

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Achieving Dreams Supporting People With Complex Needs

Explaining to others what you do when you work as a Direct Support Professional (DSP) can be difficult at best, but when the people you support have a variety of complex needs, the job can be even more difficult to explain. But for many in the field, like Aaron Masden, the challenge and the satisfaction of supporting people with complex needs is a critical part of the profession. Like Aaron, many stay in the field because supporting people with complex needs requires an ability to think critically and problem solve on a daily, and sometimes minute-by-minute, basis.

Aaron works for a residential support agency for people with developmental disabilities which was founded on the vision of providing service to those who have not been readily accepted into our communities. ACR Homes (Acceptance, Communication and Relationships) started with a plan to support those with autism or similar disabilities. Over time the agency found it has strengths in

providing supports to people with complex medical needs as well.

In recent years, ACR has been using person-centered planning as a way to assist staff in better understanding what the people they support need and want. Because many of the people receiving services at ACR have a variety of complex needs, including a lack of effective communication skills, the staff

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Pat Latshaw of Bradley/Cleveland Services in Cleveland, Tennessee tells how she learned to be a better DSP. (See page 4, *The Change That Made a Difference*)

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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 you face as you forge ahead in your role as a Direct Support Professional (DSP). Seth has been a DSP for many years, and he loves to give advice. He may ruffle your feathers, but hey, it's for your own good! Clifford and Seth tackle this one with a few suggestions.

True Choices

Dear Clifford and Seth,
I am a Direct Support Professional and my supervisor has asked me to come up with a way to determine how people we serve make their own choices and if they are *really* making the choices they want. Do you have any advice on how I can get started in helping people make choices they believe in?

— Jane from Los Angeles

Dear Jane,
First, simply sit down and talk with the person in a comfortable setting, somewhere he or she enjoys. Ask the person some simple, basic things to begin with, such as whether she likes where she's living and working or not. Also, carry a note pad with you so when you notice something that a person likes or dislikes, you can record it, which may be very useful when the person has difficulty using words. Also, talk to those closest to the person — friends, family, the DSP who works with him or her most. They will know a lot about what the individual enjoys. When the person has a team meeting, create a statement of choices, needs and wants in clear language.

She can then know that her choices are being understood. A few days after the meeting, go over the notes and comments again with the person to make sure everything really went the desired direction. Follow up with friends, family, and coworkers and talk about how to make these things happen. Then, your job is to see that these choices and preferences become a reality.

— Clifford

Dear Jane,
I think the best way to start finding out how people you serve are making individualized choices is to find out what a person's dreams are. If the choices people make are in line with their dreams, you are doing a great job. If the choices they make are not following their dreams, check to make sure they have exposure to a variety of options. It is this important step that is at the heart of your question. People need choices that somewhat realistically meet each step towards their dreams. So, options have to be very individualistic and flexible. Is that what your agency is doing now, or do you have only a set range of choices that are very general? Talk to your supervisor about his or her thoughts.

— 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

Achieving Dreams,

continued from cover

at ACR have been trained in many methods of person-centered planning, allowing them to choose which methods work best for each individual they support. They have found that the cornerstone of effective person-centered planning is knowing the person's daily routine well and having a close connection to that person. Often, a DSP plays a vital role in shaping these plans.

Aaron started as a DSP at a home for people who are medically fragile when ACR was first beginning their new methods of planning. He now supervises a home for four children and young adults who have complex needs, including autism, dual diagnoses of MR/MI, profound hearing loss, communication difficulties, challenging behaviors such as personal endangerment, property damage, aggression, and yelling. Despite their complex needs, the people at this home have been able to identify and achieve several personal goals.

Aaron, who still spends 15-20 hours a week providing direct support, offers the following suggestions for supporting people with complex needs.

Identify people's goals by —

- Using the knowledge of a variety of people when seeking to identify a person's goals. Aaron finds that all members of a support team (often the family, case manager, a representative from the school or vocational support team, and a full-time DSP who knows the person well) make valuable contributions. One individual who doesn't use words to communicate was going to move. Those who knew her recognized

Continued on back cover

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 Disabilities
- 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
- Irwin Siegel Agency Inc.
- 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 for 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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The Change That Made a Difference

When I began to work as a Direct Support Professional three and a half years ago, I had been doing in-home supports for 15 years. I was ready for a change. As a Certified Nursing Assistant, I knew I could get a job in a hospital or nursing home, but that wasn't what I wanted. A friend of mine, who is a nurse, happened to be working at a group home for people with developmental disabilities. She knew I was looking for a change and encouraged me to apply for a job where she was working.

