

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Recovering the Meaning of "Professional"

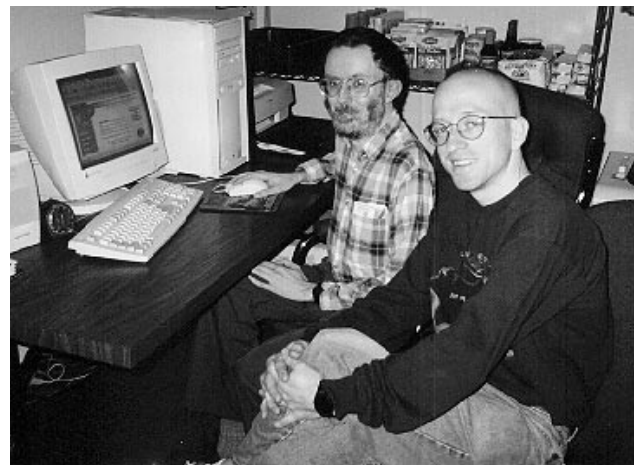
Are people in direct support roles really "professionals" and do we want them to be? As the National Alliance for Direct Support Professionals works on recognizing and enhancing the pivotal role of direct support workers, one of the potential dangers we face is that we might try to enhance the role and status of the Direct Support Professional (DSP) in a manner that is based upon an outdated model. What does it mean now to identify oneself as a "professional," especially in a world where roles between professionals, consumers, family members, and communities are changing? Is professionalism a matter of training and credentials, or is it something else?

In defining Direct Support workers as professionals we need to invite people not to emulate the worst stereotype of professional e.g., distant, quick with advice and diagnosis, obsessed with control, fiercely protective of position, privilege, power, and having all the answers. We need to create a new definition of professional or to recover an old one. The word professional has its roots in the word "profess," and the act of "professing vows" (within a religious order). In fact, in a world of conflicting

loyalties and allegiances, to profess vows meant to be very clear about one's values and beliefs, and thus trusted because others knew where you stood. In this sense, to be professional is an affirmation of commitment and willingness to walk with others even when you don't have all the answers. Said another way, the professional would not be the stereotypical know-it-all, but one who cares for another from a clear set of values, principles, and commitments, and can do so in many contexts.

That's not easy. People and communities are incredibly diverse. DSPs need to carry out all the mandates, regulations, and

Continued page 3



John Gallagher and Kent Ferris (DSP, foreground) assisting each other while surfing for baseball news. (See story page 6)

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The Real Scoop DSP Q&A

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Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's ready to give you his spin on how to deal with issues that come up as you forge ahead in your role as a Direct Support Professional. Seth is a Direct Support Professional who loves to give advice. He has been a DSP for too many years to count. He may give you a hard time, but hey, it's for your own good! Clifford and Seth tackle this one with just a few suggestions. How would you handle this situation?

Mending Fences

Dear Clifford and Seth,
I recently had a major disagreement with staff members at another service provider agency and need to "mend fences" in this situation. How can I serve as an advocate for those I support without being labeled as biased or argumentative and without causing friction with other provider agencies?

— *Alicia in Maryland*

Dear Alicia,
I think you can begin "mending fences" by explaining why you were advocating for the services you were needing for the consumer. You weren't being argumentative or biased, but were doing the job you were being paid to do. As professionals we have to understand that there will be disagreements and that one has to work very hard to solve them and work together for the people whom you serve.

— Clifford

Dear Alicia,

As an advocate you will always find yourself fighting for the rights and benefits for the people you serve — that's the job. Your normal work day will consist of many minor and major disagreements with staff members, not just at other service providers but within your own agency. You don't need to mend fences, just be sure there's an open gate for the benefit of those for whom you provide supports. I do this by being diplomatically assertive. Still, no matter what you do, it is likely that you will be labeled negatively by someone. However, your colleagues will understand why we do the job we do. To the consumers and families who are benefited by your determination and drive, your reputation will be of someone who can get things done on behalf of the consumer. You will be respected by the people who matter. It's not easy but it's well worth it.

— Seth

Ask Clifford and Seth

Do you have a burning question about direct support, but didn't know who to ask? Submit it to —

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Please include your name, day phone for verification, and alias, if desired.

NADSP Member Organizations and State Contacts

Professionalism *continued from cover*

programs of the greater systems while at the same time following the guidance of consumers and families in connecting people to natural supports and community life. They have to be willing to accept that the choices consumers make may not be the choices they would make.

