



Frontline Initiative

A Quarterly Newsletter of the Alliance for Direct Support Professionals

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About This Issue

This newsletter is dedicated to promoting the interests of DSPs who serve people with disabilities by encouraging a better trained, more respected, and more involved work force. This issue addresses how DSPs and people with disabilities can foster and enhance their relationships to improve the quality of services. Frontline Initiative is a project of the National Alliance for Direct Support Professionals and is published by the Research and Training Center on Community Living at the University of Minnesota's Institute on Community Integration.

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The Importance of Partnerships

Support is a Two-Way Street for DSPs and Consumers

Across the country, agencies that work with people with disabilities are struggling to change from putting people in programs to supporting people in the lives that they want. This change begins with learning to plan *with* people rather than planning *for* them. Many agencies struggle to learn what's important to the people they support in order to help them move toward the lives they want. This must be done within the constraints of available resources and the presence of health or safety issues. As agencies continue to struggle with this conversion, they find they need to broaden their focus. They discover that people with disabilities can't be empowered unless the people providing support are also empowered.

Many managers in agencies moving toward supporting people to create lives they want have discovered the power of partnerships. Rather than managers accumulating power, they've learned that the management practices that best encourage a support model require that the people delivering the support feel respected, trusted, and valued. Managers can't just change

the way they talk – they must also change the way they act. They have to change their agency's practices to reflect the values that underlie these types of partnerships. The following are examples of this kind of partnership in action.

At Community Living-Wilmington, a supported living agency in North Carolina, the people who are supported and the people providing support mutually select with whom they will work. Neither the people receiving supports nor the people providing them need to have "cause" to terminate the partnership; however, team leaders are there to insure that a request doesn't just reflect transient irritation and that the people being supported aren't left without the support they need.

At a public provider agency in Manchester, England, efforts to build partnerships begin with staff exploring what's important to them as well as to the people they support. A manager then facilitates the development of a plan where the staff seek to get more of what's important for both the people they support and for themselves.

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Alliance Update

The Alliance Develops Its Goals

Since our last issue, the Alliance has new member organizations and has continued to develop, define its mission, refine its goals, and begin to build strategies for achieving its goals. The Alliance is a formal collaborative among national and other organizations committed to a common mission and the goals – listed below – which were developed by representatives from the Alliance's member organizations.

Mission

The National Alliance for Direct Support Professionals promotes the development of a highly competent human services work force that supports individuals in achieving their life goals.

Goals [in order of priority]

- 1 Enhance the status of direct support professionals.
- 2 Provide better access for all direct support professionals to high quality educational experiences (e.g., inservice training, continuing and higher education) and life-long learning that enhances competency.
- 3 Strengthen the working relationships and partnerships between direct support professionals, self-advocates, other

consumer groups, and families.

- 4 Promote systems reform that provides incentives for educational experiences, increased compensation, and access to career pathways for direct support professionals through the promotion of policy initiatives (e.g., legislation, funding, practices).
- 5 Support the development and implementation of a national voluntary credentialing process for direct support professionals.

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Frontline Story

Do We Make a Difference?

As a direct support professional, I often wonder if I can really make a difference in my day-to-day work. Throughout my career as a direct support professional at Johnson County Developmental Supports in Kansas, I've participated in a vast array of activities that have affected almost every aspect of the lives of the people to whom I provide supports. Besides the core supports of household maintenance or vocational development, my co-workers and I are out there fostering relationships with the housing authority, Social Rehabilitation Services, Social Security, banks, grocery stores, parks and recreation departments, parents, families, friends, contractors, apartment managers, doctors, hospitals, churches, and employers just to name a few. As all direct support professionals know, this list could go on and on, and I believe every DSP knows first-hand the trials and tribulations that can occur as we go out into our communities to advise, educate, mediate, and advocate for equal rights for the people whom we serve.

As a direct support professional, both the big and small achievements made by the people I support make me feel proud. I get excited when I see someone write a check independently for the first time; or proud when I see the look of pride and accomplishment of someone getting their first job in the community; or joyous when I see the spark of excitement as someone first communicates with a friend using adaptive communication equipment. Situations like this are what it's all about and where it all comes together between the people we serve and us, the direct support professionals.

