



***The Arc***<sup>®</sup>

*New York*

**Comments on the Office for People with Developmental Disabilities  
2023–2027 (5.07) Strategic Plan**

**July 28, 2022**



## **Comments on the Office for People with Developmental Disabilities (OPWDD) Draft 2023–2027 Strategic Plan**

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### **Introduction**

In May of 1975, the State of New York entered into the Willowbrook Consent Decree following public outcry over the deplorable conditions at Willowbrook and the treatment of the people who resided there. The conditions at Willowbrook and the subsequent legal actions, led by The Arc New York and its family advocates forever changed the way society viewed people with intellectual and developmental disabilities, ensured basic human rights for them and their families, and facilitated a transformation to community-based supports and services. OPWDD’s 5.07 Plan memorializes the State’s ongoing commitment to this promise. We offer these comments on the plan in our continued partnership to ensure this essential system of services is sustained and thoughtfully evolving for the future.

The Arc New York is the largest non-profit provider for individuals with I/DD in New York state. Our 36 local Chapters collectively support 60,000 people and employ more than 30,000 staff. The parents who created our organization were among the earliest advocates for quality services and opportunities for people I/DD. In New York, more than 80% of services provided to people with I/DD are through voluntary, non-profits like The Arc New York. 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.

The Arc New York appreciates the opportunity to comment on the 2023-2027 strategic plan proposed by OPWDD (hereinafter “Plan”). We are encouraged by the latest Plan draft proposal, which endeavors to address critical issues in the field, including the needs of our direct care workforce; regulatory reform flexibilities; person-centered residential and day habilitation reform; diversity, equity, inclusion and access initiatives; telehealth, and serving children with complex needs, among others. In 2021, we offered comments<sup>1</sup> on both the previous 5.07 strategic plan draft and suggestions for regulatory reform. We are pleased that these recommendations remain at the forefront of the revised plan and are key objectives moving forward.

Much of the Plan acknowledges the issues faced by voluntary providers of supports and services, caregivers, and family members. To this end, the Plan is laudable. However, specific benchmarks and metrics for short- and long-term goals would provide a greater sense of what the field will look like in five years’ time. Immediate conversations on system operations and regulatory reform are necessary, and solutions must be identified sooner than later.

Furthermore, it would be beneficial to know which portions of this Plan can be accomplished through stakeholder input, official OPWDD regulatory changes, waiver amendments, and legislative actions, including a specified timetable. This inclusion would better enable us to focus our collective advocacy to advance these important goals.

Finally, The Arc New York would suggest removing the multiple references to one-time federal funding that occurred in 2022 as a strategic tactic. It is outside the 2023-2027 timeframe for the Plan and represents less of a strategic initiative than a result of COVID-pandemic relief.

### **Guiding Principles**

The Arc New York continues to affirm that 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:

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<sup>1</sup> <https://files.constantcontact.com/c80b6f60101/b702730c-d482-47bd-b733-8bc7d656f0af.pdf>

- 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 providers and individuals supported, 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

### **Supporting People in the Most Person-Centered Way**

Increasing opportunities for community integration and participation are key to ensuring diverse options are available to a person as they pursue their life goals and desires. It should be underscored that providers will require adequate and properly trained staff to achieve these goals. Supporting individuals in the community comes with a high-level of responsibility for staff, particularly when situations and circumstances unexpectedly shift and threaten health and safety. We should also be mindful that not all people choose to be out in the community, preferring alternative options. Being person-centered means adapting and honoring those decisions with sufficient flexibilities. Expanding access to assistive technology has the potential to help some individuals we support achieve greater community integration in a manner of their choosing. Additionally, intensive supports and services are required for some individuals with higher and more complex level of needs to live in the community rather than in a skilled nursing facility. New and continuous funding and training is needed to support this additional access.

