

RAP Sheet

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

Winter Issue 2007

TAKING A HARD LOOK AT QUALITY



The Erosion of Developmental Services

Richard A. Cohen, Esq., Executive Director, Disabilities Rights Center

Welcome to our Winter Issue. The past decade has seen a significant diminishing of New Hampshire's ability to meet the needs of its citizens with disabilities. Our developmental and mental health services were once cited as national models, today New Hampshire struggles with inadequate funding, workforce shortages, and growing waiting lists. This issue takes a hard look at where we are now and what we need to do to get back on track.

I was recently viewing *Parallels in Time*, a multimedia history of disability developed by the Minnesota Governor's Council on Developmental Disabilities and available on their website (<http://www.mncdd.org/>). My attention focused on the events in the 70's. It was a time when history and forces converged to propel the "DD Rights Movement" into what felt like warp speed. Institutional exposés, emerging education and behavioral strategies, parent advocacy, court decrees, passage of state and federal laws affirming rights and establishing community-based systems all dramatically changed where and how individuals with developmental disabilities lived and spent their days. At the same time, leaders in the field like Wolf Wolfensberger and Mark Gold, were helping to change our ways of thinking about disability. University research, along with personal stories, presented us with mounting evidence that even people with the most significant and multiple impairments could be integrated into the workplace, home, and the community. Later, as people with disabilities gained greater freedom and the tools to become empowered, People First and other self-advocacy groups formed.

As I watched *Parallels in Time*, I was drawn to Mark Gold's training videos. Dr. Gold, a researcher, trainer, and humanist, worked in the disability field from the 1960's through the 80's. With his *Try Another Way* approach, Dr. Gold assisted individuals with the most significant disabilities, including those whose IQ's were reportedly as low as 10, to develop complex work skills and habits. Using positive behavioral approaches, his simple training techniques enabled individuals who had been highly devalued to assemble items as complex as 18-piece bicycle brakes and electronic circuit boards, all in accordance with industry quality and time standards.

As a result of Dr. Gold's and others work, our expectations about the capabilities and futures of individuals with developmental disabilities, and the type of services and supports they needed to achieve those futures, rose exponentially.

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SUSAN COVERT, EDITOR

A COLLABORATIVE EFFORT BY THE

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

Those high expectations, based on basic human values, constitutional mandates, and scientific research, were put into federal and state law. These laws, still on the books today, set forth basic service guarantees and the methods to assure that individuals receive quality services aimed at improving their independence, productivity, and quality of life. In 1975, the New Hampshire Legislature passed and the Governor signed into law RSA 171-A, which mandates that services be provided "within the limits of modern knowledge." The law requires that the state Health and Human Services Department establish, supervise, and monitor a regional area agency and case management system as the prime mechanism to deliver community-based services. After years of neglect, expectations about what people could achieve with the right services were indeed high. They rose still higher in 1981 when *Garrity v. Gallen*, the Laconia State School lawsuit, was decided and New Hampshire became the first state in the nation with a completely community-based system of services for individuals with developmental disabilities. With active oversight by the court, the state provided appropriate levels of funding to the newly developed area agency system.

Unfortunately, the promise of the 1970's and 80's has been followed since the mid 1990's with stagnation and the increasing erosion of the service delivery system. Along with this erosion has been a continual lowering of expectations. These developments and the reasons for it were well documented in the Department of Health and Human Services' *Renewing the Vision* (2001) and more recently in the 2005 report from the Governor's Commission on Area Agencies.

I most recently witnessed this erosion while representing an area agency client at her service planning meeting. My client, a former resident of Laconia State School, is currently working sporadically and only about ten hours a month. She wants and needs educational courses and would like a non-menial job with more hours and better pay. During the past three years the area agency has made little or no efforts to assist her in furthering her education or finding paid employment.