Direct service is my career. It's not just a job, but my *career*; my livelihood, and my desire. I take my career seriously but I also have a lot of fun in doing so. I know DSPs play important roles in the lives of millions of people. Since direct support professionals are the ones most aware of the day-to-day events and obstacles, it's only appropriate that our opinions and observations about the needs of the people we serve are viewed as critical. It's my hope that roles will change, and as we become empowered, we will be part of the leadership of a new generation of direct support professionals.

In March of this year, I was asked by Gary Blumenthal, the executive director of the President's Committee on Mental Retardation (PCMR), to be part of the advisory board for the planning of the Next Generation Leadership Symposium. I accepted this opportunity and felt proud to represent direct support professionals. The symposium, held in Washington, DC, brought together direct support professionals from all over the United States and Guam. It was a forum that allowed us to come together and share our experiences as DSPs. We had the opportunity to listen to motivational and inspiring speeches by people like Duane Alexander, director of the National Institute of Child Health and Human Development; Claudio Grossman, dean of Washington College of Law at American University; Allen C. Crocker, program director for the Institute for Community Inclusion at Children's Hospital; and Representative Patrick Kennedy from Rhode Island.

We also had the chance to break

into small groups to discuss issues surrounding public policy, research and development, community development, civil rights/cultural diversity, building natural supports, health promotion and wellness and education/early intervention. After group discussions, we joined together to summarize our sessions and developed recommendations that will be presented in a report to President Clinton. It was a wonderful experience for me.

Things are always changing in our field, but we share similar concerns wherever we are. One common strand ties us: we strive to improve the lives of people with mental retardation and other disabilities. The PCMR symposium provided direct support professionals an avenue to come together to foster improvement and change. I believe many of us left there with a sense of being heard and having made a difference.

With our continued efforts for reform, equality, and individual empowerment in the supports we provide to people with disabilities, we can and will continue to facilitate opportunities for people with disabilities to stand up and be counted. In this process, we – as direct support professionals – must likewise stand up and be counted. In many cases, we are their voice and, in other cases, we continually strive to give them their own voice. I can firmly say, with all confidence, that we *do* make a difference – a powerful difference.

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Wages – A Major Issue in the DSP Work Force

In my job, I have the daily opportunity to think about and discuss issues concerning direct service work. Over the past several years, I've had the opportunity to discuss these issues with thousands of direct support professionals, people with disabilities, supervisors, managers, and executive directors. What I've heard and seen in these discussions has convinced me of some key points researchers and professionals in the disability field knew even twenty-five years ago: 1) The quality of services is directly related to the relationships established between direct support professionals and the individuals to whom they provide services; 2) direct support professionals don't earn appropriate and adequate wages for the roles and responsibilities they assume in society, 3) DSPs aren't valued and respected as a collective work force within our society and within many organizations, and 4) direct support professionals have specific roles and responsibilities that require them to have specific knowledge and skills in order to perform their jobs. Twenty-five years later, we're still struggling with the same issues: high turnover, difficulty in recruiting, inadequate training, and inadequate wages.

The dilemma we face as an industry is where to start when we address the issues related to the direct service work force. Do we try to increase educational and training opportunities for DSPs? Do we try to value DSPs by showing society their importance? Do we develop quality indicators of service based on the relationship between workers and the people who receive services? I've always professed that we must do all of these

things simultaneously. However, a recent letter from a *Frontline Initiative* reader made me realize the importance of wages in any attempt to develop a high quality direct service work force: *People want respect in their work. Decent pay equals respect in our society. Training and education is necessary to get decent pay. People receiving supports deserve consistent professional care.*

To that end, I'd like to present the results of two national studies on direct service wages. One study surveyed 1,612 agencies providing residential services to people with developmental disabilities across the nation (Braddock, 1992), the other surveyed 3,300 community-based organizations including Big Brothers & Big Sisters of America, Boys & Girls Clubs of America, Camp Fire Boys and Girls, Girl Scouts USA, National Network for Youth, and YMCA/YWCA of the USA (National Collaboration for Youth, 1996). The data presented in the table below reflect hourly wages for full-time workers.

