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The Arc New York Comments on Statewide Comprehensive 5.07 Plan

The Arc New York is a family-led organization driven by the shared mission to provide people with disabilities the ordinary and extraordinary opportunities of life. With 37 operating Chapters across New York, our organization is the largest voluntary provider in the state, supporting more than 60,000 individuals and families and employing more than 30,000 people. Because of our size, statewide presence, and family-led governance, The Arc New York brings a unique perspective to the 5.07 process and appreciates the opportunity to share its feedback.

New York State is required under Mental Hygiene Law to develop a comprehensive 5-year plan that defines and adequately resources supports and services for individuals with intellectual and developmental disabilities (I/DD). This plan must be guided by stakeholder feedback, identify statewide priorities and goals, focus on obtaining positive measurable outcomes, and design supports and services that promote health and wellness as overarching goals. OPWDD's last plan under this requirement was adopted in 2012 and expired in 2016.

As part of our FY22 advocacy platform, The Arc New York championed a renewed effort to engage in a new 5.07 plan after years without this important roadmap. We believe that transparency and accountability are paramount as we move forward with initiatives to transform our system to better meet the needs of New Yorkers with I/DD and ensure quality supports are available into the future.

The Arc New York believes the State of New York's 5.07 Plan for the Office for People with Developmental Disabilities (OPWDD) should be guided by the following values and principles:

- Funding must be available to support current and future needs
- Services and supports should be planful, including needs-based forecasting using robust data-driven information, including but not limited to demographics of individuals supported and providers, waiting lists, system expenditures and costs, and quality and outcome-based measures
- Individuals with I/DD must be supported in the least restrictive setting of their choosing
- OPWDD must be fully transparent, proactive and inclusive in partnerships with self-advocates, individuals, families and providers
- The dignity of risk must be acknowledged and rebalanced, particularly for individuals living in non-certified settings
- The role of state-operated services must be clearly defined, particularly in light of funding model differences and the escalating workforce crisis

The parents who created our organization were among the earliest advocates for quality services and opportunities for people with I/DD. In the more than 70 years since our founding, we have witnessed – and at many times driven – massive transformation and progress in our field. Over those seven decades, New York has developed a robust system of exceptional, comprehensive, individualized services and programs that aid independence, support families, and emphasize inclusion in communities.

New York has a legal and ethical obligation to provide essential services, quality care, and integration for its citizens with I/DD. Our shared responsibility to the people we support is nonnegotiable. However, decades of fiscal pressures, under-investment in our workforce, and regulatory burdens have driven our system to the tipping point.

The COVID-19 pandemic highlighted the state's systemic failure to ensure the sustainability of this system, or heed the warnings offered year after year by The Arc New York, its families, self-advocates, Chapters, and allies that our system is in crisis. As an early champion of change and transformation, we look forward to aiding in the 5.07 process to correct our severely destabilized system and realign it towards sustainability, accessibility, and equity. We have come this far to build and fulfill an immutable promise, and we must take decisive action to preserve it.

Workforce Needs

New York is known as the Empire State, in part, due to its wealth and variety of resources, and its shared commitment to fulfill the social welfare responsibilities defined in the New York State Constitution. One of these responsibilities is the care and support of New Yorkers with I/DD, and our direct care workforce is our greatest resource in fulfilling this responsibility.

New Yorkers with I/DD depend on caring, capable, and consistent Direct Support Professionals (DSPs) to provide the support they need to live rich lives in their community. But our system is experiencing a rapidly escalating workforce crisis that has been years in the making. The pandemic exposed and magnified this existential threat to our system of care.

The data from the most recent workforce survey conducted by New York Disability Advocates (NYDA), paints an alarming picture. The statewide vacancy rate for DSPs escalated 74% over the past two years. A full one quarter of these essential positions are currently vacant across the state. Forty percent of providers were unable to open programs due to staffing shortages. Forty-eight percent were forced to close programs or reduce operations because they lacked the staff to sustain them. Senior and administrative staff at 69% of providers were pulled from their leadership responsibilities to cover direct support shifts. The trajectory of this crisis is only escalating, and will continue to force interruptions in essential services, program closures, and loss of care throughout the state.