It may be, though, that the role and challenges of “Direct Support Professionals” in fact call for our understanding of “professional” to change. That change may mean the recovery of the much older understandings of what it means to be “professional.” Recovering “professionalism” may mean recognizing and validating the sense of vocation and calling that, in fact, many direct support workers feel in their roles. It may mean developing strategies that recognize and enhance the commitment that many DSPs already demonstrate in their jobs. That commitment is nourished by acknowledging the incredible value of the DSPs’ role to others by opportunity to reflect on, and integrate the value base of that commitment, and by support through knowledge, training, and adequate compensation.

So as we talk about, and work on, “professionalism,” let’s be careful about what we ask for. Let’s recognize that it may be a quality many good direct support workers already have. What needs to change may be our understanding of what it means to be a “good professional.”

Bill Gaventa is Coordinator of Community and Congregational Supports The Boggs Center on Developmental Disabilities, The University Affiliated Program of New Jersey, UMDNJ. He can be contacted at 732.235.9304.

Frontline Initiative is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration of organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals. The following are some of those organizations—

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- American Association of University Affiliated Programs
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation Commission
- Consortium for Citizens with Disabilities
- CUNY Consortium for the Study of Disability
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UAP), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- National Association of State Directors on Developmental Disabilities
- National Association of State Directors of Vocational Technical Education
- National Center for Educational Restructuring and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers Association
- National Organization of Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President’s Committee on Mental Retardation
- Program in Child Development and Child Care, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy of America

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A Dream of Direct Support

I cannot remember a time in my life when I did not want to work in the field of disabilities. When I was four years old, I saw a deaf actress on Sesame Street and was fascinated by her. I had a million questions about what it was like to be deaf and about sign language. Once my sister had answered my questions the best she could, I decided that I wanted to grow up to teach deaf children to sign and speak. I dreamed of working with people with disabilities. Little did I know at that age that I had a learning disability and how this would affect my life, including my desire to pursue the career I wanted as a Direct Support Professional (DSP). I would eventually receive services from DSPs such as getting weekly help with my schedule and budgeting, but I didn't think that receiving services would be a conflict with my dream to provide them as well. My desire stayed with me, and by the time I was in high school, I began to take steps toward fulfilling this dream.

I set out on a twelve-year road that led me to my current position as a Direct Care Worker in a group home. I first worked with kids who had developmental disabilities at a day camp and an after-school program. I loved being with the kids and began thinking about working in a group home. After that I worked as a teaching assistant for a kindergarten class, and later as a field assistant for the Self Advocacy Association of New York State for six years. During these twelve years, I met many who tried to discourage me from my dream. Nevertheless, my goal all fell into place this year.

The agency that provides supports for me at the apartment where

I live was opening a new group home. One of the people who would be living there was someone for whom I had already provided supports for six years. (He had participated in a recreational program of On Your Mark for which I work.) At this point I was at a very bad time in my life. Alone and not knowing where to turn, I ended up talking to the director of my agency. The people at the agency had helped me and impressed me so much with their services that I often thought of working for them, but I didn't think it would really happen. I mentioned my desire to expand my experience in direct support and told the director about my dream. Much to my surprise, he said, "You know, that's not a bad idea. I'll have the residence manager of the new group home call you to come in for an interview." She called me the next day and had me come in for an interview. As I was getting ready to leave, she shook my hand and said, "Welcome to residential." I wanted to laugh because I had already been a resident in the program for five years. Just when I had thought my life was hitting bottom, I ran home with wings on my feet. I got the job!

Yet, just as quickly as I'd gotten the job, it almost slipped away from me. That same night, the manager of the apartment program where I live told me, "Well, I have reservations about this. I don't think this will work because some of the residents in that house are your peers, but the decision is up to the director of residential." My case manager and a few other staff felt the same way. This really hit me hard because these were people I trusted and had loved like family. I

waited a month before I was called in to meet with the manager of the new group home, again, and the director of residential services.

My fears vanished, and my dream returned. I still had the job! They hired me as a Direct Care Worker and they expected me to do everything that other staff personnel do. I liked that. The house has been open for 18 months. When it comes to work, I am very happy. I primarily work with two young men who have autism. I teach them daily living skills (cleaning, cooking, etc.) and behavior management. Six individuals live in the house and each is very special to me in his/her own way, and all of the staff are very understanding toward my disability. No one stops me from doing a single thing, and they always ask before they step in to help me.

