TESTIMONY SUBMITTED TO THE NEW YORK STATE LEGISLATURE

Joint Hearing of the
Senate Finance and Assembly Ways and Means Committees
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2022-2023 Executive Budget
Mental Hygiene

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Good afternoon, Committee Chairs and members of Senate Finance, Developmental Disabilities, Mental Health and Assembly Ways and Means, People with Disabilities and Mental Health Committees. Thank you for your ongoing support of people with Intellectual and Developmental Disabilities (I/DD) and for the opportunity to present our legislative priorities and reaction to Governor Hochul's 2022-23 budget proposal. We thank Governor Hochul for recognizing the extensive needs so many years of underfunding has created in the I/DD community, and we trust the legislature will only build upon the items she has proposed for the 2022-'23 NYS budget (SFY'23).

The Cerebral Palsy Associations of NYS (CP of NYS) is a statewide, family-founded organization with more than 75 years of advocating for and supporting people with CP and other significant developmental disabilities across the State. Our Affiliates employ almost 20,000 people, but most importantly we support close to 100,000 people with I/DD and their families through OPWDD, SED, DOH, OMH, and OCFS programs. The family of CP Affiliates have filled a niche time and again and when services were unavailable, our Affiliates stepped up. When there were no clinical services or therapies, CP worked with families to establish clinical services in every part of the state; when Willowbrook closed, CP was the leading agency to ensure the State safely transition people to homes in our Affiliates and we even began a new residential program in NYS to meet the need. Today, our Affiliates are the leaders in providing complex care to medically fragile New Yorkers as well as nationally and internationally recognized innovators in supporting autism spectrum disorders and medical complexity.

CP of NYS is also a partner in **New York Disability Advocates (NYDA),** a statewide coalition of seven provider associations representing more than 300 not-for-profit agencies that are responsible for providing vital services and support to more than 130,000 New Yorkers with intellectual and developmental disabilities (I/DD). The CP Affiliates and our NYDA partner I/DD agencies, regulated by the Office for People with Developmental Disabilities ("OPWDD"), provide lifelong, comprehensive, individualized services to support people with developmental disabilities in all areas of their lives. In addition to delivering physical and behavioral health services, they assist with transportation, housing, medication administration, cooking, and feeding, as well as developing personal care, community living, employment, and money management skills.

We fully support the NYDA agenda and priorities and offer the following brief amplification of those priorities for our Affiliates. The absence of a COLA and the impact of that withdrawal of support over the years is intricately woven into the current workforce crisis – while the worker shortage's impact is broader than I/DD services, the impact on our field has been particularly harmful due to the lack of investment in our system for so long.

COLA

Prior to the COVID-19 pandemic, 37% of providers reported losing money on their OPWDD services, and cash on hand has been a significant challenge for agencies. At the start of 2020, half of NYDA's providers had less than 40 days and 33% had less than 30 days of cash on hand, and more than 1 in 3 providers had already closed, reduced or modified programs due to the financial hardship they were under.

Cost-of-Living Adjustment (COLA)

The lack of a COLA for over a decade has significantly deprived providers of vital resources needed to maintain operations. Sizable cost increases related to mandated fringe benefits, repairs and maintenance, utilities, food, supplies, transportation, insurance, and other increases over the past 10 years have resulted in significant financial pressure on agencies. Additionally, since they are solely funded by Medicaid, agencies are unable to increase reimbursement which has directly led to the inability to invest in workforce wages for direct care workers and other essential front-line staff, resulting in wage stagnation.

