

# RAP Sheet

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

Fall Issue 2011

## SUPPORTING A QUALITY LIFE



### DIRECT SUPPORT PROFESSIONALS - WHAT THEY NEED TO DO THE JOB RIGHT

By Robin Carlson

*"The greatest good you can do for another is not just to share your riches, but to reveal to him his own."* - Benjamin Disraeli, British Statesman

*Welcome to our Fall Issue where we consider the role of direct support professionals in the lives of people with disabilities. Quality services are not possible without a competent and committed direct care workforce. DSPs are the backbone of the service system, yet they are the least trained and lowest paid. They know the person they support better than any staff member, yet DSP's are not included on the individual's planning team or consulted about critical decisions. It's time for this to change.*

In human services, direct support professionals (DSPs) play a critical and unique role. For people with disabilities, especially those who have significant disabilities, their quality of life is determined in great part by the quality of those who provide their direct care and support. As part of their work, DSPs often are responsible for a person's physical wellbeing. DSPs need to be knowledgeable about proper nutrition, the effects of medications, and modifications that will increase mobility or enhance communication. More importantly though, direct support professionals need to *truly* know and appreciate the individuals they support. They need to understand what matters to them, who matters to them, and what they were put on this planet to do. People with disabilities possess unique gifts and talents that often go unrecognized.



Ray Chagnon and Robin Carlson

DSPs can help create opportunities for individuals with disabilities to share their gifts. By supporting individuals to be part of their communities, DSPs help to promote increased patience, tolerance and diversity - all factors that make society better for everyone.

To do their job well, direct support professionals need to understand the social issues that impact those who have disabilities. They need to be aware of the systematic devaluation that people with disabilities regularly experience. They need to know

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SUSAN COVERT, EDITOR

A COLLABORATIVE EFFORT BY THE

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

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how to diplomatically and ethically address issues of misunderstanding or discrimination that may come up. DSPs need to be able to help people with disabilities master the skills they need to make meaningful contributions to their communities. Finally, DSPs need to be able to talk about their work and the people they support in ways that help build connections and increase understanding and acceptance.

The job expectations for direct support professionals are indeed awesome. While some DSPs may be naturally great at what they do, every DSP can benefit from continuing education and a supportive work environment. Like all workers, DSPs need opportunities where they are inspired and motivated. They need to know best practices and be kept informed about changes in their field. They need to be challenged and encouraged to take risks on behalf of the people they support.

Finally, direct support professionals need a way to connect with one another. They need the opportunity to share ideas, offer support, and solve problems together. New Hampshire has a history of helping people with common issues connect with one another. The state's

family support system and People First are examples of this. The New Hampshire Alliance of Direct Support Professionals is being formed to provide a vehicle for DSP connections. A website, list serves, and regional DSP groups are all in the works. The New Hampshire Alliance will be affiliated with the National Alliance of Direct Support Professionals (<https://www.nadsp.org>) and offer DSPs a way to access local and national information, share stories and resources, and strengthen their professional knowledge and skills.

People with disabilities need and deserve a competent and caring workforce to support a life of their choosing and to make important contributions in their communities.

*Robin Carlson has been a Direct Support Professional for 27 years and for the last 21 years has shared her home with people who have disabilities. Ms. Carlson has written and presented about her experiences. She currently shares her perspective as a DSP as a member of a number of statewide groups, including the Bureau of Developmental Services Quality Council and the New Hampshire Coalition on the Direct Care Workforce. She is New Hampshire's contact person for the National Alliance for Direct Support Professionals and can be reached by email at [robincarlson@metrocast.net](mailto:robincarlson@metrocast.net)*



## **National Alliance for Direct Support Professionals**

*The National Alliance for Direct Support Professionals (NADSP), is a non-profit organization, that has developed a national agenda to strengthen the direct support workforce and address the following goals:*

- ◆ *Enhance the status of direct support professionals.*
- ◆ *Provide better access for all direct support professionals to high quality educational experiences (e.g., in-service training, continuing and higher education) and lifelong learning that enhances competency.*
- ◆ *Strengthening the working relationships and partnerships between direct support professionals, self-advocates, and other consumer groups and families.*
- ◆ *Promote systems' reform that provides incentives for educational experiences, increased compensation, and access to career pathways for direct support professionals through the promotion of policy initiatives (e.g., legislation, funding, practices).*
- ◆ *Support the development and implementation of a national volunteer credentialing process for direct support professionals.*

*For more information please visit the NADSP website at <https://www.nadsp.org/>*

*To learn about joining the New Hampshire Chapter of NADSP contact Robin Carlson at [robincarlson@metrocast.net](mailto:robincarlson@metrocast.net)*



# TRAINING OPPORTUNITIES AVAILABLE THROUGH DIRECTCONNECT

By Scott Trudo, Project Director, DirectConnect, Institute on Disability

New Hampshire DirectConnect offers the following training opportunities to direct support workers and to those interested in pursuing a career in direct care.

## College of Direct Support

The College of Direct Support is a nationally recognized web-based curriculum that covers a broad range of informational, skills-based, and values-based topics. The 25 available courses includes such classes as: the History of Disabilities, Individual Rights and Choice, Positive Behavior Supports, and Community Inclusion.

The College of Direct Support is fully accredited by the National Alliance of Direct Support Professionals (NADSP); its curriculum may be applied to the NADSP Direct Support Professional credential. The curriculum also is recognized by the US Department of Labor as satisfying Direct Support Professional Apprenticeship program requirements.