Addressing the workforce crisis must be our top priority over the next five years, and must be addressed with sustainable solutions, not temporary fixes. We must provide new and ongoing investment in our dedicated workforce. We need to significantly raise DSP compensation to ensure all DSPs receive a living wage that reflects their expertise and the level of skilled care they provide.

Businesses across the nation are currently struggling to reopen post-pandemic and, like us, they are trying to recruit essential front-line workers with highly creative approaches. We have always known the value of our staff. We advocate for them consistently and strive to compensate them as fairly as possible under current rate structures. Moving forward, New York state must acknowledge the professionalism of DSPs and compensate them accordingly, in line with peers with similar skill sets and responsibilities.

Not only do we need to become more competitive to survive in the short term, but we must look to the future and ensure the sustainability of our workforce. The pandemic underscored the critical importance of frontline workers. They make and deliver the food and products we rely on. They care for our sick, they care for our elderly, and they care for and support the complex needs of people with I/DD. The recognition of the critical role they perform in our society cannot be a passing moment. Unless we transform the DSP position into the professional role it has always been in practice, we will lose our heroic frontline workers to other employers. In the words of a parent and board member of The Arc New York:

“The quality of our loved ones’ lives on a daily basis is totally dependent on the direct care professionals who are working with them. We can talk about and create wonderful programs and activities, but they are only as successful as the DSPs who are carry these programs out. We need to change the culture to truly place value in our DSPs. The positions need to be professionalized. . . . We need to recognize the direct care workers for the work they do. We need to improve and standardize training and create certifications. Only then will this be considered a profession worth pursuit by young people. Only then, will DSPs be adequately compensated.”

Raising DSP compensation is not a panacea. It will not solve the recruitment and retention crisis on its own, but it is a necessary starting point. The higher compensation OPWDD provides to its own DSPs indeed creates better results – the NCI Direct Support Professional survey data¹ confirms that OPWDD’s turnover and vacancy rates are substantially lower than those of its voluntary-operated providers.

We need to immediately and substantially raise the compensation of DSPs in the voluntary sector using the majority of the enhanced federal matching funds the state will receive through the American Rescue Plan Act (ARPA) in 2021. If used wisely, this funding will give us up to three years to transform the DSP role, the programs we operate, and our regulatory systems to become more sustainable. For New York state to fully maximize the influx of federal funds generated by voluntary providers, there must be a long-term acknowledgement and commitment to fully fund home and community-based services (HCBS).

¹ https://www.nationalcoreindicators.org/upload/core-indicators/2019StaffStabilitySurveyReport_FINAL_1_6_21.pdf

Regulatory Reform

Our overall approach to regulation in New York is driven by risk aversion. Responding to high-profile, politically sensitive, and potentially singular events as if they are indicative of deeper systemic issues creates an arbitrarily restrictive environment for individuals and those providing supports and services. The combined weight of these mandates is crushing our programs, our DSPs, and the individuals with I/DD these very regulations are intended to protect. At times, the state serves as a “helicopter parent” more than a support, infringing on people’s independence. We need to admit to ourselves, our families, and the people we support, that more regulation and documentation does not always create a better quality of life, and the unintended consequences of protection can become a disservice. Every moment our DSPs spend in documentation is time away from face-to-face care and support.

In addition, we need to address the highly regulated environment surrounding services supporting the retirement interests of elderly individuals with I/DD. Currently, we are relying heavily on our most costly, most regulated, day habilitation programs to support such individuals. We could produce better outcomes by finding ways to fully utilize the site-based respite fees that exist to provide supports more focused on leisure and recreational interests than continued habilitation and skill development. In this and many other instances, less regulation equates to less cost, generating savings that can be reinvested in our workforce.

In 1980, the annual cost of care for an individual in a certified community residence was \$12,000. Adjusted for inflation, such cost today would be approximately \$40,000. The average cost of care today is more than twice this amount, but the portion of that cost that goes to wages has not kept up. Since then, we have vastly expanded the community-based system of care and the level of need of individuals we support, adding to the average cost of care. Our approach to regulation under the Medicaid program and the HCBS waiver has contributed substantially to this cost. Unless we find ways to further support and build our workforce, DSPs will spend more time filing reports than they do supporting individuals. This is simply unsustainable. Regulations and reporting need a thorough review, to ensure we keep service quality and outcomes at the forefront, rather than checkboxes.

