



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 the educational and training innovations and needs of the nation's direct support professionals. 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.

What's Inside

Frontline Story • 2
Alliance Update • 3
Frontline Research • 4
Organizational Perspective • 5
Education Initiative • 5
Agency Initiative • 6
Direct Support Perspective • 7
Self-Advocate Perspective • 8
Policy Initiative • 9
Family Perspective • 10
Frontline Resources • 11

Educating Today's DSPs

Training is Essential to Quality Services

The President's Committee on Mental Retardation (PCMR) is committed to the improvement of the lives and the stature of people with mental retardation across the country. There are many components that need attention for this to happen, but one of the most critical is the role of the direct service provider, because they stand as the culmination of our efforts. Ultimately, we must rely on their intentions and their abilities in order to see real, long-term advancement in the area of supports to people with mental retardation and other disabilities.

We know that there are many competent, caring, and dynamic DSPs currently providing supports, but we also know there are problems: high turnover, burnout, a lack of qualified candidates to fill open positions, and all of these exacerbated by low status, lack of career paths, and low-wages. Perhaps one of the most discouraging prospects is the fact that there are people with good intentions and great potential who are simply lacking the skills and knowledge to help them succeed in this type of work. For this reason, educa-

tional and training opportunities for direct support professionals can't be overlooked or minimized as an essential component in quality services.

This area will take on even greater importance as we continue to implement person-centered approaches to planning services. Providing person-centered supports requires a more sophisticated level of reasoning on the part of the DSP, and because of its highly individualized nature, it accelerates the decentralization of services. In short, the direct support professional of the future will have less direct supervision and a higher and more complex level of responsibility for services. Without the opportunity for advanced training, education and professional development, these direct support professionals will be ill-equipped to meet the challenges ahead.

Fortunately, there are many exciting things happening in the area of training and education for DSPs around the nation. These various initiatives have come from agencies, counties, and collaborative work groups or are part of states'

[Continued on page 8]



The College of Education
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Frontline Story

Sharing Knowledge

My Reward as a Direct Support Professional

I started working with people with developmental and physical disabilities in the summer of 1994. A college friend had introduced me to the direct support profession by allowing me to volunteer at a Community Integrated Living Arrangement (CILA) home with Options, Inc. in Chicago. At the time, I was a senior in college, pursuing a double major in psychology and social science.

After volunteering for about three months, I started as a part-time community support worker with Options, Inc. and then became a live-in at a CILA. I worked ten hours per week helping the full-time staff take the women living there out to movies, grocery stores, churches, and restaurants. I found it rewarding to give of my time, knowledge, and energy.

What I found most rewarding was when I saw the women with whom I worked gain more independence in their daily lives, financially, socially, and in the community. Many things that I'd taken for granted, such as grocery shopping, buying a blouse, or eating at a restaurant with friends, were activities that were greatly enjoyed and appreciated by these women. Their smiles were evidence of their happiness, and these were well worth my effort.

I now work in at the Shore Training Center, a sheltered workshop and school for people with disabilities, in Morton Grove, Illinois. My responsibilities are a bit different – more focused on job-related social skills, hygiene, and monetary familiarity. I run curricula ranging from arts and crafts to story telling. Each day I enjoy

finding ways to bring out the best from a variety of personalities. I love the nine people I serve. I enjoy that I have an effect on their lives as I strive to give them every opportunity to progress and live more independently. Like a teacher, I'm trying to acquaint them with new ideas and concepts.

At times, I become frustrated when there are more behavioral challenges or people seem bored and uninterested in working. Yet, I know I'll have another opportunity tomorrow to try to create new paths to success. I work where I do because I enjoy learning, teaching and helping others. It's a great joy when I work with a person toward a goal and he or she learns something new. I like sharing my knowledge and feel good when they're able to learn and apply it.

Occasionally, when I took them out to stores, or while walking down the street, I noticed that people were watching us. At times, this could be annoying, but many times I sensed that the women enjoyed being the center of attention. I took pride in this and in the fact that I'd provided an understanding and supportive environment for them within the community as well as at their home. I worked with this residential program for four and a half years, and it functioned smoothly because each member lent a positive, team-oriented attitude to this environment. I could tell that we'd made a difference for these women.

