



Joint Legislative Budget Hearing - Mental Hygiene

2/7/19

Testimony on behalf of the StateWide Advocacy Network (SWAN) by Patrick J. Curran (Eastern NY Developmental Disability Advocates)

Honorable Chairs, Members, Staff: Thank you for your ongoing work on these critical issues and for the opportunity to submit testimony and appear before these Committees.

The StateWide Advocacy Network (SWAN) is a coalition of family groups from across New York State. These are independent, all volunteer organizations of parents, families and friends of people with intellectual and developmental disabilities. Our sole mission is to educate policy makers, the media and the public on the issues impacting our children with disabilities. We have no stake in the process other than their safety and well-being. We are self-funded and take no government or Provider organization money. The membership and contact lists of our combined organizations represent thousands of families in NYS and we fairly believe we are representative of many tens of thousands more.

What we strive to offer the perspective of, and give a voice to, those tens of thousands of children, many of whom cannot speak for themselves, but who are the ultimately the focus and object of what you are doing here today.

There are a number of critical issues directly impacted by the Governor's proposed budget which we would like to address, including: sharp cuts to the Early Childhood Direction Centers and the Special Education Parent Training Centers; the perennial need for additional residential facilities; issues regarding Consumer Directed Personal Assistance Programs; and so many others.

However, due to constraints on both the Committee's time and our resources, we will limit our focus here to the items impacted by the proposed budget that we current consider to be of the greatest and most immediate urgency.

I. DSPs Living Wage -

There is one overriding issue which, if not addressed quickly, will render everything else the State is doing in this regard moot in terms of the funding and actions necessary to ensure the availability of services and supports for our children, and otherwise worthy and well intended Legislative actions will amount to little more than rearranging deckchairs on the Titanic: that is the need to provide Direct Service workers, the DSPs, with a living wage.

We truly appreciate what the Legislature and the Governor did, two years ago, to help DSP salaries at least partially catch-up after a decade of neglect and stagnation in which salaries that were then barely adequate at 45-50% above minimum wage, were allowed to fall below minimum wage. But its no surprise that, despite these efforts, DSPs continue to lose ground to the current minimum wage, to workers in other (often far less demanding) fields, and to the reality of what constitutes a living wage. And in the face of a strong economy and low unemployment elsewhere, it is no surprise that they continue to leave the field, that fewer new people are entering, and that those who remain are increasingly overworked and burned out.

The proposed a budget currently includes zero dollars to fulfill the six-year plan to bring these same Direct Support Professionals (DSPs) up to a living wage. One hundred thousand DSPs, and another 140,000 intellectually and developmentally disabled individuals, and their families, are wondering what happened to the promise of 2017.

You have already heard, or will hear, the hard data from others, better equipped than we are as Moms and Dads of the disabled, to provide facts and figures. We know that NYState is facing the highest DSP turnover and vacancy rates that it has ever experienced. What we know, and are better equipped to provide for you, is a picture of what this data means in the lives of our children.

For our loved ones, the workforce crisis is personal. It is first and foremost a matter of basic health and safety. The DSP workforce is the cornerstone of all our children's services and supports. Without Direct Support Professionals, nothing happens – no programs, no respite, no administration of life sustaining medications, no basic human care. Vacancies, turnover, and burnout, mean inadequate supervision, broken promises of services and programs approved but delayed or not delivered at all; most importantly, they mean lives are being put at risk.

So this is no longer just a matter of quality of life, of helping people with developmental disabilities to grow and progress as individuals, to help them live happy, rewarding lives; those goals are merely aspirational now. This is now fundamentally an issue of safety, of significant risks to health and the potential for serious injury and death. It is only a matter of time before one more overworked, under slept, under paid DSP on their third overtime shift in a week, makes a mistake, resulting in a tragedy. And then in some quarters there will be calls for punishment and retribution, for action by the Justice Center, and for felony penalties on exhausted DSPs who make mistakes, which the media will then pick up on, and to which government will then have to respond; when instead, with an adequate number of more experienced, well trained professional staff, attracted or retained by a living wage, these tragedies might well have prevented in the first place.

Less dire and immediate, but still critically important, is the impact of the workforce crisis on the continuity of care is which is so critical to the well-being of people with developmental disabilities. It often even takes a parent years of close loving care to learn how to read and understand all the subtle difficult signs, the needs, personal care tasks required just to provide basic care to keep them alive and healthy, much less to develop a relationship, help them be happy and grow as a person. And every such child is different, often very different. Moreover these are often children for whom the world and change is more difficult to comprehend and deal with than it is for the rest of us. They rely on routine and familiarity, more than most of us, just to cope; disruptions and change are much more difficult for them. Bonding with their personal caregivers is central to their lives. This is why we say that in no form of service from one human being to another is the continuity of the caregiver more important than in the care of people with developmental disabilities.

It is that crucial continuity that is damaged or destroyed by this workforce crisis - and it is our kids that pay the price. And society pays a price.

Ultimately there is a moral imperative on this body, and the Governor, to prevent the next tragedy or tragedies before they happen, before they become issues for the media, the Justice Center and its critics, and you, to deal with.

