



2022 Advocacy Priorities

Medicaid

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 individuals 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. Many of these funding streams are included in the proposed Better Care Better Jobs Act, which operationalizes the care economy infrastructure plan proposed by President Biden. As the need for HCBS continues to grow, the funding and increased investments is more important now than ever.

Position:

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 will tirelessly advocate for equal care for all individuals in all circumstances, settings,

and situations and for increased Medicaid funding needed to appropriately support individuals with I/DD. To this end we will not waiver.

Workforce Crisis: Direct Support Professionals

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 should be treated as such.

Nonprofit provider agencies funded by OPWDD employ nearly 100,000 DSPs, and deliver 80 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. These dedicated individuals would thrive with a clear career path. 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 more than 140,000 New Yorkers with I/DD. The existing workforce crisis escalated dramatically in the wake of the COVID-19 pandemic. Without immediate action, this emergency will

continue to force service reductions, program closures, and loss of supports for people with I/DD throughout the state.

It is absolutely critical that we secure the funding necessary pay our DSPs a wage commensurate with their ability, experience, and performance. If we do not, 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. We have already seen valuable DSPs leave the field due to the hardship they face. They are our front-line essential workers and deserve more.

State-run programs and staff are reimbursed at a higher rate than those in the voluntary sector and the disparity continues to widen. The reality is, if nonprofit programs are eliminated due to insufficient staffing, state operations would have to provide services at a much higher cost. This is a disruption that individuals and families do not want to see, but unfortunately, programs have already been impacted by a workforce shortage.

In addition to the program closures, a survey conducted by New York Disability Advocates (NYDA) during the 1st quarter of 2021 found that:

- 93% of providers saw a decrease in job applicants
- Statewide vacancy rates increased 75% since pre-pandemic levels
- 25% of all DSP positions were vacant statewide
- 39% of providers did not reopen programs due to staff shortages
- 69% of providers pulled senior & administrative staff from leadership responsibilities to cover direct care shifts

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

Position:

Voluntary providers of supports and services for people with I/DD are facing a critical workforce shortage, which needs immediate action. We will continue to advocate on behalf of our workforce for New York state to treat I/DD DSPs fairly as highly-skilled health and human services professionals, rather than minimum wage hourly workers. DSPs want the opportunity for more than a job, they want a career. We will make sure this becomes a reality. Our request for adequate funding investments will be multi-year and ongoing to redress the inequities of the past.

The goals will be three-fold:

1. Bring voluntary providers' wages at least in line with state-operated salaries
2. Commitment to a plan that will result in raising the field to a living wage, as we had proposed under previous campaigns
3. Ensure that new initiatives are funded with new financial resources and not moved from other programs that are part of the OPWDD budget.

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

- Establish a Living Wage: Include not-for-profit providers in the statutory Cost-of-Living-Adjustment which has been virtually eliminated for more than a decade. Unlike for-profit entities that have the ability to raise prices, not-for-profit providers have only been able to pay rates as afforded by the funding provided by OPWDD, which has caused stagnation in the wages.
- Create a Standard Occupational Code (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 individuals with I/DD deserve a passionate advocate at their side daily.
 - We support S.1437 (Hassan)/H.R.4779 (Rice), Recognizing the Role of Direct Support Professionals Act, to accomplish this goal
- 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 2023.
- Establish a Personal Income Tax Credit for DSPs: We recommend that a \$2,500 refundable personal income tax credit be established for individuals 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 individuals with I/DD. This tax credit could phase out on incomes over \$50,000 and could be capped on individuals with incomes in excess of \$100,000.
- Create a Joint Credential and Career Ladder Program for DSPs: The state must implement a multi-tiered credential program for DSPs with a hybrid model of on-line, classroom and work-based learning tied to increased pay for individuals completing each tier of the credential. By doing so, the state will be able to increase DSP tenure, job

satisfaction and provide a career path. In addition, the state should 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 should provide job-specific higher education and career development to frontline workers in health, education, and human service occupations.

