



Frontline Initiative

A Quarterly Newsletter of the Alliance for Direct Support Workers

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About This Issue

Welcome to the first issue of Frontline Initiative. This newsletter is dedicated to promoting the interests of direct support workers (DSWs) who serve people with developmental disabilities. Our goal is to improve services by encouraging a better trained, more respected, and more involved workforce. We hope these articles are of interest to people concerned about the quality of care to people with developmental disabilities and especially DSWs who can benefit from sharing their ideas about being a DSW today.

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A Forum for Change

John F. Kennedy, Jr. Looks at the Alliance

In 1989, several colleagues and I founded Reaching Up, Inc., a non-profit organization devoted to improving educational and career opportunities for direct care workers. Since 1994, we have been meeting with leaders of national organizations who share a concern about the low wages, high turnover, minimal training, and lack of career opportunities for dedicated, hard working staff. Recently, a number of national organizations including Reaching Up have joined together in convening a National Alliance for Direct Support Workers. The Alliance creates a national network for professional and provider organizations, consumer and advocacy groups, academic and research institutions, government agencies, and private foundations to develop effective strategies to strengthen the role of direct support workers within an evolving service delivery system.

Frontline Initiative is an Alliance-sponsored newsletter of the American Association on Mental Retardation Special Interest Group for Direct Support Professionals, Reaching Up, and the University of

Minnesota-Institute on Community Integration Direct Service Training Initiative. An Alliance goal is to increase access to competency-based training, higher education, and career mentoring for all direct support staff. Improving services to people with disabilities by acknowledging and rewarding qualified staff is also an Alliance priority. To support these activities additional work force research is needed that focuses on the relationship between the quality of services and opportunities for career advancement for exemplary employees. The expectation is that this newsletter will promote an ongoing dialogue and an exchange of ideas in these related areas.

In recent years, all sectors of the disability field have increased their outreach to both workers and self-advocates. One result is that members of these constituencies attend more regional and national conferences. We need more forums like these, outside of the service environment, where workers and people with disabilities can talk directly to each other to discuss their common interests as

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The College of Education
& Human Development

UNIVERSITY OF MINNESOTA

Frontline Story

Lightbeams – A Personal Experience

How can we not share the best that we know... for there is no greater service that any of us can do than to help others find meaning and purpose in their lives. Personally, this quotation from a spiritual publication, is the essence of why I do what I do. I'll admit it – I'm an idealist. I'm a person that feels that if I try hard enough, I can make a difference in this world – not unlike that bumper sticker from the '80s that says "Think Globally, Act Locally." Naive? Maybe. But chances are if you're reading this publication and working in this field, you're one too.

I have been working as a direct support worker with adults with developmental disabilities on and off for about three and a half years in several positions: as a one-to-one aide in a leisure setting, a program instructor in a work/activity program, an independent living instructor, and as a supported living counselor (same job, different title and state). Initially, I didn't choose this profession. It's not like I woke up one morning and said, "I'm going to be a direct support worker supporting people with developmental disabilities."

The first job I took was on my way to my "chosen" career in elementary education. I enjoyed the work; it was challenging, fun, and certainly rewarding. However, I left the field after a year because I experienced all the things that the Alliance for Direct Support Workers is trying to change: low wages, minimal training, and lack of career opportunities. In addition to these, I also left because I had the general feeling from outside that this wasn't a valued profession. It was more like a transitory arena one passed through on the way to

being something else. After trying many other professions, I've since revised my thinking. I know in my heart that this is the perfect career for me and am encouraged that this Alliance exists out there and is attempting to initiate change.

When I was interviewing for my current position as a supported living professional in a fairly large agency, the supervisor used the term "mentor" as a job descriptor. I had never thought of myself as a mentor to the people I've served. In reflection, I know that I've taught them skills that have made their lives more efficient and organized, and I've helped them achieve their desired goals. But if the truth be known, it is *they* who have been my mentors. They've helped me discover many things about what's really important in life, about what should be valued, and sometimes about what should be left alone.

I learned the meaning of *true spirit* from a young woman who was trapped inside a body that was failing but who had a mind that refused to be limited. She was always joyful, always ready to go. She taught me to truly listen – not with my ears (because she couldn't say many words) but with my heart. I've also learned the true meaning of *determination* from another woman who wanted so badly to earn a paycheck that she struggled for months against a physical barrier until she was successful. Another woman's example taught me the importance of *balance* in my life. This is a subtle message that's taken me years to learn. My "balance mentor" works at her job and equally enjoys her leisure time with family and friends. Her desires are simple and her life works

because it's balanced.

