OFFICE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES ADVISORY COUNCIL

Minutes
September 25, 2013

I. Call to Order

The meeting was called to order at 11:05 am.

II. Chairperson's Remarks

Mr. Cappoletti called the meeting to order, and noted it was a smaller group than usual. Mr. Cappoletti welcomed Commissioner Kelley as acting commissioner and noted her service in the DDAC.

Jeff Weiss, Justice Center director, was requested to speak last time and is confirmed for the December 11 meeting. There have been two changes to council membership: David Liscomb has resigned to focus more on work with SANYS, and Mary Patricia has resigned but will stay active on the board of visitors. The service of both is greatly appreciated.

The meeting was video-recorded, and copies are available upon request.

III. Commissioner's Briefing

Acting Commissioner Kelley began by noting it was an honor to be appointed acting commissioner, and that Courtney Burke had laid out a road map that must now be implemented. Before serving as an ARC executive director for the past 12 years, Commissioner Kelley worked in hospital administration for 20 years. She has seen the transition to managed care in that context, which helps with CMS and other negotiations. While the system has not focused on outcomes in the past, healthcare in general is centered on outcomes, and the system needs to demonstrate results and the wise use of resources.

Commissioner Kelley's education includes undergraduate work in nutrition, leading to a certification as a registered dietician, and also an MBA in business--both an "analytical mind" and a "huge heart." At the ARC, Commissioner Kelley worked to help people get the lives they truly want, with the belief that everyone has the ability to contribute, and she is not afraid of a challenge.

Reflecting on the creation of the field, the Commissioner noted that parents' aversion to institutions was the start of the developmental field. The shared view of stakeholders that people should be in control of their lives is not without challenges, but the OPWDD system is something to be proud of and to retool for the future. OPWDD engaged CMS to obtain federal matching funds, and this led to growth but also comes with a partner we have to please; OPWDD has not done that over the years. Now the question is how to move forward to reach the deliverables CMS wants.

It is apparent there is not a flood of money coming in, and OPWDD has less autonomy than desired, so how do we make it so people can control their lives? On the agenda is our relationship with CMS, which has undergone a huge evolution with the closures of DCs. The closure plan submitted to the state

indicates OD Heck will close by March 2015, Broome by March 2016, Brooklyn by December 2016, and Bernard Fineson by 2017. Sunmount will stay open along with Valley Ridge.

With change, certain things will need to be leveraged. People who can move to the community to gain more personal autonomy ought to do so. By the end of the year, 20 people currently living in DCs will take part in Money Follows the Person. To take advantage of MFP, individuals will need to move to facilities that are four beds or smaller. People living in a nursing home or ICF could be supported by MFP.

The theme is always the same—how to help a person get into the smallest, most integrated setting possible with appropriate supports.

- START model: OPWDD is partnering with community mental health providers and creating emergency teams to help stabilize people in crisis. The primary goal is to address challenging individuals who do not have wraparound supports. Kicking off January in Regions 1 and 3.

- Individualized Supports: The CMS model is very individualized. Educational sessions tied to the front door focus on individualized service models—people need to understand there are opportunities out there. There is going to be a rebalancing around individual supports, and there needs to be a continuum so people can move through the service system. At present, 350 individuals are slated to be enrolled in individualized services through CSS and ISS with community hab.

- Employment: An additional 226 people have been employed since March, for at least minimum wage. There are plans for workshop closures being developed. Each workshop is different, and some are truly affirmative businesses. We need to look at what these workshops are really doing and examine retooling the venues.

- Rate Rationalization: CMS has made it clear OPWDD's rates will be price based going forward.

- Coordinated Assessment System (CAS): The tool still must be statistically validated. The CAS will be tied to the reimbursement process eventually. OPWDD needs to formulate/demonstrate to CMS how it will work. The CAS is a version of the InterRAI tool. The InterRAI is used by other state agencies, but OPWDD added to the tool to get to the nuances of the needs of people with developmental disabilities.

