

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

**Joint Legislative Public Hearing on 2026 Executive Budget Proposal:
Topic Health Feb 10, 2026**

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

Via email prior to close of business 5 PM on Feb 10, 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 Health (previously known as Health/Medicaid).

I submitted a written public testimony to the Joint Legislative Budget Hearing on Mental Hygiene last week. In that testimony I said that it was Part 1 and Part 2 would be the present testimony. I seek to highlight the ongoing joint responsibility for legislative review and corrective action needed in several areas where the Department of Health (DOH) and OPWDD have shared responsibility for HCBS waiver services. Today I do not have the luxury of approaching this testimony within the context of policy making and funding decisions in the large sense or in advocacy for specific programs and services. Over the past eight years, I have submitted various public testimony and public comments during legislative budget hearings, waiver proposals and other policy matters. I am person with developmental disabilities and have worked in a professional capacity in disability services research. I will address some policy matters here but that is not the primary focus.

Instead, I must use this opportunity to have testimony entered into the public record to call out deep and ongoing failures of DOH and OPWDD to:

- (1) protect Medicaid beneficiaries from serious abuse, neglect and financial exploitation,
- (2) prevent individual loss of Medicaid beneficiary status or suffer penalties when local departments of social services avoid or dismiss their responsibilities
- (3) fulfill its obligations under the OPWDD HCBS waiver agreement for the assurances to CMS regarding oversight in the areas of quality of care, quality improvement, and incident management/reporting
- (4) enable proper independent functioning with adequate transparency of the Development Disabilities Advisory Council (DDAC) and OPWDD Independent Ombudsman Program (IDDO) enacted by the state legislature
- (5) engage stakeholders in full, open and useful discussion of changes to the OPWDD HCBS waiver.

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There are certainly other important matters that Senate and Assembly committees related to healthcare, Medicaid, long-term care and services to people with developmental disabilities should collaborate on with stakeholders on issue specific committee meetings. These issues include: CDPAP services for people with OPWDD eligibility, redesign of self-directed services, the roll out of the new Coordinated Assessment System (CAS), the use of the CAS to put in place new procedures for service access, rate setting for traditional agency-based programs, and the setting of personal budgets for people using self-direction, oversight of the Care Coordination Organizations (CCOs), the quality of Life Plans, and many other issues that families/self-advocates called out for many years. All of the issues just noted fall within the scope of shared responsibility of DOH and OPWDD. Glaring problems remain in the functioning of the CCOs. And OPWDD tries to distract from the fact that the CCOs are primarily the responsibility of DOH. The CCOs are health homes and they are state plan services. We need new action – **joint action** – by Senate and Assembly committees on health and disabilities to hold joint meetings on these problems after the budget is enacted this year.

It is extremely painful to finally acknowledge that the NYS legislature does not take corrective action when a terrible situation of harm befalls an individual with disabilities until it reaches the front page of major newspapers.

It may be better to just say – this testimony is not primarily aimed this time around to legislators or members of the executive agencies – this testimony is aimed at getting information into the public record for journalists and investigators. Given my personal challenges in the past week in the stability and availability of direct support staffing to assist me with medical/dental and other essential service needs I will not be able to complete the task I set for myself in this document. I will not be able to fully present the details of what I outlined above. Be that as it may this testimony sets down a marker – sets the stage for sending detailed statements in follow up to Senate and Assembly chairs and committee members. More importantly, it sets the stage for communication to Senate and Assembly leadership. In the past year, after some radical changes to disability services in the closing days of last year’s budget, many other advocates have made it clear that the good will and hard work of individual state legislators is all for nothing if the leaders of the Senate and Assembly do not have our backs – do not fully enable and enact protections for people with disabilities.

I pause here to ask you all to consider some of the investigative reports that Newsday has made in the past several years. One of the worst stories that struck me as a person with autism spectrum disorder was the story of Thomas Valva, an 8 year old boy with autism who froze to death when his parents had him sleep in an unheated garage. The Newsday investigation on April 30, 2023 examined aspects of the case, in particular the failures of Suffolk County Department of Social Services, Child Protective Services, to heed warning signs and protect that

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boy. OPWDD and DOH were not evidently involved in that case and failures of oversight appeared to occur at the level of the local department of social services. It is my direct experience, concurring with reports that I have heard other family advocates, that similar systemic problems of protective oversight for people who receive OPWDD services. I have not heard of cases that led to the death of a person with developmental disabilities, but I know of failures in the OPWDD incident management system. More recently, Newsday published an investigation entitled “Unregulated Home Care” on November 23, 2025. The take away for my testimony is that it appears that DOH dragged its feet and did not fully proceed with action against an unregulated home care agency until a major newspaper did an investigation. I urge you all to read the full investigation.

Unlike my budget public testimony in prior years and various public comments I must add personal matters to this testimony. I do so in a careful way and avoid using specific names of parties involved in personal disputes involving abuse, neglect or exploitation and do not use names of individuals in state agencies or provider organizations. I address points (1), (2), and (3) above here. In August 2021 I had an interruption in the assistance from both the regional OPWDD office and my CCO in efforts they were making in regard to abuse, neglect and financial exploitation from my siblings. I have referred to this in a bit more detail to put a dollar number on it in a public comment I made at the conclusion of a DDAC meeting last year. In the past two years I have sought corrective action from my county Department of Social Services and then sought review and action by DOH. My efforts with DOH are still underway and not concluded. However, so far DOH has delayed and avoided its responsibilities related to Medicaid beneficiary status and although I have continuous Medicaid benefits now there are retrospective risks. DOH has failed to do proper oversight and corrective measures related to financial matters that siblings have intervened on wrongfully and DOH has failed to act on violations of privacy in this matter. I should not provide further detail now out of caution. However, I see I am running close to the deadline to submit this document. I will focus in the coming days to send more detail on the failures of DOH and OPWDD to perform its duties to protect us and address details on policy matters noted above. My focus in the coming days is clear – send this information first to the leadership of the Seante and Assembly, then send it to the relevant committee chairs. And of course bring it to the attention of mainstream media.

The following section inserts the public testimony I submitted to the
Mental Hygiene hearing last week

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

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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

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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.

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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.