Human Services Financial Sustainability Funding

Issue:

Every day, approximately 100,000 individuals with intellectual and developmental disabilities (I/DD) rely on 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. If non-profit programs are unable to operate due to insufficient funding, those 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 its citizens with I/DD rely on. Our field has received virtually no cost-of-living adjustment (COLA) to keep up with inflation and rising costs in the last decade. To date, the field has received only a 0.2% COLA in more than 10 years, and has been anticipating a 1% COLA, which was included in the 2021-22 NYS enacted budget. However, that small increase has yet to be included in provider rates. Over this same period, the inflationary rate rose to over 25%.

Although separate workforce investments provided a much-needed wage increase for Direct Support Professionals (DSP), these increases have yet to bring staff to a wage commensurate with their skills and duties. In addition, meaningful increases for the majority of other staff have not been achieved.

The FY22 mid-year update to the New York State Financial Plan confirmed the incredible fiscal strength of the state. Economic growth is steady, with revenues projected \$4 billion higher than prior estimates for the current year. As a result, the state budget will be balanced in every year through FY 2025. While this is wonderful

news, we are disheartened to hear that the state plans to place \$3.3 billion of this windfall into reserves, when we are facing an emergency which threatens the health, safety and wellbeing of the people we support, and the permanency of services for New Yorkers with I/DD.

A decade without any meaningful COLA has stripped at least \$5 billion from voluntary providers, like our Chapters across the entire field, making them less and less capable of remaining financially viable. Meanwhile, state operated facilities have seen year over year growth despite voluntary providers' ability to support individuals and families at a lower overall cost.

On top of the workforce crisis, maintaining existing facilities and infrastructure provides an additional challenge. For many of our Chapters, we have seen the percentage of the remaining useful life of our fixed assets, such as buildings, equipment, and vehicles, decrease as Chapters have not been able to make necessary reinvestments. In addition, state-operated facilities reported a significantly lower turnover rate than our Chapters, presumably due in large part to the higher wages they are able to pay.

Any business needs a reasonable contingency to appropriately manage operations, particularly when virtually no COLA have been funded. The rate rationalization methodology, which applies to voluntary providers, does not allow Chapters like ours to produce the necessary contingency funding during the base year, which is every other year, without getting a rate reduction. Furthermore, rates are consistently late from the state resulting in additional lack of predictability and instability, since those rates are adjusted retroactively.

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.

Position:

To achieve financial viability, we will work with a broad coalition of providers and focus on campaign to secure predictable and sustainable funding opportunities for workforce, infrastructure, and planned investment. It is critical that the I/DD field speak with one clear and consistent voice.

We will also work with oversight agencies, government officials, and legislators, to allow for administrative flexibility, which can help our providers operate more efficiently, and to redirect and reinvest our savings in our workforce and infrastructure. Additionally, reducing burdensome and sometimes duplicative regulations can help reduce the financial burden on our chapters.

The State of New York must recognize the unsustainable financial position of voluntary IDD providers like The Arc New York's Chapters, and agree to propose and deliver budget funding that provides adequate, consistent, and predictable resources.

- Maintain statutory COLA in the NYS Budget, which stands at 5.4% for FY23
- Include an additional and ongoing sustainability investment comparable to the workforce funds received through the American Rescue Plan Act (ARPA), preventing a fiscal cliff at the end of the funding period and continuing the commitment to our workforce.

Residential Cuts

Issue:

The New York State Department of Health has begun the process of implementing cuts in reimbursement for Individual Residential Alternatives (IRA) and Intermediate Care Facility (ICF) residential programs by eliminating the occupancy adjustment resulting from vacancies and reducing reimbursement by 50% for days when residents are in the hospital or are taking therapeutic leave days for family visits. The cut also enacts an annual "cap" of 96 days of therapeutic leave days, after which reimbursement would be reduced to zero.

