

Joint Legislative Budget Hearing on Mental Hygiene

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Testimony to the Assembly Ways and Means and Senate Finance Committees

Joint Legislative Budget Hearing on Mental Hygiene

February 14, 2022

Thank you, Chairpersons Krueger and Weinstein, and Committee Chairpersons Manion and Abinanti, and all the Legislators here today. I appreciate the open forum and your enabling written testimony from individual/family advocates for I/DD services in this Joint Legislative Budget Hearing. I am a self-advocate who has been in OPWDD self-directed HCBS waiver services for about the last eight years. I have been very active in state-wide and regional advocacy for Medicaid long-term care services and OPWDD services for the last six years. Some of my personal experiences and concerns drive me to highlight how OPWDD/DOH assessments and services neglect and discount the profound biological problems unique to people with developmental disabilities. I approach this testimony having done professional work in program evaluation and research in disability services.

My comments are consolidated on the fly so to speak. And I want to urgently ask that the legislature be more proactive and assertive: (a) change laws to protect us with regard to our benefits, resource allocation, program operations, data reporting, required open and formal processes for stakeholder involvement in decision making process and more; (b) fund our services to enable safe, predictable, respectful, and useful services from the perspective of individuals and families; and (3) advocate for corrective action for your constituents when it is needed. I heard examples of each three of your

I am writing after having waited to hear Acting Commissioner Neifeld's testimony today and noting her responses in the question and answer period with legislators. I will use Committee on People with Disabilities, Assembly member Abinanti's framing of the challenge - Will we have an OPWDD Commissioner and a state agency that is an Advocate or an Apologist? I think two other Assembly members picked up on this theme to assess our progress going forward.

I will use that theme. And I want to provide a different set of contrasts to use in the problems and dangers I bring to your attention for people who rely of OPWDD services and Medicaid. Each of these are separate dimensions and must be measured separately:

- **Hope**
- **Hype**
- **Openness**
- **Outcomes**

There is a good deal of **Hope** that Acting Commissioner Neifeld can bring a new working relationship with the legislature and with family/self-advocates. There was less **Hype** today in the presentation from Acting Commissioner Neifeld. Examples of **Hype** are words or phrases like streamlining, scalable, that did not come up today. But there are phrases like "evidence based" that did come up and those phrases can obscure what is really happening on the ground in people's lives and what works in practice for individuals or groups of people.

Openness is still a huge chasm and wall of fog facing us as OPWDD continues the programs and projects that were discussed today. I urge all legislators to evaluate what is happening with the RFP process for Self-directed Services Redesign and for the RFP on the evaluation of the Care Coordination Organizations (CCOs). There are certainly examples in other states where I/DD stakeholders are invited to help formulate the scope of work of an RFP/RFA and to also be part of determining scoring criteria and exclusion criteria for bidders for the RFP/RFA. Some of advocates have asked that and the requests are basically dismissed. We get something that sounds more like an apology or worse. Please see comments on the OPWDD system design RFPs below.

Outcomes are what we need and deserve. But at this point, it would be better to say we deserve more than broad goals that have no measurable accountability. There was one or two questions from legislators today that asked for this in a clear way on the topics of housing, work force and employment for people with I/DD.

Acting Commissioner Neifeld said that her goal is a service system that is fair and balanced. She should be applauded for that. The state legislature needs to put in place statutory changes that will make that goals real and do so by requiring a broad range of stakeholders (individuals/families) to participate in defining measurable outcomes and evaluating them.

I am someone on the Autism Spectrum with related medical problems (some are co-causal medical conditions, and some are co-occurring medical disorders). I emphasize this at the start of my testimony because there is a continuing drift to move OPWDD into the frameworks (diagnosis and treatment) behavioral health care and from there to managed care. Note that problems with managed care were acknowledged by the relevant commissioners today for OMH and last week for DOH. The biomedical causes of many problems and support needs of people with I/DD are being covered over. This should be most obvious for people who are considered high needs.

