

Written Public Testimony from Ralph Warren Jr., Self-advocate

**Joint Legislative Public Hearing on 2026 Executive Budget Proposal:
Topic Mental Hygiene Feb 4, 2026**

Respectfully Submitted to wamchair@nyassembly.gov and financechair@nysenate.gov

Via email prior to close of business 5 PM on Feb 4, 2026

Hello and thank you for the opportunity to provide written public testimony to the Chairs of NYS Legislature Senate and House finance committees managing the Joint Legislative Budget Hearings and to the committees relevant to the hearing on Mental Hygiene.

I am a self-advocate who receives OPWDD HCBS waiver services, using the option for self-directed services. I have been actively involved with public advocacy for OPWDD specific services and Medicaid services for people with disabilities and long-term care needs for the past ten years. I have closely followed the joint legislative budget hearings for many of those years and submitted written public testimony several times for both the Mental Hygiene and Health/Medicaid hearings. I am an official board member on several bodies related to OPWDD services. I have been actively involved in various advocacy groups for Medicaid and OPWDD services statewide for the past ten years and submitted formal public comments to NYS agencies and CMS regarding NYS DOH 1115 waiver, the OPWDD HCBS waiver and other topics during that time. I am an older adult with and was invited by a national organization last year to be an advisory board member on the project to improve services for older adults with I/DD.

The proper context for this short testimony is the increasing destruction of accountability that is driving deeper conflict in our country and society. We did not just wake up one day and find this happening suddenly. It has been a slow drip, drip, drip and the focus here is how the destruction of protection and accountability have proceeded downhill over the course of many years with NYS DOH and OPWDD programs and services.

It is a sad fact that action in the NYS executive agencies and in the NYS legislature only happens when extreme harm or deaths to individuals with disabilities gets coverage front and center in mainstream media.

I label this testimony, this current brief document, as part 1 of 2. Part 2 examines shared responsibilities of DOH and OPWDD. For example, most people who get OPWDD services do not realize that the CCOs are health home state plan services and in various ways DOH has primary responsibility for the CCOs. So this year I am writing a brief testimony for the Mental Hygiene hearing and writing a longer and more detailed public testimony for the Health/Medicaid hearing and in that second testimony I will cover more extensive issues that overlap NYS DOH Medicaid and OPWDD. The issues I am most concerned with involve the joint

responsibility of NYS DOH and OPWDD. It is important to note that in recent revisions to the OPWDD HCBS waiver, the Centers for Medicare and Medicaid Services, insisted that OPWDD lay out the areas where DOH or OPWDD have primary responsibility and those areas where there is joint responsibility. I will submit a written testimony for the Health/Medicaid budget hearing on Feb 10th that examines these matters in more depth.

I attended in person two of my region's forums on OPWDD Strategic Plan in the past four years. At the two in person forums the family members spoke up about significant incidents of abuse their sons or daughters experienced within the service system. They spoke about how the incident management/reporting system failed them. They said they had to turn to the media to get help or would do so to get help. They were roundly applauded. More people who rely on OPWDD services have disengaged from the ways OPWDD does it's "listening". More people have quietly started the process of documenting problems and abuses to go to national, regional or local media or they have already started the process of engaging the media rather than engaging state agencies or the legislature. I am not surprised. I have had to take that same path myself.

We need action by the NYS legislature beyond matters of funding. We need changes in statute and legislative oversight regarding:

- How people become eligible for OPWDD services and later obtain HCBS waiver eligibility
- Proactive Senate/House Committee formal public hearings on OPWDD's plans for HCBS waiver changes at least four months prior to OPWDD presenting proposed HCBS waiver changes to stakeholders because when we see the proposals they are already a done deal
- The operation of the Care Coordination Organizations (CCOs) with at least one legislative public hearing a year on evaluating the CCOs
- An evaluation of the Life Plan/Staff Plans (our service plans) – who is involved, do approved OPWDD services get delivered, integration of medical/dental services, privacy concerns, what are the complaints from individuals/families, due process rights, etc.
- The transition to the CAS (the Coordinated Assessment System from the DDP2. The CAS assessment of individual needs is a financial planning tool that will be used by OPWDD to perform rate setting for agency-based programs and set individual budgets in self-directed services
- Ensure OPWDD's plans for redesigning the self-directed services in the HCBS waiver are examined in a public hearing
- An evaluation of the structure and functioning of the DDAC and changes in statutes to make all committees fully open to public scrutiny
- An evaluation of the Independent Ombudsman program (IDDO) created by the legislature for OPWDD and an annual public hearing on the IDDO and the Office of Advocacy created by the OPWDD Commissioner

In the past couple of days, I went back through some of the video recordings of the Developmental Disabilities Advisory Council (DDAC) and other forums related to OPWDD services. I went back through some of the reports OPWDD contracted for with outside consultants on assessing the feasibility of managed care for OPWDD services, evaluation of the Care Coordination Organizations (CCOs), and the evaluation of self-directed HCBS waiver services. I paid closer attention to what families/individuals said in those video recordings and in the appendices of those reports. I read the recent OPWDD Annual Report, Strategic Plan and Data Book materials. Before going further, I call attention to something simple – OPWDD’s publications, website information and more are deficient compared to what NYS DOH makes available – more on this in part 2.

