

# Striving for Fairness in Funding

## A Closer Look at the NJ Comprehensive Assessment Tool

By Brenda Considine

On its website, the NJ Division of Developmental Disabilities (DDD) makes clear that Division-funded services for adults with intellectual and developmental disabilities are *not* an entitlement and are dependent on resource availability.

Those last few words are worth repeating: ***“dependent on resource availability.”***

Each year, the New Jersey legislature distributes state funds, along with any federal dollars, to state agencies to carry out their work. For DDD, that means roughly \$1.8 billion in state and federal funds. With limited resources, and a “funding pie” that is not growing as fast as the need for services, how does DDD decide who is eligible for services and how much funding each person gets?

### **Determining Eligibility. Determining Need.**

The New Jersey Comprehensive Assessment Tool (NJCAT) is a mandatory assessment used to determine eligibility for DDD-funded services. It assesses an individual’s support needs in three main areas: self-care, behavioral, and medical. The NJCAT is a 30-40 minute questionnaire completed by parents and caregivers either online or over the phone with a representative from the Developmental Disabilities Planning Institute (DDPI) at Rutgers University. There is no paper version of the assessment tool, and once submitted, respondents cannot go back to make changes.

Responses to the NJCAT produce a score that DDD uses to establish a funding tier for an individual budget or to determine the reimbursement rate a provider will receive for that individual’s services.

According to Jonathan Seifried, Acting Assistant Commissioner of the Division of Developmental Disabilities, (DDD), the NJCAT helps achieve two significant goals: providing individuals with the services they need and ensuring consistency across the service delivery system.

“The tool is a standardized assessment that ensures individuals with similar support needs have access to similar services. It also is intended to simplify the process by streamlining multiple assessments into a single tool,” he said.

### **Completing the NJCAT: “You really have to know what you’re doing.”**

Lisa Weissbach-Efrat, a licensed clinical social worker from Camden County, recently completed the NJCAT for her 17-year-old son, who is non-verbal. She describes him as “on the severe side of the spectrum,” with significant challenges in self-regulation. He has also has dual diagnosis of bipolar and pica, a disorder in which a person eats non-food substances with no nutritional value (i.e. wood, clothing, dirt, paper, chalk, drywall.) She believes the NJCAT score he received accurately reflect his needs, but admits that her professional experience helps when filling out such forms.

“Somebody with less experience would be at a significant disadvantage,” she said.

Although she is satisfied with the process and the results for her son, she is critical of the NJCAT.

“With someone who has intellectual disabilities or mobility issues, it is clear what they can and cannot do. For someone with autism, they may be *able* to do a task, but won’t. Or they may

need to be prompted or need to be redirected to do it. I had to use the ‘other’ and ‘comments’ section extensively in order to paint a clear picture of my son and the issues that we face,” she said.

Carla Johnson (\*) was also satisfied with the results of the NJCAT. A professional in the field of special education, she talked to other parents before she completed the survey for her 24-year-old son with Down syndrome.

“You really have to know what you are doing when you fill it out,” she said. “It does not assess what happens if the person is left unsupervised. The question should be: ‘If left alone in the house, how long would it take for them to get into trouble,’” she joked.

Jolene Miller (\*) also works in the field of special needs. Her child with Down syndrome recently transitioned into the adult system.

“The problem with the NJCAT is that families do not understand the questions. The questions ask for ‘yes’ or ‘no’ answers. I would like to see more room for families to explain their answers

so that professionals can gain a clearer picture of the person in need,” she said.

She also thinks the online process is flawed and especially hard for families who do not have access to a computer.

Oscar Wright (\*), a parent, believes that the questions are too general and parents do not understand how to properly answer.

“They ask a question like ‘can your child dress him or herself?’ The answer is ‘yes’ but with help. The NJCAT doesn’t allow me, as a parent, to explain that my child can dress himself only when I provide the clean clothing and fix their buttons or zipper. The question would be better stated ‘Can your child independently purchase and wash their own clothes and then dress themselves on a daily basis?’” he said.

For some families, the problems were not with the NJCAT, but with the system itself. Denise Buzz is the guardian for her 55-year-old sister, Angelique. Her difficulties came *after* her sister was assigned a budget of more than \$212,000 per year.

## TIPS ON COMPLETING THE NJCAT

**1) Imagine your child lives in his or her own apartment where you visit once a week. During your visit you ensure your child showers, brushes his or her teeth, and puts on clean clothes. You also make sure the laundry is done, meals are prepared, and the apartment is clean. You leave and return one week later—What do you find?**

- Has your child showered?
- Brushed his or her teeth?
- Is he or she wearing clean clothes?
- What does the apartment look like? Is it clean?
- What has your child eaten? Is there food in the refrigerator?
- What has your child been doing?