One aspect of my job that I've always had a particularly hard time with is the "tracking" of people's lives – setting goals and making workable plans to achieve these identified goals. Of course, it was always explained as a way of making sure we were doing our jobs – as *accountability*. Recently, it occurred to me that this really is a positive thing, a valuable tool, one everybody should incorporate into their lives. It's all about growth, and frankly, I've met many people without disabilities out there who are simply lost because they've never learned this skills of goal setting and accountability – valuable skills they could possibly learn if they began careers in direct support work.

Working with adults with developmental disabilities is rewarding, but not always easy. Let's face it, people are unpredictable. The job can be stressful and problems with burnout are things that face every direct support worker. But every once in a while the reasons for doing this kind of work shine so brightly it's almost blinding. Recently, I had one of those blinding moments. It happened three thousand miles away from where I live now. An individual I worked with seven years ago recognized me. He was pleased to see me and took great pride in sharing the details of his life. He also reminisced about the ways I helped him during our working relationship. It was truly a great moment – one that made me realize a single person *can* make a difference – validation in its brightest form.

Elaine Wilson is a supported living professional in southern California.

Agency Initiative

Rethinking Staff Recruitment & Retention

Recruiting and retaining experienced and qualified direct care personnel in community programs for people with developmental disabilities is an administrator's dream that never seems to come true. The main problem, of course, for many programs is low pay for direct support staff – although other factors contribute, such as lack of program and support resources, benefits, facilities, difficulty of the populations served, lack of opportunity for advancement, and burnout. Even if pay weren't an issue, why would qualified, well-trained, experienced staff work for a community program if they could work for the school district or state or county programs where, in general, benefits, facilities, support and opportunity for advancement are better?

The Nevada Association for the Handicapped (NAH), Nevada's largest community program for persons with disabilities, employs more than one hundred full-time staff. NAH has always understood the importance of good, stable direct support staff. For several years, NAH has implemented an aggressive inservice training program and has reimbursed staff for program-related training to find only too often that as soon as staff have met minimum training and experience qualifications for a state or school district position, they left – taking with them a significant NAH investment. In addition, losing long-term staff and training replacement staff is disruptive to both the program and consumers.

In 1995, the NAH management team and board of directors decided to try a new approach to recruiting and training DSWs:

- The first step was to develop a uniform staff classification and grade schedule based on education, training, and experience. NAH ensured that the top grade was competitive with state and school district salaries. Highly trained and experienced personnel are hired into the higher grades; lesser qualified individuals, through training and experience, can be promoted to a higher grade.
- Reimbursement for training expenses was increased up to

a day program to a community supported employment program. The cross-program assignment not only allows staffing patterns to be assigned by program need but, more importantly, provides a vehicle for advancement, flexibility, and a chance to try new things in a different work environment.

The personnel policy changes NAH has initiated are expensive. But so is staff turnover, absenteeism, and lack of staff motivation. Furthermore, NAH believes a

NAH believes a highly qualified staff with a sense of opportunity for advancement in both pay and professionalism will pay for itself.

\$100 per year, and training offered by NAH was scheduled after working hours and made strictly voluntary, with the understanding that the training would count toward promotion to a higher grade.

- To promote longevity and reduce absenteeism, NAH developed a bonus system that includes an extra four hours of annual time off for every year of service and a cash bonus for anyone who doesn't use any sick time within a six-month period.
- NAH also introduced a cross-program training and assignment system which allows staff to be assigned voluntarily to different programs depending on need and opportunity. For example, staff may switch from

highly qualified staff with a sense of opportunity for advancement in both pay and professionalism will pay for itself with greater consumer satisfaction, community support, and staff involvement in fund-raising and special events.

NAH's approach to personnel management clearly can't eliminate all the staff problems encountered by community-based programs that serve people with developmental disabilities. And, while it's still too soon to say definitely that the NAH initiative has improved staff morale and commitment, reduced turnover and burnout, and increased staff involvement and motivation, NAH is convinced it's a necessary investment.

Vince Triggs is the executive director of the Nevada Association for the Handicapped.

