

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Fall Issue 2007

DIRECT CARE IN THE GRANITE STATE



The Growing Crisis in Attracting and Keeping Direct Support Workers and Home Providers, and What We Can Do About it.

Bob James, Executive Director, Community Developmental Services/Region VIII

Welcome to the Fall Issue of the Rap Sheet. Direct support professionals are the glue that holds our social service system together. These are the workers who support people with disabilities to live at home and to be active community members. With increasing demands for direct supports and a diminishing workforce, New Hampshire's community-based system is facing a crisis. In this issue we look at what we can do to turn things around.

If you speak with anyone who is involved in the developmental disabilities service system you will soon be talking about the shortage of people to do the work. This is true whether you're speaking with a family needing services, a legislator funding them, the director of the agency providing them, or the direct support professional (DSP) working overtime to deliver them. Turnover has reached 50%; vacancies are at an all-time high, and new hires are often rushed into service with insufficient training. And it is projected to get steadily worse over the coming decades.

It is a national crisis. A recent report by the U.S. Department of Health and Human Services states that "Between 2003 and 2020, H.H.S. anticipates that the number of DSP's needed to provide for the growth of long term support services for individuals with ID/DD (Intellectual Disabilities/Developmental Disabilities) will increase by...37%. This increase will be largely due to population increases, increases in life expectancy among persons with ID/DD, aging of family caregivers, and expansion of home and community-based services. This increase in demand will be occurring at a time when the labor supply of adults age 18-39 years, who traditionally have filled these jobs is expected to increase only by 7%." If we look at women age 22-44, a more accurate reflection of our workforce, the figures are even worse. And after 2020 the gap increases at an even faster rate.



Sara Leavitt

Bob James, Executive Director for Community Developmental Services

(Continued on next page)

SUSAN COVERT, EDITOR

A COLLABORATIVE EFFORT BY THE

DISABILITIES RIGHTS CENTER, INSTITUTE ON DISABILITY, AND NH COUNCIL ON DEVELOPMENTAL DISABILITIES

(Cover story continued)

Clearly, we have a problem on our hands that will require a comprehensive, long-range solution, similar to the successful drive to end the wait list for developmental services. The viability of our service system and the dream of community inclusion for all are at risk if we fail to rise to the challenge. Without a substantial investment of resources there simply will be too few people to operate the system.

Fortunately, we know what is needed. Here are five strategies that address the needs of both direct support professionals who hold staff positions and home providers who provide residential care for someone living in their home:

1. **Establish a minimum livable wage and benefit package.** We must make wages competitive with business and industry (since we are competing with them for workers) and figure out how to offer benefits, especially health coverage, to our workforce – including our home providers. The legislature should establish a reasonable package and fund it.
2. **Invest seriously in training.** It is important that new staff and home providers receive a full training and orientation before starting on the job, and support once they are in it. There are some very successful training practices that we can learn from. I know of one agency that requires applicants to successfully complete 24 hours of training before being selected as a home provider. This has resulted in high quality, long lasting placements. Another provides a clinical consultant to help work through problem situations. It is equally important that staff be given opportunities for professional growth and advancement. On-line initiatives like the College of Direct Support provide new avenues for training DSP's and home providers – while giving them a means of advancement. (In addition to training opportunities, the Internet has the potential to open new lines of communication and reduce the isolation felt by some staff and home providers.) The National Alliance for Direct Support Professionals has developed a national credentialing program for DSP's. Utiliz-

ing these (or other) exemplary training practices on a statewide basis would improve the quality of services while attracting and keeping our more motivated workers. A review of the training provided throughout the state would be a first step in making system-wide improvements. Substantially increased funding for training – and for the staff time to participate – would be a sound investment.

3. **Greatly expand the practice of involving DSP's and home providers in decision making.** Often overshadowed by the focus on wages and benefits, this is a "best practice" that lies at the heart of job satisfaction and has the potential to significantly reduce staff turnover. Our most successful examples of longevity occur in situations where the DSP's or home provider's judgment is trusted and relied upon, where relationships are characterized by respect, and the worker has a personal connection with the individual served. This is often the case with consumer-directed services, an innovation that is rapidly gaining in popularity in New Hampshire. Here is one solution that requires little or no additional funding – just a vigorous championing of best practices that are currently happening. For example, one residential agency includes a home provider on every hiring committee – including those for senior managers.
4. **Sponsor a statewide recruitment campaign.** A strong public relations campaign would do two things: it would advance the cause of inclusion while creating a positive image for the work we do. If we actually implement the recommendations above, we can truly say "*Work to change your community one person at a time. Inclusion for all. It's a career – not just a job.*" A consulting firm could develop a PR campaign for a reasonable one-time cost; getting the message out by maximizing use of the web, public service announcements, and donated air time could significantly improve staff recruitment. Area Agencies can expand the use of scholarships for graduating high school students choosing a career in human services.

5. **Coordinate state policy making.** In the 1980's and 1990's, New Hampshire was steadily marching toward full community inclusion for people with disabilities, and the state's policies unequivocally supported that direction. Idealistic people were drawn to join in the cause, and many saw it as the new civil rights movement. "The dignity of risk" was considered a right for disabled and non-disabled alike. This has changed. The movement to make the everyday lives of people with disabilities more like the lives of everyone else has slowed significantly. Accountability and reporting, one-size-fits-all rules, and paperwork have increased. Jobs – direct care and otherwise – have become more bureaucratic and less creative – and less attractive. Home providers are subject to increasingly intrusive inspections and required home modifications that don't make sense to them. For instance, under newly proposed window size regulations, most of the existing homes in my region fail, which means providers must agree to have their windows enlarged or have the individual with disabilities removed from their home. On the one hand, New Hampshire is committed to a community-based system for elders and people with disabilities; yet on the other, it is developing regulations that seriously hamper that. This is because the state departments and local officials who have a say in these matters have differing views and have not been able to agree on one consistent policy. Until this is resolved, it will remain a significant obstacle to solving the workforce issues discussed here.

The growing crisis in finding and keeping qualified DSP's and home providers can be solved. It will require strong statewide leadership, a new comprehensive strategy, and dedicated funding from the legislature. To view these strategies as "nice, but beyond our means" will result in the eventual breakdown of services to our most vulnerable citizens. We really have no choice. In this case, the right thing to do is also the only smart thing to do.

SB 138 Workforce Development Committee

Most people are aware that in the last legislative session New Hampshire lawmakers passed Senate Bill 138 to address the wait list for developmental services. In addition to providing funding to reduce the wait list, SB138 also established a committee to develop a plan to address long-term workforce and related human resource issues. That committee held its first meeting on August 21, and its recommendations are due to the legislature by December 1, 2007. The membership of the group was stipulated in the bill and is broadly representative. It consists of:

Matthew Ertas, Department of Health and Human Services
(serving as chairperson)

Nancy Rollins, Department of Health and Human Services

Diane Carignan, People First of New Hampshire

Beth Dixon, Kirsten Murphy, and Cathy Spinney of Area Agency Board of Directors

Susan Gunther, Bobbi Gross, and Michael Umali from Family Support Councils

Ellen Edgerly, New Hampshire Brain Injury Association

Gordon Allen, New Hampshire Council on Developmental Disabilities

Mike Skibbie, Disabilities Rights Center

David Hagner, Institute on Disability – University of New Hampshire

Dennis Powers, Community Support Network

Deborah Hopkins, Private Provider Network

The plan must:

1. Provide for annual or periodic salary increases for all Area Agency and provider agency staff, in addition to direct support staff increases mandated elsewhere in the bill. In addition, direct support wages must be brought at least to parity with Mental Health Worker I positions at New Hampshire Hospital by July 1, 2011.
2. Provide for increased enhanced family care [home provider] rates and rate structure, in addition to those mandated elsewhere in the bill.
3. Address whether and how free college tuition programs could be accessed.
4. Address whether and how affordable health insurance could be offered to Area Agency and provider staff, and enhanced family care providers.

It will be up to the legislature to act on the recommendations in the plan.