We know that some regulations are necessary and valuable. We recognize others are outside our control – dictated by CMS, driven by NYS statute, and difficult to unilaterally change. But many are within our control and their reform could effectuate meaningful change. As an illustrative model, OPWDD is redesigning its survey process with the intent

to stratify providers based upon their compliance track record. Those with satisfactory compliance levels will receive less survey activity and those with poor performance will receive more. This presents an opportunity to reduce the collective weight of our regulations. Historically, the best results have been realized when OPWDD transformed its survey process to focus on the critical standards in regulation. We support this effort and urge OPWDD to be bold in its approach and timely in its implementation.

Residential/Day Habilitation Reform

We have defined and are required to treat residential habilitation and day habilitation as if they are two entirely different services, when they are realistically the same service occurring in different settings. Removing these arbitrary distinctions in how we fund providers for individuals who receive both services from their agency will allow the necessary flexibility and clarity to appropriately meet the needs of individuals we support.

When it comes to service delivery, we must focus on outcomes and have an understanding that individuals, families, and providers work collaboratively to establish a person-centered framework and goals.

How can we achieve the same or similar outcome of a per person/per month or global budget approach for the combined residential and day supports for these individuals?

- This approach provides the flexibility necessary to respond to an individual's dynamic, day-to-day support and community engagement interests
- The Arc New York has found that more fluid deployment of our day and residential habilitation DSPs creates better outcomes for individuals, DSPs, and our bottom line
- We need OPWDD to respond accordingly by finding ways to meld the ADM service and documentation distinctions, and the CFR time recording and allocation distinctions, so that we can move this approach forward

Sustainability, Equity and Access

In addition to stabilizing the workforce by securing DSPs a living wage, the following approaches will guide OPWDD in meeting the growing demand for services throughout a person's life and ensuring sustainability, equity and access in our system:

- Supporting innovation in service models that allow for greater flexibility, require less staffing, or allow for reinvestment of cost savings into technology, wages, and other programmatic needs

- Collecting, using, and sharing available data that projects and anticipates needs across the lifespan of individuals we support
- Acknowledging that true person-centered, community-based supports are more expensive and require more staff to successfully execute, and that a “no growth” philosophy in the annual OPWDD budget will not appropriately meet the needs of individuals currently supported or the needs of individuals waiting for services
- Amending the Front Door process to ensure greater equity and access; success in accessing services is currently dependent on families and individuals having the skills and resources to navigate a complex system, especially in historically underserved communities

Diversity, Equity and Inclusion (DEI)

The Arc New York makes the following specific recommendations regarding how OPWDD can include the values of diversity, equity and inclusion throughout the service delivery system:

- Ensure uniform access to transportation in all regions, particularly those in rural areas
- Improve transparency and use of demographic information to examine and assess inequities
- Acknowledge and address the inherent inequity that results in a lack of living wage paid to direct support professional staff who are overwhelmingly female and people of color
- Create collaborative training, education, and round table opportunities with all stakeholders, facilitated by experts in DEI

Self-Direction

The self-direction program can be improved in the following ways:

- Self-directed services could be made more sustainable by decoupling its rates from the regional model, which is not an appropriate comparable due to the lack of hard costs that are otherwise built into traditional, regional services
- Fiscal intermediaries would be more readily available if their rates were more adequate, particularly given the significant responsibility and risk FIs take on
- Accessibility and ease of navigation of the self-direction program must be improved to ensure equity and fair access
- Enriched training for participating agencies, brokers, and families must be developed and made available

Technology, Including Telehealth

Technology can be an important tool to support a person's life goals. The Arc New York proposes the following improvements to enhance the technological resources in our system:

