

Opportunities and Challenges In Establishing a Direct Support Worker Association In New Mexico

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■ Introduction

The purpose of this briefing paper is to present relevant information about opportunities and challenges associated with implementing a Direct Support Worker (DSW) associations in New Mexico. The information was gathered from a variety of sources, including a review of relevant literature and interviews with key players in numerous states who have been involved with DSW associations.¹

In gathering this information, we looked for answers to five specific questions.

- What roles do these associations play - that is, is there a "typical" role or focus for them? What types of roles or functions seem to work best?
- What was the process used to establish these organizations and based on experience, what are seen as the critical steps to ensure success, as well as steps to avoid?
- How long did the process take from start-up to a "steady-state" organization?
- What types of supports are needed to ensure the sustainability of these organizations?
- What are major obstacles encountered in establishing successful organizations, and what are some strategies to mitigate against them?

The demand for direct care workers to provide home- and community-based services is growing fast. Not only are privately paying consumers increasingly seeking out such services, but the U.S. Supreme Court's *Olmstead* decision and President Bush's *New Freedom Initiative* have mobilized states to provide more long-term care in homes or other community-based settings.² The U.S. Department of Labor expects personal and home health aide jobs to grow from 414,000 in 2000 to 672,000 in 2010.³

¹ See References at the end of the briefing paper for sources used contacted or used in the preparation of the paper. We would like to thank a number of people for providing information on which this paper is based. First, thanks to Kate King of Centers for Medicaid and Medicare Services (CMS) who encouraged us to pursue this endeavor accessing CMS resources. One of these resources is Carrie Blakeway of The Lewin Group who shared multiple documents and contact information for DSW associations across the nation. Many of these documents are available through the National Clearinghouse on the Direct Care Workforce, a project of Paraprofessional Healthcare Institute (PHI) funded by CMS. We also wish to recognize those who took the time to share their experiences with us. These individuals include: Genevieve Gipson, RN, M.Ed., RNC, Director, National Network of Career Nursing Assistants; Roy Gedat, Executive Director, Maine PASA; Terry Carleton-Bucher, Executive Director and Founder, Florida Association Nurse Assistants.

² *Direct care worker associations: Empowering workers to improve the quality of home- and community-based care*. Workforce Tools. Number 3. (Spring 2004). Page 1. Paraprofessional Healthcare Institute. Bronx, NY.

³ U.S. Bureau of Labor Statistics, Economic and Employment Projections, Table 3b: *Fastest growing occupations, 2000-2010*. Found online at www.bls.gov/news.release/ecopro.t06.htm.

States and long-term care consumers, workers and employers are seeking ways to address the growing demand for a high quality and stable long-term care workforce. Difficulty in finding workers, low wages, a lack of benefits and training opportunities for many workers are among the barriers to achieving this goal. DSW associations are one vehicle some states have used to address these issues.⁴

DSW associations are one of a number of initiatives developed and implemented nationally to ensure adequate supply of qualified workers. The premise is to involve workers more directly in advocating for themselves and their work through the formation of professional associations. Direct support worker associations can give individual workers a means of gaining additional skills, accessing support and recognition, and networking with peers. In addition, they can raise awareness of the value of caregiving work and help workers develop the leadership skills they need to become actively involved in discussions about long-term care policy and workplace practices.⁵

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There are three broad models for organizing direct support workers: 1) worker-based associations, 2) employer-sponsored associations, and 3) public authorities. The models vary as to the breadth of settings and workers represented.⁶

■ Findings

Functions of DSW Associations

Four main functions were identified for DSW associations. It should be noted that these functions are above-and beyond those involved in establishing the DSW association in the first place - that is, they require an additional knowledge base and infrastructure that is different from (even though it may be a part of) the DSW association.

Peer Support, Identity and Advancing the Profession

A number of the associations reviewed have as one of their functions advancing the professional and personal growth of DSWs and promoting the identify of DSW as a distinct profession within the systems of care in their states. Some of the activities associated with

⁴ Gillespie, J. *Direct care worker associations and public authorities*. Community Living Exchange Collaborative: A National Technical Assistance Program. National Academy for State Health Policy. New Brunswick, NJ.