Loving my work as a Direct Support Professional

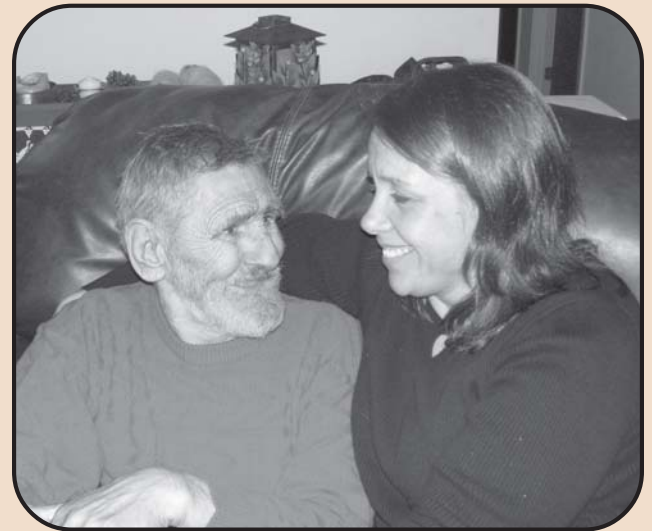
Robin Carlson

I have truly found my purpose in life – for more than 22 years I have been a direct support professional. I began working in the human services field just as Laconia State School was closing and New Hampshire was beginning to build a community supports system. I felt I was part of a civil rights movement that was liberating citizens who for decades had been cast away. As a new worker in New Hampshire's developmental service system, I received training from national leaders in the disability field. I learned about the systematic devaluation of people with disabilities from Dr. Wolfensburger. John and Connie Lyle O'Brien taught me about the importance of focusing on people's talents rather than their deficits. I learned about positive behavioral supports from Herb Lovett and community capacity building from John McKnight. From all these teachers I came to understand that people with disabilities are my equals and if our society is to be whole, we need their contributions.

In 1989, while working for an area agency, I met Frank Caswell. As a young boy, Frank spent three and half years at Laconia State School until his grandmother, appalled by the deplorable conditions, took him out the institution. Life for Frank continued to be difficult. When I first met Frank he had returned to his hometown after 17 years of wandering across the country and living on the streets. He was an extremely isolated man who allowed no one in his life except his sister, Patricia. As his support worker, it took me a solid year to gain his trust and develop a relationship. We got to know each other better as neighbors living in separate apartments in a big house. When my husband and I bought our first home and got ready to move, Frank decided he would like to live with us. Seventeen years later we are still together.

I believe our success is rooted in the value-based trainings I received early in my career. This training inspired me to align myself with people who needed a strong voice for justice. I also was immersed in a person-centered culture working with others who held the same vision of building an inclusive community. In helping people with disabilities achieve their personal goals and creating accepting communities, the role of the direct support professional is pivotal. While my work has been personally rewarding, the pay has never been adequate. I have seen many dedicated direct support professionals leave the field because they could not earn a living wage. While moving into management positions offers better pay, this is something that not all direct support professionals have the ability or even the desire to do.

In order to ensure quality community supports to people with disabilities, New Hampshire needs an effective direct support professional workforce. To accomplish this, workers must have access to value-based training, connections to local and national associations that promote professionalism and respect for direct support, opportunities for career development, *and* the ability to earn a living wage. When New Hampshire truly invests in direct support professionals, the outcome will be the creation of a vibrant and tolerant culture where communities value and actively seek everyone's contributions. The sky is the limit.



Frank Caswell and his support person, Robin Carlson

As Frank's support person, I measure success by the people Frank has allowed into his life and with whom he has mutual, respectful, and caring relationships. When Frank had his birthday in July, thirteen people came together to help him celebrate! Friends, family, and community are what make life worthwhile for Frank and for me.

Robin Carlson is chairperson for the Planning Committee for the 2007 Direct Support Professional Conference, an Institute on Disability Leadership Graduate, Workshop Presenter, and state contact person for the National Alliance for Direct Support Professionals (NADSP).

New State Law provides for Medicaid Coverage of Disposable Incontinence Supplies and an Independent Review Process for All Items and Services

Carol Stamatakis, Esq., New Hampshire Council on Developmental Disabilities

On July 3, 2007, Governor Lynch signed into law House Bill 826, relative to coverage of services and items under the Medicaid program. Effective September 1, 2007, New Hampshire's Medicaid program will cover incontinence supplies for adults, and new standards will govern access to a wide array of medical services and items, including durable medical equipment. As stated in the bill, "It is the intent of the general court to support persons with special health care needs and disabilities with coverage of medically necessary services and items under the medical assistance program so that they may live in their homes and communities as independently as possible and with the maximum ability to be mobile and exercise self care."

Rep. Tom Donovan of Claremont, prime sponsor of HB 826, has worked for many years in human services. He has seen first hand how the lack of coverage for medically necessary items impacts the lives of those who are unable to afford them. Motivated by the stories he heard from families, as well as the experiences of his older clients, Rep. Donovan introduced a bill to require Medicaid coverage of disposable incontinence supplies. When he learned that the Department of Health and Human Services (DHHS) was considering administrative rules that would make it more difficult for adults with disabilities and elders to access some durable medical equipment, Rep. Donovan expanded the scope of his bill to include these items.

In the absence of explicit state laws, the DHHS has used administrative rules to determine the extent of Medicaid coverage for durable medical equipment and other services. At times this has resulted in denials of items and services that families and health care providers believed were medically necessary. New rules being proposed by DHHS raised concerns that there would be increased denials for medically necessary services and items that could jeopardize the ability of some New Hampshire citizens to remain in their homes. HB 826 provided an opportunity for the legislature to take a comprehensive look at how

coverage of medical equipment, supplies, and services could be a cost-effective alternative to institutionalization and other expensive services. Passage of HB 826 also underlined the State's commitment to home and community-based care. In addition to Rep. Donovan, co-sponsors of the bill included Rep. Daniel Eaton, (Cheshire 2); Rep. Frank Tupper, (Merrimack 6); Rep. Susan Emerson, (Cheshire 7); Sen. John Gallus, (District 1); Sen. Martha Fuller Clark, (District 24); and Sen. Iris Estabrook (District 21).

The legislation establishes an independent review process to allow access to those items or services not otherwise covered that are permitted under the federal Medicaid program and that meet certain objective criteria. While coverage of durable medical equipment is the main focus of the legislation, it also includes any item or service that could be covered by Medicaid under federal law. For example, an item not otherwise covered would be allowed if a denial for coverage is clinically contraindicated; if it would prevent the need for a more costly covered service or item, including prevention of hospitalization or institutionalization; or if new scientific evidence supports the medical appropriateness of the requested service or item.

The many telephone calls to legislators and the testimony of people with disabilities and families at the legislative hearings were particularly compelling and convinced policymakers of the critical need for this legislation. Rep. Donovan commented, "I would have done something on my own, but to have so many advocates and families behind me to help was both humbling and empowering."

DHHS is working to develop rules and procedures to implement the new law. Interim rules are expected to be in place by the end of September. The development of final rules will include a process for prior authorization for incontinence supplies based on documentation of medical need, applicable service limits, and a process to request an independent coverage review for other services and items.

It shouldn't have to be so hard to get what you need

Susan Woods

Taking care of Ryan is a 24-hour job. My son has significant disabilities including: developmental delay, seizure disorder, severe sleep apnea, and cerebral palsy. He is legally blind and has Herrington Rods for scoliosis and kyphosis and an intracranial shunt for hydrocephalus. In addition to providing his personal care, I have the responsibility of making sure that Ryan gets the services he needs. This requires a lot of time; if you're poor it takes even longer because you have to complete lots of paperwork to prove you are eligible for help.

Fighting to get what my son needs is exhausting! For example, we needed a bathtub in our home for Ryan, but Medicaid denied our request because it's a household item that everyone would use. They kept saying, "We'll buy you a shower stall." Ryan has limb extension issues and showers don't work for him. I kept pressing and we finally got a bathtub. I had to fight Medicaid to get him a bathtub chair; they consider that a luxury item. That's crazy! Ryan has no muscle control – he needs a chair.

When Ryan turned 21, Medicaid denied our request for disposable diapers even though we had a doctor's prescription. Ryan is 6 feet tall and 215 pounds; he needs to be changed six times a day and because of problems with his skin breaking down he needs disposables. I contacted the Disabilities Rights Center and they helped me appeal Medicaid's denial. When I went to the hearing with my DRC lawyer, Cindy Robertson, I was really intimidated. The state asked all these questions about why Ryan couldn't use cloth diapers. Medicaid will pay for a covering to go over cloth diapers, but this doesn't work for Ryan. I showed them a photo of the marks on Ryan's legs caused by the covering. It took months to get a decision, but Medicaid finally agreed to cover disposables. I was so thrilled when the legislature passed the "diaper bill" (HB 826). Now other families won't have to go through what I did. What I never could understand was how Medicaid figured that once people turned 21 they would suddenly be potty trained.