Tonia Brock is a DSP at the Shore Training Center in Bellwood, Illinois. She may be reached at 847/581-0200.

Editorial Board Members

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- *Herminia Torres, DSP, Bronx, NY*
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- *Elaine Wilson, supported living professional, ARC-San Diego*

If you are interested in commenting on or contributing to Frontline Initiative or in becoming a member of the editorial board, please contact:

Tom Beers
Editor, Frontline Initiative
101A Pattee Hall
150 Pillsbury Drive SE
Minneapolis MN 55455
Phone 612/624-0386
Fax 612/625-6619

Alliance Update

The Alliance States Goals for DSP Credentialing

The Alliance has identified as one of its goals to support developing and implementing a national voluntary credentialing process for direct support professionals. A work group of Alliance members has developed a position statement and definitions regarding a national voluntary credentialing process. This position statement will be reviewed and discussed by the full Alliance membership at our spring meeting. We are also very interested in your ideas and feedback regarding the position statement and definitions identified below.

National Voluntary Credentialing Process

The Alliance supports the development of a nationally recognized, voluntary credentialing process for DSPs. The credential is received and held by direct support professionals and the process for obtaining it would be voluntary and coordinated at the agency, local, state or regional level after receiving endorsement from the Alliance (a national collaborative body consisting of representatives from key national industry organizations and human service educators). The Alliance is committed to creating access to this credential for DSPs by promoting opportunities to create a credentialing process at agency or local, regional, and state levels. Upon request, endorsement of a nationally recognized credentialing process will be given to agencies, local collaboratives, states, or regions based upon strong evidence that the applicant has developed and will implement and coordinate a credentialing process that includes the following specified components of the national credential for direct support

professionals: 1) promotes consumer and family choice and satisfaction as an integral component of direct service; 2) delivers training/education based on specific knowledge/skill sets; 3) includes an assessment process which measures knowledge/skill competencies; 4) is guided and monitored by a local partnership of stakeholders which must include, but is not limited to, people with disabilities or their families and direct support professionals; and 5) includes work-based learning and competency demonstration components.

Definitions of Terms

The National Alliance for Direct Support Professionals endorses the following definitions regarding the development of a national voluntary credentialing process:

- **National** • National in scope; endorsed by a national collaborative body within the industry but coordinated and monitored at the agency, local, state or regional level, and is transportable from one endorsed entity to another.
- **Voluntary** • Cannot be forced or required of any person, agency, or state.
- **Credential** • An industry award which recognizes that a direct support professional is excellent at what they do; that they have knowledge, skills, and experience above and beyond the typical entry-level worker and have achieved mastery of specific knowledge and skill sets. (The term *credential* was chosen over *certificate* because the latter often restricts entry into a profession or can exclude people from practice.)

- **Process** • The steps an entity must go through and the components of a training/educational program an entity must prove in order to gain endorsement from the national body.
- **Direct support professional** • The direct support professional assists individuals and their families in making choices; in leading self-directed, self-determined, and empowered lives; and in contributing to their communities. The DSP also encourages attitudes and behaviors that enhance the inclusion of individuals in communities.
- **Local entity** • A local entity is a public or private organization or educational institution that is committed to direct support professional development and opportunity. A local entity could also be a collaborative of local industry stakeholders who share a commitment to DSP development and opportunity.

To share your ideas regarding a national voluntary credential, or for more information about the Alliance, contact one of the following co-chairs:

Amy Hewitt
 Institute on Community Integration
 150 Pillsbury Drive SE, Room 107
 Minneapolis, MN 55455
 612/625-1098

Seth Krackauer
 AHRC
 446B 124th Street
 Rockaway Park, NY 11694
 718/474-4103

James Meadours
 Self-Advocates Becoming Empowered
 3321 Edenboren Avenue, Apt. 315
 Metairie, LA 70001
 504/779-7817

The Community Support Skill Standards

Pathways to a Professional Identity

As a senior research associate for the Human Services Research Institute, I've had the opportunity to work with many direct support professionals from across the country and have heard many of their stories. The most personal of them have come from my brother Joe, who works with children in Pennsylvania. He's shared many stories that illustrate the multiple facets of his job and affect my emotions in ways that are sometimes disturbing, though often inspirational. His stories illustrate that his role as a DSP bears enormous responsibility, involving the ability to teach, love, comfort, protect, and guide those in his care toward a positive future.