The cuts total about \$230 million on an annual basis and would result in a reduction in reimbursement by as much as 7.5% for certain residential programs with significant vacancies, including vacancies due to deaths and relocation. This action was taken without any consultation or discussion with stakeholders.

Occupancy adjustments resulting from vacancies would slash reimbursement in half for days when our brothers, sisters, sons, and daughters must go to the hospital, receive therapy, or visit family.

These cuts are not simply about empty beds; they are the homes our loved ones return to. This would jeopardize that basic security. Just as our own expenses do not go away when we on vacation or in the hospital, the cost to a provider for caring for our loved ones does not simply vanish when they are away from home. Imagine an individual who is burdened with knowing that spending time with his/her/their family could cause financial harm to the place they call home. This is not how to treat people.

The costs for direct care staffing, 80% of which is the salary paid to direct care staff, clinical staff and residence supervisors, are fixed and can't be reduced simply because our loved one is out of the house. Our dedicated staff provides care around the clock for everyone in a home, and if one person is in the hospital, providers can't just place a staff member on unpaid leave until the hospital stay is over.

Position:

Voluntary providers have been cut yet again after years of underfunding by the New York state. We cannot take \$230 million out of the system, especially given the strong fiscal strength of the state's finances and unprecedented federal funding.

This action will no doubt cause a decrease in the number of residential openings in the state at a time when there is a waiting list for many families, which is estimated to be around 5,000 people. New York has a constitutional obligation to care for its most vulnerable citizens. We will fight to make sure that our family members are not just numbers on a spreadsheet, where their home is safe and available for them regardless of whether they visit family or need medical assistance.

Rate Reform

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 an individual, which in turn determines how much an agency should 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 an individual, leaving open the possibility of individuals being placed into lower tier classifications that do not reflect the level of staffing required, and improperly reimbursing providers at a lower rate.

Position:

- The new reimbursement methodology should 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 workforce should 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 should 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 an individual and completed within a reasonable timeframe to ensure an appropriate placement and proper provider reimbursement.

Self-Direction

Issue:

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.

Within the FY 20-21 enacted NYS budget, there was a modification made to self-direction through the MRT II. This provision restricts eligibility of services to two or more or three or more Activities of Daily Living (ADL). Exemptions were made for those with Alzheimers and dementia but left out individuals with I/DD. Assembly Gottfried and Senator Rivera introduced A4309/S3055 (NYS Legislature 2021-22 session) to correct this oversight and include I/DD within the exemption. We ardently support this legislation.

Under the current Self-Direction model, families and individuals 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.

In addition to the reporting and administration challenges, there is often a disparity in salary between staff hired directly by individuals through Self-Direction and staff hired by provider agencies. This discrepancy exacerbates the difficulty providers have recruiting and retaining skilled employees.

Self-Direction is further complicated by the “joint employer authority” status for self-hired staff. Individuals participating in Self-Direction may hire and manage their own staff. However, provider agencies overseeing the larger Self-Direction program bear the full billing and employment risk with virtually no authority to manage that staff.

Position:

The Arc New York supports the Self-Direction service model, but believes this program will not serve populations who need it most, unless the Legislature acts to pass A4309/S3055 during the 2022 legislative session. Additionally, it will only see long-term success if OPWDD simplifies the system of service documentation and clarifies the employer/employee relationship and pay scale. We advocate for solutions that will make Self-Direction viable for both provider agencies and the families and individuals participating in the program.

Telehealth and Teleservices

Issue:

During the COVID-19 crisis expanded use of telehealth services were permitted as a means to meet the critical medical needs of people. Across the state, residents experienced swift care at a time when meeting in person with medical professionals was difficult or entirely forbidden.

Access to care across multiple medical disciplines finally became a possibility and many of those flexibilities remain in place due to their inclusion in FY22 NYS Budget. We have witnessed efficacy with this technology and support additional flexibilities and uses of technology.