Medicaid will cover 56 hours a week of LNA (Licensed Nursing Assistant) services for Ryan. It is a challenge to find LNAs to cover that many hours and what we get is closer to 37 hours. I have worked with three different agencies at once trying to get coverage for the hours that Ryan needs. We have one LNA who has been with us for many years; she comes six nights a week for 4 ½ hours. It's hard to get other times covered. Ryan has sleep apnea and I stay up with him during the night. I would like to have a LNA to help get him ready for Easter Seals in the morning, but that time slot is very hard to fill and I end up doing it. Finding care on the weekends so that our family can go do something is especially difficult.

Ryan finally got off the waiting list for adult services. After high school Ryan sat home for months waiting for day services. It was hard on him. Ryan loves consistency and he didn't understand why he wasn't going out that door every day like he had for the past 18 years. Ryan loves people and now that he is at Easter Seals he shines.

Even with his services, there still have been problems. The Easter Seals van is supposed to be level for safety reasons and the driver wouldn't drop Ryan off in the driveway because of its slope. All winter I pushed Ryan up the drive to our house. I couldn't afford a new driveway. Finally, Community Bridges found some funding to fix the driveway. It was more paper-



Susan Woods with her son Ryan

Julia Freeman-Woolpert

work and I needed to find a contractor who would do a rush job or the money would go away. Luckily, we did get it done.

Ryan is not on the waiting list for residential services. Community Bridges told me that Ryan has to stay in our home unless I can prove I can't take care of him. I resent that – I've been caring for Ryan for 23 years. While I don't want Ryan to live anywhere else right now, there may come a time when I physically just can't do it anymore. I also would like to have somewhat of a life someday.

There is no out of home respite for someone like Ryan. He used to go to Crotched Mountain, but the state changed their rules and made it so difficult that they no longer do respite care. The last time I had a weekend away was when Ryan was in the hospital. I needed that break and needed time to do things with the rest of the family. I knew Ryan would be cared for, but I still worried about him the whole time I was gone.

During the last several years, Ryan has had four or five case managers. They keep leaving. It's very frustrating; as soon as I'd explain something to one case manager, I have to explain it all over again to a new person. It wears you down. We had one case manager who stayed for a while, but wasn't able to rearrange her hours so she could finish her degree. She recently left, the person who replaced her didn't even stay two weeks and now we have yet another case manager.

Fortunately, I'm really good at advocating for Ryan. I know what I want and I'm persistent. I feel badly for the people who don't know what to do and just accept that this is the way it has to be. My advice is to talk with whoever you need to talk to. If you need to bypass your area agency and go to the state, then go to the state. Don't be afraid to go to your legislators or to the Governor. If you have a problem, write them and call them. If they don't hear from families and individuals then they have no idea how difficult our lives can be.

I don't understand why the state makes it so hard. It shouldn't have to be so hard to get what you need. You shouldn't have to always fight for it. It's not like this is a joyride for us.

NH's Direct Support Professional Conference: Past and Present

David Ouellette, New Hampshire Council on Developmental Disabilities

Thirteen years ago the New Hampshire Developmental Disabilities Council, under the direction of Al Robichaud, organized the state's first Direct Support Professional (DSP) conference. The intent of the conference was to recognize the contribution of DSPs and offer training relevant to their work. The conference provided a forum where DSPs could share their ideas, concerns, and dreams. Participants also had the opportunity to make connections, relax, and re-charge their batteries! After all direct support can be challenging, hard work.

DSPs have served on the conference planning committee from the beginning helping to ensure that the conference fulfills its mission to educate, value and respect the DSP in order to change the world to include all people. Barbara Wilson, planning committee member and DSP, created the conference



logo – a tree with the words compassion, wisdom, and honor embedded in its leaves.

Over the years the DSP conference has been fortunate to have great keynote speakers including: Don Shumway, Greg Galluzzo, Francis Kee Brunside, Rachel Simon, and Peter Leidy. Conference workshops have covered a wide range of topics including the history of Laconia State School, sexuality, system change through advocacy, and building community. In response to requests from conference attendees the conference now includes more DSP presenters who

(Continued on page 9)

Making Connections

Julia Freeman-Woolpert

Louise Cassidy has been Ken Ohlson's direct support provider for five years and loves her job. It is no accident that Ken and Louise get along so well. When Community Bridges hired Louise they had her spend time with Ken before deciding whether or not she would be his support provider. Louise explained, "They have to make sure that you're compatible. They call it shadowing, where you go out and you watch the person, how the job should be done, and you get to learn about his preferences."

When Louise arrives at Ken's house in the morning, she helps him get up and ready for the day. They have breakfast together and then are off to one of Ken's volunteer jobs. Ken works part time at Concord Hospital, New Hampshire Hospital, Harris Hill Nursing Home, and Friends of Forgotten Children. At Concord Hospital, he delivers supplies to all the departments; one of his favorites is Biomedical Engineering, where the hospital's medical equipment is repaired and maintained. The folks who work there have a goofy sense of humor and are partial to practical jokes and slapstick comedy.

Louise is a natural connector. She has a big personality, laughs a lot, and makes friends wherever she goes. Ken loves people and loves to interact, but he doesn't use much speech. Louise helps to break the ice. All day long she reaches out to people; she introduces Ken and helps people get to know him. During their break in the hospital cafeteria, Louise and Ken sat next to the cash registers. Anyone coming through the line had to pass right by them. As people approached, Louise greeted them with a big hello. When Ken's coworkers came over, she let them know that Ken's grandfather was coming for



Louise Cassidy and Ken Ohlson share a laugh with a co-worker at Concord Hospital.

*We cannot hold a torch to light another's path
without brightening our own.*

~ Ben Sweetland

a visit and that Ken was the one picking him up at the airport in his van. Once the connection was made, Louise sat back and let Ken continue the conversation. This is one of the hardest parts of her job, being quiet. Louise is naturally talkative and Ken is naturally quiet. Louise observed, "He needs to take the time to speak and I need to stand back, shut my mouth, and make sure he speaks for himself."

Everyone at work knows Ken's name, but not so many know Louise's. There are times she feels invisible – and that's fine with her. "That means I'm doing my job!" she explained. After Ken was greeted by another coworker, Louise leaned over and pointed out, "See. 'Hi Ken.' Did you hear, 'Hi Louise'? No."

Louise grew up in a household that included her grandmother who had severe physical disabilities. Louise remembered how she found ways to get her grandmother out of the house, "I put boards and made a ramp and took her out. Back then you didn't do that and I didn't know that was wrong to do. I was grounded." Louise was undaunted; she wanted her grandmother to be a part of things. She kept taking her grandmother out, even though she kept getting punished. When her grandmother went to a nursing home, Louise went too. At the age of 12, she got a job at the nursing home doing laundry and delivering trays. Once Louise had a driver's license, she and

her boyfriend (now her husband) would take her grandmother out to visit her great-grandmother, whether her family approved or not.

Her experience with her grandmother left Louise with a strong belief in inclusion and a calling to support people with disabilities to be part of their community. Louise loves working for Ken

and his family. She is proud to be part of Community Bridges and feels their philosophy of providing support matches her own. She also noted, "Community Bridges has excellent training and it's mandatory." The agency's training covers a wide range of topics including: driver's safety, CPR, and client rights.

Louise has considered leaving her job for one that pays better, especially as she looks towards retirement. She makes less than half of what she made when she worked at Blue Cross-Blue Shield in customer service. "But," she said, "I have a wonderful husband who is working harder than he probably should so that I can continue doing this job. He says this is what you do; this is what makes you happy. And when you're happy, everyone's happy."

Asked if she would recommend direct support as a profession, Louise answered, "You'd never be able to support yourself or a family on this, but yes, definitely! You get up in the morning and you are excited about going to work with that person and what you can do that day to be fun. You leave at the end of the day and you know he's had a good day and he's happy."