Influencing Direct Support Worker Retention

The people who provide direct supports to people with developmental disabilities are critical to ensuring the quality of those supports. Unfortunately, research shows that for every ten direct support workers in a home, between five and seven workers leave in a given year. These high turnover rates increase recruiting, orientation, and training costs, decrease communication among staff members, decrease the continuity of treatment and care, increase administrative costs and job stress, and may reduce productivity and job satisfaction among those who choose to stay. The following study was implemented to identify factors that influence whether workers will stay or leave and to develop strategies to improve direct support worker retention.

Study Description

In 1993, researchers at the University of Minnesota began studying retention among newly hired residential direct support workers in 173 group homes in Minnesota. The study examined facility practices and characteristics that affect recruitment and retention. It also examined the experiences, perspectives, and characteristics of 172 direct support workers from when they were hired until they either quit or completed a year on the job. Preliminary results from the first of two facility surveys are available. Results from the staff surveys and the second facility survey will be available in 1997.

Results

Preliminary results from the first facility survey are available for 103 homes with six or fewer residents. Forty-one of the homes operate as

Intermediate Care Facilities for persons with Mental Retardation (ICF-MR), and 62 operate under the Home and Community-Based Waiver Program. On average, these homes opened in 1989 and support an average of 4.7 people with mental retardation. Of the 465 people who live in these homes, 67% walk without assistance, 61% have severe or profound mental retardation, and 53% have a specific intervention program to address challenging behavior. Approximately 17.5% of these homes use live-in staff members.

These homes employ 975 direct support workers. Of those workers, most (77%) are female, and the mean age was 32 years. These houses experienced several recruitment and retention challenges. For example, 64% of the supervisors reported having problems finding new direct support workers to replace those who have left, 43% reported problems with staff turnover, and 40% reported problems with staff motivation. The overall turnover rate in these homes was 46%. Notably, of the direct support workers who had quit within the previous 12 months, the majority quit in the first year of employment, with 41% leaving within six months of being hired and another 25% leaving between six and twelve months after hire.

In a preliminary analysis of factors associated with turnover, a significant percentage (23%) of the differences in turnover rates between homes could be explained. Higher turnover rates were associated with lower beginning wages, higher daily per diem rates, lower county unemployment rates, having fewer direct support workers, and supporting more people with

severe or profound mental retardation. Once those factors were taken into account, county population, number of years the facility was open, ICF-MR status, and the use of live-in staff members did not help to explain differences in turnover rates of different houses. A separate analysis showed that homes in which a higher proportion of workers were eligible for paid leave time (in the form of sick time, vacation, or holiday pay) had significantly lower turnover rates.

Discussion and Recommendations

Based on these preliminary results, several strategies might be helpful to reduce turnover rates and to improve retention of new direct support workers. First, most of the people who quit did so after a short time on the job. One way to reduce this type of turnover is to use realistic job previews (RJPs) to make sure that recruits have good information about the job before they decide to take it or not. RJPs use strategies such as videotapes, booklets, oral presentations, work sample tests, and interviews to present undistorted information to job applicants about the job and the organization before a job offer has been made (Wanous, 1992). RJPs for residential settings should address things like relationships with co-workers or supervisors, opportunities to do fun things, pay and benefits, hours and scheduling practices, and difficult or unpleasant tasks such as assisting with personal care, supporting people with challenging behavior, providing transportation, and paperwork responsibilities.

Another useful strategy is to

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provide incentives to current employees to recruit new workers. Workers recruited this way are likely to know more details about the job than applicants identified through newspaper advertisements and would therefore be less likely to leave shortly after hire because the job did not meet their expectations. A final recommendation is

to examine paid leave policies. It may be less expensive to increase the proportion of direct support workers eligible for paid leave time than to continue to struggle with the costs of recruitment, training, and supporting new workers.

Sheryl A. Larson is a research fellow at the Institute on Community Integration. For more information, con-

tact Sheryl at the Center on Residential Services and Community Living, University of Minnesota, 214B Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455, 612/624-6024.

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Self-Advocate Perspective

A Good Support Person Works for Me

Learning from Consumers of Direct Support Services

I think a person with a good attitude and values usually makes for a good staff person. Sometimes, I think the way people are raised determines how they will treat other people they work with. If the direct support workers act mature, responsible, and dependable, that's usually a good sign.