Following a decade of provider agencies not receiving the statutorily required cost-of-living adjustment (COLA), the significant fiscal impacts of COVID-19 and the current level of inflation, **agencies' costs have increased significantly necessitating that the full 5.4% COLA be included in the SFY '23 Budget.**

BUDGET REQUEST: Accept HMH Part DD

WORKFORCE INVESTMENTS

Because I/DD providers have been deprived of resources to invest in staffing, we have lost the ability to attract and retain workers. Compounding the lack of funding, the demographics in NY and the country do not bode well for improvement in our ability to attract and retain workers:

The ratio of the population of 18-44 year olds divided by the population of people 65 & over, the US Census is forecasting for that ratio:

	2016	2020	2030	2040	2050
Ratio*	1.51	1.32	1.04	0.95	0.91
* population of 18-44 year olds divided by the population of people 65&up					

This shows that the competition for workers will be even more intense in future years; investment in the workforce and other initiatives to help recruit and retain works is

absolutely critical to ensuring the workforce will be there for people with I/DD in years to come. Given that pressing need, we support the Governor's proposed investment strategies and ask that the Legislature include the following recommendations:

1) **Continued and sustained investment in DSPs' salaries is essential to recruit and retain staff and for the future viability of the field.** The Executive Budget includes a proposal to make up to $3,000 bonus payments to frontline health care and mental hygiene workers. This is a welcome proposal that will provide additional resources to help address the current workforce crisis.

   BUDGET REQUEST: Amend Part D to ensure agency definitions and include part-time employees of 15 hours or more and full time of 30+ or greater hours is recognized.

2) **Permanently continue investment in I/DD workforce** – Providers will have had access to one-shot funding through eFMAP and other federal pools that will not be available at the end of this budget year. We ask that the Legislature continue a multi-year investment in the I/DD workforce to ensure the benefits of the one-time funding mechanisms are permanent.

   BUDGET REQUEST: Invest in the 4th quarter of the SFY '23 budget to make the first step in a multi-year commitment to invest in the disability workforce.

3) **Establish a personal income tax credit for direct care staff** – As an additional way to address the significant I/DD and mental hygiene service delivery systems workforce challenges and recognize the vital work that DSPs do to support individuals with disabilities, a personal income tax credit should be established to provide recruitment and retention incentives and recognition to these vital employees.

   BUDGET REQUEST: Include S.7643/A.9200, in the SFY'23 budget, to establish a refundable personal income tax credit for direct care staff employed by provider agencies.

4) **Nurses Across America** – I/DD providers historically have had significant challenges in recruiting and retaining essential nursing staff. The proposed Nurses Across New York program will provide loan forgiveness for nurses working in underserved communities, which would support recruitment and retention. Individuals with I/DD and

behavioral health needs are medically underserved but do not only live in certain zip codes or communities. Therefore, it is critical that nurses who are employed by I/DD and behavioral health agencies be included in the loan forgiveness program.

BUDGET REQUEST: Amend HMH Part A to specify I/DD and behavioral health agencies are included as eligible places of employment for loan forgiveness.

CAPITAL FUNDING

The Executive Budget proposes authorizing additional funds for the Statewide Health Care Transformation Program (SHCTP) and new funding for the Nonprofit Infrastructure Capital Investment Program (NICIP). The NICIP was because nonprofits are generally not eligible to apply for the more than $ 1 billion in SHCTP funding. The need and applications for the first round of NICIP, which was created to make targeted investments in capital projects that aim to improve the quality, efficiency, and accessibility of nonprofit human services organizations. were far greater than the $100m allocated. While we greatly appreciate and support the proposal of an additional $50 million NICIP in the Executive budget proposal, I/DD nonprofits need additional access to the capital grants supported by the SHCTP These investments by the state are vital to spurring innovation and efficiencies in the service delivery system to improve outcomes for individuals with disabilities.

BUDGET REQUEST: Accept the inclusion of the nonprofit infrastructure capital investment program (NICIP), and amend the Statewide Health Care Facilities Transformation Program (SHCFTP) to include community-based I/DD providers that are authorized, approved and/or funded by OPWDD as eligible applicant

INVESTMENT IN I/DD HEALTH SYSTEM INTEGRATION

One of the results of the COVID epidemic's impact on the I/DD community has been the highlighting of the critical role I/DD residential, clinic, and other supports and services play as part of NY State's health delivery system. The I/DD community has been focused on the whole person and the accompany factors that determine health – i.e., the social determinants of health – for years before the health community adopted an acceptance of that perspective. As such, the I/DD supports and services that help keep some of our most vulnerable New Yorkers out of the ER and reduce unnecessary acute care stays must be supported. We need to look to ways to identify those challenges in the current siloed funding approach that caused hospitals to unsafely discharge COVID positive patients to certified I/DD residences. Additionally, we need to examine cross-agency supports that

should be explored to improve efficiency in the delivery of I/DD community supports. In particular, medically complex people with I/DD must have a system that supports and works for them; by doing so we will both increase their quality of care and quality of life, and achieve cost avoidance or savings as a result of the efficiencies that these updated models of support will achieve.

