

Testimony to the Assembly Committee on Mental Health and Developmental Disabilities

Barriers to the successful implementation of OPWDD's Transformation Agreement

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Thank you for giving me the opportunity to address this committee. My name is Brad Pivar. I'm the father of a developmentally disabled young man. My 31 year old son, Scott, lives at home with his mother and me and attends a site-based day program here in Albany. Scott's needs are serious. He is non-verbal, non-social and requires help with all activities of daily living.

The legislature has played an important role over the years in the growth of the developmental disabilities service system – a system that keeps redefining and reinventing itself. Unfortunately, I'm afraid that today's Transformation Agenda and the current Transformation Agreement that is being implemented will cause more problems than it will solve. The Transformation Agreement has many admirable goals. There is, unfortunately, one huge barrier to its successful implementation. It's called reality. Now that may sound glib or silly, but consider the components of the Transformation Agreement. OPWDD lists six main goals of the agreement and I'd like to go thru them.

Developing new service options to better meet the needs of individuals and families in a truly person-centered way, including allowing for more self-direction of services

Person Centered Planning (PCP) has been the stated goal of service delivery for as long as I can remember. In school there was an Individual Educational Plan. In adult services there's an Individual Service Plan. The problem is not with the theory of PCP but the reality that it is incredibly difficult to deliver the services. For example – in 2004 OPWDD (then OMRDD) launched NYS Options which was in their words ' a new program to deliver services that would be flexible, inclusive and reflect the personal choices of consumers'. Scot was approved for In Home Res Hab – a program designed to facilitate Scot's interaction with the greater community. During the first two years our service agency sent a number of prospective direct care workers to work with Scot. None lasted for more than that initial meeting. After two years of no service we were given the option to convert the program – at 25 cents on the dollar – to a family support grant to be used for the same purpose. But similar to the current individualized person centered plans this grant allowed us to recruit, and to determine the pay rate, for a worker. The grant is more flexible than individual services being developed today. Over the last 8 years so we have had a couple of successful Res Hab workers who made a difference for Scot, but even with this almost total flexibility, we've had long periods where Scot has received no services. Last year Scot was approved for In-Home Respite. Again this sounds great in theory , but the reality is that we've had a number of first meetings with prospective direct care workers that have resulted in little to no service. You have heard and will hear over and over again about the need to increase the wages of direct care workers. It's impossible to overstate the importance of this. It won't solve all of the staffing issues, but it's an important and necessary step. No matter how creatively we design individualized programs, you still need people to implement them.

Creating a specialized managed care system that recognizes the unique needs of people with disabilities, and is focused on a habilitative model of services and supports

It is difficult for me to understand why it is accepted as given that outsourcing program management to an independent managed care organization will produce an improved system. The reality of managed care has not lived up to its promise of what managed care can and should deliver – and that’s in healthcare, where we have had managed care for decades. Managed care for developmental disability services has been implemented in a number of states with very questionable results, so why are we going to experiment in the largest service system in the county? And why do we need to ‘create a specialized managed care system that recognizes the unique needs of people with disabilities, and is focused on a habilitative model of services and supports’ when we already have one – it’s called OPWDD. It’s ok to criticize OPWDD and demand that they improve management, but family advocates fought for decades to get NYS to create a separate agency to serve the developmentally disabled. Let’s improve OPWDD – let’s not subcontract its mission.

Ensuring that people live in the most integrated community settings

This is certainly a laudable goal. One has to wonder, however, how this goal can be achieved without residential development. And, if we’re going to provide residential services in an integrated community setting, shouldn’t we begin with the community that our children have grown up in? Today’s reality is that the only residential placements that are occurring are emergency placements in whatever and wherever an opening becomes available. Agencies can no longer plan with families or groups of families to develop a residence in their neighborhood. For aging parents, and there are many thousands of us, we want to be there to help our adult children transition from home to a different residence. The transformation agenda wants to encourage creative and less expensive residential opportunities – supported apartments – independent living. This is fine for those individuals who want this kind of independence, and who can be successful with this kind of independence, but it’s meaningless for Scott. Scott needs help with daily activities. Scott needs to have someone watching over him at all the time. And there a lot of Scotts.

Increasing the number of individuals who are competitively employed

I’m all for improving employment for our guys and gals. Let me tell you about my nephew. He has the same genetic condition that my son has, but he is much more independent. After graduating from his local high school – a non-academic program, he went, on his own, to a local grocer where

he'd done an internship and asked for job. No pre-voc no job coach. He's been competitively employed now for 12 years. But the reality is that individuals like my nephew are the exception. The majority of our folks are unlikely to ever be competitively employed. The 20,000 New Yorkers in sheltered workshops are having their lives turned upside down. This is national policy and no doubt there are those who celebrate the demise of the sheltered workshop, but the best of intentions often have unintended consequences.

Focusing on a quality system that values personal outcome goals for people, such as an improved life or access to meaningful activities

This sounds great. And if you visited day services around the state you would find some terrific programs that are filled with life improvements and meaningful activities. But, the reality is that far too many of the day programs are little more than babysitting. We need better day programming – more creative day programming - programs that develop skills and provide meaningful activities. But good day programming costs a lot of money - and let's not forget - programs are only as good as the people working in them. So funding to improve day programs is going to be needed to meet this Transformation goal.

Working to make funding in the system sustainable and transparent

I can only imagine that the demographics impacting service needs keeps the folks at DOB awake at night. I get that we're going to have to deliver more for less and that the way to do that is to do it smarter and better. But whether that will be either sustainable or transparent is hard to say. Much of the dilemma that the system faces today is a result of service development being driven by reimbursement goals – Medicaiding everything – Is that sustainable? Congress wants to block grant Medicaid. What happens if they get their way? And transparency? No comment. One thing I will say though is that we need to Transform and develop services based on the best way to do things, not on the best way to generate federal dollars.

Thank you