Louise looked over at Ken. "If you're happy, I'm happy," she said.

This issue of the Rap Sheet is dedicated to Louise Cassidy and all those direct support professionals whose care and dedication make such a positive difference in the lives of people with disabilities. On September 15, 2007 Louise Cassidy was killed in a car accident. She was a loving wife, mother, grandmother, and caregiver. She will be greatly missed.

Support the Rap Sheet!

For the past three years, the Rap Sheet has provided an in depth examination of issues affecting people with disabilities and their families. The federal grant dollars that have helped to finance the publication of the Rap Sheet are drying up. We are asking for your support to help ensure that we can continue to bring you the latest in disability research, advocacy, policy, and practice.

To make an online donation, please go to: <http://www.drcnh.org/donate.htm>, or send your check to the Disabilities Rights Center, 18 Low Avenue, Concord, NH 03301. Donations are tax deductible. Thank you!

(Continued from page 7)

conduct workshops on how to provide quality services. At every conference, DSPs have the opportunity to discuss the issues and challenges that affect their work. In their conference evaluations participants consistently report that the DSP conference provided them with information and networking opportunities that they would not otherwise have had.

While the DSP conference has gone through many transformations, the outcomes have remained the same – education, networking, and renewal. The conference offers an opportunity for DSP's to improve themselves and give the people they support a better quality of life. The 2007 DSP Conference – *Goals: Yours, Mine, and Ours* – will be held on October 26th and 27th at the Grand Summit Resort in Bartlett. Kathy Bates, Tracy Cintron, and Jim Piet will be the keynote presenters. The conference registration fee is \$50 and includes all workshops and meals. To reserve a room call the Grand Summit Hotel directly at 1-888-554-1900; be sure to mention that you are attending the DSP Conference. The deadline for hotel reservations is October 5th and October 12th for conference registration. For more information or to register contact David Ouellette at the New Hampshire Council on Developmental Disabilities – 271-3236 or by email at david.l.ouellette@ddc.nh.gov



My Way

Leslie Boggis, New Initiatives Manager, Area Agency of Greater Nashua, Inc.

Frank Sinatra claimed, "I did it my way!" Now many individuals and families in New Hampshire are singing the same tune. They have requested the option to receive services their way, and the state of New Hampshire has listened. More than eight years ago the Area Agency of Greater Nashua, Inc., following the Medicaid guidelines for the state's Division of Developmental Services, used Medicaid funds to establish Consumer Directed Services (CDS) for individuals and families who want greater control over how their services are delivered and a say in how their support dollars are used.

CDS enables individuals and families to tailor supports and services to meet their unique needs and interests. Our agency's CDS program works hard to live up to its motto – *Your Choice, Your Community, Your Home, Your Worker, Your Schedule!*

A single mother in our region who was looking at services for her daughter after high school realized that the traditional 9:00-3:00 day program wasn't going to work for her family or her daughter. She needed to work full time and her daughter requires 24-hour care. With support from CDS, this parent was able to design a program that includes essential personal care services for her daughter, as well as, horseback riding, swimming, a variety of other community activities, and time at home. She has recruited, trained, and continues to

manage the two employees who support her daughter. She sets the weekly schedule and, with the workers, plans activities that match her daughter's needs and interests. Working with the Area Agency, this mother sets the rates of pay for the workers and authorizes expenditures from her daughter's individual support budget. The Area Agency is the employer of record for her daughter's workers and provides workman's compensation insurance, benefits, liability coverage, payroll, and tax functions. Using the CDS option, this mother was able to keep her job and had the opportunity to create an individualized program to meet her daughter's needs.

Self-directed supports are a partnership between individuals, families, and the Area Agency. The individual and family design services, oversee the supports, set schedules, and authorize payments. The Area Agency provides employer and payroll functions for any workers that are hired, offers education and support to individuals and their families, and conducts oversight required for regulatory compliance. Last but not least, the Area Agency provides fiscal management through monthly budget statements. Simply put, the individual budget gives the individual and family a "fixed checking account" to pay for services. The Area Agency writes the checks that the individual and family authorize and keeps them informed about their ongoing

INTRODUCTION TO SPECIAL NEEDS TRUSTS

Special Needs Trusts (also called "Supplemental Needs Trusts") are irrevocable, discretionary trusts established by someone other than the person who is the primary beneficiary of the trust. In most cases, a parent, other family member, or a legal guardian creates the trust for an individual with a disability. The primary purpose of the Special Needs Trust is to enable the beneficiary to receive or continue to receive Medicaid and other benefits, while being

able to draw on the trust for items or services that governmental benefits do not cover.

BACKGROUND

Although Special Needs or Supplemental Trusts have been around for decades, it was not until 1993 when Congress recognized and affirmed their validity under the Omnibus Budget Reconciliation Act of 1993 (OBRA '93) that they became widely popular.

There are different types of Special Needs Trusts. A "self-settled" trust is one where the source of the trust consists of funds (e.g. an inheritance, personal injury settlement, retroactive Social Security Disability award) that are owned or received by the individual with the disability who is to be the trust's primary beneficiary. Self-settled trusts contain a "pay-back" provision to reimburse the state for Medicaid advanced to the individual during his or her lifetime. Pay-back

balance. This allows individuals and families to manage the ebb and flow of life knowing they can't overdraw their account.

At the Area Agency of Greater Nashua, Inc. over one hundred and fifty individuals with their families or allies have chosen to design and manage their own supports and services. Many individuals and their families opt to totally customize services, as did the mother in example above, while others use their budget to purchase services from traditional day or residential programs or arrange for a combination of traditional and customized services. A former Laconia State School resident who manages his own program had a worker with whom he was very close move out of the local area. While this worker was no longer available to help with weekly grocery shopping and other supports, the Area Agency recognized the importance of helping maintain this long-term friendship. A consumer directed option with individual budget control was used to support these friends spending time together; the individual's independent living supports now are purchased from a local vendor.

Parents with children under the age of twenty-one who have chosen self-directed services have used funds for personal care and supports, behavioral consultations,

respite care, and home and vehicle modifications. Most parents have used the self-directed service option to custom tailor after school care to meet the needs and interests of their child and to address the specific scheduling needs of their family. One mother designed an after school experience for her daughter that included therapeutic horseback riding, adaptive dance, and yoga.

The individual and family directed option goes beyond paying for personal care or supporting participation in community activities. CDS has provided the opportunity for many individuals to pursue and maintain employment that matches their talents and interests. Individuals and families have used CDS to pay for workers who consult with employers, provide supports on the job, and assist in finding employment. A family who used their personal network to secure employment for their daughter has a customized plan and individual budget that pays for a mentor who works with their daughter on social skills, cooking, budgeting, and who also provides consultation when needed to her employer.

Work, learning, personal care, recreation, and health are all areas where individuals and families can custom tailor supports and services to meet their unique needs and circumstances. With consumer directed services, individuals and their families can say, "I did it my way!"

John MacIntosh, Esq. and Representative Ruth Bleyler

is required when the trust terminates; that is, when the beneficiary dies.

In the second type of trust, typically created by a family member (a parent or grandparent), trust funds were never owned or received by the beneficiary. This type, commonly called a "third-party" trust does not require a pay-back provision to the state.

The final type of trust, called a "pooled trust," is managed by a not-for-profit corporation. These are

occasionally used by family members who do not want to serve as trustee, but more often these are established for individuals who are 65 years of age or older. In New Hampshire, Enhanced Life Options, a not-for-profit corporation located in Bedford, administers a pooled trust for persons of all ages with disabilities. Pooled trusts are allowed to retain or withhold a certain percentage (this varies from state to state) of the Medicaid pay-back; the retained funds

may be used to assist other beneficiaries in the pool whose needs are greater than their individual trust resources.

