



On behalf of the Cerebral Palsy Associations of New York State and our 24 Affiliates supporting people with disabilities in communities across New York State, we thank you for this opportunity to provide comments on the proposed New York State Medicaid Redesign Team (MRT) Delivery System Reform Incentive Payment (DSRIP) Amendment Request (9/17/19).

We strongly support funding and extension of DSRIP for three years as outlined: "\$5 billion DSRIP performance; \$1 billion Workforce Development; \$1.5 billion Social Determinants of Health; and \$500 million Interim Access Assurance Fund. As with the original MRT waiver, NYS seeks continuation of DSRIP for the 1-year balance of the 1115 waiver ending on March 31, 2021 and conceptual agreement to an additional 3 years from April 2021 to March 31, 2024."

However, while the funding amounts will offer significant opportunity for NYS to make headway to achieving DSRIP goals, we believe the construct of DSRIP and the plans for phase two need to go beyond the modifications suggested in the proposal. For example, incorporating managed care entities in the collaborations that will be encouraged make good sense, yet there are no explicit assurances or requirements that whole sectors of the population driving much of the areas to be addressed will be included in the collaboratives that evolve. People with developmental and other significant disabilities and the agencies that support them were not prioritized in the first round of DSRIP. Various PPS initiatives included system supports and services for people with intellectual and developmental disabilities, but the amount of Medicaid funding for this high-need, high cost population has not been proportionately reflected in DSRIP activities across the state. Incentives, preferably requirements, must be strong enough to ensure value driven entities (VDE) include I/DD providers.

### **Why should I/DD be recognized?**

Within the I/DD system, there are a significant number of people who access multiple aspects of the health service system; they are high users of the system due to their medical complexity not because they are over-using services. Specialty services, mental health services, and other supports are not well integrated, leaving people with disabilities and their families struggling to efficiently access and use the systems available to them. High need demands higher costs, but doesn't necessarily warrant the

highest cost option for accessing the system – unfortunately the highest cost option is often the one that is left when our traditional primary care, mental health, and specialty providers are ill-prepared from a training and/or physical plant perspective to treat people with intellectual and developmental disabilities.

It should also be noted that a large part of the reason NYS can claim cost savings at the federal level is directly related to cuts in the I/DD system. The I/DD system of providers through the cuts made to the system 10 years ago, and through the lack of a trend over that same period have reduced New York State’s Medicaid spend on I/DD services. In fact, if you take the original cut of \$260 million annualized for 10 years (\$2.6 billion) and combine it with the lack of a trend on provider payments conservatively estimated at 2% compounded over 10 years (\$5.5 billion), New York State I/DD providers have already saved the federal government over \$4 billion. If half that savings were to be invested in the I/DD community to achieve DSRIP goals, then justifiably \$2 billion in I/DD DSRIP spending is warranted. We recommend that a significant targeted component of the State’s \$8 billion be invested in the sector of the Medicaid spend which generated a significant savings to help make the argument that DSRIP should be continued.

### **A Value Based/Social Determinants of Health System**

DSRIP in the years 2020 – 2024 must wholly integrate people with disabilities, who, according to the Centers for Disease Control and Prevention are twice as likely not to receive medical care due to costs as the general population, as part of the State’s response of health equity and system measures for all populations served. DSRIP activities must address current shortfalls in the New York State health system’s ability to meet the needs of people with developmental and other significant chronic disabilities, e.g., traumatic brain injuries, who do not have access to health and social service supports needed for positive health outcomes. People across New York State and throughout the world living with disabilities are under-served: “People with disabilities have less access to health care services and therefore experience unmet health care needs.” (World Health Organization, January 2018)

In addition, we looked to Healthy People 2020 who uses the “World Health Organization’s (WHO) model of social determinants of health, which recognize that what defines individuals with disabilities, their abilities, and their health outcomes more often depends on their community, including social and environmental circumstances. To be healthy, all individuals with or without disabilities must have opportunities to take part in meaningful daily activities that add to their growth, development, fulfillment, and community contribution.” It is significant to focus on the Healthy People 2020 report

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which found that for social determinants of health, people with disabilities not only require support to attain improvements in the social determinants of health, they also are a significantly under-served sector of our community. Research shows that people with “physical disabilities or cognitive limitations had significantly higher prevalence rates for 7 chronic diseases than persons with no disabilities [and they] were also significantly less likely than the no disability group to receive 3 types of preventive care. [Moreover], adults with disabilities and chronic conditions receive significantly fewer preventive services and have poorer health status than individuals without disabilities who have the same health conditions. This indicates a need for public health interventions that address the unique characteristics of adults with disabilities, many of whom are at risk for high cost, debilitating conditions that may not have as severe an effect on other population segments.”

