



**The Arc.**

**New York**

*A family-based organization  
for people with intellectual  
and developmental disabilities*

## Executive Director Mark van Voorst's Testimony

*Joint Legislative Hearing of Senate Finance and Assembly  
Ways and Means Committees on FY 2019-20 State Budget*

**February 2019**

*Achieve with us.*



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**February 7, 2019**

Thank you for the opportunity to speak to you today. I am Mark van Voorst, Executive Director of The Arc New York. The Arc New York is a family-led organization that advocates and provides supports and services to people with intellectual, developmental, and other disabilities, emphasizing choice and community engagement. With 49 Chapters across New York state, our organization supports more than 60,000 individuals and families and employs more than 30,000 people statewide.

This year we celebrate a seventy-year history as advocates and service providers. Seventy years. Seven decades. The parents who founded our organization were among the earliest advocates for quality services and opportunities for people with intellectual and developmental disabilities – a fight that has since ignited federal legislation and global change.

Following the Willowbrook scandal of the 1970s, which revealed horrific abuse and neglect in a state-operated institution, public outcry drove a revolution in our field. Institutionalization made way for evolving models of care and community integration. In New York, non-profits took over the primary responsibility for this work, at the state's behest. Today, OPWDD-funded not-for-profit provider agencies deliver approximately 85 percent of the day-to-day services for more than 130,000 people with developmental disabilities in New York state. Thirty percent of those services are provided by The Arc New York.

After the shock of Willowbrook, politicians, parents, providers and advocates stood together and swore we would never let that happen again. We developed integrative models of education, employment, and living, supported by habilitative services, not custodial care. For

decades, we have consistently made forward strides for people with I/DD. And now, for the first time, I believe we are beginning to slip backwards.

After Robert Kennedy toured Willowbrook, which he described as “a snake pit,” he told the American people, “Our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, and lack of adequate manpower.” We have attention today, and awareness. We have imagination and innovation. What we do not have is manpower. Without adequate funding to resolve our workforce crisis, our non-profit system of care for people with I/DD is at risk of collapse. That scares me. It scares parents. And it should scare you.

You’re well aware of the workforce crisis we’re facing. You funded the first two installments of #bFair2DirectCare, which we fought for as part of a coalition of providers, Direct Support Professionals, families and self-advocates. We fully appreciate the initial investment. However, it funded only two years of a six-year plan to bring our DSPs to a living wage. We were hopeful about the state’s commitment to addressing this crisis, but the 2019-20 executive budget includes zero funding for #bFair2DirectCare. Resolving this crisis requires your ongoing commitment and investment, not just one third of a solution.

Direct Support Professionals (DSPs) are the backbone of our service system. Twenty-four hours a day, seven days a week, nearly 100,000 DSPs working for non-profit providers offer critical care and support for New Yorkers with I/DD. They are trained professionals whose responsibilities include medication administration, tube feeding, wound care, behavioral intervention, and supports for activities of daily living, including financial management, meal preparation, grooming and toileting.

These are not minimum wage jobs. But, DSP salaries are directly linked to rates set by the government, and after years of funding freezes and sparse increases from the state, DSPs are no longer earning a living wage. Ten years ago, the average DSP at our Chapters was making nearly twice minimum wage. Today, the gap between average DSP compensation and minimum wage has decreased by almost 50 percent. In some areas, the flat funding for DSP salaries and the steep increases in minimum wage have resulted in even more severe compression, as our starting wages for new DSPs creep closer and closer to minimum wage. In New York City, a new

DSP now starts at 26 cents an hour above minimum wage – an extra quarter to fulfill a complex role that can include life-sustaining care. In fact, the only funding in the proposed 2019-20 Executive Budget for DSP salaries is Department of Labor funding to bring our lowest paid DSPs up to the new minimum wage.

Lack of adequate state funding is quickly turning the complex and critical DSP role into a minimum wage job, and providers can no longer compete in the employment market. We are losing skilled employees to fast food restaurants and retail stores, where workers can earn more and work less. As a result, our vacancy rates are increasing, while our employment standards are dropping.