I went to work in a home where six women lived. They had come from an institution about three months before I started there. None of the women communicated verbally, and two used wheelchairs. My job included preparing meals, helping the women eat, modeling appropriate table manners, supporting positive behaviors, and seeing to their daily wants and needs.

When I started working there, the women often displayed challenging behaviors — head banging, screaming, hair pulling, and attacking each other and staff, to name a few. These behaviors usually happened when things were going on that they didn't like, and this was their way of saying it. It was hard to figure out what the problem was and correct it. I had never experienced anything like this. After being aggressed against several times, I

asked myself why I was still there. I had no answer, but had no desire to leave. I felt I was there for a reason, one that I would learn about, eventually.

At first, I felt sorry for the women and wanted to do everything for them. I was the one who was making decisions whether they would take a bath or a shower, which pajamas they would wear, when they would go to bed, and even what they would watch on TV. They had little control over what went on in their lives. I soon learned that they knew a lot more than what I gave them credit for.

After I'd been there about nine months, I had the opportunity to go through the Community Rehabilitation Agencies of Tennessee Credentialing program. I was eager to learn how to make my job easier. The program offered training in many areas; a few were —

- laws, old and new
- medication and nutrition
- how to look at problems differently and find new solutions, such as having the individual help solve the problem
- the importance of the person's vision of the future for developing his or her goals
- how difficult change in one's life can be and how to make transition as easy as possible

- the importance of training new staff, since, like myself, most have little knowledge about people with disabilities

Probably the most important thing I learned was to look at who the person is, what he or she can do, and to look for the positive rather than negative. When I tried all of the things I'd learned, like letting the women make choices in their daily activities, I realized that this gave control back to them. They became less dependent on staff and their challenging behaviors decreased. I realized that all along they had no problem understanding what I was trying to convey to them, but that I was the one with the problem of not understanding what they were trying to convey to me.

Since participating in the credentialing program, my job has gotten easier. I have a much better understanding of the people I support and no longer feel sorry for them. They have taught me how to communicate with them and what their world is like outside the group home. I have learned how to be more calm and how to see the beauty in the simple things in life. They have taught me more than I could ever teach them. They have become my teachers. I now know why I am there. I am there to learn.

Pat Latshaw is a DSP for Bradley/Cleveland Services in Cleveland, Tennessee. She may be contacted at latpat@cs.com.

“All along they had no problem understanding what I was trying to convey to them, but I was the one with the problem of not understanding what they were trying to convey to me.”

Relationships in the Workplace

Relatively little thought has been given to the development of friendships between DSPs and the people for whom they provide supports. It is often assumed that “paid relationships” between staff and individuals depend on professional distance and by definition are not friendships. It is true that such relationships shouldn’t be seen as a substitute for other relationships. At the same time, there are occasions when close, mutual friendships do form between DSPs and the people they support. More recently, however, some agencies have begun encouraging those personal ties, and many have determined that the best way to support people is within the context of social relationships. As the field puts increasing emphasis on social relationships and community building, DSPs are being called upon to play new roles beyond meeting traditional planning objectives.

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Three of the most critical issues related to these friendships are (1) the consequences of when a DSP transfers, or the person receiving supports moves, (2) the conflict of interest DSPs find themselves in when they must be a friend and an employee, and (3) when the agency relies exclusively on staff as friends versus assisting the person to establish other friendships.

The high turnover of DSPs within human service programs has reduced the possibility that friendships and other personal relationships can develop. Also, some agencies transfer DSPs if a close relationship seems to be developing. When a friendship has been established, a physical relocation of one of the friends may be enough to end the friendship. However, sometimes such a relocation strengthens their relationship. Friendships with former DSPs are recognized and supported by some agencies through a variety of means, including invitations to the former DSP to visit or attend planning meetings as a friend, and providing assistance, if needed, to the person receiving supports to maintain the relationship (e.g., sending cards, making phone calls, initiating visits). When the relationship is not supported, this may constitute a formidable barrier to the continuation of the friendship.

