

# RAP Sheet

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

Winter Issue 2016

## CRISIS IN DIRECT SUPPORT



### THE PEOPLE WE SERVE DESERVE BETTER

By Robert Arnold, Direct Support Professional

*Welcome to the Winter 2016 RAP Sheet. For many individuals with disabilities, their quality of life is directly tied to the quality of the people who support them. Unfortunately, attracting and retaining direct support workers is becoming more and more challenging. With failure to pay workers a livable wage, inadequate training opportunities, and lack of support on the job, it is not surprising that New Hampshire is facing a crisis in direct support.*

I work in a group home where I help support twelve individuals. Today it was just me working. Yesterday I had the help of one other person. Each day I cook dinner, pass out medications, make sure people are getting out into the community, all this on top of helping people in the shower, doing their laundry . . . the list goes on and on.

I'm lucky. I generally work with at least one other person and sometimes two. There's a woman who works on weekends who rarely has any help. She is on her own to provide care and assistance to twelve people, all of whom have different support needs. To say the support provided in this instance is inadequate is a gross misrepresentation of what both staff and residents go through every day.

One of the women I work with says, "It's hard to trust anyone that works here because they're in and out all of the time. Just when I start to really like someone they leave. It happens time and time again." This is a common complaint of the people I work with. In the past five years this house has seen seven different managers, and countless more "skills staff" (staff that come in for a few hours to help).

The problem is, and I'm sure always has been, compensation. We demand a lot from people

*(Continued on next page)*



Robert Arnold,  
Direct Support Professional

Photographer - Zachary Stone

SUSAN COVERT, EDITOR

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*(Cover story continued)*

in this field and expect them to do it, no questions asked, for \$9.00 - \$12.00 an hour. I ask you - would you help someone you didn't know in the shower for \$9.00? Would you take responsibility for six people by yourself in the community for \$9.00 an hour? If the answer is yes, then I have a job for you.

I was talking to colleagues about this, and one of them said, "Well this is a thankless job with no glory. Always has been, always will be." My question is, why? When did we get the reputation of being glorified babysitters, when we are so much more? We're dietitians, nurses, psychotherapists, and chauffeurs. We are an entire support system for a lot of people . . . all for \$9.00-\$12.00 per hour. People are leaving for desk jobs that sometimes pay double that. And we wonder why we can't find good people? We wonder why turnover is so high?

People are burning out left and right. Many people are just shoved into work after a few hours of online training, and little to NO hands on training. They get overwhelmed quickly, burn out, and leave. Those of us who are left to pick up the slack are stressed, and we see the effect of that on the individuals we support. The people we serve deserve better than that. They did not ask to be part of this broken system.

We need to do something. We need to look at how and where money is or is not being spent. We need to abolish the "Historical Budgets." The system's notion

that someone should be receiving the same support that they were receiving 20 years ago would be laughable if it wasn't so scary. We also need to use the money we have. This year (2015), the New Hampshire Department of Health and Human Services reported \$20 million in unspent dollars earmarked to provide services to people with developmental disabilities. I understand certain circumstances are unavoidable, but \$20 million dollars is a lot of money to just sit in limbo when it could be used to train and retain a decent workforce.

If we are serious about helping the people we serve live truly meaningful lives, then we are failing. Changes need to be made at a State level, because what I see at an agency level is people working as hard as they can with the tools they are given, but one person can only do so much for twelve people. Day services can only do so much when one DSP has (responsibility for) a group of six or more in the community.

Admittedly I have a lot to learn. I can only call it as I see it. And the way I see it, we need to stop asking for help and in the spirit of advocating for those who can't advocate for themselves, start demanding it.

*Robert Arnold delivered this testimony on November 2, 2015 at the National Council on Disability's quarterly meeting in Concord, NH. Mr. Arnold spoke during a Town Hall session on Direct Care Workforce Challenges.*



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## HAVING SUPPORT MEANS I GET TO CONTRIBUTE

By Kathy Bates, Disability Advocate and Teacher

I have several jobs I really love. I am a facilitator and member of the Self-Advocacy Leadership Team (SALT). I also work on the Disability and Public Health Project at UNH. I just recently qualified for MEAD (Medicaid for Employed Adults with Disabilities). I am 54 years old and I am finally, gainfully employed. Please understand I could not contribute to the community or the economy without the support of a dedicated personal care attendant (PCA).

I live in my own home, in a great neighborhood. I have a really nice raised bed garden and I grow lots of vegetables, which I share with my neighbors. I have a very supportive family with lots of nieces and nephews. I am pretty good at being Aunt Kathy. It is because of the support of PCAs, my family does not have to play the role of caregiver and we can concentrate on just being a family.

With this year marking the 25<sup>th</sup> anniversary of the Americans with Disabilities Act, the doors of opportunity have been unlocked for a while now and more citizens who experience disabilities are gainfully employed. The laws are in place, but some people still feel it is too risky to be employed. I need support in order to get up in the morning and to be driven to work. I live with constant fear and stress because it's getting increasingly more difficult to hire and retain direct support professionals (DSPs). I waited all this time for the laws to be in place so I could finally say I had a career, but none of that matters if I don't have good support around me. Most DSPs typically make around ten dollars an hour, but don't have health insurance or get mileage reimbursement. They usually have several jobs to make ends meet. Some DSPs even need public assistance programs, such as rent assistance or food stamps. The field is dominated by women and most of my employees have been single moms who are trying to raise their children. Medicaid



*Kathy Bates, Disability Advocate and Teacher*

reimbursement rates have to be raised so that they can make a livable wage. Direct support work is often considered a stepping stone job which leads to other better paying jobs in the health care field.