My life is pretty great right now. I'm doing work that I enjoy and I'm living out my dream. My dream is still growing, though. Eventually, I want to focus on early intervention with children with autism and would like to get training for speech pathology, too. The work I'm doing now is great experience for this and another step toward achieving more of my dream. In closing, I would like to leave you with my favorite saying: "A dream is a goal that is a little out of reach."

Marla H. Moley is a DSP for On Your Mark in Staten Island, New York. She may be contacted at 718.667.6826. This article was adapted and reprinted with permission from the Self-Advocacy News.

Professionalism Shows Respect

To me, a Direct Support Professional (DSP) is being professional when he or she shows others respect and helps others do and understand things they want or need. I have dealt with many DSPs at work, home, and other social settings. Some of them have been very professional, treating me respectfully, while others have been very poor examples of professionalism, treating me as if I were somebody without feelings, choice, or opinion.

At work, I've experienced both. My supervisors have shown me a great deal of respect. They provide myself and others with the supports we need to do our jobs well. They have also helped me when others are being less than professional. Where I work, we often have temporary employees come in and work with us, and I've found some of them to be rather disrespectful. I let my supervisors know about this. My supervisors then talk to the temps who are being disrespectful and provide them with the insight they need in order to provide me with supports rather than tell me what to do.

Another example of somebody I respect as a professional is my case manager, who has been my case manager since 1995. She is polite and doesn't boss me around or tell me what to do. Two years ago, she helped me to check out different jobs like doing laundry at a hotel and cleaning at a nursing home.

These didn't work out, so I took a job with my present employer. At the time, it was the only job available which allowed me to sit during part of my work. I can't stand all day because I have Cerebral Palsy which affects my left ankle and leg. My case manager treated me professionally in how she helped me to look at

different jobs to find one that I could do. She listened to me and helped me find options that would work with my wants and needs. I am ready to start looking for a different job and I think it would be good and professional of my case manager to help me begin that search so I could make more money and be

happier with myself.

In contrast to my case manager, I'd say that my boyfriend's case manager is unprofessional. My boyfriend and I like to spend a lot of time together, but his case manager bosses us around and tells us how to live and when we can and can't see each other. He does the same for my boyfriend's other friends. I would respect him as a case manager and as a professional only if he would respect our decisions, boundaries, and desires.

When I do my work, I try to be as professional and respectful as possible, because that's how I would want others to treat me. For instance, when I volunteer at a local

organization that holds fun meetings and fund-raisers, I answer the telephone and treat the callers with respect by listening to them and answering their questions. To me, that's a big part of what it means to be a professional. My boss at this club and the others there treat me courteously. If they need to use the telephone when I'm working, they don't tell me rudely to get off the phone but let me know and ask me politely.

These are all examples of what I think professionals do or don't look like. If a DSP wants to be considered a professional, then she or he should provide supports respectfully, treat others as they would like to be treated. All DSPs should be professional because that way people with disabilities would get more respect.

Jennifer Koch lives with her parents in St. Charles, MO.



Jennie at her graduation with her proud dad.

“

When I do my work, I try to be as professional and respectful as possible, because that's how I would want others to treat me.

”

I Consider Myself A Professional

I have provided residential support to adults with developmental disabilities for five years and I consider myself a professional in this field. Prior to working in direct support, I had worked for a college in the student development department. I supervised student staff who lived and worked in residence halls. There was no question there that I was a professional. When I got my job in direct support, however, I discovered that many questioned whether or not one could appropriately call this new position “professional.” But, despite societal and my own prejudices about people with disabilities, I quickly learned that the students and the people with disabilities I supported wanted similar things, and that I could provide these in a professional manner.

One way I believe I was a professional for both groups was simply living out my commitment to providing continued care. As I had at the college, I persisted long enough so that those with whom I worked knew that I was going to be around for awhile. It took a year for me to feel comfortable that I knew the people I supported, and I believe it took them about that long to get to know me. Maybe a year gave them the sense that I wasn't going anywhere for awhile. The revolving door experience, even in the best situations, can still be traumatic. I can say that my commitment to continuity of support is part of why I consider myself a professional.

Another aspect of my work that accentuates the similarities between my work experiences is that my skills transferred from one to the other. I had originally thought that this would be difficult, but as I mentioned earlier,

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Everybody has issues of establishing his or her own independence, coping with roommates, balancing academic/work demands with a need for a social life, and learning how to survive on a limited income.