Through the College of Direct Support, the following certificates can be earned:

**Institute on Disability Direct Support Professional Credential:** Awarded for successful completion of a 12-course curriculum that includes 6 hours of facilitated peer discussion. Bimonthly discussion groups hosted by IOD are video-conferenced to sites around the state. Courses may be applied towards a national credential.

**College of Direct Support Shared Home Provider Certificate:** This is awarded to those who complete 12 courses designed to enhance skills for shared home providers.

**Bureau of Developmental Services Overview Training Certificate:** This represents successful completion of on-line courses and instructor led classroom discussion. It is intended for use by agencies as part of new employee training and to meet BDS regulation 506.5 requirements.

**Becoming a Direct Support Professional:** A certificate designed for those who are considering a career in direct care. Courses cover the baseline knowledge, skills and values needed to work in direct support services.

For additional information about the College of Direct Support courses and the enrollment process please contact Andy Trudo at [andrew.trudo@moorecenter.org](mailto:andrew.trudo@moorecenter.org) or 603-206-2753.

## Community College System of New Hampshire

DirectConnect is working in collaboration with New Hampshire's Community College System to offer scholarship assistance covering tuition and books for courses that support careers in direct care. Approved courses include those available through the Community College's Allied Health, Nursing, and Wellness; Social Services; and Education and Early Childhood programs.

To be eligible for scholarship assistance, applicants must be:

- ◆ Pursuing a course of study to obtain or further a career in community-based direct care. This is care that supports people in home and community settings (as opposed to institutional or nursing facilities).
- ◆ A resident of New Hampshire – or if a non-resident, employed in a direct care setting within New Hampshire.
- ◆ Applying for a course(s) offered at one of New Hampshire's Community Colleges and included on the DirectConnect Approved Program's list.
- ◆ Adhering to Community College guidelines for admission into certificate and degree programs. No special admissions treatment will be given based on DirectConnect funding.
- ◆ A student in good academic standing, consistent with college policy. Students who receive two "F" (failure) grades for courses funded by DirectConnect will be ineligible to receive future funds. (Students may drop no more than two courses after the end of the school's stated add/drop period.)

Additional information about Community College scholarships may be found at [www.ccsnh.edu/directconnect](http://www.ccsnh.edu/directconnect) or by contacting Teri Laflamme at 603-271-6783 or [tlaflamme@ccsnh.edu](mailto:tlaflamme@ccsnh.edu)

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## DSP, SRV & ME:

*My experiences as a direct support professional and the influence of Social Role Valorization in my work*

Leif Gerjuoy, One Sky Community Services

In the summer of 1987 I was looking for something more meaningful in my life. I was working in a microscope slide factory and cutting my hands almost every day, not a good thing for a musician. My friend Allison worked across the street from the factory. I often heard people at the factory talking about the people going into Allison's building as if they were a fearsome strange lot. One day Allison said to me, "You know they're looking for people here. I think you would be good at this."

After doing some research, I took Allison's advice and applied for a job with vocational services at Community Developmental Services (now One Sky Community Services). Many of the people I worked with had recently moved from the Laconia State School, which was in the process of closing. This was a time of great transition in the state's developmental services system and there was a lot of opportunity for training. In the winter of 1988 I participated in PASS, a training that gave me a whole new perspective on what people with disabilities experience and educated me about the inherent problems with institutional care. What I learned from PASS and later from Normalization and Social Role Valorization training has had a profound influence on my work as a direct support professional.

Social Role Valorization (SRV), developed by the late Dr. Wolf Wolfensburger, explains how society creates devalued groups (such as people with disabilities) and how those who are devalued are at risk of social and emotional harm. SRV provides a pathway for people working in human services to reverse the effects of this devaluation. One tenet of SRV is that *all* people need enduring relationships and meaningful social roles. There are many valued roles in our community for people - including the people we serve - to fill. This is why it is so critical that those who are supporting people with disabilities really know about and are a part of their communities. SRV has led me at various times to join the League of Women Voters, serve as a member of the local transit authority, volunteer at the art association, and play piano at the food kitchen.

Speaking of the food kitchen brings me to Theo Parent, the man I have provided supports to for the past 21 years. About three years into our relationship, Theo told me he would like to do something to help poor people. I helped Theo make arrangements to volunteer with a local food kitchen. I had planned to fade out once Theo got settled, but found my involvement was crucial to making sure that he got to the food kitchen on time. So I started playing piano Thursday nights at the food kitchen while Theo served the drinks. After 18 years I think we can qualify as a tradition. And as long-time community volunteers, we both have valued social roles.



Photographer - Melissa Marquis

*Leif Gerjuoy and Theo Parent at One Sky Awards dinner.*

Working fulfills another positive role. With supports from One Sky Community Services Theo has managed to be employed for the greater part of the last 20 years. When a corporation purchased the company where Theo works and relocated to a neighboring town, the management stepped up to find Theo transportation to the new work site. This only happened because Theo was recognized as a valued employee.

Theo's strong artistic interests have led to other valued and meaningful roles. Three years ago he took up photography and we are now members of our local camera club. Theo has exhibited his work and sold some of his prints. Through the efforts of his community coordinator, Theo also has attended community theater groups, had the opportunity to develop acting skills, and has been part of local performances.