- Centralize the investigation, piloting, and implementation of technologies to a single statewide team to avoid local duplication of efforts
- Continue adequate funding for remote services, if selected by individuals
- Prioritize innovation in technology that can increase independence and improve skills, including smart homes, medication administration tools, and transportation to assist in employment
- Support uniform access and funding for Internet support, hardware, software, and training for staff and individuals, to ensure equitable access to services
- Revise regulations that hamper rather than encourage the use of technologies that increase independence
- Invest in technology to support the use of telehealth for clinical services and medical supports needed within residential and day services

Serving Children and Adults with Complex Needs

Data is essential to thoughtful and effective planning. This holds true for our field, and the collection and availability of critical data on the needs of children transitioning from school to adult services would assist in better serving this population. In addition, The Arc New York suggests the following:

- Support the flow initiative to encourage state-operated providers with greater resources to serve individuals with more complex needs
- Improve coordination between the State Education Department and OPWDD, and enhance education for families to ensure a supported and appropriate transition
- Implement acuity-based funding mechanisms to properly support individuals with complex needs
- Remove barriers to collaboration between various state agencies who support this population

Care Coordination

There needs to be a clear indication on whether OPWDD is moving to a managed care reimbursement system. The Care Coordination Organizations (CCOs) were designed as a transition to the managed care model. How they should function depends on the direction we are headed.

This question cannot be answered without an assessment of how well the CCO/Health Home model is working. The problems and challenges with the current implementation of this model need to be acknowledged. In particular, the 35,000 people living in certified settings have distinctly different needs for "health home care coordination" than the 80,000–90,000 people living outside of certified settings. The needs of the people outside these settings are not uniform, and should not be funded or treated as such. Unlike a health home for a special population that is defined by a medical condition, people with I/DD have a full range of needs and lifelong support, so one health home model does not fit all. This has resulted in confusion and a lack of continuity and consistency during the transition.

The pandemic demonstrated how disconnected care managers are for people living in our residences. In essence, they became one more person to contact with little discernable benefit. The entire Life Plan process needs to be modified and simplified so it can be a truly person-centered discussion, rather than a "check the box" session that the CCO and the provider must rush through to meet their paperwork requirements.

Care Coordinators need to understand the service system and get to know the people they are working with. Today, unless you are lucky enough to have someone who was an MSC, the care coordinator will likely be the least informed person at a planning meeting about the individual or the system of supports that might be available to support that person. Before care coordinators can begin to assist people with complex needs, the issues with the current model must be addressed.

Managed Care

Our system has made significant investments in response to the state's plan to transition to managed care, including the implementation of CCOs and the proposed creation of Specialized I/DD Plans – Provider Led (SIP-PL). However, these investments pale in comparison to the potential startup and ongoing costs of managed care administration. Should the state move forward with managed care for the I/DD field, funds must be appropriated as new investments and not drawn from the current OPWDD budget.

In the interim, we should create a value-based payment system and shared savings incentives to support individuals in a less costly and more person-centered, efficient and integrated setting, through the flexibility afforded under the existing 1915(c) waiver. Transforming our fee-for-service funding methodologies can accomplish this goal. Moving from a cost-based rate methodology to an acuity-based fee methodology is a concept that should be finalized and implemented to better support and incentivize providers.

There is a substantial gap in average annual funding between supervised and supportive IRAs. Closing this gap by creating multiple acuity tiers will enable individuals to appropriately and voluntarily make transitions that will produce a net savings. This needs to be a high priority. In addition to generating savings for the overall system, we need to create mechanisms that allow voluntary providers who successfully support such transitions to reinvest these savings into the DSP workforce, not returned them to the general fund.

Conclusion

On behalf of The Arc New York we wish to thank you for initiating this important planning process. Our organization recently completed the development of a Strategic Plan. This plan will drive our organization's decisions and direction for years to come. The 5.07 Plan must perform the same function for our field. Considering the uncertainty and instability we currently face, OPWDD must take the leadership role in ensuring services and supports for our most vulnerable citizens are equitable, sufficient, and sustainable. We trust these comments will aid in achieving that goal. We are happy to discuss any of the comments in this letter in greater detail at your convenience.

Sincerely,

A handwritten signature in black ink, appearing to read "Erik Geizer", with a long horizontal flourish extending to the right.

Erik Geizer
Chief Executive Officer
The Arc New York