

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Changing Roles
Frontline Initiative Newsletter

Changing Our Ways

Staff roles at two agencies changed dramatically when the agencies moved from traditional supports in group homes to individualized supports. Stories of this were collected by the Center on Human Policy at Syracuse University.

Onondaga Community Living (OCL)

“It’s like heaven forbid that OCL should be in someone’s way. So that’s what I want to make sure [that] we are not in someone’s way of being the best that they can be and having the life that they want.”
— Richard, DSP

The staff people of OCL dream, plan, and work with individuals and families.

They are there to help in a crisis and to provide support through good and bad times. Staff members are the most important resource of the agency.

In many ways, working at OCL is seen as more difficult than in working at a more traditional agency. OCL staff must be able to make important decisions, solve problems, and help people get involved in their communities. However, along with the responsibilities are freedoms and flexibility that go well beyond those typically enjoyed by staff members of other organizations. Creativity is encouraged and rewarded at OCL.

Because staff roles and tasks are determined primarily by the changing needs of

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DSPs from the Peoples Republic of China welcome their American guests. See the story, page 6.

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Frontline Notes

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This past Fall has been a trying time for our nation and for many of us individually. Our thoughts go out to those of you who were directly affected by the events of September 11, and to the on going struggles we all face as we adapt to a new understanding of the world. We profoundly respect, admire, and thank the hundreds of Direct Support Professionals (DSPs) who helped people with disabilities in New York City and Washington D.C. survive the terrorist attacks. Hundreds of people with developmental disabilities are survivors because of the competent, skillful and committed DSPs who ensured their safety. You are our community heroes.

As our President has asked us to do, we are going on to try and live our lives as normally as possible.

People with disabilities who we support still need our attention. DSPs still and will continue to provide a valuable service for this country — services which continue to undergo dramatic change.

Large institutions were once the only place people with disabilities could find services. As the move towards smaller community settings occurred, so did a change in the practice of direct support. We came to believe that people with disabilities should be a part of their communities and that people with disabilities ought to lead a life similar to other adults in their communities. “Integration” and “normalization” became marks of quality community services, forever changing disability-related services.

More change is underway. People with disabilities came to realize that living in a community wasn't

enough, nor was simply leading a “normalized” life. Control of the resources and services provided to people with disabilities came into question. It became clear to people with disabilities, their families, advocates and others, that until people with disabilities were able to make their own choices about the services they received and the way in which they lived their lives, their needs were not truly going to be met. These principles of best practice are switching focus to self-determination and consumer directed supports.

This is where you as DSPs are so critical. Without your skills, knowledge, relationships, and support of people with disabilities all of the great ideas in this field will never happen. In this issue of *Frontline Initiative* we address the changing roles of DSPs — from asking a person who receives services what they want, to hearing the stories of some agencies that have changed their practices. We will all also learn about the direct support profession in the People's Republic of China, a situation which provides an interesting contrast to the activities here in the United States promoting direct support as an important profession, and also shows us there are many things we too still need to address in this profession.

Our next issue is about legislative advocacy — What is it and how do you do it? We will hear from DSPs that are taking action on their own behalf in their state Legislatures and learn what legislative actions have occurred and are pending which may impact DSPs.

—The Editors

NADSP Member Organizations and State Contacts

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
- JFK Jr. Institute for Worker Education
- 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 on 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 Association

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Join NADSP and Represent Your State

For information on NADSP membership or becoming an NADSP State Contact, please contact one of the NADSP Co-Chairs (listed above).

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Frontline Initiative is available in alternate formats upon request.

The Real Scoop

Welcome to *The Real Scoop*. Clifford is a self-advocate who has been politically active for years. He's here 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.

Looking to the Future

Dear Seth and Cliff,

I am a DSP working in a home supporting four individuals with severe disabilities. I have read about new technology that allows individuals to communicate through a computer and I think it would benefit more than one of the people that I support. My agency seems only concerned with the bare essentials of food, shelter, cleanliness, and clothing. How should I go about advocating for those I support to gain access to the funds for these devices and also increase the motivation of the agency and my fellow staff to start considering more than just the basics?