## Social Role Valorization

Five years ago Theo learned about the opportunity to buy a house through the Home of Your Own Program. Through the sustained efforts of Theo, a family member, some of us at One Sky, and the New Hampshire Community Loan Fund, Theo realized a lifelong dream and in 2009 assumed another valued role – homeowner.

It is important to understand that it has not always been easy. There are many things that have to be done to just help people get through their day or week. There also are tasks like submitting monthly documentation and getting people to appointments that need to happen to ensure money for services is flowing. These are all necessary, but none of them will save a life from being wasted. I believe we can't let the smaller things keep us from the more important work of supporting individuals to live valued and meaningful lives, something that all of us expect and want for ourselves.

Last year I was selected to be the Direct Support Professional of the Year for the State of New Hampshire. That same year, in recognition of his many achievements, Theo was awarded the Walker Prize for Consumer of the Year in Region 8.

I was honored to receive my award, but I know there are DSPs across our state who also deserve recognition for their work.

As for Theo, his many valued roles - employee, photographer, community volunteer, award winner, and homeowner - have made his life so much richer and more meaningful than the limited role associated with the label of client or consumer.

Social Role Valorization (SRV) is a set of approaches designed to enable devalued people in society to experience a full and good life. For individuals with disabilities, their most significant problem is not the disability, but rather how they are treated because they have a disability. In our society, a person's disability often defines the opportunities and dimensions of his or her life. Individuals are at risk of becoming permanent and full time clients of the service system. SRV offers practical strategies to help devalued people make connections and achieve valued social roles in their communities.

In the Spring of 2012, the New Hampshire Council on Developmental Disabilities is sponsoring an SRV workshop with Darcy Elks. Ms. Elks has worked in a variety of human services and been a long time advocate for persons with disabilities. She has presented and consulted throughout the United States, Canada, England, and Australia. She is the mother of three children, one of whom has Down Syndrome.

Those who are interested in this workshop or would like more information about SRV, please contact David Ouellette at [David.L.Ouellette@ddc.nh.gov](mailto:David.L.Ouellette@ddc.nh.gov) or Dave Yeiter at [David@mds-nh.org](mailto:David@mds-nh.org)

**Direct Support Professionals Conference**  
**"Mapping the Paths"**  
*~ Journey to a better Tomorrow.*

**October 21 & 22, 2011**  
Grand Summit Hotel & Conference Center Bartlett, New Hampshire

**For Conference Information call the Council on Developmental Disabilities at 603.271.3236**



# DIRECTCONNECT: PARTNERING TO EXPAND AND TRAIN NH'S DIRECT CARE WORKFORCE

Jennifer Rabalais, MA, DirectConnect Project Director, Institute on Disability

With a population that is aging faster than the national average, New Hampshire can anticipate an increasing demand for healthcare and support services. It is projected that the need for qualified direct care workers in home and community based services will increase significantly in the near future and will rapidly outpace the supply. In 2007, the New Hampshire Coalition for the Direct Care Workforce was established to address this critical workforce shortage. In response to the challenges, barriers, and recommendations identified by the Coalition through provider and worker surveys, a plan was created to recruit, train, and retain high quality direct care workers. The Institute on Disability, with support from the Coalition, submitted a grant proposal to the Department of Labor to fund this plan. In 2010 the Department of Labor awarded the IOD a \$2.9 million 3 year grant for DirectConnect, a statewide collaborative project that utilizes a multi-pronged approach to help meet the state's need for an expanded and well trained direct care workforce.

## Training/Education

DirectConnect offers a variety of training and educational opportunities including: on-line courses through the College of Direct Support, a Community College Scholarship Program, and with Lutheran Social Services, a Vocational Healthcare Program for immigrants and refugees. (For more information see *DirectConnect Training Opportunities* on page 3 in this issue.)

## Retention

DirectConnect is addressing worker retention issues in a number of ways. PHI, a nationally recognized leader in efforts to strengthen the direct care workforce, is providing intensive training to five organizations - Armistead Caregiver Services, Regency Nursing Care, Monadnock Developmental Services, Lakes Region Community Services, and Community Partners. The sites, which were chosen through an application process, receive training in communication skills and problem solving for all levels of staff and support in developing a peer mentor program. PHI

helps organizations improve the workplace environment, minimize staff turnover, and create a more inclusive and relationship-centered culture.

According to PHI, most turn over among direct care workers occurs during the first few months of employment. Providing peer mentors during this critical period can help new employees to improve their confidence, reduce stress, and allows for early identification and support of needed skill development. Experienced direct care staff are recruited as peer mentors and provided with training and supervision. Creating a peer mentor program not only supports new workers, but also provides experienced workers with recognition and opportunities for professional growth.

With input from Coalition members and project partners, DirectConnect has created an industry wide direct care career lattice. The career lattice provides an overview of available positions within the field, including opportunities for lateral movement that allow for professional growth without advancing to a new position. By showing all the job opportunities available, a career lattice can be a great tool for both retaining workers, as well as recruiting new employees for this workforce.

## Recruitment

If New Hampshire is to meet the current and future need for quality support services, the state will need a significantly increased direct care workforce. DirectConnect includes a statewide marketing effort to attract new workers to careers in direct care. As a direct care professional you can make a real difference in someone's life. Working in direct care offers the opportunity to open your life and heart to new relationships and learn about the world from someone else's perspective.

To learn more about becoming a direct care worker or the opportunities available through DirectConnect call 1-855-696-3922, email [careers@directconnectnh.org](mailto:careers@directconnectnh.org) or visit our website at [directconnectnh.org](http://directconnectnh.org).