On the other hand, if staff have a poor attitude, or are aggressive and show lots of anger, I don't think they're very good staff. For example, when they snap at me and say, "Don't do that," or forget important things I need or just don't care or make sense about why they want something done or not done, I can tell they will not be a good direct support worker.

While I lived in the group home, I had a big problem with one of the staff. We became very angry with each other. But after awhile, we agreed to talk our problem out and became friends again. She helped me to learn that even the really tough arguments can be worked out if both sides are willing to talk it through.

Then there was the time when I was working at a workshop. I had been there three years. We got a

new green house manager and the change was difficult for me. I was comfortable with the old manager. The new manager didn't like how I was performing and, one day, told me to sit down and quit working. I had to sit out for thirty minutes without pay. I had never been told before that there was a problem with my performance. She told me that she wanted me to do the work her way and was very defensive about it. This did not make me feel good and I did not feel like she was willing to talk it through with me so that I understood what she wanted. I do not think she thought about how the change was affecting me.

I have received support from direct support workers at school, in the workshop, in the group home, and, now, in my assisted living program. I believe that staff are important to help with emergencies and to help make things go easier in my life. A good support person works with me and my schedule. Once, a staff person made me ask my boss at the clothing store if I could get off work earlier to help accommodate the staff person's schedule. Although this was done

so the staff person could give me the support that I needed, it was to help the staff person. I was uncomfortable doing this and I could tell my boss didn't appreciate me asking. Later, I told another worker who helped me to understand that it was unethical of the staff person to ask me to do that.

All in all, I think direct support workers should be rewarded for good performance. It will help if they know that the person with a disability wants to work with them and have a good relationship. Maybe self-advocates and agencies could work together to develop a quality assurance evaluation on direct support workers. The people needing support should be a significant part of the evaluation process. This is something the Alliance for Direct Support Workers could talk about and work to make better for both direct support workers and people with developmental disabilities.

James Meadours lives and works in Tulsa, Oklahoma. He is co-chair of Self-Advocates Becoming Empowered and a member of the Frontline Initiative's editorial board.

Direct Support Perspective

“Cautiously Optimistic”

Examining the Proposed Alliance's Goals and Potential

If nearly seven years in this field has taught me anything, it's that the nature and responsibility for direct support work is far from matched by the compensation and standards for the worker. Low wages, minimal standards and poor career opportunities have resulted in both an inability to attract highly skilled workers and a high level of turnover among those who do join the direct support worker ranks. That situation may be about to change.

A proposed alliance for DSWs made up of representatives of professional and provider organizations, consumer and advocacy groups, academic, government, union, and private institutions will seek to address many of these issues. This Alliance for direct support workers proposes to develop strategies and activities to achieve a number of goals related to improving conditions for DSWs.

The idea of a representative group for direct support workers is very appealing. As of yet, there is no such specific body and there are certainly issues it could be helpful in addressing. However a concern surrounds the Alliance's ability to affect change at the level of the individual worker. The proposed Alliance membership seems very broad. While this no doubt provides important perspectives to the issues the Alliance will address, this group may also face difficulty in arriving at a consensus and implementing specific strategies.

Two of the Alliance's proposed goals include improving job skills and competencies for all DSWs and reducing turnover. Although job skills and turnover are vital

concerns for every agency, they are ultimately improved at agencies' direct service levels. Another concern for this Alliance surrounds its ability to affect these issues with anything beyond rhetoric? A national organization like this risks setting goals that are too idealistic and disillusioning their constituency by failing to provide significant change. It will be important for the Alliance to continue to determine what's needed within a

veloping specific strategies across agencies and states may be a more appropriate goal.

Although, thus far, this article has focused on areas of caution for the proposed Alliance and may appear critical of it, the truth is that this proposed organization should excite anyone in this field. The advocates for this Alliance have clearly done their research and know the issues and challenges facing not only the DSW but also

The Alliance seeks to do everything from improving communication to establishing effective standards to even offering funds for DSWs to attend annual conferences.

changing service system and to examine and understand these complex issues as they seek to address them at a national level.

Another of the Alliance's proposed goals that causes at least this taxpayer to be a bit cautious is that of “disseminating model legislation that provides incentives to agencies for staff training, salary increases, and career ladders for qualified workers.” The purpose of the Alliance is to increase the ability of the people closest to this field to implement change. This goal seems to hand that power back over to the government. I caution the Alliance that legislation at the federal level won't likely affect change at the individual level; networking and de-

the people they serve and the agencies in which they work.