Sincerely,

Searching for More than the Basics

Dear Searching:

Is happiness and living a productive life a bare essential? I know it is. If your agency has some brains, they know it too. They hired you, didn't they? If there isn't a consumer advocate on staff in your agency and/or your memos to your supervisor prove

fruitless, there are other steps that you can take. Start doing research on local or national resources. Some good web sites are <http://www.abilityhub.com/>, <http://www.netaccess.on.ca/~galambos/tech.htm> and <http://fctd.ucp.org/>. Some self-advocate groups have contacts for grants and possible low-cost options for needed technology. You may also want to connect with the person's support coordinator (case manager) about possible resources. You could also have your consumers' families start a letter-writing campaign to your agency. Together, your agency might listen to a proposal that you and the families put together. It is going to take work, diplomacy, and time. Your consumers are worth it and you will grow from this experience in your own life.

Let me know,
— Seth

Dear Searching for More,

Try contacting The Office of Technology in your state. They should have funds available to the community. There should also be funds through the individual's vocational rehabilitation agency because of the need for communication in the workplace. It is very important to educate the other DSPs and administration by explaining the benefits to be gained by the agency and the people that are supported. The agency will be better off in that if you provide the needed service in the present, it will be a lot cheaper than in the future. Especially in the area of communication, if someone can speak for themselves, problems and issues can be addressed now before they develop into crisis. Most importantly, communication is essential for individuals to have quality of life. It is everyone's right to have access to devices necessary for communicating wants, dreams, and needs.

— Cliff

Ask Clifford and Seth

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

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

Changing Your Role

Five years ago, my friend Cory decided that he wanted a home of his own. Cory already owned his own car, and he had a steady job at a local supermarket. But, what he really wanted was a home of his own, in his hometown, and near his parents' home so he could continue the close relationship he enjoyed with them. He shared this desire in conversations with his parents and with his community case manager. He and his father set out to work within the system to find a way to make his dream come true. To make what could be a long story much less excruciating, three years ago, Cory moved into his own home using creative financing and with the participation of supportive direct support professionals (DSPs).

The evolution of the disability rights and self-advocacy movements within the disability community have brought about significant changes in the roles of DSPs and the types of services they provide to individuals with disabilities. More and more, DSPs are required to provide support services that enable the empowerment of people with disabilities, and not merely provide the traditional direct care supports we have known since the beginning of the deinstitutionalization movement in the late 1960s. Even the role of personal care attendants (people who provide in-home supports to people with disabilities and the elderly) is changing, moving from the traditional medical model to a more consumer-directed approach that ensures individuals with disabilities the ability to self-direct their daily care and supports.

DSPs are required to provide support services that enable the empowerment of people with disabilities, and not merely provide the traditional direct care supports we have known since the beginning of the deinstitutionalization movement in the late 1960s.

It is believed by many that the traditional model creates situations that promote long-term dependence and deny individuals who receive supports a direct decision-making role in determining the course of their lives. The evolving consumer-directed model, evidenced at more than 450 Centers for Independent Living Nationally (NCIL, 2001), as well as other community direct service provider agencies, allows individuals with disabilities to have a more direct say in deciding the contents of their individual support plans (also known as habilitations plans or service plans).

The role of DSPs is also changing dramatically in classrooms, community-based settings, residential services, and social services settings

that provide services to young people with disabilities. Because of the increasing attention being paid to transition services, young adults with disabilities are often connected to community supports at earlier ages. Supported employment and individualized day supports are also more prevalent, resulting in DSPs working in diverse settings and striving to meet the unique needs of people with disabilities. Families also have different expectations that have resulted in changing roles for many DSPs. Often families want the DSP to support their son/daughter or brother/sister within the context of the family and within the specific community in which the person lives. Additionally, families want assistance from DSPs in making community connections, and establishing new relationships and friendships.

How can DSPs effectively prepare themselves for these changing roles? First, be informed. Learn more about the principles and practices of the Independent Living (IL) movement and consumer-directed supports. The principles of the IL philosophy are at the heart of the self-advocacy movement and can make DSPs aware of the expectations held by many individuals with disabilities about the services they need and want and how they should be delivered. You can visit your local Center for Independent Living (CIL) to learn more about this, and to gain insight into consumer-directed services model. If you are unsure of the location of the CIL

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The Role of DSPs in the People's Republic of China

During the summer of 2000, I was invited by the AAMR to be a delegate to the People's Republic of China (PRC) under the auspices of the People to People Ambassadors Program, the Brain Injury Association, and the Ministry of Health of the PRC. People to People was started by President Eisenhower in 1958. He saw the need to work to prevent war like the one he had experienced all too personally. The idea was to have small group interactions to share professional information and important cultural values in order to build bridges of understanding instead of walls of suspicion.

