

January 6, 2022

OALTC

New York State Department of Health Attn.: E. Palmiero One Commerce Plaza, Suite 1624 Albany, NY 12260

Via E-Mail hcbsrule@health.ny.gov

Re: New York State's (NYS) Home and Community-Based Services (HCBS) Final Rule

Statewide Transition Plan (STP)

Dear E. Palmero:

On behalf of DDAWNY, the Developmental Disabilities Alliance of Western New York, these comments are being submitted in response to New York State's Home and Community-Based Services (HCBS) Final Rule Statewide Transition Plan (STP) being submitted to the federal Centers for Medicare and Medicaid Services (CMS) to achieve compliance with the HCBS Final Rule. DDAWNY seeks to comment on New York State's request to CMS to provide additional flexibility, via a federal Corrective Action Plan (CAP), with its current deadline of March 17, 2023, to come into full compliance with those HCBS Final Rule Standards that are impacted by the Public Health Emergency (PHE) and New York's request to have until July 2024 to come into compliance with HCBS standards relating to community integration and ensuring employment opportunities are made available to those HCBS recipients who are interested in them.

DDAWNY is a collaborative group of member voluntary agencies providing supports and services to people with developmental disabilities. While honoring individual agency missions, it is the intent of the Alliance to assist agencies to develop relationships, promote unified strategies and share risks for the mutual aim with and for the benefit of people with disabilities.

DDAWNY member agencies employ over 22,400 individuals in the seventeen Western and Finger Lakes counties of New York State providing supports and services to over 33,000 individuals with intellectual and/or developmental disabilities (IDD) and their families and/or circle of supports. DDAWNY has also formed a Family Committee to give voice to the people served in the disability arena, but who are often unheard.



DDAWNY is a member of New York Disability Advocates (NYDA) (formerly the Coalition of Provider Associations-COPA), NYDA is a Statewide group of five associations - the Alliance of Long Island Agencies, Inc. (ALIA), Cerebral Palsy Associations of New York State (CP of NYS), the Developmental Disabilities Alliance of Western New York (DDAWNY), the InterAgency Council of Developmental Disabilities Agencies, Inc. (IAC), and the New York Association of Emerging and Multicultural Providers (NYAEMP).

We have unified our efforts to maintain and improve services and supports for children and adults with developmental disabilities and their families through over 300 non-profit organizations serving hundreds of thousands of New Yorkers with IDD, educating over 15,000 special education students and employing more than 120,000 dedicated professionals with combined annual operating budgets of nearly \$5.2 billion.

DDAWNY has reviewed and is pleased to provide comment on New York State's Home and Community-Based Services (HCBS) Final Rule Statewide Transition Plan (STP). DDAWNY appreciates that this STP seeks CMS approval of a federal CAP allowing NYS additional flexibility and time (until July of 2024) to achieve compliance with the HCBS standards related to community integration and employment opportunity. Efforts by DDAWNY providers to meet these standards have been and continue to be adversely impacted by the current COVID-19 PHE.

DDAWNY understands that the STP provides a roadmap to describe how the state will ensure compliance with the HCBS Final Rule at both the state level and in their provider communities, providing transparency to stakeholders.

In April of 2022 CMS outlined key components of Systems Transformation and how States can assist providers in System transformation to achieve setting compliance. CMS identified five key components of system transformation these five key components included:

- Transparency and open lines of communication;
- Ensuring a person-centered approach to services and supports;
- Capacity Building; Fiscal Resources; and
- Value-based payment reform.



DEVELOPMENTAL DISABILITIES ALLIANCE OF WNY

In reviewing the OPWDD STP, DDAWNY is concerned that its STP fails to ensure a person-centered approach to services and supports and fails to outline a strategy to provide the fiscal resources necessary to ensure a successful systems transformation.