A relationship between a DSP and the individual he or she supports sometimes results in a conflict of interest. The DSP is both an employee of the agency and a friend of someone who receives supports from that agency. Tensions and difficulties in the relationship can result. The DSP may need to advocate for his or her friend, questioning the agency’s policies and regulations. The agency may view the DSP’s actions as insubordination and be-

yond the job’s responsibilities. The nature and extent of the friendship is shaped and defined through such tests, interest, and loyalty. In addition, agencies may learn more about the individual needs of those they support if they allow these natural tensions and conflicts to inform their policy.

Finally, the process of assisting some people with disabilities who have been previously isolated from the community to establish friendships can be challenging and time-consuming. Some agencies may put much effort into the development of close friendships among staff and the people they support, though devote less energy toward creating other connections and relationships. It is important that the agency channels its resources in both directions to maximize the person’s options for friendships.

People receiving supports and DSPs can establish and enjoy genuine friendships with each other that are deeply significant for both involved. Such relationships should not be a substitute for the possibility of other types of relationships. However, it is important to recognize and value these relationships, because they can enhance the lives of both the DSP and those receiving supports.

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Learning From Brian

Facing Barriers of Complex Needs Made Me a Better DSP

My parents always taught me that “it is better to give than to receive.” It was this frame of mind that inspired me to work with individuals with disabilities, many of whom have complex needs. I have continued for 16 years, but I have found that a more apt saying might be, “It is by giving that you receive.” About a year ago, I began working with Brian, an individual who has complex needs; he has a diagnosis of mental retardation, he aggresses toward others and property, has difficulty using words, and receives mostly one-on-one supports. Working to overcome his barriers has taught me a lot about my own limitations and strengths and about listening to him.

Before Brian came to the employment supports division of the agency I work for, he had become aggressive toward others, was destroying property at home, refusing to eat, and getting very little sleep. When I agreed to take Brian onto my caseload, I knew he would require intensive supports. I found out from a teacher who knew him well that he didn't deal well with change. The transition from school to work would be a big change for him, and I knew his first day would likely be a challenge for us both.

Brian's first day and many following were very stressful. We had decided to try a picture schedule to help him understand his routine. Brian was quick to show us what he thought of it all. Work materials, his shoes, the pictures, and more went sailing across the room. I spent most of the day with Brian picking up what he had thrown or guarding against his attempts to hit me or other staff. He was exhausting, yet

I knew that he had real potential.

While his behaviors persisted, I used several strategies to help me cope with the stress. Sometimes I sought encouragement from our behavioral specialist and other staff. It's important to have outside support on an ongoing basis in stressful environments. Other times I would use creative imagery, which worked well for me. For example, I would imagine I was lying on a beach with a cold drink in hand and was listening to waves lap against the shore. When this didn't work, I would ask another DSP to step in to give me a break. Recognizing one's limitations and being willing to ask for assistance are crucial skills for a DSP to have to remain effective. In every situation, regardless of the technique

or support, I also needed to have a sense of humor. One must not take challenging behaviors personally, but react to them with a sense of humor. Finally, when the day is over, leave your work at work.

One of the most important things Brian taught me was the importance of establishing trust. It was clear that it was important to be firm with him and to follow through with what you said you were going to do. When he first arrived, he would hit people, break glasses, tear clothing or throw materials, daily. Many staff were afraid to work with him, but I decided to stick with him. After a few months, he began seeking me out and communicating his preferences with his pictures. His aggressive behaviors are



Tricia Grosdidier (DSP), right, assists Brian Seelbinder in his work shredding paper.

In Commemoration of John F. Kennedy, Jr.

Lost Champion of Direct Support Professionals and People with Disabilities

now rare. I would attribute this change to the trust established between us. By being strong and following through, I was able to show Brian that he could trust me.

Remaining calm while learning how best to communicate with Brian was also invaluable for providing him supports. It can be very difficult to understand what he says, so I must watch his gestures and facial expressions and use a lot of trial and error. For instance, when I asked him where he wanted to go for fun, he would say, "Orange Crown." We had no idea what this meant. After many attempts at guessing and talking to residential staff, we figured out that he was referring to a marquee outside a bowling alley that had a giant orange crown on it, though it wasn't part of the place's name. It was well worth the time it took to understand what he was saying.

