

# Care Design NY Advisory Board Plan Input Letter to OPWDD Commissioner

Individuals' and families' input into OPWDD's  
five-year comprehensive strategic plan.

July 30, 2021

Office for People with Developmental Disabilities  
Attention: Dr. Theodore Kastner, Commissioner  
[planning@opwdd.ny.gov](mailto:planning@opwdd.ny.gov)

Re: Individuals' and families' input into OPWDD's five-year comprehensive strategic plan

Dear Commissioner Kastner:

The Care Design NY Individual & Family Advisory Board advocates on behalf of the 29,000 members who receive care management from this Care Coordination Organization (CCO). We're submitting this letter as our input into OPWDD's formulation of a comprehensive five-year strategic plan.

Many individuals and families, and especially those who have seen the system evolve over the last ten years, experience the system as one that is in crisis. OPWDD hasn't released data on the wait for services, on shortages of staff and care managers, or on the need for more person-centered options in the least restrictive settings. The lack of transparency itself points to a system that cannot be accountable to its stakeholders. Nevertheless, the collective testimony of the five regional 5.07 forums speaks to the urgent need for stronger supports for people who have intellectual and/or developmental disabilities (I/DD). Formulating a comprehensive strategic plan with the collaboration of stakeholders is an opportunity for OPWDD to begin to repair and restore its system of services.

In a fiscal climate where we expect the executive budget to underfund services, there will be strong motivation to shape the strategic plan to the expected budget. But the statute requires otherwise. Section 5.07 of the Mental Hygiene Law mandates the agency to formulate a plan that will "identify services and supports . . . that are designed to promote the health and wellness" of people with developmental disabilities and that will "encourage and promote person-centered, culturally and linguistically competent community-based programs, services, and supports." The commissioner submits the plan to the governor each year "in order that such plan may be considered with the estimates of [OPWDD] for the preparation of the executive budget". Should the budget underfund the services, changes are to be included in the interim report submitted by March 15 of each year along with budgetary or other justifications. To uphold the integrity of the process, the plan's priorities and goals, strategies and initiatives, must fully represent the needs of its stakeholders.

## Care Design NY Advisory Board Plan Input Letter to OPWDD Commissioner

Prioritizing person-centered care will allow OPWDD to design a system that can succeed. In the strategic plan, the compromises that a system makes to conserve resources must be avoided. Using a crisis model, delaying access, constricting services by acuity, offsetting gains with cuts, and applying unrealistic rate setting – all create inefficiencies and inequities that would undermine the plan from within. As advocates and self-advocates, we wish to support OPWDD in formulating a plan that has person-centered care as its guiding principle: a plan which is informed by individual- and family caregiver- determined needs.

This letter highlights some of the specific goals and initiatives that we believe a person-centered plan requires.

### Workforce Stability of Direct Support Professionals (DSPs)

**Bolster DSP recruitment and retention with no offsetting cuts.** We strongly agree with the overwhelming sentiment of the advocacy movement that OPWDD should address the system-wide workforce crisis by making major investments in DSP recruitment and retention. For these investments to not destabilize the system elsewhere, the strategic plan must reject the premise of budget neutrality, which would force offsetting cuts through measures such as reducing staff-intensive services, increasing staff-to-person ratios, or setting unsustainable reimbursement rates.

### Care Management

In a system that delivers life-sustaining care to 122,000 people across 11 service categories, care coordination is the service that makes all the others accessible. For each individual or family member who testified at the 5.07 regional forums about their difficulty accessing a service – regardless of acuity level -- there is a care manager who is identifying a need, researching providers, submitting applications, arranging meetings, and updating Life Plans. Every weak point in the system compounds the work that the care manager must do for the same outcome. For individuals who don't have a strong advocate in their circle of natural supports, their care manager is the only person they can look to for conflict-free advocacy. Person-centered care cannot exist without a robust network of local Care Coordination Organizations/Health Homes. We urge OPWDD to adopt the following goals:

- 1. Increase the average time per person that care managers devote to coordinating care.** Overburdening Care Managers results in otherwise avoidable lapses in care and less selectivity in program placement for individuals. We urge OPWDD, as a priority, to establish a plan with reasonable timelines that will
  - a. reduce regulatory and non-regulatory requirements that OPWDD places on care managers, and support remaining requirements with better data infrastructure
  - b. assign priority levels or tiers to individuals that more accurately reflect relative need

## Care Design NY Advisory Board Plan Input Letter to OPWDD Commissioner

- c. prioritize funding to expand the care management workforce in proportion to the expansion of the I/DD population
- d. make it easier for care managers to track the status of each request for service, from the initial application through approval and final receipt
- e. ensure that supporting individuals during pre-enrollment is a duly considered part of the care manager's workload
- f. improve the template for the Life Plan to make it more user-friendly, flexible, and person-centered

We believe that all stakeholders will benefit if OPWDD seeks the CCOs' input on reforms that will result in manageable workloads and invites their increased participation at meetings that impact policy.

