



# 2024 Advocacy Priorities

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## Preserve Medicaid Funding

### **Issue:**

Medicaid funding is the backbone of services to people with developmental disabilities across the nation, and particularly in New York State. Medicaid comprises approximately 90 percent of the funding to The Arc New York and other developmental disabilities providers in our state. Cuts to Medicaid funding would prove devastating to the families we support and services we provide.

Medicaid is still at risk and advocates across the nation and state are working tirelessly to keep people with intellectual and developmental disabilities (I/DD) at the forefront of policy decisions. Dedicated funding for Home and Community Based Services (HCBS), paid leave for caregivers, and increasing the Supplemental Security Income (SSI) resource and asset limit continues to be part of our federal priorities. As the need for HCBS continues to grow, the funding and increased investments is more important now than ever.

Every day, New Yorkers with I/DD rely on not-for-profit HCBS providers in the voluntary sector for programs and supports to lead a fuller, more inclusive life. A trained and dedicated workforce, along with consistent financial investments, are needed to provide these services, which are funded through the 1915c Medicaid waiver. If programs are unable to operate due to insufficient funding, these still needed services will become the responsibility of state agencies, at a higher cost to taxpayers.

For decades, New York state has not made adequate investments to sustain the programs and services people with I/DD rely on. Our field has received very few cost-of-living adjustments (COLA) to keep up with inflation and rising costs in the last decade. The annual COLA is intended to increase budgets appropriately to adjust for these factors. In the past decade, inflation rose nearly 30%, yet our field received only a 10.5% COLA over that time period. The proposed 3.2% COLA for 2024-25 is derived from NYS statute, which states the annual COLA will be calculated based on the Consumer Price Index (CPI-U) from July of the previous year. Upholding the COLA will support the increased cost of delivering quality services and sustain supports for the future.

On the federal level, the Federal Medicaid Assistance Percentage (FMAP) for New York state remains at 50%, which is the minimum for any state. This is despite New York taxpayers sending more to the federal government than it receives. In order to provide vital supports and services, HCBS must be appropriately funded via a permanent increase to the FMAP.

Simply put, it is absolutely critical that we secure adequate government funding to invest in our workforce and our programs to provide supports for the people we serve. Without this, our programs could be reduced or eliminated due to lack of staffing, and many years of progress toward community integration, choice, and deinstitutionalization will be lost.

## **Call to Action: Sustain and Expand Funding Supports for People with Disabilities**

The Arc New York, along with thousands of other developmental disabilities providers and advocates across the state and nation will vigilantly defend the Medicaid program from any actions in Albany and Washington that seek to reduce Medicaid funding.

We call on Congress and New York state to:

- Increase the FMAP for New York state by 10 percentage points. This is in line with the proposal advanced through the Better Care Better Jobs Act. ([H.R. 547/S.100](#))
- Include the statutory COLA in the NYS enacted budget, which stands at 3.2% for FY25

- Close the historic funding gap between state and non-profit providers by providing an additional and ongoing sustainability investment in the form of a Direct Support Wage Enhancement (DSWE) of \$4000 for direct care staff.
- Raise SSI asset limits from \$2,000 to \$10,000 for individuals and from \$3,000 to \$20,000 for married couples, indexing both to inflation moving forward. ([S.2767/H.R.5408](#))
- Reintroduce [H.R.761](#) (117<sup>th</sup> Congress), which would end consideration of a spouse's income and assets and disregard marital status for SSI recipients with intellectual and developmental disabilities. Currently, SSI is reduced by 25% for a married couple, which is termed a "marriage penalty"
- Champion Funding for Medicaid HCBS Introduced through the [Home and Community-Based Services \(HCBS\) Relief Act of 2023](#) (S.3118). This bill would increase funding for people with disabilities to live in their communities. The bill would provide two years of additional Medicaid funds to:
  1. Improve access to HCBS by increasing direct care worker pay and benefits;
  2. Decrease the number of people on waiting lists for HCBS (currently over 650,000 nationally); and
  3. Pay for assistive technologies, staffing, and other costs that facilitate community integration.

We will tirelessly advocate for the Medicaid funding needed to appropriately support people with I/DD in all circumstances, settings, and situations.