This data is clear. Many direct service workers who have families live at or below the poverty level and many are eligible for food stamps and other public assistance. It's common for direct sup-

port professionals to work two or more jobs to make ends meet. Despite the fact that DSPs are highly-skilled and provide services to our most vulnerable citizens, they're not paid an appropriate or adequate wage. All too often, fast food restaurants offer higher wages than DSPs earn. Perhaps one pressing and specific strategy toward bringing value and respect to the direct service work force is to educate the public, policy makers, and our legislators about the pitiful wages DSPs currently earn.

References

Braddock, D. & Mitchell, D. 1992. *Residential Services and Developmental Disabilities in the United States*. American Association on Mental Retardation, Washington, DC.

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Table 1 · Hourly Wages for Direct Support Professionals

Youth DSPs	Average	Median
Child/youth care worker	8.06	8.16
Direct support professional	8.42	8.17
Program aide/assistant	7.73	7.48
Child care assistant	5.79	5.25
<i>DD DSPs</i>	<i>Entry</i>	<i>Average</i>
Residential worker – private	5.22	5.97
Residential worker – public	6.93	8.57

Self-Advocate Perspective

Progress!... With Support

My name is Mia Peterson and I'm from Webster City, Iowa. I work at a Hy-Vee Grocery Store. I worked with Supported Employment to find my job. I looked for work myself and all Supported Employment did was support me and assist me now and then. I got services from them for two years, but now I do my job on my own. Now I'm not getting *any* services from them!

I'm also co-editor of a newsletter called *Community Advocacy Press*, and I get support from the business Capabilities Unlimited (CU). I like working with CU because I've learned to work hard for myself and others and it's a lot of fun. For three years, I've also been regional coordinator of the Iowa Systems Change Network. I get support from the statewide coordi-

nator, Nancy Witt. She got me started on this. I'm also an appointee to the Iowa Governor's Developmental Disabilities Planning Council. I am the youngest member, am the only one with a disability – Down syndrome – and am the first person with this disability on this council.

I'm also an investigator on a research project, Learning Language on Communications, with the assistance of Laura Meyers, the co-investigator. Laura is a linguist with a Ph.D. She works to help people with disabilities to have a voice, and in a way that's what my research project is all about. I'm trying to find out how people with Down syndrome learn language. I ask other people with Down syndrome questions from a survey

about what it was like when they were little and what it's like now. I get to talk to many people and find out how they feel, which I think is fun. Dr. Meyers showed me how to make up a grant that got funded! She taught me to have fun even if it's a lot of hard work.

Everyone needs support – but some people still don't get *any*. Sometimes I forget that part of how people show they care is by giving support. I didn't always like all the supports I received and I didn't always want advice, but I've learned that we have to help each other.

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Education/Training Initiative

Supporting DSPs Through Training

Everything is more positive. I think of what the people I support can do, not what they can't.

I try harder to respect – and to advocate for – the rights of people with disabilities.

These are just a few comments from direct support professionals after completing *An Introduction to Developmental Disabilities (AIDD)*, a training curriculum developed by the Kansas University Affiliated Program (KUAP). Since 1993, the Kansas Department of Social and Rehabilitation Services has required all community organizations that support people with de-

velopmental disabilities to provide AIDD training. This 116-hour curriculum focuses on the values and skills needed to provide person-centered services in community settings. Forty-six percent of Kansas DSPs have now completed training. AIDD has often been taught through the state's community colleges, providing an introduction to post-secondary education for many DSPs. One of AIDD's primary benefits is increased communication between DSPs, management, staff, and people receiving supports. DSPs report that the training has given them the confi-

dence and knowledge to advocate for people they support.

KUAP has also addressed the continuing learning needs of DSPs by channeling information about support strategies through a network of training coordinators, a library of training materials, and distance education methods. UAPs in sixteen states now have community service training initiatives.