The cost for two weeks in China was around \$6000 (not affordable on my DSP salary). Fortunately, due to the support from several sponsors, I was able to go. My sponsors included Area Agencies Regions VI and X in New Hampshire, the Nashua Center for Multiply Handicapped, the New Hampshire Brain Injury Association, the Division of Developmental Services in New Hampshire, the New Hampshire Developmental Disabilities Council, and the Nashua Exchange Club. I have been doing direct support in New Hampshire since 1991, and for the past 6 years, I have also been involved in NH's direct support movement. I have done volunteer work representing DSPs for most of the above agencies. Trust me, it pays to be involved!

The group going to PRC was larger than originally planned. Among the 36 of us, there were self-advocates, family members, administrators, therapists, lawyers, a

Although jobs are assigned in PRC, human service jobs are not desirable. Pay, prestige, and the like are low, as is the marriage rate for people working in human services. It is unpopular work in society's eyes. They dress in white gowns, the color of mourning in China — not exactly inspiring!

the capital of PRC, with 14 million people. Xian is an ancient city at the end of the old Silk Road and has a significant Muslim population. Guilin is a subtropical riverine and a beauty that only a small city (600,000) can show.

We saw few people with disabilities in the community. A few individuals with physical disabilities were seen begging at tourist sites. We did not see a single person with an obvious

doctor and one other DSP. She and I did what we could to carry the spirit of direct support to China.

We hit three cities in ten days: Beijing, Xian, and Guilin. Beijing is

developmental disability out and about. There were very few accessible places beyond some hotels and airports, and there were various barriers, beyond physical ones, that



Nurse station at Xian Mental Health

we faced. Time was short, only a couple of hours per visit, and the size of the group made movement slow. Other barriers, such as “loss of face”, were due to cultural differences. Disability is viewed as an embarrassing thing in PRC, not something to share with others. Also, there is the Communist system, which by nature is secretive. Furthermore the language barrier stymied interactions.

There were some obvious differences in supports to people with disabilities in China that I observed. China has long used practices such as acupuncture and aromatherapy and therefore, seemed more advanced that way. They also made family involvement key to any therapy or support services. Communities support those individuals without a family. This was all part of the community context. Everything

in PRC is done for the group, community, and society.

It seemed that some people with disabilities lived at home, while others lived in institutions. But we did not catch more than a glimpse of the institutions, so I can't really comment in depth on the care provided within them.

Although jobs are assigned in PRC, human service jobs are not desirable. Pay, prestige, and the like are low, as is the marriage rate for people working in human services. It is unpopular work in society's eyes. They dress in white gowns, the color of mourning in China — not exactly inspiring! Yet, those in this field seemed to genuinely care even though concepts such as self-determination seemed far away, and the environment was cold, clinical, and sterile. However, there was a sense of common purpose. Although

they worked in a service system very different from our own, we could see our colleagues struggling with some similar issues: little funding, low morale, and the deep desire to reach out to others.

One of our members toasted us at the farewell dinner, saying: “To the DSPs like Michelle and Andrew, without them we are nothing, without them we can go nowhere, and without them there is no hope.”

Andrew P. Horton is a DSP and can be reached at 603.230.9930 or andrew@wooglin.net.



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You are invited to an international conference led by experts from every continent. This conference will challenge and inspire participants to develop direct care as a profession.

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Direct Care Conference 2002

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New Paltz, NY 12561

It Can Be Done

My dream is to go to college, get a decent paying job, own a car and be able to drive it, and eventually have a house and raise a family. At many times over the years, it didn't look like dreams would ever come to be. But I kept saying, "It can be done. It can be done. IT CAN BE DONE. PERIOD."

The main support I need is in getting integrated into the community. Ever since I can remember I had a provider agency providing DSPs to do this. There were lots of things that frustrated me about this arrangement. I had to deal with no shows and excuses for reasons things were not getting done. Everyone admitted that there were things not being done, but there seemed to be nothing happening to change things. It was a constant frustration with support staff and the agency itself to support and encourage activities that I wanted to do. They would decide what activities I "should" participate in. I wanted to meet people, to begin dating, and get my driver's license. But they wanted to dictate who I should date and where I should be meeting them. They didn't want to support me in getting a driver's license because of liability issues.

I was on the waiting list [for a Home and Community Based Services Waiver] for a long time, but not as long as some people. I was nervous I wouldn't get approved. Some people have been waiting on the list for 17 years and still didn't get approved! But, this past June I heard the news — I was approved! I was now on my way to really living my life the way I wanted.