- Front Door: The front door was launched in the spring, and is having some issues. A group has been assembled to evaluate the front door from different stakeholders' vantage points. The regions have added more to it so it is not a consistent statewide process. After the initial contact the rest should flow quickly, and that is not happening right now. Everyone needs to go through the same process, which may not be logical if only light touch services are needed. We want uniformity, but not one size fits all. We are recreating data points—how long it takes to actually get services, not just to have the information session or assessment. **Please let us know your comments on the front door—we need to logically figure out the problem and fix it.**

- Shift Happens: Delaware Arc was the founder of Shift Happens. The outcome for that agency has been a positive effect on staff morale and reduction in the use of restrictive interventions. Looking at what people really need leads to good outcomes. Shift Happens along with the Code of Ethics and Core Competencies are all being rolled into operations. All three are to be merged into a

timeline with a 3-year rollout. There are learning centers being created throughout the state to support DSPs.

Discussion:

- Ms. Maroun: Sunmount is not going to close? Could you elaborate?
- Commissioner Kelley: The end status of Sunmount will be to house about 125 people and another 25 at Valley Ridge, mostly for people with forensic backgrounds.
- Dr. Bossert: People stay at Sunmount for over 30 years, and the model used should be instead intensive treatment. Sunmount is doing a terrible job of preparing people to work in the community. Most people in Sunmount are close in intelligence to the prison population; we should help them develop skills.
- Commissioner Kelly: Agreed.
- Ms. Maroun: I hope New York State will focus on development up front—pre-planning is the key to lessening extended stays, placement issues are also a problem. It must be stated up front that the person will be returned to the county they are referred by, and that planning must be done to transition them back.
- Commissioner Kelley: I toured Sunmount and was told about the same problem.
- Ms. McFadden: Counties do follow these individuals and pay a cost (county share)
- Ms. Maroun: The first concern should be the interests of the person; the second should be the interests of the community. It is unfair to individuals and the community to have a disproportionate number of people with high needs in one location. County planning is needed to avoid this.
- Ms. Durfee: Regional offices have a role as well in ensuring people return to their county of origin.
- Ms. Maroun: It comes down to communication.
- Mr. Cappoletti: One thing this discussion of reducing the institutional population brings to mind is using the START model to build community capacity in mental health. In Central NY we are seeing a lack of mental health services for people with developmental disabilities. Children are moved out of state or to a residential model because resources have been exhausted. The lack of mental health services makes it difficult to move people back into the community.
- Ms. Goddard: It is very hard to find psychiatric services.
- Commissioner Kelley: The broader need for specialty services compounds the problem.
- Mr. Cappoletti: It's an obstacle for people to move to the community.

- Mr. Cappoletti: Front door experience with my son—the service coordinator said he didn't qualify for services because he didn't have eligibility. What he had was system-generated eligibility, which means no documentation. I had to call the front door (as a parent) and it was not as painful as I thought it would be, but it was intimidating because I had to put together an eligibility transmittal package which required the collection of data on my son regarding genetic testing, medical and psychological information. It was turned around fairly quickly, but you might want to look into the issue of system-generated eligibility.
- Ms. Tegtmeier: The real problem is not being able to get services. In our region you need to be in crisis, and even then it can still take months. My agency is getting bombarded with calls, as since the information sessions started people are talking to each other about what could happen. It's not necessary to do the front door for family support services, but FSS programs are bottlenecked. This has been devastating to families—the message is that even if you do what you are supposed to, you still won't get services. People have everything lined up but can't enroll in programs.

- Ms. Pieper: Resources are used disproportionately and not directed enough to families. It is imperative to get data to help us with the legislature, etc. We need to be creative and spend and leverage funds wisely. There is software which can be used by customers to follow every step of a business transaction, and we should borrow that model.
- Ms. Tegtmeier: If you need even just service coordination, you must go through the front door. Staff are not doing assessments and conversations the way they want to because they are too overwhelmed.
- Ms. Puddington: Eligibility should be done first, and the information session after. They need to be separated out. No one is getting through to front door staff in NYC.
- Ms. McFadden: It seems all regions are asking for different information based on their region—are they looking at this for eligibility? I will forward examples to Tracy.
- Commissioner Kelley: This comes down to customer satisfaction, and how to improve the process so people get what they need.