We strongly support the goal to make new investments and transition people to the least restrictive environment possible. Thousands of New York's citizens with I/DD are waiting for placement in a community residential setting, and many are in

immediate need. This could be addressed with reform to crisis services as detailed in the Plan. Vacancies within certified residential settings have grown in recent years due to an administrative requirement to fill the opening with a person from the “Emergency Need” placement category. Extraordinary staffing shortages have also impacted the ability of voluntary providers to fill vacancies. It is our hope that OPWDD seeks to ameliorate or eliminate these issues through the Plan.

### **Serving Children, Youth, and Young Adults**

More involvement between school systems and OPWDD is essential in smoothly transitioning students into services after they graduate. This process is currently not well coordinated, and young adults are at times forced to stay at home with no services, or transition into a service that may not be the best fit.

In terms of complex needs, we agree with the comments in the Plan that some people have additional needs, including complex medical and behavioral needs and dual diagnoses, which require additional support. In response, we encourage OPWDD to work with the legislature to secure additional funds to identify the root cause of an individual’s challenges and develop an appropriate plan to support them. Often, supported individuals are unable to process circumstances or communicate effectively, which can manifest additional challenges and aggressive behaviors. Our Chapters have had success with discovering underlying medical conditions and addressing those head on, with appropriate supports.

### **Serving Diverse Communities**

Diversity, equity and inclusion is a strategic initiative being explored across the state and country, including within The Arc New York and OPWDD. We commend OPWDD for establishing a separate and distinct Office of Diversity, Equity, and Inclusion and recruiting a Chief Diversity Officer. An equitable system naturally leads to diversity and inclusion – and an equitable system is the one that will lead to peace of mind for people supported, their families, and providers.

The Urban Institute released a study<sup>2</sup> that examined increasing diversity in the medical field. More specifically, it “aims to advance racial equity in the health care workforce, focusing on African American/Black, Hispanic/Latinx, and Indigenous/Native American students, doulas, midwives, nurses, physicians, fellows, researchers, policymakers, and other health care professionals in the US.” Our direct care workforce are essential employees drawn from all walks of life. Supporting our workforce in the ways mentioned in this Plan reinforces our commitment to DEI and sends a message that we are championing growth and opportunity. Today’s DSP can be tomorrow’s clinician.

### **Promoting Practices that Strengthen the Workforce and Infrastructure**

We cannot stress enough the importance of developing and supporting initiatives to address long-standing workforce shortages. Creating a resilient workforce infrastructure requires substantial investments across the continuum of care, both in policy and through appropriate funding.

Our workforce has shown exemplary strength and fortitude and continues to demonstrate their commitment to the people they support. These are not just jobs. They are careers, and should be treated as such. Nonprofit provider agencies funded by OPWDD employ nearly 100,000 Direct Support Professionals (DSPs), and deliver 80 percent of the needed services to approximately 140,000 people with I/DD in the state.

While wages are not the only factor contributing to the workforce crisis, they must certainly be at the fore when approaching any long-term solution to the workforce crisis. We firmly support developing and strengthening career pathways and ladders to provide incentives for employees to stay in the field and grow their skills, while creating additional pipelines for new staff. The Arc New York has worked with stakeholders to pilot similar programs to accomplish these goals and welcomes additional expansion.

Short-term financial benefits of the American Rescue Plan Act (ARPA) and subsequent actions by the NYS legislature were only a salve on the issue of pay equity for DSPs. This temporary injection of funds does not offer a long-term solution to the workforce issue for all staff, and the limitations of the funding exacerbated the

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<sup>2</sup> <https://www.urban.org/projects/diversifying-health-care-workforce>

