



NEW YORK STATE ASSOCIATION OF COMMUNITY & RESIDENTIAL AGENCIES

**Testimony of Joseph Macbeth
Before the Administration on Developmental Disabilities'
"Envisioning the Future" Summit
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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.

As I envision the future, I am reminded that just a mere 40 years ago, most individuals with developmental disabilities who couldn't live independently or with their families were confined to public institutions. Litigation, new funding streams, and a growing chorus of voices from parents, professionals, and self advocates demanding change transformed that system of care. Yet, I doubt that the leaders of that transformation clearly envisioned, back then, where we would be today, any better than we can precisely envision where we will be in the next several decades.

But we can see in the transformation a trajectory which will undoubtedly continue. While we've moved from institutions to agency-operated group homes, individuals with developmental disabilities want to live in their own homes, and increasingly have that option. While we've moved from segregated, isolated campuses to communities - individuals with developmental disabilities want to be part *of* the community, as fully participating and responsible neighbors, not simply *in* the community, and increasingly they are achieving that dream. While we've moved away from medical models of care to a variety of options with a different relationship with their staff, people with disabilities want to self-direct their supports and hire their own direct support staff, and increasingly they are enjoying that opportunity. That trajectory of fully exercising their rights will continue, consistent with the goals that our nation has set for people with developmental disabilities: social justice, self-determination, empowerment, family support, health and wellness and employment in real jobs for real wages. And that is good.

However, we cannot realize the promises we've made to people with developmental disabilities without investing in the direct support staff (the titles vary) who know them best. Direct support professionals make it happen for people with disabilities and their families. When people with developmental disabilities get a job, it is direct support professionals who help them get and keep the job; find their own home and live in it, and when they go to vote

Today, approximately 1.2 million persons with developmental disabilities receive services from direct support professionals. However, several issues are converging which demand that we tend to this workforce if we are to assist people with developmental disabilities to continue to grow in their communities and grow in the exercise of their rights.

Currently, it is difficult to recruit and retain direct support professionals because of inadequate salaries and benefits. In fact, wages for direct support professionals have actually declined over the past ten years when adjusted for inflation. Access to benefits of any kind have been reduced or eliminated in virtually every state in the country. Vacancy rates average 10 to 11 percent nationally and turnover rates are above 40 percent. It is estimated that the demand for direct support professionals by people with developmental disabilities will grow by 40% by 2020.

Of course, this situation will only worsen as baby boomers age. These people who do not have developmental disabilities will require direct support services due to aging and health reasons at the very same time that the pool of available workers shrinks.

Finally, with the abandonment of institutions, the nature of direct support work has changed dramatically, requiring increased competency in a variety of skill-sets, independent thinking, and keen judgment., direct support professionals today assist people in navigating complex community-based social service systems; they monitor individuals' health status, promote healthy life-styles, and serve as individuals' medical advocates; they support individuals in their educational, vocational, and social endeavors; and they empower individuals to lead lives of opportunity, well-being, and contribution in their communities. The nature of direct support will continue to evolve as more and more people with developmental disabilities who require our support pursue their dreams.

The future, as I envision it, will require a direct support workforce that is valued, present and stable, competent and committed. It will require action, and we need to begin now.

We must truly recognize direct support as a profession to which people will aspire as a career. We must provide direct support professionals with salaries and benefits commensurate with the critical role they play in our society. We must also develop career paths within the profession so that support staff will not be forced to seek other jobs. Given the complexity of direct support work, and the unique needs of individuals requiring support, we need to offer direct support professionals training and education programs that are competency-based and wedded to the principles self-determination and person-centered planning, and tie them to

career advancement opportunities. We must also ensure that the independent thinking and judgment demanded of direct support professionals is guided by a Code of Ethics.

The National Alliance for Direct Support Professionals (NADSP) has taken a lead in advancing the work that must be done to nurture a professional direct support workforce. University Centers for Excellence in Developmental Disabilities have also played a role in providing training. In looking toward the future, I would urge the Administration on Developmental Disabilities to partner with NADSP and UCEDDs in taking these nascent initiatives to their next level.

I would also urge you to revisit Title III of the DD Act of 2000, which describes efforts to grow a direct support workforce, and update its language and expectations to promote the *profession* of direct support.

Again, thank you for this opportunity to share my thoughts.