HOW SPECIAL NEEDS TRUST WORK

Although there are strict income and resource rules governing eligibility for SSI and Medicaid, a properly crafted Special Needs Trust should allow an individual with a disability
(Continued on page 14)

I am a Caregiver

Ellen Edgerly, Community Organizer, Brain Injury Association of NH

For the past fifteen years I have been the primary caregiver for my daughter Sara. My personal experiences and the connections that I have made with other caregivers through my job at the Brain Injury Association of New Hampshire have convinced me that we are an invisible class of people. The definition of invisible found in Webster's Dictionary – 1) impossible to see, not visible; 2) not accessible to view, hidden; 3) not easily noticed or detected, inconspicuous – describes myself and most of the caregivers that I know. It is odd to feel invisible, when in any given year more than 50 million Americans provide care for a chronically ill, disabled, or aged family member or friend. (*U.S. Department of Health and Human Services, Informal Caregiving: Compassion in Action. Washington, DC: 1998*)

When she was 11 Sara was involved in a near drowning accident and as a result, sustained a brain injury and is a quadriplegic. She spent two years in hospitals and rehabilitation centers before she was able to come home. Today, Sara lives at home with her sister Emily and me. She is a beautiful 27 year-old woman who is 100% dependent on caregivers. I am her primary caregiver and when her scheduled nurse

The Value of the services family caregivers provide for "free" is estimated to be \$306 billion a year. That is almost twice as much as is actually spent on homecare and nursing home services combined (\$158 billion) –

Peter Arno "Economic Value of Informal Caregiving" Presentation to the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006

fails to show up I am the one who is always there. I am grateful that Sara is in our lives and I am committed to giving her the highest quality of life possible. However, I am worn out by the ongoing struggle to find responsible and committed caregivers for my daughter.

Unfortunately, there is little to indicate that this situation will improve for myself or other family caregivers; in fact, our caregiving responsibilities are increasing. There are a number of reasons for this including: inadequate public funding, a rapidly aging population that is driving up the demand for caregivers, low hourly rates for direct care, and shortage of caregivers. Over the years I have noticed a significant decrease in the ability of agencies to recruit and retain qualified caregivers.

When Sara first came home after her accident, agencies were able to provide back up staff when her scheduled caregiver did not show up. Now, it is hit or miss. With a significant nursing shortage, agencies have begun to promote flexibility and their help wanted ads invite job applicants to *Choose your own hours to work around your family's schedule*. While flexible scheduling may help recruit caregivers, it makes it very difficult for family caregivers to continue to work outside of their home. Caregivers frequently have to take time off in order to care for family members and many are forced to leave their jobs. There have been many times when 48 to 96 hours of scheduled shifts have gone uncovered and I am the only one avail-

able to care for Sara. Holidays are especially difficult because agencies do not require their staff to commit to working holidays.

As their caregiving responsibilities increase, family caregivers experience increased physical and mental stress and are at risk of stress related illnesses. A Maryland neuropsychiatrist has even coined a name for this, Caregiver Syndrome – "A debilitating condition brought on by unrelieved, constant caring for a person with a chronic illness or dementia." I know from personal experience that this syndrome exists. When I am not adequately supported, my caregiving responsibilities leave me exhausted and overwhelmed.



Sara Edgerly enjoying time in the garden.

Over the years, I have found myself thinking about my fellow caregivers. In particular, those who are trying to stay on an even keel and who are feeling that they have lost control. I want to share what I have learned and that is the best way an individual can manage her life is to realize that none of us – caregivers or not – really have any control. An older woman, who is a loving caregiver to her grandson, recently told me, “If you want to make your god smile, tell him your life plans.”

I try to enjoy the simple blessings of my life, the smell of a beautiful autumn day or the laughter of my grandchildren. I also enjoy sitting on the porch swing with Sara beside me in her wheelchair watching the hummingbirds come to the feeders. George and I have been known to bundle Sara up at 1:00 in the morning and wheel her outside to watch the awesomeness of an August meteor shower.

More importantly I have learned to take care of myself. I am committed to being Sara’s caregiver for the long term. To stay healthy physically and mentally, I need to occasionally put myself first without feeling guilty. With all that said, please know that I there have been times when I melt down and imagine getting in my mustang and driving off, but these times are few and far between. I also worry about caregiving responsibilities interfering with my work. If I lose my job, then what will I do? How will I support Sara, Emily, and myself? OK Ellen, Stop. Remember the reality – we have no control.

The Coalition of Caring – Statewide Caregiver Conference

This daylong conference will be held November 3, 2007 at Springfield College in Manchester. The conference is designed for parents, spouses, adult children, and friends who are caregivers. Workshops include: Well Being of the Caregiver – Grief and Loss – Finding Humor In Your Life – Setting Boundaries – Legal and Financial Issues.

Conference registration is \$20 and includes lunch. Registration deadline is October 22, 2007. Space is limited; so please register early.

To obtain a Caregivers Conference Registration Form, please contact Ellen Edgerly by e-mail Ellenedge@metrocast.net or telephone 603-332-9891.

The Direct Care Workforce

Initiative *is a program of the New Hampshire Community Loan Fund. Its goal is to improve the quality of low-wage paraprofessional direct care jobs so people needing support can rely on the availability of a stable, experienced workforce. The Initiative is particularly interested in developing alliances to advance policy resulting in a higher quality of care and support for people who are aging and living with disabilities in New Hampshire’s communities. Best practices are tested at Quality Care Partners, a home care agency based in Manchester. For more information, contact Terry Lochhead at tlochhead@theloanfund.org.*

(Continued from page 11)

to be eligible for Medicaid and SSI, even if he or she is the primary beneficiary of a trust worth thousands of dollars. In general, a Special Needs Trust should not be used for basic needs such as food, clothing, and shelter. However, it may be used to supplement care beyond what SSI and Medicaid provide. Expenses covered by a Special Needs Trust might include, among other things, dental care, therapies, therapeutic trips or vacations, home ownership, and companionship or support services.

In the 2007 legislation session Representative Ruth Bleyler introduced HB 273 to resolve a long-standing disagreement between officials at the New Hampshire Department of Health and Human Services and trust attorneys and families over whether the state could treat distributions from Special Needs Trusts more restrictively for Medicaid eligibility than other states which generally follow

the SSI rules. The bill was passed by the Legislature and the law, which goes into effect on November 1, 2007 (Ch. Law 166, RSA 167:4(v)), will align New Hampshire's distribution rules with those of the rest of the country. In effect, the new law provides that if distributions from Special Needs Trusts do not violate federal SSI eligibility rules, then the distributions will not be disqualifying for New Hampshire Medicaid either. This will ensure uniformity and predictability for parents and trustees going forward.

WHO CAN ESTABLISH A SPECIAL NEEDS TRUST?

Oddly enough, the one person who cannot establish a Special Needs Trust is the individual who is the primary beneficiary. In general, Special Needs Trusts must be established ("settled") by a parent, grandparent, legal guardian, or court. The individual with the disability who is the

primary beneficiary must be under the age of 65 (except for pooled trusts) and must have a disability that qualifies under the Social Security Disability standard. Again, if the monies comprising the trust are or were those of the person with the disability, it must contain a "pay-back" provision to the state. The funds or other assets **not** owned by the individual with the disability do not require reimbursement to the state.

WHO NEEDS A SPECIAL NEEDS TRUST?

Special Needs Trusts are commonly used when an individual with a disability receives an unexpected "wind-fall" such as a retroactive Social Security Disability award, an inheritance, personal injury settlement, or other large sum of money. Parents and grandparents often use a Special Needs Trust to plan for future financial support for family members with disabilities. In making decisions that will affect the future for a person with disabilities, the importance of maintaining Medicaid eligibility cannot be overstated. Not only is Medicaid an important medical insurance program for hospital care and other medical needs (including medications), under its various "waiver" programs Medicaid is also the most significant method by which people with disabilities receive long-term care and residential and vocational supports. Consequently, individuals with disabilities and their family members should consult with lawyers about the utility of Special Needs Trusts.



Governor Lynch signs into law HB 273.



The Family and Medical Leave Act: A Brief Overview

Rose Wiant, Esq., Disabilities Rights Center

In 1993 Congress passed the Family and Medical Leave Act (FMLA) to enable employees to take time away from work to deal with a personal illness, to care for a family member with an illness, or to care for a new child. The FMLA is a means for employees to “balance the demands of the workplace with the needs of families” and is intended to “promote the stability and economic security of families.” The FMLA makes it possible for an employee to take an unpaid, but job-protected, leave of absence for up to 12 weeks per year.

To be eligible for FMLA leave, the employee must have worked for the employer for at least 12 months, although the 12 months do not necessarily need to be consecutive. Over the 12-month period immediately preceding the leave, the employee must have worked at least 1,250 hours, not including paid vacation or paid sick time. Finally, the employee must work for a covered employer, that is a private employer with 50 or more employees or any public employer.