## SARASWATI'S STORY

By Kerstin Ahlgren, Education and Employment Specialist, Lutheran Social Services of New England

"I never saw a wheelchair in Nepal," Saraswati Bhattarai told the Vocational Healthcare class run by Lutheran Social Services (LSS). Students had been asked to compare support services in the country they had come from with what they were seeing in New Hampshire. Saraswati became emotional as she continued, "My grandparents lives were miserable. They were confined to their beds and only got up when they were helped to the toilet."

LSS Services for New Americans, with funding from DirectConnect, developed the vocational healthcare program to help immigrants and refugees improve their English skills and receive the training necessary to become employed in home health services. LSS is a partner agency with DirectConnect, a 3-year grant awarded to the Institute on Disability by the US Department of Labor to help the state meet its increasing demand for direct care workers.

LSS has provided vocational healthcare training to new Americans in Laconia and Concord and plans to offer training in Manchester. Saraswati was enrolled in the Concord program, attending classes three days a week and spending two days a week job-shadowing a personal care service provider in the LSS In-Home Care program. Other job-shadowing opportunities in Concord included Community Bridges, the area agency for developmental services, and the Concord Regional Visiting Nurse Association.

Saraswati talked with the class about her childhood in Bhutan. Fearing that members of her ethnic group, the Lhotsampa, would form a majority and threaten his power, the King of Bhutan enacted harsh policies. He forbade Lhotsampas from speaking their language, practicing their religion, or wearing their traditional dress. In the end, he drove them out of the country.

"When I was eight years old, the government people came to my house," Saraswati remembered. Her family's home, belongings, and bank accounts were all seized and the family was told they had one week to leave Bhutan.

Saraswati's husband, Mahendra added, "We did not know anything about war. We were scared and heard stories about bad things happening to people who didn't leave."

The family fled and eventually landed in a United Nations refugee camp in Nepal. There they lived in makeshift housing and tried to create a normal life. Saraswati began college, got married, and helped her mother care for her grandparents. Finally, after more than 20 years in Nepal, Saraswati and her family came to America and found a permanent home in Concord, New Hampshire.



*Saraswati Bhattarai, Personal Care Service Provider with Lutheran Social Services*

Photo Credit - Kerstin Ahlgren, LSSNE

Ever since caring for her grandparents, Saraswati has wanted to work in healthcare. However, with a no formal job experience, limited connections, and a lack of confidence about her English she had been unable to find a job. When she learned about the LSS Vocational Healthcare class she jumped at the opportunity. "Without the class," Saraswati said, "I wouldn't have been able to understand my clients. I use the language we learned in class everyday."

When asked about Saraswati's performance, her supervisor with In-Home Care said that the results speak for themselves. Lutheran Social Services hired Saraswati and the program's other intern as soon as their training ended in April.

Saraswati is now employed fulltime supporting an elderly couple who have serious multiple health problems. "I bathe my clients, feed them and entertain them. My mother had to wash my grandparents' clothes and undergarments by hand and I use a washing machine. I can help them get around in a wheelchair and make sure they enjoy the end of their lives. This work is easy and rewarding!"



## PHI: HELPING ORGANIZATIONS PROVIDE “QUALITY CARE THROUGH QUALITY JOBS”

Jennifer Rabalais, MA, DirectConnect Project Director, Institute on Disability

With DirectConnect’s focus on recruiting and retaining a quality direct care workforce, a partnership with PHI makes sense. PHI, a nationally recognized leader in training and organizational development, works to improve the lives of people receiving home or residential care by improving the lives of the workers who provide that care. Through its partnership with DirectConnect, PHI is providing intensive training to five New Hampshire organizations: Armistead Caregiver Services, Community Partners, Lakes Region Community Services, Monadnock Developmental Services, and Regency Nursing Care.

PHI’s Coaching Approach™ helps senior management and supervisors develop the skills essential for providing quality support to front-line workers. With PHI’s support, agency managers and supervisors are learning how to help direct care workers master skills such as active listening, self-reflection/self-management, communicating without blame or judgment, and collaborative problem solving. PHI also is working with these five agencies to establish peer mentoring, pairing experienced direct care staff with new workers or staff who need additional support.

PHI’s goal is to improve the workplace environment and minimize turnover by creating a shared skill set and common language. Equipping supervisors and direct care workers with communication tools that strengthen their ability to listen and work collaboratively not only has a positive effect on staff morale, it enhances the quality of care provided.

“We are partnering with these organizations to create changes that will allow them not only to retain their workers, but to attract workers in their communities seeking fulfilling work with a respected employer. Our goal is to create what we call a relationship-centered organizational culture with the goals of improved job

satisfaction, improved quality of care, and greater customer satisfaction,” said Kathy McCollett, Organizational Culture Change Specialist with PHI’s Training and Organizational Development Team and lead for the project. “Knowing how to communicate in a way that creates safety and trust is essential. It requires intentionality in trying to understand the perspectives of the folks doing the work in the field, the individuals we support and their families without holding on to your own agenda. It also means being less guarded, making an earnest effort toward transparency about what is really happening in the organization.”

By the end of the grant period, PHI will have trained four trainers and eight peer mentors in each of the participating organizations. The trainers will have responsibility to continue the PHI Coaching Approach™ training for new supervisors and managers and provide training to direct care workers in communication skills and problem solving. Utilizing a train the trainer approach helps ensure that there is the capacity within the organization to continue trainings and maintain the relationship-centered workplace culture after the grant ends.

