

Margaret Puddington
562 West End Ave., 2A
New York, NY 10024
212-799-2042
Margaret.puddington@gmail.com

**Public Hearing Sponsored by New York State Senator Perkins, Assembly Member
Rodriguez, and Assembly Member Wright
January 14, 2016**

Critical Issues for People with Developmental Disabilities

My son Mark, now 35 years old, is the warmest, sweetest guy you would ever want to meet. He has friends up and down Broadway. But he could not survive without direct support 24-hours a day. He is not able to speak, his walking is unsteady, he needs his meat cut up, his shirts buttoned, he cannot cross a street safely, or protect himself from danger.

Salary Increase for Direct Support Staff

Mark lives in a wonderful 24-hour residence in Washington Heights. He loves his direct support staff. They keep him safe and healthy. They teach him new skills. They encourage him and comfort him.

Direct support staff are highly trained and bear much responsibility: they administer medications, handle challenging behaviors, teach new skills, and much more. Depending on the individuals they support, they may need to work a mechanical lift to transfer a person from wheelchair to bath; they may need to learn sign language or feeding techniques. They are often on their own without a supervisor in community activities, where they must have the judgment to deal with medical or behavioral emergencies. They need to be part social worker, part psychologist, part nurse.

Yet starting pay is currently \$10-\$12 per hour, about the same as the federal poverty level and well below the proposed \$15 per hour minimum wage. Most staff work 2, even 3, jobs to make ends meet.

Direct support is NOT a minimum wage job. If the state increases its minimum wage to \$15 per hour, as many of us hope, then direct support staff must get not only the \$15 per hour, but a higher wage that maintains the differential between their current wage and the current minimum wage.

In any case, direct support staff must be given a significant salary increase. Most of our service providers are non-profits funded by government. Non-profits have no other source of revenue to pay for higher salaries, unlike McDonalds, which can raise its

prices or cut profits or use cheaper ingredients. Therefore, any wage increases must be funded by New York State and not taken out of funding for existing services.

Need for 24-hour Residential Services

I was one of the lucky ones. My son was able to obtain 24-hour residential services before the gates clanged shut about 8 years ago. Since then, OPWDD has developed new residences for people leaving the developmental centers and people aging out of residential schools. But for individuals living at home, there has been virtually no development.

The NYS Legislature recognized this critical unmet need when it directed OPWDD to report by February on the scope of residential need. OPWDD did conduct a phone survey of needs, but reached only 4,000 people out of the 11,000 on its original residential waiting list. Moreover, parents complain that when they attempted to call back, they were unable to reach anyone at the call center. Many parents who wanted to be added to the residential waiting list report that the call center refused to take information on people not already on the OPWDD list. It appears that OPWDD's survey may not fully reflect the need.

New York State cannot forever deny the reality that sooner or later most people will need some type of out-of-home residential services.

- First, OPWDD should dedicate 50% of all new residential development to people living at home.
- Second, OPWDD needs to remove barriers to residential development by increasing its scandalously outdated rental AND PURCHASE thresholds.

CMS Overreach

I would like to raise a federal issue, especially because it is quite possible that tonight we are addressing a future Congressman.

As you know, Medicaid funds over 95% of services for people with developmental disabilities. The Centers for Medicare and Medicaid (CMS) has taken to micromanaging our services, dictating the minutiae of the service settings they will and will not pay for. For instance, every residential service recipient must have a key to his/her room, must have 24-hour access to food, must be permitted to have visitors—including overnight visitors—at any time, must control his/her personal resources. My son is incapable of managing a house key, let alone his money. For the many thousands like my son, these criteria are nonsense. Although providers may file modifications to these requirements for individuals for whom they are not appropriate, that exercise will entail a huge expenditure of time and resources with no benefit to the individuals involved.

CMS's intent seems admirable: to give people choices in how they want to live and to keep them out of isolating institutional settings. However, CMS seems not to understand the nature of intellectual disabilities—that there is a tremendous range of competencies from the mildest of impairments to the most severe. Many people lack the capacity to make such decisions. Moreover, CMS seems to have misunderstood the Olmstead decision on which most of this micromanagement is based. CMS seems to believe that Olmstead mandates everyone to be served in the least restrictive community-based setting. But the actual decision states that community-based services must be provided ONLY IF such services are appropriate and ONLY IF the individual does not oppose that type of service. The CMS-dictated settings eliminate sheltered workshops, clusters of small residential units, and intermediate care facilities even for medically fragile people who would otherwise be forced into nursing homes. These are the settings of choice for many individuals, but will no longer be funded by CMS. It seems choice is fine with CMS as long as it matches the CMS party line.

I urge you, as state or federal legislators, to oppose CMS's micromanagement of service design.

Thank you, Senator Perkins, Assembly Member Rodriguez, and Assembly Member Wright for sponsoring this hearing