The Alliance seeks to do everything from improving communication to establishing effective standards to even offering scholarships for DSWs to attend annual conferences. Although achieving their goals will take considerable time, effort and a great deal of support from all of us in the field, the rewards will be enormous. The Alliance for Direct Support Workers is an idea that is long overdue and should be welcomed by all of us. If successful, it could be a powerful catalyst for needed changes.

Steve Moser is a residential counselor at Nekton/Norhaven in Minneapolis, Minnesota.

Agency Perspective

A Look at the Alliance

Feedback from an Arizona Agency

I was recently invited to assist as a member of the editorial board for the *Frontline Initiative* newsletter and, as a component of that role, to solicit and prepare a reaction from the Arizona Training and Evaluation Center (Aztec) about the proposed Alliance for Direct Support Workers. Having worked in the field of developmental disabilities for over twenty years, the first half in a direct contact capacity, I was excited by the concept of working collaboratively with others to identify opportunities to professionalize the people who are the backbone of the service delivery system – direct support workers. The Alliance is an avenue to provide this needed networking and collaboration.

I asked Aztec direct support workers to provide their reactions to the Alliance for Direct Support Workers. Discussions with these workers reflected an excitement about the goals proposed by the Alliance. These comments from two Aztec DSWs are illustrative of their concerns.

One DSW responded, “Of all the goals of the Alliance, I feel the greatest need is continuing education and training. Better education and possible certification of direct support workers would ensure proper care and training to all individuals. Enabling us to become professionals is so important. Sadly, many of my peers don’t see themselves as professionals, and they lose sight of their importance. What happens then is the quality of care to those we serve can diminish. Thinking about the future scares me. To be in need of direct care is something that could

happen to any of us, and I wonder what type of person would care for me?”

Another DSW stated, “The idea of a publication for direct support workers will hopefully enhance our knowledge of what others are doing, and perhaps help us learn better ways to do our job. It’s going to take a lot of public education and people working together within each state to make sure direct support workers are aware of what this group is trying to do, and what it’s all about.”

Despite the positive aspects of the Alliance, a number of important questions remain. One of the major concerns centers around a national alliance setting standards for companies across the country. As Congress and many agencies have tried to lessen the burden of over-legislation and over-regulation, some view the Alliance as a well-meaning group, yet possibly on a mission to mandate national standards. This will become more of an issue when revenue is provided to states in block grants, and especially when a particular state may decide to provide a type of service in ways that may differ dramatically from delivery of the same service in another state. Knowing this, standardized requirements for people who provide these services may then pose a problem.

Hopefully, in the end, solutions can be provided which will enable direct support workers to be seen as professionals.

Donna Ohling is a manager at the Arizona Training and Evaluation Center (Aztec) in Peoria, Arizona, and a member of the editorial board.

About the Editorial Board

The following people are members of Frontline Initiative’s editorial board:

- Tom Beers, DSW, Nekton Inc., Crystal, MN
- Tonia Brock, DSW, Shore Training Center, Belwood, IL
- Bill Ebeinstien, executive director, Reaching Up, New York, NY
- James Meadours, member, Self-Advocates Becoming Empowered, Tulsa, OK
- T.J. Monroe, member, Self-Advocates Becoming Empowered, PCMR, AAMR, Cincinnati, OH
- Donna Ohling, manager, Arizona Training and Education Center, Peoria, AZ
- John Rose, chair, AAMR Special Interest Group on DSW, Irwin Siegal Insurance, Rockhill, NY
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Family Perspective

“Only the Best”

Parents Getting Involved in Supporting DSWs

When I was asked to write a few words about building an alliance with the caregivers who are now a part of my son's life, it forced me to give my thoughts real words. Some of these words don't look so nice! It makes me realize how important this relationship has to be for Scott to be successful in his new home.

The words that rise in my mind regarding direct-care staff are *dedicated, caring, underpaid, jealous, wary, hard-working, mistrustful, over-reacting, trusting, no common sense, and under-trained*. Doesn't this list sound contradictory? It tells of my admiration for Scott's staff, but also my motherly instinct of not being comfortable with him being out from under my wing.