IV. Council Presentations and Discussion

Community Dialog Feedback and Sheltered Workshops
Ceylane Meyers-Ruff

Community dialogs were held around the state, which some DDAC members participated in, and included providers, parents and self-advocates. Feedback obtained included concerns with the transition plan, which will comprehensively address increasing competitive employment and efforts to transform workshops. That plan is to be submitted to CMS by October 2013. Another round of community dialogs will be held. Most of the feedback was on sheltered workshops.

Common themes from feedback:

- July 1 policy on sheltered work enrollments: People said OPWDD should have been more specific about options aside from sheltered workshops before enrollment ended. Some workshops had to turn people away because of having no new employees. The parents of 40/50 year old individuals who cannot retire but are not interested in community employment argue they have established strong relationships and feel proud of their work and pay from sheltered workshops. Their needs will be addressed in the plan OPWDD is developing.
- Transportation: Lack of paratransit should be given consideration in the context of supported employment.
- Business models: Discussion of business models to change the nature of workshops, including affirmative business models and social integration models.
- Self-advocates expressed concern that we live in a society where people are not always tolerant, and the larger issue of awareness. Some self-advocates shared their experience of moving from sheltered work to paid employment, but talked of the need for a sheltered work safety net. It was expressed that each workshop be judged separately as some truly prepare people for employment.
- State Education Department: OPWDD needs to partner with SED so that school administrators know that OPWDD exists, and plan for transitioning children out of the school system and changes related to the end of the IEP diploma, and to convey the expectations to be put on teachers to prepare students for employment.

Discussion:

- Mr. Cappoletti: How many people are currently in sheltered work?
- Ms. Meyers-Ruff: 7900 people. About 60% are from the ages of 18 to 53, and 40% are from the ages of 54 and higher.
- Ms. Pieper: A different category is needed for people aged 64 and up. There should be a retirement age. Transportation could be improved by a successful model where people could buy a unit of a van for their limited needs.
- Ms. Maroun: Think about the transitions, it there any dialog going with ACCES-VR, which I hear is very overtaxed?
- Ms. Meyers-Ruff: We are talking to both the office of special education and ACCES-VR. ACCES-VR is the front door to SEMP. We hope to negotiate a new SEMP MOU with ACCES-VR. ACCES-VR is not moving the process along fast enough, so families are left with no option but day hab.
- Mr. Cappoletti: ACCES-VR needs to be clear about who they serve. An ACCES-VR rep once said "we serve people who aren't too severely disabled," and "if someone can't speak don't expect them to be able to work." [paraphrased]
- Ms. Meyers-Ruff: The statute talks about providing supports to the most severely disabled. Work needs to be done at the regional office level. There are many different interpretations of policy and system change needs. Change at OPWDD is forcing change at ACCES-CR
- A discussion of comments heard from other ACCES-VR reps followed, which were seen as indicative of not supporting OPWDD's position on all individuals being able to work.
- Ms. Maroun: ACCES-VR resists accepting individuals leaving any other major service system. With regard to sheltered workshops that function under a business model—is there any movement for others to take on these best practices?
- Ms. Meyers-Ruff: There is system change going on at ACCES-VR. The problem with the current sheltered work model is that it is not integrated—it is now segregated. Wages are less of an issue because DOL can issue certificates to allow a sub-minimum wage. In terms of changing this sheltered workshop model, there is the affirmative business model. In this model, contracts are executed but the workforce is more diverse. Some government contracts require 70% of workers to have a disability. There is also the social enterprise model, in which a business in the community employs people with and without disabilities. Strategies for OPWDD to promote these models are included in the employment plan.
- Mr. Cappoletti: What about disability based enterprises?
- Ms. Meyers-Ruff: The framework for many high performing SEMP states includes building around MWBE and expanding it to businesses run by people with disabilities.
- Ms. Tegtmeier: I went to a community listening forum, and Ceylane did an excellent job. The way information was presented was interactive and generated conversation. Acceptance of people with disabilities affects every area of our life, at the forum it was stated there should be more initiative on our part to get society to be more accepting. Every time my daughter is at an event I ask staff how her experience was, and it's often negative. It is different when a family member is not there.

