



Joint Legislative Budget Hearing - Mental Hygiene

2/3/20

Testimony on behalf of the StateWide Advocacy Network (SWAN)

by Jim Karpe (NYC FAIR)

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), a coalition of family groups from across New York State are independent, all volunteer organizations of parents, families and friends of people with intellectual and developmental disabilities. We have no stake in the process other than the safety and well-being of our children. 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.

We are at a critical time for those with intellectual and developmental disabilities. But this isn't the first time NY has faced this crisis. When the conditions at the Willowbrook Developmental Center dominated the headlines and people demanded a new approach, NYS rose to the occasion. From the late 1970s thru the 80s and 90s a new service system of community based not-for-profit organizations opened homes to replace the institutions and established a variety day programs. These not-for-profits were a direct outgrowth of family advocacy groups – the ARC, UCP and local community-based organizations. Today's families owe a great debt to these trailblazers who continue to deliver necessary services to our children. But we are told repeatedly that the current system is not sustainable. The need to change with the times – to

SWAN of NYS is an independent coalition of volunteer advocates working to achieve the best quality of life for all individuals with Intellectual and Developmental Disabilities. Formed in 2015, SWAN of NYS represents families and individuals throughout all regions of New York, coordinating with leadership from the following groups: DDAWNY Family Committee, ENYDDA, NYC FAIR, LLAND and others. To learn more about SWAN of NYS, visit our website at www.SWANNYS.org



evolve – to define and deliver the 21st century service system is not just desired, but critical. We cannot simply do more of the same.

Yesterday’s grass-roots advocacy groups are now part of today’s multi-billion-dollar system – a system that like any other industry seeks to maintain the status quo. But the status quo won’t do. Last year our colleague, Pat Curran, testified in front of this committee and told you that we are not constrained, that we will say things that others won’t.

So let’s get started with six questions.....

1. How do we solve the workforce crisis that continues to leave services without adequate staffing?
2. Will we continue to move towards a more integrated and inclusive system or retreat to the separation and isolation of the past?
3. How do we provide services to the growing population of those who need services?
4. How do we serve those with complex and expensive needs?
5. Is government the solution or the problem? Will we continue to support a strong OPWDD or privatize the oversight of services thru managed care organizations?
6. How do we find a path forward? How do we pay for everything?

In spite of some modest increases in the last several budgets – increases that have largely been focused on increasing wages – there remains

- a critical shortage of staff;
- an inability to serve those with complex needs;
- a shortage of residential opportunities;
- a growing population of unserved and underserved;
- an aging population requiring more services;
- and many more issues that cry out for more resources.

OPWDD has identified some ways to find more money – \$10million in state-only services to be converted to \$20 million with the federal match; reducing the amount for CCOs by \$30 million, to reduce overtime in state services by \$7million **but that requires more staff**; find



\$20 million in reductions to not for profit services and continue to limit administrative costs in the not-for-profit sector to 15%. As there are already over 150 agencies on the Financial Watch list this proposal is dangerous for the service system as a whole. Even if successful in all of these efforts the total savings may near \$100million – or a little over 1% of OPWDD’s \$8 Billion budget. Does anyone think this will even begin to solve the problem? Is the legislature prepared to come up with another billion or two that might really make a difference? So what can we do? The elephant in this particular room is the exorbitant cost of state services. OPWDD must restructure and redefine its role as a direct provider of services and this body must have the political courage to enable them to do this. We cannot afford to exempt state run services from the efficiencies that we are demanding from the not-for-profit sector. This is not an attack against the unions. We strongly believe in unions. But CSEA and PEF must find a way to work with OPWDD administration to address the imbalance that state services cause our system. OPWDD management must have the ability to discipline staff or close facilities if they are going to continue to be service providers. We know this is uncomfortable to talk about but re-allocating resources from State services must be part of the answer for the same reason that Willie Sutton robbed banks– “because that’s where the money is.”

We place supporting OPWDD as crucial to making the necessary changes. For us that means not only finding every dollar available but supporting the new management team. We would like to give the OPWDD team a chance to implement the vision of sustainability, equity and accessibility that Dr. Kastner has committed to. We would like to add one thing to that. We urgently believe that New York State must make Choice part of the critical mission. . Individuals with developmental disabilities must be allowed to choose where they live and who they live with. This is New York State’s moral and legal obligation.