The true costs for NY state Medicaid and OPWDD programs that serve us are hidden because OPWDD needs assessments and rate setting methodologies do not take medical problems (diagnoses and medications to use two simple factors in risk adjustment). I am not talking the old DDP2. I am saying that the new system based on the CAS – the Coordinated Assessment System- and the databases that the CCOs use for our Life Plans do not properly measure and record basic medical information. In prior public testimony or public comment, I have noted how the current rate setting methodologies are flawed. Many advocates continue to call upon the legislative committees to hold hearings on the CAS, and the resource allocation process OPWDD is developed to put individuals in tiers that determine what types of services they may receive and what caps are put in place for amounts of a service or the cap used for the global personal budget in self-direction (the PRA).

Honestly these are problems that advocates have brought to the legislature in the past four or more years. And its awkward to say but I have to take a path used when the Assembly Hearings were conducted examining the impeachment of Governor Cuomo. I will pass on to two committees a presentation from Optumas (doing actuarial and program planning consulting to OPWDD) on the development of a tiered resource allocation model using the CAS. I received this presentation several years ago from a fellow advocate who was on a so-called work group of a handful of advocates that were not allowed to say anything about their activities. I will have to ask for protection perhaps just to share this with the state legislature. This is wrong on so many levels and in so many ways.

Optumas did the same type of work in Nebraska and developed a tiered rate setting methodology and resource allocation framework. And that work was done in a very public manner with periodic open involvement of legislators and stakeholders. I am not opposing the framework in general but the devil is in the details and the dangers are most severe when the process is hidden from us. Or take the state of Texas as a contrast to New York. Deloitte (the company that has been the DOH contracted actuary for the past several years) did an actuarial study of what would happen if Texas were to move to managed care for people with I/DD. Several scenarios were modeled. That contractor work was published by the state of Texas and a web video of a review of the Deloitte report is still available. Deloitte did very similar

actuarial work for DOH/OPWD here on costs of moving to managed care here. The information was never released by DOH/OPWDD. You could say that in Nebraska and Texas with an evaluation of programs and costs in I/DD services you get the **whole H.O.G. (Honest Open Government)**. But in New York we only get **Half the H.O.G.**

I ask the state legislature in its present budget bills (statutory changes) to require the Commissioners of DOH and OPWDD to present to the relevant committees, in an open public meeting, all contractor preliminary data, presentations and reports that have been and are being used to do rate setting, resource allocation and service authorization. This should also include internal OPWDD work on the needs assessment tools – the CAS, the forthcoming assessment tool for housing options and similar tools. Acting Commissioner Neifeld may not be immediately implementing the housing placement/options tool for use in determinations right now. But these tools can be turned on so to speak in short order to become a tool for service authorization.

Housing – There are many issues here and I am thankful that the Chairs Manion and Abinati and several legislators addressed the sudden closure of group homes and related issues of how and when those homes can be made real again for those that lived there. Yes! I say it that way because I am a self-advocate. There are many other things that are out of balance and unfair regarding the residential options people have who rely on OPWDD services. I am sure other organizations and individuals will provide written testimony about those problems.

I am challenging the accuracy of the claims made by current OPWDD leadership that the proposals for the increasing housing stipends and support for individuals who live alone. I am someone who has been living in my own studio apartment for four years with the housing stipend assistance from OPWDD. The same basic scenario I describe would apply to those of us in self-direction and the other independent housing program stipends. Some of us have had severe reductions in the monthly stipend in the past six months. At least this is what I heard from support brokers. They say people have ended up homeless because of reductions in the housing stipend. But you have to realize that brokers are independent contractors, and they fear speaking the honest truth in public. This must change. You need to help us. You can help us make this data reporting regular and open and part of what the CCOs and OPWDD reports. In my individual situation, I lost about \$260 a month in my housing stipend. I will run out of any funds I have in checking/savings and pool trust funds by the end of this year. Then for me it's a severe downward spiral where I cannot afford rent, and out-of-pocket medical expenses. The housing stipend is not a fixed percentage of income in the way OPWDD states. It is unfair and unworkable in many ways.

