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DELAWARE

A collaborative effort of the Center for Disabilities Studies & the Delaware Developmental Disabilities Council

ABOUT THIS ISSUE

Direct support professionals (DSPs) help people with disabilities connect to their communities, providing an incredible range of supports with employment, recreation, and other aspects of day-to-day life. Throughout the development of this issue of *delAware*, we talked with many people with disabilities, their families, and DSPs. We learned about job coaches, personal care attendants, companions, aides, and assistants. We heard from people like Jane who receives assistance from her aide with transportation to and from her doctor's appointments, Kent who goes to the movies and out to dinner every weekend with a personal attendant, and Charlie who receives support from an employment specialist as his job responsibilities increase due to a recent promotion. While the titles and specific responsibilities were often different, the value of personal supports was consistent. In this issue of *delAware*, the personal stories of a Delaware family and a long-term DSP illustrate the significance of positive direct support relationships for those individuals.

To the Coffins, of Seaford, the relationships with their sons' DSPs are invaluable. Dwayne and Wayne each live on his own, and Paul and Cheryl Coffin rely on their sons' DSPs to provide each son the supports he needs. The DSPs value the cooperation from the Coffins to best support Dwayne and Wayne.

Relationships are also important to Erica Dessausure, a direct support

professional for 14 years, who shares her experiences as a DSP and the many ways in which the job enriches her own life. Her story illustrates the intangible benefits of working in the direct support field, and the value she places on continuing education and leadership opportunities.

Strengthening the direct support workforce is necessary to address the increasing and overwhelming demand for DSPs. The Workforce Recruitment and Retention Project at the Center for Disabilities Studies has developed strategies to address the demand for DSPs in Delaware. The project provides training seminars, mentor programs, and advocacy to increase the value of the direct support profession and the job satisfaction of employees.

This past May, Delaware's Second Conference for Direct Support Professional was held. An article on page 3 covers this year's event. To date, more than 550 people have participated in this annual event. Based on the DSP turnout and the feedback the conference organizers have received, this conference is an important networking opportunity and an important step toward making this field an even stronger profession.

If you are an individual or family with a DSP, please share this newsletter with your DSP and other in your community. We hope to see you all at next year's conference.

Sincerely,

Tracy L. Mann, Editor

Direct Support Professionals: A Mainstay in the Disability Community



Unequivocally, direct support professionals (DSPs) are essential members of the disability community. They provide a range of assistance to people with disabilities, including those with physical, psychiatric, sensory, or cognitive disabilities; chronic illness; substance abuse; at-risk children and youth; and families who need assistance to care for loved ones. DSPs may have various job titles, such as residential counselor, employment specialist, family advocate, and personal support assistant. According to The College of Direct Support, a national online training organization, over two million Americans are estimated to be working in these roles.¹ The number of DSPs may be even higher, as their many different job titles obscure their actual number.

Along with the range of job titles and needs of people with disabilities in the community, the tasks and skills of DSPs vary. They may help individuals with activities of daily living, communication, transportation, recreation, or home management. A DSP, for instance, might help a person bathe and dress, shop for groceries and prepare meals, or manage medications and health care appointments. The individual's unique needs dictate the services provided and the skills required of a DSP.

Mutually Successful Relationships

Direct support professionals must be open-minded and flexible, able to adjust their approach based on an individual's requirements and requests. Agencies should help foster successful working relationships by carefully matching staff and people with disabilities. Furthermore, consumer choice is critical. A DSP must recognize what is important *to* a person, such as likes and dislikes, and what is important *for* a person, such as essential health care needs. Balancing these two considerations enables a DSP to provide appropriate assistance and necessary care without impinging on consumer rights.

A working relationship based on trust and respect also helps develop camaraderie. The profession does not simply demand specific skills and knowledge; ethical judgment and the ability to create long-term, mutually satisfying partnerships is also a key goal. DSPs must work to develop a strong, constructive relationship with people with disabilities and their family members, honoring requests and supporting life dreams.

People with disabilities play a part in building good relationships by learning how to communicate their needs and desires. A positive relationship between a

DSP and a person with a disability increases the contentment of the person with a disability and the career satisfaction of the DSPs. The sense of accomplishment derived from a successful working relationship becomes a shared experience for both participants.