Those who are participating in DirectConnect and receiving training from PHI report that they are already seeing a difference in their organizations. A program manager stated, “I will continue to practice and teach the information I have learned.”

“This has been an invaluable experience. I wish more things like this were offered,” added a direct care professional.

Eric Proulx, Human Resource Manager for Regency Nursing Care, observed, “Since we started implementing our peer mentor program into our new employee orientation there has been a shift. People feel more supported and feel they are a part of the team from the very beginning.”





# THE ROLE OF PARAPROFESSIONALS IN SUPPORTING STUDENTS WITH DISABILITIES

Frank Sgambati, Institute on Disability

In my work with teams that are collaborating to include students with special needs into regular classrooms, I am amazed at how much success depends upon the quality of involvement that these students have with their paraprofessionals. Instructional assistants and other school paraprofessionals are typically the ones who spend the most time with special education students, including those students who have the most complex and challenging needs. Having input and feedback from paraprofessionals in the planning process is crucial. Unfortunately, not all districts include paraprofessionals as full members of the student's educational team nor do they provide them with adequate training or support. Those schools where the teachers and team members - *including* paraprofessionals - plan together regularly are in the best position to create an environment where all students can be successful.

I have worked in education my entire career. My introduction to the field - and perhaps 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 saw me as another teacher who was there to support all of them. Drawing from my experience in schools, and

especially the lessons I've learned from the students I have worked with, I would like to share what I have found to be 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 and the school 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 should receive quality training and supervision. They should have a voice in the planning process and be included as full members of the student's team. Finally, paraprofessionals should be recognized for the essential role they play in our schools.

*(This is an encore article, an earlier version appeared in the Fall 2007 Rap Sheet)*



Photographer - Dan Habib

# RECOVERY FROM MENTAL ILLNESS: COMMUNITY SUPPORTS

By Julia Freeman-Woolpert, Disabilities Rights Center

*"In your crystal ball, what does life look like?"*

Kathy Raymond from the Center for Life Management (CLM), the community mental health center in Derry, asks this question to help the people she works with envision a better future.

When Mike\* looks into his crystal ball his anxiety is under control and he can go beyond the comfort zone of his parents' home. He is confident around people, has a job, and is getting a place of his own.

Mike lives with schizophrenia and extreme anxiety. Now in his 40's, he's lived with his parents his entire life, the only exception being periods when he was hospitalized. Mike's anxiety and paranoia make it terrifying for him to go into many community settings. Shopping malls with teenagers are the worst. He spends most of his time alone at home listening to music and watching videos.

Mike has been participating in CLM's Illness Management and Recovery Program. For the last two years, Erin Wood, an Illness Management and Recovery Specialist, has been Mike's community counselor. Mike is learning to confront his fears and develop coping strategies to manage his anxiety. Talking about Mike, Erin observed, "He's a very smart guy. He's also very caring. He treats others well."

With Erin's support, Mike has learned about his mental illness and how to handle stress. He has begun to set goals and has a vision of what he wants in his life. A primary goal for Mike is to get out of the house more and go to public places without being paralyzed by anxiety.

Functional support services are helping Mike become more confident and independent. Erin has provided Mike with behavioral supports or "tutoring" on how to cope in a stressful situation. They started by spending time in less crowded places, ones without a lot of loud teenagers. It was a slow process. First they drove by a store, the next trip they looked in the door, and on the third trip went inside where Mike practiced making eye contact and saying hello. As Mike got more comfortable they ventured further. They went to the mall early in the morning when few people were out. Mike practiced going into stores on his own while Erin waited outside.

Mike wanted to become involved with the new peer support center in Derry. Again, Mike and Erin went about this one step at a time. They began with a brief tour of the center. They later returned to fill out membership paperwork. On a third visit they sat down with a member of the center who helped Mike create a wellness plan. Now Mike no longer needs Erin to accompany him to the center. He is part of a music appreciation group and joined a walking group.



Photo Credit - Julia Freeman-Woolpert

In moving towards his goal of having a job, Mike began as a volunteer at an assisted living facility. Erin supported Mike in learning how to communicate with staff and other volunteers at the facility. She helped him to understand his responsibilities and worked with him to arrange transportation to and from work. Mike is now able to do all of this independently and is working with a Supported Employment Specialist to find a paying job. He also is concentrating on developing the skills he needs to live on his own. This includes learning to manage his finances so he no longer will need the services of a representative payee.

For Erin, seeing Mike and the other people she supports beginning to recover from mental illness and reach their goals has been extremely gratifying. As she observed, "If you believe in a person they can do great things."

*\* Mike prefers to remain anonymous due to the stigma associated with mental illness.*

## Individualized Resiliency and Recovery Oriented Services

Most people are familiar with the use of medication and psychotherapy to treat mental illness, however, a wide variety of other services and supports can help individuals with mental illness gain control over their lives. Among these are evidence-based practices developed by Dartmouth Medical School and referred to as Individualized Resiliency and Recovery Oriented Services. These community-based services typically are provided by community mental health centers and include: illness management and recovery, supported employment,

and functional support services. Direct support professionals are essential to the delivery of these services. DSPs work with people in their communities, providing crisis intervention, medication support, behavioral services, and family support. They teach life skills and go with their clients into schools, jobs, driver education classes, and shopping malls.