OPWDD in its introductory remarks for the OPWDD section of the State's HCBS Transition Plan highlighted its stakeholder engagement activities. DDAWNY concurs that the impact of the PHE and COVID-19 was felt throughout the system. These negative impacts continue. As OPWDD has stated, as part of the OPWDD Statewide Comprehensive 2023-2027 Strategic plan, mandated by Mental Hygiene Law § 5.07, also known as the 5.07 Plan, stakeholders were offered the opportunity comment on OPWDD's draft 5.07 Plan. OPWDD references stakeholder engagement in May and June of 2021 but fails to discuss stakeholder engagement in July of 2022 or thereafter. The STP should discuss the concerns expressed in 2022. DDAWNY concurs that in 2021 common themes expressed included the need for more staff and increased wages for direct support professionals (DSPs); more flexibility in the provision of services; expanded housing options; use of data to inform decision-making; improved supports for those with complex needs; and improved crisis services.

In July of 2022 DDAWNY commented on the OPWDD draft 5.07 plan and specifically raised concerns regarding the need for continued investment in the Direct Care Workforce and the need to focus on increasing the employment of individuals with developmental disabilities. As earlier stated, CMS indicates the STP is supposed to provide a roadmap to describe how the state will ensure compliance with the HCBS Final Rule at both the state level and in their provider communities, providing transparency to stakeholders. Sadly, the OPWDD STP fails to provide this roadmap.

As OPWDD indicates, longstanding workforce shortages have been exacerbated by the COVID-19 pandemic, making it increasingly difficult for people to access the services and supports they need. As DDAWNY told OPWDD as part of the 5.07 planning process:

"Continued investment in the Direct Care Workforce is essential. DDAWNY agencies have been dealing with significant staffing challenges for several years. The COVID-19 pandemic has amplified this crisis. The DSP staff is a vital part of New York's "care economy" and the backbone of the system of supports and services for people with disabilities. Enhancing the hourly rate of pay for all staff that have direct care/support responsibilities on an ongoing, annual basis for the duration of the 2023-2027 Strategic Plan is the best way to ensure that people with developmental disabilities enjoy meaningful relationships, experience personal health and growth, live in a home of their choice, and fully



DEVELOPMENTAL DISABILITIES ALLIANCE OF WNY

participate in community life. DSPs provide vital supports and services in group residential settings, independent apartments, and homes; recreational and therapeutic day support settings; clinics; as job coaches and vocational counselors. Staff working with the IDD population do not have an easy job. These jobs require a high degree of responsibility, skill and compassion. They are essential to ensuring individuals with IDD are safe, lead fulfilling lives in their communities, and receive attention for complex medical and therapeutic needs.

While DSPs often provide personal care to people with IDD, they are also expected to facilitate engagement in the community, assist in skill development, and contribute to improved quality of life. They are expected to provide habilitative supports and services, those that help individuals keep, learn and improve skills and functioning for daily living. The role encompasses efforts that support increased independence, pursuit of individual goals, prevention and navigation of crises, relationship and friendship building, and participation in broader society. DSPs often require a different level of skills and knowledge than personal care attendants offering primarily physical personal care."

In addition, as OPWDD indicates, prior to COVID-19, people with disabilities were employed at a substantially lower rate than those without disabilities. COVID-19 has wreaked havoc on the ability of OPWDD providers to maintain individuals in employment, much less increase the number of individuals in employment services. DDAWNY, as part of the 5.07 planning process indicated:

"OPWDD should have a goal of increasing the number of individuals in employment services and needs to reduce barriers in the OPWDD SEMP process which discourage employment. DDAWNY believes OPWDD needs to recognize that a very significant portion of the population it serves require a great deal of support and will require significant day habilitation services before the goal of employment can realistically be an option. Day Habilitation progress may not lead to employment but can lead to a more fulfilling community life and should be respected and honored.

According to New York State Education Department documents only 3% of students with disabilities are leaving high school, "college or career" ready. In recent years nearly 3,000 students with severe cognitive disabilities took the New York State Alternative Assessment. Generally, these students are going to leave school with a Skills and



Achievement Commencement Credential (SACC). This credential is not recognized by employers or the United States Military as a high school diploma and without a diploma, only a very few low paying jobs will be available to this group of students. "

New York State and OPWDD's proposed STP and Corrective Action plan fails to provide a roadmap which appropriately addresses the critical support needs of this population and their transition to an employable workforce.