I have worked with many like Brian who have complex needs during my 16 years in the field, and I've found that the behaviors people display are barriers to a better life. By persisting, I have been able to help these individuals live better lives. I still believe it is better to give than to receive; but now, I think I am often the one receiving by working with people with complex needs. Working with Brian has been very rewarding and has helped me be a better DSP and a better listener.

Tricia Grosdidier is an employment provider for Johnson County Developmental Supports in Lenexa, Kansas. She may be contacted at 913.492.6161, ext. 423.

The loss of John F. Kennedy, Jr. leaves us saddened and has many of us pondering his legacy. Of the many things for which he will be remembered, it is hoped that his contribution to those who provide direct support to people with disabilities will be among them.

Aware of how underpaid, under recognized and undervalued frontline workers are and how this impacts the people who need support, John F. Kennedy, Jr. responded in 1989 by founding Reaching Up, Inc., a nonprofit organization devoted to providing higher education and career opportunities for Direct Support Professionals (DSPs). Since that time, Reaching Up, Inc. has provided mentoring, higher education, opportunities to join professional associations and attend national conferences, and other support for DSPs who are committed to their work. Through Reaching Up, Inc., John F. Kennedy, Jr. also helped to found the National Alliance for Direct Support Professionals.

Mr. Kennedy recognized the need for both DSPs and people with disabilities to share dialogue around important issues on an ongoing basis. It was for that reason Reaching Up, Inc. supported the publication of *Frontline Initiative*. Writing in the premier issue of the *Frontline Initiative*, he said, "We need more forums like these, outside of the service environment, where workers and people with disabilities can talk directly to each other to discuss their common interests as well as differ-

ences. As allies with a shared agenda, they can help each other achieve their goals." John F. Kennedy, Jr. saw this publication as a way to foster communication and networking among the millions of DSPs and Self-Advocates around the country. Reaching Up, Inc. funded several initial printings of the newsletter, and the organization continues to support this publication through editorial participation and writing assistance.

While serving on the President's Committee on Mental Retardation, Mr. Kennedy co-sponsored many initiatives of the President's Committee that promote better lives for both DSPs and people receiving supports. Among them are, the *Next Generation Leadership Symposium*, an annual conference for developing leadership among younger DSPs, and several publications, including *Opportunities for Excellence — Supporting the Frontline Workforce*, *Voices of the Next Generation*, and *With a Little Help from My Friends*.

As an expression of gratitude for the many contributions John F. Kennedy, Jr. has made to improve the status and well-being of direct support workers, the next issue of *Frontline Initiative* will be a special feature tribute to him and his accomplishments in this arena. The issue will be a commemoration by those who knew him and worked with him on these issues, including DSPs whose lives he influenced through his foundation and personal attention to their issues.

Human Services Research Institute (HSRI)

As a new millennium approaches, Human Services Research Institute (HSRI) prepares to celebrate 25 years of nonprofit service to people with disabilities and their families. Throughout its quarter century of achievement in research, policy evaluation, and community support development, HSRI has worked vigorously to raise the voices of people with disabilities in their call for better quality support, freedom from institutions, and for support at home. Under the leadership of the founder and president of HSRI, Valerie Bradley, the thirty staff in Cambridge, Massachusetts and in Salem, Oregon share a commitment to improving the quality of human service support provided to people with disabilities nationwide.

Human Services Research Institute was established in 1976 to assist states and the federal government to enhance services to people with mental illness and people with mental retardation, and to support the development of alternatives to congregate care facilities. HSRI was active in the 1970s in assessing the potential of federal programs, such as Supplemental Security Income, housing subsidies, and vocational rehabilitation, to expand community services for people with disabilities. HSRI staff also participated in implementing the Community Support Program at the National Institute of Mental Health and in designing a housing research agenda for people with disabilities. The Institute also completed a book on the community movement in developmental disabilities — *Deinstitutionalization of*

Developmentally Disabled Persons: A Conceptual Analysis & Guide (Bradley, 1978).