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Agency Initiative

Focusing on Outcomes Changes Relationships

The development of personal outcomes as a planning process for people with disabilities is an important alternative to the traditional developmental/behavior modification process. Traditionally, a person's strengths and needs are assessed and then goals and objectives developed relating to deficit areas. Training and habilitation become the focus of the relationship between direct support professionals and the people they support. Outcomes, an alternative approach, looks at people as people first, with the understanding that each person is different and has different dreams and aspirations regardless of disability. Instead of trying to remedy a deficit, personal outcomes nurture achievement and accomplishment – an important shift in focus. Furthermore, we're learning at Nekton-Norhaven that this shift has opened new potentials in thought and practice concerning the direct support professional.

Since we began looking at the achievement of personal outcomes as a hallmark of good services, our approach and attitude has changed toward the people we serve and also toward the direct support people we employ. Traditionally, our employee evaluations concentrate on observable, measurable criteria based on training and compliance with rules and regulations. This encouraged top-down relationships between the management and the DSP and also between the DSP and the consumer.

An outcomes approach to services, however, results in many changes in direct support professionals' responsibilities and roles. The primary responsibility of the DSP becomes assisting the person

receiving services to achieve personal outcomes. The person receiving services chooses who is on his or her team (or support network), and this often includes one or more DSPs. The person's plan is developed by those who know the person best – this is usually a direct service professional. When an organization moves toward an outcomes approach, power roles within the organization invert. The person who knows the person best is responsible for assisting the person to determine their outcomes and provides the follow-through necessary to realize these outcomes. Direct support professionals are the key to whether outcomes are achieved or not.

High turnover for DSPs is difficult for people who receive services because they have to work with new staff. They should have some input into the hiring process. When people receiving services have a choice about who works with them, DSPs focus on that person rather than on agency process. As an agency, we've traditionally filled *openings*; now we're concerned about relationships and enhancing people's lives.

Training DSPs also takes on a different form when personal outcomes are the primary focus. Competency switches from knowing and reciting rules to knowing and respecting the individual. Some important questions include: *Does the direct support professional understand this person's outcomes? Are they familiar with and can they communicate with others on the support network? Are they supportive and helpful rather than controlling and dogmatic? Does the organization encourage the direct support professional to be creative and*

imaginative? The answers to these questions become far more important in developing effective training programs than does compliance with rules and regulations.

With a personal outcomes model, satisfaction with services is an important issue. Is the person receiving services and his or her support network satisfied with the services? Are direct support professionals satisfied with the organization where they work? In outcomes, there must be an ongoing dialogue between the people providing direct support and the organization because if they're satisfied with where they work and the support they receive, they will likely be in a better position to provide better services to consumers.

Employee evaluations are also looked at differently. In our agency, people receiving services are asked what they think of the DSP's performance, and DSPs are asked to provide examples of their own "best practices." Stories of how people receiving services worked toward or achieved personal outcomes become the basis for employee evaluations.

In an outcomes model, when we look at services provided by the organization, our primary focus is on the relationship between the direct support professional and the person receiving services – that's where the action occurs. The desired outcome for our agency? Competent, creative, long-term professionals who understand their role in supporting others to achieve personal outcomes.

Sandra Wessman is project coordinator at Nekton-Norhaven, Inc., in St. Paul, Minnesota.

Direct Support Perspective

Building Supportive Relationships

The Key to Quality Direct Service

Take some time to imagine a life in which the central figures in your daily life are there for the sole purpose of collecting a paycheck. People only talk to you about what you should or shouldn't do. They decide when you wake, eat, bathe, and sleep. And it's been a long time since anyone had an actual conversation that included your input – usually these conversations go on without you or as though you were invisible.

This is the life that many people with disabilities experience. Is it any surprise, then, that many of the people who receive supports lack the skills and knowledge necessary for interpersonal relationships? Is it any surprise that low self-esteem is so pervasive among consumers of support services?

