Care Design NY Individual and Family Advisory Board
Comments on OPWDD's 2023-2027 Draft Strategic Plan

July 29, 2022

Office for People with Developmental Disabilities
Attention: Commissioner Kerri Neifeld
planning@opwdd.ny.gov

Re: OPWDD's 2023-2027 Draft Strategic Plan

Dear Commissioner Neifeld:

The Individual & Family Advisory Board of Care Design NY is submitting this letter as our response to OPWDD's draft of its 2023-2027 strategic plan. Over 27,000 people who have intellectual and/or developmental disabilities (IDD) receive care management from this Care Coordination Organization (CCO).

For many people with IDD, the system has unraveled beyond the ability to provide even basic supports. A self-advocate, BJ Stasio, testified at a senate hearing last September that he sleeps in his wheelchair because he doesn't have staff who can help him in the mornings. He had been doing that for two years. In June, The New York Times profiled three families whose children had recently spent 44, more than a hundred, and 154 days confined to a hospital room as they waited for a placement in a residential school. The article linked to a Kaiser Health News investigation that found New York had "some of the longest hospital stays in the nation". That study was published in 2017.

OPWDD doesn't release data on the wait for services or the scarcity of options. The lack of transparency itself points to a system that cannot be accountable to its stakeholders. But all over the state, Local Government Units (LGUs) have been bluntly documenting the "high unmet need" for more essential staff, day programs, housing, employment, clinic services, transportation, and budget supports – since long before the pandemic. The collective testimony from stakeholders at public hearings and in the 5.07 forums describes an ever-worsening state of emergency that can be accepted as the status quo only if the basic needs of people with IDD are discounted.

The new leadership at OPWDD can begin to change this. It can submit to the Governor a robust strategic plan that lays bare the unmet needs, describes the actions and investments that are sufficient to meet them, and prioritizes those initiatives. We wish to support the Commissioner in revising the draft plan to better accomplish its goals.

Unmet Need, Anticipated Utilization, and Measurable Outcomes

Section 5.07 of the Mental Hygiene Law requires the plan to have the critical purpose of informing the executive budget. The draft plan acknowledges that there are gaps in services and a workforce shortage, and provides summary data on some service use over the past five years. But we don't see the "analysis of current and anticipated utilization of state and local, and public and private facilities, programs, services, and/or supports" that the plan is to provide. A solid analysis would answer questions about current utilization that would drive policy and, critically, estimate what current utilization would be if everyone who needs a service could access it. What does the input from stakeholders, the DDAC, and the LGUs – and OPWDD's own data -- say about the gap between the demand for services and their availability? To anticipate utilization without first addressing the current unmet need for each type of service would imply that the strategic plan is a plan for some people with IDD but not for others.

What is OPWDD's projection of the need for services going forward? The lack of any analysis of anticipated utilization in this draft makes it virtually impossible for the plan to be strategic. Will OPWDD continue to be caught unprepared for the rapid increase in people who choose self-direction? Is the system ready for the number of people who will age out of children's services or receive a diagnosis of autism, and to provide the kinds of supports that they'll likely seek? Are programs flexible enough to accommodate people with IDD who are reaching advanced age? It's been ten years since OPWDD has had a comprehensive strategic plan. It is time for the agency to share its vision of what the need for services will be through the next five years, taking into consideration the changes that will result from demographic shifts, financial pressures, and its own policies.

In the forums that the agency has hosted for stakeholders, many individuals and families have called for the plan to include specific, measurable outcomes. We're confident that the Commissioner has heard us. Measurable outcomes will allow us each year to evaluate whether the initiatives are meeting their goals. But immediately, measurable outcomes will tell stakeholders and the legislature how much of the actual need OPWDD intends to meet.