”

a need for a social life, and learning how to survive on a limited income. Realizing this, I found I could use the motivational techniques, knowledge of human interactions, creativity in posing new ideas about fun things to do, and money-savings strategies I had used on a college campus to support adults with disabilities as well. The transferability of skills alone warrants that we recognize direct support as a profession, and my willingness to transfer these skills across fields exemplifies a professional attitude.

My desire to improve myself through education and training further warrants that I call and recognize myself as a professional. When I was in student development, I read books and articles about my work, participated in field-related organizations and found ways to

enhance my job performance by any means possible. When I moved to direct support, I did the same things. I went to the library and copied and read articles. I joined the American Association on Mental Retardation. I read books like *No Pity*, by Joseph P. Shapiro and *The Road to Daybreak* by Henri Nouwen to gain historical and non-traditional perspectives on direct support and those who have disabilities. With all this I began to take responsibility for my own development — and I continue to do so — and this too is part of why I now consider myself a professional.

The commitment to continuity of support, transferring skills and being responsible for my own development motivate me to operate in a professional manner. I think that these factors have allowed others to see me as a professional as well. Those whom I support appear to be appreciative of my commitment. Those to whom I report in the work organization have in turn afforded me some opportunities and have continued to allow me the latitude I need to be creative and develop new ideas. Hopefully others too, whether they are family members, social workers or other community members, come to know that what I do, I take very seriously. Maybe because I consider myself a professional, others do too.

My hope for those in direct support is that individual commitments can in turn be translated to common standards, which will allow all to see ourselves, and be seen by others, as the professionals we are.

Kent Ferris is a DSP for Owakih Inc. in South St. Paul, MN. He may be contacted at 651.455.5335.

From Invisibility to Recognition

Almost twenty years ago, I started my first shift as a direct support staff in a large institution. I was quite nervous, having no experience working with people with mental retardation, no training, and very little self-confidence. As I entered the building, I was greeted by a shift supervisor who took me to a room about 12'x12', where twelve children sat. Each had a small carpet square as his or her designated space, and one staff person was there to supervise all twelve. The staff person quickly introduced me to each child and then announced that her shift was over and she had to leave. As she was leaving, she said "dinner is at 5:00, showers are at 6:00, meds at 7:00 and bedtime at 7:30." She also pointed at three of the children and said, "Don't take your eyes off of those three — they run." I was entirely on my own the rest of the evening. After observing a person having a few seizures, watching someone nearly choke, wondering how to respond to people who seemed to be having "tantrums," responding to a missing child (not one of the three), observing children banging their heads, and responding to a broken window, we all somehow managed to "survive" that first shift.

That experience has always reminded me of the importance of communication, training, and support to new employees in this field. Back then emphasis was on health and safety, and direct staff were only expected to take care of basic needs. Direct support staff

were seen as caretakers rather than contributors and as subordinates rather than professionals. Consequently, valuable human resources were often overlooked. I was fortunate that within a year after starting, a new administration came in and made changes, which increased the opportunities for

Direct Support Professionals (DSPs) to participate in professional growth and development.

Now I am also fortunate to work for a private provider in the community that believes that they get back what they put into the development of

direct support staff, a philosophy which I believe can serve as a model for professionalism in direct support. To cite some examples of this philosophy in practice our company benefits by allowing input from DSPs in forming policies and procedures and including them on committees, addressing issues such as human rights, program management, grievance, staff development, etc. In addition, the agency has developed a mentoring program for all DSPs that offers management and programmatic responsibility and experience. New employees receive hands-on training and support, as well as ongoing communication and technical assistance.

As a provider of community residential and employment services, we recognize the need to train, educate, and reward DSPs. Asking

for help is considered a strength rather than a weakness, and necessary supports are available to minimize problems. A formal educational assistance program has been implemented as well as internal curriculum for management and programmatic training. A resource library that includes videos, books, articles, training packets, etc. is open to all employees. Offering a forum for direct-support input and involvement in service delivery, including two-way communication and decision making, enhances continuity and promotes progress. The company promotes people within the company who have the hands-on experience and organizational commitment as another way to ensure the delivery of best-quality services. These practices are only a few examples of how providers have changed from seeing support staff as caretakers to recognizing them as professionals.