It didn't happen exactly that quickly though. We had several large meetings to work out what we have to do to participate in the Waiver program. Then we had to make a yearly budget stating what the services would be and where

I hope that I can find DSPs who will support me in my own life and how I want to live it. I'm looking for the basics: trust, loyalty, someone who shows up when they say they are going to, and some one who has an interest in what I am doing.

the funds would be going to. Then we had to send it into the state of Minnesota to get approved. Almost everything was approved. Again, another step towards living my life the way I wanted to.

Right now we are trying to get good people to work for me. I still work with a provider agency. The waiver money still goes through an agency and then is paid to employees, but I get to decide who works for me and who doesn't. I also get to develop the goals and say what I want to do.

One of the biggest things that I have done is attempt to hire new people and fire the bad ones. I hope

that I can find DSPs who will support me in my own life and how I want to live it. I'm looking for the basics: trust, loyalty, someone who shows up when they say they are going to, and someone who has an interest in what I am doing. It's a lot of work to interview and decide who to trust. I also get to pay people a decent wage and they get a bonus if they do what they're supposed to do. But no matter how hard it might be, it's worth it because I am the one who is doing the deciding!

I am privileged that I am now the decision-maker; however, a lot of people don't have that option. It really is a civil right for people to be able to make their own decisions. The only time that it is acceptable to intrude on that is if someone is in danger. The best way to understand this is to put yourself in your clients' shoes. Is this what you would like your life to be? And work from there. Eventually, these things will work out. We have come a long way in the disability rights movement. I look forward to a time when my dreams are being fulfilled, when agencies improve, when funding and training improve, when policies protect DSPs that take risks. I look forward when we all don't have to wait for agencies, but can make changes and obtain our goals on our own schedule, instead of waiting for an agency to okay it. I look forward to when all people with disabilities are recognized as equal citizens with the same rights as anyone else in this country. It Can Be Done. It Can Be Done. It Can Be Done. Period.

Nathan Perry is a self-advocate who works in the shipping department of an electronics company in Minneapolis, MN.

Member Profile

The Commission on Accreditation of Rehabilitation Facilities (CARF) is a private, not-for-profit organization. It was formed in response to the need to promote quality programs for people with disabilities and others in need of services. CARF continues to develop and maintain practical, consumer-focused standards to help organizations measure and improve the quality, value, and best outcomes in the lives of the individuals they support.

Both CARF's vision and mission statement explain the purpose for all of the services that CARF provides —

- The mission of CARF is to promote the quality, value and optimal outcomes of services through a consultative accreditation process

that centers on enhancing the lives of the persons served.

- Through responsiveness to a dynamic and diverse environment, CARF serves as a catalyst for improving the quality of life of the person served by CARF-accredited programs and services.

One of the main ways that CARF works toward its mission and vision is through its accreditation process. CARF accredits programs and services in Adult Day Services, Assisted Living, Behavioral Health, Employment and Community Services, and Medical Rehabilitation. Each year CARF invites consumers, family members, providers, payers and other interested individuals to play a part in reviewing the standards for accreditation to keep pace with changing conditions and consumer needs.

While many think of an accreditation survey as an inspection that an agency will or will not pass, CARF uses a consultative approach to actually assist agencies in improving the quality and value of their services. The survey team is selected by matching the surveyor's area of expertise with the agency's unique needs. The survey team then offers helpful consultation to meet the individual needs of the agencies.

In addition to providing consultation during an accreditation survey, CARF coordinates three international conferences and regional CARF seminars across the country. These seminars and conferences provide the latest information on the standards for accreditation and new procedures that will assist agencies in receiving accreditation.

Best Practices Nominations

The Research and Training Center on Community Living (RTC) at the University of Minnesota's Institute of Community Integration is seeking nominations for best practices in Direct Support Professional (DSP) workforce development. The program or initiative can be large or small, a single agency or state wide, but must advance the goals of the NADSP —

- Enhance the status and image of DSPs.
- Provide better access to high quality educational experiences and lifelong learning which enhances competency.
- Strengthen the working relationships and partnerships between DSPs, self-advocates, other consumer groups and families.
- Promote systems reform which provides incentives for educational experiences, increased compensation and access to career pathways for DSPs through the promotion of policy initiatives.
- Support the development and implementation of a voluntary credentialing process for DSPs.

For further information and a nomination form please email Amy Hewitt at hewit005@umn.edu or call 612.625.1098. The nomination deadline is **March 30, 2001**.