As it stands now, we notice that the draft plan has only a small number of initiatives that would require ongoing state funding. A majority of the proposed initiatives rely on already-designated funds from the American Rescue Plan Act of 2021 (ARPA) or the Office of Mental Health (OMH). Many other initiatives are time-limited pilot programs, one-time studies, or unspecific commitments to "explore". We appreciate the plan's proposals to train, educate, and engage stakeholders and other members of the public. We also recognize OPWDD's steps to make the rate increase for Intensive Behavioral Services (IBS) permanent and to increase housing subsidies and new capital funding for its Integrated Supportive Housing program (ISH). We're encouraged by the establishment of the Offices of Diversity, Equity, and Inclusion (DEI) and of the Chief Disability Officer. These and other initiatives are welcome and needed**.** But when we

look to the draft plan for a sizable expansion of any service or support -- a year-over-year increase in program capacity or the recognition that Direct Support Professionals (DSPs) must earn a living wage -- we see little commitment to meet the needs of the moment. At a time when all of us are struggling with the consequences of years-long underfunding compounded by the long-term effects of the pandemic and the workforce emergency, excluding initiatives that require state investment would be a plan for the system to fail.

If cost-cutting is the driving force of strategic planning, OPWDD will be proposing initiatives that work against its own goals. Incentivizing providers to replace site-based Day Habilitation (Day Hab) with Programs Without Walls (PWWs) will leave more people with complex medical or behavioral needs without a program that will accept them. Making certified group homes accessible only to people who have the most urgent need will mean that thousands of other people will have no choice but to remain in their family home for years into adulthood. Maintaining unrealistic subsidies and reimbursement rates will mean than access to services will become more dependent on whether the person has a family who can pick up the costs. Underpaying DSPs will leave people without the staff who will help them integrate in the community.

We urge OPWDD to submit a plan that fulfills its purpose of informing the budget. As the 5.07 statute anticipates, should the executive budget underfund the services that are needed, OPWDD can modify its plan of services with budgetary justifications in the interim report that the Commissioner submits in March. But the limits on what OPWDD can promise should not determine what the agency can acknowledge. Acknowledging the full extent of unmet needs in the strategic plan argues for funding in the best interests of its stakeholders and allows OPWDD to maintain person-centered care as its guiding principle.

This letter highlights some of the analyses and measurable outcomes that we believe the draft plan should provide and some of the investments and reforms that we believe its goals and objectives require.

DSP Workforce Shortage (Objective 2.1)

We strongly agree with the IDD advocacy movement, OPWDD, and Governor Hochul that the system-wide workforce emergency must be resolved by launching a major campaign to recruit and retain DSPs. Like other advocates, we remain convinced, however, that people with IDD will have a reliable, skilled workforce only when New York pays DSPs a living wage. Without these new investments, the supports that OPWDD designs and even approves will remain on paper. Estimating the scale of that investment would require:

1. Data on the workforce shortage. The data that the draft plan provides on DSP vacancy and turnover rates doesn't tell us the full scale of the workforce shortage. The average vacancy rate among the voluntary providers who responded to the NCI Staff Stability Survey in the 2020

calendar year (CY) was 17.2% and 21.34% for full-time and part-time DSPs, respectively. (No comparable data for the OPWDD workforce was reported for any year). But we don't know how these vacancy rates translate to the number of new hires needed systemwide. Nor do we know the vacancy rates among the different service categories. In the middle of a workforce emergency, the most recent data are over 1 ½ years old. And perhaps the biggest unknown isn't the number of positions that DSPs have vacated, but the number of positions that would need to be filled to deliver all of the services that eligible people want. How will vacancy rates be calculated when so many programs have closed and so many others were never opened? The draft plan should report what is known about the extent and characteristics of the workforce shortage and describe how OPWDD will collect the data that it doesn't have.

2. Identifying the reasons for workforce stability. Major investments to increase DSP retention will be strategic only if OPWDD resolves the reasons why DSPs leave. DSP representatives have testified that wages, forced overtime, and the lack of training in behavioral management are some of the reasons for high turnover. According to NCI Survey data for CY2020, the turnover rate was 14.6% in the OPWDD workforce and 35.6% among voluntary providers. It seems apparent that the widening disparity in wages between the two sectors is a major factor in the two-fold difference in turnover rates.