**The answers to these questions will help you assess your child’s self-care, independent living, and self-direction skills. If your child cannot perform these tasks without your intervention, prompting, directions, and assistance; then your child needs lots of assistance with these tasks. Be sure your responses on the questionnaire make this clear.**

- Think of your child on their worst day.
- Do not take into account the growth your child may have experienced over the last few years.
- Compare your child to a typically developing person of the same age. This form is often completed when your child is 21 years old. A typically developing 21-year-old may be living completely on their own or living in a dorm at college.

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“I found the NJCAT to be useful and easy to use, but now that the budget is allocated, DDD won’t let us use it. When we asked for a new hospital bed for my sister, they said no, even though we have \$110,000 left,” she said.

Daniel Szyper has had a similar experience. Daniel has Asperger’s syndrome, as well as psychiatric and medical challenges, including obesity and insulin dependent diabetes. He lives at home with his mother. Daniel is pleased with his budget for day services—\$32,000—but says the money exists only on paper.

“Right now, the only thing the DDD is funding is my gym membership,” he said. “I need housing—my mother won’t be around forever,” he added.

His mother, 78 year-old Mira Szyper, is frustrated and frightened because she has no family to care for Daniel when she is gone. When she completed the NJCAT for Daniel, she found it hard to understand.

“You have to know how to answer these questions,” she said. “They asked, ‘can he eat independently?’ and I said yes, but later, I found that the question means something different. The truth is this: he can eat, but he cannot plan his meals, shop for his meals, cook his meals, and clean up,” she said.

“Why can’t they sit down with us to ask the questions and explain things to us?” she asked.

In nearly half of the states in the nation, that is just what happens.

### **Another Way To Assess Need: Supports Intensity Scale**

Currently, 23 states, the District of Columbia, and three Canadian Provinces use the Supports Intensity Scale (SIS). Like the NJCAT, the SIS is a tool designed to evaluate the support needs of a person with an intellectual disability. Unlike the NJCAT, the SIS is a structured interview process administered by a trained professional in the human services field with a 4-year college degree. The interview takes about 2.5 hours. And unlike the NJCAT, the SIS is tested and nationally ‘normed’ so that there is fidelity in the instrument. In fact, the SIS is the only standardized norm-referenced tool that looks at support needs.



*Mira and Daniel Szyper at their home in Kendall Park, NJ.*

Margaret Nygren, Ed.D., Executive Director of the American Association on Intellectual and Developmental Disabilities (AAIDD), acknowledges that there are plenty of what she calls ‘home grown tools’ that attempt to do the same thing as the SIS.

“You need a tool that has been *normed* so that you can look at the score and know how this person compares to others in the same population. A lot of these ‘home grown tools’ have limitations because they are not normed,” she said.

“We don’t just give it to parents and tell them to fill it out,” said Dr. Nygren.

“The SIS assessment brings people together. Several people have to be interviewed, and ideally the individual himself or herself. It is labor intensive,” she added.

“By using a structured interview process, and having a test administrator who makes sure parents understand the questions and the process, there is less chance for error, and less chance to ‘game the system,’” she said.

The result is an accurate picture of someone's support needs.

## A Score is Not a Budget

SIS scores—or any assessment scores for that matter—do not set the budget for the individual. States do.

“States set the budget, based on how much the state is interested in spending and the number of people they have to spend it on,” Nygren said.

She sees states using the SIS as part of a larger system change.

“States often have a legacy system with some glaring inequities in the ways in which resources are allocated. They do not have more money to spend, but they want to spend it more equitably. Since they cannot make the pie any bigger, they want to be fairer in the way the pie is sliced,” she concluded.

Indeed, the NJCAT came into use as DDD was shifting to a fee-for-service model, and was looking to increase fairness and equity in the allocation of limited resources.

Dr. Daniel Keating, Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD) was part of a New Jersey task force that recommended the use of the SIS. In spite of the task force recommendations, DDD opted to use the Developmental Disabilities Resource Tool, (DDRT), a predecessor to the NJCAT.

“The problem with the NJCAT is that there are no independent standards of validity. We don't know for sure that it measures what it says it does, and we don't know about its reliability,” said Keating.

“This is where the SIS is better—you have to be trained to use the tool and you are objective. When there is no objective criteria, you end up with a lot of variation based on who fills out the form,” he added.

“I realize a different process would be expensive, but we have to recognize that the current process is flawed,” Keating concluded.