A Professional Crisis

Clearly, the work of direct support professionals must be based on respect for the people whom they assist. Likewise, DSPs must be respected—by their agencies,

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people with disabilities, family members, the disability community, and the community at large. Currently, however, DSPs work in a field characterized by low wages, poor benefits, and inadequate training, which results in high employee turnover and low recruitment rates. Consequently, there is a critical shortage to fill the growing need for these employees. According to the U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy, unfilled demand for DSPs averages ten to eleven percent across the country.²

In the coming years, the need for DSPs will grow. The growth in the baby-boomer population and need for long-term care will escalate demands on the health care system. More DSPs will also be needed to fully realize the current trend toward integrated community living for all people with disabilities.

The Centers for Medicare & Medicaid Services is developing a clearinghouse of best practices in home and community living

(www.cms.hhs.gov/promisingpractices) to highlight state efforts that "enable persons of any age who have a disability or long-term illness to live in [an] integrated community setting appropriate to their individual support requirements and preferences, exercise meaningful choices, and obtain quality services."³ The disability community on national and state levels has taken constructive steps to attract qualified DSPs.

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delAware is sponsored by the Center for Disabilities Studies, University of Delaware and the Delaware Developmental Disabilities Council. If you would like to contact us, please call (302) 831-6974 or TDD at (302) 831-4689, fax (302) 831-4690, email to Tracy Mann, tmm@udel.edu, or write to *delAware*, University of Delaware, Center for Disabilities Studies, 461 Wyoming Road, Newark DE 19716. Editor: Tracy L. Mann, Center for Disabilities Studies; Contributors: Johanna Homan, Graduate Assistant, Center for Disabilities Studies; Becca Dougherty, Center for Disabilities Studies; Copy Editor: Nina Leech; Designer: Cindy Dolan

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Creating Solutions

National organizations are now mobilizing support for initiatives to increase awareness of and appreciation for the direct support profession. The National Alliance for Direct Support Professionals has 28 affiliates across 19 states. The organization continues to grow in its advocacy efforts, improving workforce practices and supervision along with pay and benefits.

Efforts to improve the direct care system through better wages and benefits have reached as high as the United States Congress. During the 110th Congress, Rep. Capps (D-CA) is expected to re-introduce a bill entitled the *Direct Support Professionals Fairness and Security Act, H.R. 5197*.⁴ Because poor compensation leads to high turnover, this bill proposes funding to states to help

ensure that direct support professionals will be paid sustainable wages with appropriate benefits.

At the University of Delaware, the Center for Disabilities Studies (CDS) supports projects, such as the Workforce Recruitment and Retention Project, designed to improve the status of DSPs. In May 2007, CDS and partner agencies hosted Delaware's Second Annual Conference for Direct Support Professionals to honor the profession and its practitioners.

All DSPs should help empower the people they support,

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All direct support professionals should help empower their consumers, honoring goals and dreams and facilitating self-direction.

...
facilitating self-direction. Freedom to live in their chosen community is the ultimate goal. To achieve this standard

of care, however, DSPs need training, career security, and job satisfaction. Just as they support persons with disabilities, the disability community must support them. A mutually beneficial direct care system is in the interest of all.

¹ <http://www.collegeofdirectsupport.com/CDS50/content/CDSContent/dsp.htm>

² <http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm>

³ <http://www.cms.hhs.gov/promisingpractices>

⁴ The 2007 Disability Policy Seminar Fact Sheet

Personal Satisfaction and Professional Achievement Produce High-Quality Services



When you meet Erica Dessausure, she radiates warmth. When you speak with her, she conveys integrity. A direct support professional (DSP) for 14 years, Ms. Dessausure's passion for her job shines. "I love what I am doing," she says simply.