**2. Increase the average time per care manager that supervisors devote to oversight and support.** Unmanageable workloads and vacancies among care managers lead to supervisors' taking on caseloads in addition to their supervisory duties. Temporary assignments to supervisors disrupt the continuity of care that individuals need with their primary advocate. These assignments also impact the ability of supervisors to provide quality oversight and support to the care managers in their team. We urge OPWDD to establish a plan with reasonable timelines that will

- a. reduce the regulatory and non-regulatory requirements that OPWDD places on supervisors
- b. reduce the necessity of supervisors to assume the role of care manager

**3. Improve workforce stability among care managers and supervisors.** Delivering person-centered, comprehensive, and integrated care coordination across all life domains, as OPWDD has committed to do in previous waivers and strategic plans, requires a stable workforce of care managers and supervisors who are highly trained and experienced. However, turnover and vacancy rates among care managers and supervisors threaten a workforce crisis similar to the one currently involving DSPs. Often overlooked is the personal cost to the individual that results from each assignment to a new care manager: disruptions to the already difficult process of accessing services and needing to build a time-intensive relationship anew. We urge OPWDD to plan for sustained CCO funding that will allow CCOs to address issues of recruitment and retention of qualified care managers in a competitive job market.

**4. Give care management teams ongoing access to nursing and medical professionals.** One of the imperatives driving the creation of CCOs was the mandate for comprehensive care management as a Health Home (HH). We believe that it is not feasible for care managers to meet this standard without ongoing access to a corps of nursing and medical professionals who can timely respond to concerns and consistently review the members' health and medication records. We urge OPWDD to establish in its comprehensive plan the support that CCO/HH organizations require to provide this critical health promotion resource for people with I/DD.

## Housing

A system of certified residential services, at an average cost of \$128K for approximately 37,000 individuals -- at a total cost of over \$4.7B in FY 2020 – is a prime target for obvious and not-so-obvious cost-saving measures. Individuals rely on OPWDD to uphold person-directed care in the least restrictive setting as the driving motivation for the residential goals and initiatives in the strategic plan. A person who doesn't have suitable housing options cannot have self-determination. Even when the residential setting is available and appropriate, low DSP-to-resident ratios and arbitrary group-home compositions will significantly restrict an individual's community integration and home contentment. We look to the DDAC and advocacy groups to provide stakeholder input that comprehensively addresses the ongoing residential crisis for people with I/DD who need housing support. As individuals and families, we urge OPWDD to establish a plan with reasonable timelines that will

**1. Collect and release data that show the full extent and duration of the unmet need for housing services.** To estimate the resources that are required to provide a home for all of the people who need one, the strategic plan must include, for each priority level, the data regarding

- a. the wait for a first home
- b. requests to transition to a different type of residential option
- c. requests to transfer to a different home and/or agency within the same category of housing
- d. the need for more staffing support or other types of residential services within the person's current home

**2. Increase the availability of non-certified and self-directed housing supports with tailored services that meet the full range of individual- and family caregiver- defined needs.**

**3. Redefine acuity-based staffing needs.** Residential reimbursements and staff-to-resident ratios should be determined by the amount of support a person needs in order to realize the person-centered Residential Habilitation goals in their Life Plan. The amount of support that a person needs to meet their goals is often not correlated with their assessed level of disability.

**4. Deprioritize Adult Foster Care, which OPWDD calls Family Care.** According to OPWDD's Data Book, Adult Foster Care has already seen a 25% reduction in the number of people using this service since FY 2016. We believe Adult Foster Care is incompatible with person-centered care for the vast majority of people who have moved out of their own family's home as an adult.

**5. Increase training of DSPs in positive behavioral management.** People with I/DD can experience many challenges in their social environment. Positive behavioral management is an area of staff development that has been shown to be effective in improving quality of life for individuals and job satisfaction for staff.

### Day Programs

Over the past several years, OPWDD has promoted a shift from site-based Day Habilitation programs to community-based day services, commonly known as Programs without Walls (PWW). The agency's proposed expenditure plan for funds from the American Rescue Plan Act of 2021, for example, includes \$30M for just this purpose, contingent on providers' compliance with a capital expense reduction plan. The justification for this shift, as offered in the expenditure plan, is that these new day supports "are more person-centered and better integrated in the broader community, increasing capacity to serve more people". As individuals and families who have collective experience with both types of programs, we believe OPWDD would better achieve these goals with the following approaches:

**1. Maintain site-based Day Habilitation programs with adequate availability as an option.** Advocates and self-advocates testified during the 5.07 regional forums that individuals who have complex needs have disproportionate difficulty in finding day habilitation services. For many of these individuals, programs that lack their own facility are not viable. Moreover, removing the physical center does not by itself make a program more integrated. There were many site-based programs which have since closed that had extensive community activities. There are also many Programs without Walls whose activities in the community allow for little meaningful interaction between individuals and people outside the program. A comprehensive plan that is needs-based rather than cost-based would support the option of site-based day services with the flexibility to offer community activities. This would include specialized site-based day programming within immigrant communities.