In our 5.07 remarks, DDAWNY noted:

"Enhanced funding for individuals transitioning from school and entering employment and day services are necessary to address the reality that students with disabilities require additional and intensive supports to become career ready and/or able to meaningfully participate in community life."

DDAWNY further advised OPWDD that," funding disparities between site-based day services and community-based services create silos and prevent the integration of day services and employment services."

DDAWNY strongly supports reforming payment methodologies to support providers who seek to deliver a continuum of day service options including prevocational and career planning services. The OPWDD STP fails to suggest a roadmap to allow for this transformation.

Unfortunately, the \$27.76 million general fund investment described in the OPWDD CAP portion of the STP, a \$6.9 million per year investment in increased general fund support targeting the employment needs of individuals with disabilities is woefully insufficient to truly enhance vocational, educational, employment and training programs. Sadly, OPWDD mistakenly believes disability provider only train soft skills and need to train on actual job skills. This is highly insulting and goes to the heart of the problem. OPWDD is not an employment agency, and its staff are out of touch with the field and not able to oversee true employment first public policy. OPWDD wants providers to develop curriculum for culinary, janitorial, and landscaping courses for people with disabilities. Ignoring the fact that various programs and community colleges already provide these courses and ignoring the fact that currently OPWDD providers successfully run integrated bakery, janitorial, culinary, landscaping and back-office businesses. Our agencies provide training, mentoring, job coaching services and work with individuals using a person-centered approach to assist individuals to obtain jobs in the community. Meanwhile, OPWDD's HCBS STP and CAP fails to articulate any initiatives to deal with the reality of limited transportation options for people with developmental disabilities



which are a primary barrier for people with disabilities who may be ether seeking employment or seek to maintain employment.

OPWDD notes that its DQI Survey Protocols were redesigned to include all HCBS Setting standards, with the first updated protocols implemented in 2016. DOH is happy to advise CMS that OPWDD uses its existing quality surveyors to review each program and setting on-site for compliance with the HCBS Final Rule annually because the resources exist within OPWDD to integrate the HCBS Final Rule into existing quality processes and protocols and that the NYS Mental Hygiene Law (MHL) requires review of all facilities overseen by OPWDD at least annually. OPWDD indicates that as part of the Site remediation process, "in Day Habilitation settings, individuals being encouraged and supported to have access to the broader community was identified and is a concern directly related to having adequate staffing to support participation in individualized and meaningful community activities."

DDAWNY would note that DQI surveyors are aggressively citing providers for violating the access to broader community standard because individuals are engaged in activities such as the Miracle League, Therapeutic house riding, and exercise classes run in the community that are modified to address the unique physical and mental issues individuals with developmental face because only others with disabilities participate in these programs. DQI surveyors ignore the fact that coaches, trainers, certified yoga instructors, parents and other non-disabled volunteers from the community participate with these individuals in valued life affirming community activities. DQI fails to recognize these activities are developed as part of a personcentered planning process and with the informed consent of the person participating in these activities. OPWDD has not provided clear guidance on what its expectation is in regard to frequency of access to "broader community access" and DQI surveyors fail to take into consideration the wishes of the individual who pursuant to a person-centered plan has chosen specific community-based activities with his or her peers and friends. OPWDD point to one size fits all toolkits developed by the Department of Health, which do not address the unique needs of individuals with intellectual and developmental disabilities. There are no specific FAQs or other sub regulatory guidance made available to providers or developed with provider and participant input on what constitutes "access to the broader community" to guide the development of community access services and supports. Instead DQI surveyors cite providers and expect remediation and the correction of non-compliance identified on DQI reports within timeframes establish by DQI with no recognition of the individuals being served, the level of support they may need and the conditions in the community. Agencies have been cited for not having enough access to the broader community for severely compromised individuals in the mist of the COVID-19 pandemic. The individual choices of people with disabilities are discounted or minimized by these DQI surveyors as part of OPWDD HCBS remediation efforts.



