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### **Testimony Before the Medicaid Commission**

March 14, 2006

Good morning. My name is Margaret Puddington. I live in New York City.

My younger son, Mark, is 25 years old and has significant developmental disabilities. He has mental retardation, physical impairments, and he cannot speak. Every task of daily life is an enormous struggle for him, whether it's opening a door or putting on a shirt. Yet he is an extraordinary person, with an irresistible smile and a great talent for making friends.

Living with Mark presents profound challenges. He is still very dependent on us for most aspects of his care. He demands constant attention. At times he behaves in some very unpleasant, and even dangerous, ways. My husband and I are not so young any more. I have a heart condition, and my husband is legally blind, and his vision has deteriorated to the point where he simply cannot do certain chores for Mark anymore. Our daily lives are exhausting and acutely stressful.

We survive because of the services we receive. Medicaid funds an in-home training service, which provides experienced workers who come to our home weekly to work with Mark on specific goals. This service helps Mark develop skills, such as handwashing, that will eventually make him less dependent on others. There is another benefit to this service, too: it gets me through the week by giving me time off from childcaring responsibilities. I need these breaks - to run errands, to go to a doctor's appointment, or just to spend a quiet moment with my husband.

Another invaluable service we rely upon, also funded through Medicaid, is overnight respite, where Mark spends occasional weekends together with a few other young men with disabilities, supervised by well-trained staff. Overnight respite gives Mark the healthy experience of socializing with people his own age and learning to rely on staff, not Mommy and Daddy, for assistance. My husband and I love these tension-free weekends. Both overnight respite and in-home training renew our energy, reduce our level of stress, and give us the strength to continue to keep Mark home with us.

During the day, Mark attends an adult day program, also funded through Medicaid. There he is learning many independence skills, doing some volunteer work with his group, and, for the first time, accepting responsibility for certain chores. For my husband and me, this program is absolutely critical. Because Mark goes to a day program, my husband and I can work, can be productive, can have an identity aside from "caregiver." We cannot imagine how we would survive without it.

These three services are the linchpins that hold our family life together. There is absolutely no question that without them, we—along with thousands of other families in the same situation—would have been forced to seek residential placement years ago. These services sustain our families; they are not luxuries. And they have saved government many millions of dollars a year in residential services.

Nevertheless, the time is coming when residential services, also funded by Medicaid, will become a necessity for Mark and the many others like him who cannot take care of themselves. Residences are the most critical of all services for our children, especially when we parents pass on. Residential services will govern all aspects of Mark's life, and the quality of those services will absolutely determine the quality of his life every minute of the day.

We families are terrified at the prospect that Medicaid cuts could decimate all of these critical services for people with developmental disabilities.

Medicaid cuts would mean no new residential services. I cannot bear to think of what would happen then. A parent's heart attack or death would leave even someone as vulnerable as Mark without a safe, staffed place to live.

As for residences that already exist—and day programs, too—Medicaid cuts would do to them what funding cuts did to New York's Willowbrook state institution for people with disabilities decades ago. Budget cuts slashed the staffing and resulted in horrendous abuse and neglect. Medicaid cuts today would have the same result. Programs would be overcrowded and staffing would be cut. People would sit idly day and night, neglected, while overburdened staff responded to noncompliant people by screaming at them. Or worse.

We parents will never subject our children to that kind of treatment. We have learned the lessons of Willowbrook, and government should have, too.

One of the most critical lessons is that staff are our most precious resource. Even now, the greatest challenge in our field is that inadequate salaries of direct support staff are making it extremely difficult to hire and retain qualified staff. Staff have enormous responsibilities and receive extensive training in everything from medication administration to behavior management, alternative communication systems, and teaching strategies. But just as important: staff are the people who will tie our children's shoe laces, take care of them when they have fever, console them when they are sad. When we parents are no longer around, staff will be the most important people in our children's lives. That is why parents' number one priority now is to get significant raises for direct support staff so that they can afford life's basic necessities. As it is, staff commonly juggle two or even three jobs just to get by. It breaks our hearts when our children's favorite staff quit because they can't make a living in this field. We are desperate for Medicaid to fund salary increases so that staff can make the decent living they deserve.

On behalf of the families of people with developmental disabilities, I urge you not to cut Medicaid funding for long-term services for people with developmental disabilities. I also urge you to raise salaries of the direct support staff so critical to the safety and well-being of our children. Please do not compromise on these issues. All of us are counting on you to help us protect our very vulnerable children.

Thank you.