Generally speaking, an eligible employee is entitled to take FMLA leave to care for a new child or to address a “serious health condition.” A new child can be a newborn infant, a newly adopted child, or a newly placed foster child. A serious health condition can pertain to the employee’s own health or to the health of a family member. The FMLA enables the employee to take time off to deal with his or her own serious health condition or to care for a spouse, parent, son, or daughter who has a serious health condition.

Under the FMLA, a serious health condition is “an illness, injury, impairment or physical or mental health condition that involves a period of incapacity.” The period of incapacity could be a result of inpatient care or continuing treatment for a health condition lasting more than three days, pregnancy or prenatal care, a chronic serious health condition that requires periodic visits to a healthcare provider, a permanent or long-term condition for which treatment might not be effective, or multiple treatments for a condition that would likely result in more than three days of incapacity if not treated. Substance abuse treatment may be covered. Unless there are complications, FMLA leave is not intended for conditions such as the flu or other minor illnesses or routine dental work. Simply put, serious health conditions are those that are likely to require professional treatment and a period of recuperation.

The employee must notify the employer of the need for FMLA leave and, when possible, provide 30-days advance notice prior to taking the leave. The employee needs to provide enough information related to the reason for the leave so that the employer can determine whether the requested leave will qualify under FMLA. Generally, FMLA leave is unpaid. However, the employer must hold the employee’s job and must maintain the employee’s health insurance.

Upon return from FMLA leave, the employee can expect to return to his or her original position. If not the same position, the employee must be restored to an equivalent job with equivalent pay and benefits. However, the employee must be able to perform the essential functions of the job. The FMLA makes it possible for an employee to take time away from work to recuperate from an illness or to care for a family member without fear of losing his or her job or of losing critical health insurance.

If you would like additional information about the FMLA, a good place to begin is the U.S. Department of Labor website (<http://www.dol.gov/esa/whd/fmla/>). Your employer also can provide information about your rights and responsibilities under the FMLA.

Source: 29 U.S.C. § 2601 *et seq.*; 29 CFR § 825.

The Role of Paraprofessionals in Supporting Students with Disabilities

Frank Sgambati, Institute on Disability

As I travel the state working with teams that are collaborating to include students with special needs into regular classrooms, I am always amazed at how much success depends upon the quality of involvement that students have with paraprofessionals. Unfortunately, not all districts include paraprofessionals as full members of the student's educational team or provide them with the training and support that they need. Instructional assistants and other school paraprofessionals need to be recognized for the valuable role that they play. These members of the school community are typically the ones who spend the most time with special education students, including those whose needs are the most complex and challenging. Paraprofessionals often have the greatest insight into the student and should be included in the planning process; their input and feedback is crucial. Those schools where the teachers and team members, *including* paraprofessionals, plan together regularly and where paraprofessionals are routinely asked for their input and feedback create an environment that supports students' success.

I have been working in education for more than 35 years. My introduction to the field - and probably my most valuable learning experience - was working as a classroom assistant. I was fortunate to work with a teacher who understood that our working as a team would benefit the whole class. The students in the room saw me as another teacher who was there to support all of them. Drawing from the lessons I've learned in my work in schools, and especially from the students I have worked with, I would like to share what I believe are best practices for paraprofessionals who are supporting students with disabilities in general education classrooms:

Best Practices for School Paraprofessionals

- ◆ Provide support that helps the student to become more independent
- ◆ Promote and facilitate social connections and friendships
- ◆ Be a resource for all students in the class and less of a one-to-one aide
- ◆ Support the student to be a *fully* participating member of the classroom community
- ◆ Support the classroom teacher to be a teacher for **all** students, including those with special needs
- ◆ Support the student to be actively involved in all aspects of the general education curriculum
- ◆ Work with the team to promote collaboration and on going support between family and school
- ◆ Seek out and take advantage of professional development and training opportunities

Without competent paraprofessionals, schools would struggle to include students with disabilities as valued members of the school community. Paraprofessionals deserve recognition for their work and should be included in the planning process.

SAVE THE DATE

PRESIDENTIAL CANDIDATE FORUM ON EQUALITY, OPPORTUNITY, AND ACCESS

Friday November 2, 2007 — 8:30-4:00

Radisson Hotel Ballroom, Center of NH, 700 Elm Street, Manchester, NH

Hosted By

Granite State Independent Living

For more information visit our website: www.gsil.org

Or call (603) 228-9680 • 800-826-3700 • 888-396-3459 (TTY)

Co-hosted by

**NH Council on Developmental Disabilities • Disabilities Rights Center
NH Institute on Disability • NH Spinal Cord Injury Association • People First of NH**



College of Direct Supports

David Johnson, Director of Communications, Moore Center Services

Career opportunities in Direct Support are on the rise. This is especially true in New Hampshire, the state that pioneered community-based care. With an increased demand for community services, a greater number of direct support professionals (DSPs) are needed.

Moore Center Services in Manchester recognizes the importance of attracting committed, compassionate, and competent personnel. Moore Center – a non-profit organization that serves individuals with developmental disabilities and acquired brain disorders and older adults – credits its reputation as an innovator in human services to its exceptional team of direct support professionals.

"There is no question that the lifeblood of our agency is our Direct Support workforce," said Paul Boynton, President and CEO of Moore Center Services. "Their hard work and dedication is critical to the Moore Center and the clients we serve."

To ensure that there is a qualified direct support workforce DSPs need access to advanced training. As part of its commitment to quality direct support, Moore Center Services offers training through its College of Direct Support, an intensive, online curriculum developed by the University of Minnesota. This training is open to direct support professionals across the Granite State and has become a valuable state-of-the-art teaching tool for New Hampshire's social service agencies.

"It's an excellent program," observed Rachel Kingston, Direct of Individual Development Services for Moore Center. "The College of Direct Support gives my staff a new perspective on the work they do. It makes them feel even more professional."

Recently, the College of Direct Support has offered a major incentive for those enrolled in the program. Completion of the curriculum now can be applied



David Johnson

Pat Bolieau meets with Jillian Poole, Moore Center DSP and the 2007 ANCOR (American Network of Community Options and Resources) DSP of the YEAR for NH

towards a two-year Associates Degree in Human Services from the New Hampshire Community Technical College at Manchester. In addition, many agencies offer wage increases or bonuses to staff members who complete courses through the College of Direct Support.

While access to advanced training is one benefit of a career in direct support, the real pay-off for direct support professionals is the satisfaction of helping others and making a positive difference in someone's life. "I enjoy the people here so much," said Helen Bennett, a DSP of 12 years who works in the Moore Center Elders Day Program. "They give us much more than we give them."

UNH student Nick Ho, who worked in the Elders program over the summer, summed up the feelings of many direct support professionals when he said, "This is the best job I have ever had."

For more information about The College of Direct Support, contact Scott Trudo at 603- 206-2816 or scott.trudo@moorecenter.org.



Consumer-Directed Personal Care Services

For over 26 years, Granite State Independent Living has provided consumer-directed personal care services to New Hampshire residents. Consumer-directed models of home-and community-based long term care (LTC) services are at the forefront of LTC changes across the nation. Consumer-direction is rooted in the belief that individuals should have the power to decide the types of LTC services that they need, who will deliver the services, and when and how the services are delivered. This premise is essential to independent living.

At the heart of the consumer-direction movement in LTC are personal care services. Non-medical in nature, personal care is assistance with activities of daily living, such as bathing, dressing, transferring from bed to chair, toileting, mobility, and nutrition assistance. It also includes housekeeping, cooking, shopping, and laundry.

Personal Care Service Options

Granite State Independent Living (GSIL) offers three options for personal care services: the Personal Care Attendant Program (PCA), the Personal Care Services Program (PCSP), and Independent Care Options (ICO). These programs are self-directed, giving consumers complete control over their personal care. Individuals select and hire their own personal care workers, and decide how, when, and where their care is provided. GSIL Personal Care Service Coordinators teach consumers or their designated representatives how to select, hire, and manage personal care workers to meet their lifestyle needs.

While each program offers a similar scope of service, there are differences in eligibility requirements.

