

Mariette J. Bates

Mariette.bates@gmail.com

646-732-4600

**Testimony on the Adequacy of Supports and Services for I/DD
Assembly Committee on Mental Health and Developmental Disabilities**

I am the Academic Director of the Disability Studies program at the CUNY School of Professional Studies, part of the City University of New York. I am also the stepparent of a 51-year-old man, Michael, who has 11-q 2, 3 Syndrome, craniosynostosis, blindness, autism, Von Willebrandt's Disease, Hepatitis A and B. His IQ tests at 20, which means he has a label of profound intellectual disability.

When he was five, his parents placed Michael in Willowbrook State School, where he lived in an award-winning children's ward. In the two years he was there, he got pneumonia, broke his hip, and contracted Hepatitis B.

In his 46-year career as a service recipient, Michael has been in several residential schools, but he found a permanent home – or so we thought – when he went to live in a group home in the Bronx. Because of his age and his disabilities, many of the people in his group home have multiple disabilities because they were born during the Rubella epidemic of 1964. All of the residents of the group home are visually impaired, hearing impaired, and have medical issues which are worsening as they age.

Parents of these children started the agency that operates his group home. The parents met over many years – often until late at night – discussing their plans, becoming an incorporated nonprofit, holding fundraisers, and writing grants. As time passed, they hired initial staff, and supervised the creation of the program. I was part of this process, so I can attest to their hard work, but also what they wanted for their children – a home that provided good quality of life, the medical and therapeutic care they needed, and warm and caring staff. Michael has lived there for 25 years and has the consistency and continuity he needs.

Michael's group home is designated as an ICF – an Intermediate Care Facility - a designation for community residences where a higher level of support, including clinical staff - is needed. While many people who have intellectual disabilities need more independence and the opportunity for work, for Michael and the other residents of his group home, this is not a realistic future plan.

We now understand that ICF's will no longer be supported by OPWDD under the Medicaid Redesign and new waiver, although the State could choose to continue the program and that the program will be 'downsized.' Michael's father, who will be 80 next month, and who has

been a lifelong advocate in this field, feels betrayed and extremely apprehensive when we hear about these plans. It's neither a realistic option for Michael to come home with supports, or for him to be in a less supervised situation. Moreover, since he's lived with the same people for 25 years, 'downsizing' will mean, in effect, breaking up his family.

For all of those parents who worked so diligently over a number of years so that their children would have a permanent home, and meaningful day activities with the supports they need, I can only say that the policy for people overseen by OPWDD over the last decade has been so unpredictable and erratic as to be a public policy travesty. Communication has been sporadic and contradictory; policies are announced and then abandoned with alarming frequency.

There is no permanent commissioner overseeing OPWDD. There is a crisis in the workforce because of the lack of any reasonable rate of pay for direct support professionals. There has been a lack of consistency and responsiveness in either developing a plan for future services that takes the service recipient's and their family's preferences into account or how families actually live. The rhetoric about providing choices is wonderful, but only if individuals with disabilities and their families are actually given choices.

Families who desperately need services are given no hope or any supports while their home situations deteriorate. How can it be humane social policy to tell aging and ill parents that there is no place for the child they have kept home and supported for an entire lifetime? How can we waste years of building skills in school programs to find there are no places for young adults to use those skills, so they are at home losing the skills they acquired?

There is a network of nonprofit agencies in New York that has developed trust and respect with those they serve – both parents and service recipients - over the last forty years. They have worked tirelessly to incorporate the preferences of those they serve, and the best thinking of the disability community, and the programs they developed work quite well. Any plans to marry these nonprofits to the insurance industry will be a failure as it has been in other states that have tried this particular form of managed care. The only people who think this is a good idea are the health care consultants who sold our government a bill of goods while ignoring common sense and the experience of states elsewhere.

Surely this state can develop a plan that is responsive to the needs of people who need services while appreciating the need for cost stabilization. In order to do so, however, we will need a permanent commissioner to advocate for us both with the federal government and in Albany, who is committed to listening to individuals with disabilities and their families about what they need.

Individuals with intellectual and developmental disabilities deserve lives of dignity and purpose, and their families need assurances that promises that were made will be kept. Families with younger children deserve quality services and staff that are well trained and compensated fairly. New York has a responsibility to its citizens and particularly to its citizens with disabilities and their families, and it's time to make that a reality.