3. Person-centered measures of impact and success. While systemwide vacancy and turnover rates are the metrics most often used when speaking about the workforce, it's important to consider workforce instability from the individual's point of view. A person may look around and see no direct care staff who's known them for more than three years. Their group home may have lost a number of full time equivalent DSPs months ago and still not have staffed those hours. Having only the minimum staff-to-resident ratio means that an individual can't go out into the community unless a group of their peers all want to do the same thing, or at least are all willing to go along for the ride. They may have a small fraction of hours of day services per week compared to what they had in the past or what they're eligible to receive. The recently hired staff may not notice gradual changes in behavior or physical condition. Staff tenure, vacancies, and turnover have compound effects that will be lost if the workforce shortage is measured only by those metrics. A career ladder may be an excellent way to increase DSP recruitment, but leave individuals with more staff who have little tenure working with them. Staff tenure, vacancies, and turnover can be seen not just as quick ways to gauge workforce stability but also as social determinants of health for people with IDD.

4. Past performance and projected outcomes. The draft plan describes several recruitment and retention initiatives that either replicate a pilot program or continue an existing collaboration. The plan should report on the outcomes of these initiatives and project, with timelines, the impact that all of the proposals are expected to have on specific measures of workforce stability.

Residential Services and Housing Supports (Objective 3.1)

For Residential Services and Housing Supports, as is the case for other key points, the draft strategic plan, at a high-level, sets forth goals and actions such as "strengthening internal review processes," "enhancing support for people in crises," and "maximizing certified residential capacity" (page 30). But the plan contains little or no detail to accurately measure success. OPWDD and others who rely on the plan, including the Legislature, need the ability to assess whether the mentioned actions achieve measurable goals.

We urge OPWDD to include in the revised plan:

1. Data on current and future need for residential services and housing supports. OPWDD needs to fully determine and disclose the numbers of individuals who have pending requests for all levels and categories of residential services and housing supports inside and outside of self-directed services. Without these numbers, it is impossible to know whether the existing resources are adequate or as is likely the case, inadequate to meet the current and future needs.

OPWDD also needs to make reasonable projections and disclose the numbers of adults who have not yet requested support or services but are likely to need residential and housing support in the coming years. OPWDD also needs to include reasonable projections for the numbers of individuals who within the next five years will be "aging out" of their existing housing and for those who wish to "age in place" and need accommodations.

This data needs to include full disclosure of waiting times for existing residential services and processing times for requested housing supports. Waiting times for services and processing time for supports, including updated housing subsidies, need to be measured and addressed, as an aid to planning and improvements in timely access. It is required to avoid adversely affecting individuals who otherwise will be unable to access the housing and supports they need in a timely fashion.

2. Data on currently available housing resources. OPWDD needs to fully determine and disclose the numbers and types of certified and non-certified housing (supervised and supportive IRAs) opportunities that are currently available in the State, including the locations of such housing and whether existing housing is currently utilized. An assessment of the number of affordable independent housing units also needs to be developed as OPWDD explores portable funding for people who choose to change their residential supports.

3. Accurate assessment of housing needs. OPWDD needs to accurately assess the needs and desires of those who currently request housing and those who will likely do so in the near future. This should include the needs of those who request transition from supervised to non-supervised settings, as well as those being transferred from residential settings outside of the State. OPWDD is apparently now using the Coordinated Assessment System (CAS) to develop

provider costs for a tiered rate structure to address the need to incentivize the placement of individuals with differing levels of need. Yet stakeholders continue to express concerns about the ability of the CAS to make accurate assessments of those with developmental disabilities. Many defects have been discussed with OPWDD including the inability of the tool to accurately assess behavioral and medical conditions that are serious but do not manifest within the 3-day look-back utilized by the CAS instrument. Additionally, a person-centered plan must, within reason, consider the desires and needs of the individual, and the planning tools should not lose sight of this important factor.

An effective plan also needs to recognize that for uncertified housing, the issue is not only support for a continuum of needs, but also the supports required to accommodate individualized choice.