**2. Monitor and reduce travel time in both site-based and community-based programs.** In all regions, many individuals are spending an excessive amount of time in travel – during pickup, drop-off, and between activities. Some PWW programs try to reduce travel time by composing groups according to where individuals live. This approach can lead to groups in which members' needs and goals are so disparate as to make a person-centered program virtually unattainable. We urge OPWDD to monitor travel time as one measure of the availability of programs, in conjunction with how day habilitation groups are composed.

### Self-Directed Services

**Provide supports that allow people to continue to live their self-directed lives in their communities after their families are gone.** Increasing numbers of people served by OPWDD are opting for Self-Directed Services, and many will be moving into non-certified housing. Although each participant has a circle of support, the bulk of administration for the plan usually falls on their parents, who will inevitably age and die. OPWDD must ensure that self-directed services are accessible and sustainable for people who no longer have families. The answer to this may look different in different areas of the state and should be developed by initiating pilot programs that are designed to explore options.

## Coordinated Assessment System (CAS)

**Conduct an annual quality assurance evaluation of the CAS.** Under Section 5.07, the advisory council on developmental disabilities (DDAC) is charged with providing recommendations for statewide priorities and goals to guide “evaluation processes for state and local services” for persons with developmental disabilities. OPWDD is charged with considering such recommendations when it establishes the five-year statewide comprehensive plan. As one key evaluation process, we urge the advisory council and OPWDD to ensure that the 5.07 recommendations and plan include an annual CAS quality assurance evaluation process. Such a process should evaluate the reliability of the CAS assessment tool and would take into account individual, family and stakeholder issues and complaints surrounding the CAS process and results. This quality assurance evaluation is especially vital if OPWDD intends to use an individual’s CAS acuity score to determine eligibility for services and programs, as OPWDD has signaled.

## Inclusion, Equity & Access

We agree with OPWDD’s emphasis on improving inclusion, equity and access. This goal can be accomplished only through planning for dedicated recruitment and retention of Direct Service and Care Coordination Organization staff with demonstrated language and cultural competency to meet the needs of the State’s diverse population. Planning should also include ongoing training of all staff in these areas.

## Transparency and Accountability

To safeguard OPWDD’s mission and system of care, transparency must become one of the agency’s highest priorities. Maximizing transparency allows stakeholders to identify trends and impending crises in the system. It gives individuals and families confidence that decisions are being made on a rational basis. And in times when resources are scarce, it gives us a way to advocate for evidence-based needs and reforms. We urge OPWDD to embrace transparency in service utilization, program effectiveness, compliance, and budgeting as an integral and indispensable element in carrying out its mission. To advance this priority, we look to OPWDD to:

**1. Release an analysis of unmet need during OPWDD’s collaboration phase with the advisory council on developmental disabilities and other stakeholders.** Section 5.07 mandates that the strategic plan will “provide analysis of current and anticipated utilization of state and local, and public and private facilities, programs, services, and/or supports” before it is submitted to the governor. An analysis of anticipated utilization must include an analysis of current unmet need in a strategic plan whose mission is to fully meet the needs of the people it serves.

**2. Include an independent, comprehensive review of transparency and accountability as a major initiative.** Such a review would encompass:

- a. the adequacy of OPWDD's data infrastructure in supporting the analyses that are required to develop, administer, and report on its system of services
- b. the extent to which the agency assesses individuals' needs and satisfaction with services, as determined by the individuals and family caregivers
- c. accountability measures that are available to OPWDD and to stakeholders for assessing and improving on the delivery, quality, and equity of person-centered services
- d. the extent to which the agency assesses the stability of the residential and care management workforces and the factors that impact it
- e. OPWDD's compliance with mandated disclosures to government and non-profit entities, on public-facing websites, and to the public upon request
- f. the correlation between budget allocations and the full extent of individuals' self-determined needs
- g. the additional resources that providers and CCOs would require to provide data to OPWDD without incurring additional unfunded mandates

To help OPWDD advance its strategic objectives, such an independent review should be prioritized and its recommendations implemented by OPWDD.

**Conclusion**

It's been approximately ten years since OPWDD has benefited from the annual review process of a strategic plan. Many individuals and families are experiencing a system in crisis at the same time that OPWDD has been making efforts to remove resources from the system. As a result, the partnership between OPWDD and stakeholders has been eroding, as was evident from much of the testimony during the regional public forums.

The goals and initiatives that we propose here are designed to place people's needs at the center of the strategic plan, and to advocate for those needs by bringing to light the disparity between them and the supports that are currently available. The process mandated by Section 5.07 creates an opportunity for individuals and families to join with OPWDD in creating a vision of a system of care that above all else respects the people whose lives it will shape. Its success will depend on the commitment and transparency it has to the people it most directly impacts.

Sincerely,



Karen Azarian, on behalf of the Care Design NY Individual & Family Advisory Board

cc: Christopher Tavella, Deputy Secretary for Human Services and Mental Hygiene, Office of Governor Andrew M. Cuomo  
Nick Cappelletti, Co-Chair, Developmental Disabilities Advisory Council  
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