

A Quarterly Newsletter of the National
Alliance for Direct Support Professionals

Frontline Initiative

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Direct Care Issues in Industrialized and Developing Countries

All over the world, cultural, economic, political, legal and social factors are forcing significant changes in the way people with disabilities and their families are being supported. As the articles in this issue illustrate, support delivery models differ in scale and scope, but many of the situations that Direct Support Professionals (DSPs) face are the same in both developing and industrialized countries. A consensus is growing worldwide that a partnership between people with disabilities, families, communities and

frontline workers should be the starting point and center of any service model. As new service delivery models have emerged, dialogue between representatives of these newer models and traditional Western models has begun, resulting in greatly enhanced support efforts. For instance, in 1995, *Reaching Up*, a nonprofit organization founded by John F. Kennedy, Jr. and The City University of New York (CUNY), started

an exchange program with disability advocates in Jamaica and Vietnam in order to promote this dialogue.

The roots of the support systems in these two countries goes back to the late 1980s. During much of that decade, the practice was to attempt to transplant traditional Western rehabilitation models in developing countries. When these efforts failed, the World Health Organization (WHO) developed what is known as the Commu-

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Steve Smith (right) gives his support staff Joe Morrone a friendly hug after receiving an Award of Excellence at an Annual Appreciation Banquet. Frontline Story page 4.

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The Real Scoop DSP Q&A

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

Complaint Sessions?

Dear Clifford and Seth,
Our Division Director recently indicated that he did not want to hold staff meetings with DSPs. He said he didn't want to deal with what he called "complaint sessions." This makes me feel like I am not a valued or respected member of the organization for which I work. How can I express my suggestions and legitimate concerns to management under these circumstances?

— *Anonymous*

Dear Anonymous,
Your Division Director does not show respect for you, the person receiving supports, or the organization by not holding staff meetings. You should remind him that listening to your concerns is part of his responsibility and that it is very crucial for you, the consumer, and him, to be able to voice your concerns. Remind him that you are the closest contact to those you provide supports and that staff meetings can be a very valuable means for improving the quality of service delivery.

— Clifford

Dear Anonymous,
A Division Director who doesn't want to meet with frontline workers is not looking out for the best interests of the people seeking the agency's services. It sounds like he is afraid to face the realities of situations DSPs face every day. Your Division Director may feel threatened when confronted in a group setting. I suggest having a DSP-only meeting where all legitimate concerns are documented, then elect one DSP to request a meeting with your Division Director to address them in a one-to-one meeting. Hopefully, your Division Director will begin to trust and respect the workers who are closest to the consumer. Let me know how it goes.

— Seth

Ask Clifford and Seth

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

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

NADSP Member Organizations and State Contacts

Direct Care, *continued from cover*

nity-Based Rehabilitation (CBR) model. It is a delivery system that relies mostly on community workers, home visitors, family members and volunteers. Ninety percent of people with disabilities live in developing countries, but funding for a large professional workforce is impossible. Many have recognized that providing training for committed, local, and mostly voluntary, community personnel is the only viable option.

CBR is based on the idea that mobilizing people with disabilities and their families, friends, neighbors and local communities as the focus of support is the only credible way to provide basic services for everyone. With proper training, families and communities supported by CBR workers can provide an enriched, integrated, social context for even the poorest homes in the most under-served areas. Implementing CBR, however, requires a large-scale dissemination of knowledge to individuals with little formal education. Thus, in 1989, WHO published a training manual, *Training in the Community for People with Disabilities*, that offers a simple, demystified set of essential rehabilitation skills such as mobility training, behavior modification methods, and assessment methods. Its materials have been fitted for specific locales. In Jamaica and Vietnam, CBR has emerged as the most promising approach to supports delivery.

In Jamaica, CBR workers are employed on a volunteer and paid basis by a private, charity-supported, non-profit agency called the *3D*

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

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I Love What I do

When I graduated from college and set out to start a career, I had no idea where I was going or what I wanted to do. I did know that I wanted to do something that made me happy and wanted to work with people in some capacity. I looked for a job for six weeks after graduation and interviewed for jobs with many companies. It was very frustrating. Finally, on September 27, 1994, I accepted a job with Martin Luther Homes, Inc. of Colorado, an agency that provides supports to people with disabilities. Little did I know that this first job out of college would allow me to more than meet my goal of being happy. Although this job was intended to be a stopgap until finding an ideal one, I have been with them ever since.