4. Methods for measurement of success. A meaningful strategic plan needs to include a method to measure any success and setbacks in meeting the stated goals. In the draft, some general housing related goals are set forth, including "maximizing certified residential capacity to support people with the most complex needs and advocating for an increase in housing subsidy". But without the data and assessments mentioned above, there is no meaningful way to measure whether OPWDD is accomplishing these goals.

The Plan also mentions a few concrete action items for meeting the broad housing goals, namely 1) tiered rate setting based on people's need for support to recognize providers' costs; 2) smart home technology; 3) use of paid neighbors; and 4) development of portable funding for those who choose to make changes to residential supports (page 30).

Again, the plan needs the data and assessments to determine whether these actions once undertaken are working. For example, without an assessment of need and availability for 24/7 certified housing, and an accurate assessment of the level of care needed by the individual, how will OPWDD know whether the tiered rate setting is working? Even if more individuals are placed, the question will remain: Are individuals being correctly placed? How many are still waiting? And is the system able to place those who will be requesting such housing within the next years?

5. Further planning for 24/7 Housing Alternatives. The draft plan mentions as an alternative to 24/7 Individualized Residential Housing (IRAs) (page 30), supportive IRAs and Family Care.

a. **Pilot study for non-certified housing options.** The draft plan mentions the use of ARPA monies to increase access to non-certified housing, including those seeking placement into and transfer from certified housing. The broadly stated goal of expanding supportive housing to support more independent living arrangements considering the needs and preferences of the supported individual is an appropriate one. However, we believe that the touchstone of any supportive housing pilots should be flexibility. The studies should include the devotion of sufficient supports both during and after a

reasonable (not an artificially short) period for transition, methods to determine whether the new setting and supports are working, and flexibility for the individual to return to a higher level of support if that is needed.

b. **Family Care.** Most families consider Family Care as simply Adult Foster Care and are alarmed that this option has resurfaced in this plan as a meaningful housing option. We recognize that it can meet the needs for some people on a short-term basis and in emergency situations, it is simply not a stable alternative. Family Care is not robustly monitored by OPWDD and a provider can abruptly terminate the arrangement without ensuring an appropriate replacement. OPWDD should not promote this option as part of its strategic plan.

Coordinated Assessment System (CAS) (Evaluation, Objective 3.1)

Appropriate means to evaluate an individual's level of support need is vital to all plans related to person-centered service delivery. In conformance with 5.07 requirements regarding "evaluation processes for state and local services", such a process should evaluate the reliability of the CAS as an assessment tool and as part of that evaluation, consider individual, family and stakeholder issues and complaints surrounding the CAS process and results.

Whether or not an annual CAS quality assurance evaluation is undertaken, the plan should include a process to consider individual, family and stakeholder issues and complaints surrounding the CAS. This would also further OPWDD's stated goal to "promote additional opportunities that increase transparency and access to information." Individuals, families, and other stakeholders remain concerned about the CAS's validity and reliability, and the way it is being administered. Listening to and addressing these concerns could result in improvements to CAS administration to ensure that it is a credible assessment tool that truly reflects the strengths and weaknesses of those it assesses.

Care Management (Objectives 3.1 and 3.3)

Care Coordination Organizations/Health Homes were designed, established, and put into operation during a period in which OPWDD had no strategic plan. CCOs not only coordinate every service request for 122,000 people but are also now responsible for guiding every new applicant who wants to enter the system through the extremely complex process of applying for eligibility. The draft plan's sole new initiative for care management is, in collaboration with CCOs and stakeholders, to use ARPA funds to engage an external consultant to conduct a program evaluation that will inform a quality improvement strategy.

Individuals cannot enter the OPWDD system, develop a person-centered plan, access any service, or have conflict-free advocacy in a crisis without a care manager who is experienced,

available, and supported by a CCO. Every weak point in the system compounds the work that the care manager must do for the same outcome. As a result, individuals experience avoidable lapses in care, errors, and hurried decisions. The approximate 20% vacancy rate among care managers is comparable to the vacancy rate among DSPs that we recognize as an emergency. Each assignment to a new care manager or temporary assignment to a supervisor comes at high personal cost to the individual, disrupting the continuity of care that they need with their primary advocate.

