**Testimony submitted to Transformation Panel-September 30, 2015**

I am the sibling of an individual who has a developmental disability and other challenges. I am only a few years older than my brother but have always looked out for him, cared for him and advocated on his behalf. I am the constant he has had in his life from birth.

Over the years, I have participated in support and advocacy groups and I have often been disappointed that more siblings do not choose to do the same. These days I find myself part of a passionate, knowledgeable, feisty and loving group of parents fighting to secure the best possible future for their children.

I am surprised that though I am not a parent myself, I feel the same anxiety as I think about my brother’s future and the decisions of OPWDD that put that future at risk. Like so many parents, I fear that I will die before my brother and he will have no one to speak up for him. He and our family are blessed that he lives in a residence administered by a respected and caring organization that values him and wants him to experience the full richness of life. In turning over his welfare to this organization it was our wish that it would become the constant in his life; not that we were intending not to be in his life, but the organization would be able to take advantage of so much more than we could and would certainly outlive us all and be the anchor on which he could always depend.

But for organizations funded by OPWDD, the hard won gains that have enriched my brother’s life for so many years are now in jeopardy. He can no longer expect that the direct service professionals whose care for him ensures his safety, health and happiness, will be there when he needs them because they cannot care for themselves and their families on the salaries they receive. There is a lot of talk about increasing the minimum wage but shouldn’t the focus be on a living wage that allows everyone to meet life’s most minimum needs? The Justice Center’s well intentioned purpose to protect the vulnerable has the unintended consequence of demoralizing and damaging the reputation of good staff who responsibly perform their job duties. So many are looking to leave the field rather than see it as a path to a long and meaningful career.

The organization that serves my brother is funded at a rate that does not adequately and consistently keep pace with the rising cost of living and additionally, there have been cuts in their rate. Essentially, the cost of care is not fully covered by OPWDD.

What this all means for my brother is that the *constants* that he needs are at risk of disappearing. There is high staff turnover at his residence and day program, and it is challenging for the organization to attract the best and brightest to a field that is more punitive than rewarding. The long-term sustainability of the organization itself is also at risk as it struggles to stay responsive to the needs of the people it serves in a world of inadequate funding, unfunded mandates, and unreliable cash flow. The impact of this is that service quality is negatively affected.

The future we are charting now is one that will be inherited by children and families currently served by the Department of Education. Many of these families are so consumed with their present day challenges that they are unaware of the proposed transition of auspices from OPWDD to DOH, the freeze in residential development, the closure of sheltered workshops, the lack of services for an aging population of people with intellectual/developmental disabilities – all important to anyone in need of adult services. I am left to wonder, what is OPWDD’s responsibility (perhaps working with the DOE) to educate, enlighten and guide these families as their children age?

My brother and others like him should not be a casualty of decisions and policies made to support and protect him.

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