I love what I do. Yes, there are drawbacks — working odd hours, supporting people who have seizures or who are up all night because of illness, etc. — but the rewards far outweigh the drawbacks. The best part of my job are the relationships and, more importantly, the friendships I have developed with those with whom I work. I am currently a companion home provider for one person, an experience which has proven to be fantastic. His progress over the last two years has been nothing short of spectacular. He has gone from having anxiety in crowds to going to college football games and loving every minute; from having trouble waiting even a few minutes to having more patience than most people I know; and from living in a group home with several others to living in an apartment with a single roommate. Being a part of his progress has made me richer than any amount of money

that I may have been paid. The relationship that I have developed with him includes that of staff/client, but also is a situation where we are truly friends.

Wouldn't we all like to have jobs where the rewards of our efforts are tangible and measured daily? Unfortunately, the rewards and victories in the field of developmental disabilities are often small and the setbacks can be frustrating. Every person has certain goals and many of them cannot be reached immediately. As direct care staff, we share those goals and do whatever we can to help the people we support achieve them. At the end of every workday there are no scoreboards, no applause and no one to tell you whether or not you were successful. We quickly learn to appreciate every positive step that the people we support take, no matter how small the step may seem to others. While big victories may not occur as often as we would like, when they do, the feeling of accomplishment is unbelievable.

For example, I once worked with a man who wanted to learn to cook. I had set up a color-coded strategy to teach him how to set his oven to certain temperatures because he didn't know the difference between numbers. I would ask him to preheat the oven to blue, and he would attempt to turn the dial to blue. Six months later — zero success. I had given up, but continued the instructional program to meet policy requirements. Then one night, I asked him to preheat the oven to green. I turned away to do something else and a few seconds later I heard him say, "Ok, I did it." As I walked over to readjust the

oven knob, I saw that it was set correctly and said, "You did it, you did it!" As long as I live I will never forget the big smile on his face and how excited he was. He had reached a goal and achieved a feeling of accomplishment that cannot be measured tangibly. As for myself, his victory was my victory. To some it may seem insignificant, but that feeling of victory and excitement provides a level of satisfaction that keeps me in this field.

As one DSP to another, I urge you to remember that you are a very important person. As a society we are taught that the people who make more money and have the fancy titles are the most important people. In our work, though, the people to whom we provide supports may not care who the human resources director is, but they do care about the people who can help them with whatever they need help with, and they rely heavily on the people who are there every day. Because we spend the most time with the people who receive the services, they count on us to look out for their safety, health and happiness. So when that overnight shift, or the twelve-hour Saturday shift seems like it will never end, please remember that you are appreciated. Someone once said that the job is its own reward. I like to think that they were talking about the field of developmental disabilities when they said that. To all of you who are currently working in direct care, THANK YOU!

Joe Morrone is a DSP for Martin Luther Homes in Fort Collins, CO. He may be contacted at 970.223.1751 or mlhlmer@frii.com.

Kishor Village Integration Kibbutz Style

Israel is a country of immigration with a very diverse population. It faces enormous problems in reaching and providing community supports to people with disabilities. Demand for services in the community has increased at a time of strained public budgets, and despite the relatively rapid increase over the last two decades in the number of people with mental retardation placed in community living arrangements (CLAs) nationwide, those who receive these services constitute only 38 percent of all persons with developmental disabilities who do not live with their family.

CLAs in Israel currently include a wide range of services, representing a continuum from the most restrictive to the least. The "hostel," or big group home (16-36 people), is the most restrictive type of CLA, where Direct Support Professionals (DSPs) provide 24-hour supervision and intensive services. About 66 percent of the people with mental retardation who live in the community live in a hostel. On the other end of the spectrum is the Independent Apartment, where two to six people live, and DSPs provide services as needed and do not live with them.

One of the most recent community support efforts to meet these demands in Israel is an integrated rural village established and situated next to a kibbutz, a settlement

whose members cooperatively generate and dispense revenues based upon communal expenses and individual salaries. In 1994, a group of parents and professionals established an integrated community for adults with mental, emotional and learning disabilities at the Kishor kibbutz. DSPs at Kishor work alongside people with disabilities in an integrated setting that provides opportunities for them to earn a profit that supplements the Kishor community and personal wages. DSPs make decisions about the village's operation and, at weekly staff meetings, each consumer is encouraged to make decisions about his or her private and social life. The village

provides four kinds of services: residential, occupational, health, and leisure time services. Each DSP has an identified vocational skill in which he or she is an expert, and all DSPs are knowledgeable about social service skills. The role of the DSP within the kibbutz is to support those with disabilities in exploring and realizing their potential by providing teaching, encouragement, friendship, counseling and needed supports.