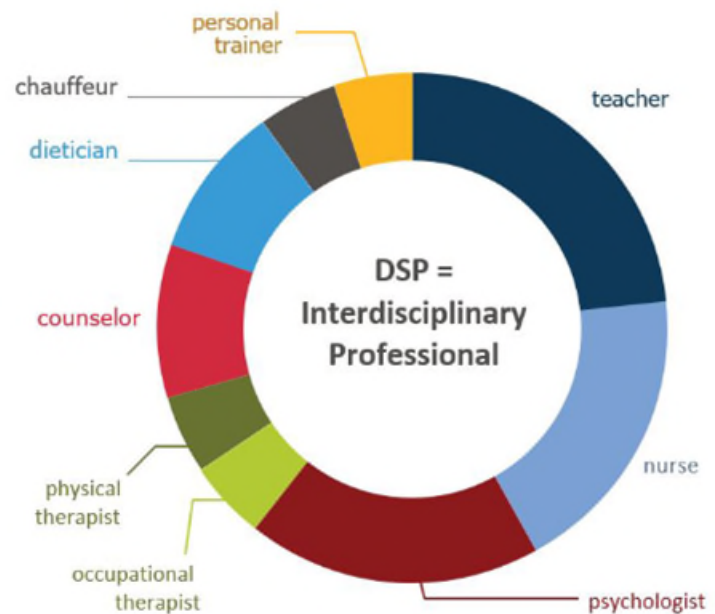
crisis in some aspects. I/DD providers cannot offer competitive wages to recruit and retain skilled direct support professionals and other staff that provide the foundation of care. This includes everyone from cleaners, cooks, and drivers to accountants, clinicians and people who fall outside the traditional DSP 200 code. If we want to transform the system, we need appropriate resources to support the entire system of care.

Feedback from our Chapters indicates that staff want and need long-term investments rather than one-time bonuses. Just as providers cannot plan without long-term investments, our workforce does not find security from an organization that does not pay them a consistent wage.

As noted in the OPWDD strategic plan, there are structural barriers that hinder advancement opportunities and a clear career ladder for DSPs. The United States Bureau of Labor Statistics (BLS) classifies workers into occupational categories called the Standard Occupational Classification (SOC) for the purpose of collecting, calculating, or disseminating valuable wage and occupation data. All workers are classified into one of 867 detailed occupations according to their occupational definition.<sup>3</sup> Unfortunately, a discrete SOC does not exist for DSPs. Without this classification, meaningful wage and occupation data for the direct support profession is unavailable and not accurately captured.

The BLS combines DSP data with that of Personal Care Assistants and Home Health Aides, positions which have varying levels of responsibility compared to DSPs and different funding streams. In addition to wage data, information on employment

**Figure 1. DSP Scope of Practice**



<sup>3</sup> <https://www.bls.gov/soc/>

costs and the job market in the I/DD sector are not accurately reflected.

The work of a DSP is interdisciplinary in nature (as indicated in Figure 1). Throughout the course of their duties, DSPs fill the role of other health and support professionals. They administer medication, assess needs, implement specific treatment plans, document progress, and communicate with medical professionals. In their role as social workers, they connect to community resources and benefits and like counselors, they listen, reflect and offer suggestions. DSPs provide whatever support it takes so people can live and participate in their communities with greater independence and dignity.<sup>4</sup>

DSPs are the backbone of services for New Yorkers with I/DD. Their 24-hour duties also include:

- Supporting activities of daily living
- Tube feeding, wound care, mobility support, and oxygen administration
- Delivering physical and behavioral health services
- Teaching money management
- Transporting to appointments and community activities

A discrete SOC will assist states and federal agencies in better understanding a workforce that is facing increased demand at a time when recruitment and retention are low and turnover is high. From the available research, it is evident that DSPs are not compensated, nor acknowledge for the vast array of supports and services they provide.

We commend the Plan for including advocacy around SOC as a strategic initiative. It is our hope that our combined advocacy efforts will correct this course.

### **Improve OPWDD's Use of Data**

Data access and transparency from OPWDD is vitally important for individuals, families, and providers. We are encouraged by this administration's openness to sharing data freely, and hope that additional information will be openly accessible and available through the OPWDD website. While much of the newly shared data

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<sup>4</sup> [https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)



offers valuable insights, we stress the importance of sharing all data related to people who have applied and are eligible for services but remain on a waitlist.

It has been noted by some of our Chapters that numerous surveys are completed by providers and sent to OPWDD, but very little information comes back. To that end, OPWDD should consider proactively sending survey results back to providers. This small step would help immensely as they continue to find new and innovative ways to provide supports and services.

