



# 2020 Advocacy Priorities

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## 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 over a decade, our Chapters have not received adequate funding to address workforce challenges or for other investments. Since 2010, voluntary providers like our Chapters have only received a total cost of living adjustment of 0.2%. Over this same period, the inflationary rate was approximately 19%. Although the bFair2DirectCare campaign provided a much-needed wage increase for direct support professionals, these increases have still not brought our staff to a living wage, nor have meaningful increases for the majority of other staff been funded.

A decade without any meaningful cost of living adjustment 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. Maintaining existing facilities and infrastructure is equally as challenging, on top of the workforce crisis. For many of our Chapters, we have seen the percentage of remaining useful life of our fixed assets

(buildings, equipment, 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 cost of living adjustments 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.

In an effort to achieve financial viability, we will work with a broad coalition of providers and focus on a 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.

## **Position:**

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

# Residential 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. 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 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. The Arc New York will also continue to collaborate with Keep the Promise Family Coalition to advocate for solutions.

## **Position:**

We continue to advocate for increased residential development, and an improved placement process, especially for people living at home with aging caregivers. We propose the following actions be taken to ensure there is sufficient residential development to meet the growing need:

- 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; and
- 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.

## Guardianship

### **Issue:**

In New York State, when a person becomes 18 years old they are assumed to be legally competent to make decision for themselves. However, some individuals with intellectual or developmental disabilities may have difficulty doing so independently. Article 17-A of the Surrogate's Court Procedure Act was enacted in 1969 to allow parents and family members to continue to have legal responsibility for loved ones with intellectual and developmental disabilities after the age of majority. An Article 17-A Guardianship is very broad and covers most decisions that are usually made by a parent for a child such as financial and healthcare decisions. This continued legal authority recognizes the lifelong nature of intellectual and developmental disabilities, and is essential for families to help their loved ones make critical decisions into adulthood, including decisions on life-sustaining treatment.

The Arc New York recently supported legislation to reform Article 17-A in response to Constitutional concerns raised by surrogate courts that guardianships do not sufficiently recognize the due process rights of people with disabilities. Also based on this concern, Disability Rights New York (DRNY) initiated a lawsuit in federal court to repeal Article 17-A. The Arc New York hoped that its bill would strike a balance between respecting

the rights of the individual and giving parents and family members the legal authority to care for their loved one in a manner appropriate to the unique needs of the individual.

Family members rely on Article 17-A to provide the reassurance that sound decisions will be made on behalf of their loved one. If Article 17-A were to be repealed, it would imperil critical programming decisions, financial decisions, and health care decisions 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 loved ones, 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 could force families to revisit a period in which people with intellectual and developmental disabilities could not make 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. 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 giving parents and family members the legal authority to care and advocate for their loved one in a manner appropriate to the unique needs of the individual. Article 17-A of the Surrogate's Court Procedure Act was enacted in 1969 to allow parents and family members to continue to have legal responsibility for their loved ones with intellectual and developmental disabilities after the age of majority. This continued legal authority recognizes the lifelong nature of intellectual and developmental disabilities, and is essential for families to help their loved ones make critical decisions into adulthood, including decisions on life-sustaining treatment.

## **Medicaid**

### **Issue:**

Medicaid 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 serve and services we provide.

If previous attempts to repeal and replace the Affordable Care Act (ACA) had been successful, the cuts would have cost New York State between \$4 billion and \$7 billion in federal Medicaid funds. That represents nearly a 10% cut to all Medicaid providers, and would devastate the state's system of programs and services for people with developmental disabilities.

Medicaid is still at risk. Advocates stopped previous attempts to repeal and replace the Affordable Care act, but key members of Congress continue to target Medicaid as a solution to contain the nation's growing federal deficit. Proposed actions include cuts to the Nation's Medicaid program, and attempts to eliminate it as an entitlement program by converting it to a block grant or per capita cap system of reimbursement to states.

## **Position:**

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

# Managed Care

## **Issue:**

The OPWDD system will transition to managed care in phases, beginning 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 TBD pending finalization of the SIP-PL document by OPWDD. Given the delays in doing so, it appears that scheduled voluntary enrollment in I/DD specialized plans has been delayed.

