



**ASSEMBLY STANDING COMMITTEE ON MENTAL HEALTH AND
DEVELOPMENTAL DISABILITIES - Public Hearing regarding access to mental
health and developmental disability services and supports -
12/6/18**

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

Madame Chair, Hon. Members, Staff: Thank you for your ongoing work on these critical issues and for the opportunity to appear before this Committee today.

My name is Patrick Curran. I am the Father of Katie Curran, a beautiful, profoundly disabled 30 year old woman. With me is my friend and colleague Jim Karpe, the Father of two young adults with developmental disabilities.

We are here today on behalf of organizations it is our privilege to serve, respectively: the Eastern NY Developmental Disability Advocates here in the Capitol region, and NYCFAIR. We also both serve on the Steering Committee of SWAN, the StateWide Advocacy Network. a coalition of similar family groups from Montauk to Buffalo, to which our regional organizations belong. These are independent, all volunteer organizations of parents, families and friends of people with intellectually and developmentally 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 10s of thousands more.

What we will try to do is offer the perspective of, and give a voice to, those tens of thousands of children, most of whom cannot speak for themselves, but who are the ultimately the focus and object of everything you are doing here today.

Jim will briefly address key concerns related to the transition to managed care, after which I will briefly address the key issue regarding the need for additional resources to ensure the availability of developmental disability services and supports.

I. Transition to Managed Care -

Committee members and Chairwoman Gunther-

I speak today as the father of two young adults with developmental disabilities; and as a representative of SWAN, the StateWide Advocacy Network for people with Intellectual and Development Disabilities. We are a grass-roots coalition of family members and activists from across New York State. Most of us parents.

I am going to talk to you about the transition to Managed Care in New York State. This future presents us with lots of challenges. We have big problems to solve. It can be completely over-whelming. So let's get there by easy stages, and start with a small problem: My son Eli.

Eli is 22 years old, and tests out with an IQ of 55. And, he has a great life. He does volunteer work in Central Park and at a donation center. He travels completely independently on familiar routes, including taking the Long Island RailRoad into Penn Station, where he switches to a subway train to go uptown two stops. Sometimes he goes downtown by mistake, but he has learned to ask for help. Without any supervision

or assistance, Eli does his own grocery shopping, and cooks simple meals using stovetop, microwave and toaster oven. Eli lives in his own apartment with a live-in care-giver. We are aiming to wean him off that care-giver over the next few years.

So Eli has a great life, and to support him in that great life, New York State pays about half what it would to have him in a group home and traditional day-hab. Over time, as Eli continues to grow and develop, that cost will fall to about one-third.

My son's story is a success story, but I promised to tell you about problems with Managed Care. I will now keep my promise. Eli's life highlights X problems with Managed Care.

The first problem is: How did we get here, and how do we sustain it? The simple answer: I have been Eli's Care Manager. I have hunted down programs and funding and personnel. I have been creative, resourceful and persistent. And I have also been Eli's watchdog, monitoring his progress towards goals and the performance of his providers. Which is great for Eli, but what about the tens of thousands of others? And, what happens to Eli when I am gone? I have experimented with turning responsibility over to the professional who has the Care Manager title. She is a lovely person, dedicated, warm-hearted, and highly skilled. But she is overwhelmed with an excessive caseload, and charged with executing multiple time-consuming assessments. She has only 3 hours a month to spend on Eli. After mandatory meetings and mandatory assessments, she will have approximately 5 hours each year to devote to managing Eli's care. So unless there are dramatic changes, when I am gone there will be no more glue to hold together Eli's wonderful and relatively in-expensive life. He will wind up costing New York State \$120K per year, rather than \$40K.

Second problem: How do you Manage the Care of an outlier? Because, my son is an outlier. He is an exception, a special case. There are people who look almost identical to Eli on paper, but who require much more intensive and expensive supports. Most of the people who are supported by OPWDD will not be able to travel independently. Most

will never be able to shop for themselves, or prepare their own meals. But it is not just Eli who is an outlier--we are a population of outliers. How do we manage that?

I don't have the full answer, but I am certain that a big part of it is a radical shift to greater transparency and visibility. We need to be able to "see into" the system, so that problems are made visible. Then they can be addressed.