Throughout her career, Ms. Dessausure has supported children and adults with a range of disabilities. For the past four years, she has provided assistance for five women in a group-home setting. Ms. Dessausure knows the value of creating caring, respectful relationships with each individual she supports. "You have to learn the needs and desires of everyone. You have to learn to balance the wishes of each person in the house," she explains. However, balancing these wishes can often be challenging. "At times, four women may want to do an activity in the community, but one woman may not. If you happen to be the only staff person on duty, you have

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"You have to learn the needs and desires of everyone. You have to learn to balance the wishes of each person in the house."

to be very reassuring, helping the women to understand why everyone's desires cannot be met that day."

As a DSP, Ms. Dessausure also strives for relationships built on sensitivity and comfort so that she can discuss intimate aspects of her clients' lives. "You have to win an individual's trust," says Ms. Dessausure. "You share their lives. Just imagine the confidence they need to place in you." The relationships are reciprocal. "Just as I teach them, they teach me," Ms. Dessausure continues. "They teach me love and patience. I also notice they do not let their disabilities hinder them. They have the same opportunities in life and the same rights to take advantage of those opportunities."

"I have the perspective that there are situations out there in life that could cause me to need the same care as some of the individuals I support," reflects Ms. Dessausure. "The public still needs a lot of

education as there are people who don't care about the needs of individuals with disabilities. We have a long way to go. It is one of the challenges, but we just need to keep pushing forward." Part of this challenge involves increasing community opportunities, such as employment, available to people with disabilities. "There simply are not enough resources out there,"

Ms. Dessausure says.

"One woman whom I support has little to do at her job placement.

Though she really enjoys working, it ends up that she and her colleagues do puzzles or arts and crafts projects all day."

Ms. Dessausure strives to increase her personal knowledge by seeking out educational opportunities whenever possible. "Learning has no age limit on it," states Ms. Dessausure. She has completed several training programs at the Center for Disabilities Studies at the University of Delaware, at the Division of Developmental Disabilities Services, and at her own employer agency, Mosaic. Further, Ms. Dessausure has taken control of her own career advancement. "There is always room to grow, but it is up to each person to take advantage of opportunities," she states. When an assistant manager position opened up at her company, she applied and was hired for the job.

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"Learning has no age limit on it... there is always room to grow, but it is up to each person to take advantage of opportunities."

I had to learn, too."

Now a 14-year veteran, Ms. Dessausure knowledgeably describes the qualities a DSP should possess: "You should be a people-orientated person who is caring, energetic, and dedicated. You have to be flexible and open to change and learning. But most importantly, you have to give it your whole heart."



Conference Honors Delaware's Direct Support Professionals

In recognition of the vital role that direct support professionals play in the lives of people with disabilities, various state and local agencies joined to organize Delaware's Second Annual Conference for Direct Support Professionals. The conference, held on May 3, 2007 in Dover, Delaware, was a day to celebrate the contributions of direct



Wendy Gordon, center, was one of five DSPs recognized at the event for outstanding service. She is pictured with Sharon Stull, left, and Malisa Knox, who nominated Gordon for an award.

support professionals to the disability community. More than 250 attendees, including 209 direct support professionals, attended the second conference, which continued the success of the first conference in 2006.

May 3, 2007 was also declared Direct Support Professionals Day in Delaware through resolutions by Governor Ruth Ann Minner and a tribute by the Delaware House of Representatives. One attendee stated, "I appreciate the fact that the governor recognized us."

"It is refreshing to know that direct support professionals are cared about and appreciated. It is so nice that there is a special day of thanks for the love and services they endlessly render to the individuals they support," said Deborah Matthews from Independent Resources, Inc.

Applauding the Work of Direct Support Professionals

Keynote speaker Al Condeluci, Executive Director of United Cerebral Palsy in Pittsburgh, Pennsylvania, has been a catalyst for change in the disability community for more than 35 years. A former direct support professional himself, Dr. Condeluci delivered an earnest speech about the roots and future directions of the profession, addressing both its frustrations and rewards. He described how the work and passion of direct support professionals are instrumental to create inclusive communities that promote the welfare of people with disabilities.

"With his animated and encouraging presentation, Dr. Condeluci was an inspiration to all direct support professionals. He gave us wonderful tips on reviving our enthusiasm and love for our work," said Katie

Sheridan, a program manager at Bancroft NeuroHealth and a

member of the conference planning committee.