Functional support services not only improve an individual's quality of life, they reduce or prevent costly hospitalizations. Mental health services used

to be relegated to therapist's offices or segregated day programs. Today these services happen in community settings. Kathy Raymond, Director of Functional Support Services at the Center of Life Management, said, "Providing mental health services in natural environments was a shift of thinking in the way we delivered services. Community based services provide a greater degree of connection and allow the opportunity to connect and assume a role in the community."

## Crisis in Community Mental Health Services

A recovery-based approach and the use of evidence-based practices and functional support services are required under New Hampshire's behavioral health rules. However, the availability and quality of community-based mental health services varies significantly from region to region.

In 2008 DHHS Commissioner Nicholas Toumpas reported, "New Hampshire's mental health care system is failing, and the consequence of these failures is being realized across the community. The impacts of the broken system are seen in the stress it is putting on local law enforcement, hospital emergency rooms, the court system and county jails, and, most importantly, in the harm under-treated mental health conditions cause New Hampshire citizens and their families." DHHS issued a ten-year plan and created a task force to address these issues.

A faltering economy, State budget cuts, and other factors have stalled efforts to implement the Department's plan to improve services. The condition of New Hampshire's community mental health system has continued to deteriorate. Over the past year, both the Disabilities Rights Center and the US Department of Justice have notified the State of New Hampshire of their findings of numerous deficiencies in the state's mental health services. The Department of Justice noted that these deficiencies result in "unnecessary institutionalization, prolonged institutionalization, and a heightened risk of institutionalization for persons with mental illness who could be served with more independence and dignity, at a fraction of the cost, in more integrated settings in the community."

*(Continued from page 5)*

### **Lutheran Social Services**

In partnership with Lutheran Social Services, DirectConnect offers training to participants of the United States Refugee Resettlement Program. The program includes classes in vocational ESOL (English for Speakers of Other Languages) and orientation to employment in the United States, as well as courses in first aid, crisis intervention, and community living skills. Training is approximately 28 hours per week for eight consecutive weeks and includes job shadowing with partner agencies. Participants completing training are assisted by Lutheran Social Services to find work in the field.

To qualify applicants must:

- ◆ Be a refugee, immigrant, or asylee residing in New Hampshire.
- ◆ Have good verbal and written English skills (basic ESOL proficiency).
- ◆ Demonstrate a financial need.
- ◆ Demonstrate the ability to commit to 8 weeks of training.

For further information please contact: Augustin Ntabaganyimana at 603-224-8111 or email: [augustin@lssne.org](mailto:augustin@lssne.org)

To learn more about DirectConnect training opportunities visit <https://directconnectnh.org/>



# IT'S ALL ABOUT RELATIONSHIPS



By Marlyn Curtin

My daughter Jocelyn was 28 years old when she received an individualized budget through the state's developmental services system. I initially wanted someone else to be responsible for organizing the supports that Jocelyn needs and to take care of all the details that go along with that. For the first time in our daughter's life, we worked with a vendor agency. This arrangement lasted less than one year. I was very disappointed with the quality of services that Jocelyn received.

I made the decision to act as the vendor. I knew I could do a better job; after all I had been doing this pretty much on my own for the past 28 years! In looking for people to support Jocelyn, the first thing I did was to connect with a young woman who had been working with her and doing a good job. She agreed to continue supporting Jocelyn, but would now be working for me. I also placed an ad on the NHTI student bulletin board. I got one response and interviewed a young woman. I really liked her enthusiasm and energy and hired her.

When Jocelyn was 30 she received funding to provide the support she needed to live in her own place. Arranging 24/7 staff coverage was a new challenge for me. Jocelyn had a relationship with a woman from VNA who had been a support person for more than 12 years. They both wanted this relationship to continue. This left me with the job of finding a roommate for Jocelyn and getting weekend coverage. Jocelyn's respite care provider, who had worked with her for years, wanted to continue to support Jocelyn in her new home. She also suggested that a young woman who had gotten to be friends with Jocelyn during respite weekends might be a good roommate.

I met this friend of Jocelyn's and liked her attitude. She had a real appreciation of Jocelyn and said she realized how much Jocelyn could teach her. Another one of Jocelyn's staff had become a good friend was available for some early evening hours. We now had our team of 5 and the 24/7 coverage that Jocelyn needed to live on her own. We had "training sessions" over pizza and talked about the best ways to support Jocelyn. We continued to get together to talk about how things were working out and how we could support each other. I called this our Dream Team; they referred to themselves as Team 007 (the five of them, plus Jocelyn and me).

In January our team of five became two. Three support workers left, all for different reasons, but all on good terms.

Both Jocelyn's roommate and her day support person have assured me that, for now, there was no need to add more staff. They have everything under control and will let me know if this changes. So far this has been working. Having fewer support staff is possible because Jocelyn has been included in her community throughout her life.

There are many people who know Jocelyn and she has friends who are watching out for her. These friends have been especially helpful in recommending great support staff. I have found that having quality care is based on building and nurturing quality relationships with those who are providing support. An important part of my role is doing the best I can to support the people who support Jocelyn. In her own way, Jocelyn also supports her staff and they have become very close to her. The support workers in Jocelyn's life actually feel much more like family than staff.

## What I look for in a direct service provider:

- ◆ Someone who sees Jocelyn as a young woman first, not just a client who needs support.
- ◆ Someone who is fun and includes Jocelyn in things they enjoy doing, as well as supporting her to do the things she likes.
- ◆ Someone who will expand Jocelyn's experiences and brings people into her life who truly enjoy spending time with her.
- ◆ Most of all, someone who can make Jocelyn smile. Jocelyn is one of the best judges of people that I know and her smile is the key that tells me things are working.