At the meeting I learned that because the area agency lacked sufficient funds my client had to choose between having a chipped tooth fixed or having her teeth cleaned. Because her chipped tooth was painful, she elected to have the tooth fixed. No one at the meeting knew when she had last had her teeth cleaned. The area agency told us that there is no money this year for dental cleanings.

While I was not surprised that she was being underserved, I was shocked at how meager the services were both in amount and type. The area agency was only providing three hours of service per week, mostly to help with grocery shopping. When I questioned why services were so limited, the agency told us that because my client is verbal and can read that she should be able to obtain services on her own, with only minor assistance from them. In effect the area agency said it was her responsibility that she was not able to obtain or pay for educational coursework.

We were told that because of their limited funds for any additional services (apparently beyond the three hours), she would have to go on the waitlist. For employment assistance, she could be referred to VR (Vocational Rehabilitation), an agency that has not served her well in the past. While we are now making progress toward addressing her service needs, I suspect that without an advocate present, her meager service agreement would have just been rolled over for the next year. Interestingly, when we initially contacted the service coordinator to tell her a representative from the Disabilities Rights Center would be attending the meeting, the coordinator questioned why an advocate needed to be involved. How far have we fallen since the 1980's.

Hopefully, we will continue to cooperatively work out the differences in this case. However, I could not help but be struck by the gap between what I had viewed on the Gold video a few days earlier and the narrowness and miserliness of my client's service agreement. There are many worse scenarios across the state. Individuals with significant disabilities are languishing on waitlists; with little or no services from area agencies they are being permitted to regress

or deteriorate. There are many more who, while receiving some services, are not getting the type or amount of services they need to lead more independent, quality lives. While thankfully no longer in institutions, too many New Hampshire citizens with disabilities have stultifying lives passing their days in programs that consist of "mall walks" or car rides.

This regression since the mid 1990's is due in large part to inadequate funding, but that is not the only reason. Our laws and regulations have continued to reflect high standards, and our body of knowledge has continued to improve, but as funding and services have decreased, so have expectations and accountability. A vicious cycle has been created: the lower the funding and services, the lower the expectations and accountability, and in turn the lower the funding. Since the mid 90's funding has dropped from an average of \$58,000 per person to \$41,000 for those served under the DD Medicaid Waiver, taking into account inflation. For those coming off the DD waitlist onto the Waiver in the past 4-5 years, the average per person funding is about \$30,000.

It is more important than ever that expectations and accountability for quality remain high. People both in and out of the "system" have remained vigilant about *access* to services by addressing the waitlist issues with at least partial success. But the vigilance regarding the *quality* of services has flagged as expectations of stakeholders – families, self-advocates, advocates, area agency and provider personnel, and state officials – have steadily diminished. If expectations and accountability remain low, we will never get back on track. In two accompanying articles, I describe some of the causes and effects of this erosion and some solutions to turn it around.

On the positive side for those waiting for services, there is strong governmental support for recommendations of the Governor's Commission on Area Agencies and the Legislative Oversight Committee to permanently address the adult waitlist. This effort warrants strong advocacy from all stakeholders. At the same time we must be prepared to act if those taken off the waiting list, as well as those currently in the system, are not provided with the level and quality of services that they need.

What are the chief causes of the weakening of the developmental service system?

Richard A. Cohen, Esq., Executive Director Disabilities Rights Center

There are a number of pressures on New Hampshire's developmental service system that have seriously compromised the well-being, independence, and quality of life for individuals with disabilities.

Low wages and benefits for direct support personnel. The salaries of job coaches, residential staff, and other support workers do not come close to matching the responsibilities of the job or what is paid for similar work

in the private sector and in state government.