What the Legislature and the Governor now have is an opportunity, not merely to prevent these tragedies and to get ahead of the crisis, but at same time, by providing basic fairness to DSPs in the form a living wage, to develop a meaningful employment program for the 21st Century, targeted at working class New Yorkers who have historically filled these rolls, including a large percentage of women, people of color, and young people, people of compassion and empathy who are not afraid of hard, rewarding work on which they can build a career and support a family, in jobs that cannot be outsourced and cannot be automated.

There are a number of good ideas being discussed as to how this might be accomplished, including: professionalization of the field involving certification programs or Associate Degrees; enhanced training and career track development beginning at the High School and undergraduate levels; development of recruitment programs at High Schools, Community Colleges and elsewhere. These are all good ideas, but first, last, and foremost, this will not happen unless a living wage is established and maintained for qualified Direct Service Workers.

As to what exactly constitutes a “living wage”, we know that experts have different definitions, and ultimately we defer to you, your expertise and resources. While SWAN and its member family groups support and participate in the BeFair to Direct Care campaign, we made clear two years ago in testimony offered in this room, that we believed then, and we believe now, that just to get the DSPs back to the then barely adequate salary level they had relative to the minimum wage 12 years ago, the total funding increase provided by the State would need to be on the order of \$90 million, or double the \$45 million provided in 2016. Since then the minimum wage and entry level wages generally have gone up and that number is probably no longer adequate. However much above the \$90 million number is necessary to achieve a “living wage” (realistic estimates range as high as \$300 million), it should not be a problem in a State where our

Governor, in the context of the State budget process, has, within the last two years, described an amount of \$160 million as a “rounding error”.

Fundamentally this is an issue of safety, of significant risks to health and the potential for serious injury and death, which can best be prevented by providing DSPs a “living wage”, one on which a DSP, working full-time (but not necessarily overtime) can sustain themselves and their family for the long term without falling below the poverty line. We don’t think that’s too much to ask. We are asking as if our children’s lives depended on it; because they do.

II. Transition to Managed Care -

There are troubling issues with the transition to Managed Care in New York State. First is the reality that people with Developmental Disabilities are all “outliers’ with unique issues that need unique planning. Truly person centered planning is the key in the transition to Managed Care, a system that is designed to provide for health care, not long term developmental or habilitative needs.

Managed Care is uncharted territory for people with IDD. The plan for people with developmental disabilities is supposed to include their long term habilitative services. Figuring out how to quantify these to fit a medical model raises many troublesome issues - how do we capitate payments for people, even those with the same diagnosis exhibit a wide variety of needs, how do you assign value in Value Based Payments outside of medical goals to people’s day to day lives? What is value in this situation? How do we protect individuals with the highest needs, with proven safeguards and oversight from being excluded because they may threaten provider payments as they may not ‘get better’, may not be able to ‘get better’? There is a real danger that a Managed Care organization may opt out of taking care of those with the greatest needs in fear of being penalized for the fact that measuring the value of taking care of them is difficult as it is also likely their needs will increase with aging, not decrease.

The initial step in the transition, moving Medicaid Service Coordinators (MSCs) into Care Managers (CMs) working for Care Coordination Organizations has not gone smoothly. On July

1st of 2018 the Care Coordination Organizations were launched. Five months in: actual caseloads are substantially higher than the “recommended” levels; some people do not yet have the name and contact info of their assigned Care Manager; some CMs do not have access to the history of the individual that was accumulated by the legacy provider.

The technology to support the Care Managers is not yet working reliably, and consequently portions of interviews and assessments are lost. Care Coordination Organizations have not yet been able to focus on organizing and coordinating care.

After the technology problems have been addressed, and after the caseloads are worked out—the what? In the absence of adequate transparency and oversight, and particularly if for-profit insurance companies are involved in the Managed Care service system, how can we know that needed services are being delivered to people with intellectual and developmental disabilities by companies that have a profit incentive not to meet those needs?

The following issues have already emerged in this transition: OPWDD policy is to not correct non-medical errors in assessments, and those assessments will serve as the basis for capitated payments; value Based Payments have not been defined well enough to prevent a disincentive to take the most involved people; data needed to monitor the system is not yet in place; conflict-free case management may disappear almost before it begins.

The legislature has already provided almost \$39 million to support the transition to Coordinated Care Organizations. This is a good start, but it is actually less than what the system spends over a three-day weekend, on providing care. Below is one suggestion as to what the legislature can do today to prevent nightmares and to instead deliver on our hopes. Transparency is necessary for a successful transition. Routine data delivery is the actualization of transparency. For transparency, fund the creation of data for insight. Specifically, we would request that the Legislature find a way to fund the following features and add-ons to the Medicaid Analytics Performance Portal (MAPP); these are drawn from SWAN’s March 2018 request to OPWDD and DOH, <http://swannys.org/2018/06/09/mapp-requests-from-swan-3-11-18/> : 1) public access to anonymized performance metrics (items 1-6, 9-11); 2) creation of the “watch-dog messaging system” (item 7); 3) access by authorized people, such as family members, to non-anonymized MAPP data for a selected individual (item 8).

Thank you. As always, SWAN and its member organizations remain fully available and fully committed to working with the Legislature and the Executive to address these and all issues impacting our children.