With all that said, if direct support workers were making a livable wage the turnover rates would not be so high and more people would be willing to stay in this field. By the year 2030, a full 20 percent of the U.S. population will be over 65. This phenomenon has been referred to as the "White Tsunami". The need for well paid, qualified direct support workers will be extremely important; in fact, impossible to live without. I often say that if society does not care about my direct support workers, then society does not care about me.

***Kathy Bates delivered this testimony on November 2, 2015 at the National Council on Disability's quarterly meeting in Concord, NH. Ms. Bates spoke during a Town Hall session on Direct Care Workforce Challenges.***



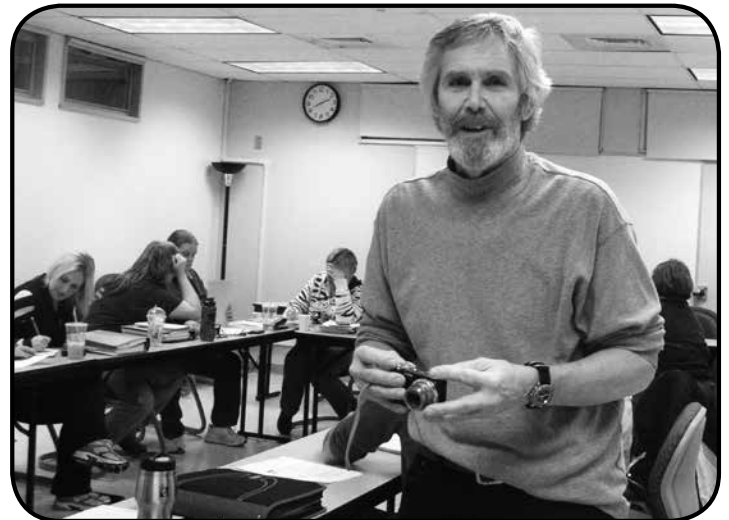


# QUALITY TRAINING – A KEY TO QUALITY SUPPORT

By Yeiter, Instructor, Supporting People in Community Living – Certificate Program

**F**or 45 years I have worked in institutions and in community settings with people who have been defined by their labels. Over time some things have changed for the better, but not by much. Why? Because direct support workers - the people who most need the knowledge and wisdom to deliver quality supports and create welcoming communities - are not seen as important players. If we fail to make an investment in our direct care workforce, then all the efforts that go into creating and maintaining human services are a huge waste of time and money. Never mind the wasting of lives for those who are on the receiving end of inadequate services.

In 2002, frustrated by the lack of progress people with intellectual disabilities were making in spite of advances in developmental services, Joy Eason Hopkins, a disability advocate in Georgia, took steps to address the problem. She began by asking direct support professionals (DSPs) what they needed to know in order to do their jobs well. She then consulted national leaders in the field of disability, including John O'Brien, Connie Lyle O'Brien, Beth Mount, David Pitonyak, Michael Callahan, and Michael Smull, to get their thoughts on what support workers could do to help make real life happen for people with disabilities. Drawing from what she learned, Hopkins developed the curriculum for Georgia's Direct



*Yeiter and his Direct Support Professional Certificate Program class*

Photo credit: Robin Carlson

Support Professional Certificate Program. She purposefully established this training outside of the service system; the program is offered as a course through Georgia's community and technical college system.

Through the efforts of Robin Carlson, a leader in New Hampshire's DSP movement, in 2011 Hopkins and a team of DSPs and individuals with disabilities participating in the Georgia program traveled to New Hampshire to meet with key stakeholders. As a result of this meeting, the New Hampshire Bureau of Developmental Services, and the New Hampshire Council on Developmental Disabilities provided support to pilot a DSP training program using Hopkins' curriculum. The course, retitled Supporting People in Community Living - Certificate Program, has been offered at NHTI in Concord, Great Bay Community College in Portsmouth, and at Antioch New England in Keene. I was privileged to be part of this effort and it is by far the best educational experience of in my entire career. And this is why...

For 20 weeks, direct support professionals, family members, and other human service workers come together to discover our own potential and to learn how to truly see and value people with disabilities. The ultimate goal of the training is to learn how to



Photo credit: Robin Carlson

*Members of Yeiter's class learn how to put person-centered planning into action.*

support people in developing meaningful personal relationships and in achieving a quality life of *their* choosing. This includes learning how to put person centered planning into action and how to work towards accomplishments that mean something. Participants also learn to identify behavior as a means of communication and to teach skills that will lead to true community participation and contribution. Participants also are expected to put the lessons from each class into practice with their learning partners; these are individuals who receive services and have agreed to work with a student enrolled in the certificate program.

The importance of having a learning partner cannot be overstated. Roxanne Etsy's experience illustrates why. Roxanne's learning partner Richard uses a wheelchair and is a resident in the group home where she works. Roxanne knew that as young man Richard loved motorcycles, but had not been around them in the 20 years since his motorcycle accident. Roxanne arranged to take Richard to the local Harley Davidson dealership. When they pulled into the lot, Richard practically ripped his seatbelt off to get out and look at the bikes. It was a transformative experience. During the visit, the dealership asked Richard if he would like to volunteer at one of their promotional events.