Additional facts about people with disabilities:

- 19 percent of people with disabilities reported that they did not receive medical care needed in the previous year, compared to 6% of nondisabled persons.
- Those who did not receive treatment attributed the failure to reasons that included a lack of insurance coverage (35%), high costs (31%), problems getting to provider offices or clinics and inadequate transportation (11%), and difficulties or disagreements with doctors (8%).
- Among women with physical disabilities, nearly 1/3 report being denied services at a doctor’s office solely because of their disabilities, and 56% of women with disabilities who have given birth in hospitals reported that the hospital had failed to prepare for needed disability-specific accommodations.
- Children with DD were more likely than typically developing children to have a fair or poor health status (27.7% vs. 1.1%), have two or more overnight hospitalizations (8.5% vs. 0.7%;), experience delayed treatment (10.1% vs. 2.4%;), and have one or more unmet healthcare needs (19.6% vs. 5.7%).
- The Kaiser Family Foundation reports that New York’s 2017 data demonstrates that 1 in every 2 people with disabilities are covered by Medicaid; the rest are dependent on private insurance or have no coverage at all.

People with disabilities face a number of disparities and poorer outcomes compared to non-disabled peers due to an “increased risk of exposure to socio-economic disadvantage.” People with disabilities are more likely to live in poverty, face social

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isolation, and have trouble finding affordable accessible housing . . .[disability] also impacts people with disabilities' health and outcomes.”

Within each of the key domains in the social determinants of health, compared to individuals without disabilities, individuals with disabilities are more likely to experience challenges finding a job, being included in regular educational classrooms or attending college, receiving preventive health care services, being able to visit homes in the neighborhood, using fitness facilities, using health information technology, and obtaining sufficient social-emotional support. The I/DD system is grounded in a broader health context and as such, the State’s I/DD providers should have a dedicated amount of DSRIP funding set aside to enhance and ensure the social determinants of health are measured and included in the State’s efforts in the next round of DSRIP.

DSRIP must address the inequities confronting the high needs group of people with disabilities. If as a system we are to move to a more integrated, community of supports for people with disabilities, the regulatory and financial infrastructure needs to support and align with those goals. Ensuring quality outcomes and incentivize performance, efficiency and innovation with greater equity of access to supports and services need to be fundamental to all aspects of the waiver program; the current construct and the waiver as proposed in this renewal has resulted in outcomes and a reality for families and service recipients that fails to meet the needs for the I/DD population to be more centrally integrated in achieving DSRIP goals.

That said, there have been some successes when PPS’s have focused on the I/DD community’s inclusion in their projects. For example, in the Staten Island PPS, the disability CBO component was recognized in a pilot program to reduce ER utilization through a triage program in a medically fragile residence. The two homes initially studied found a higher than 75% decrease in ER visits; when the program was expanded to more than 100 homes, that same level of decreased utilization of ER visits was maintained. The program worked and the results are replicable. The disability community is working to further expand those results, but the disability provider system has not had the investment in all parts of the state to address these and other high utilization practices.

This experience shows that when made a priority, I/DD providers can deliver in meeting NYS DSRIP goals. This is why we recommend that I/DD should be among the high priority areas for phase II and there be added aligned incentives/requirements to ensure disability providers are able to maximize the returns for the State. DSRIP performance funds need to be aligned with establishing value-based metrics for the I/DD field and

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VDE's need to work with MCOs expected to support the I/DD community. Interim Access Assurance funds also should have a set-aside for disability providers who have an expertise that is not found in the general community and without those providers, only high cost, inefficient options remain. For example, when dental services are no longer accessible for the developmentally disabled population in any part of the State, we know that demand for expensive operatory time for dental procedures increases 6-9 months after because there are no other dental practices able or willing to support people with I/DD. Similarly, when providers are forced to end their services in mental health services, primary care, etc., for people with I/DD, the overall system costs increase many times. Specialty care for people with I/DD is cost effective when access points are maintained.

The I/DD funding in New York State has assisted the entire Medicaid program demonstrate to the federal government that savings had been taken from the system. As the I/DD field moves to managed care, there are less assurances that providers will be maintained in all geographic regions of the State. The DSRIP model focused on I/DD will help raise system awareness of the need to access and integration with other providers.

Thank you for the opportunity to comment on the proposed DSRIP Waiver Amendment; please let us know if you have any questions or would further clarification of our comments.