He once described how staff were given rancid butter to use for the children's meal. Because my brother objected, good butter was provided – but with opposition from program administrators. This story reminded me of the vulnerability of many of the people who depend on human services for support and the importance of the direct service practitioner in delivering good supports. Knowing how difficult it can be for DSPs to speak up in these kinds of situations, this story left me concerned about how direct support professionals could be empowered.

In recent years, through the Community Support Skill Standards Project (CSSS), I've worked with direct support workers and others to move toward a public and collaborative search for ways to strengthen and support the direct service workers in performing their many roles, including advocacy. One outcome of this search

has been the creation of the CSSS.

The Community Support Skill Standards are a body of practice standards that describe the knowledge, work practices, and philosophical basis of the direct service role in a concrete and comprehensive way. This is especially important given that the direct service work force isn't currently identified or counted correctly by the Department of Labor – nor is the role visible or well understood by the general public. By describing what direct support practitioners know and do, the Community Support Skill Standards have defined a valid title and role that can be recognized and valued within a professional context.

DSPs have collaborated to construct the content and the vision of the CSSS. Direct support workers serving various populations converged for a series of two-day workshops. Using a prescribed methodology, a DACUM (developing a curriculum) analysis, facilitators led these practitioners in discussions of many aspects about their day-to-day activities as well as exercises designed to identify industry trends and values which were then distilled into a the following definition:

The Community-Based Human Service Practitioner assists the participant to lead a self-directed life and contribute to his or her community, and encourages attitudes and behaviors that enhance inclusion in his or her community.

Data from these workshops were synthesized and then validated through a survey of stake-

holders and used by expert panels that included consumers, educators, workers, and employers to write the standards. The formulation of these standards bridges the gap between anecdote and practice. These are a just few examples of how people are using them:

- Tyngsborough, Massachusetts' high school uses the CSSS to introduce students to human service and to build career exploration activities involving work-based learning in human service environments.
- Nekton, Inc., of Minneapolis used the standards to assess organizational training needs, devise competency-based worker self-appraisal systems, and design pre- and in-service training content specifications.
- City University of New York used the standards to strengthen curriculum in four-year degree programs.
- The technical colleges of New Hampshire used the CSSS to strengthen curriculum, enhance faculty development, and create virtual workplaces for students.

While stories like my brother's provide an important means of understanding the direct support role, the CSSS marks the first attempt to use a systematic and national approach to defining this role and communicating it to a wide spectrum of people.

Marianne Taylor is senior research associate at the Human Services Research Institute in Cambridge, Massachusetts. She may be reached at 617/876-0426.

Organizational Perspective

Continuous Learning in Mississippi

Competent, well-trained direct service workers and supervisors are essential to providing the best possible services to people with disabilities. As a regional service provider, the South Mississippi Regional Center (SMRC) offers individualized programs and supports to about six hundred citizens and families each year. One way the SMRC has sought to improve its services has been through a new writing curriculum especially for DSPs with supervisory duties, because they must have a sound working knowledge of policies and regulations and be skilled in written and verbal communication, management, and leadership.

With the provision of the Mis-

issippi Workforce Education Act, the SMRC designed a technical writing module to sharpen basic reading and writing skills among DSPs at all levels of responsibility. In collaboration with the Mississippi Gulf Coast Community College, the SMRC constructed a technical writing course.

Direct service supervisors and program coordinators piloted and refined the preliminary module, and as development of the module continued, supervisory staff and project coordinators refined it on-site at SMRC. This collective effort produced an eight-hour class taught by instructors provided by the college. The training costs less than one hundred dollars per each

training day for the entire class.

Since the module's inception, staff have been enthusiastic and positive about the it as a part of their training and its value to their on-the-job success. The class is required for staff to be promoted among the direct support capacities, specifically for the direct care supervisory positions. Direct service staff and supervisors give the module high marks and praise the learning experience for its obvious value in improved communications at all levels of client services.