Position:

We support A4839(Gunther)/S2990 (Harckham) and A669 (Rosenthal)/S2989 (Harckham), which seek to bill telehealth and telephonic services at standard in-person rates.

We will continue to seek service model innovations to include teleservices on par with current programs and rate conventions. Billing codes must be clear and embrace new methods of achieving an individual's life plan. Rates for services should be based on outcomes, rather than mode of delivery. We have historically served as a model to other states; we must continue to forge forward despite our collective challenges.

Residential Placement and Development

Issue:

Thousands of New York state citizens with intellectual and developmental disabilities 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 intellectual and developmental disabilities 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 these individuals 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 individuals from the Current Need or Substantial Need categories.

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 individual’s opportunity for choice in their own housing.

We are working with OPWDD to improve the flexibility and timeliness of the placement process, to more expeditiously place individuals into available vacancies that are compatible with their needs.

During the COVID-19 pandemic, there was a concerted effort to move to single room accommodations within houses, but with staff shortages this practical step may not come to fruition. We will require the necessary support to use development funds to meet urgent needs. This will ensure the stability of housing moving forward and protect

individuals with I/DD, who are generally have higher instances of infection and fatalities, due in part to certain comorbidities.

Position:

We continue to advocate for increased residential development, and an improved placement process, especially for people living at home with aging caregivers. No provider should be compelled to continue a placement that causes health and safety issues for staff, the individuals themselves, or housemates. There must be a crisis system that works in emergency situations, but that should not be a sole basis for expedited placements. We propose the following actions be taken to ensure there is sufficient residential development to meet the growing need:

- 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 individual 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 handle such populations;
- the state should ensure that wages and reimbursements support an adequate network of supports and services for people in the system and people on the wait list;
- transparently assess the number of people who have requested or need residential services and keep a wait list with a publicly available summary;
- streamline the eligibility process so that people on the wait list can have their eligibility rapidly assessed and established;
- make administrative enhancements necessary to more efficiently match people seeking placement with existing vacancies;
- match and place individuals in already existing residential settings which can meet their individualized needs;

- provide capital and operating funds to establish as many new residential opportunities as necessary to meet the needs of New Yorkers with intellectual and developmental disabilities, particularly for those individuals with behavioral and psychological needs; and
- Support S.6305 (Mannion), which requires the Office for People with Developmental Disabilities (OPWDD) to develop and maintain a community residence opportunities (CRO) waitlist.

Managed Care/SIP-PLs

Issue:

For several years, OPWDD system 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 is still to be determined, pending finalization of the Specialized I/DD Plans – Provider Lead (SIP-PL) document by OPWDD. In June, 2020, this document was revised again and The Arc NY provided comments. Given the delays, it appears that scheduled voluntary enrollment in I/DD specialized plans will be delayed further as there has been no movement on this process.

Prior to 2020, it was anticipated that the state budget would apply ongoing DOH Global Cap resources to support the initial start-up costs of transitioning the OPWDD service delivery system from a fee-for-service payment structure to managed care. However in the FY21 budget, that provision was conspicuously absent and in FY22 the only mention of the OPWDD transition to managed care was, “The State continues to assess the potential effectiveness and sustainability of the proposed delivery system to ensure individuals continue receiving appropriate services in the most cost-effective manner.”

OPWDD is the last remaining Medicaid system to transition to managed care and there are doubts with respect to the state’s capacity or willingness to fund MCO administrative costs as originally planned. Without necessary sustainability investments and participation of all individuals from state operated programs, the current fee-for-service system and models of support and services for individuals with I/DD will become broken; our system is at a major crossroads and we require stability.

Transitioning to managed care under the SIP-PL provider-led MCO approach with necessary financial investments and with appropriate regulatory flexibility could provide a pathway leading to a more sustainable system for the future, but the state has cast doubt on this commitment.

Position:

New York state must decide whether they are proceeding with managed care for the OPWDD system. This uncertainty leads to instability and a lacking understanding of where investments must be made into the future.