Not all agencies have made the shift to seeing direct care staff as professionals, but they should. DSPs should be recognized and respected for what they do. They should have access to the information, training and education they need to do and improve their jobs, and they should be directly involved in the formation of agency policies and practices. The Direct Support Professional should not just be called professional, but also be recognized, supported and respected as a professional.

Bonnie Duvall is the Operations Director for Danville Services Corp. in Provo, Utah. She may be contacted at 801.374.0119.

“The Direct Support Professional should not just be called professional, but also be recognized, supported and respected as a professional.”

ANCOR: Informing DSPs on Policy how legislation affects their work

The American Network of Community Options and Resources (ANCOR) currently represents over 600 agencies and organizations across the U.S. that together support more than 150,000 people with mental retardation and other disabilities. ANCOR promotes and assists private providers by serving as an accurate and timely source of information from the legislative, regulatory, and judicial branches of the federal government. ANCOR provides members with information regarding trends and innovations in the field. As members share with each other the practices that have led to the best outcomes for people with disabilities, this effects change in the way services and supports are provided the nationwide.

Staffing and labor-related issues have been a major concern of the organization's members since its beginning years. ANCOR has worked with the U.S. Department of Labor since 1973 to understand wage and hour requirements that pertain to Direct Support Professionals (DSPs) who work in residential programs, and to develop new policies more appropriate for a relatively new and growing industry. For example, inflexible federal labor rules often limit the ways providers can staff residences, even when DSPs are requesting the changes. Much of labor law was written in the 1930s, before employees were seeking flexibility in their schedule and duties. ANCOR has endeavored to keep track of interpretations that expand opportunities to accommodate employee needs.

In the human service field, DSPs often wish to socialize with the people they support outside of their regular working hours. Yet, there is a

broad prohibition against permitting employees to volunteer to do the same type of work they are paid to do. The Labor Department has ruled that DSPs may therefore not "volunteer" to support the people they are otherwise paid to serve. This prohibition has often proved a problem when the DSP wishes to invite someone from a group living arrangement to come home with him or her for a weekend or accompany him or her on a family outing. In 1980, ANCOR obtained a letter defining labor policy to permit home visits specifically initiated by the DSP. This letter has enabled agencies to reverse policies prohibiting DSPs from voluntarily socializing with those they are paid to support.

Sometimes DSPs also want to become foster care providers. While there is a general rule that prohibits an employer from contracting with an individual who is an employee, ANCOR has a copy of a letter from the Department of Labor which states that employers *may* also contract to provide foster care in their homes. This exception expands opportunities for DSPs. ANCOR is also currently working on amendments to the U.S. Tax Code which will revise the confusing statutory language that excludes some, but not all, foster care payments from income taxes. Currently, these payments are *taxable* when adults are supported in a foster home and they are placed by and/or payments are made by a private agency rather than directly by a state or county government agency. Many are unaware of these differences and are at risk of having to pay back taxes. By revising the tax codes, so that

provision can be made for private agencies to arrange for foster care, DSPs would be able to provide foster care and receive an exclusion from taxes for these services.

ANCOR also supports the development of strong networks among members and other organizations at the local, state and national levels. ANCOR's membership in the National Alliance for Direct Support Professionals (NADSP) is one example of its dedication to effecting change for the improvement of services to those with disabilities. Last March, ANCOR cosponsored a NADSP conference and continues to provide much of the networking information necessary for current research in DSP labor issues.

Through communication and coordination with many entities across the U.S., services and the systems that support people with disabilities have improved greatly since the 1970s. ANCOR has played a major role with the service delivery system in multiple networks to improve the quality of life of people with disabilities. The organization looks forward to the coming millennium with expectations that life will continue to get better for all of the people in our nation.

Joni Fritz is executive director of ANCOR in Annandale, VA. She may be contacted at 703.642.6614.

Alliance Seeks New Co-Chairs

The National Alliance for Direct Support Professionals (NADSP) met in August 1998 in Washington, DC prior to the President's Committee on Mental Retardation Next Generation Leadership Symposium. By holding our meeting in conjunction with the Leadership Symposium a number of Direct Support Professionals (DSPs) and other interested individuals were able to attend the meeting.