Direct Support Empowerment

The Key to Effective Person-Centered Organizations

Many self-advocates, families and professionals have utilized person-centered planning as a tool in developing quality supports for people with developmental disabilities. Independent Living, Inc. began its evolution toward a person-centered organization in 1990. The Independent Living, Inc. staff responded to person-centered training with excitement and enthusiasm, developing a shared vision of inclusive and supportive communities.

The culture of Independent Living, Inc. is similar to a nurturing family. The majority of the DSPs, managers and administrators are African-American, many belonging to the same social organizations, churches, and community clubs. The culture lends itself to open communication and mutual respect. In addition, the history that is shared by the African-American staff supports a high level of commitment to the mission of the organization. The staff have personal knowledge of the challenges and benefits of self-determination and community membership.

After many years of a commitment to person-centered supports, we took a critical look at quality outcomes and discovered limited effectiveness in supporting meaningful community membership experiences. There were examples of community membership, such as Dorothy, who despite a life-long label of severe mental retardation, had become a member and equal participant in her church beautification club, and Rita who got the job of her dreams at age 45. However, these examples did not represent

typical life for most of the persons we supported. Life for most continued to be of isolation and friendlessness.

Our key challenge was to reorganize in a way that would be more likely to deliver the outcomes of community membership. The core

DSPs had to become more active, more empowered and more supported as the key person-centered thinkers of the organization.

organizational change was redefining the role of Direct Support Professionals (DSPs). DSP roles had to become more active, more empowered and more supported as the key person-centered thinkers of the organization. We promoted this change by developing two self-directed work teams comprised primarily of DSPs: SPAN (Support Professionals' Action Network) and LaCumba (Louisiana's Community United Membership Building Alliance).

Using the self-directed team structure gave DSPs the necessary authority to take action, gain access to the resources of the organization, and provide accountability for outcomes. The primary role of

managers on the team was to provide support. The teams took direction from the identified mission of the group. The self-directed team structure encourage DSPs to use and value personal skills developed through life experiences.

The LaCumba, (a Swahili word meaning "the heart of our community") team has as its mission the promotion of community membership for persons with disabilities. The team is made up of staff who are interested in the mission and who themselves are active in their communities. The DSPs brought to the team an extensive knowledge of their community. The project identified community leaders and asked them to take an active role in developing and implementing a plan to bring citizens with disabilities into full community life.

After each meeting with community leaders, the LaCumba team met to implement the strategies developed. This follow-up phase required DSPs to act as connectors and facilitators rather than as skills trainers, a role so often associated with direct support. DSPs state that these new roles are much more rewarding and support more meaningful results. Six of the eight persons participating have been connected with membership opportunities supported by a community leader.

SPAN, the second DSP work team, has as its mission: To support each other emotionally and professionally. The SPAN team surveyed all employees and used the results to prioritize activities. The need for peer support and employee recogni-

He Allowed Me in His Life

Being employed directly by a person receiving supports is an important change that is occurring for many Direct Support Professionals (DSPs). Sally McGurn interviewed JoAnn, a DSP in Kansas who was hired directly by the person she supports, and heard an inspiring story.

Sally: How were you hired?

JoAnn: I worked with Nathan at a residential setting and got to know him well. Nathan and his mother were not happy with the services he was receiving at the time. His mother heard about an apartment that might work for Nathan and checked it out. Nathan and his mother decided that the apartment would work out and so Nathan moved. It just happened that I ended up supporting Nathan after he moved. I had been providing supports to Nathan for about a year and knew him so well that his parents hired me and I chose to work for him. I left the agency I was working for to provide supports for Nathan. Nathan likes me and he likes doing things with me. We have a good relationship. We were excited about working together! The move was a scary time for Nathan and it helped to have the security of someone he knew and of someone who knew him. It really helped with Nathan's transition. People were coming in and out of his life and this was an opportunity for him to have someone he had known for a long time to continue to provide supports for him.

Sally: How do you work out conflicts with Nathan?

JoAnn: I deal with things in a positive way with Nathan. He is not able to verbally communicate his needs so we play 101 questions. I ask a lot of yes/no questions. Nathan is very adamant that you understand exactly what he is trying to communicate and he will not stop until you understand. He is not one to give up! It takes patience and really getting to know Nathan and his likes and dislikes. He likes things a certain way. For example, he likes the closet doors shut, his bed made, and the arm rests in the van up!

Sally: What are the benefits of being hired directly by Nathan?

JoAnn: I have a lot more say about providing Nathan's supports. There are not as many people you have to consult with to make a decision. It makes more things happen in a more timely manner because you don't have as many people to go through. There is direct communication and direct contact with people involved in his life. I feel strongly that I work for Nathan first and foremost — before anyone else.