During the 1980s, HSRI expanded its interests to include quality assurance, needs assessment, and family support. In the area of quality assurance, HSRI developed a wide-ranging report on quality assurance for the Department of Health and Human Services titled, *Assessing and Enhancing the Quality of Services: A Guide for the Human Services Field*. In the area of needs assessment, HSRI designed the “Quadrant Method” for The National Institute on Mental Health to assist in determining the number of people with severe and persistent mental illness requiring services. HSRI also developed computer simulation models for allocating and planning mental health resources. In collaboration with Developmental Disabilities Councils around the country, HSRI supported families in grass roots movements to lead the way toward flexible, individualized supports that are person-centered rather than prescribed by the service system. These efforts resulted in progressive family support legislation in a number of states. HSRI also tracked and evaluated much of the deinstitutionalizing effort during the '80s, a period of intense examination of deinstitutionalization in states such as Pennsylvania, New Hampshire, Michigan, Maine, Minnesota, and Massachusetts.

Currently, HSRI is working with several states to evaluate and describe best practices in family support. The Institute has become a

Technical Assistance Center for the evaluation of system change in mental health and continues to offer support for state and local health systems. HSRI is now studying the development of participant-driven managed care approaches to providing long-term supports for people with disabilities, as well as the use of performance indicators to monitor and improve system performance.

HSRI is also committed to strengthening the nation's direct support workforce. Empowered, competent support staff are vital partners in the walk toward self-determination and participant-driven supports. Working in collaboration with Direct Support Professionals and other key stakeholders, HSRI facilitated a national dialogue on the skills, knowledge, and values associated with excellence in direct support work that resulted in the *Community Support Skill Standards* (CSSS). Since their publication in 1996, HSRI staff have developed several tools and strategies to use with the CSSS in many educational and training settings (see our Web site at www.hsri.org). HSRI is proud to support the National Alliance for Direct Support Professionals which shares our mission of a strong and competent workforce and high quality supports.

For more information on HSRI, contact Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140; phone: 617.876.0426, fax: 617.492.7401, or the Oregon Office, Human Services Research Institute, 850 Lancaster Drive SE, Salem, OR 97301; phone: 503.362.5682, fax: 503.362.7729.

Resources for Your Summer Reading (or Viewing) List

As Good as it Gets

This movie, available on videocassette, stars Jack Nicholson as Melvin Udall, a romance novelist who suffers from obsessive-compulsive disorder and very bad manners. Helen Hunt won an Oscar for best actress for playing Udall's love interest, Carol Connelly, a waitress at the local cafe. Greg Kinnear plays Simon Nye, Udall's ill-fated neighbor. These three characters come together, separate, and come together again throughout the movie in various circumstances, both tragic and comic. Like most Hollywood movies, you have to set your skepticism aside about how Udall ever got his best-selling romantic prose into the hands of an agent who would work with him, but some other aspects of the movie ring true.

DSP points to ponder while watching — Why do people work so much harder when they have a reason to? Why do real relationships have so much more power than medical or other professional advice? Try to note all the things Udall starts to do differently once he falls in love.

A Special Kind of Hero

by Chris Burke and Jo Beth McDaniel

We know Chris Burke from his role as Corky Thatcher the star of the television show, *Life Goes On*. Chris was born in 1965 with Down syndrome. Despite the advice of his doctors, his parents decided to raise him at home. In this autobiography, Chris describes how his interest in acting, which began at age 5, be-

came a dream and then a reality as he took acting classes and moved into adolescence and adulthood. If you enjoyed *Life Goes On*, you will enjoy this story. This book is currently only sold as a Barnes & Noble bargain book for \$3.98 and may be purchased at some of their stores. Another source to check out is your local library.

She's Come Undone

by Wally Lamb

This novel is a somewhat sad, but very thought-provoking look inside the world of Dolores, the main character. Dolores experiences a very agonizing and painful coming of age by dealing with issues of extreme obesity, as well as issues of abuse and mental health. What is most heart-wrenching about this story is that many of the people who have contact with Dolores do nothing to show their care or concern for her situation. Dolores has great potential for success, with a tough grittiness that at first seems unappealing, but can later be seen as an enormous asset to her survival in a world that can sometimes be cruel and uncaring. By standing in Dolores' shoes, DSPs who work with youth and young adults with or without disabilities can gain tremendous perspective on how they can support individuals to find their gifts, talents, and strengths and to help them feel welcomed and valued in the world. This novel is published by Washington Square Press and can be purchased at most bookstores for \$14 in trade paper format. Its ISBN is 0671003755.

