



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

New Jersey Comprehensive Assessment

A Review

Updated September 27, 2023

To Include Addendum

Summary

An evaluation of supports needs is fundamental to the individualization, design, and provision of services to people with intellectual and developmental disabilities (I/DD). To the extent that the support provided are aligned with their needs, objectives and desires, the person's quality of life will be enhanced and their rights as citizens, enforced. In NJ the assessment process must capture all the influential variables to not only plan but also allocate resources for the individuals life choices and needs. ABCD believes that certain improvements should be considered since the instrument is no longer just tied to service needs but to resource planning. More than ever before the NJCAT is central to the life of the individual in the community.

In New Jersey, individuals are assessed when applying for Division eligibility and when an individual or their guardian request a reassessment for their level of care and ongoing needs for services using the New Jersey Comprehensive Assessment Tool (NJCAT). This single assessment tool designed in 1999 initially included both the Functional Criteria Assessment and the Developmental Disability Resource Tool (DDRT) which were gradually phased out over time so that the NJCAT was a stand-alone assessment. In 2013 as part of the Community Care Waiver Renewal of that same year which collapsed multiple Medicaid waivers into one comprehensive waiver and transitioned services from contract-based to fee-for-service, in addition to planning, the allocation of resources was now based on the support needs established from the NJCAT.

The NJ Department of Human Services, Division of Developmental Disabilities (DDD) stipulated that the rate study and resulting standard fee schedule must be complex enough to address the needs of all individuals, robust enough to accommodate the full range of service needs presented by the individuals, and simple enough to be administratively feasible. ¹ Johnston, Villegas-Gibbs, and Associates (JVGA) through cost impact analysis, modeled the rates and determined that 5 (expanded to 6 in 2019) base tiers were necessary each with an acuity factor that would be established through the NJCAT.

Seven years following NJ's major system change from a contract-based to fee-for-service system, enough time has elapsed for the quality of the NJCAT to be measured for its validity, reliability, and absence of bias. Though providers believe the NJCAT is simple and expansive, there are three issues mentioned ad infinitum at the mention of "NJCAT."

¹ Standard Fee Rate Setting FAQ 2013

Validity

“The NJCAT largely disregards behavioral/mental health/dementia issues as a driver for additional care needs. That is why people who are otherwise independent but have serious mental health concerns are tiered in A or B with no acuity.”

It is estimated that 30-57% of people with I/DD experience mental health challenges.² Despite this frequency, many mental health professionals don't recognize mental health symptoms in I/DD, people with I/DD are unlikely to access mental health centers in the community and end up in crisis centers and emergency rooms, and the workforce is not prepared to serve them.³ In NJ, some ABCD support coordinators report that individuals who may have mental health issues either do not have an MMCO care manager for mental health or, if they do, their existence is not apparent to those who develop the plan of care. In addition, because the annual Mental Health Pre-Screen Checklist is completed by the support coordinator who are not diagnosticians, some may be uncertain and uncomfortable making referrals that may prove unnecessary in an overtaxed mental health care system. (This is especially problematic when there are no other respondents completing the NJCAT other than the individual and the support coordinator.) During assessments, symptoms are not set up to be discussed and, as a result, may be viewed as merely behavioral challenges, overlooking possible underlying causes such as trauma, depression, dementia, and psychosis. Far too often, people independent with their ADLs but with trauma and mental health issues which lead to a high frequency of problem behavior are not scored accurately.

For mental health services and supports to be embedded on a systemic level to ensure that I/DD population has access to services along the continuum from promotion and prevention to treatment and rehabilitation, the NJCAT must be used to identify individuals at risk. To this end, consider the following:

- Establish flags within the NJCAT which will trigger professional screening for mental illness. The screening tool could be modeled after the NJDHS Level I Pre-Admission Screening and Residential Review (PASRR) used during nursing home admissions.
- Through the NJCAT assessment process, if an answer indicates that the person has a diagnosis for mental illness and/or has been seen by a psychiatrist/psychologist in the last 3 months, additional questions must be triggered for the purpose of helping to elaborate on the extent of the mental illness and services provided. This is necessary because many people with I/DD are misdiagnosed and underdiagnosed for mental illness, additional questions could trigger the need for a new diagnosis and/or additional services. At minimum, this probing could better inform service providers in planning with the individual.
- The MMCO MH care manager must be made apparent and required to participate in the planning team process.
- A mechanism to identify secondary trauma and access treatment to help caregivers deal with the challenge of living with and caring for someone with I/DD and mental illness.

Many social barriers have been decreased for people with I/DD. But there is more that must be done for them to become independent and involved in the world.⁴ Good mental health is important to be able to be engaged in the community; I/DD must have the tools and information to make healthy choices know how to prevent illness. What better time than when they enter the adult system through the NJCAT?

