



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Redress the Fracture

Establish a Mental Health Acuity Rate

“It is now widely accepted that people with IDD experience the full range of psychiatric disorders as people without IDD.”¹

For decades families and providers with firsthand experience, maybe a little exposure to mental illness and a dose of empathy, bore witness to the depression, anxiety, trauma, and psychosis of the people they cared for and about. They may not have had the language to name it and maybe they were dismissed when they did; they knew. In a recent essay by author and father, George Estreich shares, “Most of what I had come to learn about Down Syndrome and disability was not common knowledge, and what was commonly believed was often false and poisonous.”²

But the research process takes time, and the historical lack of urgency and resources needed to analyze the IDD population probably added to the wait. We are pleased the time has arrived.

Under the previous conceptualization that people with IDD could not have co-occurring mental health conditions, challenging behaviors³ were attributed directly to a person’s disability.⁴ Recent terminology has shifted away from this label in recognition that norms are culturally situated, and that behavior often serves as communication.⁵ This understanding has led to the debate about the relationship between behavioral support needs and mental illness⁶ in people with IDD. Various research concluding that the diagnosis of Autistic Spectrum Disorder

¹ Gomez, L., Navas, P., Verdugo, M.A. Tassé. Empirically Supported Psychological Treatments. The Challenges of Comorbid Psychiatric and Behavioral Disorders in People with Intellectual Disability. *World Journal of Psychiatry*. November 19, 2021. www.wjgnet.com/2220-3206/full/v11/i11/1039.htm.

² Estreich, George. Concision. A Spread. *The Best American Essays of 2023*. 2023 P. 87

³ Painter, J, Hastings, R. Ingham, B., Tevithick, L, Roy, A. Associations Between Mental Health Problems and Challenging Behavior in Adults with Intellectual Disabilities: A Test of Behavioral Equivalents Hypothesis. *Journal of Mental Health Research in Intellectual Disabilities*. 2010. In this article, Challenging behaviors (CB) were defined as culturally abnormal behaviors that posed a risk to the individual’s safety or ability to interact with the community. www.tandfonline.com/doi/full/10.1080/19315864.2018.1431747

⁴ Lineberry, S., Bogenschutz, M., Broda, M., Dinora, P., Prohn, S., West, A. Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities. *Community Mental Health Journal*. February 5, 2023. www.ncbi.nlm.nih.gov/pmc/articles/PMC9899157/

⁵ Friedman, C. Reducing ‘Challenging’ Behavior by Training Support Staff to Promote Dignity and Respect. *Journal of Developmental and Physical Disabilities*. 2022

⁶ Mental illness is a medical condition involving changes in emotion, thinking, and behaviors.

predicted the presence of challenging behaviors whereas diagnosis of mental illness did not,⁷ that problem behavior was more of a challenge to the environment rather than manifestation of pathological process;⁸ or that major depressive disorder is significantly higher in groups with problem behavior.⁹ At this point, research appears to be inconclusive.

While researchers continue to tease out many different causal agents ranging from organic conditions, psychiatric diagnosis, environmental factors, or a combination, providers on the ground must minister to individuals in crisis. Tragically, for those whose behavior is a manifestation of a pathological process, New Jersey's additional services provided under Behavioral Acuity may help with a symptom but not with proper treatment. One needs only consider a member of the IDD population with a serious mental illness (SMI) who repeatedly damaged property, attempted to elope and begged to be readmitted to an institution, despite provider's orthodox continuation of an approved behavioral plan and state staff's insistence that it is all behavioral. For too many in this subgroup interventions are either insufficient, incorrect, or beyond the capabilities of agency staff. Then there is the cohort of individuals with SMI who do not exhibit enough or any behaviors to warrant an acuity factor by the NJCAT and subsequent resources. Support coordinators report that for this subgroup "resources are terrible" because mental health professionals don't understand the IDD population, forcing the support coordinators to take on the role of intensive case manager, for which they are unequipped and unqualified. In 2021, there were an estimated 14.1 million adults aged 18 or older in the United States with SMI. This number represented 5.5% of all U.S. adults.¹⁰ Though we do not know the percentage for the IDD population, we work under the assumption that the percentage of SMI in IDD is equivalent to that of the public at large.

