



## **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.

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.

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

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.