

# Bridges to Community: The Challenges and Necessity of Building a Quality Direct Support Workforce

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*"One of the challenges facing the US in the 21st century will be to ensure that individuals of all ages receive, throughout their lives, the health and social support services they need to live with dignity as fully included members of our society. For the estimated 4.3 million Americans of all ages with intellectual disabilities and/or developmental disabilities (ID/DD) living in residential settings, their own homes, or with members of their families, ensuring access to and quality of direct support professionals (DSPs) is key to realizing national goals established in the Americans with Disabilities Act, the Developmental Disabilities Assistance and Bill of Rights Act, and other statements of national purpose with regard to the full citizenship and inclusion of individuals with ID/DD."<sup>1</sup>*

**T**he quality of direct support provided to people with intellectual and other developmental disabilities (I/DD) lies at the heart of their satisfaction with the services paid for by the state of North Carolina. Moreover, North Carolina's commitment to its frontline human services workforce in the field of intellectual and developmental disabilities—as well as in mental health, addictive diseases, and aging—is essential to the state's efforts to build a person- and family-centered community system that is cost-effective and achieves outcomes associated with quality of life, such as good health, community integration, and participation in activities of one's choice.<sup>2</sup> Individuals with I/DD and their families know that the quality of the direct support workforce can be the difference between a satisfying life or a life fraught with emotional distress or even harm. To begin to grasp this statement if you are among those who are "temporarily able-bodied," imagine depending each day, wholly or partially, on one or more individuals who are paid to assist you in participating fully in those ordinary activities that we call living. Imagine, if you will, being left in the tub while the water

turns cold, unable to warm it up; trying to reach a wallet that's been placed in the wrong pocket—or isn't there at all; or having someone change the channel on your TV in the middle of an Atlantic Coast Conference basketball game and ignoring your exasperated protest. Imagine further that when the service provider who employs the worker finally sends someone who gets your hair just right; who has the professional demeanor appropriate to accompany you to your workplace; and who employs the skills to transfer you safely from your power chair to bed, the worker leaves because she's allergic to the cat she didn't know you had, or because she was not told in advance that she had to do that, or because she's found a better paying job. This is the dilemma of all too many people with I/DD and their families—especially in a budgetary crisis, when services are already limited or nonexistent. At a systems level, these challenges are the tip of an iceberg that could undermine the ability of the state to deliver on its renewed promise of high-quality I/DD services and supports.

North Carolina is facing a workforce crisis that compromises all human services. The aging of a large part of the population—the "baby boomers"—means that there are more people who need human services of all types and less people to provide them. Human services, already hard hit by a budget crisis expected to last several more years, must compete with other sectors of the economy for a shrinking pool of available workers. In this climate, people with I/DD are more significantly impacted than

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other groups. They require more support of more varied types, with more activities of daily living, over a longer period of time than others with disabilities.<sup>2</sup> Many of these services are provided by frontline workers known as direct support professionals (DSPs). DSPs work in diverse settings, including people's homes, group homes, sheltered workshops, supported employment programs, day activity centers, public developmental centers, nursing homes, and, increasingly, just about anywhere out in the community that we all go. DSPs work with people across the lifespan, from birth to old age, in different sectors of the human service delivery system, sometimes with several people in the same week. DSPs often know the individual better than other paid staff and are responsible for activities such as ensuring that support plans and interventions are correctly and competently carried out and the intended outcomes are achieved. A crisis in this sector of the workforce is one that people with I/DD and their families experience personally, daily, and profoundly.

"Direct support professional" is a relatively new occupational title. It unifies for the first time a workforce that has previously gone by many names (e.g., direct support workers, direct care workers, personal care assistants, home health aides, and nursing aides).<sup>3</sup> It is a workforce for which demand is growing exponentially in North Carolina and across the nation. From 2004 to 2014, the North Carolina Employment Security Commission projects that DSP occupations will be among the top 10 fastest growing occupations in the state. Jobs for home health aides are expected to increase by 48.3% over this period; nursing aides, orderlies, and attendants by 27.8%; and personal and home care aides by 49.5%. Over the next decade, these occupational titles alone are expected to create a total of almost 40,000 job openings.<sup>3</sup> Changing demographics, however, are already pressuring the state to meet workforce demands. The number of baby boomers over age 65, including people with I/DD, is rapidly outpacing the much smaller cohort of workers available to support them, and the turnover among existing DSPs is high.<sup>b</sup> Waiting lists for I/DD services are growing, with estimates of an increased demand for services at 37%. At current turnover rates, data indicate that by 2020 approximately 18,780 new DSPs will

be required to support those receiving services.<sup>4</sup> Attracting and—just as importantly—retaining an adequate supply of workers to this newly-named profession will require large-scale marketing initiatives and clear, coordinated, and cohesive policy change.

Such policy change flows in large part from the emerging role of direct support professionals in North Carolina's emerging community-based, regionally-managed mental health, developmental disabilities, and addictive diseases system. The state is undergoing a transformation from an institutional care model to a community-based human services model. The new model places primacy on person- and family-centered services and support, provided in one's own home and community. The shift in orientation from centralized, congregate care towards personalized services and supports calls for new, more robust roles for DSPs, in addition to their role in medication support and health and wellness activities. DSPs are "bridge builders" who facilitate connections to the people, resources, and experiences necessary for those with I/DD to live full and safe lives. One of the implications of this role change is reflected in the addition of the word "professional" to an occupation historically viewed as paraprofessional. Direct support staff once worked almost exclusively in congregate settings where their performance could be readily observed by supervisors and managers. Increasingly, however, people with I/DD grow up, go to school, live, learn, work, play, and retire in communities and move through the same settings as do people not affected by disability. This means that DSPs working in the community may not have daily, face-to-face contact with supervisors. The increased responsibilities and exercise of independent judgment associated with the delivery of services and supports in the community settings that all citizens share make it essential that DSPs indeed be professionals. Like any professional, they must demonstrate the competencies and the knowledge, skills, and attitudes required to be effective.