Starting wages for direct support workers are as low as \$7.00 an hour with minimal or no benefits, compared with \$10.50 for mental health workers at New Hampshire Hospital. Indeed, jobs requiring far less skill, such as retail or fast food work, command starting salaries of over \$8.00 an hour. Poor wages make it difficult to attract and retain qualified staff. With vacancy rates as high as
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Richard Cohen is Executive Director of the Disabilities Rights Center. He was lead trial counsel for the plaintiffs in Garrity v. Gallen, the lawsuit that resulted in the closing of the Laconia State School and Training Center. For over 30 years attorney Cohen has been an advocate for individuals with disabilities; he has been a court monitor in Minnesota and Massachusetts in system-wide disability rights cases, a senior official in Massachusetts state government, and most recently, Chair of the Governor's Commission on Area Agencies, which conducted a review of New Hampshire's developmental service system.

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36%, individuals with developmental disabilities experience a revolving door of people coming in and out of their lives. Too often staff never get to know the individual well enough to provide personal, high quality supports.

An erosion of the administrative infrastructure.

Professional and administrative support at the Department of Health and Human Services (DHHS), area agency, and provider levels has been seriously undermined. While it is popular to talk about efficiency and eliminating waste, the system for many years has been cutting into bone to save funds. Over the last five years, staff positions at the DHHS Bureau of Developmental Services have been cut from 31 to 20. Area agencies and providers have suffered from similar cutbacks. These administrative and professional positions are critical for supporting field staff, addressing complex needs, proactively responding to needs, and assuring accountability and quality of services.

Inadequate funding to maintain and improve services.

David Braddock's 2005 State of the States Report (a national review of developmental services), found that the average annual cost per person on the state's Developmental Disability Medicaid Waiver declined from \$58,000 in 1994 to \$41,300 in 2004. From 1996 to 2004, New Hampshire's fiscal effort (funds spent on developmental services relative to a state's wealth) dropped from 10th in the country to 35th; compared to other New England states, New Hampshire is lowest by far. Nationally, New Hampshire ranks dead last in private sector contributions. New Hampshire can and must do more. Even with increased funding, a more adequate community based approach is far less expensive than the institutional alternative that costs on average between \$125,000 to \$250,000 per year.

Lack of independent, rigorous safeguards. The developmental service system is riddled with conflicts of interest, has little transparency, and lacks a professional independent, entity to ensure adequate quality assurance and monitoring. Critical issues include:

- Area agencies in six regions are effectively the sole source of service provision, case management, and monitoring.
- Even in area agencies that contract with providers for direct services, independent advocacy by service coordinators is not encouraged.

- There is a pervasive failure by area agency service coordinators to document unmet needs in individuals' service agreements.
- The current system's provision of quality assurance is neither independent nor adequate, and lacks any real enforcement capability.
- The system for investigating and remediating abuse, neglect, and client rights violations does not have adequate independence and enforcement authority.
- Individuals, families, guardians, and advocates typically do not invoke the grievance system, and particularly administrative appeals, to address issues concerning quality of services. In 2003 of 846 appeal hearings at DHHS, only two concerned service quality or rights. Three factors seem to be at work here: 1) Individuals and families do not know about, or are daunted by, the appeals process; 2) they fear retaliation from area agencies; and 3) they have low expectations regarding the amount, type and quality of services they receive.

In New Hampshire there is a lack of transparency and disclosure about the overall quality of the developmental service system and the performance of individual area agencies and providers as measured by relevant standards. Other states, and even other service systems in New Hampshire, have done a far better job of this using rating systems and website dissemination. New Hampshire appears to have a culture of nondisclosure, fueled in part by the fear that any bad news will cause elected officials to provide even less funding for services. Good policies and decisions can only be made in the light of reality. No one – individuals, families, or the public – benefits if the full picture is not provided.

WHAT ARE THE SOLUTIONS?

We must restore *higher expectations* of what individuals with disabilities are capable of achieving. Certainly, more resources are needed, but with creativity and higher expectations much can be accomplished. Increased expectations will not produce more funding, but unless we have them the system will continue to stagnate and we will never be able to provide the quality services that New Hampshire citizens with disabilities deserve. Let us restore and act upon the vision that once made New Hampshire a nationally recognized leader in developmental services.