We urge OPWDD not to wait for the findings of a consultant after a lengthy process before addressing obvious unmet needs in the care management system. As members of the Individual and Family Advisory Board, we are intimately aware of the many challenges CCOs and their members are facing.

1. Unmet needs in care management. Given OPWDD's recent engagement with CCOs and stakeholders, the draft strategic plan should identify unmet needs in care management, measures to assess them, and future planning that addresses them. We would identify the most impactful unmet needs as:

a. average time per person that care managers devote to coordinating care
b. average time per care manager that supervisors devote to oversight and support
c. ability of care managers and supervisors to intensively advocate for people in a time of crisis
d. average length of the individual's relationship with their care manager; number of different care manager assignments in a period of time
e. care managers' access to nursing and medical professionals
f. using the Life Plan as an opportunity to collect data that OPWDD can use to assess unmet needs and drive policy reforms

2. Initiatives to address unmet needs in care management. Individuals and families need immediate support in obtaining services and managing crises, a need that has been intensified by the workforce emergency, delays and obstacles in the approval process, and an appeals process that overwhelms the individual. The strategic plan should include initiatives that improve care management, such as:

a. Reduce nonproductive regulatory and non-regulatory requirements that OPWDD places on care managers and supervisors.
b. Assign priority levels or tiers to individuals that more accurately reflect relative need and individual/family wishes
c. Ensure that support for individuals during pre-enrollment is a duly considered part of the care manager's workload
d. Prioritize funding to expand the care management workforce in proportion to the expansion of the I/DD population
e. Launch a recruitment and retention campaign for care managers and their supervisors

f. **Establish an interactive OPWDD portal that will make it easier for care managers to track the status of each request for service, from the initial application through approval and final receipt**
g. **Improve the template for the Life Plan to make it more user-friendly, flexible, and person-centered.**
h. **Enhance care manager recruitment outside the IDD system.** DSP staff constitute the main pool of care manager recruits, making CCOs compete within the IDD system for professionals who are already scarce and in high demand. Allowing CCOs to develop intensive paid internship programs with institutions of higher education as an alternative to the two-year experience requirement could bring new care management professionals into our system.
i. **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, behavioral health and medical professionals who can quickly respond to concerns and consistently review the members' health, behavioral, 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.

Employment (Objective 3.1)

We appreciate the initiatives that OPWDD promises to begin or explore that are designed to close the wide gap in the employment rate between people with IDD and New Yorkers in general. These include, among others, improving measurement of employment outcomes, incentivizing Day Hab programs to include Pre-Voc and career planning activities, training Care Managers to support employment goals, and promoting the inclusion of people with IDD in job placement initiatives. However, we believe that for employment to be a viable option for many more people with IDD, OPWDD should implement a systemic approach over the next five years:

1. Prioritize the measurement and transparency of employment outcomes and unmet need.

a. **Collaborate with the Department of Labor to collect data on the number of employed New Yorkers who are in the distinct subgroup of having neurodiversity or IDD.** This data should distinguish extents of employment, such as part-time, full-time, per-diem, or through contract.

b. **Use IEPs, Life Plans, and Vital Research interviews to collect actionable employment data on unmet needs and positive outcomes.** Life Plan and Vital Research data fields could include average hours per week in employment, volunteer, pre-voc, and Day Hab programs or activities; desire to receive employment services or increase employment

hours; and average hourly wage. Employment data should be analyzed with enough depth to allow publicly reported analyses to inform policy, including how to address disparities in access to employment programs by underserved populations.

c. **Specify year-over-year performance standards and report on performance outcomes for the Department of Education's ACCESS-VR and BOCES and OPWDD's pre-voc and SEMP programs**. Public reports should again present enough analysis to inform decision-making, drive reforms, and reveal any disparities that affect underserved populations.