According to the most recent #bFair2DirectCare provider survey, more than 14 percent of all DSP jobs statewide were vacant in 2018. The average staff turnover rate is 26.7 percent annually. If you drill down to the individual providers, these statistics become more extreme. The average vacancy rate for all of The Arc New York chapters was 16.8 percent — several percentage points above the #bFair numbers. However, Chapter-specific data shows that 23 of our 49 Chapters pierced this number. Many of these Chapters are operating with vacancy rates in the high 20- to low 30-percent range. We have one Chapter with a DSP vacancy rate of nearly 40 percent. These vacant shifts can't be left unfilled. Care must still be provided, and in many cases, legally-defined staffing patterns dictate these requirements. So, DSPs and supervisory staff cover the shortfall with excessive overtime that leaves them overworked and exhausted. More than 12 million overtime hours were logged in 2018, as providers attempted to deliver needed services with minimal staff.

High turnover rates compound the problem. Our statewide turnover rate was 24.5 percent, or slightly below the average for all providers. However, we have 20 Chapters with turnover rates higher than the statewide average. The majority of these Chapters had turnover rates in the mid to upper 30-percent range. Several of the Chapters had rates that pierced 40 percent. At one of our Chapters, almost half of their DSPs rolled over in a 12-month period. In a field where continuity of care, and comprehensive understanding of an individual's complex medical, emotional and communications needs is so crucial, these numbers are terrifying.

The #bFair campaign focuses primarily on DSPs. However, if you speak to providers, they will tell you that we are having enormous difficulties finding and holding clinicians as well. I recently asked the Executive Directors of our 49 Chapters to provide me with some data on their clinical staff. In many instances, it took months to find replacement clinicians. Some Chapters recruited for vacant RN and LPN positions for five to seven months. And yet, during this time, we continued to provide care to the individuals in our residential and day programs.

These challenges carry a huge financial cost for providers, and, in turn, for the state and our taxpayers. Providers statewide paid nearly \$90 million in overtime wages, and over \$30 million in administrative and training expenses for new hires and employee turnover in 2018.

But the true cost of this crisis can't be measured in dollars – nor can the true risk.

Vacancy rates, turnover rates, overtime hours, these aren't just numbers. The lack of adequate funding to recruit and retain quality staff is eroding our ability to provide quality care and support. Every day for our providers and the people we serve, these statistics become a more and more dangerous reality.

One of our Chapters is currently offering a bonus to DSPs willing to commit to working a full 8-hour overtime shift for four weeks straight. Another noted 14 staff members who each worked more than 1,000 of overtime in 2018, and one DSP who worked more than 1,900 overtime hours – a full second job. For many DSPs, working 100 overtime hours in a single pay period is not uncommon. With turnover rates as high as they are, many of our DSPs are new and inexperienced. Compound that with the fact that they, and their supervisors, are understaffed and exhausted. With no one to relieve them, mistakes will happen – and in this field, mistakes can mean injury, neglect or death.

Some providers are experiencing noticeable increases in medication errors as the staffing crisis escalates. Medical appointments are being missed or rescheduled due to lack of staff on hand to transport individuals. Staff have fallen asleep on the job after a string of double shifts, or after coming to work ill because there was no one to cover their hours. At some providers, individuals are being moved from their normal residences and placed in alternate homes on weekends or holidays to consolidate staffing. Community outings and social

opportunities are being cancelled because of insufficient staff to support them. Without these opportunities, some individuals begin decompensating, potentially hurting themselves or others, as once-managed behavioral issues resurface. While there is funding in the executive budget for new residential development, it means little. Providers across the state are unable to open new residential programs because they can't staff their current homes. Aging parents fear they won't find placements for their children as beds sit open in understaffed homes. In fact, many providers have closed homes altogether due to lack of available staff.

This reality is not acceptable to us, and it should not be acceptable to you.

We anticipate policy makers will blame violations of quality standards and degradation of services for people with I/DD on poor management. However, the root of this pervasive, system-wide problem is inadequate funding, and the solution is within your control.