Since the inception of the NADSP, the Alliance has been co-chaired by Seth Krakauer, DSP, Amy Hewitt, workforce development professional, and James Meadours, self-advocate. At the August National Alliance meeting it was formally announced that Seth Krakauer and Amy Hewitt would be stepping down from their co-chair positions, Seth to spend more time with his recently born son and Amy to spend time with her new born son. Both Seth and Amy have been energetic and creative leaders, shaping and guiding the Alliance to its current state. The growing recognition of the NADSP and its commitment to addressing direct support workforce development issues at the local, state and national level indicates the successful tenures of these co-chairs. We thank Seth and Amy for their contributions to the Alliance. It should be noted that they will continue to be involved as committee members and *Frontline Initiative* editors. We would also like to thank James Meadours for his work and continuing contribution as he remains in his position as co-chair of the NADSP. We recognize this opportunity to draw in new leadership and maintain a body that will continue to grow in its efforts and contributions.

Though the agenda for this Alliance meeting seemed unrealistically full, the energy from Alliance members and new attendees showed how much can be accomplished in two days. The four major tasks addressed at the National Alliance meeting included — 1) identifying a process for selecting new co-chairs and further defining the leadership structure of the Alliance, 2) taking initial steps toward the development of the Direct Support Professional Code of Ethics, 3) approving a final drafts of National Alliance informational documents and principles of national credentialing, and 4) defining the roles of state contact persons/coordinators.

At the next Alliance meeting a newly appointed ad hoc nominating committee will provide the names of candidates being considered for the co-chair positions. Those attending the meeting will then approve the slate or make recommendations as necessary. The nominating committee will be responsible for identifying qualified, interested candidates through communication with affiliates and organizations of the coalition. The National Alliance remains committed to a leadership body that represents self-advocates, DSPs and workforce development professionals. Marianne Taylor, workforce development professional, and Mark Olson, DSP, will serve as interim co-chairs until we have implemented our new leadership structure process.

Alliance members and meeting attendees spent some time identifying the skills, qualities and characteristics needed to provide quality direct support to individuals with disabilities. The qualities identified

will be used as a starting point for the establishment of a code of ethics. We are excited to have the professional expertise of Christine Reid from Community Rehabilitation Agencies of Tennessee in developing these ethical statements in conjunction with the active participation of DSPs.

Finally, in order to facilitate the process of recruiting state coordinators of the NADSP and supporting the efforts of these representatives and state-wide and local activities, the Alliance will develop a toolkit of information and strategies to assist them as they serve in this new role. This toolkit will provide information to assist state representatives in identifying initial goals and activities in their states, soliciting support for their activities, marketing the *Frontline Initiative* and the goals of the Alliance, and increasing involvement of DSPs in local activities.

A list of state coordinators will soon be published. The state coordinator will serve as a contact for any individuals interested in the NADSP within their state. Stay tuned for more information. In the meantime, if you are interested in the activities of the NADSP and would like to work toward its goals at the state level, please contact an Alliance Co-Chair or state coordinator (see page 3).

The next National Alliance for Direct Support Professionals meeting date and times will be announced in the winter issue of Frontline Initiative.

Improving Communication Between Consumers and Health Professionals

The Role of the Direct Support Professional

Despite the recent movement toward empowerment and choice, many people with disabilities defer to their support worker when it is time to go to a doctor appointment. Direct Support Professionals (DSPs) play a vital role in ensuring that consumers have the opportunities and the skills to communicate directly with their doctors and others. In many ways, these staff are the primary facilitators of communication between patient and doctor. This facilitation requires that DSPs know the individual well, focus their attention on the patient, and support the person in communicating even when the doctor may not be used to such active communication. Thus, it would be best for individuals with disabilities to be brought to medical appointments by staff who work directly with them on a regular basis. In addition, it may be inappropriate for staff and medical professionals to discuss the person's needs without the person's input. Finally, it should be the individual's choice whether or not to recruit staff support in communicating.

The following are recommendations for how DSPs can support both the doctor and people with disabilities in establishing direct and effective communication. Many of these suggestions are based upon work done at the Nisonger Center Women's Health Groups, where training is available for women with disabilities and their female support staff.

Help people prepare for medical appointments

Some people are afraid of doctor visits. One short-term solution DSPs sometimes use to keep such individuals from getting anxious is to avoid telling them that they have an appointment. This, however, teaches the consumer that they cannot trust support staff, and that they have no control over what happens to them. It is essential for DSPs to develop trusting relationships with individuals who are afraid of medical procedures and to recognize and understand their fears. People who are afraid of going to the doctor should also be prepared for medical appointments so that they can gradually overcome their fears. DSPs can prepare individuals by teaching them about the procedure through discussions, photographs, video demonstrations, or visits to the doctor before the appointment. In some instances, an individual might be afraid because of past abuse perpetrated by health professionals. Finding another health professional should be a consideration if fear persists.