Positive, growth-supportive relationships between direct support staff and the people who receive services are a necessity which has long been overlooked. In fact, it has repeatedly been stressed that we need to adhere to stringent “staff-client” boundaries, in which our roles as service providers are strictly maintained in an emotional vacuum. We've been taught to always remember that we're “staff,” never friends. This perspective is now being replaced by a growing understanding of the multi-faceted nature of our roles and of the importance of relationships. We're not only counselors, teachers, supervisors, or caregivers, but also learners, mentors, friends, and real people – real people who communicate, respect others, support joint growth, and commit themselves to these principles. Only by building and main-

taining meaningful relationships with the people we support can we foster real, lasting growth for them as well as for ourselves.

Mutual respect and understanding are the building blocks for supportive relationships. This involves a resolution that all people, regardless of ability, are entitled to the same levels of self-expression, self-determination, and positive regard. This seems very simple in theory, but often becomes lost in practice. For instance, some direct support professionals develop a “split personality” – a distinct difference in voice tone, manner, and facial expression used when communicating with people with disabilities. The same lack of respect is communicated when staff talk about someone's life without regard for their presence or input.

In order to relate to each other, we must communicate, and to communicate we must first listen. We often spend so much of our “work” time talking and very little actually listening to the people we support. We get so lost in striving toward goals set by assessments and legal regulations that we don't take enough time to try to hear and observe what people are really expressing. We need to take time to really get to know each person as a *person* rather than a *case history* or a *diagnosis*. When it comes time to talk, it's important to avoid esteem-defeating, labeling language, and to rely on accurate, descriptive language.

Perhaps the most important factor, though, is to simply be a real person and expect the same of others. A real person experiences a variety of emotions and possesses a

variety of expectations regarding others, and a real person shares some of these with those to whom he chooses to relate.

Building a solid relationship requires a steadfast commitment to consistency of positive regard. In order to have a healthy sense of self-esteem, everyone must spend time with others who think of them positively, regardless of accomplishment or failure. We've all worked before with people whose “bad reputations” precede them and influence how others approach or interact with them. Balanced with communicating genuine feelings and reactions, at some point we need to be able to forgive people for past mistakes and allow for a new beginning. Few of us have the misfortune of being forever labeled with a permanent record of our past transgressions, and no one should be held to this standard because he or she receives supports.

So, we need to balance many roles as we offer support to people with developmental disabilities. We serve as a mix of teacher and friend and rely on the relationships we build as a foundation for mutual growth and support. By listening and learning, by speaking well and with respect, and by being genuine, we can open doors to individual growth and accomplishment. And we can truly find a better reason to do what we do – because we grow from these relationships as well.

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Family Perspective

A Sister Relates Her Brother's Story of Abuse

Being the younger sister of a person with a developmental disability, someone who relies on outside services and supports, has been an interesting and often frustrating journey. As my brother's guardian, I have frequent opportunities to advocate on his behalf. Since I also work in the field of residential services for people with mental retardation, I often find myself wishing I didn't know the what the possibilities are or how much better it could be. It's hard to settle for things that most of us take for granted in our lives – things like being able to make choices or being free from abuse and neglect. My brother's story reminds us that these things are more common than we'd like to think.

I'm amazed at the series of injustices he's had to endure in his thirty-three years of life. In addition, I must mention I didn't always live with or even near my brother, so what I know is probably only a small part of what his real experiences have been.

My brother was first institutionalized while my father served a tour of duty in the military in Hawaii. Not once, but twice, he was allowed to suffer sun stroke and heat exhaustion at the "special school" he attended. Because my parents felt the school couldn't safely provide services to my brother at that time, he was sent to live in a state institution in Wyoming. This state was chosen because my father's parents lived there and they were eager to provide my brother with the support that he would need while the rest of us concluded our stay in Hawaii. While in Wyoming, the "counselors/teachers" at the state facility documented him as having

great hygiene but being "hyperactive," "unmotivated," and "lazy." I've known other eight-year-olds without disabilities who had the same characteristics, but they were seen as normal. The strongly negative adjectives used to describe him gave me a feeling for how he must have been treated. When my brother returned home from the institution, most of his belongings were missing and he was terrified that people would steal his food. I've heard other in the field casually refer to this as "institutional behavior," but I can sympathize with the outbursts and frustration that comes from living through these kinds of experiences.