Vulnerable

Julia Freeman-Woolpert, Disabilities Rights Center

David Tripp and his sister, Susan Leveillee, share a love of music and poetry that goes back to their childhood. David knows by heart pieces as diverse as Tennyson's "The Charge of the Light Brigade" and Ricky Nelson's "Garden Party," complete with the beginning and ending riffs. While David has a remarkable gift for memorizing and reciting verse, simple communication is difficult for him. Medically fragile and dependent on others for his most basic needs, David is vulnerable to abuse, neglect, and exploitation.

David, who is now 52, has lived for many years in a community residence. The home, formerly run by the Center of Hope, was recently taken over by Northern Human Services, a change that came about when the state merged the two area agencies serving the North Country. Susan, who is her brother's guardian and lives 200 miles away in Rhode Island, said when the residence was managed by Center of Hope she frequently worried about David. On nights when inexperienced staff were on duty, she had trouble sleeping.

In 2005 David injured his hand. In spite of significant swelling and Susan's request that David be taken to a doctor, it was two days before he received any medical attention. When he finally was seen, X-rays revealed two broken bones. While the ensuing internal complaint investigation never determined how David's hand was broken, it did cite numerous problems with the quality of David's services, and made recommendations to improve David's care, recommendations with which Susan agreed.

Finding that the residence lacked competent staff supervision, the investigator recommended changes in management structure including hiring a residential manager for the home. While the Center of Hope acted on some of the investigator's other recommendations, it did not improve the supervisory structure for residential services. When Susan attempted to appeal this matter, the Department of Health and Human Services Administrative Appeal Unit informed her that they had no authority to rule on the agency's implementation of recommendations. Susan was shocked to find that the Center of Hope later fired the staff person who conducted the internal investigation, since in Susan's estimation, the staff person had done an excellent job.

The problems for David continued: missed doctor's appointments, poor communication, and failure to implement the goals in his behavior and service plans. Susan was especially concerned about the lack of competent and caring staff who knew David well. "The importance of continuity is everything to him. Routine is everything. It's his security. It's his safety. It provides the environment that can provide a very good day for

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The report from the Governor's Commission on Area Agencies included 35 recommendations that would address many of the issues raised in this edition of the RAP Sheet. Recommendations that were determined to be a high priority or a pre-condition to the others, included:

- ◆ Improved collaboration and community partnership at all levels, including the business community, to increase employment opportunities for people with disabilities.
- ◆ Legislative action to increase wages of direct support staff and enhanced family care stipends.

- ◆ Development of a human resources enhancement plan to increase adequate numbers of qualified administrative, professional, and supervisory personnel.
- ◆ Establishment of a central registry of abusers to prevent known abusers from working in direct care. *Note:* Legislation passed during the past session has made this recommendation a reality, and the registry is in the process of being established.
- ◆ Recommendations aimed at improving technology and quality assurance and accountability mechanisms.



Have our dreams come to this? The current quality of the developmental service system

Richard A. Cohen, Esq.

How have budget austerity and lowered expectations over the past 12 years affected New Hampshire's developmental disabilities system and the people it is supposed to serve?

Hundreds are waiting too long for needed services. Others have had Medicaid waiver services denied outright. Despite increases in the numbers of individuals with developmental disabilities, funding for services has not kept pace. Every two years families and advocates plead with the state Legislature and Governor to increase developmental services funding. Sometimes they are successful; sometimes they are not. At present, with recommendations from the Governor's Commission on Area Agencies and proposals coming out of the Legislative Waitlist Oversight Committee, we have the best chance in years of addressing the adult waitlist.

Individualization and choice are more buzzwords than reality. While individual examples of people exercising choice can be found, overall our system offers very few services options despite state regulations and agency mission statements requiring choice. Low provider reimbursement rates make it increasingly difficult to attract and retain qualified service providers and personnel, further limiting choices for individuals needing services.