Sally: What are the disadvantages of being hired directly by Nathan?

JoAnn: I work for Nathan, but there are boundaries. When you work so closely for a person as I do with Nathan and his parents, versus in a group home, it is important to establish boundaries. In a group-home setting staff would never go over to the parent's house. But relationships still need to stay on a professional level. I don't need to be a part of Nathan's family. I need to be something a little bit different — I am Nathan's advocate. I need to be

objective and do what is best for Nathan — what Nathan needs. My main points are that I am his advocate, not a family member, and that it is important to keep and set boundaries.

Another disadvantage is that I do not receive benefits such as health insurance, leave pay, a retirement plan, etc. I pay for my own benefits. I do receive a small amount from Nathan's parents that pays for some of my off time. I pay out of my pocket for any expenses when I am out and doing things with Nathan. I would like to see an organization that helps people who are private providers pay for health insurance.

Sally: How does working for Nathan differ from working in more traditional settings like a group home?

JoAnn: I worked in group home settings before where we supported six to eight people per home. You work with two to three individuals but really don't have a whole lot of time to spend with them. Do you really get to know people? This is unique with Nathan because I am one to one with him. We really need to increase staffing for more one-to-one time so we can get to know the people we support.

The problem I saw in the group-home setting was high turnover. It is unfair to the men and women getting supports. I think we ask more of the individuals we support than we ask of ourselves. Security and a safe feeling is critical. In a group home setting I think it is important to talk more frequently with the direct support staff because

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nearest you, contact the National Council on Independent Living (NCIL) at www.ncil.com. If there is not a CIL located in or near your community, you may wish to search out a local branch of a self-advocacy organization like People First (primarily focusing on issues important to individuals with developmental disabilities), TASH (www.tash.org), your state office of your State Council on Disability (SCD) and/or Developmental Disability Planning Council (DDPC), or the National Council on Disability (NCD). Becoming aware of the philosophy and activities of such organizations will give you powerful insight into the national self-advocacy movement.

Second, talk and listen to people with disabilities. Many individuals with disabilities will be forthcoming about their needs and wants. It is up to us as DSPs to listen and act on their statements. Many people with disabilities have been taught to be compliant in order to avoid retaliation or removal of services. No one should live under fear of retribution, particularly people requiring support services to live their lives, people who have historically been subjected to worst kind of dehumanizing treatment, and people who have been isolated. It is up to DSPs to listen to the people they support and to work with their employers to create new service models that respect individuals with disabilities. Even if you believe you and the agency for which you work are providing high quality services (and you probably are), it means little if the person who receives those services is never asked about

unique needs, preferences, and level of satisfaction.

Third, read. There are numerous publications available that will give you additional insight into the self-advocacy and disability rights movements and the new demands these place on DSPs. Reading material can be found at your local CIL, from the University of Minnesota's Institute on Community Integration, and from the National Association of Paraprofessionals. You can also check with your local university or community college to determine if they offer any classes for DSPs. Increasing your skills and competencies in providing quality direct services is important for your career development and to ensure that your capabilities in providing the most up-to-date, state of the art community based services.

Finally, choose. As a DSP you can encourage successful community inclusion for individuals with disabilities. I also know that the decisions you make daily as a DSP about the way you choose to interact with individuals with disabilities are critical. It is up to you, the individuals working on the "frontlines," to ensure an environment that promotes dignity and choice for individuals with disabilities. If the environment is not currently one that guarantees simple forms of consumer choice, ask yourself a question, "What am I willing to risk today?" Are you willing to take a risk for another person's fundamental dignity? I hope so, because it is truly the DSPs that will make the difference. Legislatures can pass all the laws they want, administrators can make all of the policy decisions they choose, and boards of directors can come up with all

the fancy slogans they wish. Believe it when I tell you, it is up to the DSPs to make the real difference. So, that is my final piece of advice: be willing to take a risk.

David Hancox is Executive Director of the Metropolitan Center for Independent Living which serves the seven-county metro area of Minneapolis/St. Paul. He can be reached at 651.646.8342.

Direct Support Empowerment,
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tion were listed as high priorities. The team developed mentors who offer training and technical assistance to employees who request it. Peer support is also offered in the form of social activities and informal gatherings. All new hires are given the names of the SPAN steering committee along with phone numbers and an invitation to participate in activities.

Although the use of self-directed work teams is relatively new to Independent Living, Inc., the success of the teams is undeniable. Such success is due to the empowerment of DSPs along with the shared values dictated by person-centered thinking. The team allows direct support professionals to draw on their individual a cultural consciousness to build toward better communities for all.

