



Teleconference – SWAN/OPWDD

Tuesday March 5, 2019

Attendees

SWAN: Barb DeLong, Kathy Bunce, Brad Pivar, Roy Probeyan, Fran Kerimian, Elly Rufer, Meri Krassner, Jim Karpe

OPWDD: John Barbuto, (Dep. Asst. Commissioner State Operations), Neil Mitchell, Greg Roberts, Al Pruett, Kate Marley

Highlights:

- Jim Karpe has a follow-up meeting with Tamika Black about data. Will invite other members of ad hoc data committee to participate.
- SWAN members will “spread the word” to family members and individuals that families can now request a review of their CAS directly to OPWDD. Details below.
- OPWDD strongly encourages every family with an issue to get in touch with them. They will go through item by item.
- OPWDD’s website will be updated to describe how, but in the meantime any family member or individual with a concern about the CAS should:
 - send an email to coordinated.assessment@opwdd.ny.gov
- Turnaround time for the initial response is estimated at 3 to 7 days but not a promise.
- It will take several months to come to a conclusion
- Next topic for extended call should be Life Plans

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Summary:

The focus of the call was to review the CAS: the tool itself, the process, and technology. SWAN shared many first- hand accounts of how the CAS has failed to capture accurate information about the person being assessed. In summary experiences have included:

- The document is “ugly”; it looks institutional and is NOT person centered.
- There is a lack of transparency as the drop downs are based on the prior question. Individuals/Families have no idea if something is being left out if the entire question set is not available.
- The inaccuracies are considerable. We know of incorrect diagnoses, significant medical issues not noted, abilities being stated incorrectly, abilities being over inflated.

Additional issues of concern include the following:

- Where is the quality control?
- How Performance vs. Capacity is being interpreted re: services
- 3- day look back is not person centered and not revelatory
- The could not/would not response creates the perception that the person is being non-compliant instead of not capable.
- Family members have not been notified that the CAS was being done and that they could choose to be present

OPWDD's response to our concerns:

- OPWDD stated that the lack of access to the CAS tool is the universal approach to proprietary assessment tools. They also said that the assessors are trained for 2 weeks, addressed in categories. The CAS will be redone every year, as well as when there is a change in a person's life, a "sentinel event." It is an interpretative document and is only one element of the assessment.
- In terms of quality control, many different documents feed into the CAS. They are in the process of changing their admin efforts and learning which documents are the most important.
- If the error on the CAS is health, safety or a diagnosis error this will trigger a possible change to the CAS. Otherwise if it is an inaccuracy that doesn't affect the Care Plan it will just be noted.
- The 3 day look back is limited to only a small set of questions. Test makers chose this timeframe as being a more accurate measure because of "memory failure" on the part of the one being assessed. Present but not exhibited captures things accurately.
- The "would not, could not" language as well as the "appearance" of the document is being reviewed. They have received this type feedback from others as well. The Care Planning team is currently reviewing this

Significant discussion occurred regarding what the future intention is regarding use of the DDP-2 and the CAS, both present and future as it relates to areas such as:

Care planning, Acuity, Service Authorization, Service Delivery, CCO Tiering, PRA's, & Managed Care Rate Setting

OPWDD's response indicated that they are working on policy development in all these areas and as such it is difficult to provide a factual response at this time. They committed to working closely with us and as progress occurs they will keep us informed. We reminded them of OUR



reality that as we are the individuals/families served we are the ones that are directly impacted by these decisions and therefore we must be involved.

SWAN expressed HUGE concern regarding acuity of the person and the real cost of appropriate care for people. It appears that the individuals with the most complex needs are not being considered. This could lead to Managed Care companies not accepting these individuals into their plans OR not providing the level of care required to meet their needs creating a HUGE risk to their health and safety, as well as being a violation of their civil rights

We agreed that we will have a follow up discussion on this topic at a later date and include members of the Department of Health.

Additional discussion topics:

- Clinical Advisory Group will be coming up with recommendations on VBP. They will confer with the Joint Advisory Council which will have family member participation. BP- **Value-Based Payments**—the Clinical Advisory Group (CAG) will be coming up with the recommendations.
- MAPP has been stalled
- SWAN inquired regarding date website would be updated regarding the new CAS process improvement and other matters.

In closing, SWAN extended their appreciation to OPWDD with working with us during these very challenging times. We appreciate the willingness to share information and to listening to our concerns and ideas moving forward. This is critical as we strive to keep supplying family groups across the state with factual and accurate information.