Employment and day supports are not meeting individual's needs or desires. Approximately 1065 people are enrolled in supported or competitive employment or sheltered workshops, however, individuals are working on average only thirteen hours a week and in some regions, as little as seven hours. Less than 8% of those employed receive vacation or sick time and fewer than 3% receive employer medical or dental benefits. The Area Agencies 2003 Survey found that 50% of those unemployed wished to work. Once a national leader, New Hampshire's ranking has slipped to fourth in New England for the percentage of people served by the developmental service system who are employed.

For those developmental service clients who are not working, the Governor's Commission found that too many "remain isolated and not nearly as active and engaged as they could or should be." Those in the system counter that not everyone chooses to work, and that people are satisfied with their services. This alleged satisfaction is based on surveys conducted by the area agencies; Community Support Network Inc., the area agency's association; and the Department of Health and Human Services (DHHS). The data from those satisfaction surveys may be only slightly more reliable than the former defense secretary's assessment of the Iraq war. The truth is New Hampshire has strayed far from the vision of what we used to think was possible for our citizens with disabilities.

Residential Services leave much to be desired. Enhanced family care, New Hampshire's primary housing model, has many advantages over staffed residences. However, family care providers have not received an across the board rate increase in more than a decade, making it increasingly difficult to attract and retain qualified providers. In addition, enhanced family care is not ideal for everyone, particularly those with significant behavioral challenges or more complex needs, yet few other options are available. Too frequently, people bounce from one enhanced family home to another or land in more restrictive settings such as New Hampshire Hospital or nursing homes. Other individuals remain in their family home past the time that their parents can adequately care for them, putting themselves and their families at great risk. As recommended by the Governor's Commission, rate increases and more options are needed.

The more specialized or complex needs of many individuals are not being met. People who are aging or have significant behavior, communication, sensory, or assistive technology needs are not being well served. This is due in large part to the reduced use of qualified professionals and lack of support for staff training. While funding again is an issue, there also seems to be a philosophical belief among some that it is not the role of the area agency system to provide these professional services. Whatever the reasons, there is a substantially diminished use of speech and communication specialists, occupational therapists, physical therapists, behavior specialists, learning specialists, mobility experts, trained job coaches and developers, and those with expertise in working with the individuals who are deaf and blind. The following are examples of this decline in professionalism.

- ◆ Providers are now hiring young high school graduates or under-qualified or under-trained people to do job development and job coaching. This is in contrast to twenty years ago when providers hired trained college graduates for these positions and paid them teacher level salaries.
- ◆ The DHHS "Duals Team" is no longer in existence. This was a group of professionals who assisted providers and area agencies in addressing the needs of people with dual diagnoses of mental illness and developmental disabilities.
- ◆ From 1998 to 2003, there was a 450% increase in the number of individuals with developmental disabilities admitted to the state psychiatric hospital in Concord (this number continues to remain high). Given that hospitalization costs five to ten times more than community services, this is a very expensive approach to serving those who have dual diagnoses.
- ◆ The so-called "DD forensic issue," – mandating services for individuals who are a threat to others – is a frequently used (and exaggerated) excuse for many of the ills in the system. The forensic issue is in large part the result of a lack of capable professionals to address the needs of this population and thus prevent potentially dangerous behavior.
- ◆ A review of DHHS data shows that a major factor in abuse and neglect is due to untrained staff attempting to address needs of individuals with behavioral issues.

Respite and in-home supports are woefully inadequate. In most regions of the state support for both families and for enhanced home providers remains meager, illusory, and highly variable. This creates untold stress on families and their members with developmental disabilities. Investment in this service makes economic sense as it enables families to continue in their role as primary care givers. In the long run, inadequate respite care not only has negative consequences for individuals and their families; it also results in more, not less, costly services.

In short, the paucity of professionals and professional services means that many peoples' physical or emotional health or functioning is not being maintained; they are more susceptible to abuse and neglect, and are prevented from leading independent, productive, or enriching lives. These consequences affect not only the individual, but in the short and long term are more costly to society. Reacting to a crisis is almost always more costly than a proactive approach, emphasizing increased function, independence and productivity of individuals by definition is better social and economic policy.