The Other Sister

In this uplifting, romantic comedy, 24-year-old Carla Tate (Juliette Lewis), a person with a developmental disability returns home to live with her parents Elizabeth (Diane Keaton) and Radley (Tom Skerritt) after she graduates from a special education program at a private boarding school. Carla is convinced that she has the capacity to live a more independent life. She successfully finds a job, makes new friends, and wants to live alone in an apartment despite her mom's many objections and overprotective instincts. Carla meets Danny (Giovanni Ribisi) and the two of them embark on a journey to experience many of life's tough challenges and to find answers to some of life's questions. Together they prove that each person is unique, that life can be fun, challenging, and mysterious, and that even overprotective parents can learn to appreciate and accept their adult children no matter what path they choose. This film will be available on videocassette September 7, 1999.

DSP Points to Ponder while viewing — How are your thoughts and feelings regarding relationships, love, and sexuality different or similar to Carla and Danny's friends and family members, and how do your perspectives influence those to whom you provide supports? How can individuals, teams, and the organization modify their policies and practices to be more supportive of individuals in making choices that better meet their needs and dreams?

Understand Me Not My Disability

“ I want you to understand me.” These words were articulated by two young adults who have complex communication needs in an interview about how Direct Support Professionals (DSPs) can offer better supports to them.

As a speech pathologist at South Mississippi Regional Center (SMRC), a state agency that supports people with developmental disabilities in community homes and through other programs, I work with many individuals who have complex communication needs. Both Chris and Donna have formal diagnoses of cerebral palsy and mental retardation and require intensive support to complete the activities and tasks of daily living. They wanted to share their insights into how DSPs can help them live a meaningful life.

Chris lives in a community group home and is employed in a work program. He uses a Dynavox communication device, gestures, facial expressions, and a communication book and display to express himself. Donna lives at the regional center and works at White Harbor Industries. Although Chris and Donna couldn't use words to communicate, they related their thoughts to me through the Dynavox, communication books and displays, gestures and facial expressions. DSPs who know them well verified that I accurately interpreted their comments.

Chris said some of his main problems are talking, walking, and using his hands. Donna firmly denied

seeing herself as having disabilities. She stated that DSPs need to see her as an individual with challenges rather than disabilities. “I don't think of myself as having disabilities. I think about having challenges and opportunities. I want to be good on

a computer, go to school and become a teacher who works with babies. My challenge is to achieve these dreams.”

Chris and Donna made several recommendations for how DSPs could better provide supports for people with complex needs. Chris said, “Talk to me. Talk to

them. Talk to us more. Show me how to talk on my Dynavox to my friends. I really want to be able to talk on the phone. People can help me get the basic things done. I really want more fun time with my friends.” Donna said she also wanted things that most people want: “I want to spend money in a big department store. I need ways to earn money and this means I need Craig and Marsha [my DSPs] to help me get work that I can do. It's hard work to help me and my friends, and I thank them.”

Chris and Donna could recount details about the DSPs who made real differences in their lives. For Chris, that person was Kathy, who moved away six months ago. “Kathy doesn't work here anymore, but she knew what was important to me, like my birthday and making money. She made me feel handsome.” Donna described the influ-

ence that Tracy, a DSP, made on her life — “Tracy went with me on a trip to the T. K. Martin Center. This meant I could be evaluated for a communication device. I wasn't scared because Tracy went. I also had another big trip. Carol and Naomi went with me to Disney World. It was so fun. We played all the time!”

Donna and Chris agree that DSPs can do a lot to help them fulfill their dreams. “Because Tracy helped me get this evaluation, I have new hopes and dreams about what I can do. I want to be a teacher and have a regular life. DSPs can help me get it.” Chris said, “I know it's hard work, but you go with me like I'm your family. You take me places I love. My dream is to go camping with all the people who have been important to me.”

Like all people, individuals with communication challenges share the need for connectedness with the people, places, and events in their lives. Assistive technology has created remarkable opportunities for advancing communication and connecting with experiences that add depth to life. But no device can replace the essential personal connections with other people. DSPs play important roles in facilitating these personal connections. DSPs who live, work, and learn with Chris and Donna recognize that they can and will go far in life with the essential supports provided by trained, caring professionals.