### **Improve Stakeholder Involvement**

Without question, engaging stakeholders and involving them in the process of change and reform is incredibly important, and necessary to gain the insight required for effective and informed decision making. The latest draft of the Plan is testament to the importance of this engagement. Throughout the document, comments from stakeholders have been noted and modifications were appropriately made. This demonstrates the importance of community and provider involvement, while highlighting that OPWDD has taken this feedback seriously. We encourage the continuance of these dynamic interactions moving forward and hope that community members and providers remain appropriately informed.

### **Advancing System change and Innovation across the State**

As noted in the Plan, OPWDD has been working towards a transition to managed care, which began with an enhanced care coordination model through the development of regional Care Coordination Organizations (CCOs). Scheduled rollout for approved specialized I/DD plans has yet to be determined, pending finalization of the Specialized I/DD Plans – Provider Lead (SIP-PL) document by OPWDD<sup>5</sup>. In June 2020, this document was revised again and The Arc New York provided comments stressing the importance of employing SIP-PLs for the I/DD population.<sup>6</sup>

The question of whether New York state is proceeding with managed care for the OPWDD system and how it will be funded has created uncertainty and confusion about where investments must be made into the future. The Arc New York does support an assessment of the care management model and acknowledges that

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<sup>5</sup> <https://opwdd.ny.gov/news/revised-sip-pl-document-now-available-public-comment-deadline-may-11>

<sup>6</sup> [https://www.thearcny.org/application/files/1116/0149/4024/TheArcNewYork\\_CommentsOnSIPs-PLDraftDocument\\_62520.pdf](https://www.thearcny.org/application/files/1116/0149/4024/TheArcNewYork_CommentsOnSIPs-PLDraftDocument_62520.pdf)

there are opportunities for improvement that need to be carefully studied prior to any further decisions about managed care. These considerations include identifying and understanding the funding for managed care and, more importantly, ensuring that managed care would result in improved outcomes for the people we support and their families.

A more regional and holistic approach to person-centered care will help people with complex medical, social, and behavioral needs and break down barriers for accessing such basic services as primary care physicians, dentist, and clinicians who are specialized in their field.

If the goal is to eventually include people with I/DD within a managed care structure, we must be present to inform future decisions as it pertains to this vulnerable, underserved population whose health and supports needs are unique and not always fully understood.

### **Access to Health Services**

Improved access to comprehensive healthcare is a strategic objective that should be fast-tracked within the Plan. Assessing how to integrate services provided by Article 16, Article 28, and Article 31 clinics would be an important step with understanding what healthcare capacity is available for people with I/DD. Holistic and integrated approaches more effectively address dual diagnosis, co-morbidities, oral care, and numerous health disparities.

The Plan makes general references to healthcare and Article 28 and 16 clinics, but does little to squarely acknowledge or address the issues with health access and quality facing New Yorkers with I/DD.

Individuals with I/DD experience poorer health outcomes, more barriers to healthcare access, and higher healthcare costs than the general population. Data from the NYS Department of Health showed that Medicaid health expenditures associated with this group are disproportionately high on a per capita basis.

Individuals with I/DD are 4 to 5 times more likely to have a chronic disease & preventable mortality.<sup>7</sup> The people we support are almost 1.5 times more likely to visit

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<sup>7</sup> <https://doi.org/10.1111/jar.12067>

the ER, and more than twice as likely to be admitted.<sup>8</sup> Yet, according to a survey of 57 medical providers, almost 60% felt that they provide unequal care to patients with I/DD due to a lack of training, time constraints and communication barriers.<sup>9</sup>

Approximately 50 people with I/DD identified as stable remain in acute in-patient settings awaiting long term supports and services.<sup>10</sup> Holding people in hospitals while suitable placements are identified is both costly for the state and inappropriate for the individuals.

New York state must develop a cross-systems strategy that will help reduce health disparities facing this population, improve health outcomes, and better manage healthcare costs.

In addition to cross-sector efforts, OPWDD should assemble an advisory group of service, support and clinical partners to more aggressively establish effective integrated care models for people with I/DD. A strategic partnership with New York State DOH and OPWDD would substantially increase the likelihood of success.