2. **Overhaul current services for a better employment journey from beginning to end.**

a. **Enhance the ability of Life Plans and any assessments, such as the CAS and IAM, to better incorporate employment goals.**

b. **Ensure a person-centered approach in assessments of employability and in job development.** People who can be successfully employed can nevertheless be excluded from Pre-Voc or SEMP programs. Barriers to access include poor preparation for the assessment or interview process, staff who are unfamiliar with an individual's conditions for success, assessments that have implicit bias, or a range of job options that is too narrowly circumscribed. Job-carving – customizing a job in the community so a person with disabilities can perform it and still meet the needs of an employer -- should be promoted. OPWDD should ensure that programs that determine access, train, or place people for employment are using holistic approaches that can accommodate a variety of skill sets and interests among people with IDD.

c. **Improve job-readiness and the transition from school to employment among youth across the state.** Children with IDD receive very uneven preparation for employment. Outcomes-based payment models using data from IEPs, school job training programs, ACCESS-VR, and BOCES should be used to incentivize performance. More effective collaboration among care managers, schools, families, and employment programs can facilitate the transition to adult services by educating families about which programs to apply for and communicating the person's skills to those programs.

d. **Reform regulations to facilitate employment.** If as mentioned in the draft, Day Hab programs will be incentivized to provide Pre-Voc and career-planning services, Day Hab staff should be cross-trained and reimbursement regulations should allow for seamless job development and placement. DDRO approval should be fast-tracked for temporary, more intensive job coaching if an employee's existing responsibilities change or they experience a new challenge.

e. **As mentioned in the draft, enhance work pipelines and post-school education and training opportunities.** Initiatives could be based at colleges and universities, trade

schools, and on-site with businesses and potential employers. Robust and accessible job boards need to be created for individuals, advocates, employment specialists, and care managers to access. Digital/virtual avenues such as LinkedIn, OPWDD's website, and other social media platforms can also be leveraged to connect employers with job-seekers in real time.

f. **Expand the "model employer" initiative and inclusive hiring practices.** We hope to see OPWDD collaborate with the Department of Labor to acknowledge and support businesses and entities who become "model employers", incentivizing others to follow suit. In addition, the DOL must move towards a set of DEI standards around hiring practices that expand and diversify employment opportunities for neuro-diverse candidates. Employers should be measured on their ability to meet such standards and be supported in their journey, which includes education, training, and resources in the areas of recruiting, onboarding, and retaining employees with IDD.

g. **Propose innovative models to provide transportation.** As relates to most OPWDD service delivery, transportation has become a significant barrier to access employment services, especially in the more rural upstate communities.

3. Ensure that outcomes-based payment methods do not create a barrier to access. Outcomes-based incentives can have the unintended effect of restricting programs to people whose successful outcome is most immediately apparent. When program availability is limited and assessments of "employability" are subjective, people can unjustifiably be shut out of having any job prospects. OPWDD must ensure that its incentives are not designed to penalize programs and DSPs who work with people who present initial challenges.

Self Direction (Objectives 3.1 and 3.3)

We appreciate OPWDD's recognizing the importance of Self-Directed Services (SDS) to people with IDD and their families. We also appreciate OPWDD's goals to improve access to and strengthen the system, though we believe that they would benefit from being more specific, including action plans, and using measures of success that can be regularly reviewed. As stated on OPWDD's website: "Anyone who is eligible for OPWDD services and enrolled in the Home and Community Based Services (HCBS) Waiver can choose to self-direct their services." OPWDD should continue to move toward that promise.

SDS participants and families must be an integral part of planning. The 5.07 plan reports stakeholder concerns in great detail. We see that you have heard those concerns. However, individuals, families, and advocates have been providing almost identical feedback along with concrete recommendations for over ten years.

OPWDD's only substantial proposal for Self-Directed Services in the five-year plan is to use ARPA funds to engage a consultant. The consultant would "work collaboratively" with OPWDD and stakeholders to produce a plan to improve SD. This sounds fine in theory. In similar past efforts, however, the role of families and individuals has been marginalized. Individuals and families have been given a forum to express opinions, but no opportunity for robust involvement in policy development. This has led to impractical recommendations. For example, the last OPWDD consultant report recommended eliminating independent brokers, which was unrealistic given the structure of our current system.

