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**Need for 24-hour Residential services:**

I was one of the lucky ones. My son Mark, now 35 years old, was able to obtain 24-hour residential services before the gates clanged shut. Mark is the warmest, sweetest guy you would ever want to meet. He has friends up and down Broadway. But he could not survive without 24-hour supports. He is not able to speak, his walking is unsteady, he needs his meat cut up, his shirts buttoned, he could not cross a street safely, or protect himself from danger.

No one disputes the tremendous need for 24-hour residential services for people like Mark. But over the past 10 years or so, residential development has been negligible for people living at home with their families. OPWDD has developed residences for people leaving the developmental centers and for people aging out of residential schools. But individuals still living at home get practically nothing—despite having saved the state years' worth of residential costs.

Theoretically, individuals at home can get 24-hour residential services, but only if they are in urgent situations. There is no room for crisis prevention for families who don't complain but can barely hang on. Families who are offered a vacancy in an existing residence feel they must take even a bad placement because the opportunity may never come again.

This has to change. 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 with their families. And second, OPWDD needs to remove barriers to residential development—increase scandalously outdated rental AND PURCHASE thresholds.

**Managed Care:**

Families' greatest fear about managed care has always been that if managed care organizations do not receive sufficient funding, people will be denied needed services.

To make matters worse, we now hear that managed care will not be managed by DISCOs—developmental disabilities agencies experienced in providing services to people with developmental disabilities. Instead, DISCOs will be subordinate to

managed care insurance companies that will conduct the assessments of our children's needs and make the determinations about which services and what levels of service to authorize.

This is a terrifying prospect: that insurance companies, probably for-profit companies, with no understanding of people with developmental disabilities and their service needs, would control the allocation of resources. In their ignorance, insurance companies would base their decisions on what they do know: medical necessity and medical cures, rather than habilitative and long-term service needs. Developmental disabilities cannot be cured; people with developmental disabilities may improve their skills but they will always need supportive services. My son will always require 24-hour residential services: even if he does learn to put on his shirt by himself, he will always need someone to keep him safe in the shower, to prepare his meals, to give him his medications.

Already, fiscal resources for our population are inadequate. In a managed care world, if overall funding is not sufficient, and in the interests of their bottom line, the insurance companies will limit or deny services, especially for those with complex needs; moreover, they will impose cuts that will erode the quality of services and suppress the indecently low salaries of direct support professionals.

Some professionals in the field contend that we already have managed care: OPWDD manages care through its Front Door, where each individual receives a determination of eligibility, assessment of service needs, authorization of services, and allocation of resources. So what possible advantage is there in tearing all this up and installing profit-driven insurance companies whose understanding is limited to medical models that are incompatible with the needs of people with developmental disabilities? All this at a tremendous cost that, despite OPWDD's protestations to the contrary, will unavoidably come out of services, depleting our already inadequate funding pool.

Instead, what OPWDD should do is to bolster its Front Door staffing and streamline the process so that the individuals can receive needed services in a timely fashion. This of course takes additional funds, but far less than would be required for an external managed care infrastructure.

We hope the Assembly will firmly oppose this new plan.

### **Salaries of Direct Support Staff**

My son Mark loves his staff. His staff keep him safe and healthy. They teach him new skills. They advocate for him. They comfort and reassure him. When my husband and I are no longer around, they will be the most important people in his life. These staff are highly trained and bear tremendous responsibilities.

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

Direct support staff must be given a significant salary increase—whether or not the state increases its minimum wage. Our services providers are non-profits, and services are funded by government. So any wage increases must be funded by the state because the non-profit providers have no other source of revenue (unlike McDonald's, which can raise its prices or cut profits).

We must never forget that direct support is not a minimum wage job. Direct support salaries are currently higher than the minimum wage, and that pay differential between minimum wage and wages for direct support staff must be maintained. Moreover, the pay differentials between wages for direct support staff and supervisors and middle management must also be maintained.

Thank you for the opportunity to testify.