In short, a comprehensive review of what families/individuals report presents an appalling indictment of OPWDD that is far from the slick public relations you see on the OPWDD. It is worth noting that SANYS’s testimony this year takes a very different approach and calls for systems change in a broader sense for the first time. I am involved with SANYS, the statewide self-advocate organization but infrequently and had no role in the creation of their testimony. I support their shift. I also do not want to lay blame on any one individual in state government for the failures in our service system.

Advocates must pursue a stronger tone and a more specific set of claims are needed if people with I/DD are to get the services and protections that we need. I am profoundly disappointed and beyond frustrated that the current OPWDD Commissioner has selectively spun up a positive story and dismissed complaints. The current OPWDD Commissioner may be well-intentioned but so far OPWDD is following the playbook of governing by and for public relations, the playbook of great disappointment in the current and previous governor.

I am a member of my regional family support council, a member of my CCO family advisory board and involved with many other advocacy groups. For the past several years one of the most common areas of concern is Access to services - including roadblocks and delays to OPWDD eligibility, and waiver eligibility, delays and denials of service authorizations, and housing opportunities and more. I am sure legislators have heard these complaints individually. But when you hear a series of painful individual stories its easy to lose sight of the systemic causes and its easy to sidestep the legislative action that can fix these problems.

OPWDD has gradually dismantled the partial and limited openness and accountability we had with the DDAC. This occurred during the past six years or more, and it can be demonstrated in viewing and assessing videos of DDAC meetings from 2019 to the present. This is, quite frankly, a failure of legislative oversight and can be corrected through legislative action. Other states, (as noted in some of my prior public comments) like Texas and New Hampshire have open, recorded public meetings down to the sub-committee level of official state bodies similar to the

DDAC. The contrast is clear and stark. Compared to many more states than just these two New York stakeholders and tax payers are denied accurate and timely information regarding service delivery, program operations/costs, rate setting for programs and services, and much more.

Here is one example to get a bit more specific and it is based on my personal situation. I have had to contend with abuse, neglect and exploitation from siblings. This began in a significant way in 2017. I had sporadic assistance from my CCO and the OPWDD regional office staff until 2021. The regional office pulled their assistance in 2021 and the CCO became less consistent and effective in their assistance. Neither has fulfilled their responsibility to enable proper incident reporting. The operation of OPWDD DQI has been anything but helpful. Clearly I need to be careful in public comments but if I do not speak out more harm will come to myself and other individuals/families who rely on OPWDD services. This also involves the county Department of Social Services and NYS DOH and in some ways for almost a year now I am in a situation where my Medicaid benefits can be at risk under a retrospective review. These are not insignificant risks whatsoever. And responsibility for corrective action lies both with NYS DOH and OPWDD.

I have reported this on video in a public comment section of a DDAC meeting in April 2025. I quote out from a section of the CCO evaluation – I quote my own words – submitted anonymously to the consultant organization at that time. It was included in two places in their 800 page report. See page 131 from https://opwdd.ny.gov/system/files/documents/2025/04/ccohh_final-report.pdf

“Communication Between CCOs and OPWDD: Additional frustrations stem from a lack of coordinated communication between CCOs and OPWDD. Some enrollees explained that they feel CCOs, Care Managers, and OPWDD are not escalating issues as appropriate and/or questions go unanswered. One described, “The CCO has distracted and delayed my getting necessary Incident Reports filed that concern neglect/abuse and possible serious financial exploitation. OPWDD is significantly responsible as well in these matters. However, the current Care Manager seems to be ignorant of my unresolved Life Plan issues, avoids problems, does not schedule the Circle of Support meetings, and seems ignorant of self-direction. There are serious unmet medical/dental problems, and the CCO is avoiding these as well” (Appendix B, Enrollee Survey Instrument, open-ended Question 13A; Family Survey Instrument, open-ended Question 16A).”

To this day OPWDD and the CCO delay resolution and the cost to me since 2021 is immeasurable. Direct staff have quit my self-directed services because of abuse from family members, and I have been understaffed, leading to loss of access to necessary medical and dental services. This situation has damaged relations with the CCO. This is the tip of the iceberg. It is a useful place to pause the overview and present more in Part 2.