Rate Rationalization
Kevin Valenchis

Materials: PowerPoint

Phase 1 and 2 of the transition of rate setting are now reporting to the Department of Health (DOH). DOH has been responsive to the Commissioner's and stakeholders' feedback regarding "winners and losers" under the new methodology. DOH introduced a Wage Equalization Factor (also used in nursing home rate setting) to take into account regional and agency-specific wages. The formula used gives providers a significant portion of their historical costs for direct care wages, 75% agency factor, and the rest (25%) is a regional average. The proposed methodology recognizes the direct care staff hour as its core. It creates standard fees for services that contain all the costs of the DSP providing support. OPWDD was able to add in additional justifications regarding Willowbrook class members and e-score adjustments. Hours are added to provider rates to ensure fire safety is maintained. Additional components of the rates include property payments, res hab capital and board payments, ICF day services were added to the ICF rate, and transportation to and from day habilitation will be added to the day hab rate.

The PowerPoint discussed the guiding principles of reimbursement reform: reasonable, adequate, cost effective, and predictable. Rates for residential programs serve as the cost floor for managed care. There is a quality pool with incentives for providers. The transition plan was meant to phase in the methodology over 2 years, but OPWDD is requesting that be extended to 6 years.

Also discussed was New York's costs compared to similar other Northeastern states. New York State has costs similar to other Northeastern states and is not an outlier. This information is being provided to CMS.

Discussion:

- Ms. Puddington: Is the method updated periodically to increase wages for staff?
- Mr. Valenchis: The method is capable of recognizing inflationary costs, and we want a regional update to provider acuity scores that incorporates individual changes to get the pricing right.
- Commissioner Kelley: Just to note again, CMS has not approved this methodology yet so it may still change.
- Ms. Joanne Howard (OPWDD): An independent wage factor was considered, but that rate would have been lower so CFRs were used to establish the rate.
- Dr. Goldstein: Is the rate used to tell the DISCO what to pay?
- Commissioner Kelley: It will be used in the fee for service world for now, and will be the floor for core services (such as residential) in managed care.

- Dr. Bossert: Voluntary agencies are not being paid on time. Is there any relation of what you are presenting to this failure?
- Mr. Valenchis: A modernizing fiscal platform group selected the brick methodology for use by OPWDD. There were proposals to regionalize costs, but they were not pursued.
- Dr. Bossert: Payments are late or never, has this developed in the last few months?
- Commissioner Kelley: There has been no change in practice. Claims are submitted electronically so this is a surprise.
- Ms. Pieper: The state workforce has complained about a 2-week lag pay, but not the voluntaries.
- Mr. Cappoletti: Sometimes provider errors are misinterpreted as a systemic problem.
- Ms. Puddington: In managed care, could a provider be reimbursed at a higher rate if providing a specialized service in an area?
- Commissioner Kelley: The state sets the flow for payment, but the provider can negotiate a better rate from a DISCO.

- Mr. Cappoletti: Does the rate include all of OPTS?

- Ms. Howard: Some costs are state-only paid, so would not be included in the rate.
- Ms. Maroun: Why is the Hudson Valley clinical rate so high?
- Ms. Howard: This is driven by the few providers in the area, but other methodologies have shown Hudson Valley costs to be higher than those in New York City.
- Mr. Pieper: This rate is more concrete.
- Ms. Howard: Yes, because it is based on actual costs.

- Mr. Cappoletti: Is the transportation component of the rate based on averages?
- Ms. Howard: Transportation rates are specific to each provider. Program transportation is another component.

- Mr. Cappoletti: This is budget neutral for providers, but is the opportunity to serve unserved people being lost? Why not reinvest funds to serve the underserved instead of leaving that money with providers?
- Ms. Howard: As a percentage, surpluses are not great. As the methodology progresses, we will be looking at more opportunities—
- Mr. Cappoletti: I know the percentage is not great, but it is big for families in crisis. $175 million could serve 5000 families.
- Ms. Howard: Providers need a certain level of surplus to be viewed favorably by financial institutions, to show that they are financially viable.
- Ms. Puddington: Does the surplus have to do with a historical rate? There is a huge variety, some providers are underfunded.
- Commissioner Kelley: CMS is looking at price; they do not care about history. Providers need to be able to provide services, but also need to pay attention to the margins.
- Ms. Puddington: "Winners" may just get equalization.