While no tool is perfect, Siefried believes that with the right training and support, the NJCAT assessment gives DDD the information needed to best assess an individual's needs.

“Where families or providers have questions in completing the assessment or believe a

reassessment is necessary, we are happy to provide assistance,” he stated, adding that DDD remains open to future improvements.

## Navigating the NJCAT

Maria Fischer, Esq is the mother of a 25-year-old daughter who receives services from DDD, and an attorney who specializes in disability law. Every year, she and her colleagues at Hinkle, Fingles, Prior & Fischer, Attorneys at Law, handle scores of cases for families who believe the NJCAT failed to adequately capture the needs of their son or daughter.

“I am a mom so I know how parents set their child up for success by providing ‘invisible supports.’ We do things that enhance independence without even realizing it,” she said. “If questions were framed differently and parents were given

### (\* ) “PLEASE DO NOT USE MY NAME.”

Nearly a dozen families were interviewed for this story; roughly half asked that their names not be used. Carla Johnson, Jolene Miller, and Oscar Wright are pseudonyms used because the parent/caregiver asked that *P&F* keep their names private.

- “I work in the field and I am afraid I could lose my job if my name was made public. It would not look good for my employer,” said Jolene Miller.
- “Parents don't want their names used because we are totally vulnerable to a system we don't understand and that our children depend on for their lives,” said Carla Johnson. “My son finally has a great program and great supports. I would not want to risk it.”
- “People are afraid of the system. We do not want retaliation,” said Oscar Wright.

When asked about these comments from families, Siefried emphasized that the Department of Human Services does not tolerate retaliatory behavior.

“We encourage families to communicate concerns to the Department and in fact individuals and families routinely request reassessments by the state,” added Seifried.

better instructions, the NJCAT would do a better job at capturing need,” she said.

Fischer believes that when completed correctly, the NJCAT forces parents to confront the degree of disability their child faces.

“They have to answer all the questions as if their child were typically developing. They have to ask: would a typical 21-year-old really need the help I am providing?” she said.

Like many parents, Fischer believes the NJCAT fails to capture deficits around judgment and decision-making

“There is not a single question about responding to an emergency. The NJCAT does not fully assess the ‘supervision piece’ of things. They may not need a lot of services—but what happens when something goes wrong?”

Fischer knows first hand what happens when families do not know how to answer the questions.

“Families who fill the form out badly get very low scores and as a result, they get very low budgets for their child, some as low as \$19,000 for a day program—a person with that budget cannot even go to a day program every day,” she said.

She also said that the person can be deemed not to have substantial limitation, and that may require an appeal—a process that can take more than a year and often requires legal assistance.

Families and individuals have the right to appeal. It is the process where a person requests a formal change to an official decision. The person

making the request must do so in writing, usually within a certain time frame. In most cases, submitting additional or new supporting documentation when requesting an appeal is required.

When faced with an unfavorable decision, the first step is to contact the person, district, or agency directly. If you’re not satisfied with the result after going through a review process or re-evaluation, you may submit a complaint, and request a reconsideration or a mediation. If that doesn’t resolve the problem, you can file an appeal or due process. (See the resources section for more details)

DDD will consider a request for NJCAT reassessment only for individuals who have an assigned Support Coordinator, and a completed Person-Centered Planning Tool (PCPT) and Individualized Service Plan (ISP). The link to the form is in the resources section of this article.

In some instances, the appeal is well worth it. Fischer recently handled a case in which the individual’s case manager completed the form and indicated that the person had no behavior problems, but the individual had a history of significant behavioral challenges over the course of years. Based on her advocacy, the individual went from a budget of \$117,000 to \$317,00, an increase of \$200,000.

“Parents fill out many forms, but they will need help and guidance as they complete the NJCAT. It is one of the most important forms they will ever fill out for their child,” she concluded. **P&F**

## RESOURCES

**The Arc of New Jersey has recently launched a “DDD Eligibility ‘Go Bag’”. It describes, step-by-step, the process for DDD Eligibility and includes information about the NJCAT and the appeals process.**

<http://www.thearcfamilyinstitute.org/resources/dddgobag.html>

### **NJCAT - Q&A**

<http://www.state.nj.us/humanservices/ddd/resources/njcat.html>

### **Webinar on How to Complete the NJCAT**

<https://www.youtube.com/watch?v=nluCSO5kFWk&feature=youtu.be>

### **How to file an appeal with DDD**

<http://www.state.nj.us/humanservices/ddd/documents/ddd%20web%20current/CIRCULARS/DC37.pdf>