In an email to her course instructors, Roxanne wrote about the importance of making this connection. *"Hello everyone, thought I would share some pictures of Richard today at the Harley Davidson Shop. He had such a great time. He met new people from different places. He really got into seeing all the motorcycles - even fell in love with a few. It was really cool that a motorcycle came through and it was all fixed up so that a gentleman in a wheelchair could drive it himself while still sitting in his chair. Was so cool! Richard had a smile on face like none other most of the day. I asked about three times if he was ready to go home, and he would smile and say no in a funny voice. Who knew taking a little time would make someone so happy."*

*Founders of the Supporting People In Community Living Certificate Program are pursuing community grants and private donations to continue this important training. To learn more about the program, visit their website at [www.supportcommunitylife.com](http://www.supportcommunitylife.com) or contact Robin Carlson at [robincarlson@metrocast.net](mailto:robincarlson@metrocast.net).*

### **The Importance of the DSP Certificate Course to Graduates**

I care for a young gentleman who always makes me smile. He uses a wheelchair, doesn't speak, and hates his hands being touched. One of the goals (in his individual service plan) was to volunteer in the community. When we (his DSPs) asked how we should do this, they told us he could go to school activities and maybe hand out flyers. We replied that he cannot use his hands and they said that we would have to do hand over hand. Now remember he doesn't like his hands touched. This was all set up at his ISP.

I have been with this gentleman for about a year and a half. I started to watch him and this is what happened. When I would lay him down in the afternoon, I would put his TV on for him. If he didn't like what was on he would make a noise to let me know. If I changed the channel and asked if that was OK, he would shake his head yes with a big smile. I continued watch and work with him. I took him into a store and asked him which CD's he would like. I would hold one at a time and wait for a reaction. I also did this to give him choices to pick out his own clothes and to decide where he wanted to go. He even picked two concerts to go to this past summer.

*(Continued on page 7)*



## ARE WE IGNORING SOLUTIONS?

By Jeff Symes

**F**or several decades, developmental services across the country have been focused on expanding integrated employment, getting people with disabilities into competitive jobs with pay equal to workers without disabilities. In spite of numerous state and national programs, initiatives, and incentives to support the effort, the number of people working in integrated employment has actually decreased. The National Survey of State Intellectual and Developmental Disabilities Day and Employment Services reported that growth in supported employment primarily occurred between the mid-1980s and mid-1990s and in the years since, the number of people with IDD (Intellectual and Developmental Disabilities) in integrated employment has declined.

The water is pouring through the ceiling and the focus has been on emptying buckets instead of repairing the roof. The repair that is needed – providing a well trained and fairly compensated workforce to support community inclusion for people with I/DD – is something that has long been recognized at national and state levels. Unfortunately, it's also a solution we have chosen to ignore.

In 1994, the President's Committee on Mental Retardation (now known as the President's Committee on Intellectual Disabilities) expressed "concern about the low wages, high turnover, minimal training, and lack of career opportunities for direct service workers in the developmental disabilities field. ... The problems associated with the paraprofessional workforce have been

chronicled for over 25 years, spanning institutional, community-based and independent living models of service delivery. Indeed, an experienced, well-trained and motivated workforce may be the single most important factor in the delivery of quality services, regardless of the particular service paradigm."

In 2001, the New Hampshire Department of Health and Human Services report, *Renewing the Vision: New Hampshire's Plan to Provide Essential Community Supports for Individuals with Developmental Disabilities*, also noted that "the quality of life for individuals (with disabilities) is directly related to the quality of care provided by their direct support professionals." The report went on to state, "A significant impediment facing New Hampshire's developmental service system is the ability of the Area Agencies and community providers to attract and keep qualified direct support professionals. In the best of circumstances, the low wages and limited benefits for direct support professionals make it difficult to attract people to this profession."

In 2011, New Hampshire took an important step in addressing this issue. A thoughtful group of activists pushed for and got support from the Bureau of Developmental Services to fund a comprehensive certificate course for direct support professionals. The result: in a field noted for extraordinarily high turnover, agencies reported an 89% retention rate for DSPs who completed the 20-week course and earned their certificate. Ironically, State funding for the course is no longer available.

### • The Direct Care Career Guide •

The Direct Care Career Guide was developed by DirectConnect, a project of the Institute on Disability at the University of NH. It is an easy-to-use interactive career resource tool for individuals interested in entering the direct-care field or advancing their

career in direct care. The guide identifies direct-care career opportunities tailored to fit individual needs, preferences, and career aspirations.

To connect with the guide, go to:

<http://chhs.unh.edu/cacl/interactive-career-lattice>



# CHALLENGES TO PROVIDING QUALITY SUPPORTS

By John Richards, Acting Director, NH Council on Developmental Disabilities

Talking about her 17 years working in direct care, Terry Poulin said, "It has its ups and downs. Do I feel valued and appreciated? No, in general not much at all." She went on to add, "I don't think that there's a lot of understanding out there about the difficulties of this work and all the things we need to understand like consumer's medical issues and behavioral health. All that we need to know is underappreciated."

Terry, who began her career as a direct support professional (DSP), is now a program manager hiring and supervising direct care staff. Asked about the challenges of her job, Terry talked about the difficulty of managing staff and programs and finding appropriate coverage for people who need services. She is currently trying to find a DSP to work a 30-hour week with a man whose support hours vary depending on the day. She observed, "At \$10.00 per hour, why would anyone want the job?" Terry noted that making sure you have a good staff match for those who need supports can be tricky. "We try to make sure people will connect before we put them together, but sometimes we just have to hire someone quickly."

