



Alliance for the Betterment of  
Citizens with Disabilities

---

Empowering People: Providers Shaping Policies

**Developing a System of Mental Health Care for Individuals with Intellectual and  
Developmental Disabilities**

November 2020

Despite the prevalence of mental health conditions for individuals with intellectual and developmental disabilities, New Jersey's person-centered system of care does not adequately provide mental health programs and services for the individuals they serve. It is therefore incumbent upon the New Jersey Division of Developmental Disabilities to develop a service continuum which will help the vast number of individuals who have both an intellectual/developmental disability and mental illness so that they may live and control their lives rather than have their lives continue to be controlled by mental illness. ABCD maintains that there are certain parameters and concepts which are essential for a superior plan of action whether via creation of a pilot program, adoption of an outside model or expansion of the current model of care. The issue is complex; creating a plan that will make a positive difference in people's lives will be no small feat. Though there is no clear path, a good place to start is with what we know.

**The Last and the Least Served<sup>1</sup>**

The incidence and prevalence of mental health conditions for individuals with intellectual and developmental disabilities is typically two to three times that of the general public.<sup>2</sup> This supports the estimate that between 30-57% of people with intellectual and developmental disabilities also experience mental health challenges.<sup>3</sup> Despite the frequency of individuals with intellectual and developmental disabilities having mental health conditions, this concurrence has often been misdiagnosed, understudied and undertreated. Possible explanations for this include:

- For years the common thought was that you had to have a certain intelligence level to have a mental illness; that individuals with intellectual and developmental disabilities didn't have a high enough IQ to get depressed or to experience trauma.<sup>4</sup>

---

<sup>1</sup> Beasley, Joan B. *An Overview of START with Dr. Joan B. Beasley*, (Institute on Disability/UCED, University of New Hampshire, 2016.) Webinar at [www.centerforstartservices.org](http://www.centerforstartservices.org)

<sup>2</sup> Ibid.

<sup>3</sup> Nicholson, D., Calhoun, A., McLaughlin, A., et al. *Care Experiences of Adults with Dual Diagnosis and the Family Caregivers*. (Global Qualities Nursing Research, 2017) *Jan-Dec: 4:2333393617721646, 1-2.*

<sup>4</sup> Beasley, *Overview of START*.

- Behavioral issues in people with intellectual disabilities were most often viewed as a function of their cognitive impairment rather than a symptom of an underlying mental health problem. It did not occur to clinicians that there might be an additional diagnosis, so they did not think to look for other explanations for behaviors.<sup>5</sup>
- A diagnosis of intellectual or developmental disability often overshadows the mental health issues so that the condition goes unrecognized.<sup>6</sup>
- People with intellectual and developmental disabilities experience trauma, including abuse and neglect, at higher rates than the general population and are at increased risk of developing more severe post-traumatic stress symptoms than people without intellectual and developmental disabilities when exposed to the same traumatic event (Texas Health and Human Services). Trauma responses are often mistaken for willful noncompliance or lack of motivation.<sup>7</sup>
- Mental and substance use disorder treatment providers may underestimate the barriers of accessibility to their programs or they may have specific exclusion criteria for some people with disabilities.<sup>8</sup>

“Immune,” unnoticed, overlooked, minimized and excluded; whatever the reason(s) the personal, familial and societal suffering and loss is immeasurable.

## The Cause of What Ails You

### The Need for Visual Literacy in Diagnosis

Diagnosis is often defined as both an art and an act of identifying a condition or disease. One’s diagnosis is the linchpin for one’s treatment, the medicines one takes and the services one receives. Nothing happens without it, but if it is wrong nothing else done by a doctor or clinician can ever be fully right. Because clinicians were slow to recognize the role of trauma in this incredibly vulnerable population, many people with intellectual disabilities were given other psychiatric diagnoses and prescribed psychoactive medication that served to sedate them and not treat them. Concluding that symptoms are attributable to cognitive impairment rather than mental health issues, resulted in an over-reliance on behavioral strategies rather than an array of treatment modalities. The ability to carefully observe and assess individuals without these long-standing misconceptions, is fundamental for mental wellness. If we wish to better serve individuals with I/DD who have mental health disorders, doctors, clinicians and providers must learn to see through the bewildering array of physical, cognitive and behavioral information to accurately read and interpret what is truly before them.