The uniqueness of the Kishor Village lies in its combined emphasis on the integration of those living alongside the kibbutz members while making common use of, and contributing equally to, communal life. As part of the village's industry and effort to promote the economic

independence of the village, the residents there operate an olive tree plantation, a goat farm, a dairy facility, an electronics plant, and a Mini-Schnauzer kennel, among other industries. At the orchard, DSPs teach the community members the process of planting a tree, harvesting the olives, extracting the oil, and selling the produce. Sales from this production will fund the village's operation and will decrease financial dependence of those with disabilities on their families and on government assistance.

When applying to be a DSP at Kishor, one must already possess a skill related to the village's vocations and then take courses offered at or near Kishor for training in interacting with individuals with disabilities and integration training. DSPs at Kishor say they are very satisfied with the education, training, and

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The guiding principle of the Kishor village is to support persons with disabilities so that they can become better established within society.
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DSPs Help Define Quality in Denmark

The social pedagogue in Denmark is a Direct Support Professional who has completed a specific vocational training of three years. The training is a combination of theory and practice and includes training in psychology, pedagogy, social civics, health care, communication tech-

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How do we eliminate the social, psychological, physical and technical barriers that prevent full participation in all of life?

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niques, organizational management, sport activities and culture. This training qualifies the social pedagogues to work in many settings within the field of social welfare services. For example, some social pedagogues work with people with developmental and physical disabilities, some work as nursery school teachers, while still others may participate in drug rehabilitation programs, or provide family support to families with few other resources.

A predominant trend in social welfare services in Denmark has been the ongoing decentralization of services and deinstitutionalization. Much attention in social pedagogy has been focused on developing the role of professional support in the local community. The focus has shifted from dysfunction and disability to resources, possibilities and the personal development of persons with disabilities. Moving from institutions to community housing or assisted living, however, often causes a breaking up of a

person's existing social network. In Denmark and in many European countries, full social integration in the local community has been difficult to achieve for people with disabilities. Many experience loneliness and run the risk of being isolated.

The challenge for social pedagogues in Denmark is to support the building of new networks in a close dialogue with persons with disabilities. In this dialogue, the following concepts and questions are becoming increasingly important —

- *Independence and Autonomy.* How do you structure your own life, balancing opportunities of independent choices and the need for support? How do you organize services (social, educational, health, etc.) in order to accomplish this balance?
- *Inclusion and Participation.* How do we support people with disabilities in actively shaping their own lives? And how do we eliminate the social, psychological, physical and technical barriers that prevent full participation in all of life?

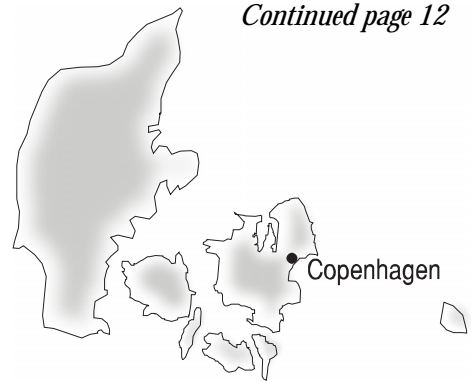
In Denmark, one way we have approached these issues is through the use of a new general evaluation model for evaluating home and care services in which the consumers are directly and actively involved as co-actors. The model incorporates consumer-defined standards as a basis for an evaluation guide. A team consisting of consumers, relatives, and social pedagogues actively participate in evaluating and submitting suggestions for development and change. All parties

involved hold a stake in assuring the best possible quality of the support and services provided. It is thus important to bring together the parties and form a partnership where dialogue and exchange of points of view are the key issues.

The standards for the evaluation guide were developed by two groups of people with disabilities who were asked to share what they found important in their lives. For several days they developed many statements, some filled with experiences of suppression, some voicing hopes and dreams of a better future. The statements were then summarized in the following areas: housing and roommates, work and education, leisure time activities, autonomy and experience of the self, social network, support, and civil rights.

An evaluation team trained in observation, interviewing, evaluation and analysis techniques uses these standards to evaluate what services the consumer wants. The team compiles the data in 4–5 days by interviewing the consumers and

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DENMARK

A Glimpse of Direct Support Work Down Under

Greetings from Sydney, Australia, the Olympic city! We'll take a break from the "barbie" (the barbecue, not the doll) to tell you about the situation for direct support workers in one accommodation service in Australia. We are from the Macarthur Accommodation System (MAS), a small non-profit private accommodation service for people with intellectual disability in southwestern Sydney. We support 18 adults in seven households. Most people have low to moderate support needs. None of the houses have overnight staff.