What can and should parents do to help make sure people with mental retardation who live in

community settings are successful? We must continually voice our concerns in a positive manner. We must fight for increased salaries for direct care staff by lobbying legislators and raising the status of these positions. We need to insist on quality being the norm, not just rule or regulation compliance standards driving the system. Lastly, we need to advocate for better training to help staff recognize the unique personalities and challenges our sons and daughters present.

The current direct care staff turnover rate is appalling. How can Scott, or anyone, be expected to lead a normal life when they never know who may be there when they wake up or come home from work? He's expected to accept whomever comes through his

door. This constant turnover causes problems for everyone involved. Is it the pressure of the job, low wages, lack of good training, or all of the above? Whatever it is, we must work together to break this cycle.

By forming coalitions and alliances, we can share our concerns, victories. We must be more aware of different perspectives when coming to agreement on what's in the best interest of the individual. Parents *will* fight hard to achieve the best services because they have a vested interest in the outcome. We want stable, well-trained, well-paid, happy staff working with our family members and promise to work hard to achieve that end.

Joan Thompson is the mother of Scott who relies on DSWs.

State Initiative

Fostering Interest in Human Service Careers

An Innovative Effort in Massachusetts

The course about mental retardation that I took during the spring semester made dramatic changes in my life, ideas, and perceptions. It also helped me notice the evolution of my feelings. I am so glad that I took this course. Mr. Robison and our guest presenters taught me about humanity. As a course requirement, we had to interview someone who had a disability. I interviewed a man who had mild retardation. When I went to meet him, I was very nervous because I did not know what to expect.

Maybe I was expecting someone very different who might act weird and disturbing. My fearfulness grew while I was waiting to meet him.

Then the man came home and his parents introduced us. At that moment, I saw him as a person just like myself. He looked like any other person on the street. I was ashamed of myself. He was sweet and sensitive. I realized I could advocate for his rights and well-being in this society with people who were fearful and blind about mental re-

tardation. I believed that this man and others deserved better life standards and acceptance in this society. They were humans with very real emotions and many abilities. I refused to see people with mental retardation as devalued anymore.

These excerpts from a personal reflection paper by Aysem Oytun Atahan, presented at a 1996 "Future of Direct Service" conference in Boxboro, Massachusetts, illuminate the reasons behind a collabo-

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rative effort between state government and higher education in Massachusetts. Increasing understanding about disability issues, teaching, fostering interest in human service careers, and educating the public are the major goals of a partnership formed between the Massachusetts Department of Mental Retardation (DMR) and the University of Massachusetts (UMass).

The UMass-DMR partnership seeks to foster leadership on a range of social issues dealing with public practice, values, and customs which affect the lives of people with mental retardation and their families. The partnership has already strengthened existing relationships between the DMR and the five UMass campuses and has created a new undergraduate course at UMass-Amherst.

This course, entitled "Current Issues in Mental Retardation," examines current practices in providing supports to people with mental retardation and their families. Students are introduced to the life experiences and issues of individuals with developmental disabilities in contemporary society, and they explore new models for providing supports occurring across the country and internationally. One of the requirements of the course is for students to spend some time with individuals with mental retardation and/or their families.

"We are very excited about this partnership," Philip Campbell, DMR Commissioner, said of the collaboration. "It's important to look ahead. We need to educate a new generation of human service professionals so that people with disabilities can have more opportunities to lead satisfying and productive lives. This association will help us to develop a more capable and diverse work force so that we can meet the needs of people with disabilities and their families."

On June 8, 1996, the *Future of Direct Care* seminar was held in Boxboro to assess how the collaboration has progressed since its inception in September 1995. The seminar explored directions the partnership could take in the future. Representatives from UMass, the DMR, various advocacy organizations, and the private provider community came up with strategies for possible future directions. In his welcoming remarks, Commissioner Campbell outlined his thoughts on the future goals of the UMass-DMR collaboration. Included were:

- To develop more courses of study on the college level;
- To create internships so students can learn first-hand what it is like to provide support to people with disabilities;
- To increase understanding and share experiences between students and individuals with disabilities;
- To use the resources and expertise of academia in social science, psychology, public health, research, etc. to improve the lives of people with disabilities;
- To create more opportunities for people with disabilities to share their thoughts and experiences within the context of higher education;
- To encourage more research into issues that effect the disability community; and
- To gradually improve the education and training of direct support staff and managers who care for people with developmental disabilities.