We are pleased that the state is reviewing the NJCAT, implementing a START program, and funding 3000 DSPs to be certified through the National Association for the Dually Diagnosed Competency Based IDD/MI Dual Diagnosis Direct Support Professional Certification Program. As we have advocated, it is our hope the NJCAT will be improved to be complex enough to accurately identify and assess individuals at risk so that the appropriate number of resources will be allocated for the individual's life choices and needs.¹¹ NJ's START program will be administered as pro-active clinical services to prevent escalation and the need for hospitalization in IDD with co-occurring mental health challenges. Clinical knowledge and interventions will be passed on to the NJ START program's 6 clinicians which will eventually circulate into the system.¹² The two-year pilot certification program will reinforce the mental health care provided by self-directed and provider agency workforces.

⁷ McCarthy, J. Hemmings, C., Kravariti, E., Dwarzynski, K., Holt, G., Bouros, N., Tsakanikos, E. Challenging Behavior and Co-Morbid Psychopathology in Adults with Intellectual Disability and Autism Spectrum Disorders. *Research in Developmental Disabilities*. March-April 2010. www.sciencedirect.com/science/article/pii/S0891422209001711

⁸ Baudewijns, L., Ronsse, E., Verstraete, V., Sabbe, B., Morrens, M., Bertelli, M. Problem Behaviors and Major Depressive Disorder in Adults with Intellectual Disability and Autism. *Psychiatry Research*. December 2018. www.sciencedirect.com/science/article/pii/S9165178117318917

⁹ Ibid 2018

¹⁰ National Institute of Mental Health <https://www.nimh.nih.gov/health/statistics/mental-illness#:~:text=In%202021%2C%20there%20were%20an%20estimated%2014.1%20million%20adults%20aged,5.5%25%20of%20all%20U.S.%20adults.>

¹¹ ABCD White Paper., Updated., September 2023. New Jersey Comprehensive Assessment: A Review www.abcdnj.org

¹² START trainers will be active in the state for 4 years.

Upon consideration of the aforementioned and the recently instituted behavioral health stabilization homes and beds thanks to this administration, we pause to take stock of how far we have come in the last few years and in the next few years how far we may be.

Nonetheless, we continue to press for accessible proactive and preventative social and environmental support and interventions (low need, low cost) to enrich the day and residential environments be widely available. ¹³ Additionally, Waiver services must be expanded to include psychological interventions with empirical support for people with IDD, which include not only ABA but Cognitive behavioral therapy, mindfulness-based therapy, mindfulness-based positive behavior support, compassion-focused therapy, dialectical behavior therapy, acceptance and commitment therapy¹⁴ in addition to a support brokerage for mental health option, available on an as-need basis.

Create a Rate for what is Happening and For What Needs to Happen

“Stigma and ignorance about IDDMH created a fractured system that has been a driver for failed care and negative outcomes.”¹⁵

The structural discrimination against individuals with IDD and co-occurring mental health conditions must be replaced through the creation of a mental health acuity rate and related services. Funding a higher rate will encourage and enable residential and day program providers to work for and with these individuals who must live with a chronic condition while specialized support brokerage can assist those living with family or on their own, outside of programs. These steps will also enhance true prevention and real recovery efforts which require continuity of care from the people who are there for the long haul – family, informal caregivers, and providers.

¹³ Examples include education about mental illness, substance abuse, and sexual abuse, support groups on bullying and conflict resolution, requiring all staff to be versed in trauma informed care.

¹⁴ Ibid. Gomez (2021) p. 6

¹⁵ Zisman-Ilani, Y. The Mental Health Crisis of Individuals with Intellectual and Developmental Disabilities. *Psychiatric Services*. March 1, 2022.