We oppose spending any more resources in order to move forward with the transition of OPWDD services into managed care. It is not surprising that having successfully captured over two thirds of the entire Medicaid population nationally for health care services, the insurance industry has turned its formidable powers of persuasion to the long-term supports and services (LTSS) provided to the I/DD population. But the promises of managed care for LTSS are unproven at best and empty at worst. When looking at the entire landscape of



Medicaid managed care, the Medicaid and Chip Payment and Access Commission (MACPAC), the congressional commission tasked with evaluating the success of Medicaid programs concludes

“While much research has been conducted on whether Managed Care delivery systems result in better outcomes than fee for service (FFS), there is no definitive conclusion as to whether managed care improves or worsens access to or quality of care for beneficiaries.”

<https://www.macpac.gov/subtopic/managed-cares-effect-on-outcomes/>

A 2018 study by the University of Texas School of Public Health of fifteen states that have moved some I/DD LTSS to managed care concluded

“most states did not realize a cost savings...” and that “there are no commonly accepted measures of quality” for the IDD population.

Pg. 35, [Final Report: Intellectual and Developmental Disability Care Evaluation](#), University of Texas School of Public Health. December 31, 2018

All the available data shows that applying Managed Care principles to LTSS results in zero net savings. This is because the modest savings in reduced service costs are overwhelmed by the large increase in administrative overhead. This is not our opinion, but the result of a detailed analysis that Deloitte produced for the State of Texas, published in early 2019.

“While there are savings achieved on LTSS claims, the amount of increased administrative expenditures outweighs savings from claims.”

pg 12. [IDD LTSS Carve-In Cost-Effectiveness Evaluation - Final Report](#)

Our experience here in NYS is consistent with this cautionary outlook. Partner’s Health Plan (PHP) is currently in the fifth year of the FIDA demonstration to provide LTSS to dually eligible individuals with I/DD. Their results to date are marked by continuing losses even as they seek a contract renewal and financial relief from their current losses.



So why is the administration still committed to this transition to managed care? The 20-21 budget briefing book no longer states that the start up costs for this transition will come from the global Medicaid cap. While this isn't surprising given the headlines about our Medicaid shortfall, it certainly begs the question – where will these hundreds of millions of dollars come from? The only place Managed Care companies can find this money is by taking it from supports and services.

In the last 18 months, the 'first stage' of managed care for IDD, Care Coordination Organizations (IDD Health Homes) has cost of hundreds of millions more than the Medicaid Service Coordination system that it replaced. These increased costs have not impacted NYS as they were a 90/10 match from the Federal Government. for the first 24 months. The 24 months end this June. This puts pressure on OPWDD to to save money on CCO expenditures. But regardless of who has paid for this, we have to ask what have we achieved by this increase in spending on care management. OPWDD points to 100% completion of Life Plans, but there is very little data on the quality of these Life Plans and ,more importantly absolutely no data about whether these new Care Managers are helping their clients access services. We suggest you look at the CMS definition of a health home and then ask your constituents who are members of these CCOs how it's going. We have. For some it's been ok. For a few it's been excellent. But for many more, the CCO experience has been little more than an endless process of questionable assessments and a revolving door of care managers. There are those who have graduated high school, gone through the Front Door who are sitting at home for a year or more because their Care Manager has not connected them to adult services. We were told that the CCOs are necessary to comply with the CMS mandate for conflict-free case management. While we understand the principle of separating the case manager from the provider of services, we don't understand how this conflict is eliminated when the ownership (for those that are for profit CCOs) or control (for those not-for-profit) remains with the providers. This relationship would become even more confusing if the services were managed by provider led managed care organizations that also are responsible for case management. Finally, we would like to state that we strongly support the Article 7 amendment that will give authority to issue operating certificates for DOH services that serve the I/DD population, like CCOs to OPWDD.



Here are our issues. Our workforce must have a living wage. 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. Ultimately there is a moral imperative for 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.

Our service providers must be able to operate without the endless documentation and unproductive regulatory requirements that consume so much of their limited resources. We need serious regulatory reform. We need to innovate. We need to give real meaning to person-centered planning and community integration.

After Willowbrook, it was the families that led the way to a new era of helping those with I/DD, an era during which NYS was model for the country on how to do it best. 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 so that NYS can regain its leadership in I/DD services.

Thank you.