



**Oral Testimony of Joseph M. Macbeth
Before the Administration on Developmental Disabilities
Philadelphia, PA
October 18, 2010**

Commissioner Lewis and staff of the Administration on Developmental Disabilities, thank you for this opportunity to participate in your "Envisioning the Future" Summit Series. I am Joseph Macbeth, Assistant Executive Director of the New York State Association of Community and Residential Agencies (NYSACRA). NYSACRA is an association of 200 non-profit agencies that support nearly 60,000 New Yorkers with developmental disabilities. We serve as a catalyst and leading advocate for people who have developmental disabilities and organizations that support them. I am also a member of the board of directors for the National Alliance for Direct Support Professionals (NADSP).

In the interest of time, I will not repeat the written testimony that I've given you. Rather, I want to tell a story to put flesh and blood on the bare bone facts and statistics presented in my written testimony.

This summer I was facilitating a forum in Upstate New York where direct support professionals were discussing the community support skill standards - a set of universal competency areas that are promoted by the NADSP - one of the standards is Building and Maintaining Friendships and Relationships.

A young Direct Support Professional spoke about an elderly gentleman that he supports who had lived in institutions for most of his life before moving to the community. Over the years in the institution, the gentleman's parents had died and he lost all contact with his family. He knew he had one brother who lived somewhere in New York City.

Using the internet, the Direct Support Professional assisted this gentleman in locating his brother. They first made telephone contact, and spoke on the phone, becoming reacquainted. As spring approached, the Direct Support Professional made arrangements to accompany the gentleman to New York City to meet his brother. They met on Easter Sunday at the brother's home in Brooklyn. During the visit, the brother told him all about his family history and gave him photographs from their childhood. He also introduced the gentleman to his nephew. At the visit's end, the brother confided to the Direct Support Professional how grateful he was to finally re-establish contact with his long lost sibling at this stage of his life - especially since he had recently been diagnosed with cancer.

The brother recently passed away. But thanks to this direct support professional, a man who lost contact with his family many years ago met his dying brother, has pictures of his family proudly displayed in his home, a sense of his roots, and a bond with his nephew...his brother's son.

Direct Support Professionals make these things happen everyday. They are advocates, bridges to relationships, mentors, educators and role models. Sometimes, they are just plain old friends offering a hand in someone's life.

Today, this vital workforce is in crisis - a crisis that was forecasted decades ago, yet we've done very little to address it. To a large extent, if we are to meet the promises that we've made to people with developmental disabilities, we need to retain and recruit people like the young man that I just described.

Here is how I propose we do that:

- We ask the Administration on Developmental Disabilities (ADD) to ensure that the University Centers for Excellence in Developmental Disabilities (UCEDDs) engage in activities of professional development, growth and celebration of the direct support workforce and truly embrace training that is competency-based and tied to career ladders.
- We ask the Administration on Developmental Disabilities to fund a project of national significance that provides answers to some very basic questions like: how many direct support professionals are there in the United States? How much are they paid? What benefits are available to them, and do they even use these benefits, or do they forego benefits because they cannot afford their contribution?
- We must also ensure that the independent thinking and judgment demanded of all direct support professionals is guided by a Code of Ethics.
- Lastly, we ask the Administration on Developmental Disabilities to ensure that Title III of the DD Act of 2000 remains in reauthorization and that this Title finally be funded.

Direct support professionals largely remain invisible in state and federal policy. It's my opinion that this has become an issue of social justice, for the people requiring supports and for those providing them, a vast majority of whom are women and a majority of them are women of color.

In looking toward the future, I would urge the Administration on Developmental Disabilities to partner with NADSP in taking these nascent initiatives to their next level. Again, thank you for this opportunity to share my thoughts.