Staffing for the whole organization includes two full-time staff members who deal mostly with administration and management issues (but in a small agency like this, one needs to be flexible and versatile), five part-time direct support workers, seven regular casuals (temporary staff) and three relief casuals. Except for biweekly staff meetings, the direct support staff's time is taken up solely by face-to-face work with consumers in their homes or local community. There are no live-in staff. A typical week's activities may include assisting individuals with money management, cooking, household and personal shopping, doctors visits, household chores, hygiene, safety, personal counseling, and serving as a liaison with family members and work or day programs.

Typically support workers start work at 4:30 p.m. on weekdays (when the persons we support are returning home from work) and finish at about 8:30 p.m. Some support workers work in one

household, others between two houses that are located a few blocks to a few kilometers apart. To ensure activities take place regularly, a daily schedule is planned carefully. For example, budgeting may take place on Wednesdays, menu planning and shopping list on Thursdays, followed by shopping on Friday. Specific arrangements are made in consultation with consumers and usually depend on consumers' schedules. For example, some people have every second Friday off work (a "flexi day"), so shopping occurs with staff support on Fridays.

For most service users, there is no effective case management system in our state (New South Wales), so staff and family have considerable responsibility in

helping individuals make important life decisions. For example, one man in his 40s with Down syndrome has been recently diagnosed with Alzheimer's and his support needs have increased dramatically. To date,

staff have been able to support him in his home, but it seems inevitable that he will eventually move to a nursing facility. Making this decision will be distressing for all concerned because of the close relationship that exists between staff and consumers in a small and personal agency like MAS.

This man's situation also highlights funding concerns. For many months, his vastly increased support needs did not result in any additional government

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(Left to right) Sandra Pash, Roger Stancliffe and Jill Bell take a break from their busy schedules at Macarthur Accommodation System, Sydney, Australia.

DSPs in Brazil

Have Few Resources, Face Low Wages

Brazil is a country of immense size. Although much of the land is rural, most of the Brazilian population is located in large cities. These large cities are like hubs in a wheel where most goods and professional services are provided. It is often difficult for people who live in the country to access goods and services, because only narrow two-lane highways link large cities to smaller towns, and unpaved roads join towns to rural areas. Public transportation to the cities is also lacking. Though Brazil is a land rich in natural resources such as gold, semi-precious stones, and timber, the country has a history of economic instability. Presently, the economy is fairly stable, but most Brazilians worry constantly about earning enough money to meet their daily expenses. This instability and concern has greatly limited the existence of supports for people with disabilities, and of the resources available to those who provide these services.

School-age children with developmental disabilities often have much difficulty obtaining necessary supports. Children with even mild retardation typically are excluded from public education and those with severe physical, mental, or behavioral impairments usually do not attend school at all. Children who do attend school go to the APAE (Associação de Pais e Amigos dos Excepcionais [The Association of Parents and Friends of the Mentally Retarded]), which is

maintained through community funds and complemented by a small amount of federal funds. The APAE and other privately funded schools are called “institutions” rather than “schools.” Children attend a daily four-hour session at these institutions, and receive instruction that primarily focuses on “alphabetizing,” (the copying of words and numbers in an attempt to teach reading and number skills). No emphasis is put on teaching daily living, social, or vocational skills.

The APAE and all public schools operate under limited financial resources, which do not make it feasible to buy materials, hire and train full-time staff, or give staff a fair wage. The federal government sometimes supplies notebooks and pencils, although some public schools and institutions have only a blackboard and chalk. An institution typically employs a social worker, psychologist, physical therapist, and speech therapist to work twenty hours per week and are paid \$400-500 per month, which is not a high wage in Brazil (comparable to making the same amount in the United States). The average Brazilian housemaid earns a similar wage.

The lack of financial resources greatly affects Direct Support Professionals (DSPs). Most direct service jobs supporting children with special needs involve teaching, and most of these full-time positions pay \$250-300 per month. Little or

no training in special education either prior to starting work or as a part of inservice training is offered, and those who work in special education and other direct service positions often are beginning their first job or are older persons who cannot find other work. The turnover rate is very high because DSPs either try to find work in regular education or in other jobs that pay more. Direct support staff who do stay have almost no opportunity for advancement. Furthermore, many in direct support often look for other work to supplement their income. When they work at several jobs, however, increased demands of their time and skills often produces physical and emotional exhaustion that reduces their motivation, interest, and dedication to providing supports.