- Ms. Pieper: Who does future development of the rate methodology?
- Mr. Valenchis: Rate rationalization and other committees at OPWDD, and much of the leg work is done by DOH and consultants.
- Mr. Cappoletti: How do you ensure needed feedback is gained?
- Mr. Valenchis: The transformational workgroup can serve as a venue.
- Commissioner Kelley: The rate methodology is still a work in progress.

People First Waiver Update
Jerry Huber

Materials: PPT
Transformation plan goals update:

- Self-direction: education is complete and increased targets are kicking in now
- Employment: new strategies are being developed to improve retention. The plan to close sheltered workshops is underway.
- Residential transition: FL and Taconic Developmental Centers are closing; all houses must meet home-like standards.
- People First Waiver: focus on rate structure and outcome measures
- Money Follows the Person (MFP): SANYS is doing peer outreach at DCs, ICFs, and skilled nursing facilities this fall, as well as school district outreach.

Negotiations with CMS continue in weekly discussions, including finalizing the waiver agreements. JAD sessions are underway to explore critical decisions regarding managed care. OPWDD is examining using BIP funding for DISCO start up costs. Three teams are working on managed care implementation, provider efficiency and innovation, and system transformation.

Discussion:

- Dr. Bossert: When will providers start to provide direct information to parents/legal guardians regarding the transition to managed care?
- Commissioner Kelley: The current transition is looking more at moving people out of DCs (which are ICFs). Many ICFs were converted in the past to IRAs, but we have not done a communication plan for voluntaries because we are focused on the DCs now.
- Mr. Huber: Some agencies see the conversions as an opportunity to make changes they have wanted to prior, but haven't pushed the agenda. Some agencies are not used to getting feedback from parents, we should be advising them to gear up.
- Commissioner Kelley: Outreach to family is required when a discharge occurs (e.g. a person moves from an ICF to an IRA) because agencies are supposed to go to the service recipient and parent/guardian to inform them to get consent.
- Dr. Bossert: At that point it is the end of the process. I think we are slow on parent notification.

- Ms. Pieper: One other group could be helpful to transitioning—state DSPs. There could be an initiative or surveys/research to get their feedback. Do you think this would be a reasonable option? We could write a concept paper and apply for a grant to do this.
- Mr. Huber: Other states that transitioned really focused on staff that have an interest in transition.
- Ms. Tegtmeier: I did information sharing to parents; families are not getting information from providers. There is tremendous fear out there; I am getting lots of questions. When the letter of intent was put out for DISCOs, I was shocked by all the people on that list.
- Mr. Huber: We received 35 letters of intent regarding the DISCOS. 1/3 are already engaged providing services, 1/3 are existing HMOs, and 1/3 we have never heard of. Not all will meet the requirements of the readiness assessment. There will be some self-screening as well. 60-65% have a focus in New York City, which matches the percentage of people that OPWDD serves in NYC. A concern is that if managed care organizations are concentrated downstate, what about upstate?
- Ms. Tegtmeier: I knew there were provider entities that were created recently, but big health plans stood out to me (the number of them and where they said they could serve.)
- Mr. Helman: Five years ago if someone entered the front door it all moved along. The pieces of the People First Waiver are disjointed, but everyone needs to know the end point e.g. what happens to MSCs? There are a lot of details people can't wrap their heads around. With rate rationalization, if we are trying to equalize the playing field, there is still a substantial differential between what agencies cost, so it may alter the funds a DISCO has. How will the DISCOs be funded? It would be helpful to know as we move forward. Where do brokers fit in? Someone must have the vision—tell us the end point.
- Commissioner Kelley: I am not sure CMS will share their vision, so putting out information not approved by CMS is also problematic. We need greater understand from CMS regarding what the end point will be. There is still much that is not known
- Dr. Goldstein: Does CMS have a vision?
- Mr. Huber: CMS has indicated that managed care in itself is not transformational; it is a means for transformation. Self-direction, employment and residential transition *are* transformational. The big piece of the picture is the actual transformation; the smaller piece is managed care.