SIP-PLs must be approved prior to OPWDD beginning transitioning to managed care. We advocate for increased standardization, new models of care coordination, and investments at both the state agency and provider agency levels, including investing in information technology and technical assistance. Any savings resulting from the implementation of CCOs and managed care must be reinvested in the OPWDD system.

In addition, start-up and administrative costs cannot be taken from funds currently utilized for supports and services. Any attempt to use funds currently utilized for supports and services will only deepen the financial and workforce crisis facing providers and irreparably damage the service system, before any positive outcomes can be derived from managed care.

Guardianship

Issue:

In New York State, any person who attains the age of 18 years is assumed to be legally competent to make decision for themselves. Individuals with disabilities who do not possess the cognitive capacity to make autonomous decisions or to provide informed consent for personal and financial affairs, may benefit from guardianship to assist them in: accessing appropriate services; receiving advocacy; promoting quality of life; and participating as full members of their communities.

However, some individuals with intellectual or developmental disabilities may have difficulty doing so independently. The Arc New York supports the concept of supported decision making and self-determination for those individuals who are able to participate

in the supported decision-making process. A guardian offers assistance and intervention as needed, based on the individual's capacities and expressed wishes, while ensuring that the individual has every opportunity to express preferences and have them honored to the extent possible. A guardian works to strengthen the individual's capacity for independent decision-making by promoting self-reliance and participation to the maximum extent of ability in all decisions pertaining to the individual.

Article 17-A of the Surrogate's Court Procedure Act was enacted in 1969 to authorize parents, and other family members, and non-profit organizations to continue to have legal responsibility for certain individuals with intellectual and developmental disabilities after the age of majority.

The Arc New York supports legislation to reform Article 17-A in response to constitutional concerns that guardianship does not sufficiently recognize the due process rights of people with disabilities. The Arc New York has drafted a bill which The Arc New York hopes will strike a balance between respecting the rights of the individual to live a self-directed life and giving parents, family members, and non-profit organizations the legal authority to advocate for the care of their loved one who require that level of advocacy and support in a manner appropriate to the unique needs of that person.

Traditionally, family members have relied on Article 17-A to provide the reassurance that appropriate decisions will be made on behalf of the individual. If Article 17-A were to be repealed, it would negatively affect the lives of many disabled individuals throughout their adult lives: in health care, daily activities, financial management and the like. For tens of thousands of people with intellectual and developmental disabilities and their families throughout New York State, crucial decisions would be made, not by a person's relatives, but by strangers serving on the Justice Center's Surrogate Decision-Making Committee.

If the Health Care Decisions Act, which is embedded in Article 17-A, were repealed as well, it would force families to revisit a period in which individuals with intellectual and developmental disabilities and the people who know them best could not make many important decisions, including end-of-life decisions, for themselves, potentially subjecting them to needlessly painful, extreme, and futile life-sustaining treatments.

Position:

We support revising Article 17-A to remedy constitutional concerns and to strengthen the statute. We oppose any legislation that would create an onerous process and burden families with additional legal proceedings and expenses. The ultimate proposal we would support must strike a balance between respecting the rights of the individual and recognizing that for some individuals, involved parents, family members and non-profit organizations must have the legal authority to care and advocate for them in a manner appropriate to the unique needs of that individual. This includes supporting individuals to live their best, most self-directed, life as well as making important decisions to promote such well-being, even to making very difficult decisions on end-of-life care.

Justice Center

Issue:

The Justice Center was created through legislation known as the “Protection of People with Special Needs Act,” to protect the health, safety and dignity of all people with intellectual and developmental disabilities.

People with I/DD should be treated with respect, protected from abuse, neglect and mistreatment. Ensuring the safety and wellbeing of the people we serve is a shared responsibility, and is essential to the mission of The Arc New York.