The North Carolina Council on Developmental Disabilities,<sup>c</sup> the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS), and the North Carolina Providers Council are collaboratively advancing a welcome change with regard to the training

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- a. "Direct support professional" is the term adopted by the professional association, the National Alliance of Direct Support Professionals, for this sector of community human services (see <http://www.nadsp.org> for more information). While its origins are in the field of I/DD, the term is increasingly being used in other service sectors.
  - b. A review of 13 state and two national studies between 2000 and 2007 suggests that, dependent upon setting, job turnover rates in the field of intellectual/developmental disabilities range from 42% to 69%. (Hewitt A, Larson S, Edelstein S, et al. *A Synthesis of Direct Service Workforce Demographics and Challenges Across Intellectual/Developmental Disabilities, Aging, Physical Disabilities, and Behavioral Health*. Washington, DC: National Direct Service Workforce Resource Center; 2008.)
  - c. The North Carolina Council on Developmental Disabilities (NCCDD) is an independent agency established under the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). It is mandated to conduct systems change, advocacy, and capacity building on behalf of all North Carolinians with intellectual and other developmental disabilities. The NCCDD is comprised of people with I/DD, family members, policymakers, legislators, and other representatives of the state's service delivery system, including the state's Protection and Advocacy System (Disability Rights NC) and its University Center on Excellence in Developmental Disabilities (Center for Development and Learning, UNC Chapel Hill). See <http://www.nccdd.org> for more information.

of DSPs.<sup>d</sup> We are re-examining traditional, hours-based training on rules and regulations in favor of curricula built around clearly articulated standards, values, competencies, and skills. Such training could someday lead to a portable, nationally-recognized certificate or credentialing system for North Carolina's DSPs. While such developments are perhaps long overdue, it has only been in the last 100 years that nursing and social work could be deemed professions, as evidenced by the adoption of the first standardized curriculum for the former in 1917 and for the latter in 1939.<sup>5</sup>

Enhancing the competence, stability, and job satisfaction of DSPs will go a long way towards addressing the challenges identified by the North Carolina Council on Developmental Disabilities in its *Direct Support Professional Work Group Report*<sup>4</sup> (2007), developed in collaboration with the DMHDDSAS, for the North Carolina Commission on Mental Health, Developmental Disabilities, and Substance Abuse. These challenges are:

- Retaining existing direct support professionals.
- Meeting a significant increase in the demand for direct support professionals in the face of employee shortages.
- Addressing a high turnover rate that compromises services and supports for consumers, adds to provider costs, and increases the demand for replacement workers.
- Addressing direct support professionals' low wages and extremely limited access to health care insurance and other benefits.<sup>e</sup>
- Meeting the need for comprehensive training of direct support professionals to ensure knowledge, skills, and competence in provision of services to people with disabilities and their families.

Recommendations of the *Direct Support Professional Work Group Report*<sup>4</sup> include the following activities:

1. Create a permanent structure and state-wide advisory capacity.
2. Create a certificate or credentialing program for DSPs.
3. Increase the wages of DSPs.
4. Create a marketing and public awareness campaign.
5. Provide systematic training, technical assistance, and incentives to all community providers in North Carolina on effective recruitment retention and training practices.
6. Provide system-wide training to supervisors and managers on effective supervision.
7. Provide opportunities to empower DSPs.
8. Create new service options for consumer-directed services for individuals with disabilities and, as appropriate, their families.
9. Provide access to affordable health insurance benefits for DSPs.
10. Create recruitment/selection tools to assist providers in reducing early turnover.

Along with thousands of others across the nation, we are witnessing the birth of a new profession, one that has more potential for offering its practitioners a living wage and a viable career path. Just as importantly, North Carolina's next generation of direct support professionals will enhance the opportunities for people with I/DD to realize their dreams and enjoy the daily liberties and human rights that others take for granted. **NCMJ**

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d. The North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services is undertaking a review of current policy and practice with regards to staff competencies. The North Carolina Council on Developmental Disabilities has funded a grant to the North Carolina Council of Community Support Providers to demonstrate the College of Direct Supports (CDS). The CDS is an interactive, online, competency- and values-based curriculum for direct support professionals. The CDS is now being used in 23 states and by more than 300 agencies. Approximately 40,000 learners across the United States are enrolled in the curriculum. See <http://info.collegeofdirectsupport.com> for more information.

e. Direct support workers working in the private sector for persons with I/DD are paid near poverty level wages, averaging, according to one study, from \$7.30/hour to \$15.18/hour with a mean of \$8.68/hour. Many do not have health insurance or depend on Medicaid. (Larson SA, Hewitt AS, Knobloch B. Recruitment, retention and training challenges in community human services. In Larson SA, Hewitt AS, eds. *Staff Recruitment, Retention and Training Strategies for Community Human Services Organization*. Baltimore, MD: Paul H. Brookes Publishing; 2005:1-20.)

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