When my brother was a teenager, our mother suffered health problems and again he was institutionalized in a large facility in Minnesota. Again, his food was taken despite his attempts to eat as fast as he could. On two separate occasions he was diagnosed as malnourished, and his personal items continually disappeared. My parents would complain, but the situation never improved – that's just the way things were.

Later, my brother was moved to a private, but still large facility closer to where the family was living. Again, his food and belongings were stolen. Because he didn't receive the dental care he needed, he nearly lost his teeth. At this facility, dental care came in the form of a truck that pulled up into the parking lot. The residents would be ushered out to the truck to have work done. As guardian, I had to force the issue to obtain a community dentist. I felt strongly that my brother's dental care was in crisis and I felt the need to push for aggressive care. For the first time in

my role as his guardian, I was anxious about my brother's quality of care. This situation showed me just how vulnerable he was.

Over two years ago, he moved, again. This time, into a small group home with three other people. Our family was so excited, and we had great expectations that he would receive higher quality, more personalized care, and would be able to live with less fear and more control. Unfortunately, our excitement was quickly deflated. Within the first year, two separate incidences of abuse against my brother were perpetrated by staff. Both persons involved in these cases subsequently quit their positions. I've had to advocate for my brother to receive his mail and use the phone as he desires, as opposed to "earning" or using the mail and phone at the whim of the staff who are "in control."

I've discussed my concerns about dignity and respect with the direct care workers and the supervisors at the home and at his work site. I know things can be better. It's difficult to be a family member and know that the person I love isn't receiving the care he should be. I feel he isn't always treated with the respect and dignity he deserves because people entrusted to provide his services don't like him. I was recently told by the supervisor of his home that I didn't "know what it's like to have to deal with him on a daily basis." That was telling. While I don't feel the system is all bad, there's a way to go. Unfortunately, my brother's journey probably isn't too unlike those of others who receive services.

This article's author has chosen to remain anonymous.

Policy Initiative

Abuse in the Lives of People with Disabilities

Abuse happens. Sometimes it gets reported, sometimes it doesn't. Sometimes it gets investigated, sometimes it doesn't. Sometimes we do a good job of supporting people who have been abused, and sometimes we don't.

Twenty-five years ago, when I began working in a large institutional setting as a direct support professional, I wondered why people with disabilities had to live their lives trapped in an environment they didn't choose only because they couldn't express their life goals like other people. Over the past decade I've moved from the front line to various levels of administration, continually moving farther away from the realities of staff who support people in their daily lives. During this time I've seen society begin the transition from warehousing people in large congregate settings to supporting them in their own homes. I've witnessed society beginning to understand that every citizen, regardless of ability, can make positive contributions if given the opportunity and support to do so.

Unfortunately, as we've grown in our ability to understand the needs of people with disabilities, we haven't provided the same level of continuing professional development for direct support professionals. In many cases, we've taken for granted the effect and potential power that direct support professionals have on the lives of the people with disabilities. Whether a person with disability lives in a institution, a group home, supported living in the community, or their own home, the direct support professional has the power to influence a person's opportunities and success. Under-trained, under-

paid, and under-supported staff who deal with complex challenges every day are at greater risk for high levels of frustration. When these frustrations come together at the wrong place and time, people get abused or neglected.

I've never met anyone who didn't want to eliminate abuse. Waxman (1994) states that, "it is society's response to disability, not the disability itself, that accounts for much of the increased risk experienced by people with disabilities" (p. 185). Research indicates that people with disabilities experience more frequent abuse than the general population. Unfortunately, the people most directly involved in the person's life often perpetrate the abuse. We need to understand the cycle of abuse and eliminate the factors that lead to its continuation.