Brazilian special educators recognize these problems and suggest changes, but implementation of effective programs is almost impossible without financial resources. Research is being con-

“The turnover rate is very high because DSPs either try to find work in regular education or in other jobs that pay more.”

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The Role of DSPs During the Transformation of Post-apartheid South Africa

Any discussion of the roles of Direct Support Professionals (DSPs) in a post-apartheid South Africa has to be viewed within the context of the significant socio-political, economic and human transformation which has occurred since the first democratic elections in April 1994. From 1984 to 1994, the Nationalist Party enforced a policy of apartheid, the legalized political, social, educational, and geographical segregation of non-European people. As the country has since embarked on a rigorous program of *truth and reconciliation* (chaired by Bishop Desmond Tutu), as well as a national commitment toward the establishment of reconstruction and development programs and initiatives, the role of DSPs has become increasingly more diverse and labor intensive.

The role requirements, expectations, as well as the desired skill proficiency levels of DSPs greatly resembles South Africa's socio-political upheaval. Though there is a recognized need for standardized skill proficiencies, formal progress toward this has been difficult. The daily work of DSPs continues to be vague, confusing and uncertain regarding the role of their particular profession in the field of South African support and services. For example, those traditionally in youth work believe that their job

skills transfer to the mental health field, but no standard exists to measure these skills from one field to the next. As a result, there is much territorial fighting among DSPs across many fields. Many

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One of the greatest challenges that faces direct support in South Africa is the need to develop policy and practice based on the vision and feedback of DSPs and those who receive services.

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DSPs have received little formal training. Thus, there is concern that because there is no standardization of skills, those in supports services in South Africa will become more diversified, while not necessarily more competent.

A new impetus toward professionalism is beginning to predominate the DSP field, however, and more emphasis is being put on outcome-based training for DSPs. Training institutions now have to “produce” DSPs that have a far more relevant and broad knowledge base and skill level. The

HIV/AIDS epidemic in sub-Saharan Africa illustrates this increased relevance. The apartheid regime established no program for education about HIV/AIDS prevention (primarily because the widespread notion that AIDS is a “non-African” disease). Thus, DSPs had very few resources to handle this issue in their respective fields. After 1994, the National Government of Unity provided DSPs with training and materials

for HIV/AIDS education as a preventative effort. As the number of gay youth who live on the streets has increased, so has the need for these preventative efforts. Youth workers may not only secure food and shelter for them but also do the following—

- Run community awareness campaigns through all forms of the media.
- Give HIV/AIDS education, including condom distribution.
- Encourage gay youth to meet with helping professionals for safer-sex education, substance abuse counseling, psychological assistance, etc.
- Provide counseling for individuals and groups.

Financial and human resources for these endeavors have not increased proportionally. Thus, though DSPs have training that is more relevant to their contexts, their jobs are bigger, more complex and more demanding than ever.

One of the greatest challenges that faces direct support in South Africa is the need to develop policy

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TASH: A Disability Advocacy Organization that Welcomes All

TASH is an advocacy organization that embraces many constituencies in its effort to eliminate physical and social obstacles that prevent equity, diversity, full community participation, and quality of life for people with disabilities. TASH asserts and supports the belief that no one with a disability should be forced to live, work or learn in a segregated setting and that all individuals and families deserve the right to direct their own lives. Since our inception almost a quarter of a century ago, TASH has built a reputation based on our uncompromising stand against the common practices of isolation, stigmatization, abuse and neglect of people with disabilities. Chapters of TASH across the country and members in 38 countries fight for a society where the inclusion of all people into all aspects of society is the norm. While TASH is not a parent, professional, or self-advocacy organization, it is comprised of people with disabilities, family members, Direct Support Professionals (DSPs), other professionals, advocates, students and researchers from around the world unified by these beliefs and values.

TASH expresses its values through many means of action. This year, TASH held a national rally in Washington D.C. calling for quality, inclusive education for children with disabilities, and also held a candle-light vigil in Seattle protesting a new law in the state of Washington that does not allow institutions to be downsized or closed. This year, as part of an ongoing effort to eliminate the use of aversive procedures as a means of behavior modification, TASH established the Positive Practices Policy and Legal Action Operating Committee. Its purpose

is to record the ongoing use of aversive procedures and work toward their abolishment through public policy and political action. In some public and private schools and residential facilities across the country, people with disabilities continue to be subjected to electric shock, sprayed with water, forced to inhale ammonia and ingest pepper sauce, and are pinched and hit — all in the name of “treatment.” In a recent case, the director of one school acknowledged that students, at the facility he runs were sometimes subjected to over 5,000 electric shocks a day or physically restrained for weeks at a time. It is well established that it is unnecessary to use pain or intimidation to change even the most difficult behavior problems. Many with disabilities are unable to speak out against these abuses. This newly established committee will continue to work to abolish aversive procedures by exposing these abuses, promoting positive practices, and organizing support for protective policy and legislation.