Pamela Baker is director at the South Mississippi Regional Center in Long Beach, Mississippi. She can be reached at 601/867-1302.

Education/Training Initiative

Focus on Consumers in Virginia

From 1994 through 1996, individuals in three Virginia counties participated in person-centered training after the counties were selected through a competitive grant process. Each community was able to provide thirty hours of instruction and activities based on a person-centered planning curriculum. Initially, five consumers were selected at each site. Teams that would participate in the training were assembled for each of the individuals. By the end of fiscal year 1995-96, ten individuals and their teams in Chesterfield county, ten in Stafford, and five in Middlesex had participated.

During 1996, the project also

sponsored a training conference on person-centered strategies. The conference included training for parents, teachers, and professionals who sought to strengthen their skills in facilitation and person-centered planning.

Chesterfield and Stafford counties have gone on to develop a second phase based on the person-centered approach that has been the recent focus of the project. Parent mentors who were hired by the project area in each location have worked to develop positive transition opportunities for students with disabilities in Stafford and Chesterfield counties. This phase offers training in person-centered

planning to teams that include students, family members, agency service providers, paraprofessionals, professionals, and administrators. Since its implementation, parent mentors have seen enhanced teamwork, cooperation, and communication among community services, parents, and public schools and a great deal of networking between families and focus individuals.

Patricia Gonet is assistant director of community training for the Virginia Institute for Developmental Disabilities in Richmond, Virginia. She may be reached by e-mail at pagonet@atlas.vcu.edu.

Agency Initiative

The DSP Training Program in Minneapolis

Free College Education for Entry-Level Staff

At a time when agencies are having trouble recruiting and retaining direct service workers, the Direct Support Professional Training Program (DSPTP) is a unique new resource for recruiting and training new staff for entry-level support positions. The program recruits potential workers and provides credit-based education and training, on-site worker experience, employment supports, and job placement. The program was developed and is being offered by the Metro Area Training Consortium, which is made up of representatives from Anoka-Hennepin Technical College (AHTC); Loring Nicollet-Bethlehem Community Centers, Inc. (LNB), a service agency that offers employment and education services; the University of Minnesota's Institute on Community Integration; Bristol Place Corporation (a provider agency); and other area support agencies. This coordination of industry, education, and employment supports is a powerful tool in dealing with pressing issues in the field.

Potential participants are recruited through a network of community-based employment and training programs in the Minneapolis/St. Paul area. This network taps into a population that includes people who are looking for a new career but who may not have been aware of the opportunities in the human services field. Students who enroll in the eleven-week program receive twenty hours a week each of classroom training and work site experience.

The classroom training consists of the fifteen credit-hour, certificate portion of the Community-

Based Supports for People with Disabilities (CSP) curriculum, as well as other state-required training topics. The CSP is a competency-based program that offers course work specifically in the area of disabilities, and that incorporates the National Skill Standards for community-based human service practitioners. Beyond the certificate, the CSP offers specialized diplomas and AAS degrees.

For the work experience portion of the training, students are matched with participating agencies that provide financial sponsorship, work site supervision, and weekly evaluations for each of their student placements. This work site experience gives the students a chance to exercise and reinforce the acquisition of skills first learned in the classroom.

Agencies that participated in the training last fall became interested for a number of reasons:

- Looking for new ways to recruit and train staff during a “crisis”
- Opportunities to “allow more quality training” for new staff
- A chance to “work with people for a while and see if they’ll work out” as regular employees

Student and agency support is a strong component of the DSPTP. During the training, LNB coordinates communication and feedback between students, instructors, and work site supervisors in order to identify and address any issues that might interfere with a successful training or employment experience.

Agencies also benefit from the screening and training that stu-

dents receive before beginning their work experience. The orientation week includes state-mandated training required prior to initiating work like CPR certification, state adult-protection rules, and medication administration.