I leave most of the "teaching" about who Jocelyn is up to Jocelyn. I cover the basics for safety; things like lifting, feeding, and basic communication. I also make sure I am available to answer questions as they arise. I try not to micromanage. I have found that people learn more from Jocelyn than I can teach them. If I am seen as the only expert, they may not look to Jocelyn for guidance.

While Jocelyn has never spoken a word, she has taught volumes to her friends and the people who support her. They have become as well versed as I am – and maybe even better - at communicating with Jocelyn and understanding her.

Having quality direct support is all about believing in others and building mutual trusting relationships.



# WHAT TO DO IF YOU ARE DENIED MEDICAID SERVICES

By Julia Freeman-Woolpert, Disabilities Rights Center

New Hampshire offers a wide variety of Medicaid programs. There are Medicaid programs for developmental services, acquired brain disorders, mental health services, and long term care. New Hampshire also has Medicaid for Employed Adults with Disabilities (the MEAD program) and Medicaid for Children with Severe Disabilities (also known as the Katie Beckett program). Medicaid covers many doctor and hospital services, and, depending upon the program, Medicaid may cover personal care services, durable medical equipment, assistive technology, day and residential supports, transportation, as well as other supports and services.

One thing all these Medicaid programs have in common is the **right of appeal**. If you get a decision denying eligibility, a service or benefit, or a reduction in services, you have the right to challenge that decision and get a fair hearing in the matter. For all Medicaid programs, you have:

- ◆ The right to a written decision containing:
    - ◆ A statement of the intended action
    - ◆ The reasons for the denial
    - ◆ Specific laws and rules that support the denial
    - ◆ An explanation of your hearing rights and rights to representation
    - ◆ The timeline for appeals (usually 30 days, BUT there is a shorter timeline if you want services to continue)
    - ◆ The right to continued benefits/services if applicable. Often you have the right to have services continue as they were during the appeal IF you file an appeal within a very short time frame, usually 10-15 days.
  - ◆ The right to a timely decision. Timelines may vary depending on the Medicaid program
  - ◆ The right to review or get copies of your records from the Department of Health and Human Services or your provider
  - ◆ The right to appeal the decision
  - ◆ The right to a fair hearing in front of a state hearing officer
- If you wish to challenge a decision by a Medicaid program, these are the steps you can take:
- ◆ Read the decision notice *carefully*.
  - ◆ If you are not given a written notice of the decision, request one. If you are told you do not have the right to a decision or the right to appeal, call the Disabilities Rights Center at 800-834-1721.
  - ◆ Look up the state's administrative rules for coverage of your Medicaid program. They usually can be found on line at [http://www.gencourt.state.nh.us/rules/About\\_Rules/listagencies.htm](http://www.gencourt.state.nh.us/rules/About_Rules/listagencies.htm) (*check the sections starting with He-*). If you need help finding them, contact the Disabilities Rights Center at 800-834-1721.
  - ◆ You DO NOT have to agree to a decision to suspend, reduce, or terminate a service or benefit. It is NOT OK for someone to pressure you into consenting to something you don't agree with.
  - ◆ File an appeal within the time frame indicated in the decision. DO NOT WAIT! If you file too late, you may lose your right to have services continue pending the appeal, or you may lose the right to appeal and will have to reapply for services.
  - ◆ Your appeal letter should clearly indicate the decision you are appealing. You should attach the notice of decision you are appealing.
  - ◆ Always keep a copy of *every* piece of paper involved in the matter, including letters you send or receive, and any documentation concerning the benefits or services at issue.
  - ◆ You have the right to be represented by an attorney, but you are not required to have one.
  - ◆ Call the Disabilities Rights Center at 800-834-1721 for more information.

# Direct Support Resources

## NEW HAMPSHIRE RESOURCES

### ABLE NH

ABLE NH advocates for the civil and human rights of all children and adults with disabilities and promotes full participation by improving systems of support, connecting families, inspiring communities, and influencing public policy.

<http://www.ablenh.org/>  
ABLE NH  
21 South Fruit Street - Suite 22  
Concord, NH 03302  
Phone: 603/271.2336  
E-Mail: [info@ablenh.org](mailto:info@ablenh.org)

### College of Direct Support

An internet-based training curriculum for direct support professionals

<http://info.collegeofdirectsupport.com/>

In New Hampshire, the College of Direct Support is available through DirectConnect

[www.directconnectnh.org](http://www.directconnectnh.org)  
Phone: 855/696.3922  
Or Contact Andrew Trudo  
Phone: 603/206.2753  
E-Mail: [andrewtrudo@moorecenter.org](mailto:andrewtrudo@moorecenter.org)

### Community College System of New Hampshire

New Hampshire's community colleges offer a variety of certificate and degree programs related to direct care careers.

[www.ccsnh.edu](http://www.ccsnh.edu)

### DirectConnect

DirectConnect, a project of the Institute on Disability, offers scholarship funds and training opportunities for direct support professionals and those interested in a career in direct care.