Jacquelyn B. Blaney, MSW is the Executive Director of Independent Living, Inc. in Baton Rouge, Louisiana. She can be reached at 225.924.7998, Fax: 225.924. 7715.

the people that they support, day-to-day staff activities vary greatly. There is a tacit understanding that everyone will jump in and help in an emergency. People who need clean boundaries between work and their personal life do not last long at OCL, but staff retention has been excellent among those staff that enjoy the level of personal involvement required at OCL.

As the transition began, staff worked part of the time in the group home and part of the time in someone's own home. As time went on, however, it became apparent that the group home mentality was perpetuated by this arrangement. It became critically important that people's negative reputations be left behind, giving each person a fresh start as they entered their new life outside the house.

Over the years, DSPs at OCL have learned more about how people who traditionally had 24-hour staff support could be supported safely and effectively with more nontraditional means. They began working cooperatively together with family, friends, and fellow DSPs to discover how to best meet the support needs of the person. In the best situations, there is no line of authority. Rather, everyone works together on behalf of the person. Assignments or roles are determined depending upon what the need is and what personal attributes each family member, friend, and staff member brings to the group.

Finally, a principal value of staff is maximizing the opportunity for real community involvement by helping people to link up with community members and form relationships

with them. Staff are constantly and acutely aware of the importance of friendships to the happiness and fulfillment of people supported by OCL and they continuously experiment with new ways to enable this to happen.

From Fratangelo, P., Olney, M., & Lehr, S. (in press). *Coloring outside of the lines: How one agency embraced change one person at a time*. St. Augustine, FL: Training Resource Network.

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Jay Nolan Community Services (JNCS)

During the first two years of change, administrative staff were given the freedom to continuously reorganize in ways that made sense. The staff roles that worked within the group home model did not make sense with this new approach.

Overwhelmingly, DSPs who have been successful attributed it to having a positive relationship with the person they support. The chances of finding DSPs who are compatible are increased by the fact that they are selected by an individual's circle. The reality for many people, however, is that it is very difficult to find DSPs who work out well. In fact, several people have had an incredible number of changes in their DSPs. One man had over 20 different DSPs in the first year he lived in his own place. Now he has had the same DSP for almost 2 years. In the most stable situations, DSPs have included the people they support in their own circle of family and friends.

On an administrative level, staff were given the opportunity to identify their roles and responsibilities based on their particular strengths and interests. For example, some people provide training because they are good at it, and others have taken responsibility for paperwork and finances.

In order to support and assist staff, a strategy of the agency is to provide opportunities to learn from each others' experiences. Once a month, staff from the vocational, family support, and support living programs get together to celebrate their successes and share ideas. In addition, JNCS has developed a mentorship project. It is based on the belief that the typical one shot training is not an effective way to learn about supported living. For example, after staff are trained in person-centered planning, they receive ongoing support to implement what they have learned.

From Hulgín, K. (1996). *Jay Nolan Community Services: The advantages and dilemmas of converting quickly from group homes to supported living services*. Syracuse: Center on Human Policy.

Pam Walker works at the Center on Human Policy School of Education, Syracuse University and can be reached at 1.800.894.0826 or thechp@sued.syr.edu, <http://soeweb.syr.edu/thechp/>

Frontline Resources

Career connections by AAMR

This online job service for professionals in the disabilities field is an excellent site for posting resumes in a searchable national database. The service is free and almost 9,000 interested individuals and companies have visited the site over the last few months. Go to <http://www.aamr.org/Careers/careerframe.shtml> and select “search for a job”.

AAMR/Lewin RADAR

News Web Site

This Web site is an excellent place to find out about key issues and emerging trends relevant to self advocates, families, providers, DSPs, and others interested in issues around developmental disabilities. It is a compilation of articles from newspapers, newsletters, professional journals, and national and state reports. <http://www.radaraamr.com/>

Funding of Assistive Technology—The Public School’s Special Education System as a Funding Source

This is a booklet Published by United Cerebral Palsy Associations and Neighborhood Legal Services in Buffalo, New York. It can be used to find opportunities to use technology to support students, family members and personnel. Please contact Susan Goodman Esq. at sgoodman@ucpa.org to request a copy of the booklet.