It's impossible to provide an in-depth discussion of the issues that create an abusive environment in a short article. However, I believe we must consider several major themes. First, if we are to ensure a non-abusive environment for people with disabilities, then we must give them the power to control their lives. Empowered people are less likely to be subjected to another's abusive actions. A second area that's often overlooked is the empowerment of direct support professionals. When staff are provided the training and knowledge necessary to support a person's life choices, they become empowered to "do the right thing." Staff who feel confident in their commitment and skills and are respected as professionals are less likely to exhibit abusive behavior. Finally, we must know more about the people we hire. Every direct support profes-

sional involved in the life of another person is a piece in a complex puzzle. It's necessary to hire staff who have the personality and capacity to enable the person with a disability to achieve their life goals. Every direct service worker is a vital piece in completing the puzzle that makes up a person's life. By initiating hiring practices that reduce the probability of hiring a "bad" employee, (e.g., developing screening processes that include thorough background checks and evaluating potential employees for their ability to be a person-centered individual), we can reduce the possibility of abuse.

In summary, the issues we face in the attempt to eliminate abuse and neglect are complicated and complex. The only way we'll solve this problem is by admitting its existence, bringing all stakeholders to the table, and developing proactive plans to eliminate this ugly aspect of our society. While we face many challenges in the attempt to eliminate abuse and neglect, we have many dedicated direct support professionals who remain an under-utilized resource in our fight against these injustices. Eliminating abuse is done one person at a time. Proper support, training, and respect for DSPs is fundamental to reducing this problem. We must challenge ourselves each day to accept nothing but the best for the people we support, which means we must determine how to find, train, and keep excellent direct support professionals.

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Organizational Perspective

On Common Ground

Finding a Shared Voice Makes Us Strong

At the last annual American Association on Mental Retardation (AAMR) Conference in San Antonio in May of 1996, there was a multi-disciplinary session called *On Common Ground: Working Together to Ensure Quality Outcomes*. The speakers for this presentation included self-advocates, DSPs, and advocates of people with developmental disabilities. This was an important forum because the presenters shared a common goal of strengthening the relationships between the direct support professional and the people who receive the support for the betterment of both, a goal also supported by the National Alliance for Direct Support Professionals. The importance of strengthening the working relationships and partnerships between direct support professionals, self-advocates, other consumer groups, and families is illustrated by the following positions presented at the session.

By improving the quality of professional life for direct support professionals, we will significantly affect the lives of self-advocates. While many issues challenge direct support professionals' roles, (salary, job stress, lack of a career ladder, unclear responsibilities, insufficient training and support), none may be more prevalent than the frustration a direct support professional experiences in not being able to become "personally involved" with the people they support. Workers are often told they can't care, can't be friendly and can't cross personal and professional lines. In addition, their intimate knowledge of the person's daily life is often down-played as

unimportant compared to the knowledge of "professionals" (i.e., psychologists, QMRPs, etc.) who spend relatively little time with the person receiving supports. Outcomes occur through the power of the relationship between the direct support professional and the individual. Direct support professionals should be empowered to provide input on support plans, afforded the flexibility to meet the specific needs of those supported, and to structure their time to meet the needs of their lives and the lives of the people they support. These changes may likely require pervasive change. We must build systems that reward relationships and find common ground.

The working relationship between direct support professionals and consumers should be broadened. One presenter stated, "We all need to come to the table and talk." This includes parents, professionals, self-advocates, and direct support professionals. We must also keep in mind that at the center of the working relationship is the person receiving services. Self-advocates want to be part of the "team," particularly if they're expected to support direct support professionals on their issues. The advantages of self-advocates' support for direct support professionals include increasing the chance that a sufficient number of experienced, well-trained staff will be available; more support for the Alliance as it looks for ways to establish a career ladder for direct support professionals in hopes of reducing turnover; and increasing the likelihood of establishing support plans that are flexible, per-

son-centered, and that allow direct support professionals the ability to carry them out.

As we move toward greater control and ownership of services by people with disabilities, it will become important to ensure a meaningful working relationship between direct support professionals and consumers of services. This working relationship and united voice will be imperative on the national scene to ensure that "managed care" doesn't revert to less involvement by consumers and direct service staff. We will need more opportunities for self-advocates and direct support professionals to come together to discuss common issues.