The program offers students the chance to receive high-quality, credit-based course work, practical work experience, and a stable entry point into the mental health field, all free of charge. Funding, provided through student sponsorships and other resources, even includes a stipend. Additionally, the fifteen-credit certificate through AHTC gives students a solid vocational identity as well as a significant first step on a career ladder. Those who want to continue their education can go on to complete a sixty-four credit diploma program, which was recently recognized as meeting Minnesota's educational requirements for Qualified Mental Retardation Professional certification in non-ICF/MR programs.

Efforts are now under way to expand this new approach to training within the Minneapolis/St. Paul metro area, as well to some selected sites throughout Minnesota. The program's rewards are evident in the fact that all the provider agencies that participated in the pilot round are also taking part in round two which began this March. According to Nancy Schafer of St. Ann's, “We knew it was a risk, but it paid off.”

John Westerman is a senior employment counselor at Loring Nicollet-Bethlehem Community Centers, Inc., in Minneapolis, Minnesota. He may be reached at 612/871-2031.

Direct Support Perspective

Use Your Resources!

Taking Advantage of Educational Opportunities

As a direct support professional with fourteen years of experience, I reached a plateau in career advancement opportunities and salary a long time ago. I loved my chosen profession, but I felt stuck in a stagnant position. As my frustration grew, I saw no way out.

Being a young and ignorant supervisor, but still inquisitive and motivated, I regularly raved to anybody who would listen about how we needed to change the system to increase the recognition, support, and professionalism of dedicated DSPs. It angered me that our nation's priorities could be so out of whack. I couldn't believe that a person could make more money and have more career opportunities at a fast food joint than providing supports to people with disabilities! DSPs often have to work overtime or keep two jobs just to survive. In addition to these feelings, I was faced with staffing shortages, funding issues, and the difficult nature of my job. Work consumed my life.

At this point, I began to investigate what resources were available. As I did, my eyes were opened and I realized things weren't as much of a dead end as I thought. First, a good friend of mine convinced me to take a college course being offered as a pilot project at my agency, the Anderson School (a residential school for adolescents with disabilities and autism). The costs were being covered by the agency, so how could I say no? Unfortunately, I didn't do as well in the class as I would have liked and thought that maybe it wasn't for me. Six months later, however, one of the administrators who taught

at the local community college asked me if I would attend the class and act as his assistant. I eagerly accepted. This experience hooked me on education. Support and resources became my greatest asset. My agency offered several outstanding education incentives. They were just waiting for me to take advantage of them.

My next big educational opportunity again came through the information provided by a friend. A co-worker showed me a Kennedy

Support and resources became my greatest asset. My agency offered several outstanding education incentives. They were just waiting for me to take advantage of them.

Fellows scholarship application and encouraged me to pursue it. The Kennedy Fellows program is a scholarship/mentoring program that supports the education and career advancement of DSPs in the private and public sector. So, I applied, and to my great surprise, I was accepted. It's been the greatest thing that has happened to me, both personally and professionally.

The best thing about the program was its mentoring component. Each of the fellows choose a primary mentor. Mine helped me expand my understanding of available resources and possibilities beyond what I expected. I learned to use resources fully, to attack issues at their source, and to learn who the specialists are in the area of need and seek their assistance.

Although I've exhausted the scholarship program, the Kennedy Fellows continue to play a role in my life. Once you're a Kennedy Fellow, you're always affiliated with the program. Through my connection with them, I've become a person who is involved in happenings and issues concerning direct support on a regional, national, and international level. I've had the opportunity to speak at, plan, and coordinate conferences, to act as a DSP representative of

the National Alliance, to take part in a partnership with a self-advocate for mutual growth and development, to represent the Kennedy Fellows/Anderson School as a US delegate at an international conference abroad on residential child care, and more. I've received several certifications, completed one degree, and am currently pursuing another. Because of the opportunities and support from the Anderson School and the Kennedy Fellows program, I now have an opportunity to study abroad this fall and the confidence to complete anything I apply myself to.

Cynthia Mowris is an associate teacher at the Anderson School in Staatsburg, New York. She can be reached at 914/889-4373.

Lessons in Life

An Education in Customer Service

Perhaps you've heard the terms *customer choice* and *customer-directed services* and have wondered how they affect the DSP. A direct support professional must become skilled in communication, which is essential to understanding the customer's needs. There's no doubt that communicating with some people will be a challenge. This doesn't diminish their right to be heard and choose services. The DSP must be creative and find ways to understand and be responsive to their needs and wants.