I/DD service providers have long advocated for telehealth as a flexible, efficient option to deliver quality care. Overall, our Chapters and providers are pleased to see extensive support for telehealth and digital health and hopeful that more extensive use of remote service delivery models will result in both cost savings and improved flexibility and service quality.

With expanded use of telehealth, access to care across multiple medical disciplines finally became a possibility, whereas previous regulatory and statutory barriers made it logistically challenging or impossible to offer services in such a way. We have realized efficacy, increased equitability, and savings with telehealth and digital health and support solidifying these options with other flexibilities into the future.

### **Supports and Services**

As noted in the Plan, the self-direction model has many administrative complexities, which affect supported individuals and families and increases exposure for providers. We appreciate the philosophy behind the model but there is much work to be done

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<sup>8</sup> <https://www.sciencedaily.com/releases/2018/06/180619122721.htm>

<sup>9</sup> <https://aadmd.org/articles/survey-patients-families-and-providers-about-care-patients-intellectual-disabilities>

<sup>10</sup> [https://www.health.ny.gov/health\\_care/medicaid/redesign/dsrip/docs/2015-11-04\\_opwdd\\_comb\\_webinar.pdf](https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/docs/2015-11-04_opwdd_comb_webinar.pdf)

to make it truly self-directed. Streamlining processes, finding efficiencies, bolstering access to information, and engaging stakeholders as OPWDD considers waiver reforms will help address these concerns, but must be done comprehensively alongside of service reforms.

Modernization of and increased flexibilities for Employment and Day Services in the post-pandemic era are critical to sustaining and growing person-centered options. Along with the expansion and restructuring of remote and in-person services comes the obvious need for additional training and financial support for direct care workers, and in often overlooked areas, such as billing, quality assurance, and program and agency administration. Finding ways to streamline these impacted areas should be considered alongside any programmatic redesign.

Similarly, as OPWDD explores an innovative redesign of housing supports and residential services, including an acuity-based reimbursement methodology, we encourage continued diligence when assessing the true cost to providers in meeting the obligations and expectations of both OPWDD and those we support. Supportive housing models utilize administrative resources on all levels. Moving to a greater range of options may necessitate additional staff to implement and monitor a wider range of housing supports. It is our hope that additional residential opportunities will resolve the significant waitlist, especially for individuals living with aging caregivers.

### **Regulatory and Policy Changes**

Concerns have been raised by providers and family members, on “. . . over-regulation in the OPWDD system.” As stated in the Plan these “regulations for people with I/DD may lead to barriers in creating a life of their choosing. For DSPs, the job can become challenging as they deal with both regulatory requirements and providing support to individuals. For providers, the regulatory burden can delay innovation in providing those supports. Through the planning process, OPWDD stakeholders identified critical areas for regulatory reform, and OPWDD has begun implementing several initiatives.”

Having circulated reform proposals<sup>11</sup> in the past, The Arc New York is committed to reducing these burdens and streamline processes. We will also continue to advocate for increased flexibilities and innovative solutions. The current Plan includes the

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<sup>11</sup> <https://files.constantcontact.com/c80b6f60101/f9976658-5a91-4ee6-8330-60d0040327d3.pdf>

mention of future waiver amendments to accomplish the stated regulatory reform proposals. We look forward to conversations between stakeholders to discuss these opportunities.

## **Conclusion**

The Arc New York is enthusiastic about innovative collaborations. Overall, this Plan is aspirational, rather than purely tactical, in terms of a five-year vision for the field. It is evident that OPWDD has taken many of the comments offered over the last several years into consideration, and heartening to know that our voices have been heard.

However, the Plan lacks specificity and measurability, and leads to many questions about how we realize this vision. We need to develop a clear path and timeline moving forward. The vision OPWDD has outlined aligns with many of our goals, and we believe that meeting them will strengthen and enhance our system of supports. Given the desire to engage stakeholders moving forward, we look forward working in partnership to define a roadmap that will make these aspirations a reality.