A simple example—I mentioned that Eli has a Live-In Caregiver. This is a great program, an excellent addition to the collection of housing solutions. And, it was very difficult for me to put it into place. I assumed it was just due to my ignorance and special circumstances in my family life. But, I recently got hold of data, and the data tells a very different story. The data provides us with that precious gift: Action-able insight. Because it turns out that out one hundred thousand people with developmental disabilities in New York State, Eli is the 93rd to have a Live-In Caregiver.

THREE TYPES OF PEOPLE

An OPWDD official recently told me that she had seen three types of reactions to the transition to Managed Care: There are those who are on-board, those who are confused about what it is, and those who are scared. And so maybe I am an outlier myself, because I fall into all three categories. I'm on-board with re-working the system, and hopeful about the possibilities. I'm confused and concerned about how this will actually work. For example, how do we have conflict-free case management, if the Care Managers are reporting into the same corporate conglomerate which is aiming to reduce costs?

And, I am scared that we are going to end up with a system that silently fails to deliver.

HOPES

My hope is that we can work together to build a sustainable system of supports and services which meet the wide-ranging needs of all individuals with developmental disabilities in New York State. This hope is shared by all of my colleagues in SWAN, and

by the leadership of OPWDD. And this will not be easy to achieve, nor will it be easy to sustain. The transition to Managed Care is being executed by good-hearted people in pursuit of this vision of sustainable services.

But Managed Care is uncharted territory for people with IDD. We have a responsibility to create a transformation that protects individuals with the highest needs, with proven safeguards and oversight.

FEARS

My fears come in two portions. The first is that the transition is bungled. That we waste this opportunity, due to lack of foresight, administrative errors, and overwhelming technical problems. Unfortunately, this nightmare appears to be our reality today.

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.

Due to these problems, Care Coordination Organizations have not yet been able to focus on organizing and coordinating care.

The second portion of fear is about what happens after the transition to Managed Care Organizations has been completed. After the technology problems have been addressed, and after the caseloads are worked out—what might happen then? In the absence of adequate transparency and oversight, the Managed Care service system

can be twisted into a cash cow for corporate share-holders. How will we know that needed services are being delivered to people with intellectual and developmental disabilities?

HOPE AND DESPAIR

We see several reasons for hope, and several for despair. On the despair side:

OPWDD policy is to not correct non-medical errors in assessments. 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 will disappear almost before it begins. Current plans call for Care Managers to be absorbed into Managed Care Organizations. If this comes to pass, it will eliminate a vitally important built-in safeguard.

On the hope side, OPWDD and DOH have shown a willingness to:

Provide performance metrics to the advocacy community and the public at large, starting with the first delivery of one key ratio as early as July 2019.

Invite advocates into the process of creating Value Based Payment.

Create a “messaging system” which will allow out-reach to individuals, based on the performance metrics.

ACTION TODAY

The legislature has already provided almost \$39 million to support the transition to Coordinated Care Organizations. Which is great, but is actually less than what the system spends over a three-day weekend, on providing care. Below is what the legislature can do today, to prevent nightmares and to instead deliver on our hopes. Transparency is the key to a successful transition. Routine data delivery is the actualization of transparency.

For transparency, fund the creation of data for insight.

Specifically mandate and fund the following features and add-ons to MAPP, the Medicaid Analytics Performance Portal. 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/> .

public access to anonymized performance metrics (items 1-6, 9-11).

creation of the “watch-dog messaging system” (item 7).

access by authorized people, such as family members, to non-anonymized MAPP data for a selected individual (item 8).

II. DSPs Living Wage -

In terms of the funding and actions necessary to ensure the availability of services and supports for our children, there are many issues and programs we would like to be able to address. Unfortunately, there is only one overriding issue which, if not addressed quickly, will render everything else you are doing here today moot, and other worthy and well intended Legislative action will amount to little more than rearranging deckchairs on the Titanic: that is the need for Direct Service workers, the DSPs, to receive 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. You have already heard 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 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 has become 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 an adequate number of more experienced, well trained professional staff, attracted or retained by a living wage, might well have prevented the tragedy 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 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 try to deal with.

And in so doing, what the Legislature and the Governor have now 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, a 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”, 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”.

Ultimately, for us a “living wage” is one on which a Direct Service Provider, 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.

Thank you. We would be happy to try and answer any questions if we can.