Many ask what the acronym TASH stands for. Originally, it stood for, The Association for the Severely Handicapped. The name was changed to The Association for Persons with Severe Handicaps in 1983, but the acronym TASH remained. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization because it no longer reflected current values and directions. Perhaps the best answer to the question, “What does TASH stand for?” is ...equity, diversity, and social justice.

TASH offers many timely printed and online resources about issues critical to the lives of people with disabilities, their families, DSPs, and others. TASH also offers opportunities to share personal and professional expertise with other advocates, family members, DSPs and community members, through chapter activities, and regional, national and international conferences. TASH’s Web site <www.tash.org> provides information on TASH activities, current issues in the disability field and links to other disability resources. Although TASH’s work is often on a global level, equally, if not more significantly, is the support we provide individuals with disabilities and their advocates and family members. We serve as a clearinghouse for the reporting of treatment that is unjust or that limits opportunity. We provide information, linkages with resources, expert assistance toward fighting inequities, legal expertise, and targeted advocacy. We assist individuals in need with the backing of our international network of members and the support of an organization with an unwavering commitment to social justice for all people. If you share our values and vision, we invite you to join us in membership. Together we can work to shape the future for and with people with disabilities and their families.

Nancy Weiss is the executive director of TASH. She can be reached at 410.828.8274, ext.101 or, nweiss@tash.org. For membership information, call 410.828.8274, ext. 107 or email info@tash.org.

Creating a Code of Ethics for Direct Support Professionals

Most professions have ethical statements that embody a set of common values for those who work within their respective fields. The Hippocratic Oath taken by physicians is the most commonly recognized example. All human service professionals require guidance on ethical matters from time to time. The nature of working directly with individuals on a personal level can raise many complex questions and issues. This is especially true for Direct Support Professionals (DSPs) who are often faced with ethical dilemmas but do not always have the necessary tools or resources to help guide them. Resolving these dilemmas with little support or guidance can be a frustrating and overwhelming experience, which may lead to low morale, interagency conflict and potentially higher turnover rates. To provide quality support, DSPs require concise and practical guidelines to handle the ethical challenges encountered in their daily work settings.

The National Alliance for Direct Support Professionals (NADSP) is working on a code of ethics to assist DSPs with making difficult decisions and to unify the profession by articulating a common set of values. The purpose of the Code is not only to assist DSPs in providing better support but also to help them demonstrate a commitment to the highest standards of professionalism. To reflect the values held by DSPs and provide real guidance in meeting the challenges they face, the Code must include the voice of

DSPs. Focus groups with DSPs, self-advocates, and family members will be held to identify and define ethics based on their experiences. Written surveys will also be used to gather information. Enclosed in this issue of *Frontline Initiative* is a survey on ethics to be completed by DSPs (see page 13).

The NADSP ethics subcommittee will gather all survey and focus group results and analyze the data gathered. Key areas will be identified that will serve to form the Code of Ethics. The NADSP Code of Ethics subcommittee is also researching ethical statements currently used in other professions, such as social work and nursing. This information will be brought together in a format that will have a general introduction and a list of brief ethical statements, each followed by an expanded explanation.

If you would like further information on the development of a code of ethics for DSPs, please contact Christine Reed at 615.254.3077, or Marianne Taylor at 617.876.0426 (ext. 330).

Christine Reed is the credentialing program director for CMRA in Nashville, TN. She may be contacted at 615.254.3077. Lori Sedlezky is a graduate student in the Social Work Program at the University of Minnesota, and is currently an intern at the Institute on Community Integration (UAP). She may be reached at 612.624.0060.

The next National Alliance for Direct Support Professionals meeting will be held in New Orleans, LA on May 23rd, with the AAMR conference.

DSP Web Site

www.ici.coled.umn.edu/dsp

Check out the DSP Web site! It has a discussion board, an event calendar, information on NADSP activities, publications, and lots of useful links!

Kishor Village, continued from p.5

supervision they receive for their work. DSPs are also encouraged to obtain outside training relevant to their jobs. Currently, six DSPs and 27 individuals with disabilities work at Kishor. Of the six DSPs, three are counselors, who make a minimum salary with extra compensation for work on weekends, holidays and nights, and the other three are heads of teams, who earn a little more, about an equivalent of \$1,400 in U.S. currency per month.