The commissioner also announced that the DMR will commit \$500,000 over the next three to five years toward the fulfillment of these goals.

An unexpected but very emotional highlight of the seminar came when a UMass student,

Aysem Oytun Atahan, who had just completed the new course in the spring '96 semester, shared her personal reflections on the lessons she learned.

After attending this course, Ms. Atahan shared her goals. "The first is to work to see this course offered as a requirement in the psychology department at UMass. This is important because I witnessed many of my classmates in clinical psychology referring to people with mental retardation as devalued or abnormal beings. Universities are the most powerful and appropriate places to correct misconceptions about mental retardation.

"My second goal is to learn more about mental retardation. With the valuable knowledge and experience I have gained here in your country, I would like to go back to my country [Turkey] and stop the ignorance and suffering. As we all know, it is very hard and a very long way to go, but at least I am not blind anymore. I believe that this awareness of mental retardation is the cornerstone to overcome problems in this area." Ms. Atahan is now exploring human services as a career option. Her comments serve to underscore the tremendous value of a project like this. We are excited in Massachusetts about the possibilities this newly created partnership will bring. It has already proven invaluable to the many students who have participated in the courses and seminars brought about by this effort.

Dr. Richard J. Robison is director of Community Relations for the Massachusetts Department of Mental Retardation and adjunct professor at the University of Massachusetts. Further information on this collaboration may be obtained from the Massachusetts Department of Mental Retardation, 160 N. Washington St., Boston, MA 02114, 617/727-5608.

Policy Initiative

New Hampshire Listens & Learns from DSWs

In 1991, New Hampshire became the first state in the country with a completely community-based developmental service system. Government officials, regional administrators, and state policy makers have all been praised and recognized for their contributions in the creation of this system. In contrast, little public attention has been given to those providing the day-to-day, person-to-person support and assistance that is the backbone of New Hampshire's services.

During 1995, in acknowledgment of its overdue debt, New Hampshire planned and held its first Caregivers' Conference. Organizers and sponsors included the New Hampshire DD Council, the Association for Persons in Supported Employment, Arc/NH, Community Support Network, Inc., the University of New Hampshire's Institute on Disability, the New Hampshire Bureau of Developmental Services, and the American Association on Mental Retardation/NH. The conference was designed to provide caregivers with:

- A better understanding of state and national issues that affect individuals with disabilities;
- Information about innovative approaches for supporting people with disabilities;
- An opportunity to share their ideas, concerns, and dreams;
- A relaxing environment where people could meet with colleagues, enjoy themselves, and recharge their batteries.

How Caregivers View Their Jobs

When asked to describe how they felt about their work, the overwhelming majority of caregivers

gave positive responses. When asked to use three separate words that best describe how they feel about the work they do, participants responded:

- Rewarding (34)
- Frustrating/Stressful (25)
- Challenging (19)
- Satisfying/Enjoyable (17)
- Caring/Helpful (12)
- Positive Adjectives:
creative, valuable... (59)
- Negative Adjectives:
unappreciated, bored... (14)

When asked what things they most wanted to have continue, the caregivers' primary concerns were for the individuals they served. One worker summed it up this way: "I want to continue, assisting people with their independent living; giving them the chance to live the life I take for granted."

Talking about changes they'd like to see in their jobs, caregivers spoke of the need to place more importance on the person's quality of life and less emphasis on meeting tasks and objectives.

Those providing direct supports wanted to be acknowledged and respected for the role they play in the service system. They wanted better pay, full benefits, and increased training opportunities. Caregivers wanted to be represented not only on the person's planning teams, but also included in the agency's decision-making process.

Incorporating Workplace Ideas

Caregivers were asked what it would take to implement best practices in care and support in their own agencies. They identified

the following four necessary organizational changes.

Increased Respect for Individuals with Disabilities

Some suggestions included:

- Administrators need to get a taste of the reality and issues for both consumers and staff.
- Consumers must be provided with as much information as possible so they can make informed decisions about what happens in their lives.

Include Caregivers in the Decision Making Process

Some recommendations included:

- Invite caregivers to serve on all relevant committees and teams.
- Have a committee of employees meet regularly with directors and other administrators.

Increase Training Opportunities

Some of the requests included:

- Let agencies know that more conferences and workshops for the direct caregivers are needed.
- Use experience of caregivers as trainers.