Using "people-first language" when working with people with disabilities in one way of recognizing who is the customer. By using people-first language the focus is on the individual and not his or her disability. It's a reminder that they're people, not merely "clients" or "patients." Some examples of people-first language include:

- *People with mobility problems*
- *Person with a speech impairment*
- *People with visual impairments*

Above all else, talk *to*, not *at* or *about* your customers. Rather than trying to "fix" people with disabilities or solve our problems, the DSP should involve us in making decisions about service delivery. I'm a fifty-one year old man with cerebral palsy and average intelligence, and I've yet to meet a provider who has been able to fix me.

Failing to communicate, not using people-first language, and trying to fix rather than support people can have negative results. Expectations drop, which can become a barrier, or hostile relationships can develop which inhibit positive growth of the relationship between the DSP and the person receiving supports. The following are guidelines that can help establish a good working relationship:

- Look at the person when talking and give him or her your full attention.
- Make every effort to listen and to understand what the person wants or needs.

- Consider people as people first, then as decision-making customers second and as consumers of services.
- Keep your expectations high and believe the person can know his or her own capabilities.
- Communicate directly with the person even if they're accompanied by a parent, case worker, or an attendant.
- Be courteous to the person.

These guides are fundamental ways of respecting the dignity of people with disabilities. They help establish a new partnership where both the provider and the customer work together for the same interest. This way of doing business can be challenging, but the rewards will be gratifying to all.

Ed Turner is training associate at the Rehabilitation Research and Training Center on Supported Employment in Richmond, Virginia. He can be reached at 804/828-1851.

[Continued from page 1]

efforts to help keep DSPs knowledgeable and competent. Many are highlighted in this issue of *Frontline Initiative*. There's no doubt that there is a great need to continue to focus on this area and disseminate the information we have. Since the initiation of the National Alliance for Direct Support Professionals, I've seen a gratifying and surprisingly vigorous response from around the country to issues concerning the DSP. Not only are indi-

vidual agencies clamoring for more information on how to improve conditions for the DSP but outside entities like community colleges are coming to us seeking materials and advice.

As we continue to offer and develop educational opportunities, it will be fundamental to work with those who can fund these options – from agencies all the way to the federal government – to help them recognize the importance of educational and training opportunities.

And, we mustn't forget that the heart of this kind of effort must be connected to the people who have the best knowledge in this area: the experienced and competent DSPs, and ultimately the consumers of these services and their families.

Gary Blumenthal is the executive director of the President's Committee on Mental Retardation in Washington, DC. He may be reached at 202/619-0634.

Policy Initiative

Massachusetts' 1998 Budget and the DSP

Broader Funding and Inclusion Long Overdue

Before 1996, provider organizations working with the Massachusetts Department of Mental Retardation (DMR) received no increase in state funding for nine years. This appalling lack of funding left provider organizations little budgetary leeway for salary increases for direct support professionals. With the aggressive lobbying of several agencies – the Massachusetts Association of Community Organizations, Inc. (MACRO), Arc of Massachusetts, the Association of Developmental Disabilities Providers (ADDP), the Massachusetts Council of Human Services Providers – and the support of Phil Campbell, the commissioner of the DMR, this situation changed. The fiscal year 1997 state budget included a four percent salary increase for direct care staff earning under \$20,000 a year. The average salary for direct care staff statewide was \$16,850, thus the majority of direct support professionals qualified for the increase. Unfortunately, as appreciated as this increase was, it still left their salaries low in comparison to their responsibilities.

With this in mind, provider organizations continued to lobby the legislature for more funds. One approach used was to educate the legislature about direct support services by telling the stories of direct support professionals and their activities and responsibilities. These efforts resulted in a new proposal for 1998. This year, the governor's budget included a line item that read:

For a [15 million dollar] reserve [to be set aside] to provide salary

increases for direct care employees and supervisory staff earning less than thirty thousand dollars in annual compensation [and who are] employed by private human service providers that deliver residential services under contract with departments within the executive Office of Health and Human Services.

