News Blast

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NYSELFD has continued to hear concerns from families who have participated in a CAS assessment. To attempt to get useful data, we put together a brief survey using survey monkey.

Here's the introduction we sent with the survey:

> The Comprehensive Assessment System (CAS) is a new tool being used by OPWDD to measure the type and intensity of supports that people need. Is it working? If you've participated in a CAS, please take this very brief survey, and tell us!

The survey was distributed by parent groups (not just groups associated with self-directed services) around the state over a period of about two weeks in early May 2018. **89 people responded**.

Background

The Coordinated Assessment System (CAS) was recently introduced by OPWDD. With OPWDD Waiver services being bundled into the State's 1115 waiver, and the move to managed care we understand the need for a consistent, computerized assessment that can be integrated with the rest of the State's database. As described by Acting Commissioner Delaney in a letter announcing the CAS Validity Study:

> …the Office for People With Developmental Disabilities (OPWDD) uses the Coordinated Assessment System (CAS) to help us understand the unique health and support needs of the people we serve. Using the CAS, assessment specialists work closely with individuals, families, support and clinical staff to gain a thorough understanding of a person's strengths, needs and desires for his or her life.
>
> OPWDD News and Publications, 10/23/17
> https://opwdd.ny.gov/news_and_publications/commissioners-message-press-release-news/acting-commissioner-delaney-0

Of course, we are also aware that:

> Once the tool is validated, it will be ready for use and will be used to establish acuity measures and ultimately to determine needs-based rates for service provision.
>
> OPWDD Transformation Agreement, January 1, 2014, OPWDD's Self-Direction Policy submitted to the Centers for Medicare and Medicaid Standards, p.9

Assessment drives service allocation, so the CAS will affect both service providers and people receiving services. However**, people who self-direct are the only group whose total Waiver supports and services must fall within a dictated budget; and that budget is primarily determined by their assessment. Therefore, thorough and reliable testing is critical for this group.**

Survey Results

1. A significant percentage of people felt the CAS gave an inadequate picture of the person's needs

Q4. Did the summary give a full picture of your child's needs? For example, were mobility, medical, mental health, behavioral issues all addressed?

Yes	**56.32%**
No	**43.68%**

Almost half of the people who replied believed the CAS did not fully document their child's needs. Even if we assume that people who were unsatisfied were more likely to respond to the survey, this is disturbingly high.

After the Yes/No question above, the survey asked **"What, if anything was left out?"** with a comment box.

Comments fell into several categories, and are bulleted below:

a. Many families believed that the results were incomplete or incorrect.

- When we read the report it didn't sound at all like the info we gave. If we ever do another CAS. I will tape it. The report makes it seem like my daughter is perfect yet she continues to have melt down hurts her self can't hold a job

- My daughter's cognitive disability was greatly understated. Her disability is NOT mild as was reported

- Issues of judgment and incapacitation of absence seizures when they occur

- Sexuality events more than three days prior

- Errors were made. Participant was erroneously marked as convicted of felony assault

- There was incorrect information and was told that I would need to appeal

- Some of his diagnoses were left out

- Dental needs

- Didn’t ask if she could read. She can not. Didn’t ask if she could use her hands. She can not.

- Many questions that were answered on the summary were never even posed in the interview. Apparently the interviewer determined the answers without asking them (which led to many inaccuracies). E.g "Do you find meaning in your life?" Outrageous that interviewer presumed to answer "no" on behalf of my son who would not have responded that way. Additionally, most of the medication information was incorrect even though interviewer was handed a typed detailed list. Too many additional inaccuracies to list here.

- Participant’s behavioral needs were not explored

- Communication issues

b. The three-day time frame limited the ability to get a true picture of the individual:

- Full details on behavioral issues because many questions only wanted answers for last 90 days or last week to my recollection. Found this very frustrating

- The time line requested for medical, behaviors and MH concerns was TOO limited as these needs cycle over months

- I found the narrowing of time frame to last 3 days too tight and could allow for an inaccurate profile of my son

c. The assessor demonstrated a lack of awareness of the effects of the evaluation process on the person being tested

- The length of the questionnaire was too long for a person with a developmental disability, making most answers after they became disinterested irrelevant
- Mental health issues could not be fully discussed in front of the participant due to the agitation that might develop during such a discussion

d. Many families never got results:

- Who knows? The survey was done months ago and I have yet to receive a report
- Never saw a summary
- This assessment was done during the summer of 2017. Mistakes were made in the narrative. Our MSC called the supervisor who said it would be updated. It has not been changed to my knowledge.
- I have never been made aware of the CAS findings.

2. The majority of families were not told what to do if they disagreed with the results

Q6 Were you told what to do if you disagreed with the CAS findings?

Yes	**41.86%**
No	**58.14%**

- Our MSC did not know what to do and said she couldn't change it. We sent a letter to the head of OPWDD and a psychiatrist's letter about our child's diagnoses so they could see what was left out in the CAS.