She is especially frustrated that a direct support professional working full time is unable to earn a livable wage. She said that a lot of her staff borrow from their 401K's to make ends meet. Several have had their cars repossessed and almost no one can afford the higher level of car insurance required for DSPs working in State funded programs. The cost of health care is often unaffordable and many workers are uninsured. Terry said, "Many of my staff have to apply for State benefits and welfare because the pay is so low. A lot of my staff can't stay because they can't afford to stay. As a manager, I am sympathetic, but I can't give them anything (more). Their bottom line is clear; if you can't pay the rent and you can't feed your family, of course you can't stay. What we can offer them are flexible hours, so they will be able to go work at a second job."

She is also frustrated with the excessive amount of paperwork that has become part of the job, "We seem to spend most of our time on documentation; that

requirement has gone way up. But documenting stuff does not help to locate desired community events and activities (for the people we support)." Terry reported that while some documentation is necessary, there is an incredible amount of duplication, especially on medical documentation. She concluded, "It would be nice and greatly appreciated by DSP's and program managers, if everyone would get together and find a format that is simple to use and easy to learn. A lot of times we are unable to retain people long enough to teach them all of the requirements."

Terry is concerned that all these challenges are having a profound effect on the quality of services. "We have fewer and fewer staff who have been around for a while. Our staff are not as skilled or trained as they used to be. ... We just don't prioritize community opportunities. We may get people out of the house, but it is not a quality activity. (Staff) don't have the time or experience - nor is it a priority - to find meaningful activities that the person wants."

*(Continued from page 5)*

When we had his quarterly (ISP meeting) I was asked how his volunteering was going. My reply was, "It's not." I explained again that he did not like his hand touched. Asked what I suggest that we do, I said do away with this goal and give him one he can handle and let him make his own choices. They looked at me and said, "He can't do that." In that meeting I turned and said to the gentleman, "Would you like to make your own choices?" The biggest smile came over his face and he shook his head yes. I (showed) them some of examples of choices he was making and they were pleasantly surprised. They could not believe it.

Because I took the time to watch, listen, and learn he has a new goal that he can make his own choices and he's gained some independence in his life. This is all because of the class that I took with you (Robin Carlson) and David (Yeiter). I can't thank you two enough.

*Thank you again – Roxanne Etsy Direct Support Professional*

# THE CHANGING FACE OF NH'S DIRECT CARE WORKFORCE

By Julia Freeman-Woolpert, Outreach Advocacy Director, Disability Rights Center - NH

**E**ven though he has lived all his life in the Granite State, Justyn Shaw is a multicultural kind of guy. He loves momos, samosas, curry, and all Nepali food. Justyn has participated in Nepali celebrations and received the Hindu blessing of red tika on his forehead. He even speaks a little Nepali.

Justyn used to live in an enhanced family care arrangement with a Nepali family and his current direct support provider Rajesh Chauwan is also Nepali. Justyn loves spending time with Rajesh. He said, "I never thought I would have a best friend from another culture."

The admiration is mutual. Talking about Justyn, Rajesh said, "He's awesome."

The face of New Hampshire's direct care workforce is changing. There has been an influx of immigrants to the Granite State and many of these new arrivals, especially from Bhutan and Nepal, have become direct support professionals (DSPs). Low unemployment and a competitive job market mean fewer applicants for all jobs and especially for entry-level positions. New Americans who are just beginning to build a work history in this country are more willing to accept low paying direct support positions.

Rajesh, who lives in Concord, was originally from Bhutan and spent many years in a refugee camp in Nepal. He now works for Community Bridges, the Area Agency for Merrimack County. He loves his job. "DSPs are changing peoples' lives," said Rajesh. "It makes me feel good to help someone have a wonderful day."

Another New American from Nepal, Sayuj Shakya, has been a direct support provider for several years working all across the state. He specializes in supporting people who have difficult behavior. He is skilled at calming someone down and turning around potentially volatile situations. He too loves working in this field. "If I can change someone's life for the better, I feel good," said Sayuj.

Melissa Moore, the Community Bridges supervisor who hired Rajesh and Sayuj, thinks highly of their work. She also believes that having Nepali support providers has been an enriching experience for many of her clients. She said she doesn't have to explain the importance of inclusion to Nepali and Bhutanese providers. In Nepal there are very few human services; family and community members



## NO WONDER

By John W. Richards, Acting Director NH Council on Developmental Disabilities

**J**im, an accomplished public relations specialist and committed disability rights advocate, has significant physical disabilities. Much of Jim's youth was spent at Crotched Mountain Rehabilitation Center in Greenfield, New Hampshire. When he turned 21 Jim left the Center and moved into an apartment. Several hours of support a day from personal care assistants (PCAs) made it possible for Jim to live on his own.

From the beginning Jim was able to clearly state his support needs and explain the best way to provide his

care. Crotched Mountain recognized Jim's talent for instructing his PCAs and frequently enlisted his help to train their newly hired direct support workers. However, like others who rely on PCAs, Jim said it took time to learn how to be good at hiring and supervising his staff. He admits that when he was younger he had a tendency to hire attractive young women, who were great to look at and fun to have around, but who were not always the best at care-taking. Jim said, "I was lucky - there were only a few times I was left in bed all day. I was only stolen



are the ones providing support for people with disabilities. As former refugees who were forced to flee their country by the dominant ethnic group, these New Americans also understand what it feels like to be marginalized.

