June 28, 2021

Office for People With Developmental Disabilities
Attention: Dr. Theodore Kastner, Commissioner
planning@opwdd.ny.gov

Re: Input into OPWDD's establishment of a statewide comprehensive plan of services in accordance with 5.07 of the Mental Hygiene Law

Dear Commissioner Kastner,

Care Design NY (CDNY) and Partners Health Plan (PHP) together support 29,000 individuals with intellectual and/or developmental disabilities (I/DD) and, as such, are writing this letter to provide input into OPWDD's establishment of a statewide comprehensive plan of services in accordance with 5.07 of the Mental Hygiene Law. The comprehensive plan must include statewide priorities and measurable goals that guide the planning, resource allocation and evaluation processes.

We divided our response into several key areas as follows:

Establishing Statewide Principles:

A comprehensive plan must reflect/support the following principles:

1. Data capturing and transparent analysis, identifying needs compared to available resources and utilization.
2. Supports and services:
   - must be equally and timely accessed by persons with I/DD;
   - are person-centered and planned, accessed and delivered in a high quality manner;
   - are offered through self-direction as a first choice; and
   - must maximize flexibility, innovation, and integration (I/DD with behavioral health, health, and other services).
3. The Direct Support Professional (DSP) as the backbone of the service delivery system.
4. Availability of a robust service provider network.
5. Predictable and adequate system funding.
6. Reinvestment of savings back into the service delivery system.
7. Emphasis on health and safety of individuals with I/DD.

Data and Analysis to Project Need

Adequate system planning cannot occur without data to inform the process. This includes data that reflects new people needing to enter the system and those already receiving supports and services but have changing needs. The latter has become even more important as the people supported in the system live longer lives.

New enrollees

OPWDD must improve its ability to project future growth in overall system enrollment. Last year, OPWDD projected a modest 2%-3% growth in new enrollments when, in fact, OPWDD-authorized enrollments grew by approximately 10%. According to the Centers for Disease Control and Prevention (CDC), 1 in 54 children have autism. The CDC also found that 17% of children aged 3-17 years were diagnosed with a developmental disability, including autism, during a study period of 2009-2017. These facts alone suggest OPWDD's projections of future need may be extremely low and will not result in adequate funding to support the increasing need.

It is recommended that OPWDD work together with the Care Coordination Organizations (CCOs), the primary entities working with individuals and families, to realistically project need and enrollment growth over the next 5 years. The CCOs have now gained three years of experience and are a valuable resource to collaborate with OPWDD on the projections for the 5-year plan and for annual updates thereafter.

New Service Needs

New system enrollees

Identifying service needs for new enrollees should be based upon both historic data OPWDD has related to such individuals and data the CCOs collected as they work with new individuals and families in the process of entering the system. This would include individuals and families interested in self-directing their supports and services. Increasingly, families of younger individuals (pre-school through high school) with I/DD are approaching OPWDD for wrap-around supports and services. To date, OPWDD has not adequately planned for or recognized this growing need, and therefore must address in the comprehensive plan.

Existing system enrollees

The needs of individuals already being supported by OPWDD, some 120,000, continue to evolve and change over time as the population ages and becomes more complex. OPWDD must be able to project changing service needs for individuals living at home with aging caregivers; aging out of the educational

system (residential and day); living on their own; self-directing their services; and/or living in certified homes or attend certified day services, including those individuals of retirement age.

OPWDD must work with service providers and the CCOs to better project the changing service needs of those currently receiving supports and services.

Residential Service Needs

A caregiver's number one fear is "what will happen to my loved one when I am gone?". In accordance with Mental Hygiene Law, the State of New York is ultimately responsible for the care and support of persons with I/DD, yet OPWDD has not conducted a residential needs survey in at least 5 years, even though it is required by law. OPWDD must utilize the survey to develop an overall housing strategy for the system.

It is recommended that OPWDD both publish and utilize its existing residential needs list to develop the baseline and work with the CCOs to fine tune and update that list through care managers engaging with individuals and their caregivers over the next several months to plan for appropriate levels of residential capacity building needed over the next 5 years. This plan should be updated on an annual basis.

In addition, while identifying the future need, OPWDD must also examine the system's current capacity to meet individuals' residential service needs especially considering the impacts of the COVID-19 pandemic. This examination would include, but is not limited to, such details as the type, capacity, age, number of bedrooms, accessibility, and location of homes. While it will not be possible for OPWDD to have such an assessment completed by the time the plan is due, OPWDD should address in the comprehensive plan how it plans to undertake this effort with a timeline that links completion in alignment with next year's annual update.