The Personal Care Attendant Program was GSIL's first personal care program. Individuals who are eligible include those who:

- ◆ Are Medicaid eligible
- ◆ Have a severe physical disability
- ◆ Require a wheelchair for mobility
- ◆ Require at least two hours of personal care services daily
- ◆ Are 18 years of age or older
- ◆ Are their own legal guardian
- ◆ Are able to self-direct their care
- ◆ Are medically stable
- ◆ Do not require 24-hour care

The PCA program assists individuals with tasks of daily living, such as bathing and dressing, toileting and grooming, housekeeping and cooking, nutrition assistance, mobility assistance, and errands and shopping

UNH Carsey Institute Studies Direct Care Workers

Direct care workers are known by many names: caregivers, direct support professionals, personal care attendants, homemakers, respite workers, home care aides, and companions. The work that they do – assistance with personal care, housekeeping, and running errands – helps older Americans and individuals with physical or developmental disabilities to remain in the community living in their own homes. Direct care workers earn low wages, have few benefits and little hope for advancement. The majority of these workers are women.

The Carsey Institute at the University of New Hampshire is nationally recognized for its research on the challenges facing families. The Institute has a particular interest in low-income working women. Recently, the Carsey Institute's faculty and staff have developed research capacity and expertise in the area of the Direct Care Workforce and the Aging Population. Their analyses will provide a better understanding of who direct care workers are and the factors that are affecting the high turnover rate in this workforce.

Jill Burke, Vice President of Long-Term Supports, Granite State Independent Living

In 2000 the option for consumer-directed personal care services was made available through the Home and Community Based Services Waiver for the Elderly and Chronically Ill. Granite State Independent Living was one of the first organizations to be certified by the state to provide these services. Individuals who are eligible this program include those who:

- ◆ Qualify for the Home and Community-Based Elderly and Chronically Ill (HCBC-ECI) Waiver program; and
- ◆ Are able to direct their own care, or
- ◆ Have an authorized personal care services representative who acts on his or her behalf to direct care.

The PSCP program offers assistance with the same tasks-of-daily living as the PCA program, but PCSPs can also help consumers access their communities by driving them to and from appointments, visits, and other activities.

The newest addition to GSIL's personal care program is Independent Care Options. While the other two personal care options are restricted to individuals who are on a Medicaid program, Independent Care Options is available to individuals who can or wish to pay for personal care services. Individuals who are eligible include those who:

- ◆ Are 18 years of age or older
- ◆ Are a New Hampshire resident
- ◆ Can direct his or her own care, or
- ◆ Have a personal care representative who acts on his or her behalf to direct care.

The Independent Care Options program provides services that are individually-tailored to meet consumers' lifestyles. Services include but are not limited to:

- ◆ Basic personal care services
- ◆ Assistance with accessing the community
- ◆ Companionship
- ◆ Respite Care
- ◆ Chore services
- ◆ Household Management Services

Granite State Independent Living currently serves over 400 consumers and acts as the "employer of record" for over 700 personal care workers in New Hampshire.

For more information about personal care services please call 603-228-9680 or visit the Long Term Supports section of Granite State Independent Living's website at www.gsil.org.

In addition to its focus on direct caregivers, Carsey researchers examine the economic status of working women in New Hampshire and New England. The Carsey Institute provides information to policy makers, practitioners, the media, and the general public on issues concerning working women and family life and work in rural America. For additional information visit www.carseyinstitute.unh.edu



The RAP Sheet is a free quarterly publication; to subscribe please contact the Disabilities Rights Center at 603-228-0432



Did you know? The ADA offers protections for family members and caregivers too

James Fox, Esq., Disabilities Rights Center

It is well known that the American with Disabilities Act (ADA) protects people with disabilities from discrimination by public accommodations, public entities, and employers (so-called covered entities). But did you know that the ADA also protects the associates of people with disabilities – family members, friends, caregivers – from discrimination based upon their **known** relationship or association with a person with a disability? Under the ADA, covered entities are not permitted to take adverse action against any individual based upon an unfounded or stereotypical fear or belief centering on a third party's disability. The ADA does NOT require covered entities to make reasonable accommodations to a person without a disability who is an associate of a person with a disability.

Here are some examples:

- ◆ An employer may not refuse to hire or promote a person because that person has a child with a disability and the employer has an unfounded belief that the caregiving responsibilities for the child will mean problems with work attendance.
- ◆ A restaurant may not refuse or provide substandard service to a person who has a friend who uses a service animal, due to a desire to exclude the person with the service animal.
- ◆ An employer may not discriminate in hiring against a person who has a family member with AIDS, due to an unfounded belief that the person will themselves contract AIDS or infect others within the workplace.
- ◆ An employer may not refuse to hire a person who has a spouse with a disability due to an unfounded belief that health insurance coverage costs would go up.
- ◆ An employer may not exclude an employee from a company's family picnic based upon an unfounded belief that the employee's child with autism will attend and be disruptive, or make the other children uncomfortable.
- ◆ A doctor's office may not refuse to take on a new patient who has a spouse with a mental illness based upon an unfounded belief that the spouse will accompany the patient to appointments and disrupt the office.
- ◆ A law firm that allows its attorneys to take administrative leave to provide pro bono services may not discriminate by refusing to allow an attorney to take this leave to provide pro bono services to people with mental illnesses, based on an unfounded belief that it will tarnish the image of the firm.

For more information see "Questions and Answers about the Association Provision of the Americans with Disabilities Act" on the website of the Equal Employment Opportunity Commission here: www.eeoc.gov/facts/association_ada.html

If you find yourself in a situation where an adverse action has been taken against you based upon your association with a person with a disability, there are steps you can take to protect your rights. For more information about your rights and remedies, contact the Disabilities Rights Center at 1-800-834-1721, www.drcnh.org, or the NH Commission for Human Rights, (603) 271-2767, www.nh.gov/hrc/.



Direct Care Resources

The Arc of the United States

The world's largest grassroots organization of and for people with intellectual and developmental disabilities.

1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
(301) 565-3842 / (800) 433-5255 (toll free)
www.thearc.org

Carsey Institute at UNH

The Carsey Institute, a nationally recognized research, is examining factors affecting the high turnover rate in the direct care workforce.

For additional information visit
www.carseyinstitute.unh.edu

College of Direct Support

An internet-based college for direct support professionals. Educating a workforce of Direct Support Professionals – "Building Careers, Supporting Lives."

111 Center Park Drive, Suite 175
Knoxville, TN 37922
(865) 934-0221 / (877) 353-2767 (toll free)
www.info.collegeofdirectsupport.com/

In New Hampshire, Moore Center Services is the distributor for the College of Direct Support: contact either Dave Jenkins or Scott Trudo: 603.206.2818 or scott.trudo@moorecenter.com.

Direct Care Workforce Initiative

NH Community Loan Fund

The Initiative works to improve the quality of low-wage paraprofessional direct care jobs so people needing support can rely on the availability of a stable, experienced workforce.

7 Wall St.
Concord, NH 03301
(603) 224-6669
Contact: Terry Lochhead: tlochhead@nhclf.org
www.nhclf.org/programs/economic/workforce.html

National Alliance for Direct Support Professionals

A coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce.

New Hampshire affiliate:

Laura Lassins
Lifeshare Inc.
225 Eddy Road
Manchester, NH 03102
(603) 625-8825
E-Mail: john@lifeshareinc.org www.nadsp.org

ABLE NH

Over the past several months disability advocates and family members from across New Hampshire have come together to create an independent advocacy organization. Advocates Building Lasting Equality in New Hampshire (ABLE NH) has recently been incorporated and will be an affiliate of the Arc of the United States. To become a member of ABLE NH or for additional information please contact Julia Freeman-Woolpert at the Disabilities Rights Center (603) 228-0432 or by email at JuliaF@drcnh.org

New Hampshire Family Voices

Families and Friends Speaking on Behalf of Children with Special Health Care Needs
(603) 271-33451 / (800) 852-3345 (toll free)
www.nhfv.org

Paraprofessional Healthcare Institute

PHI works to improve the lives of people who need home and residential care – and the lives of the workers who provide that care.