While this was yet another step in the right direction, there's still more to do. For instance, this language excludes all services provided outside residential sites. In addition, the 15 million dollar reserve still isn't nearly enough to give all direct support professionals in Massachusetts the salary increases they deserve.

In response to these deficits, "Campaign for 26,855" (the number of people in Massachusetts who qualify to receive supports, but can't get them because of budget restrictions), an umbrella group consisting of providers, advocates, and Department of Mental Retardation advisory board members, is continuing to appeal to the legislature. They're asking the legislature to change the language in the line item to read, "direct care employees, supervisors, and support staff" and to include "providers that deliver services." This will be more inclusive of the many direct support professionals working in the state.

In regard to the 15 million dollar reserve, "Campaign for 26,855" is seeking an increased figure. If the language were changed to include day service providers, the proposed reserve would barely cover Department of Mental Retar-

ation contracts. There are 11,100 full-time equivalent positions in Massachusetts (8,000 residential and 3,100 day staff) paid less than \$30,000 – and salaries for persons working under Department of Mental Retardation contracts average \$19,100. In order to give Department of Mental Retardation workers earning under \$30,000 a six percent increase in addition to mandatory payroll taxes and workers compensation, it would cost the commonwealth 14.6 million dollars. In order to accommodate contracts that aren't affiliated with the Department of Mental Retardation, the reserve would have to be increased to 30 million dollars. Again, although this increase would be very welcome, it would still fall short of inflation and cost of living rates.

Massachusetts' governor, legislature, and provider community continue to struggle with ever decreasing funds and increasing need for service. The direct support professional is the person who must deliver the quality of care and support that individuals with disabilities need, desire, and deserve, and that the commonwealth of Massachusetts expects. The continuing struggle is to pay those direct support professionals a wage commensurate with the responsibilities of their jobs.

Jay Jackson is program manager at Attleboro Enterprises, Inc., in Attleboro, Massachusetts. He may be reached at 508/695-4046.

Family Perspective

Caregivers of People with Traumatic Brain Injury

Better Training is Desperately Needed

The world of brain injury is beyond the comprehension of those who only observe the situation from the sidelines. For the injured and his or her family, life is a continuous struggle in an effort to find hope and make a difference in the life of the injured person.

My husband, Milton, and I live in Jasper, Minnesota, a small town of 750. We are the parents of three children and have four grandchildren. Before August 6, 1987, our lives were typical of small town, rural living. But on that day, our lives were dramatically changed when our son Keith suffered a brain injury after a blow to the head during a softball game. He was in a coma for four and a half months during which we had to “wait and see.”

Because every brain injury is unique, we soon learned that even the most skilled professionals make no firm diagnosis or prognosis. Yet we have many questions for which there are no answers.

Once Keith came out of his coma, we had more questions and concerns. He was affected both mentally and physically. The most devastating is the loss of his short-term memory because it keeps him from living independently. His brain no longer stores information, yet he retains the technical and personal knowledge he had before the injury.

There aren't words to describe all that's happened in the last seven years. I quickly learned that services for people with traumatic brain injury aren't adequate. Caregivers often have no training in brain injury. In long-term care facilities, there's little emphasis on

working with the person to regain independence. The lack of basic care due to ignorance is alarming.

I became determined to educate myself in every way possible so that Keith could receive the best care possible – the goal being rehabilitation toward more independence for him. This is a formidable task. It's accomplished through phone calls, correspondence, seminars, visits to rehabilitation centers, and numerous follow-ups. It's also done in conversations with the community of families in similar situations. Whenever I gained some knowledge or skill I shared it with the round-the-clock caregivers we had with Keith.

Keith is presently in an expensive, highly-regarded facility in Colorado to help him overcome his most complex behaviors. Here, as in most places we've tried, they seem more clinical than caring. When I visit, I sometimes observe that they're understaffed and inconsistent in their procedures. What I see in every area confirms my conviction that every caregiver, from the primary to the professional, needs training in how devastating the effects of brain injury are to everyone concerned. In facilities that provide services to people with TBI, there absolutely needs to be a minimum amount of education for staff. Current training specific to TBI is optional for the people who provide the care. There need to be requirements.