Tell people what to expect at medical appointments

Sometimes medical procedures are painful or uncomfortable. Saying that something "won't hurt" when it does teaches a person that support staff are either immune to pain or untrustworthy. Furthermore, it does not allow them to prepare adequately for the pain or discomfort they may experience. It is better to prepare people for a painful procedure than to deny it. If a procedure

is going to be painful, the individual can learn how to cope with it by using techniques like muscle relaxation or deep breathing.

Help people communicate with the doctor

Threats like "You better listen to the doctor" may teach people to be compliant, but also puts them in a vulnerable position. People should learn why it is important to listen to doctors, but also why it is important to inform the doctor when something hurts or when they disagree with a recommendation. It is often necessary to teach people to speak up for themselves and express their discomfort, fear, concerns, and questions. DSPs should also find out what information will be requested at the appointment and familiarize individuals with this information. This way, the individual can take the lead and contribute to the discussion with his or her doctor.

Show the doctor how to communicate with the patient

Physicians may not know how to best interact with patients, especially at the first visit. DSPs can help tremendously by modeling respectful behavior such as asking the patient questions directly, rephrasing difficult concepts for the patient, and asking the patient for permission to discuss a particular issue with the doctor.

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Frontline Resources Websites and Media

Communication

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As the role of the DSP evolves from that of caretaker to facilitator, it is no longer sufficient for the DSP to report the person's problems or concerns to the doctor or to relate the doctor's concerns to the person. Rather, it should be the DSP's responsibility to facilitate such communication between these two parties.

Yona Lunsky completed her Ph.D. in clinical psychology at Ohio State University and the Nisonger Center (UAP). She is currently working as an intern at Toronto Hospital and may be contacted at lunsky.1@osu.edu.

Assistive Technology

The *Washington Assistive Technology Alliance* is a Web-based project funded by the National Institute of Disability and Rehabilitation Research, and mandated by the Technology Related Assistance for Individuals with Disabilities Act (1994). Their address is <http://wata.org>. This page contains links to further resources and information related to assistive technologies.

ABLEDATA is a nationwide source of information on more than 23,000 assistive technology items available from domestic and international sources. You can reach them at 8455 Colesville Road, Suite 935, Silver Spring, MD 20910; 1.800.227.0216; or check out their Web page at <http://www.abledata.com>.

Assistive Technology Source-book (1990) and Assistive Technology: A Funding Workbook (1991). These guides to assistive technology include information on resources, equipment evaluation, personal care, education, employment, recreation, mobility, computer access, and funding. These are available from RESNA Press, 1101 Connecticut Ave. NW, Ste. 700, Washington, DC 20036-4303; 202.857.1199; or <http://www.resna.org>.

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Resources *continued from page 11*

Why Do I Stay in this Field? This is Why!

DSPs share testimonials that include some common answers to the question of why direct support, but then offer a variety of thought-provoking answers you may not have considered. It encourages DSPs to evaluate the importance of their profession and provides a perspective that clarifies the sense of isolation and separation from other professions which DSPs may feel. This 20-minute video is perfect for staff inservice discussion. To obtain this and other resources like it, contact Bethesda Lutheran Homes and Services, Inc., at 800.369.4636, ext. 541. Rent (30 days) \$45; purchase, \$60.

Direct Support Professionals Web Site

www.ici.coled.umn.edu/DSP

This website features on-line resources for DSPs, including reports, a training event calendar, descriptions of DSP-related organizations and projects, and hotlinks to other resources. Users can use a web-based form to submit their resources to the DSP web site, share information about special events, other web sites, and whatever else might interest all the DSPs in the webbed wide world. The DSP web site is sponsored by the Research and Training Center on Residential and Community Living at the Institute on Community Integration, University of Minnesota, College of Education and Human Development. For more information or to submit links or events, visit the site, or call 612.624.1349.

The Community Support Skills Standards

Tools for Managing Change and Achieving Outcomes

This report contains nationally validated practice standards for Direct Support Professionals in human service roles spanning all categories of service delivery populations (e.g. mental health, physical disabilities, developmental disabilities, at-risk elders and youth, etc.) Introductory sections include an overview of contemporary challenges and issues in human services work force development and education and a description of the methodology used for developing and validating the standards. To obtain this publication, call 617.876.0426, ext. 332.

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