- Ms. Kelley: Managed care is just how the system is funded; we still need fee-for-service day services, physical and occupational therapy. The leading question is the MSC—if care coordination is done correctly, do we really need MSC?
- Mr. Helman: How close are we on policies regarding self-determination?
- Mr. Huber: We are on target—CMS looks at self-direction as peer self-direction. Budget and staffing control must be a part.
- Ms. Kelley: We are not blaming CMS; they are a partner and pay 50% of system costs, which we need for the system to function.

- Mr. Huber: Gary Goldstein and the dental task force have been looking at transitioning from fee for service to managed care, and had a meeting with Dr. Shah (DOH Commissioner) regarding key standards in practice and availability of oral health services – DOH has been receptive.
- Dr. Goldstein: We did the same presentation for Dr. Shah we did for the advisory council. He pushed back on grounds of return on investment, but it has been done elsewhere and we are looking into papers that support what we want to do with evidence-based research. DOH proposed that they are willing to fund demonstration projects. The timeline to do this will be discussed in the coming weeks.
- Mr. Cappoletti: What kind of demonstration projects?
- Dr. Goldstein: Prevention, telemedicine, quality assurance, metrics development. We thank the Commissioner for her great support.

V. Current Council Business

Committee Reports:

- FSS (Ms. Puddington): We discussed many of the same topics at our most recent meeting: rate rationalization, the front door, shared complaints about what is not working. We have questions regarding the future of FSS. [Commissioner Kelley: Both full-scale and light-touch services, including Family Support Services, will continue to be needed.] We had a presentation on school district outreach strategies. OPWDD transition coordinators in each region are looking into interventions to avoid residential school placements. We are working with OPWDD and families to get light touch services soon. Most schools at the local level are not aware of OPWDD. We also discussed the culture change initiatives.
- Special Education (Mr. Helman): Much conversation today mirrored that of the special education committee. We talked about the MSC as a special education advocate. If they go away, what replaces them?
    - Commissioner Kelley: Two models have helped. A community service board went to each school to address issues and educate districts (e.g. OPWDD can provide respite, etc.) This resulted in collaboration between OPWDD and school district supports. Also, different employment venues were leveraged in a school district-OPWDD partnership, resulting in a 95% employment rate for high school graduates, post-graduation.
- Regulatory (Dr. Goldstein): All are invited to attend our meetings. A memo with updates and potential impacts of regulatory changes will be distributed.

Other Comments:

- Mr. Cappoletti: Ms. Fratangelo (absent today) said that the implementation of the Justice Center has caused problems in the field related to significant days in hiring staff (5 to 7 weeks from hire to unsupervised work.) This is making it hard to fill vacancies.

- Ms. Maroun: As a surrogate decision making committee member, we are doing more technical work due to the Justice Center, that the JC is not able to help resolve. There has been a change in the function of this committee—we are carrying out minutia rather than making decisions.

VI. New Council Business

Ms. Pieper: I noticed you are hiring a Medical Director. Please try to get someone who is very independent if they can be sought out from a bigger universe.

Mr. Greenfield: I compliment Commissioner Kelley on being here for the whole meeting.

- Commissioner Kelley: You are an important group and thank you for your insights. Much change is coming, and we need to think about how to make those changes. New York State will need to be a model for the nation again. I look forward to your participation.

VII. Public Input

Mr. Carl Tegtmeier of the Special Dentistry Task Force thanked the Commissioner and Mr. Huber for helping the group take their proposal to DOH.

VIII. Adjournment

Mr. Cappoletti: Thank you for your advocacy and involvement.

The meeting was adjourned at 3:00.

Developmental Disabilities Advisory Council
September 25, 2013 Attendees

Members

Shameka Andrews
Jim Boles (v/c)
Richard Bossert
Nick Cappoletti
Tammy Elowsky (v/c)
Shirley Goddard
Gary Goldstein
Paul Greenfield
Mike Helman
Ellen Maroun
Delores McFadden
Betty Pieper
Margaret Puddington
Mary Somoza
Maryellen Tegtmeier

Excused

Marc Brand
Carolyn Corcoran
Pat Fratangelo
Sally Johnston
Harriet Kang
LaRenz Pickens

Absent

Gary Burkle
Joel Rosenshein

Guests

Rhonda Frederick (v/c)
Mrs. Greenfield
Anna Lobosco
Carl Tegtmeier