New York's SDS option is unique among the states, both by the amount of money spent and the flexibility available to support people with complex needs. Family members, brokers, advocates, and fiscal intermediaries have developed extraordinary on-the-ground expertise which would take a consultant a lot of time and money to acquire. Further, there are many challenges and innovative practices that we should be starting *now*, not in the months to years it will take to produce and act on a report.

We recommend:

1. Use the ARPA-funded consultant to facilitate a broad stakeholder group, including people from OPWDD with decision-making power, to collaboratively come up with solutions. This would leverage the breadth and depth of knowledge and creative ideas that NYS already has developed.

2. Ensure timely access to Self-Directed-Services by decreasing delays in approving SD budgets and making budget modifications more flexible and less onerous.

Everyone involved with SDS is aware of the tremendous delays in the approval and re-approval of budgets, as well as major and cost-neutral budget amendments (CNBAs). These delays essentially result in denials of service and have real effects on peoples' everyday lives. Two potential strategies to increase flexibility and streamline administrative processes are:

- Reducing the need for CNBAs by combining categories within the lines for Other Than Personal Services (OTPS) and Individual and Directed Goods and Services (IDGS).
- Raising the $1,000 limit on CNBAs, which would be cost-effective and align the limit with current costs.

We are aware that some states have chosen to engage an outside administrative organization in an attempt to "simplify" SDS and make it "more efficient." While there are many aspects of fiscal intermediary services that should be improved, such as a centralized clearinghouse for self-hired staff, contracting out FMS to an outside agency will inevitably degrade the quality of service delivery and how people live their lives.

3. Develop options for people who don't have family to support them to stay in their homes and communities. We are disappointed that this five-year plan contains no substantial initiatives to increase the access to or sustainability of SDS for people who do not have a strong circle of support.

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. At the same time, there are many people who would opt for SDS but don't have family available to help. Innovative brokers throughout the state have begun to do this "enhanced broker" work on a small scale, but these options must be further developed and evaluated.

In stakeholder discussions with OPWDD on the use of ARPA funds, families were told multiple times that RFPs would be issued to support pilot programs for enhanced support models, but none have been forthcoming. We can avert inevitable emergency placements by including these pilot projects in the 5.07 plan.

4. Expand and improve SDS services for people with complex needs, including people who need behavioral supports. SDS should be accessible for all. It is not an option on a continuum, acceptable for only those people with the least intense support needs. Instead, people should get the supports they need in the environment they choose. There are many participants with intense cognitive, health or behavioral support needs who are successfully living the life of their choice using SDS. In fact, OPWDD data collection several years ago indicated that there was a larger than anticipated number of participants with histories of significant behavioral challenges successfully being supported with SD. We recommend that initiatives designed to support people with complex needs, including behavioral supports, should consider that these will be used by people who self-direct as well as those in traditional services. Models including *ongoing* direct clinical consultation to family and support staff should be developed.

Diversity, Equity, and Inclusion (Objective 1.4)

We would like to recognize and strongly support OPWDD's Objective 1.4 -- "Identifying gaps in services to better meet the needs of underserved, culturally and ethnically diverse communities". The recruitment of a Chief Diversity Officer, ongoing participation in the Ramirez June initiative, and the targeted focus on addressing the needs of the Chinese and Spanish speaking communities are all welcome developments, as is the stated commitment to evaluate the impact of this work.

We recommend that OPWDD:

1. Publish more refined baseline data on the current level of participation of all communities in current OPWDD programs to measure improvement. Confining data collection to the use of overly broad demographic categories (e.g., Black, Asian, Hispanic, white) will inhibit planning and outcome measurement. It is essential to collect and share data on peoples' primary languages, including relevant dialects (e.g., multiple Chinese dialects, Haitian Creole, Urdu, etc.) Data should also reflect an individual's self-identification based on country of origin. This refinement would allow OPWDD to differentiate among Spanish speaking communities such as Dominican, Puerto Rican, Mexican, Cuban, and others; the diverse East and South Asian communities; and the multiple English-speaking Caribbean communities who are now reflected in the data as "Black".