## Address & Close Critical Workforce Shortages

### **Issue:**

Direct Support Professionals (DSPs) are essential workers who provide daily care, services and supports to people with intellectual and developmentally disabilities (I/DD) 24 hours a day, 7 days a week. Caring for people with

complex needs is a rewarding yet challenging job, which requires ongoing training, high-level of responsibility, and skill.

This workforce has shown exemplary strength and fortitude throughout the COVID-19 pandemic crisis and continue to demonstrate their commitment to the people they support. These are not just jobs; they are careers and must be treated as such.

Nonprofit provider agencies funded by the Office for People with Developmental Disabilities (OPWDD) employ nearly 100,000 DSPs, and deliver 85 percent of the needed services to approximately 140,000 people with I/DD in New York State. Almost all funding for these agencies comes from the government.

Statewide reimbursement for voluntary sector DSP salaries has increased only very modestly over the past decade, but still puts starting wages at or barely over minimum wage. By contrast, DSPs in state-operated programs receive consistent step increases year after year, with the current wage nearly 50% higher than the voluntary sector. Many of our most knowledgeable DSPs are being lost to higher-paying entry-level job sectors, which continue to increase their hourly wages. Their contributions, ingenuity, and dedication are immeasurable. We cannot afford to lose their skills and insight. However, the federal government and New York state struggle to acknowledge their contributions.

Without adequate funding, I/DD providers cannot offer competitive wages to recruit and retain the skilled direct support staff that provide the foundation of care for New Yorkers with I/DD. The existing workforce crisis pre-dates the COVID-19 pandemic, but escalated dramatically in its wake. Without immediate action, this crisis will continue to force service reductions, program closures, and loss of supports for people with I/DD throughout the state. With approximately 5,000 to 7,000 people on waitlists for supports and services, resolving the workforce crisis is pivotal in order to fully address the needs of New Yorkers with I/DD.

It is absolutely critical that we secure the funding necessary to pay our DSPs a wage commensurate with their ability, experience, and performance. We have already seen valuable DSPs leave the field due to the hardship they

face. If we do not act, many years of progress toward community integration, choice, and deinstitutionalization for people with I/DD will be lost. DSPs are our front-line essential workers and deserve more.

Cost increases related to mandated fringe benefits, repairs and maintenance, utilities, food, supplies, transportation, and insurance have resulted in significant financial pressures. Non-Profit provider agencies are solely funded through Medicaid and are thus unable to increase reimbursement for services to compensate for increased costs of operations.

In addition to the program closures, a survey conducted by New York Disability Advocates (NYDA) during the 3rd quarter of 2022 found that:

- Average statewide non-profit provider workforce turnover rate is 31%
- Turnover costs for non-profit providers have risen to more than \$100 million annually
- Average statewide staff vacancies for voluntary, non-profit providers totals nearly 20,000 unfilled positions
- Average statewide starting wage for DSPs on average is \$16.14, only 7% above minimum wage, compared to DSPs employed by NYS, who earn \$23.75 on average – that is a 47% difference in starting wages for the same exact position
- All of the above exacerbates an already long waitlist for people that need services

We are no longer talking about a future crisis, the crisis is now!

## **Call to Action: Address the Critical Workforce Shortage**

We call on the governor and legislature to support people with I/DD in the FY25 NYS budget by:

- Establishing a new Direct Support Wage Enhancement (DSWE) as part of the SFY 2025 New York State budget. Through the proposed DSWE, provider agencies would receive an annual funding allocation 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 people with I/DD. This will provide agencies with the ability to increase the hourly pay by approximately \$2.19/hour annually for eligible staff presuming each staff member receives the same increase. Funding must be utilized by provider agencies to enhance the rate of pay for direct support employees.

- Including the statutory 3.2% Cost of Living Adjustment (COLA) in the FY25 budget, which is based on the US Bureau of Labor Statistics' July 2023 CPI-U 12 month percentage change.<sup>1</sup>
- Commit to an acuity-based rate methodology, which fully compensates providers that support people with higher levels of behavioral and medical needs, requiring increased staff at a level on par with state-operated programs supporting people with similar needs.