It has been 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. OPWDD is

the last remaining Medicaid system to transition to managed care, which has shown enhanced quality outcomes and cost control for other Medicaid populations. Shortfalls in the Global Medicaid budget have raised doubts with respect to the State's capacity to fund MCO administrative costs as originally planned.

Without necessary sustainability investments, 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. A considerable number of OPWDD service providers have failed and others will continue to do so under the current system. This is a system that is not sustainable. 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.

## **Position:**

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 result in the creation of a financial crisis that will rapidly and irreparably damage the service system, before any positive outcomes can be derived from managed 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; and
- 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;
- 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.

## **Rate Rationalization**

### **Issue:**

Rate Rationalization is the current methodology by which reimbursement rates are calculated for providers in New York state. Rate rationalization has significantly

restricted the interchange of funds between various OPWDD-funded programs. This flexibility is essential to maintaining program continuity and viability. In many instances, providers are being held to revenue levels that are lower than actual cost. Rate rationalization also acts as a disincentive to providers that might otherwise wish to operate more efficiently, because if the provider achieves program savings, these savings will simply be stripped away in the next round of rebasing.

Prior to cost-based rate rationalization, providers were funded under a budget-based methodology for their largest programs (i.e. Individualized Residential Alternatives (IRA); Prevocational Programs; Day Habilitation; and Intermediate Care Facilities). Such methodology provided the flexibility necessary to generate an operating surplus in one program and use it to support another program in the midst of a financial challenge.

Unless these issues with Rate Rationalization are addressed, this reimbursement methodology will adversely affect the delivery of necessary services to people with intellectual and developmental disabilities.

## **Position:**

The Arc New York will continue to work with DOH and OPWDD to resolve a growing number of problems with the reimbursement methodology. We also recognize that legislative action may be necessary. We propose the following:

- apply annual trend factors. OPWDD and DOH have been unable to identify our field for selective receipt of annual trend factors, as was done in the past;
- incorporate a vacancy factor into the day program methodology to recognize that costs cannot be avoided on days when facilities are forced to close and/or attendance and billing is limited by external factors such as flu quarantines, or inclement weather;
- eliminate use of budget neutrality factors lower than 1;
- increase retainer days. The annual IRA limit of 14 retainer days for hospitalization is tied to the state's nursing home retainer day limit and applied per CMS requirement. We need to address this to obtain funding, as hospitalization days continue to increase for our aging population;

- increase Article 16 and 28 clinic fees. Two-thirds of these clinics operate in deficit and are at risk of being closed. DOH and OPWDD are open to further consideration of the need to increase such clinic fees;
- adopt a policy that supports proactive auspice change and access to “higher of rates” rather than waiting for a provider to fail financially and be consolidated in crisis circumstances; and
- consider discontinuing rate rebasing, to stabilize rates, afford greater flexibility and efficiency, and support the continued operation of all OPWDD-funded programs.

## Preschool / Early Intervention

### **Issue:**

Preschools that serve children with developmental disabilities are paid significantly less than it costs to operate them; the state reimburses these programs at 94 percent of 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.

### **Position:**

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

- include statutory index for annual tuition increases for 4410 preschools and 853 special education schools, and establish a reserve fund to maintain fiscal viability;

- provide \$18 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 4% Early Intervention rate increase to address 20+ years of flat/decreasing rates.
- In the 2019-2020 State Budget, we received a 5% increase for early intervention service providers, including PTs, OTs and SLPs. We will continue to advocate for 4% going forward.

## 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, A.1415 (Santabarbara) / S.6626 (Skoufis). 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 subminimum wage when appropriate;
- pass the Customized Job Programs legislation; and
- continue to transform sheltered workshops into integrated businesses where appropriate.

## Transportation

### **Issue:**

Reliable transportation is 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. There is currently insufficient funding and infrastructure to ensure these individuals have reliable transportation to employment, community supports and recreational opportunities.

### **Position:**

We continue to advocate for adequate transportation to bring people with intellectual and developmental disabilities to work, day settings, and recreational opportunities.

## 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.

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 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.