Focus on Quality of Life

Some recommendations included:

- Make the person's quality of life the service system's first priority.
- Learn as much as possible about the person being supported, and create a unique environment that works for that person.

Adapted from Listening to New Hampshire's Caregivers by Susan B. Covert. For more information, contact Alan Robichaud at 603/271-3236, TTY/TDD 603/255-4033.

Frontline Resources

The Human Service Training Library

A value-based multimedia training program designed by field experts for all members of the human service team. It's divided into four series: *general training*, *introductory*, *intermediate*, and *problem-solving*. Titles in the series include:

- *Neglect and Abuse of People Who Are Vulnerable* defines neglect, physical abuse, sexual abuse, and financial exploitation, and discusses the relationship of stress to neglect and abuse and reducing and managing stress.
- *The Art of Human Service* defines human service as learning to live together harmoniously and building communities that celebrate diversity. This course presents five alternative, "value-based" attitudes and practices that include people with special challenges in a community. The materials focus on human and legal rights and responsibilities, equity, freedom, and justice.
- *Planning Positive Futures* covers both designing individual plans and the team process. It discusses the roles of the major team players, the consensus model of making decisions, and how consumers, family members, and professionals contribute to quality life planning.
- *Strategies for Teaching & Learning* provides an overview of the basic information and skills need by all members of a successful planning team and demonstrates how to apply value-based principles into the teaching process.
- *Using Functional Assessment to Reach Goals* compares this alternative approach to types of traditional assessments, explains how to conduct a functional as-

essment, and offers the opportunity for hands-on experience.

- *Principles of Human Behavior* presents important basic behavioral principles that all new professionals and advocates need to know, and includes extensive study of behavior modification techniques.

For further information, contact:
Value-Based Training and Technical Services
 3502 N 49th St.
 Omaha, NE 68104
 402/455-2818
 402/551-8851 Fax

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 direct support workforce problems and creative strategies for solutions. Available October, 1996. To obtain a copy, contact:

President's Committee on Mental Retardation
 200 Independence Ave. SW
 Humphrey Building, Room 352G
 Washington, DC 20201
 202/205-9519 Fax

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

This extensive resource guide provides comprehensive reviews of 150 training materials available for trainers of direct support workers. Available November 1996. Approximate cost: \$30.00. To obtain a copy contact:
Publications Office

Institute on Community Integration
 109 Pattee Hall
 150 Pillsbury Drive SE
 Minneapolis, MN 55455
 612/624-4512

Helping Hand

This video provides a realistic industry preview for direct support workers supporting people with disabilities in a wide variety of settings. It realistically portrays the positive and negative features of a career supporting people with disabilities so that potential employees can decide whether they want a job in this industry, which type of setting best matches their interests, what age group and characteristics of people best match their interests and the next steps to take in pursuing a direct service career. Available October 1996. Approximate cost: \$30.00. To obtain a copy contact:
Publications Office
Institute on Community Integration
 109 Pattee Hall
 150 Pillsbury Drive SE
 Minneapolis, MN 55455
 612/624-4512

Tools for Change: Building Knowledge and Creating Leadership for Persons with Developmental and Other Disabilities

This participatory and accessible education program for youth and adults with developmental disabilities is flexible enough for a wide range of learning disabilities. It can be used in self-advocacy groups, rehabilitation facilities, residential service programs, and in the classroom. Available October 1996. To obtain a copy, contact:
Advocating Change Together
 1821 University Ave., Suite 306-S
 St. Paul, MN 55104
 612/641-0297
 612/641-4053 Fax

[Continued from page 1]

well as their differences. As allies with a shared agenda, they can help each other achieve their goals. My hope is that this publication will also help to foster communication and networking among the millions of self-advocates and direct support workers from all around the country.

The powerful economic, social, and political forces that are reshaping our systems of health care, special education, and social welfare will require concerted action by all members of the developmental dis-

abilities community. It appears certain that in the future the role of direct support workers will be expanded. This publication is timely because it will anticipate future trends and present ideas and innovations that can transform chronic work force problems into creative possibilities that will improve the quality of life of both consumers and staff.

John F. Kennedy, Jr. is president and founder of Reaching Up, Inc. and a member of the President's Committee on Mental Retardation.

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- **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**
- **Commissions on Accreditation of Rehabilitation Facilities**
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