In addition, we propose the state and federal government to:

- Create a Standard Occupational Classification (SOC): Direct Support Professionals are not designated with their own SOC by the Bureau of Labor Statistics, as a result, DSP wage and occupation data is not accurately captured. This diminishes the true impact of the workforce crisis, hinders opportunities for professional advancement, certifications, and the pursuit of a life-long career. We must acknowledge that DSPs deserve a path forward and people with I/DD deserve a passionate advocate at their side daily.
  - We support ([S.1332/H.R. 2941](#)) Recognizing the Role of Direct Support Professionals Act, to accomplish this goal
- Establish a Personal Income Tax Credit for DSPs: We recommend that a \$2,500 refundable personal income tax credit be established for people who are employed by or contracted by not-for-profit provider agencies who are in 100, 200 or 300 direct care positions providing supports and services to people with I/DD. This tax credit could phase out on incomes over \$50,000 and could be capped for people with incomes in excess of \$100,000.
- Create and Fund a Permanent Joint Credential and Career Ladder Program for DSPs: The state must implement a multi-tiered credential program for DSPs

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<sup>1</sup> [https://www.bls.gov/regions/mid-atlantic/data/consumerpriceindexhistorical\\_us\\_table.htm](https://www.bls.gov/regions/mid-atlantic/data/consumerpriceindexhistorical_us_table.htm)

with a hybrid model of on-line, classroom and work-based learning tied to increased pay for people completing each tier of the credential. By doing so, the state will be able to increase DSP tenure, job satisfaction and provide a clear career path for DSPs in the voluntary sector. In addition, the state must implement a statewide Career Ladder Program, which will provide a pathway to an associate's degree in the human services field for those DSPs who have participated in the credentialing program and offer it at no cost to the participants. The program must provide job-specific higher education and career development to frontline workers in health, education, and human service occupations.

- Expand the BOCES Program: A successful pilot program with Capital Region BOCES teaches students the skills necessary for a long-term career supporting people with disabilities. The pilot project aligns state education standards with quality DSP training metrics and offers certification in six areas. We recommend that the State establish a plan to replicate this program statewide by 2024.

## Reform Rate Methodology and Ensure Timely Payment

### **Issue:**

OPWDD is in the midst of developing a new rate methodology, which will have significant implications for voluntary provider agencies for years to come. Agencies have been engaging with OPWDD and other stakeholders during this process on the technical aspects of the rate redesign. The overall objective is to reform the reimbursement rate from a cost-based methodology to an acuity-based methodology.

However, provider agencies have expressed concerns about the potential outcome of the final rate methodology, which may result in significant long-term losses for provider agencies statewide. Agencies that have already invested in direct care wages above the regional average, will be penalized due to the proposed regional cost approach.

The Coordinated Assessment System (CAS) will be used to determine the relative acuity of a person, which in turn determines how much an agency must be reimbursed for supporting that person. However, it is not clear whether the CAS has the functionality to appropriately identify the level of support required for a person, leaving open the possibility of people being placed into lower tier classifications that do not reflect the level of staffing required, and improperly reimbursing providers at a lower rate.

## **Call to Action: Tell OPWDD to Reform Rate Methodology that Works with Providers and for People with I/DD**

- The new reimbursement methodology must not contain any component that would remove or negate any investment the legislature or providers have made in the workforce.
- Continuing education, training, and opportunities for the direct care and other frontline workforce must be taken into consideration when determining rates in order to retain valuable talent and expand the ability for voluntary providers to support people with higher-need.
- Access to the methodology used by CAS to determine acuity assessments must be made available to providers. Greater transparency will lead to a continually refined and more equitable system.
- CAS assessments must accurately reflect the current acuity of a person and completed within a reasonable timeframe to ensure an appropriate placement and proper provider reimbursement.
- Changes to rates, including the implementation of the annual COLA must be completed in a timely manner within 90-days from the enacted budget or final rate approval.

# Invest in Preschool/Early Intervention for 853 & 4410 Schools



## Issue:

Preschools and state approved school-age programs that serve children with developmental disabilities are paid significantly less than it costs to operate them; the state has historically reimbursed these programs at a rate below allowable cost and even less of actual cost.

And Chapters of The Arc New York cannot subsidize preschool programs without endangering other OPWDD related programs. In addition, due to the teacher compensation gap between special education schools and public schools, we also continue to have extraordinary teacher recruitment and retention challenges. Federal grants provided to states through the American Rescue Plan Act (ARPA) in 2021 assisted education providers impacted by the pandemic, but this one-time infusion of aid did not and will not sustain these programs into the future.<sup>2</sup> As these funds sunset, schools are faced with an untenable financial cliff.