Analysis and Recommendations

Our (admittedly limited) survey highlighted significant concerns about using the CAS as a tool for assessment, and eventually, rate-setting. Several possible sources of these results are:

1. The CAS instrument as used in this population
2. Criteria for selection particularly, the experience, of assessors.
3. Training of assessors
4. Oversight

<u>CAS Instrument</u>

We have not had access to the CAS instrument, but have reviewed the InterRAI IDD. OPWDD states that:

> In collaboration with InterRAI and stakeholders, OPWDD revised the instrument with language specific to New York State and created five supplements from the InterRAI suite of items (i.e., Children, Forensic, Medical Management, Substance Use and Mental Health) to further identify the needs of people served by OPWDD. The result was the Coordinated Assessment System, CAS
> CAS validity report, OPWDD, p2

It is unclear if the CAS consists of the InterRAI ID in conjunction with already existing InterRAI products, if those have been modified and added, or if these sections were created de novo. We also don't understand how the assessment is scored, so our comments on the instrument are limited.

However, many families have voiced concerns about the three-day limit-especially as pertaining to mental health, behavioral, and some medical issues (e.g., epilepsy). Note: we did not ask this question specifically in the survey, but it came up in several comments

NYSELFD Recommends:
<u>OPWDD should provide evidence that limiting questions about health, safety and behavior issues to the last 3 days provides valid, predictive information in this population.</u>

<u>Criteria for selection of assessors</u>
The Coordinated Assessment System (CAS): Validating the CAS in New York State, October 2017), states:

> The minimum qualifications are: a Bachelor's degree or higher in a Human Services Field; and a minimum of one year, post-education experience

working directly with people with an intellectual and/or developmental disability is one year of experience.

One parent, in a follow up interview of her response, mentioned that the assessor seemed very uncomfortable that her son was nonverbal and went very quickly through those questions, resulting in errors in the summary. One year of working directly with people with an I/DD seems inadequate to acquire all the necessary skills:

NYSELFD recommends:
Assessors should have at least two years of direct experience working with people with IDD, including significant time with adults.

Training of assessors

We would expect this first group to be the most carefully trained and competent. If a significant number of problems with the assessment are caused by inadequate training of the assessors, this doesn't bode well for the future, when the training is not under the direct control of OPWDD.

Oversight

No matter how experienced or well-trained people are, there are bound to be miscommunications: errors in listening, understanding, and recording information. This is to be expected in any interaction, but would be even more likely in a situation where people have never met, and may have significant differences in communication and cognition.

Because of the structure of the assessment, errors in communication could lead to not opening other parts of the test that could amplify the initial error, causing the omission of vital areas of need.

Most alarming is the **lack of established checks or balances for each individual's assessment** (unlike DDP2, where, despite its inadequacies, results could easily be reviewed for accuracy).

With the CAS, the individual assessor is in complete control; there is no mechanism to validate the data for each person. Specifically:

> Families and interested individuals often don't get results of the CAS.
>
> When families do get information, it is only a summary, and may be missing significant information. Just as in the medical sphere, where people are entitled to see all of their laboratory testing and medical records, OPWDD

should allow families and their chosen representatives to review complete results of the CAS.

MSCs (and soon Care Coordinators) get a summary, but as far as we know, they are not required to review it for accuracy and have necessary changes made.

We are not aware of any quality control measures in place that include a re-interview of individuals and people close to them

NYSELFD Recommends

The MSC (CC) should be required to give individuals/families the results of their CAS.

Family, MSC (CC), the individual/ family and others chosen by them, should have the opportunity to review the full results of testing (Note: this would not need to include information about scoring).

OPWDD should develop a transparent grievance process to address complaints of significant disparities between the assessment score and the first-hand knowledge those know the person.

OPWDD should develop a post-assessment feedback survey for participants in the CAS assessment (individual, family members, others) that will result in actionable data to furnish guidance for training improvements and assessing staff. (The current form is extremely vague). People should be able to mail the form in, or complete it online.

Sample questions:

Was the assessment scheduled at a time convenient for the enrollee and family?

Did you feel that the assessor was leading you towards certain answers?

Did you feel that all important aspects of the person's life were addressed?

Were you told what to do if you disagree with the results of the assessment?

OPWDD should establish and make public an ongoing quality assurance monitoring system for the CAS that includes at least a partial re-interview of the individual, family, and/or chosen representative. The choice could be

informed by reports from stakeholders that indicate where problems may exist.

Conclusion

Although we come from the perspective of self-direction, we are not the only group that has serious concerns about the CAS. We know that families of those living in certified residences are worried that CAS scoring could lead to people being forced to move.

We believe there is sufficient evidence to suggest that before the CAS becomes mandatory and used for rate setting, that our recommendations be strongly considered, and that OPWDD, in collaboration with families and other stakeholders, institute the changes necessary to ensure its success.

New York Self-Determination Coalition – NYSELFD

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