Bobbie Carraway is a speech/language pathologist for SMRC in Long Beach, Mississippi. She may be contacted at 228.867.1377.

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Alliance Addresses Ethics in Direct Support Welcomes New Co-Chairs

Members of the National Alliance for Direct Support Professionals recently gathered in "N'awlins" (aka New Orleans) at a meeting hosted by the American Association on Mental Retardation. Direct Support Professionals (DSPs), researchers, policymakers, and administrators gathered to discuss critical issues faced by DSPs.

Perhaps the most critical issue discussed was follow-up of the ethics survey and DSP focus groups regarding ethical practice in direct service. Alliance members decided that additional focus groups should include family members, consumers, and DSPs to gather information from more perspectives. The Washington Alliance for Direct Support Professionals (formerly Partners in Independence) offered to conduct a survey on ethical practice via their Web page — <http://members.aa.net/~juliew/jeff/wadsp>. Once this information is processed, it will be used by the Alliance to craft a, *Statement of Ethical Practice for Direct Support Professionals*.

Other exciting decisions were made regarding Alliance leadership

and regional/local representation. Upon unanimous vote, Marianne Taylor and Mark Olson were welcomed as "official" Co-Chairs to join James Meadours, who has remained a Co-Chair since the Alliance formed in 1997. Also, two states have developed new local initiatives and joined the Alliance as regional groups. Representing New Hampshire is Carole Thibodeau (3 Commerce Drive c/o Region 10 Community Support Services, Athensen, NH 03811; 603.893.1299) and representing Washington (state) is Jeff Welch (Washington Alliance for Direct Support Professionals, 6201 15th Ave. NW, PMB-532 Seattle, WA 98102-2382; 206.706.8159; jeffw@aa.net). These new regional representatives will begin participating on the Alliance Steering committee, will work to achieve Alliance goals in their communities, and will keep the Alliance informed on activities in their states.

Alliance members also committed themselves to facing the new millennium enthusiastically. Look for great changes, great materials, and effective

leadership from the Alliance in 2000. We are committed to delivering to our member organizations the following in the year 2000 —

- An ethical statement of direct support practice
- A publication that highlights credentialing and training programs for DSPs
- A publication that identifies "best practices" in workforce development for DSPs
- New recurring articles in *Frontline Initiative* — "Spotlight on States" and "DSP Policy/Legislative Initiatives"
- An updated and more interactive Web page

We look forward to moving ahead together in 2000 on these important issues. Many thanks to all Alliance member organizations and friends who continue to promote the enhanced status, better training and education, improved partnerships and new policies regarding DSPs — your commitment and effort does make a difference!

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Achieving Dreams, continued from page 3

that she enjoyed spending time with her parents, and that it would be good for her to move close to them. The family's interaction provided this insight.

- Considering what the person is trying to say through unwanted behaviors. One person would get upset when a meal was served. By seeing things from his perspective, they found he wanted to choose what food items went on his plate. When he chose them, his behaviors stopped.

Help people achieve their goals by —

- Helping people make honorable choices. One man wanted to cut down the trees in the back yard. DSPs were challenged to find alternative activities that met the man's needs without leading to property damage — instead they go to a treeless park.
- Not taking things personally. A DSP must not personalize aggressive verbal or physical behaviors.

One man would yell at staff when upset. Instead of taking offense, staff let him vent his anger and then later continued on with their usual friendly relationship.

- Celebrating the small steps. One individual is preparing to move to his own apartment. He got a checkbook to prepare for the move, but was frustrated by his lack of writing skills. Staff prepared letter-writing worksheets for him which he diligently attended to (though at times with some protest at their homework-like nature). Eventually, he was able to write his letters independently and use his checkbook effectively. The staff celebrated with him by presenting him with a certificate of achievement for excellent work.

Aaron cautions people looking into this type of work to nurture their ability to see and celebrate the small steps. Progress and change can be slow for a variety of reasons re-

lated to people's disabilities or to their experiences. Nevertheless, he feels that the rewards from seeing someone achieve a personal goal or a better quality of life definitely make the job worthwhile.

This article was written with information provided by Aaron Masden who has worked as a DSP at one of ACR's homes and is currently a residential supervisor at the ACR home highlighted in this article and program director for another ACR home. You can reach him at 612.532.8810.

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