In 2022 the Inter Agency Council of Developmental Disabilities surveyed 4410 and 853 school providers from New York City, Long Island, Westchester and Rockland Counties. Their findings show the perilous state of educational and early-intervention opportunities for children with I/DD and reflect the crisis occurring across the state.

- 1/3 of certified teaching positions remain vacant
- Over 100 SED approved classrooms closed due to staffing shortages
- Total staff loses in one year totaled 1,353
  - Certified special Education Teacher – 258
  - Certified Teacher Assistants – 576
  - One to One Aides – 220
  - Speech Therapists – 111
  - Occupational Therapists – 87
  - Physical Therapists – 39

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<sup>2</sup> <https://www2.ed.gov/policy/speced/leg/arp/index.html>

- Mental Health Professionals (certified social workers and psychologists) 62
- 86% of education providers have used school administrators or non-teaching staff to cover classrooms due to staffing shortages this school year

Special education schools need predictable and consistent growth factors and tuition rate increases along with other fiscal support to bring reimbursement in line with the cost of operations. Research shows that investing in preschool programs has a significant return on investment.<sup>3</sup>

Early intervention and Pre-school services are essential for young children with I/DD and other disabilities. For maximum brain development, it is crucial to receive education, training, and stimulation at the time in their lives when their young developing brains are at the most receptive and at their highest level of growth. As a result going forward in their school program, many children will need limited or no specialized educational services, but those who do will require less because pre-school has given them a timely and intensive start.

Students and children with intellectual and other developmental disabilities must be educated with appropriate supports and services in the least restrictive environment with free and appropriate services, which address their individual needs. However, these educational institutions have historically and inequitably been underfunded, which has caused teachers to be underpaid for their contributions and making it difficult to retain these valuable and critical educators.

## **Call to Action: Provide Equitable Funding for 4410/853 Schools**

We advocate for the following to support and sustain preschool and early intervention opportunities for children with intellectual and developmental disabilities:

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<sup>3</sup> <https://live-penn-impact.pantheon.io/wp-content/uploads/2016/2015/06/Why-Invest-High-Return-on-Investment.pdf>

- Support a tuition rate/trend factor increase in the FY25 NYS budget to support and sustain pre-school and early intervention programs and close the gap in recruitment and retention of special education teaching staff
- End unnecessary and excessive reconciliation delays for payment through the methodology and rates. Pre-school and School-age programs already suffer from the inability to retain funds, yet they are unable to plan for the future due to bureaucratic barriers
- Reintroduce legislation, S.6516 (Mannion)/A.8013 Benedetto), which would ensure funding parity in tuition and regional rate reimbursement for the provision of free appropriate public education (FAPE) to preschool and school-age students with disabilities on par with public schools
- Reintroduce 2021-22 session legislation [A.10191 \(Benedetto\)/S.9132 \(Mannion\)](#), which passed both houses, but was vetoed by Governor Hochul. The bill ensures that the calculation of the amount authorized to be retained by a school or program is conducted prior to certain applications of the methodology. This is vitally important to ensure that trend factors have a lasting positive impacts for our schools
- Allow the application of trend factors for evaluations and targeted service rates for aides and nurses. Programs, districts, and county representatives are reporting increased numbers of families seeking evaluations for their children and have noted a disturbing trend that many families are being forced to wait months for evaluations due the limited availability of evaluators.
- New York State Education Department (NYSED) must review the teacher certification process and find solutions to streamline the path towards certification. This would help alleviate barriers towards recruitment of qualified educators. The number of exams and certification reciprocity between states, particularly in the Tri-state area (NY, CT, and NJ) would provide a larger pool of potential candidates to draw from to fill vacancies.

# Secure Greater Equity and Access to Supports and Services

## **Issue:**

Barriers to equitable and accessible supports and services for people with intellectual and developmental disabilities (I/DD) has historically contributed to unnecessary hurdles. Having basic needs met such as medical, behavioral and oral health, transportation, where to live, where to work, and level of available supports remains a constant struggle.