The problem is the housing template (the formulas) OPWDD uses in calculating the housing stipend. The problem is not the total top line cap on the housing stipend in each region. OPWDD may be raising the cap. But the problem is most of us cannot reach the top cap amount. The way OPWDD presents this information is misleading. If they keep presenting the housing changes after we make clear the flaws in how it works, well then advocates can say its more than misleading – it is a lie. One of the big problems to examine is that it especially hurts people who want to and can work part time. All of their income it seems (dollar for dollar) will be deducted from their housing stipend. That is not an incentive to work by any commonsense standard.

I will say that its so bad on Long Island that the recent housing stipend reductions were put on hold in January by our regional office. I just missed that deadline and I have questioned our regional office and Acting Commissioner Neifeld directly about having people like myself who recently had severe reductions be put on hold and reverted to the previous level of financial support until a new housing support formulas are finalized. The Acting Commissioner is new and was unfamiliar with these problems and I look forward to a response from here. But to the legislature I make this point- this is a service determination, and we need an open process and due process in any service determination.

I expect that many family and self-advocates and fellow advocates will address other needs for protections in our services. I am a member of Medicaid Matters NY and I support their call for the creation of an Ombudsman program for OPWDD. Such a program can be created to fit the present context of fee-

for-service operations and does not need to be set up in the exact manner of the Ombudsman program for Medicaid long-term care programs under managed care. I support the hub and spoke model of the ICAN approach. We need this badly. The other legal advocacy organizations that should be helping us are not doing what is necessary.

There are a huge range of problems with the CCOs and I have to say this because of what I have heard of from many people for the past four years of the CCO existence. I have had good assistance from my care manager on a personal level. The overall CCO services been less then helpful for me and part of this is due to DOH/OPWD removing the requirements for direct assistance and advocacy from the care manager role. And I am on my CCO Family Advisory Board. I won't go into my specific needs here. Broadly speaking the critical needs for care manager support regarding assessment of need, service planning (the Life Plan), and active assistance in ensuring services requested are obtained are not being met. The entire data structure of the Life Plan/Staff Action Plan does not record critical information. This is a large set of problems, and we need the legislative committees to hold hearings on this to assist us.

So I end with a final warning about how 2022 is starting out for us. OPWDD is going full speed ahead with a closed process for the RFP/RFAs on the CCO Evaluation and the Self-Direction Redesign. Consider the words that OPWDD uses very carefully and help us change the actual process of how stakeholder involvement. When OPWDD leadership has said they engage us – this typical means “listening sessions” that go nowhere and have no meaningful effect on decision making. From what we can tell OPWDD leadership has hand picked the same small (literally less than two hand full) of preferred advocates. We all know those individuals. They are good people, but they cannot represent all of us. And their responsibilities have typically been almost useless and on top of that they have a gag order imposed on them and they cannot report back. This is the year when you all can and must do more than look at the top line budget numbers and promises.

I support the testimony from SOYAN, Medicaid Matters NY and other groups.

I am a member of the Long Island Family Support Services Advisory Council and the Care Design NY Family Advisory Board. I have participated in statewide and regional advocacy groups including SOYAN, and other Self-direction focused groups, SANYS, Medicaid Matters NY and others. I have submitted many public comments over the past six years (either as a participant in other groups or as an individual) on topics such as: Medicaid Redesign Team (MRT) II, Value-Based Payments, OPWDD plans and proposals for the transition to managed care (SIPs-PL), and the Care Coordination Organizations (CCOs), OPWDD directed evaluations of self-directed services, and the other issues. I have a PhD and worked in a leading national disability research/policy organization in the 1990s. I seldom bother saying that because when someone falls into a space where you rely on public welfare services it seems you never can climb out. This is true for the majority of people who rely on public benefit programs whether they have a disability or not. To be quite blunt for those of us who rely on OPWDD services and Medicaid we become something must less than we are because of the way we are treated by these service systems. That can change.

Ralph Warren Jr., PhD – Self-Advocate

(sent in as usual just under the deadline, off the cuff with references that can follow)