In terms of accessing non-certified affordable housing, the OPWDD comprehensive plan must address how they will deal with the continuing challenge for individuals with I/DD in accessing housing based upon the existing available rent subsidies set by OPWDD. Rents continue to rise while the OPWDD rent subsidy levels set by OPWDD have not risen in at least seven or eight years. Unfortunately, this housing option will be well beyond the reach of many individuals who do not have access to other financial resources to close any gaps in funding.

Lastly, OPWDD must address, in its overall housing strategy, how it plans to better support individuals living in the community who themselves or their caregivers go into crisis and need an emergency residential opportunity within 12 to 24 hours. Such occurrences happen on a regular basis and CCOs work closely with the OPWDD Regional Offices who together scramble to find an appropriate and available residential opportunity in the system. Nearly all these situations could result in the individual becoming

homeless or being sent to a shelter that is not capable of meeting the health, safety, and support needs of the individual.

Supports and Services

Equal and timely access

OPWDD has struggled to consistently ensure equal and timely access to supports and services for individuals with I/DD across the State. The OPWDD "front door" is a consistent bottleneck in every region while applying inconsistent rules and requirements, which at times conflict with federally approved program standards. There is a complete lack of accountability and regard for equity of access and timeliness to obtain services. OPWDD must address these issues in its comprehensive plan by establishing measurable goals and reasonable timelines for individuals to obtain both an eligibility determination and equal/ timely access to services.

Person-centered planned, accessed and delivered in a quality manner

Planning

Working with an interdisciplinary team, with the individual and their family at the center, the CCO care manager coordinates the development of a comprehensive, person-centered life plan. This living document delineates the service needs of the individual that supports them in achieving their goals to live a quality life.

Access

A well-developed life plan can only bring you to the next important step - gaining access to services. Linking individuals to the services they need, as outlined in their person-centered life plan, is a critical function performed by the CCO care managers if individuals are to live a quality life. However, the pandemic has brought this front and center as services were shuttered for months and have been very slow to return, exacerbated by the direct support professional workforce shortage (discussed later in this document). OPWDD must address these issues in its comprehensive plan.

Quality

Gaining access to services alone will not ensure that individuals with I/DD are able to achieve the goals outlined in their life plans. Achieving a goal can only happen if the staff action plan implemented by the service provider is carried out to its fullest and in a quality manner. Delivering quality supports and services has become an increasing challenge for service providers and is now considered a systemic issue. The direct support workforce shortage has brought the system to a point where the focus is only on meeting

the basic health and safety needs of individuals, particularly in certified residential and day services. OPWDD must address this issue in its comprehensive plan.

Self-direction as a first choice

Every individual coming into the OPWDD service system should be given the option to self-direct (SD) their services. This can be taken in the form of "agency with choice" or "with budget authority." SD has grown significantly over the last five years through the combined efforts of OPWDD, CCOs, Fiscal Intermediaries (FIs), Support Brokers and advocates however, more work is needed on the process which must be addressed in the OPWDD comprehensive plan. More specifically, for those individuals who self-direct with budget authority, there are significant delays in the process of getting both initial and amended budgets approved by OPWDD. Additionally, the lack of budget flexibility across cost categories, especially as needs change or emergencies occur, creates unnecessary delays in an individual's ability to fully utilize their approved budget.

Flexibility and innovation

The current system of supports and services, driven entirely by a highly structured, narrow focused, siloed fee-for-service system, makes it nearly impossible to create flexibility or innovation in the delivery of State Plan or HCBS services. This was painfully highlighted during the height of the pandemic last spring during which extraordinary measures at the highest levels in both the State and Federal government were necessitated over a period of months (sometimes longer) to create the flexibility for providers to operate. For example, OPWDD's comprehensive plan must address how it will allow, promote, and fund the use of technology in the delivery of services in a post-pandemic system.

The best vehicle to create the greatest flexibility and innovation for the OPWDD service system is through provider-led managed care. With a financial model driven by total cost of care and/or base payment methodology, managed care companies typically pay providers contractually-agreed-upon payments at regular intervals. The payments are tied to methodologies that are financially attractive to both payer and provider, with incentives oftentimes included for achievement of certain quality outcomes. Most importantly, payments to providers are not negatively impacted by bureaucratic or regulatory delay, as provider budgets can be properly forecast, and the provider-led managed care plans can offer swift flexibility in payment mechanisms based on external factors. Had the provider led managed care model been in place during the time of COVID-19, much of the impact felt by service providers and, by extension, individuals with I/DD and their caregivers, could have been avoided.

Integration of Supports and Services

A specific requirement spelled out in Section 5.07 of the Mental Hygiene Law is the expectation that the comprehensive plan will address the integration of supports and services that cross systems.