² Nicholson, Calhoun – ABCD MH paper

³ ANCOR p 3

⁴ www.cdc.gov/ncbddd/disabilityandhealth

Reliability

The system is not transparent. We know neither the questions nor the scoring factors.

An assessment tool which is available and employable to all stakeholders builds engagement and trust. Transparency and operability ensure that everyone involved in the process, the individual, the guardian, family members, support coordinator and provider can easily understand, monitor, and evaluate expectations, needs and outcomes. Providing more opportunities for open dialogue between parties and improving accountability results in increased confidence in the system and better outcomes for the individual.

There is very little consistency across facilitators. As a result, the NJCAT findings are inconsistent; people with very similar support needs are put into different tiers and acuties.

The DDD policy is a good one. According to the DDD website, a trained Division facilitator will schedule a face-to-face meeting (virtual during COVID 19 pandemic) with the individual and their guardian if they have one. They suggest that it can be helpful to have additional people participate in the meeting who know and spend time with the individual. They explain that the facilitator will use a computer to access the NJCAT online but will ask questions out loud. The individual and the meeting participants can talk about the questions and the facilitator will enter the answers based on the consensus of the group.

Having a uniform group of facilitators employed by the State to do NJCAT assessments and reassessments is optimal as it will maximize consistency and be a guardrail against participant conflicts of interest.

Nevertheless, we constantly hear complaints from agency staff that the results are inconsistent. They tell us of:

- Families who say they “need an Ea” and do their best to answer NJCAT to ensure that their loved one will secure the highest paying tier.
- Facilitators who do not remind family/guardians of the supports that have been put in place by redirecting them to answer as if the person was living alone or with no staff support.
- Look backs which do not span enough time to accurately reflect the intermittent but consequential behaviors and/or medical needs of the individual.

If the above are indeed systemic issues and weaknesses, they would be minimized with quality indicators like initial and ongoing trainings for and supervision and oversight of facilitators, process, and outcome measures (including documentation of discussion supporting conclusions), feedback and individual involvement, and audits to ensure the accuracy of the tier determinations.

It is one thing if quality indicators exist, and providers are incorrect. But if providers are correct that there are systemic inconsistencies, these variances can contribute to wastefulness and inadequate resource allocation. When we provide too much in the way of support we can get in the way of the person’s personal growth as well as deplete limited resources for those who truly do need them. When we provide too little, we limit the person’s opportunity to be fully actualized.

Absence of Bias

We need to do more to ensure that answers flow from the individual.

Techniques and interventions to help facilitators discover the true desire(s) of the individual in addition to quality indicators which observe the process, access feedback and measure individuals' involvement would seem to be the best way to assure and ascertain the absence of bias.

We can't turn away from an individual who communicates differently because they communicate differently.

September 22, 2021

Addendum

Increase Education, Awareness, and (Self) Compassion.

- Parents and guardians report difficulty differentiating between the treatment model, which is strength based, and the assessment, which is needs based.
- Individuals report and are observed to feel hurt and ashamed when having to admit to what their needs are; what their “worst day” requires from support staff and family.

Maximize Communication

- Facilitators must remain impartial and converse with all parties.
- Each section of the assessment must provide an opportunity for comment, elucidation, and clarification.
- Create a new section dedicated to increasing or decreasing support and services due to status changes.
- Communication and assessments must increase during the aging process.
- A response timeframe must be created. Denials must be communicated to the individual, guardian, and provider. An appeals process must be created providing stakeholders with the opportunity to submit additional information.

Individual Programs that Support the Individual aka Anticipating, Minimizing and Preventing Problems/Crises

- The system should Incentivize prevention and avert crisis. Providers shouldn't be punished financially for developing protocols, interventions and programs which support the individual and minimize obstacles to a full life in the community.
- Medical and behavioral acuity require different interventions, yet individuals with both acuities only get paid for an (one) acuity level. The system should desist from disincentivizing care for people with the most complex needs.
- Just because something didn't happen in the last 3-6 months, doesn't mean that it can't happen again immediately or overnight. The provider's prevention measures should be considered.

Accounting for Multiple and Unique Factors that May Interfere with a Persons Day/Life

- The assessment must recognize the difference between mental illness and behavioral issues.
- Mental illness must be factored into the assessment. Currently there are a mere 3 questions which pertain to mental illness on the sample NJCAT.
- Just because someone is able, doesn't mean that they are willing. A person's free will, consciousness and/or mental illness, are factors that must be considered.
- The assessment must look deeper than what is obvious.
- Many very independent individuals max out on behavioral needs and supports.
 - The individual may not have been hospitalized but there may instead have been very many 911 calls and filed incident reports.
 - A change in one section can have a domino effect. For example, a person starts wandering due to dementia. Though nothing else changes, but for the wandering, which now requires a 1:1.