Sayuj said he believes Nepali and Bhutanese people are attracted to this profession for two reasons. First because “we have a caring heart,” and second because Nepali culture is home-based. Time with family is highly valued and becoming a home provider is an attractive option. While they both love their jobs, Rajesh and Sayuj acknowledge that the work can be extremely demanding. “It’s harder than you think,” said Rajesh. “People who are just in it for the money – they won’t keep the job.”



*Rajesh Chauwan, Direct Support Professional*

In fact, direct support is not a field anyone would go into for the money. In New Hampshire, and across the nation, direct care workers are rarely paid a livable wage. Like most of his co-workers, Sayuj has to work two jobs to support his family, frequently putting in 70 hours a week. In spite of being a valued employee, he does not get raises. A few years ago Sayuj was badly bitten by a person he was supporting and was out of work for two weeks without pay. “It’s tough,” Sayuj said. “Sometimes I’m so tired.”

Given how important direct support professionals are to the quality of services, it is discouraging to see how little of the State’s funding for human services is allocated to DSP wages and benefits. Rajesh observed, “They should pay DSPs better because we are the ones who will change someone’s life.”



from once; someone stole \$200.00 from me when I was getting \$450.00 per month from Social Security.”

Acknowledging the importance of his PCAs, Jim said, “They really keep me alive.” Getting the right supports has enabled Jim to be independent and lead a full and productive life. He graduated from college, went on to receive a Master’s degree, has a full time professional job, and pays his fair share of taxes. Jim is also married and has a family.

Asked what he has learned over his years of experience with PCAs, Jim said, “Be as careful as you can about

who you decide to hire and try not to be intimidated. Remember that they work for you.” He noted that the pay scale for direct care workers makes it very difficult to find PCAs. “If they are really good at their work they can get a whopping 25¢ an hour raise each year. After only 20 years of work, they might get up to \$15.00 per hour - Wow! For this whopping salary they get to: get you up in the morning, bathe you, get you dressed, make your meals, and clean up your puke if you are sick. No wonder more people aren’t looking for jobs like this!”



# RECRUITING FOR TODAY, RETENTION FOR TOMORROW

By Maureen E. Whittemore, Attendant Care Worker Relations Coordinator, GSIL

**W**ith an aging and retiring workforce and a state economy that is on the upswing, many direct care workers are leaving the field for higher paying positions. It is currently an employee's market, with companies vying for the same applicants. Companies in desperate need of workers are upping the ante with increased wages, better benefits, flexible schedules, and other perks. Those companies that cannot afford to do the same are feeling the pinch.

Today's economy has changed the game for recruitment of care attendants and other direct support workers. Gone are the days when inexpensive help wanted newspaper ads would bring in applicants by the dozen. Corporate media outlets have bought up smaller newspapers and advertising costs have skyrocketed. In their place, hundreds of online job sites have come into existence; the online giants - Indeed, Monster, ZipRecruiter, CareerBuilder- are unaffordable and difficult to navigate.

How can these recruitment challenges be overcome? Here are some "back to basics" tips:

**Who are you recruiting?** Before you begin recruiting, know your target audience and have a strategy for how to reach them. What age are they? What are their interests? Where do they spend time when they aren't working?

**Where are you recruiting?** If workers aren't coming to you, you must go to them. Smaller local newspapers might draw in some applicants, but newspaper readership is waning. Social media - especially Facebook, Twitter, and LinkedIn - offers the best shot for connecting with large numbers of potential employees. GSIL launched a Facebook recruitment campaign in May 2015; within seven months we attracted over a thousand applicants. Online sites that target your audience can be worth the cost, but do your research before you make an investment.

**Who are you using to recruit and interview?** Community outreach, word of mouth, and networking all remain viable approaches for recruiting. However, keep in mind that older experienced workers, while an invaluable asset, may not be the best recruiters. You can expand your reach by enlisting younger employees who share similar life experiences with applicants to help with recruitment and job interviews.

## Investing in Retention

With New Hampshire's need for direct support professionals rising and the workforce shrinking, it is more important than ever to retain quality workers. Successful companies know that investing in retention is cost effective, generates motivation, builds loyalty, and increases employee satisfaction. Employees who are happy at their job outperform those who are not and stay in their positions for longer periods of time.

Taking the following steps will help improve employee retention:

**Make professional development a priority.** Never underestimate the role that training and education play in retaining employees. The fear that workers will jump ship once you've helped them acquire skills is unfounded. Most employees are incredibly thankful for training opportunities and have an increased loyalty to companies that offer regular professional development.

**Support your team.** Employees appreciate a work culture where teamwork is valued. Successful companies embrace a "we're all in this together" approach and involve employees in problem solving, including finding ways to support one another. This helps strengthen the bond between management and employees and creates an environment that promotes employee skill development and confidence.

**Pay attention to the work environment.** High stress and negative energy in the workplace not only affect productivity, they are incredibly damaging to employee morale. Unhappy workers are looking for a way out and your most competent workers are the ones who will leave first.

**Show appreciation!** "Thank you" goes a long way. All of us like to be appreciated and recognized for our efforts and this holds especially true in the workplace. Reward and recognize your great employees.