Access to care across multiple medical disciplines finally became a possibility through teleservices and many of those flexibilities remain in place due to their inclusion in FY22 and FY23 NYS enacted budget. We have witnessed efficacy with this technology and support additional flexibilities and uses of technology. Primary among these flexibilities is allowing providers from out of state to participate in teleservice. Particularly in rural areas, access transportation and the most appropriate medical care and professionals remain a challenge.

Reliable transportation is a key to independence, opportunity and a full life within one's community. Unfortunately, due to the workforce crisis, there are too few staff available to support this service. There is currently insufficient opportunities and access to transportation infrastructure to ensure people are able to live the life they choose.

Thousands of New York state citizens with I/DD are waiting for placement in a community residential setting, and many are in immediate need. The state has not provided an adequate way for families to plan for the future when providing care at home becomes difficult or impossible. People with I/DD and their families face an onerous placement process without a clear understanding of that process or the extent of their wait. However, while thousands await suitable placements, many residential vacancies go unfilled.

Vacancies within certified residential settings have grown in recent years because of an administrative requirement to fill the opening with someone from the "Emergency Need" placement category. Often, the care needs and

behaviors of some people are incompatible with the home in which the vacancy exists, which prevents optimal person-centered care. In these cases, the vacancy remains unfilled, despite the fact it may be a suitable placement for people from the Current Need or Substantial Need categories. This onerous residential placement process promotes unnecessary long-term vacancies in the voluntary sector, and often causes significant and unsustainable deficits for these organizations.

Offering housing almost solely on an emergency basis makes it nearly impossible to guarantee placements will be found in the most appropriate, least restrictive home environment. These restrictions also lessen the person's opportunity for choice in their own housing.

While not every person requires certified residential placements in their community, the array of supports and services needs to be maintained and expanded where necessary to ensure that people achieve as much independence as they need and would like.

Self-Direction is the practice of empowering people with developmental disabilities to manage the supports and services they receive. Under a Self-Direction model, the person with developmental disabilities chooses the mix of supports and services that work best for them, decides how and when those services are provided, and selects the staff and/or organizations that provide them.

Under the current Self-Direction model, families and people who seek access must navigate upwards of 10 to 15 service types, all governed by differing regulations and guidelines, and requiring different forms and templates. Providers spend a significant amount of time developing, obtaining, reviewing, and correcting required documents, including mileage reimbursements, timesheets, vouchers, vendor and contactor invoices, monthly notes, and expenditure reports. It is unreasonable to expect families to understand this complex system, and its administration is a drain on provider resources. This complexity adds a significant barrier towards independence.

Along with the pursuit of where and how to live, even though many people with I/DD want to work and have the skills to do so, there are limited employment opportunities available to them. As a result, the majority of

adults with I/DD are either unemployed or underemployed. Although there has been progress made in recent years to modernize the Preferred Source Program, there still remains lacking opportunities for people with I/DD who want to work.

## **Call to Action: Make Equity and Access for Activities of Daily Life a Reality for People with I/DD!**

The Arc New York will work to:

- Seek additional service model innovations to include teleservices on par with current programs and rate conventions
- Ensure rates for teleservices are based on outcomes, rather than mode of delivery
- Advocate for adequate and specialized transportation for people with intellectual and developmental disabilities
- Ensure that bonuses and workforce investments include frontline transportation and direct care employees
- Support [S.3142](#) (Mannion) introduced in the 2021-22 legislative session, which requires the Office for People with Developmental Disabilities (OPWDD) to develop and maintain a community residence opportunities (CRO) waitlist and publish in a transparent manner
- Reform the Certified Residential Opportunities (CRO) process to eliminate the emphasis on Priority I/Emergency Need placement and instead rely on the new acuity fees to support appropriate funding and placement of any person on OPWDD's approved waitlist for residential placement
- Reform the Certified Residential Opportunities (CRO) process to make it more efficient, to include incentivizing serving higher acuity populations while building provider capacity to support such populations
- Ensure that wages and reimbursements appropriately resource an adequate network of supports and services for people in the system and

people on the wait list. Without adequate funding of the workforce, use of current capacity and expanded opportunities are not possible

- Work with OPWDD and applicable state agencies to streamline the Self-Direction process, engaging with self-advocates and families to search for solutions
- Introduce and support expanded employer tax credits for hiring people with disabilities
- Secure additional funding for job coaches and other supports.