⁵ *Direct care worker associations: Empowering workers to improve the quality of home- and community-based care*. Workforce Tools. Number 3. (Spring 2004). Page 1. Paraprofessional Health-care Institute. Bronx, NY.

⁶ Gillespie, J. *Direct care worker associations and public authorities*. Community Living Exchange Collaborative: A National Technical Assistance Program. National Academy for State Health Policy. New Brunswick, NJ.

this function focus on improving communication among DSWs and sharing information through a variety of means including newsletters, websites, listservs and holding statewide or regional meetings. A second includes reinforcing the DSW identity and recognition, and includes include holding annual state or regional meetings, instituting awards for years of service or designing and distributing business cards or lapel pins. Finally, two associations (the National Association of Direct Support Professionals and the Iowa Care Givers Association have developed a credentialing program for DSW.

Education and Training

A third function that DSW associations attempt to provide is education and training of DSW through a variety of means. These include continuing education that supplements training offered or mandated by state governments or peer mentoring programs, as well as providing scholarships for DSWs to attend classes. I

Job Placement

Two organizations focus on assisting DSWs find jobs. Maine is piloting a web-based recruiting and matching program, while the Arizona Direct Caregiver Association maintains a job placement program.

Advocacy and Public Policy

Several associations have identified advocacy and influencing public policy as a function. This includes advocating for DSW in the areas of compensation, benefits, opportunities for advancement and working conditions; identifying and addressing barriers to recruitment and retention; tracking legislation; serves on public task forces and committees in relevant topical areas; drafting briefing papers or position statements for legislators and public officials; and grassroots organizing around wages and healthcare.

Establishing and Sustaining A DSW Association

The relative ease or difficulty of establishing and sustaining a DSW association over time depends on a number of factors, including the level of interest, awareness and organization among DSW before the organization is formed; geographic and personal factors (difficulties in securing time and funds to travel to meet across long distances), resources available and others. The length of time necessary to plan for and initiate a DSW organization also varies considerably based on these factors, but lasts from one to two years if pre-planning efforts are included in the timeline. Four additional factors were identified as being essential to successfully forming and sustaining a DSW association.

The time necessary to establish an association is most likely one to two years if pre-planning efforts are included in the timeline.

Getting Stakeholder Buy-In

There are a number of different stakeholders in the area of DSW, including of course DSW themselves but also including the agencies that employ them, state agencies that provide policy direction and funding for services delivered by DSWs, advocacy organizations and clients of DSWs. One frequent mistake is to ignore stakeholders other than DSW. For example, not involving and seeking the support of employers may result in an adversarial

relationship with them, who may believe that the association is a “back-door” step to a union. Ignoring state agencies that oversee the work of DSWs. Likewise, not including clients and advocacy organizations runs the risk of ignoring a potentially powerful source of support for the association.

Clearly Defining Mission, Goals and Objectives

Most DSW associations do not take on all the functions identified earlier in this briefing paper. Particularly at the beginning, they focus on a limited number of goals and objectives in order to increase their chances of initial success and growing over time. Moreover, not only must the initial mission be clear, it must also be the mission that will most likely attract DSW as members and contributors of time and perhaps dues. Establishing preferred goals and objectives of DSW before an association is launched is a critical factor of later success.

Funding

Existing DSW associations use a variety of funding methods, including support from state agencies, employer agencies, charges for events such as conferences or meetings, grants from private foundations and dues⁷. Depending on the level of support from DSW and the activities an association chooses undertake, dues alone can support an association.⁸ However, it is unlikely that dues will be able to sustain an association in the early stages. DSW have limited resources and must make careful choices about where these resources are directed. Without an active, well-established organization that offers clear and obvious benefits, DSW are unlikely to pay dues to such an association in the early stages.

Stable sources of funding for a pre-defined start-up period must be identified before the association is launched.

Further, given the length of time required to form an association, stable sources of funding must be identified before the association is launched for an initial start-up period. Many associations that relied on a single funding source in the start-up phase later seek funding from multiple sources.

Funding is particularly crucial to support activities that many DSWs cannot afford using their own funds, such as traveling to meetings or conferences. In some cases, employers have been asked to support the travel expenses of their employees. In other cases, funding from foundations has been used to support this function,

⁷ However, many dues-collecting organizations cannot apply for public grants.