Managed Health Care Curriculum

This is a unique training resource for self advocates, families, and DSPs who use the managed health care system. It explains managed health care in a clear, easily understood format and shows how to navigate the health care system. It also trains DSPs to support the health and well being of the individuals whom they support. To order contact —

Robin Risley, Project Coordinator
The Boggs Center-UAP
335 George Street
New Brunswick, NJ 08903-2688
Phone: 732.235.9310
Fax: 732.235.9330
Email: risleyre@umdnj.edu

Different Moms

This is a very well-done video about parents who have developmental disabilities. It is an excellent resource for anyone involved in the lives of people who are parents and have a developmental disability. For ordering information please contact —

David Stearns, Community Outreach Coordinator
Moxie Firecracker Films
180 Vacik St. Suite 1302
New York, New York 10014
Phone: 212.620.7727
Fax: 212.366.5247

In Our Words

This is a video of self-advocates in Vermont speaking about what their ideal DSP would be like. It gives an interesting view of what training and information DSPs should have. For more information or to order a copy of the video, please contact: Vermont Developmental Disability Services at 1.802. 241.2614 or visit <http://www.state.vt.us/dmh/ddstheysaidmain.htm>.

Alliance Update

The NADSP is receiving an overwhelmingly positive response to the National Code of Ethics. We are working as fast as possible to meet the requests and letters of interest that we are receiving from all over the nation. We are also discussing possible supplementary curriculum to go along with the National Code of Ethics, such as a workbook. We will keep readers posted as to the developments of new curriculum.

Another exciting accomplishment has been the creation of a new American Association on Mental Retardation (AAMR) division for DSPs. NADSP worked to gather support for the new division with AAMR. This is a large step towards creating an atmosphere within AAMR where DSPs can feel welcome, respected, and comfortable enough to express their concerns.

We are now working with the federal Department of Labor (DOL) on the development and implemen-

tation of a national DSP apprenticeship program. This program should be open to all DSPs who currently work in community supports to people with disabilities or anyone taking DSP classes. In the apprenticeship program, DSPs would be required to work a certain number of hours in the field and complete educational training designed to develop the competencies outlines in the Community Support Skills Standards before receiving the DOL certification of completion. The NADSP is thrilled that this apprenticeship program was approved by the federal DOL. We are certainly hoping that this newly approved program will give us the ability to say on a national level that DSPs are respected members of the community and that they have credentials like other professionals. The apprenticeship program will offer flexibility at the state level to develop and implement effective credentialing

programs that are customized to the needs of that state.

We are also exploring ways to increase the number of NADSP state representatives and coalitions. This will allow for more states to engage in state-level coalitions to improve DSPs quality of life and the lives of the people that we support. We would gladly accept any suggestions and/or work with you on becoming a state representative. Please call Beth Knoblauch at 612-624-0060 or contact her by email at knob0010@tc.umn.edu for more information.

Cliff Poetz is co-chair of NADSP steering committee and a self-advocate. He can be reached at 612.624.0060.

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He Allowed Me in His Life,
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they often have the answers rather than people in management positions who make decisions without knowing anything about the individuals we support. In group homes there are checklists and schedules, but with Nathan teaching is incidental and occurs naturally. Checklists being checked off is not natural.

Nathan has a lot of choices in his life now and developing relationships takes a long time.

I have seen where people who hate each other are put together in living situations. I think a person has a right to choose where and with whom they live. I also think staff should never work with more than a couple of people.

Nathan looks to me for guidance and support and I honor that. People with disabilities know when

you don't show respect and lie. It is important to show up when you say you will and follow through on things you say you will do. When people get hired to support a person it has to be about more than just a paycheck. Respect is important and you need to ask yourself, "What about now and what about today?" even if you plan to move on.

Sally: What attracted you to working directly for the person you support in the first place?

JoAnn: Nathan himself. He amazes me with the things he can do — in spite of his disability he is so amazing with what he can do; his sense of humor. We started out so well. He allowed me into his life and I wanted to be there. We had a mutual non-verbal agreement.

He continues to teach me a lot about life. I guess I am from the old school — commitment to a relationship. Nathan is a person I care

about and love. He is an individual, a human being. I talk to him like his is a 27-year-old because he is 27 years old. He has his own soul.

Sally: Nathan's mom spent a lot of time trying to get the best services for her son through out his life and she sure found them with JoAnn. I was amazed through out the interview with just how much JoAnn truly cares about Nathan and is committed to him. What a true gift they have in JoAnn.

Sally McGurn works for Johnson County Developmental Supports in Kansas, where she knows both Nathan and JoAnn. She can be reached at 613.492.6161.

Visit the DSP Web site at <http://rtc.umn.edu/dsp>

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