And even the most *basic* training needs to be available regularly so that families have the information they need to make good decisions about care. No family should be so frustrated in their attempt to

get information that they're forced to give up the care of their loved one to a facility in which they have no confidence. The constancy of care, the frustration, and the change in life-style are all damaging for a family. A major portion of my time is devoted to Keith, which leaves little for the activities we once took for granted. It's a constant drain on time, energy, emotions and finances. (Financial assistance is virtually nonexistent).

I did find some assistance in the community. I took some classes at the Pipestone campus of Southwestern Technical College. I was impressed with the way a customer service representative there took on the responsibility of offering courses to our community after a request from a speech therapist I knew. Together with the Minnesota Head Injury Association, they made information available for families and care providers at a reasonable cost. This was, at least, a good beginning. Still, there's a long way to go. Classes like these are the exception, and more of them need to be offered, more frequently, and statewide.

It's evident that there is much ignorance about brain injury. In the best of worlds, there would be an aggressive attempt to study brain injury and understand it, to share what is known and refute what is false, and to never stop talking about the mysteries that surround that delicate organ, the brain. That should start with the top professionals and filter down to the most personal caregivers.

Billie Kindt lives in Jasper, Minnesota.

Frontline Resources

Opportunities for Excellence: Supporting the Frontline Workforce

This publication reviews critical information regarding direct support workforce issues across the United States. Direct service workers, consumers, families, researchers, and provider agency personnel all provide insight to critical factors regarding DSP problems and creative strategies for solutions. For further information, contact: *President's Committee on Mental Retardation*
200 Independence Avenue SW
Humphrey Building, Room 352G
Washington, DC 20201
202/205-9515 fax

The Community Support Skills Standards: Tools for Managing Change and Achieving Outcomes

This report contains nationally validated practice standards for direct support professionals in human service roles spanning all categories of service delivery populations (e.g. mental health, physical disabilities, developmental disabilities, at-risk elders and youth etc.) Introductory sections include an overview of contemporary challenges and issues in human services work force development and education and a description of the methodology used for developing and validating the standards. To obtain this publication, contact 617/876-0426, ext. 332.

Developmental Disabilities Bulletin

This quarterly publication emphasizes articles with direct application to educational and service provision issues in serving persons with developmental disabilities. Published semiannually, its articles generally consist of research reports, reviews, case studies, posi-

tion papers and teaching suggestions. For further information, contact:

Henny de Groot
6-123D Education North
University of Alberta
Edmonton, Alberta
Canada T6G 2G5
403/492-4505
403/492-1318 fax

The Morning News

This quarterly newsletter shares a wide variety of practical information for parents and other persons working with children and adults with autism and related disorders. For further information, contact:

Carol Gray
Jenison High School
2140 Bauer Road
Jenison, MI 49428
616/457-8955
616/457-4070 fax

The New Social Story Book: Comic Strip Conversations

These books, developed by Carol Gray, provide techniques for parents and service providers to strengthen the communication skills of persons affected by developmental disabilities, particularly autism related disorders. For further information, contact:

Future Horizons, Inc.
422 E Lamar Boulevard, Suite 106
Arlington, TX 76011
817/277-0727
817/277-2270 fax

A Guide to High Quality Direct Service Personnel Training Resources – Second Edition

This extensive 360-page resource guide for trainers of direct support professionals provides comprehensive reviews of 150 training materials available in educational, residential, vocational, and other types of services, plus an extensive list of other resources. Cost: \$35.00. For further information, contact:

Publications Office
Institute on Community Integration
150 Pillsbury Drive SE
Minneapolis, MN 55455
612/624-4512
612/624-9344 fax

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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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***
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- ***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***
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Editor · Tom Beers
Supervising Editor · Susan O'Neill
Managing Editor · Amy Hewitt

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For more information about the Alliance for Direct Service Professionals, contact:

Amy Hewitt
Institute on Community Integration
University of Minnesota
107 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
Phone 612/625-1098
Fax 612/625-6619

For versions of Frontline Initiative in alternative formats, contact the project at the address above.