In reflecting on my forty years of service in this field, I fear it has taken tragedy to move the State to take action. In the 70s, exposure of the terrible conditions at state institutions triggered a new beginning. In 1999, the discovery of individuals with I/DD living on the streets of New York City launched the development of the New York Cares Campaign. Ten years ago, the death of several people with I/DD in a certified residential program initiated a host of regulations governing fire safety. Six years ago, negative articles in the New York Times about abuses in state operated programs resulted in the creation of the Justice Center.

Do we need a tragedy to occur to force New York state to recognize that our workforce crisis is very real? Do we need people to die before you'll allocate the necessary funding to address it?

I don't want a tragedy to occur on my watch. I am confident you don't want a tragedy to occur on yours. If you don't, you must commit the appropriate resources to revitalize our workforce. You need to fund a living wage for DSPs.

We request that you include the next two investments in the six-year #bFair2DirectCare living wage plan, to take place on 4/1/19 and 1/1/20, for a reported total of \$75 million. We also request that you reinstitute an annual COLA for non-profit providers.

For nearly a decade, non-profit providers have gone without a meaningful COLA, while state-operated providers continued to receive a trend factor. In that time, the gap between state and voluntary program costs and DSP wages has significantly widened, as has the gap in DSP vacancy rates. Non-profit providers have done their best to remain viable in a number of ways: delaying infrastructure investment, using cash reserves, reducing health insurance coverage, elimination and consolidation of administrative positions, and other cost-saving measures.

There is an expectation that somehow voluntary providers will simply continue to become more and more efficient, even as we serve an aging and increasingly challenging population with complex medical and behavioral needs. The state anticipates this will force providers to consolidate in order to sustain services, just like hospitals have been consolidating. Except unlike the hospital system, there have been almost no resources dedicated to support this expected transformation.

Within The Arc New York, we have implemented many shared service strategies across our Chapters and have completed five Chapter consolidations during the past two years. Several additional consolidations are in process and discussion at this time. We will continue to support efficiency and consolidation in order to sustain and improve quality services for the individuals we support. But if the goal is increased efficiency, not survival, then consolidations should be planned and proactive, and initiated prior to one of the consolidating providers devolving into a crisis where services are jeopardized. We do not believe OPWDD has sufficient resources to support proactive consolidations, and without annual cost of living increases, enough providers will slip into financial crisis that the voluntary field as a whole will become unsustainable.

This should cause you significant alarm. Without our network of non-profit providers, the State would become responsible for delivering these services directly – at about a 40 percent increase in cost.

Let me be clear: We are not asking for financial parity with state-operated providers. For decades we have delivered necessary services for less than the cost of state operations. Non-

profit providers can and will continue to do this work for less. But we cannot continue to provide quality care and support – we cannot continue to keep people safe – with the inadequate resources we are receiving today.

The leader of your largest I/DD provider is sitting here before you telling you that without adequate workforce funding, our field is not sustainable. Today dozens of providers, families and self-advocates will submit testimony to this body pleading for you to take action and fund a living wage for DSPs, as we have done year after year. I caution you to listen.

Following his visit to Willowbrook, Robert Kennedy said, “There is very little future for these children. . . . I'm not saying that those who are the attendants there, or who run the institutions, are at fault – I think all of us are at fault and I think it's just long overdue that something be done about it.”

All of us were at fault. And all of us swore never to let it happen again.

In the aftermath of Willowbrook, New York state and its tremendous network of voluntary providers rose as a beacon of hope for families with loved ones with I/DD. No other state served these individuals as well as New York. Unfortunately, after nearly a decade of static funding, this beacon of hope is fading. We risk sliding again into the darkness.

Do not let that happen. Fund years three and four of a six-year commitment to #bFair2DirectCare. Fund a living wage for DSPs. Fund a workforce that has the skills and capacity to keep 130,000 vulnerable New Yorkers safe. Ensure we fulfill New York’s constitutional obligation to provide quality care, support and opportunity for people with I/DD.