The guiding principle of the Kishor village is to support persons with disabilities so that they can become better established within society. Support staff encourage the individuals living at Kishor to pursue other employment options that suit their interests and needs in the surrounding community. This practice is in contrast to Israeli society in general, which discourages efforts to engage those with disabilities due to social stigma. Outside of efforts at Kishor, supports delivery for people with disabilities has mostly amounted to providing food, clothing and a clean place to live, but no further training. At the Kishor community, the DSP provides training for individuals to participate in every part of Israeli society, and in doing this, the DSP promotes a better image of persons with disabilities in the eyes of all.

Chaya Schwartz is a senior lecturer at the School of Social Work, Bar-Ilan University and can be reached at schwartz@mail.biu.ac.il, and Stefan Rothschild is deputy director of AKIM in Jerusalem. He may be contacted at stefroth@netvision.net.il.

Denmark, continued from p.6

their friends, relatives, support staff, and administrative staff. The data is then assessed and summed up in a report which includes a number of proposals for developing initiatives of action, which the agency and care services in question are obligated by contract to carry out within the following year.

The active participation this team approach generates has opened new perspectives for the participants. The dialogue between interviewers and those interviewed has in itself initiated a process of putting into words a person's every day experiences, which opens new perspectives for possible changes in support services. This process leads to social pedagogues, management and other agency staff reflecting more about their own work. Thus, the evaluation model can become a kind of self-monitoring instrument for an agency and its staff. The consumer becomes the focus of services and his or her desires define the function of the provider agency and the role of the social pedagogue in Denmark.

Per Holm is managing director of Social Development Center (SUS), and Birger Perlt is senior consultant for SUS. They can be reached at ph@sus-net.dk and bp@sus-net.dk.

SUS is an independent non-governmental and non-profit organization engaged in social development projects, research, evaluation and initiatives dealing with groups at risk and socially excluded people.

Down Under, continued from p.7

funding for the agency, although this was provided eventually. Meanwhile, the extra support was provided either by reorganizing existing support or spending more money than the agency receives.

A typical pay rate for a direct support worker at our type of agency is \$13.30 per hour for a casual staff member (at current exchange rates this equals \$8.25 in U.S. currency). This is the base rate. For evening or weekend work a worker receives 15% more between 8:00 p.m. and 8:00 a.m. on weekdays, 50% more on Saturdays, 75% more on Sundays, and 150% more on public holidays. Permanent staff at the same level would be paid less than this per hour because they receive holiday pay and sick leave. All permanent staff are entitled to a minimum of four weeks annual vacation (by state law). People also receive an extra 17.5% compensation on their four weeks holiday pay, ten days per year paid sick leave, and after ten years with the same agency, staff are entitled Long Service Leave, which is about eight weeks paid vacation (also mandated by state law).

Well, we hope that gives you a glimpse of direct support down under.

Roger Stancliffe is a senior research fellow for the Centre for Developmental Disability Studies. Jill Bell is a coordinator, and Sandra Pash is a senior social educator at MAS. They can be contacted at Macarthur Accommodation System, PO Box 1107, Campbelltown NSW 2560, AUSTRALIA, or Tel: 61 2 46280370.

Direct Support Professionals — You Can Make a Difference

Tell us About the Tough Stuff

by responding to this survey on
Ethical Challenges in Direct Support Work

Direct support work is hard, especially when you have to make tough choices, stand up for what is right and put your values to the test! The National Alliance for Direct Support Professionals wants to help with the tough problems you face every day by creating a set of useful and practical ethical guidelines for your work. Your voice will be included in this effort if you take a moment to respond to these important questions. We need to hear from Direct Support Professionals (DSPs) about the dilemmas you face every day. Please respond by answering a few questions below. We think it will take about 30 minutes of your time. Your response will be kept confidential.

Thank you!

1. Do you think that DSPs should have a code of ethics? yes no

Why, or why not?

2. Do you typically face ethical problems or dilemmas at work? yes no

If yes, please describe at least one ethical dilemma you have encountered at work:

3. Have you witnessed unethical actions by your co-workers? yes no

If yes, please describe at least one situation **without using the names of the people involved**:



**Please return
this survey by
March 15th**



4. Have you ever thought you would lose your job for doing the "right" thing? yes no

If yes, please explain:

5. Do you think that commitment to a direct service code of ethics should be one requirement of a national, voluntary credential program for DSPs? yes no

Why, or Why not?