For decades, the I/DD system failed to gain a sufficient foothold to integrate critical services related to medical, behavioral health, dental and long-term care services. Unfortunately, these silos continue. The

integration issue is rooted in the lack of coordination between the I/DD service system and the general medical, behavioral health and dental communities. This led to access challenges which result in either utilization of higher cost services (such as emergency room use and hospitalization) or potential duplication/overlap of services, such as personal care and community-habilitation being delivered simultaneously. While the creation of CCOs was the first step toward improving integration of services for the I/DD population, this alone cannot address the fiscal and programmatic management required for true system integration and reform. The confines of the current siloed OPWDD fee-for-service system make it difficult for providers to be efficient in the delivery of services and, in fact, rewards providers financially for increased utilization and higher costs.

Support for integrated, holistic care, which is critically needed to manage, support, and fund the services required of a comprehensive I/DD care delivery system. This can only be accomplished through provider-led managed care, which integrates disability services, healthcare, behavioral health, and other social care supports into one conduit. Provider-led managed care is the vehicle that will provide a cohesive, 360-degree platform for the care and support required by the complex I/DD population.

This comprehensive holistic approach to support has been successfully demonstrated by Partners Health Plan (PHP), the only fully integrated model in NYS supporting individuals with I/DD. PHP, not OPWDD, is the "front door" for enrollees to access services through its high touch two-person care coordination teams. PHP has developed and implemented health, wellness, disease management and polypharmacy clinical management programs. PHP also has a telemedicine program which has proved critical during the COVID-19 pandemic, as it led to the avoidance of unnecessary emergency room (ER) visits and potential hospitalizations. Research has shown that individuals with I/DD who go to the ER have a 53% chance to be admitted, versus 16% for the general population. In addition, when hospitalizations or nursing home admissions do occur, PHP's medical team, led by a board-certified medical physician, meet regularly to review members' status to ensure/advocate that proper care is being rendered during their stay, and prepare for an appropriate/safe discharge while ensuring that appropriate transitions in care are in place.

The Direct Support Professional is the backbone of the service delivery system

There is no argument that DSPs are the backbone of the I/DD service delivery system, yet they are often disrespected, under-appreciated and always undervalued in terms of their worth.

The COVID-19 pandemic serves as the most recent example of this, during which it took months of advocacy on the part of stakeholders for the State, OPWDD specifically, to recognize DSPs as "essential workers" who risked their own lives to be on the front-line supporting individuals with I/DD.

What was already a critical DSP workforce shortage prior to the pandemic has become an overwhelming crisis for every OPWDD service provider in NYS. You need to look no further than today where on average at least 25% (or 1 in 4) of all DSP positions across the State and all OPWDD services are vacant. This problem has been building for the past decade gaining steam over the past 5 years and is now a significant threat to health and safety.

There is also significant inequity in compensation of the DSP workforce between what nonprofit providers can pay their staff and what OPWDD pays its own staff, a gap that has continued to grow to the point where the State cost to operate the same programs is more than double that of a nonprofit provider. The State pays a living wage to its own DSP workforce while ensuring that nonprofit providers can pay at least a minimum wage to its DSP workforce. At the same time, nonprofit providers are increasingly asked to serve individuals with more complex needs without adequate funding for staff to do so.

Additionally, innovative recruitment and retention strategies must be expanded to include high schools, BOCES programs, county Educational Opportunity Centers and colleges.

Lastly, the State must add resources into expanding the development of "smart homes," using assistive technology, that will empower individuals to maintain control over their environment and daily activities. These advancements will eventually create less reliance on an already-strained workforce.

The OPWDD comprehensive plan must address the DSP workforce crisis head-on including the development of a multi-year financial strategy that will bring all DSP wages up to a "living wage."

Availability of a robust service provider network

Providers of OPWDD Services

Nonprofit providers of OPWDD services continue to struggle financially, several of whom report having less than 30 days cash on hand. This has resulted from a combination of factors that have been building over the years, including a fee-for-service system that has created a provider network of "haves and have nots;" continual unexpected rate reductions; regulatory burden; and dire shortages of DSPs. The quality

of services in the system has and continues to erode. Providers, for example, are not able to deliver high quality services and many are struggling to provide basic health and safety levels of support to individuals residing in certified group homes.

Since 80% of supports and services are delivered to individuals with I/DD by nonprofit service providers, OPWDD's comprehensive plan must address how it will stabilize this vital part of the overall provider network.