At GSIL the comment "I love my job because I get to help others." is something we hear often. We are immensely proud of our employees and the work they do.

*If you are looking for a great place to work, we would love to hear from you! Visit us online at [www.gsil.org](http://www.gsil.org) or call Vickie Trudell at 603.410.6562.*



# A LOOK AT NH'S DIRECT SUPPORT WORKFORCE

By Robin Carlson, Instructor, writer, activist and a direct support worker for 32 years

In the winter of 2014/2015 the New Hampshire Chapter of the National Alliance of Direct Support Professionals, with support from the New Hampshire Council on Developmental Disabilities, distributed a survey to direct support workers throughout the state. Four hundred sixty six (466) workers who provide direct care completed the survey; 72% were direct support professionals (others respondents included paraprofessionals, medical assistants, LNAs, and a small number

of registered nurses). Workers were employed by a wide variety of public and private agencies serving people with disabilities and older residents. The intent of the survey was to learn: 1) who makes up NH's direct support workforce, 2) the financial situation for direct support workers, 3) the challenges and rewards of providing direct support, and 4) what is needed to keep direct support workers inspired and motivated.

Photo credit: David Ouellette



Members of the DSP Conference Planning Committee, L to R: Wendy Lee, Robin Carlson, Marianne Morse, Barbara Wilson, Jan Skoby, Shirley Rogers, and Perry Blass.

## **NH's Direct Support Workforce**

- ◆ 82% female
- ◆ 50% married
- ◆ Age
  - 18% 20-29 years old
  - 19% 30-39 years old
  - 18% 40-49 years old
  - 30% 50-59 years old
  - 14% 60 years or older
- ◆ Education – Highest degree attained
  - 45% GED/high school diploma
  - 21% Associate's degree
  - 27% Bachelor's degree
  - 9% Master's degree
- ◆ 65% provide daily support for 1-3 people

## **Financial Reality for Direct Support Workers**

- ◆ Pay \$10 - \$12 an hour
- ◆ 34% have never gotten a raise.
- ◆ 45% work a second job
- ◆ 62% live in a household with two wage earners
- ◆ Mileage reimbursement \$.28 - \$.50 per mile (*majority receive \$.37- \$.46 per mile*)
- ◆ 63% drive vehicles that are 7 years or older

## **Greatest Challenges for Direct Support Workers**

- ◆ Inadequate Pay
- ◆ Wear and tear on vehicles and low mileage reimbursement
- ◆ Lack of training
- ◆ Isolation

*(Continued on page 13)*



## LUCAS' LONG JOURNEY

By Heather Donnell

**M**y five year-old son Lucas has Down syndrome and Attention Deficit Hyperactivity Disorder. He also has had a tracheotomy and uses a feeding tube. Lucas' significant medical issues require 24/7 care and he has been approved by Medicaid to receive in home nursing 80 hours a week. However, due to New Hampshire's extreme shortage of in home nurses, since July 2015 Lucas has received no in home nursing care. On December 9, 2015, this lack of needed care had devastating consequences. While I was getting my other two children ready for school, Lucas ripped out his trach. By the time I discovered what had happened his tracheotomy hole had closed to the point that I was unable to put the trach back in. Lucas was taken by ambulance to our local hospital and from there air lifted to Massachusetts General Hospital in Boston. I had to place my five-year old child in the arms of medical personnel I had just met and watch him being loaded onto a helicopter and fly away from me.

Lucas landed at Mass General an hour ahead of us. I arrived at the hospital to find my son in a bloodstained shirt, blood around his trach and in the secretions he was coughing out. The ENT doctors had successfully reinserted a trach, but it had been an incredibly traumatic experience for our child. It took several people to hold Lucas down while doctors used a tube to stretch the tracheotomy hole until it was large enough for a trach tube to be put back in. He was given no sedatives or pain medication during this procedure. It was an awful day that included an ambulance ride, helicopter flight, three different emergency room visits, an overnight admission in a Boston hospital, and a follow up operating room procedure to check his airway. None of this would have happened if we had adequate home nursing care.

Over and over again, I have reached out to nursing agencies begging for a trained nurse to cover Lucas' approved hours. We were told no pediatric trained nurses were available who can manage a trach. It is not possible for any parent to watch a child 24 hours a day and yet this is what I am expected to do. I am up eight to ten times a night to check on Lucas and often

have to sleep with him to be sure he won't remove his trach again. Not only is this situation physically and emotionally exhausting, it is causing huge financial stress for our family. With no available nursing, I quit my full time job two years ago in order to meet Lucas' intensive needs. Having 80 hours a week nursing coverage would allow me to sleep at night and help me to care for Lucas during the day.

We are not the only family facing this challenge. All across New Hampshire there are other families whose children with significant medical needs have been approved for in home nursing care that they are not receiving. These families are struggling every single day with no help in sight. The current situation is not sustainable. Our state needs to act and act quickly before one more child and family find themselves spiraling into a medical crisis that could have been avoided.

*Families and concerned professionals have joined together to bring pressure on the state to address the lack of adequate home nursing care for children with significant medical needs. To learn more visit the Facebook page for NH Pediatric Nursing Care Campaign. You can also email organizers Heather Donnell - heatherdonnell2006@yahoo.com or Audrey Gerkins - gerkin5@comcast.net for additional information.*



Photographer - Heather Donnell

*A smiling Lucas*

## The Importance of the DSP Certificate Course to Graduates

The Direct Support Professional Certification Course "Supporting People in Community Living" was truly a unique learning experience that provided me with more resources, insight, and feedback than any other training I've been a part of.