6. Please tell us about yourself:

I am currently working as a DSP and I have _____ years of experience as a DSP

I am not currently working as a DSP

Gender: Male Female

If you wish to be included in the prize drawing described below, you must include your name, address, and phone number.

_____ name

_____ address

_____ phone

Return this survey and you may win a Prize!

Thanks to the sponsorship of the **Irwin Siegel Agency**, an insurance company supporting those who support others, we are able to offer an added incentive for completing this important survey. If you send in your survey response by **March 15th**, your name will be automatically entered into a raffle! Here are the prizes you could win:

1st prize (one winner)

- Portable CD Player
- \$100 toward an annual membership in a professional association affiliated with the National Alliance for Direct Support Professionals (NADSP)
- Subscription to Frontline Initiative

2nd Prize (two winners)

- \$100 toward an annual membership in a professional association affiliated with the National Alliance for Direct Support Professionals (NADSP)
- Subscription to Frontline Initiative

Return this survey by **March 15th**, to—

**Ethics Survey
HSRI
2336 Massachusetts Ave.
Cambridge, MA 02140**

Brazil, continued from p.8

ducted currently at universities and in community programs to test new interventions for persons with special needs. The greatest challenge at the moment is to propose alternative solutions, that after proving effective, will be adopted by the schools and institutions. But only through these changes will the qualities of services improve, and consequently, the quality of lives for individuals with disabilities also improve.

Rosana Salvador Rossit M.Sc. is an occupational therapist in Sao Carlos, S.P. Brazil. Celso Socorro Oliveira, who translated her manuscript, is a doctoral student in the Special Education Department at the Federal University of San Carlos. Muriel Saunders of Parsons Research Center, Parsons, edited it. Inquiries can be sent to muriel_saunders@parsons.lsi.ukans.edu.

South Africa, continued from p.9

and practice based on the vision and feedback of DSPs and those who receive services. What is still needed is a shift from the medical model of viewing people in terms of weaknesses, categories, labeling and curing, toward the adoption of a more empowerment-based model which focuses on strengths, understanding and recognizing practical support systems, competency building, developing nurturing environments and viewing individuals, groups and communities as partners and consumers of support services. The main challenge for DSPs in South Africa's new democratic era is to continue its commitment in responding to the needs of people at a community-based level and ensuring that all forms of support services are offered with the view toward building empowering

partnerships with consumers. South Africa, however, has already proven to the world and to itself that it is up to the challenge of acknowledging that its greatest strength lies in the diversity and courage of its people.

Allister Butler is head of department at the University of Fort Hare, South Africa. He may be contacted at butler.a@ufhcc.ufh.ac.za.

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Direct Care, continued from page 3

Project. Services are limited to the parishes (regional districts) served by 3D. Most CBR workers are mothers of children with disabilities. The value of CBR is as rooted in the psychological and emotional bonds between the community worker and family members as in the interventions practiced. In fact, volunteers with less formal education are preferred over professionals by most families, as many volunteers already have working relationships with consumers. Training at 3D is intensive and prepares workers to be “all-rounders”— family trainers, health workers, assistant teachers and community organizers.

In Vietnam, CBR has been integrated into the country’s primary health care system. Local nurses, assistant teachers and volunteers are trained and assigned to communes. They conduct household surveys to identify people with disabilities. As several genera-

tions will often live under one roof, grandparents, parents, siblings, relatives or close neighbors are recruited as CBR workers. Vietnam as a society is also very literate, so the WHO training manual has been disseminated widely.

Reaching Up and CUNY have begun an exchange program that provides funds for DSPs in its Kennedy Fellows Program to visit CBR programs in Jamaica and Vietnam, and internships for CBR workers to work and receive training at agencies in New York City. In NYC, where Caribbean Americans represent a growing part of the workforce and those receiving services, the Jamaica exchange has helped U.S. agencies provide more culturally competent services. The Vietnam exchange focused on training personnel to work with people with cerebral palsy, an emerging disability in Southeast Asia, and physical disabilities caused

by land mines. These training opportunities are viewed as enhancements of their existing CBR programs.

The CBR focus on natural supports has much to offer the Western “institutional,” “community-based,” and “independent living” models of delivery. With the opportunity to build service delivery models anew, developing countries can demonstrate for DSPs in the U.S. what natural supports look like from the ground up. In turn, CBR workers can profit from the successes and failures of the West. Through ongoing dialogue, we will all benefit from the most promising international developments.

William Ebenstein is executive director of Reaching Up & The City University of New York Consortium for the Study of Disabilities. He may be contacted at 212.794.5486.

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