[www.directconnectnh.org](http://www.directconnectnh.org)  
Phone: 1-855-my-new-career

### Granite State Independent Living

Offers self-directed personal care service options

<http://www.gsil.org>  
GSIL  
21 Chenell Drive  
Concord, NH 03301  
603/228.9680 (V/TTY) 800/826-3700 (Toll-free -V/TTY)  
866/349.8235 (VP) 603/225.3304 (FAX)

### New Hampshire Chapter - National Alliance for Direct Support Professionals

A coalition of organizations and individuals committed to strengthening the quality of the direct support workforce

<https://www.nadsp.org/>

To learn about joining the New Hampshire Chapter of NADSP

Contact: Robin Carlson  
Phone: 603.330-0134  
E-mail: [carlet@metrocast.net](mailto:carlet@metrocast.net)

### New Hampshire Council on Developmental Disabilities

The Council supports public policies and initiatives that remove barriers and promote opportunities for individuals with developmental disabilities. The Council has taken a leadership role in addressing direct support issues in New Hampshire.

[www.nhddc.org/](http://www.nhddc.org/)  
NH CDD  
21 South Fruit Street – Suite 22  
Concord, NH 03301-2451  
Phone: 603/271.3236 Toll Free: 800.852.3345 x  
3236  
TDD # - 800.735.2964

### New Hampshire Family Voices

Families and Friends Speaking on Behalf of Children with Special Health Care Needs

<http://www.nhfv.org>  
Phone: 800.852.3345 or 603/271.3345

### Parent to Parent of New Hampshire

Offers support, information, and resources to parents of children with special needs.

<http://www.p2pnh.org/>  
Phone: 800.698.LINK





## TAKING CONTROL

By Leslie Alcorn, Granite State Independent Living

### NATIONAL RESOURCES:

#### American Network of Community Options and Resources

*Through its National Advocacy Campaign, ANCOR seeks to obtain the resources to recruit, train, and retain a sustainable direct support workforce.*

<http://www.ancor.org/>

ANCOR

1101 King Street - Suite 380

Alexandria, VA 22314

Phone: 703/535.7850

FAX: 703/535.7860

E-mail: [ancor@ancor.org](mailto:ancor@ancor.org)

#### The Arc of the United States

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

<http://thearc.org/>

The Arc

1010 Wayne Avenue, Suite 650

Silver Spring, MD 20910

Phone: 301/565.3842      Toll Free: 800.433.5255

Fax: 301/565.3843      301/565.5342

#### 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.*

Website: <https://www.nadsp.org/>

*To learn about joining the New Hampshire Chapter of NADSP*

Contact: Robin Carlson

Phone: 603.330-0134

E-mail: [carlet@metrocast.net](mailto:carlet@metrocast.net)

#### TASH

*A leader in disability advocacy for more than 35 years, the mission of TASH is to promote full community inclusion of children and adults with significant disabilities.*

<http://tash.org/>

TASH

1025 Vermont Ave., Floor 7

Washington, DC 20005

Phone: 202/263.5600

Fax: 202/637.0138

Direct service providers are key to the success of Granite State Independent Living's (GSIL) personal care programs. Thirty years ago, GSIL introduced New Hampshire to a new concept in "patient" care. Rather than viewing people with disabilities as sick and in need of specialized medical care, GSIL created consumer-directed personal care attendant programs that allow individuals to control their own care and support services.

GSIL now has three different consumer-directed personal care programs that qualifying individuals can use to locate, hire, supervise, and train their own staff. These direct service workers are referred to as Personal Care Attendants (PCAs) or Personal Care Service Providers (PCSPs). While consumers control who provides their care and how it is provided, GSIL is the employer for these staff and takes care of all human resources and payroll functions.

PCAs and PCSPs provide intimate and personal care for the individual; this typically includes assistance with transfers, bathing, and dressing. These staff also may help with homemaking and shopping. The consumer-directed model of care is guided by the premise that we all have our own preferences for how we want things done. The PCA or PCSP, under the direction of the consumer or his or her chosen representative, is trained to provide assistance based on the preferences and needs of the individual.

Consumers find their own PCAs and PCSPs through GSIL's attendant care registry, newspaper advertising, Craig's List, or word-of-mouth. Eligible attendants must be 18 or older, willing to be trained by the consumer, able to perform the tasks of the job, and available to work the hours needed by the consumer, this may include weekends and holidays. These staff are not required to be licensed, however, they must pass criminal and Elderly and Adult Service background checks. Once background checks have been cleared, it is the consumer who makes the hiring decision.

While providing personalized care at times can be challenging, it also offers many rewards. PCAs and PCSPs play an integral and essential role in supporting individuals with disabilities to live full lives. If you would like to find out more about consumer-directed personal care or if you are interested in becoming a PCA or PCSP, please contact GSIL at (603) 228-9680.

# RAP Sheet

## NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290  
Concord, NH 03301-2451

**RETURN SERVICE REQUESTED**

## INSIDE THIS ISSUE

- ◆ *DirectConnect*
- ◆ *Scholarship and Training Opportunities*
- ◆ *Resources for Direct Support Professionals*
- ◆ *Personal Stories*

◆ **The RAP Sheet is Going Electronic - to Subscribe Visit: <http://www.drcnh.org/rapsheet.htm>** ◆

### DISABILITIES RIGHTS CENTER, INC.

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](mailto:advocacy@drcnh.org) ◆ Website: [www.drcnh.org](http://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](http://www.iod.unh.edu)

### Institute on Disability/UNH – Concord

56 Old Suncook Road, Suite 2

Concord, NH 03301

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

*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.org](http://www.nhddc.org)

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

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