Providers of Health, Behavioral Health and Dental Services

Given the health and social complexities of individuals with I/DD, it is critical they be appropriately supported by providers beyond those delivering I/DD supports, to include providers from across the care continuum – healthcare, behavioral health, I/DD services, dental and social care. Individuals with I/DD and their families have struggled for years to gain consistent access to these providers.

OPWDD has not yet fully embraced the need for holistic support of the population despite the fact individuals with I/DD are more likely to have multiple co-morbid conditions, including approximately 40% of the population having an underlying mental health condition. The formation of the CCOs was meant to be the first step towards making that circle complete. However, the challenge continues today, despite the work done by the CCOs, to close this significant gap in care. The CCOs are not payers of services, and therefore are limited in their ability to impact provider behavior. The struggle stems from a combination of low Medicaid fees and the inability to create financially supported integrated care networks.

The only viable pathway to addressing this significant challenge, one that has been successfully demonstrated with other special populations, is through the creation of a fully integrated service model with a direct payer relationship with all service providers. This is exactly what provider-led managed care is expected to and will do.

Predictable and adequate system funding

In recent years, the overall OPWDD budget has included unplanned yet targeted reductions in funding of OPWDD services that are "verbally sprung" on stakeholders during "Executive Budget briefings." The lack of transparency and engagement with stakeholders in the actions has become the norm. The lack of a comprehensive and meaningful 5.07 plan for the system, that includes recommendations from the Developmental Disabilities Advisory Committee (DDAC), as required by law, along with input from stakeholders, has contributed to the lack of a predictable and adequate system of funding. One purpose of the comprehensive 5.07 plan is to inform the Executive Budget process and ultimately the enacted budget passed by the Legislature and signed by the Governor. This is critically important in helping all

stakeholders to better understand the priorities and future of the service system while helping providers, individuals and families plan for their future.

Reinvest savings back into the system

The OPWDD service system is the "last frontier" for the fee-for-service model as the primary funding stream in NYS' vast Medicaid program. It is an archaic model, one that rewards higher utilization and increased spending. The model does not support using strategies that focus on quality rather than quantity and efficiencies versus spending. There is no ability to create savings opportunities for reinvestment.

Additionally, there is no ability to share and reinvest savings generated across the siloed State agencies. For example, all savings generated in the Department of Health (DOH) for reduced ER and hospitalization utilization from direct actions taken by service providers in the I/DD system using telehealth, remain with DOH and are not shared with OPWDD and ultimately with service providers.

Provider-led managed care is the answer. It can offer opportunities for service providers to try new service and payment models, access comprehensive health care information, and employ new technologies to improve quality, while providing shared savings incentives to be reinvested into the service system.

Ensure Health and Safety

The pandemic has taught us that we all must do a better job related to emergency preparedness to ensure the health and safety of individuals with I/DD, and the staff who support them, is always paramount. The comprehensive plan must address how OPWDD will develop an emergency preparedness plan working with other state agencies, local governments, and stakeholders to be competed in the first of year of the five-year plan. At minimum, the plan will need to address access to Personal Protective Equipment (PPE); opportunities to temporarily quarantine and isolate people; emergency housing capacity; temporary resource availability tailored to the emergency; various policies and procedures tailored to the needs of the population; and a transparent communication strategy with stakeholders.

Conclusion

While the OPWDD comprehensive plan must provide a true and transparent picture of the service system needs over the next 5 years that is driven from robust data and analysis, the voices of individuals with I/DD and the people who support them must be heard loud and clear and be front and center in all aspects of the service system.

Through the lens of the COVID-19 pandemic, individuals and families have witnessed firsthand the results of an inflexible, cumbersome fee-for-service-system. Self-advocates, families, and caregivers have expressed concerns about the financial and programmatic futures of service providers who deliver critical services and supports. The flexibility, innovation, and creativity that individuals and families desire from the OPWDD system can only be accomplished through a truly integrated, whole-person approach to the delivery of services.

With the spotlight that COVID-19 shined on the instability of the system that supports individuals with I/DD, now is the time for OPWDD's comprehensive plan to truly reflect systemic change. The innovation and transformation that was brought to other special needs populations in the State (HIV, behavioral health, and other chronic conditions) through the vehicle of properly funded managed care, and in OPWDD's case provider-led, must now be extended to the I/DD community and imbedded in this plan.

Sincerely,

James Moran

James Moran, Care Design NY, CEO

Kerry Delaney

Kerry Delaney, Partners Health Plan, CEO

Cc: Christopher Tavella, Deputy Secretary for Human Services and Mental Hygiene, Office of Governor Andrew M. Cuomo
Katherine Marlay, Deputy Commissioner, Division of Policy and Program Development, OPWDD
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