⁸ The National Alliance for Direct Support Professionals (NADSP), has a membership fee of \$25 while professional membership is \$40. These memberships include one subscription to Frontline Initiative newsletter, a Code of Ethics pocket card and a NADSP membership card. In addition, NADSP offers the following membership categories: Agency/Provider Affiliate Membership - \$200; Supporting Organization Membership - \$500. Maine’s association has *primary members* who are direct-care, direct-support, and personal assistance workers and support *members* who are individuals not employed in paraprofessional jobs, but support the association’s mission.

Organization and Staffing

While identifying and engaging key stakeholders is critical for success, it is also necessary to ensure that DSW are centrally involved in forming the organization and decision-making through a board of directors, governing council or other structure. The association in Maine operates with one dedicated staff person, an active Board of Directors, and nearly 700 active members. Other organizations are operated by volunteer directors and part-time office staff. Some DSW associations use a chapter structure, with new chapters being nurtured by the central organization.

However, by the nature of their work, DSWs have little time to devote to the day-to-day tasks of running an association, including producing and mailing newsletters, producing web sites, maintaining membership lists. While a part-time director funded by outside sources can provide some of these services, even this may not be enough. Some DSW associations partner with another organization from a university or state agency to provide the infrastructure necessary to become and remain a viable organization. This is particularly true in the early stages of an association, when it has no or few identified sources of support, is unproven, and must engage in significant outreach efforts to build public awareness and the membership base.

■ Recommendations

DSW associations are performing valuable roles in multiple states. However, the care and planning that is required to start such an association should not be underestimated. There is much that is not known about a potential DSW association in New Mexico. Given what is known from other states, our primary recommendation is that the process of seeking to establish an association here be divided into phases.

Feasibility Study

The first phase would explore the feasibility of establishing the association. This would include

- Using surveys, focus groups and interviews, determine the preferred set of functions, level of support and potential for contributing to the leadership of the proposed association among DSWs in all parts of the state;
- Using surveys, focus groups and interviews, determine the views of key stakeholder groups discussed earlier in the briefing paper on potential roles for the association, potential level of support, and potential for contribution of resources or services for such an association
- Based on the responses to the needs assessment, recommend whether to proceed or not to proceed with the proposed association.

Implementation and Business Plan

If the recommendation made at the end of the feasibility study is to proceed, an implementation and business plan should be prepared. Drawing on the contributions of interested DSWs, the plan should include

- A proposed organizational structure, including both policy and governance issues as well as staff support and infrastructure issues;
- A proposed set of activities for the first two years of the association, including goals and objectives, tasks and activities to accomplish those objectives and milestones;
- A proposed budget and funding sources for the first two years of the association.

■ Additional Information Sources

Direct Care Worker Associations: Empowering Workers to Improve the Quality of Home- and Community-Based Care.....

http://www.directcareclearinghouse.org/download/WorkforceTools_No3final2.27.04.pdf

Direct Care Worker Associations and Public Authorities...

http://www.hcbs.org/moreInfo.php/nb/doc/176/Direct_Care_Worker_Associations_and_Public_Authori

Supporting Providing Employee's Association of Kentucky (SPEAK)...

<http://www.councilonmr.org/partners.htm>

Direct-Care Workers Speaking Out On Their Own Behalf....

<http://www.bjbc.org/content/docs/BJBCIssueBriefNo2.pdf>

Direct Support Worker Associations....

http://www.directcareclearinghouse.org/i_workerassoclist.jsp

■ References

(2004). Empowering workers to improve the quality of home and community-based care. *Workforce Tools*, (3), 1-8.

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NADSP unveils the first-ever National credentialing program for Direct Support Staff (2006).
<http://www.nadsp.org>

Phone interview with Terry Carleton-Bucher, Executive Director and Founder of Florida Association of Nurse Assistants

Supporting Providing Employee's Association of Kentucky (SPEAK),
<http://www.councilonmr.org/partners.htm>

Written communication with Genevieve Gipson RN MEd RNC Director
National Network of Career Nursing Assistants

Written communication with Roy Gedat, Executive Director Maine PASA