

Good morning. My name is Tom Nowak. I am the parent and guardian of my twenty-five year old son, Michael, who is a person with a developmental disability. He lives in a lovely home on Staten Island, in our community, with other young men and women who he grew up with.

I would like to address with this Committee 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 caregivers 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<sup>i</sup> 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 Developmental Disabilities Individual Support and Care Coordination Organization (DISCO), 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.

Proponents of managed care also argue that the implementation of an Accountable Care Organization (ACO) will provide greater oversight and achieve outcome based performance. From our perspective as parents/caregivers/advocates the question is: accountable to whom? Unlike the medical model referred to above, there is no standard of care, no evidence-based outcome – there are only unique human persons, many of whom are vulnerable, who have difficulty communicating even basic needs. They have come to rely on the safety and security of a structured life, now subject to the increasing turnover and unavailability of direct support professionals<sup>ii</sup>. ***The inconvenient truth of NYS is that we have a network of providers working very hard at meeting their participants' needs – expensive, yes – but in place and functioning.*** Adding additional infrastructure like an ACO, or even worse, replacing the current OPWDD with an ACO reporting to the NYS DOHMH, is like adding a huge millstone around the neck of a person, a system of care, already just treading water.

Our concerns are not without foundation: the Kaiser Family Foundation Commission on Medicaid<sup>iii</sup> (publishing in February 2012) cautions that (1) establishing capitation rates for persons with disabilities poses special challenges – that unmet needs in the current Fee For Services environment is unreliable in setting capitation rates, and (2) that risk-based managed care for persons with disabilities is not likely to generate short-term savings - that the potential for savings lies in the appropriate patterns of care over time. Risk is not a term that we, as parents/caregivers/advocates, take lightly. We are not sure that OPW, or CMS, understand the risk in the transformation effort now underway.

So in conclusion, I urge you, our elected representatives, to require OPW 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 Members of this Committee to insist that OPW and the transformation panel do the same.

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<sup>i</sup> Market Failures and the Evolution of State Regulation of Managed Care; Law and Contemporary Problems; Vol. 65, No. 4 (Fall 2002): Sloan, F.A. and Hall, M.A.

<sup>ii</sup> Trends and Challenges in Publicly Financed Care for Individuals with Intellectual and Developmental Disabilities; Center for Health Care Strategies, Inc. (September 2012)

<sup>iii</sup> People with Disabilities and Medicaid Managed Care: Key Issues to Consider; Kaiser Commission on Medicaid; The Henry J. Kaiser Family Foundation (February 2012)