Diana Price from Independent Resources, Inc. agreed, "I was very impressed with Dr. Condeluci. He was so energizing, and when I met him, he shook my hand then embraced me and thanked me for my work."

To recognize outstanding work in the field, awards were given to five direct support

professionals. The winners, selected from more than 65 nominations from across the state, were: Quintella Coleman, Lead Supervisor, Millsboro NGH, Salvation Army; Marion DiRubbio, Program Manager, Kent-Sussex Industries; Wendy Gordon, Teacher, University of Delaware Early Learning Center; Mercedes Laws, House Manager, Benedictine Group Home; and Valerie Lloyd, Resident Care Technician, Mary Campbell Center.

These five individuals represent the many hard-working and dedicated direct support professionals who form an integral network of support for people with disabilities. The conference was an opportunity to thank these individuals. "I

think this conference is very important because it is finally giving direct support professionals the recognition they deserve," said Ms. Sheridan. "Direct support professionals' work is very rewarding in many ways, yet they don't always get the respect they are warranted. I hope the continuance of this conference will bring more knowledge and understanding to the field."

Empowering Direct Support Professionals

The conference provided numerous opportunities for direct support professionals to enhance the quality of their work by building skills, obtaining career advice, and gathering up-to-date information about the disability field. Interactive presentations addressed a wide range of topics, from communication and teamwork to stress management and critical decision making. During these workshops, direct support professionals explored their own experiences, both triumphs

and frustrations, and were challenged to examine their work in new and innovative ways.

Workshops also addressed the art of networking. The conference helped direct support professionals connect with their colleagues to exchange stories and information and build relationships and rapport. "It was great to interact with other direct support professionals," noted one attendee from KenCrest Services.

Opportunities to connect with colleagues enhance career solidarity and promote a sense of belonging within a valuable occupation.

Sponsors for Delaware's Second Annual Conference for Direct Support Professionals included the AARP, the Center for Disabilities at the University of Delaware, Connections CSP, Inc., Delaware Developmental Disabilities Council, and Delaware Division of Developmental Disabilities.

A New Vision for the Direct Support Workforce



Many people with disabilities require assistance from direct support professionals (DSPs), but unfortunately, DSPs are in short supply. Though it is a rewarding occupation, high turnover and low recruitment rates combine to produce overwhelming demand for direct support services.

The Workforce Recruitment and Retention (WR&R) Project at the University of Delaware Center for Disabilities Studies developed strategies to meet this increasing level of demand in the disability community. Funded by the U.S. Department of Health and Human Services and the Centers for Medicare and Medicaid Services, the goal of the WR&R Project is to create effective methods for recruiting and retaining DSPs. For the last three years, the project has offered training opportunities and advocacy to more than 1,000 DSPs.

Examining the Values of the Field

The WR&R Project focuses on qualitative factors that affect the job satisfaction of DSPs. Specific initiatives are designed to help DSPs take pride in their jobs, including fostering a cooperative spirit within agencies, advising agencies to show appreciation for good work, and recommending quality supervision. The project aims to align the values and needs of DSPs with the values and goals of the agencies for

which they work.

To help achieve this cohesion, the WR&R Project offers a series of training seminars that focus on personal and workplace values. *Values Clarification 101* teaches DSPs to examine their own values and gain an understanding of those held by their employers. The training addresses the tension that may arise when two value systems are at odds and explores approaches to resolving possible conflicts.

Values Alignment builds on *Values Clarification 101*, helping participants apply their new knowledge and awareness of value systems to balance the demands and decisions they face at work each day. The agenda focuses on skills that support workplace success, enhance cooperation, encourage team-building, and facilitate effective communication.

Mentoring and Advanced Training

Providing new DSPs with adequate training is vital. The WR&R Project mentor training program has established a system of current employees who aid new DSPs in understanding the job's responsibilities. A two-day seminar, which includes both lecture and interactive activity, is offered. During training, potential mentors learn how to problem solve, provide support, answer questions, and give advice while maintaining an informal, personal, and reciprocal relationship. As one mentor

says, "My mentee and I both appreciate each other. We understand each other's motivation and work together to enhance the job we do."