Most CP Affiliates were founded when families were seeking access to services, typically therapy and clinic services, which were unavailable to them in the standard clinician practice or clinic. CP Affiliates' have a history of operating health clinics, including OPWDD Article 16, DOH Article 28, and OMH Article 31 clinics, and it is that history/expertise that informs our unique perspective and recommendations. Over the years we have worked closely with OPWDD and DOH to improve the system supporting people with I/DD, but with years of under-funding and the universal workforce shortage we now need to look to change the models and explore opportunities for real system improvements.

Investment in Telehealth – Expand and Create Permanent System Funding

Under the COVID public health emergency, both federal and State flexibilities that increased access and use of telehealth and tele-supports proved the value of this service for people with I/DD. Whether their mobility issues made transportation a challenge, their behavior issues decreased their ability to keep appointments, their health placed them at high risk of complications or death from COVID, clinician shortages or the complexity of their needs kept them from accessing the services most suited to their treatment, the past two years have shown us that telehealth is a service that should not be limited or restricted once we're through this pandemic.

CP of NYS is fortunate enough to have received a NYS DOH Infrastructure grant for health care triage for people with I/DD and have been supporting 8,315 people living in over 1,100 certified residences statewide. The project went live at the start of the pandemic in March of 2020 and our estimates of system savings/cost avoidance in the first 18 months are that over $50 million in health system expense have been saved as a result of this service being in place for this highly complex population. What this project has shown us is that we need to look to embed this support/service into our payment structure so that we can continue to realize these results. We need to establish a reimbursement structure within the OPWDD rate system to add the telehealth triage service to the residential rate. Similarly, we believe savings for people with I/DD living in the community are also achievable, and we would like to see the project and funding for the service expanded to include the I/DD community by making this telehealth triage a billable preventive service through the NYS Medicaid program.

BUDGET REQUEST: Establish the development of a Medicaid rate for telehealth triage services for special populations. Develop a federally approved rate setting structure to support a telehealth triage service

in addition to current services/supports funded in OPWDD certified residential programs.

Disability Clinic Integration

The CP clinics supporting people with I/DD have been losing funds for more than 20 years, with many clinics reducing services or making the switch to Federally Qualified Health Centers (FQHC) when that option was possible. What remains today are significant health equity and access issues across NYS particularly with primary care, OB/GYN, dental, neurology and other critical services. After losing on average 20% on clinic operations, there really is not much more that our agency Boards can consider to continue clinic services as they must first fulfill their fiduciary responsibilities. To help prevent an even greater loss in access to services – and an ever-greater expense to NYS, because those non-served people will present at an ER with higher costs and preventable conditions – we propose funding a pilot with an I/DD provider to offer truly integrated care for our community. This would include funding to support a provider to connect with their local hospital(s), specialist groups and other needed services to ensure access to primary, specialty and other needed care currently at risk of disappearing in the State.

BUDGET REQUEST: Fund a pilot program to support at least one I/DD health clinic partnering with acute care and other providers to demonstrate the value of integrated care for the I/DD community.

In addition, we request the removal of MRT 26, an unnecessary Article 16 clinic utilization management control which was put in place despite OPWDD's utilization management control of only approving a certain number of services for their Article 16 clinics. Additionally, repeal of MRT 26 prevents providers, who supported a large number of people in need of behavioral health supports during COVID, from being penalized for providing this necessary care.