Corrective Action Plan comments:

OPWDD indicates that it worked closely with providers and stakeholders to support individuals and their families in maintaining community-based supports and services during the COVID-19 PHE. DDAWNY was pleased to assist in innovative efforts to provide Day, Community Habilitation, Site-Based Prevocational, and Respite services using telehealth and allowing service provision in a wider array of settings. DDAWNY believes these PHE activities should be continued after the PHE is officially ended by the Health and Human Services administration.

OPWDD indicates the longstanding workforce shortages have been exacerbated by the COVID-19 pandemic. As a result, the choices and control individuals seek to exercise are limited as agencies lack staff to provide needed services. As OPWDD acknowledges, agencies face a chronic inability to recruit and retain direct support staff and even before COVID-19 hit had been dealing with significant staff vacancy rates. A lack of DSP staff and very large vacancy and turnover rates have forced agencies to close programs or reduce programming due to staffing shortages. NYS reimbursement rates for OPWDD do not allow agencies to offer a living wage to DSP staff and many are forced to work two or three jobs to meet the needs of their family. COVID-19 has made these staffing challenges even more complex. Competing jobs in the food service and restaurant industries are now offering wages significantly above what OPWDD providers can offer based upon the current reimbursement methodology. The ability for many individuals, who previously might have been employed at site based or even community-based service locations, to find jobs where they can work from home and can earn a living without the requirement of shift work is limiting the workforce DDAWNY providers can recruit and retain.

As a result of these many workforce challenges, DDAWNY is strongly supportive of OPWDD and DOH's request for additional time, as part of NY's CAP in order to meet the HCBS Settings Rule standards.

DDAWNY is supportive of ARPA funding to enable OPWDD to make immediate new investments in the direct support workforce. Certainly, the supplemental, one-time payments to support current DSPs and bonus payments for COVID-19 vaccinations, Workforce Longevity and Retention are short-term strategies to begin to repair our workforce challenges. A 5.4% human services COLA contained in the FY 2023 Enacted Budget should assist DDAWNY agencies to recruit and retain the staff necessary to meet HCBS setting requirements. But more must be done.

OPWDD in its STP and CAP fails to layout a roadmap as to how it plans to meet the workforce challenges which limit the ability of agencies to recruit and retain the staff



DEVELOPMENTAL DISABILITIES ALLIANCE OF WNY

necessary to meet HCBS setting requirements. OPWDD indicates over the long-term it will seek to strengthen the recruitment and retention of DSPs to build and sustain a robust and diverse workforce. It indicates it intends to increase retention of DSPs, decrease the vacancy rate and reduce the turnover rate. But the OPWDD STP and the CAP do not provide any information on how OPWDD plans to accomplish these goals. OPWDD tells CMS it will monitor and report outcome data by using the NCI Staff Stability Survey.

DDAWNY would propose that OPWDD be required to articulate concrete steps it plans to take to alleviate the workforce shortage. The bottom line is if NYS and OPWDD are going to meet the federally mandated HCBS setting requirements, the state is going to need to invest in New York's care economy. At a minimum, DDAWNY believes the state and OPWDD must provide a Direct Support Wage Enhancement of a minimum of \$4,000 per eligible employee to be used for the purpose of enhancing the hourly rate of pay for all staff that have direct care/support responsibilities for individuals with intellectual and/or developmental disabilities. In addition, due to significant inflation and supply chain disruptions which have resulted in extreme financial pressure on DDAWNY agencies, OPWDD and the State must include an 8.5% COLA in its upcoming budget to ensure the long-term sustainability of non-profit disability service providers and ensure compliance with the federally mandated HCBS setting requirements. These investments need to be spelled out in the STP and CAP.

DDAWNY appreciates the opportunity to comment on New York State's Home and Community-Based Services (HCBS) Final Rule Statewide Transition Plan (STP).

Respectfully Submitted

DDAWNY, the Developmental Disability Alliance of Western New York

Wendy McCarthy DDAWNY President DDAWNY 1219 North Forest Road PO Box 9033 Williamsville, NY. 14231-9033