In addition, the Governor's Commission on Community-based Alternatives for Persons with Disabilities is examining the direct care workforce in Delaware. Currently, a volunteer committee is developing a universal curriculum for DSPs in Delaware to ensure adequate training in the initial stages of their careers. Further, the WR&R Project is working to increase continuing education opportunities so that DSPs have more opportunities for career enhancement, and subsequently, enhanced job satisfaction.

Spreading the Word

In an effort to recruit new people to join the direct support workforce, the WR&R Project promotes a positive image of the field. The project uses an integrated marketing campaign, including brochures and award-winning videos to inform the public about the rewards of becoming a DSP. The WR&R Project uses brochures and videos at the Department of Labor and educational institutions, both sources of potential candidates in the field.

For more information about the WR&R Project or the Governor's Commission's volunteer committee, please contact Renee Settles-Bean, Project Coordinator, at (302) 831-3073 or rbean@udel.edu.

One Family, Two Direct Support Professionals, One Team

Direct support professionals (DSPs) fill important roles in the lives of persons with disabilities and their families. They sometimes are more than employees—they are friends, confidantes, and advocates who form integral partnerships with the people they support. Family members often enter into these partnerships to provide optimal care for persons with disabilities.

These relationships are not always present or desired by people with disabilities or their family members, however, the Coffin family illustrates what is possible when people with disabilities, their

family members, their DSPs work to maintain an active partnership. The Coffin family of Seaford and the DSPs with whom they work are an example of this harmony. Paul and Cheryl Coffin live in a neighborhood close to their two sons, Wayne and Dwayne, twins who were diagnosed at a young age with cognitive disabilities. Now adults, both brothers graduated from high school, and each lives independently in his own home.

Wayne, who shares a six-room house with a roommate, moved from his parents' home when he was 20. Dwayne

followed seven years later and now has his own apartment a short distance from his brother. Each brother is employed; Wayne works at a local restaurant (in the kitchen), while Dwayne works for Easter Seals as part of a maintenance crew.

Wayne and Dwayne both have a strong desire and fierce determination to lead independent lives. Their DSPs play vital roles in their lives. After almost six years of working together, Wayne and his direct support professional, Charles Webb, have formed an effective professional relationship as well as a

tightly knit friendship. Charles helps Wayne with a range of living skills, such as cooking and cleaning. He also attends wrestling matches or baseball games

with Wayne. As Cheryl says, "I think Charles is in the ideal profession. It takes a special person, and he is one."

Likewise, Dwayne has formed an invaluable relationship with his DSP, James Jackson, even though they have worked together for only six months. "James has made an effort to be a friend, rather than simply making an

effort to come to work in the morning and do his job," says Cheryl. "That is a big, big attribute." For instance, Dwayne and James go to the local YMCA and lift weights, play videogames, or attend wrestling matches with Wayne and Charles.

Charles and James offer Wayne and Dwayne the opportunity to be individuals, helping them pursue personal interests. Because Charles and James have formed caring friendships with each brother, they listen for and hear the unique voices of Wayne and Dwayne.

Though Charles and James support each brother in different ways, their relationships are reciprocal. "Some of the things Wayne does or says help me in my everyday living. I think we are both getting something from each other," says Charles.

James agrees, "If I come in, and I'm having a bad day, Dwayne begins talking and is funny throughout the whole day. He always cheers me up."

While Charles and James are essential parts of Wayne and Dwayne's lives, they also provide a support system for Paul and Cheryl. "We have wonderful relationships with our direct support professionals," says Paul. "Right now,



The Coffin family

we are in a position where we are very comfortable making requests. And Charles and James honor those requests."

Open lines of communication and mutual respect is critical to this process. Because Paul and Cheryl work closely with Charles and James, they utilize a team approach to their sons' care. "Even though we still have a lot of responsibility, it is shared," states Cheryl. "We work as a team, and that is extremely rewarding."

"The Coffins have been excellent," says Charles. "They have supported me, they trust me, and I thank them for that. If it weren't for the relationship we have, we wouldn't be able to help Wayne in the way that we do."

Charles and James each bring a high level of caring and compassion to their jobs, although as Charles remarks, "I don't feel like it's a job. I feel like it is a life experience."

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