BUDGET REQUEST: Repeal MRT 26/Part H of Chapter 59 of the laws of 2011

Coordination of OPWDD and Mental Health Services

One of the true siloed approaches to care has been the distinction between OPWDD and OMH services that often leaves the "system" with avoidable additional costs and our residents/patients in OPWDD services with poor care and situations that are unsafe and potentially harmful. Currently, more than 50% of patients seen in our clinics and people living in our certified residents have a mental health diagnosis in addition to their I/DD diagnoses, which the OPWDD community refers to as "dually diagnosed." Our systems are so far apart, that when the mental health community uses the term "dually diagnosed" and the OPWDD providers think we're talking about our I/DD and MH diagnoses, the MH community is actually referring to people with mental health and addiction/substance

abuse diagnoses – we literally are speaking different languages. Another significant disconnect in the OPWDD system is with the acute care system. Typically, when someone in our residences is in crisis or has escalating behaviors it might involve the emergency response or law enforcement systems in addition to a hospital emergency department. More often than not, the hospital will adjust medications and send the person back to the residence without resolving the cause of the crisis. If they are admitted to the hospital or its psychiatric ward, they typically demand that the residence "staff" the hospital/psychiatric bed and there is unclear communication between the hospital and the residential program on an appropriate discharge plan.

The OPWDD system's need for a true crisis response system needs to mirror what is being proposed between OMH and OASAS. We require funding to support provider developed pilot models that work with crisis centers that can actually respond to crisis and help people through the crisis, rather than create missed opportunities for providing and improving the quality of life for so many people. The funding that is proposed in the budget for crisis response and mental health crisis programs needs to be increased to truly make a difference in the system – sporadic at best, we need to recognize this issue and establish means of reacting appropriately across systems, i.e., OPWDD, OMH and the DOH psychiatric, ER, and acute care systems.

BUDGET REQUEST: To improve coordination between OMH and OPWDD, statutorily create an I/DD (OPWDD) Mental Health Services Board that would include representatives of both state agencies and providers supporting people with I/DD and MH diagnoses. Require the Board to provide annual reports on systemic improvement recommendations to the Governor, the NYS Legislature, and the newly proposed Office of Disability Services.

Increase funding for OPWDD mental health crisis programs from the proposed $4 M to $10 M for the development of statewide pilot programs for OPWDD providers, which are connected to OMH and Acute Care Systems, to address cross system needs.

Investment in the Centers of Excellence for Complex Care

New York State has had a perennial problem with students with complex needs not finding appropriate placements in State and, in turn, being placed at out of state schools. At the same time, students in our NYS residential school programs often have autism spectrum disorders and other complex needs which require significant supports once they graduate, at 21 years old, from residential school programs. CP of NYS coordinated the State's three largest children's residential programs (CRP's) in a BIP-funded program that developed best practices for these specialized programs, screening tools for providers to use, and SED/OPWDD funding models to ensure NYS residential schools had access to

the same interdisciplinary teams as out of State schools. That funding ended, and with it the hopes of realizing the cost savings/avoidance across multiple systems that the CRP Centers of Excellence model affords New York. We know that the model works to address the needs of students and we believe it will create improved quality of life for these students and their families with their child remaining in NYS. We also know that the planning required for transitioning students is critical. This model developed concepts that require OPWDD involvement to ensure that transitions occur in a way that best meets each students' needs and works within the funding parameters and expectations of parents.

We believe it's time for the State to commit funding to support the implementation of this model across the three Centers of Excellence (located in Central NY, the Hudson Valley, and Long Island) as well as the supports needed in the CRP programs who would benefit from the COE's expertise and assistance.

> **BUDGET REQUEST: Funding to support three (3) Centers of Excellence in the care and treatment of autism spectrum disorders and other complex conditions' development of interdisciplinary teams, development of best practices, and education and implementation of those best practices across the State.**

We thank you for consideration of our requests. This is truly a unique time in the history of the disability movement, and we hope that you will support all the needed system-transforming concepts provided above.

We look forward to working with you, OPWDD, and our other partners as we implement these changes.