2. Perform consistent outreach to Community Based Organizations (CBOs) from these communities to assist in community education and case finding. The initial challenge remains to ensure that people from underserved communities actually know about and apply for OPWDD enrollment. OPWDD, providers, and these CBOs must then collaborate in identifying the cultural enhancements that people from these communities need before they feel comfortable participating in OPWDD programs. These cultural enhancements might involve language, food, and recreational preferences, and desired employment opportunities.

3. Work closely with and support CCOs to ensure that they develop targeted care management and data collection strategies to ensure that members from underserved communities receive the same level of service referrals and have the same level of program participation as do those from well-represented groups. This would complement OPWDD's efforts to develop a consistent process for service authorization to avoid the tendency for those with the most robust and knowledgeable circles of support to achieve the greatest access.

4. Include the representation of people with language and culture competencies as a measurable outcome for recruitment and retention efforts of DSPs and care managers.

Transparency and Accountability (2.2)

We appreciate OPWDD's recognition in the draft plan that improving data access and transparency is a top priority of stakeholders. The most immediate need for data access and transparency is in the strategic planning process itself. Every section of this response highlights areas where data access and transparency can drive decision making in resource allocation and future planning. We hope that OPWDD will provide more of the analysis of unmet needs and current and anticipated utilization wherever it can in its revision of the draft plan.

OPWDD's plan to establish a Data Community of Practice would allow meaningful collaboration with stakeholders to develop the system's data infrastructure. Data collection and transparency in service utilization, program effectiveness, compliance, and budgeting, when informed by individuals and family caregivers, is integral to OPWDD's mission.

The draft plan refers to OPWDD's partnership with NYS Information Technology Services (ITS) "to transition the agency's technology to more innovative and intuitive programs, consolidate systems as appropriate, streamline workflows and upgrade capacity and staff skillsets." We hope that part of OPWDD's plans is to conduct an independent, comprehensive review that 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
h. the accessibility of OPWDD's website and public-facing information sources to all stakeholders, with accommodations to the full range of neuro- and physical- diversity.

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

Managed Care (Objective 3.3)

The draft plan revives OPWDD's interest in evaluating a possible transition of agency-funded waiver services to managed care. The RFP released on June 29, 2022 seeks a contractor to evaluate whether a Medicaid managed care model, one that would possibly include I/DD residential services in the benefit package, "would be an effective approach to achieving the agency's strategic goals of prioritizing person-centeredness, integrated care, and improving personal outcomes and social determinants of health for those that OPWDD serves."

A transition to managed care would involve a system-wide upheaval on top of a workforce shortage at a time when individuals cannot get basic services. Also, as we've noted, OPWDD has yet to provide the analysis of unmet need, anticipated utilization, and measurable outcomes that would be expected in strategic planning. It is unclear how OPWDD would assess the need for a transition to managed care for people with IDD in New York at this time.

We believe any constructive evaluation of the potential use of a managed care model for long term services and supports for people with IDD must:

1. establish solid evidence that managed care will primarily benefit the individuals with IDD from the individual- and family-caregivers' perspectives, and

2. conduct an assessment that anticipates the cost of the transition and disruption of services to individuals and family caregivers, with meaningful collaboration of all stakeholders.

Conclusion

The process mandated by Section 5.07 creates an opportunity for individuals and families to join with OPWDD in planning for a system of care that above all else respects the people whose lives it will shape. The strategic planning for this system should be based on an appraisal of what the needs of people with IDD will be over the next five years and what addressing those needs would require. The members of the Care Design NY Individual and Family Advisory Board have shared these comments on the Draft Plan based on the experiences and observations of our members and families as well as on our study of OPWDD policy. We look forward to ongoing dialogue and collaboration with OPWDD, the Governor's office and the Legislature as we all advocate for a brighter future for people with IDD in our State.

Sincerely,

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

cc: Jihoon Kim, Deputy Secretary for Human Services and Mental Hygiene, Office of Governor Kathy Hochul
Nick Cappoletti, Co-Chair, Developmental Disabilities Advisory Council
Michele Juda, Co-Chair, Developmental Disabilities Advisory Council