349 East 149th Street, 10th Floor
Bronx, NY 10451
(718) 402-7766
email: info@paraprofessional.org
www.paraprofessional.org/

Parent to Parent of New Hampshire

Resources for Parents of Children with Special Needs
(800)698-5465 (toll free)
www.p2pnh.org

TASH

Equity, Opportunity, and Inclusion for People with Disabilities since 1975
1025 Vermont Ave., Floor 7
Washington, DC 20005
(202) 263-5600
www.tash.org/index.html

UPCOMING IOD TRAINING AND EVENTS

The Autism Mini-Series: 2007 Dates

Join experts on Autism Spectrum Disorders (ASD) for topical discussions related to children with ASD, their families, and their systems of support. Each small group session is designed to be informative, interactive, and filled with practical ideas for parenting and teaching.

Location for all Sessions: University of NH, Durham, NH

Cost: \$30 each

Dates & Topics:

Wednesday, October 17, 2007: Person Centered Planning (PCP) for Young Children with ASD

Time: 3pm – 5pm

Presenter: Ann Dillon

Tuesday, October 23, 2007: Promoting Membership, Participation, and Learning for Students with ASD in the General Education Classroom

Time: 4pm – 6pm

Presenters: Michael McSheehan & Cheryl Jorgensen

Wednesday, November 14, 2007: Early Markers for Children with ASD

Time: 3pm – 5pm

Presenter: Ann Dillon

Introductory Training for Facilitated Communication (FC)

Will provide participants with a general overview of facilitated communication, FC's history, basic FC technique, determining FC candidacy, and a review of research and best practices.

Date & Location: Tuesday, October 9, 2007:

Institute on Disability, 56 Old Suncook Rd., Suite 2, Concord, NH

Time: 9am – 3:30pm **Cost:** \$95

Presenter: Pascal Cheng, M.Ed., C.A.S.

Life as a Paraprofessional

Comprehensive full-day workshops designed specifically for first-year or seasoned classroom paraprofessionals to present strategies for supporting students with challenging behavior.

Time: 9am – 3pm **Cost:** \$90 each

Presenter: Cathy Apfel, M.Ed

Dates & Locations:

Level I: Pre & Elementary School

Tuesday, October 9, 2007: E.F. Lane, Keene, NH

Thursday, October 11, 2007: The Highlander Inn, Manchester, NH

Thursday, December 6, 2007: The Highlander Inn, Manchester, NH

Level II: Middle & High School

Tuesday, November 6, 2007: Holiday Inn, Concord, NH

Thursday, November 8, 2007: E.F. Lane, Keene, NH

Strategies for Success Series

Two-hour sessions to explore academic and social success strategies for students with disabilities.

Time: 3:30pm – 5:30pm **Cost:** \$35 each

Location: Institute on Disability, 56 Old Suncook Road, Suite 2, Concord, NH 03301

Presenters: Cathy Apfel, M.Ed., and Frank Sgambati, MS

Dates & Topics:

Tuesday, October 16, 2007: Positive Behavior Support: Re-Thinking the Role of Context

Tuesday, October 30, 2007 & Tuesday, November 13, 2007: Foundations of Effective Classroom Management: A Guide for Success (Participants must attend both sessions)

Wednesday, November 14, 2007: Parents and Teachers Promoting Positive Relationships for Students with Disabilities

Thursday, December 6, 2007: Including Samuel:

Strategies on How Schools Can Work for All Kids

Thursday, December 13, 2007: Teachers and Paraprofessionals Working Together: Effective Methods of Supervision and Support

Making Choice Real: Transforming Long Term Systems of Support

One day conference outlining NH's efforts to expand and enhance a person-centered system for older adults and adults with disabilities.

Date & Location: Wednesday, October 24, 2007:

Radisson Hotel, Center of NH, Manchester, NH

Time: 8:30am – 3:30pm

Cost: \$50 (professionals); \$25 (consumers & families)

Presenters: Nancy Rollins, Director, Division of Community Based Care Services, NH Dept. of Health & Human Services; Nicholas Toumpas, Acting Commissioner, NH Dept. of Health & Human Services; Lisa Alecxih, Vice President, The Lewin Group

Building Bridges to the Social World: Strategies for Developing Social Competence and Connections for Children with Autism

For children with labels of ASD, understanding and participating in social interactions can be difficult and frustrating. CarolAnn



INSTITUTE ON DISABILITY / UCED
A University Center for Excellence in Disability

Edscorn, an adult with Asperger's Syndrome, and Cathy Apfel, M.Ed., team up to offer personal insights and strategies for developing social awareness and competence.

Date & Location: Thursday, October 25, 2007:

The Common Man, Plymouth, NH

Time: 8:30am – 3pm **Cost:** \$99

Presenters: CarolAnn Edscorn & Cathy Apfel, M.Ed.

Voices of Friendship: How Schools Can Help or Hinder the Development of Social Relationships

Will help participants learn to identify the barriers to friendship that exist in many schools and classes, as well the wide variety of strategies that schools and families can use to facilitate the development of friendships.

Date & Location: Monday, October 29, 2007:

The Common Man, Concord, NH

Time: 8:30am – 3pm **Cost:** \$90

Presenter: Carol Tashie

2007-2008 Autism Research to Practice Series

Understanding and Supporting Individuals with Autism and Their Families

First Series Date & Location: Friday, November 2, 2007:

Center of NH Radisson Hotel


Time: 8:30am – 3pm **Cost:** \$125


Title: Introduction to the SCERTS Model

Presenter: Amy Laurent, M.Ed., OTR/L

4 EASY WAYS TO REGISTER!

1  online
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2  call to register or to request a registration form
603.228.3270

3  mail a completed registration form
INSTITUTE ON DISABILITY
56 OLD SUNCOOK ROAD, SUITE 2
CONCORD, NH 03301

4  fax a completed registration form
603.228.3270

Please come to the premiere of
INCLUDING SAMUEL

A DOCUMENTARY FILM BY PHOTOJOURNALIST DAN HABIB



WHAT: The public premiere of *Including Samuel*.

WHERE: The Concord City Auditorium. For directions, see www.concordcityauditorium.org.

WHEN: Tuesday, November 6, 2007, 7-9:30 p.m.

TICKETS: Tickets are \$10 with all proceeds going to the Institute on Disability's NH Leadership Series and Granite State Independent Living. Purchase tickets soon by calling the IOD at (603)228-2084 or visiting www.includingsamuel.com/screenings.

Including Samuel examines the social and educational inclusion of youth with disabilities. The 55-minute film is built on the story of Habib's own family as they work to include Samuel, 7, in all facets of school and community.

Including Samuel has received major support from the NH Charitable Foundation, the UNH Institute on Disability, Granite State Independent Living, NH Developmental Disabilities Council, Easter Seals NH and the Endowment for Health. Additional support has come from the NH Disabilities Rights Center, the NH Trial Lawyers Association and the Episcopal Bishop of NH.

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18 Low Avenue, Concord, NH 03301-4971

Voice and TDD: (603) 228-0432 ♦ 1-800-834-1721 ♦ FAX: (603) 225-2077

TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)

E-mail: advocacy@drcnh.org ♦ Website: www.drcnh.org

"Protection and Advocacy System for New Hampshire"

The Disabilities Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.

INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH

10 West Edge Drive, Suite 101, Durham, NH 03824-3522

Phone (Tel/TTY): (603) 862-4320 ♦ Fax: (603) 862-0555 ♦ Website: www.iod.unh.edu

Institute on Disability/UNH – Concord

56 Old Suncook Road, Suite 2

Concord, NH 03301

Phone (Tel/TTY): (603) 228-2084

Institute on Disability/UNH – Manchester

340 Commercial Street, 2nd floor

Manchester, NH 03101

Phone: (603) 628-7681

The Institute on Disability advances policies and systems changes, promising practices, education and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.

NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

Phone: (603) 271-3236 ♦ TTY/TDD: 1-800-735-2964 ♦ Website: www.nhddc.com

Dignity, full rights of citizenship, equal opportunity, and full participation for all New Hampshire citizens with developmental disabilities.

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The contents are solely the responsibility of the grantees and do not necessarily represent the official views of the federal grantors.

New Hampshire

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Fall Issue 2007

NH COUNCIL ON DEVELOPMENTAL DISABILITIES

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INSIDE THIS ISSUE

- ♦ *The Growing Crisis in Direct Care*
- ♦ *New Legislation Regarding Medicaid Coverage*
- ♦ *Consumer Directed Services*
- ♦ *An Introduction to Special Needs Trust*
- ♦ *Personal Stories*