

**Tom Nowak**

**Testimony to Transformation Panel,**

**September 17<sup>th</sup>, 2015**

Good evening. My name is Tom Nowak. I am the parent and guardian of a twenty-five year old son, Michael, who is a person with a developmental disability and other challenges. He is in a residential placement on Staten Island, where we live.

I would like to address with this transformation panel my concerns regarding the use of a managed care model in providing services to my son, and other New Yorkers with ID/DD. NYS rose from the shadows of Willowbrook to build an extraordinary network of services for persons with ID/DD that in many ways respect them as individuals, recognize their abilities and celebrate their contributions to our communities. That network of service providers is now at serious risk and the great legacy of agency creation, often born of local initiative and collaboration, on the verge of extinction

We parents and care givers recognize that sustainability is essential if current and future needs are to be met. No one wants a return to the inhuman warehousing of persons with ID/DD. But the new institutionalization which threatens us is a direct result of a turn from a person centered service model to a capitation model which by its very definition sees our sons and daughters as figures on a spreadsheet or points in a decile score. It's all about counting heads and tabulating averages.

Managed care, as its name states, is about constraints: fitting the individual to a range (and cost) of service. In order to accomplish this, a significant investment in infrastructure is necessary. Where managed care has failed to meet its objectives of controlling costs while delivering quality services, it does so because the implementation is flawed from the start by not recognizing the investment in automation, alignment and education of providers, and implementation of adequate quality safeguards for recipients. From the very beginning of OPWDD's transformation efforts, I (as an insurance professional with more than three decades of experience) recognized that the infrastructure for managed care did not exist among the ID/DD service providers themselves. The recent recognition by OPWDD of this gap in the transformation process as originally conceived, and the move (as of August) to consider employing a commercial insurer to provide infrastructure to achieve capitation in conjunction with a state-wide DISCO/ACO, should serve as a warning that any attempt to schedule implementation without due consideration for the impact to persons with ID/DD or to their current support networks will result in serious unmet needs, financial and personal hardships, provider failures, threats to the safety of persons with ID/DD and ultimately litigation by parents and caregivers.

Achieving sustainability, we caregivers recognize, in ways those entrusted to our care often cannot, will require new ways of thinking and doing. We seem to have forgotten that our current network of providers was born out of such challenges: improvisation, ingenuity, community participation in the wake of the Willowbrook Consent. We cannot disregard the value of this DNA which continues to power so much of the service provider networks upon which persons with ID/DD depend upon. That

dependence is not reducible to rank in a decile score: it has a human face, requires a human touch. Persons with ID/DD or for that matter any disability, need first and foremost respect for who they are as persons. Unlike a medical model which takes as its inputs symptoms and agents, and generates interventions and cures, disability requires perspective: it is life long, it changes and develops as the person grows and develops throughout their lifetime, it is less open to technological innovation as sensitive to the quality of persons who provide that human touch, who look into that human face with kindness, engagement and mutual respect. No managed care model in existence today can adequately take into consideration this essential component of perspective. Not Wisconsin. Not Kansas. The jury is out in New Hampshire.

So in conclusion, I strongly urge the transformation panel to go slow. Transformations need not be grand sweeps, and if in fact sustainability is integral to the success of this transformation, incremental development based on small pilots during which real data on costs, outcomes, and quality as perceived by those receiving necessary supports and services can be measured, tabulated, and shared by all for debate. The rich DNA of our current service providers is at serious risk of compromise – even extinction. Consolidation does not always result in efficiency. Redundancy may be welcomed in times of environmental or economic catastrophe. Technological innovation cannot replace the confidence of a well-trained, attentive and caring staff. We can, we must, all work smarter in providing for the needs of persons with ID/DD – I invite the transformation panel to do the same.