From the first class, I was instantly at ease. The course gave me the opportunity to have an ongoing conversation with other DSPs who were up against some of the same challenges I was facing. We learned about the importance of taking care of ourselves so that we can best serve the people we are supporting. Some of the interactive exercises helped us to look at different situations through the eyes of those we support. How does it feel to have no control over who is showing up at your house in the morning to help you get ready for work?

One way we can insure social justice for individuals who experience special needs is to make sure the people supporting them are educated and know what is expected of them. We cannot expect great services if we are not willing to invest time, energy, and appropriate financial compensation to the direct support professionals.

This course will ensure that one stay educated and progress in his or her work as a direct support professional, paraprofessional, licensed nursing assistant, executive director, parent, or sibling. This class has something to offer everyone as it helps put the humanity back into a crucial workforce in our society.

I thank my Learning Partner and good friend, Mark, for appreciating the little things and for being one of my greatest teachers.

~ Alyssa Thiem, Direct Support Professional

(Continued from page 11)

### Greatest Reward for Direct Support Workers

- ◆ Making a difference in someone's life

### What Direct Support Workers Want

- ◆ Increased opportunities for training and education
- ◆ Positive support from supervisors
- ◆ Demonstrated respect and appreciation through increased pay and benefits
- ◆ A voice in decisions about their work and how to best provide supports

Eighty two percent of NH's direct care workforce is female. This is a feminist issue. Nancy Folbre, PhD, an economist at the University of Massachusetts in Amherst notes that historically women have been expected to assume the role of caregivers, providing ongoing support to family members and others for free and forever. Low wages for direct support professionals continue to reflect this assumption.

Dr. Folbre also points out that capitalism values producers; individuals with disabilities, older people, and others needing support are seen as a financial burden and are devalued in our society. By association, direct support workers share this devalued status.

Direct support workers in New Hampshire and across the nation are the foundation of our human service system. If we fail to provide a living wage, decent benefits, and appropriate training for the workers who support and care for our most vulnerable citizens then we have no business calling ourselves a moral society.

### NH Chapter – NADSP

*The New Hampshire Chapter of the National Alliance for Direct Support Professionals is an alliance of human service workers committed to the quality enhancement of the state's direct support workforce. Our mission is to create a well informed, ethical, and respected workforce to provide the best possible supports for New Hampshire residents receiving human services. Chapter meetings are held the 4<sup>th</sup> Wednesday of every month from 6:00-8:00 pm at the New Hampshire Council on Developmental Disabilities, 2 ½ Beacon Street, Suite 10, Concord. To learn more about NADSP visit - <https://www.nadsp.org/> - for more information about the NH Chapter of NADSP please email [robincarlson@metrocast.net](mailto:robincarlson@metrocast.net).*

# IOD TRAINING & EVENTS

Institute on Disability/UCED



## RENEW Facilitator Training Institute

This three-day institute will provide in-depth training about the Rehabilitation for Empowerment, Natural supports, Education, and Work (RENEW) model and process. This is also an excellent training for individuals who want to learn more about the RENEW model and implementation requirements.

**Date:** March 14 -16, 2016  
**Presenters:** Heidi Cloutier, MSW, and Kathy Francoeur, M.Ed.  
**Time:** 8:30 a.m. - 3:00 p.m.  
**Location:** Grappone Conference Center, Concord, NH  
**Cost:** \$399

## PBIS Universal Team Retreat: Improve Your PBIS Implementation

At this retreat Universal PBIS school teams will review their progress and plan for PBIS implementation. Participants will receive a PBIS Manual, organizational and self-assessment tools and will be provided with technical assistance, support to set up data systems, and communication strategies. Teams will leave the retreat with a work plan for implementation for the next several months.

**Date:** March 30, 2016  
**Time:** 8:00 a.m. - 3:00 p.m.  
**Presenters:** JoAnne Malloy, Ph.D.  
**Location:** Grappone Conference Center, 70 Constitution Avenue, Concord, NH  
**Cost:** \$119 per session; \$99 per person for groups of 3 or more

## PBIS Behavioral Support Team Retreat: Function Based-Supports

This session will take a closer look at function of behavior to develop positive supports best matched to student need and effective interventions. Teams will practice a simple FBA process that leads to improved positive behavior support plans. Tier 2 teams will have chance to review their system, data, and practices in order to more effectively and efficiently support youth. FBA tools will be shared. Participants will have time to plan, interact with others, and ask questions.

**Date:** April 6, 2016  
**Time:** 8:00 a.m. - 3:00 p.m.  
**Presenters:** Kathy Francoeur, M.Ed.  
**Location:** Grappone Conference Center, 70 Constitution Avenue, Concord, NH  
**Cost:** \$119 per session; \$99 per person for groups of 3 or more

## NEGC Annual Meeting

Join the New England Genetics Collaborative (NEGC) at their Annual Meeting to receive updates on research and projects taking place around the region.

**Date:** April 7-8, 2015  
**Location:** Hilton Garden Inn, 100 High Street, Portsmouth, NH  
**Cost:** Free

## 2016 NH Leadership Reunion Gala and Fundraiser

Join alum of the NH Leadership Series at their annual reunion and fundraiser. Each year this event helps graduates reconnect and build lasting relationships for each other and family members. It also helps the series raise much needed funds to allow the series to continue in future years.

