization (including sexual victimization) in correctional settings (45). The *Impact* issue has also served to increase recognition among judges and other justice professionals of the prevalence of fetal alcohol syndrome and crisis intervention techniques, all geared to the IDD population.

SMHAs are responsible for state hospitals that are increasingly occupied by individuals with forensic histories. Therefore, cooperation between SMHAs and developmental disabilities agencies is critical. With such coordination,

efficiency and common ground regarding proper approaches for diverting individuals with mental illness or IDD from the justice system and into supportive environments of care can be enhanced synergistically.

## CONCLUSIONS

Systems serving persons with mental illness and persons with IDD have evolved separately, and the current mental health workforce generally has little training and experience with people with IDD. Often psychiatric crisis services, inpatient services, and other mental health services are called on to support individuals with IDD. Although inpatient psychiatric hospitalization may be needed, a robust continuum of care and service delivery system that is increasingly sophisticated in working with persons with IDD, with and without co-occurring mental illness, is critical to maximize the autonomy and community inclusion of these individuals. In doing so, it is important to include a focus on critical areas, such as trauma-informed services, person-centered approaches, and behavioral and environmental supports. Attention to unique needs in particular settings, ranging from EDs to state hospital forensic units and justice settings, is also vital. Financing and policy alignment, as well as interagency cooperation and cross-training, will each be critical to maximally leverage supports and services to best help individuals across populations and develop a more robust and well-equipped workforce. It is hoped that the information and recommendations in this article help to realize the potential to improve practice in these many important areas.

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Authors' Note: The term "mental retardation" is used in this document in an historical context reflecting the term as it was used at the time of the reference. The authors recognize that it is an outdated term and is considered hurtful and pejorative. They wish to acknowledge that it is not appropriate in current use.

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## REFERENCES

1. Pinals DA, Hovermale L, Mauch D, et al: Persons with intellectual and developmental disabilities in the mental health system: part 1. clinical considerations. *Psychiatr Serv* (Epub ahead of print, Aug 4, 2021)