---

<sup>5</sup> Solomon, Andrew. *The Reckoning. The Father of Sandy Hook Killer Searches for Answers.* (The New Yorker Magazine, March 17, 2014) [www.newyorker.com/magazine/2014/3/17/the-reckoning](http://www.newyorker.com/magazine/2014/3/17/the-reckoning).

<sup>6</sup> Evans, Ike. *Trauma Informed Care and Intellectual and Developmental Disabilities.* (Hogg Foundation for Mental Health, 2017). [www.hogg.utexas.edu/trauma-and-idd?](http://www.hogg.utexas.edu/trauma-and-idd?)

<sup>7</sup> *Mental and Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities.* (SAMSA Advisory, 2019). HHS Publication No. PEP19-02-00-002.

<sup>8</sup> *Ibid.*

## Defining the Terms

Behavioral and mental health and supports are often viewed incorrectly as synonymous. Clearly, we run the risk of doing more harm than good if the problem is framed inaccurately.

**Behavioral Health Disorder.** Characterized by unhealthy habits and involve patterns of disruptive behaviors.

**Mental Health Disorder (Illness).** Medical condition involving changes in emotions, thinking, and/or behaviors.

**Behavioral Supports.** Supports which focus on improved quality of life as well as redirection of the behavior. Supports are individualized, positive, emphasize learning, offer choice and social integration, are culturally appropriate and include modifications to the environment, as needed.

**Mental Health/Clinical Supports.** Supports which protect and preserve the mental health and wellness mainly through prevention and treatment of the psychiatric disorder. To effectuate clinical treatment, it is not enough to simply modify the behavior.

## Treatment

### Customized Care Model

The care model must incorporate what we know to work and what we value. This translates into a customized model which integrates public health, biopsychosocial/interdisciplinary and person centered/wellness-based models of care.

**Public Health Model** – Full continuum of evidenced based services with an emphasis on prevention and proactive identification of secondary condition(s).

**Biopsychosocial/Interdisciplinary Model** – Integration and coordination of services, care and supports for the whole person.

**Person Center/Strength and Wellness Based Model** – Consistent with DD care values which are to engage and build trust with the individual.

## Pitfalls to Avoid

- Resist defining the need for mental health services as only a crisis requiring emergent and acute care. This narrow paradigm assures that we will fail to not only see the scope of the problem but also envision and enact meaningful solutions. This is not to imply that acute care is not under resourced and inadequate, it is. Because services in this part of the treatment continuum are expensive, inflexible and limited, prioritizing them at the expense of all else, will create a core problem of insufficient resources to treat demand downstream (where there are more and cheaper options) which inevitably leads to an increased demand for emergent services. Lather, rinse, repeat. As a result, instead of helping people with mental illness live and control their lives, we create a system where they are controlled by the mental illness.
- Resist squeezing individuals with I/DD into the current mental health care system. For the most part, mental health providers do not have experience with the DD population and equipping them to do so would require massive amounts of time and resources. Compare this to the current IDD system of providers who not only have life-long professional experience and relationships but borne out of necessity and desire, have already integrated behavioral and mental health services into day and residential programs and services. Better to reinforce, deepen and make universal that which organically exists than relocate and build from the ground up (that which does not exist).
- Resist the temptation for simplistic and invariant solutions. People with IDD are a heterogenous community and there is no one method that should be prescribed for any one problem. By way of example, neither behavioral modification nor medication are the only legitimate therapeutic interventions. If we compel a person to participate in a certain intervention before we fully understand their problem, we may make matters worse rather than better.

## Some Starting Points

- Consider the implementation of core/universal interventions which would be available to most people. Interventions are preventative and proactive (low need, low cost) and would serve to enrich the day and residential environments. 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. (The DD population is often referenced as a traumatized population having experienced physical or sexual abuse or other trauma.
- Support provider efforts to provide evidenced based practices.
- Increase the supply of DD clinicians who specialize in mental health services and care in order to increase accuracy of diagnosis and effective and meaningful interventions.
- Acknowledge the importance of and that there are no alternatives to in-person consultation.
- Focus on access and supports such as respite beds and in-home supports both before a possible acute episode and after an actual episode.