**Date:** April 15, 2016  
**Time:** 6:00 p.m. - 9:00 p.m.  
**Location:** New Location! Capital Center for the Arts, Concord, NH  
**Cost:** \$35 (suggested)

## Advocate NH 4th Annual Conference Advocacy: Learn It! Live It! Love It!

This year, we invite conference participants to *Reach for the Stars* as you set your own goals, and work together with peers and leaders in the advocacy movement to learn how to take action and achieve your dreams.

**Date:** June 11, 2016  
**Time:** 9:00 a.m. - 3:30 p.m.  
**Location:** Grappone Conference Center, 70 Constitution Avenue, Concord, NH  
**Cost:** TBD

### 3 EASY WAYS TO REGISTER!

-  online  
[WWW.IOD.UNH.EDU](http://WWW.IOD.UNH.EDU)
-  call to register or to request a registration form  
**603.228.2084**
-  mail a completed registration form  
**INSTITUTE ON DISABILITY  
56 OLD SUNCOOK ROAD, SUITE 2  
CONCORD, NH 03301**



## BETWEEN A ROCK AND A HARD PLACE

John Richards, Acting Director NH Council on Developmental Disabilities

**F**or twelve years Lee Crowell has worked for the same residential service provider. She has not had a raise in five years. Talking about her career Lee said, "This has never been just a job. Working in this field has changed my life. I give it my all, but the cost of health insurance just keeps going up. The cost of everything keeps going up. I don't know how I can keep doing this. I can no longer cover my bills, and that makes it very hard to focus on my work. Part of me is always worrying about how I will pay the phone bill or the mortgage. My husband has health issues, so I can't just work the 50 or 60 hours I would need to cover our expenses."

"What about advocacy?" I asked.

"Talking to people at the State level is just a frustration," Lee said. "What words are there to get across that DSPs (direct support professionals) deserve a living wage? People who have never done this don't realize what skills you need to do this. The people we support are devalued, so we DSPs are totally devalued as well. Tomorrow is Thanksgiving and for the fourth year in a row I will not be with my own family. I will be supporting my people. Does anyone in Concord (State government) know anything about what being a DSP is all about? What can we do to help them understand?"

Thinking about her future, Lee concluded, "I have two options - work a huge amount of overtime and extra hours or leave the field entirely."

## 2015 DSP AND HOME PROVIDER OF THE YEAR AWARDS

**T**he 2015 Direct Support Professionals Conference honored Kelly Pearson as the DSP of the Year and Louis Velasques as the Home Provider of the Year.

Ms. Pearson, a DSP with Monadnock Developmental Services, is a Vocational Trainer for the Project SEARCH program at Cheshire Medical Center Dartmouth-Hitchcock Keene. Ms. Pearson supports young adults with developmental disabilities who are enrolled in a year-long internship program to develop the skills needed to enter the workforce. She has created training tools, taken sign language classes, programmed communication devices for an intern's worksite, used her personal network to help interns find jobs, and been a resource to employers and families. She has consistently done whatever was needed to help these young adults become confident and capable workers.

For over fifteen years Mr. Velasques and his wife have opened their home to individuals with disabilities. In her nomination letter, Lee Carter, Program Manager for Residential Resources wrote, "Louis exemplifies dignity, full rights of citizenship, equal opportunity, and full participation for all citizens with developmental disabilities." Mr. Velasques has supported individuals who have struggled in other residential settings and done everything possible to ensure they feel safe and comfortable in his home. Since living with the Velasques family, one man has lost over 80 pounds and his overall health is greatly improved. This gentleman who had previously been very reclusive now enjoys taking part in family activities and has been included in the family's church community.



*NH Council on Developmental Disabilities Chair  
Kristen McGraw presents Kelly Pearson with the  
2016 NH DSP of the Year Award.*

# RAP Sheet

## NH COUNCIL ON DEVELOPMENTAL DISABILITIES

2½ Beacon Street, Suite 10  
Concord, NH 03301-4447

**RETURN SERVICE REQUESTED**

## INSIDE THIS ISSUE

- ◆ *Changing Face of NH's Direct Support Workforce*
- ◆ *Recruiting and Retaining Quality Direct Care Workers*
- ◆ *Challenges to Providing Quality Supports*
- ◆ *Personal Stories*

## DISABILITY RIGHTS CENTER - NH

64 North Main Street, Suite 2, 3<sup>rd</sup> Floor, Concord, NH 03301-4913  
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 AT THE UNIVERSITY OF NEW HAMPSHIRE

[www.iod.unh.edu](http://www.iod.unh.edu) | [facebook.com/instituteondisability](https://facebook.com/instituteondisability) | [twitter.com/unhiod](https://twitter.com/unhiod) | [youtube.com/unhiod](https://youtube.com/unhiod)

Durham Office:

10 West Edge Drive, Suite 101 | Durham, NH 03824  
Phone: 603.862.1769 | Relay: 711 | Fax: 603.862.0555

Concord Office:

56 Old Suncook Road, Suite 2 | Concord, NH 03301  
Phone: 603.228.2084 | Relay: 711 | Fax: 603.228.3270

*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

2½ Beacon Street, Suite 10  
Concord, NH 03301-4447

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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