2. Alleviating ED Boarding of Psychiatric Patients. Quick Safety, issue 19. Chicago, Joint Commission, Division of Health Care Improvement, Dec 2015. [https://www.jointcommission.org/assets/1/23/Quick\\_Safety\\_Issue\\_19\\_Dec\\_20151.pdf](https://www.jointcommission.org/assets/1/23/Quick_Safety_Issue_19_Dec_20151.pdf)
3. A Guide to Disability Rights Laws. Washington, DC, US Department of Justice, Civil Rights Division, Disability Rights Section, July 2009. <https://www.ada.gov/cguide.htm#anchor63409>
4. Rehabilitation Act of 1973, Pub L No 93-112 (1973)
5. Civil Rights of Institutionalized Persons Act of 1980. Pub L No 96-247 (1980)
6. Fair Housing Amendments Act of 1988. Pub L No 100-430 (1988)
7. Americans With Disabilities Act of 1990, Pub L No 101-336, 104 Stat 328 (1990)
8. ADA Amendments Act of 2008. Pub L No 110-325 (2008)
9. Individuals With Disabilities Education Act, 20 USC § 1400 (2004)
10. Public Law 111-256, § 2(b)(2), Oct 5, 2010, 124 Stat 2643 (Rosas Law)
11. *Olmstead v LC*, 527 US 581 (1999)
12. *Endrew F v Douglas County School District*, 580 US (2017)
13. McKenna L: How a new Supreme Court ruling could affect special education. Atlantic, March 23, 2017. <https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/>
14. Mental Retardation Facilities Construction Act. Pub L No 88-164 (1963)
15. Adult Family Survey, 2011-12: Final Report. Cambridge, MA, and Alexandria, VA, Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, National Core Indicators, 2013. [https://www.nationalcoreindicators.org/upload/core-indicators/CS\\_2011-12\\_Final\\_Report.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/CS_2011-12_Final_Report.pdf)
16. Pinals DA, Hovermale L, Mauch D, et al: The Vital Role of Specialized Approaches: Persons With Intellectual and Developmental Disabilities in the Mental Health System. Alexandria, VA, National Association of State Mental Health Program Directors, August 2017. [https://www.nasmhpd.org/sites/default/files/TAC.Paper\\_7.IDD.Final.pdf](https://www.nasmhpd.org/sites/default/files/TAC.Paper_7.IDD.Final.pdf)
17. NADD: Our Mission. Kingston, NY, National Association for the Dually Diagnosed, 2021. <http://thenadd.org/>
18. Fletcher RJ, Haverkamp SM, Ruedrich SL, et al: Clinical usefulness of the Diagnostic Manual-Intellectual Disability for mental disorders in persons with intellectual disability: results from a brief field survey. *J Clin Psychiatry* 2009; 70:967-974
19. Fletcher R, Loschen E, Stavrakaki C, et al (eds): Diagnostic Manual-Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons With Intellectual Disability. Kingston, NY, National Association for the Dually Diagnosed, 2007
20. Fletcher RJ, Barnhill J, McCarthy J, et al: From DSM to DM-ID. *J Ment Health Res Intellect Disabil* 2016; 9:189-204
21. Fletcher RJ, Barnhill J, Cooper S-A: Diagnostic Manual-Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons With Intellectual Disability, 2nd ed. Kingston, NY, National Association for the Dually Diagnosed, 2017
22. The NADD Accreditation and Certification Programs. Kingston, NY, National Association for the Dually Diagnosed, 2021. <http://thenadd.org/accreditation-certification/>
23. Fletcher RJ, Baker D, St Croix J, et al: (ed): Mental Health Approaches to Intellectual/Developmental Disability: A Resource for Trainers. Kingston, NY, National Association for the Dually Diagnosed, 2016
24. Hovermale L, Paclawskyj T, Simpson D, et al: The evaluation of intellectual and developmental disabilities; in *Emergency Psychiatry*. Edited by Channugam A, Triplett P, Kelen G. Cambridge, United Kingdom, Cambridge University Press, 2013
25. Bradley E: Guidelines for Managing the Client With Intellectual Disabilities in the Emergency Room. Toronto, University of Toronto, Centre for Addiction and Mental Health, 2002
26. Rosenbaum S: Using the courts to shape Medicaid policy: *Olmstead v LC* by Zimring and its community integration legacy. *J Health Polit Policy Law* 2016; 41:585-597
27. ACGME Program Requirements for Graduate Medical Education in Emergency Medicine: ACGME Approved Focused Revision: June 13, 2020; Effective: July 1, 2020. Chicago, Accreditation Council for Graduate Medical Education, 2020. [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/110\\_EmergencyMedicine\\_2020.pdf?ver=2020-06-26-125701-320](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/110_EmergencyMedicine_2020.pdf?ver=2020-06-26-125701-320)
28. ACGME Program Requirements for Graduate Medical Education in Psychiatry: ACGME Approved Focused Revision: June 13, 2020; Effective: July 1, 2020. Chicago, Accreditation Council for Graduate Medical Education, 2020. [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/400\\_Psychiatry\\_2020.pdf?ver=2020-06-19-123110-817](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/400_Psychiatry_2020.pdf?ver=2020-06-19-123110-817)
29. ACGME Program Requirements for Graduate Medical Education in Pediatrics: Editorial Revision: Effective July 1, 2020. Chicago, Accreditation Council for Graduate Medical Education, 2020. [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/320\\_Pediatrics\\_2020.pdf?ver=2020-06-29-162726-647](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/320_Pediatrics_2020.pdf?ver=2020-06-29-162726-647)
30. ACGME Program Requirements for Graduate Medical Education in Child and Adolescent Psychiatry. ACGME Approved Focused Revision: June 13, 2020; Effective: July 1, 2020. Chicago, Accreditation Council for Graduate Medical Education, 2017. [https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405\\_ChildAdolescentPsychiatry\\_2020.pdf?ver=2020-06-19-130331-607](https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_ChildAdolescentPsychiatry_2020.pdf?ver=2020-06-19-130331-607)
31. Establishing Effective Communication With Patients With Intellectual Disabilities: RAFT Part 1. Columbia, MD, OptumHealth Education, 2020. <https://www.optumhealtheducation.com/idd/raft-1>
32. Moseley C: "Picking up the Pieces of Our Own Mistakes:" Supporting People With Co-Occurring Conditions. Alexandria, VA, National Association of State Directors of Developmental Disabilities Services, March 2004. [https://www.researchgate.net/publication/228487204\\_Picking\\_Up\\_the\\_Pieces\\_of\\_Our\\_Own\\_Mistakes\\_Supporting\\_People\\_with\\_Co-Occurring\\_Conditions/](https://www.researchgate.net/publication/228487204_Picking_Up_the_Pieces_of_Our_Own_Mistakes_Supporting_People_with_Co-Occurring_Conditions/)
33. Tolisano P, Sondik TM, Dike CC: A positive behavioral approach for aggression in forensic settings. *J Am Acad Psychiatry Law* 2017; 45:31-39 28270460
34. Board Certified Behavior Analyst. Littleton, CO, Behavior Analyst Certification Board, 2021. <https://bacb.com/bcba/>
35. START: Mission and Values. Concord, NH, University of New Hampshire, Institute on Disability, University Center for Excellence in Disability, 2021. <https://www.centerforstartservices.org/>
36. About LEND. Silver Spring, MD, Association of University Centers on Disabilities, 2021. <https://www.aucd.org/template/page.cfm?id=473>
37. Developmental Disabilities Assistance and Bill of Rights Act of 2000. Pub L No 106-402. Oct 30, 2000
38. Criminal Justice System: Joint Position Statement of AAIDD and The Arc. Silver Spring, MD, American Association of Intellectual and Developmental Disabilities, 2014. <https://www.aaidd.org/news-policy/policy/position-statements/criminal-justice#>
39. Petersilia J: Doing Justice? Criminal Offenders With Developmental Disabilities. Berkeley, University of California, Berkeley, California Policy Research Center, Aug 2000
40. McDermott BE: Developmental disabilities; in *Oxford Textbook of Correctional Psychiatry*. Edited by Trestman RL, Appelbaum KL, Metzner JL. Oxford, United Kingdom, Oxford University Press, 2015
41. Callahan L, Pinals DA: Challenges to reforming the competence to stand trial and competence restoration system. *Psychiatr Serv* 2020; 71:691-697
42. Wall BW, Christopher PPJ: A training program for defendants with intellectual disabilities who are found incompetent to stand trial. *J Am Acad Psychiatry Law* 2012; 40:366-373
43. Pinals DA: Where two roads meet: competence to stand trial restoration from a clinical perspective. *N Engl J Crim Civ Confin* 2005; 31:81-108
44. Our Initiatives: Criminal Justice. Washington, DC, The Arc, 2021. <http://www.thearc.org/NCCJD>
45. Impact: The Justice System and People With Intellectual, Developmental, and Other Disabilities. Minneapolis, University of Minnesota, Institute on Community Integration, 2017. <https://ici.umn.edu/products/impact/301>