Forums, like the one held at AAMR, in national organizations, and mutual support groups at the community level, and partnerships are important steps toward facilitating partnership opportunities. The National Alliance, co-chaired by a self-advocate, a direct support professional, and a researcher, is also an opportunity to move toward a common agenda with a common focus to improve the quality of life for both self-advocates and direct support professionals.

Perhaps the greatest challenge to the field of developmental disabilities today is not the scarcity of resources, but our own limit on looking for opportunities.

John Rose is chair of the AAMR Special Interest Group on DSPs, Irwin Siegal Insurance, Rockhill, New York. He may be reached at 800/622-8272

Clinical Psychopharmacology Made Ridiculously Simple

This succinct sixty-page guide provides an overview of psychotropic medications and how they can be successfully utilized for emotional and mental disorders. The authors emphasize two basic elements of treatment: a thorough knowledge of psychotropic medications and an accurate diagnosis. For further information, contact:

MedMaster, Inc.
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Learning to Listen

This computer-based, interactive, CD-ROM course offers positive alternatives to behavior management told from the perspective of people with disabilities. Available in both Mac and PC formats. Computers must have CD-ROM and sound capability. PC requires 486/100 MHz or more recent; Mac requires System 7.0 or higher. For further information, contact:

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Remembering the Soul of Our Work: Stories by the Staff of Options in Community Living

Direct support professionals share their experiences in this collection of anecdotes, stories, best practices, dialogues, memoirs, and more, describing how they supported people with disabilities in their move from institutional to community homes. For further information, contact:

Options in Community Living
22 North Second Street
Madison, WI 53704
608/249-1585

Idea Connections

This monthly, one-page newsletter presents a forum for direct support professionals, their ideas, information, and resources, emphasizing the improvement of their environment. For further information, contact:

LightBulb Press
668 Stony Hill Road
Suite 261
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A Guide to High Quality Direct Service Personnel Training Resources – Second Edition

This extensive 360-page resource guide provides comprehensive reviews of 150 training materials available for trainers of direct support professionals. Available in April 1997. Cost: \$35.00. For further information, contact:

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Institute on Community Integration Publications Catalogue

This 36-page catalogue lists over 160 newsletters, resource guides, curricula, reports and briefs, videotapes, and brochures currently available from the University of Minnesota's Institute on Community Integration. Updated quarterly. The publications catalogue can be accessed via Internet at <http://mail.ici.coled.umn.edu/ici/>. To obtain a printed copy of the catalogue, contact:

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Some examples of this in action include changes in both schedules and responsibilities. Staff who are "morning people" have swapped coverage times with staff who are "evening people." One staff member who attends a music club on her own time now takes someone she supports (who also loves music) to her club as part of work time.

At Hope House Foundation, a supported living provider in Norfolk, Virginia, these partnerships have been built over the past decade. This agency makes sure that before any policy or procedure can be adopted there are opportunities for all of the people effected to be heard. Staff who want to learn something that reflects their personal interests are supported with dollars that come from fund raising regardless of whether a direct benefit is perceived for those supported. The disparity between pay for managers and for direct support staff is also being narrowed.

Agencies are finding that partnership "pays." Practicing partnership not only enhances the quality of life for those supported but also effects areas like turnover. Agencies like Hope House Foundation and Community Living report annual turnover rates that are close to ten percent as compared to the fifty to seventy percent reported by most agencies. If agencies are going to move from providing programs to providing supports, they'll also have to learn to practice partnership between the people being supported and the people who provide supports. We can't enhance respect for the people we support unless we also respect the people *providing* the support.

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Alliance Member Organizations

- ***American Association on Mental Retardation***
- ***American Association of University Affiliated Programs***
- ***American Network on Community Options and Resources***
- ***The ARC***
- ***Association of Public Developmental Disabilities Administrators***
- ***CARF***
- ***Council for Standards in Human Service Education***
- ***Human Services Research Institute***
- ***Institute on Community Integration (UAP), University of Minnesota***
- ***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***
- ***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***

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