While the creation of the Justice Center for the Protection of People with Special Needs has resulted in some positive outcomes, it has also created unfunded, administrative burdens on providers. Additionally, some people we support, as well as our workforce, have been negatively impacted by the agency established to protect them.

Position:

We propose continuing to advocate for common sense amendments to the “Protection of People with Special Needs Act” and Justice Center policy and practice, to simplify and streamline reporting requirements and investigative processes, which impede the hiring and retention of qualified personnel and lead to other problems that needlessly tie up resources critical to maintaining adequate care. Specifically, we propose to:

- narrow the definition of neglect to remove subjective and nebulous language, and to eliminate arbitrary and capricious determinations;
- call for reform of the Justice Center, which unnecessarily treats errors and accidents by staff performing this challenging work as neglect or abuse;
- expand the broader use of technology in more cases, such as conducting investigation interviews and record review remotely, rather than in-person;
- provide safeguards for staff and managers who make a reasonable determination whether a case is reportable or not to the Justice Center to prevent the Justice Center from charging an employee with “obstruction of a reportable incident” simply for making a good faith decision that the Justice Center may not agree with;
- fight for equal treatment of unionized and non-unionized employees by the Justice Center to ensure that vulnerable people are protected consistently and adequately; and
- ensure employee due process rights by reducing investigative cycle times and appeals processes, and narrow the Justice Center’s use of the “obstruction of a reportable incident” to instances in which there have been intentional efforts to impede Justice Center investigations.

Preschool / Early Intervention

Issue:

Preschools 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. Chapters of The Arc New York can no longer 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.

Preschools need appropriate growth factors and tuition rate increases along with other fiscal support to bring reimbursement more closely in line with the cost of operations.

Research shows that investing in preschool programs has a significant return on investment.

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.

Position:

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

- support of legislation (S.6516/A.8013) that passed both the Senate and Assembly during the 2021 legislative session. This legislation would ensure funding parity in tuition and regional rate reimbursement for the provision of free appropriate public education to preschool and school-age students with disabilities.
- provide \$20 million for special education schools to narrow the teacher compensation gap;
- set aside Universal Pre-school (UPK) seats to ensure classroom integration with 4410 special education preschools; and
- provide a 7% Early Intervention rate increase to address 20+ years of flat/decreasing rates.

Employment

Issue:

Even though many people with intellectual and developmental disabilities 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 intellectual and developmental disabilities are either unemployed or underemployed.

The Arc New York supports the Customized Job Programs legislation, A2381 (Santabarbara). This bill would establish a pilot program that subdivides state jobs into simpler component parts to provide opportunities for minimum-wage, integrated employment for people who could effectively perform some, but not all aspects of a job.

Position:

The Arc New York supports increased employment opportunities for people with intellectual and developmental disabilities, and will work to:

- enhance employer tax credits for hiring people with disabilities;
- secure additional funding for job coaches and other supports;
- create new state job opportunities for people with intellectual and developmental disabilities;
- pay a special minimum wage when appropriate under the current federal provision known as 14-c;
- pass the Customized Job Programs legislation; and
- continue to transform work centers into integrated businesses where appropriate.

Transportation

Issue:

Reliable transportation is a key to independence, opportunity and a full life within one's community. Very few people with severe intellectual or developmental disabilities can drive or own their own cars, therefore they rely on public transportation and transportation services. Unfortunately, regulations promulgated during the

COVID-19 public health emergency hinders access to this valuable lifeline by placing unnecessarily strict requirements for social distancing and face masks, despite the majority of people we support having been vaccinated. Individuals who are unable to wear face masks for extended periods of time have limited opportunities to participate in their community and in other social settings. Additionally, due to the workforce crisis, there are too few staff available to support this service.

Position:

We continue to advocate for adequate and specialized transportation for people with intellectual and developmental disabilities. This is a lifeline to their community when personal and public transportation are simply not an option to work, day settings, and recreational opportunities. There is currently insufficient opportunities and access to transportation infrastructure to ensure these individuals are able to live the life they choose.