More information about the current state of the developmental service system can be found in the report issued by the Governor's Commission on Area Agencies, on the internet at <http://www.drcnh.org/AAstudycomm.htm>.

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him. Without that continuity it's tough." While David has a couple of consistent support workers, finding and keeping good staff is a constant struggle. "I think a lot of that has to do with the salary, frankly," Susan said.

She related another incident where a Center of Hope staff member who worked in David's residence called to let her know that David had a psychiatrist's appointment that morning. Susan had asked the agency to give her advance notice of David's appointments so that she might attend them. Even though he had worked with David for several months and was his primary contact person, this employee seemed unaware that Susan lived out of state and would need more than a few hours notice.

In this same conversation, the employee casually mentioned that David had a cold. Worried about her brother's tendency to febrile seizures, Susan asked if his temperature had been taken; it had not. The employee, who seemed unaware and unconcerned about David's potential for seizures, suggested that the psychiatrist could take David's temperature when he went to his appointment.

"A lot of David's medical issues have been as a result of not being on top of things. We're always reacting to a situation with David," she said. In one of her regular calls to his residence Susan was told a staff member had filed a complaint against another Center of Hope employee in an incident involving her brother. David had wanted to stay in bed; the staff's response was to get him up and take away his bedding. David reportedly spent the day yelling for his sheets. Susan was concerned that not only was she not told about problems with her brother until after the complaint was filed, but that residential staff hadn't considered that David's behavior might be an indicator of a physical problem. Now, if he's not getting out of bed or shows signs of illness, Susan makes sure someone is paying attention. What she really wants is for David's behavior "to send a red flag to the staff, not just to me."

With the transition to a new area agency, David's services have begun to improve. Susan said she is feeling more optimistic. "I'm beginning to be able to call and not dread who I'm talking to or the runaround I'm going to get." She added, "I don't mind being David's guardian at all, but I'm looking forward to being his sister again."

It is tempting to conclude that David's problems stemmed from one troubled agency. Unfortunately, many of the factors contributing to David's poor services – high staff turnover, lack of staff training, and inadequate supervision – exist statewide and are endemic to the current developmental service system.

The Institute on Disability Seeks Input and Ideas

For nearly 20 years, the IOD has worked to realize a future where *all* people – including those living with disabilities – are fully engaged members of their communities. To guide us in this work, the Institute depends upon direct input from individuals with disabilities and their families and advocates. The IOD's Consumer Advisory Council helps to establish the priorities for our organization and participants in the Leadership Series and other IOD trainings provide feedback on how we can do a better job. We invite the readers of the RAP Sheet to share their thoughts on the work we do and to offer ideas to help us carry out our mission of strengthening communities and ensuring equal opportunities for all persons. We hope that you will take a moment to complete the IOD's *Consumer Satisfaction Survey*. The survey is available online at www.iod.unh.edu or you may request a hard copy by calling the IOD at 603-862-4320 or emailing – contact.iod@unh.edu. We would be happy to mail you a survey.

BUILDING A PERSONAL NETWORK

Marlyn Curtin, Board President and Joyce Johnson Ninness, M.Ed., Director Future Planning Networks of New Hampshire

"The only disability is having no relationship at all."

— Judith Snow

The Future Planning Networks of New Hampshire (FPN-NH) was established in 2003 by a group of concerned families who asked themselves, "What will happen to my relative after I am gone?" As parents of children with disabilities many of us never ask this question; we are living in the now and not looking too far into the future. In reality the future is now.

Future Planning Networks is modeled after PLAN Canada (Planned Lifetime Advocacy Network). Our mission is to assist families in developing a safe, secure, and valued future for their relatives with developmental disabilities. We accomplish this through the building of a personal network.

A personal network is a group of community members who are committed to enhancing the quality of life for the individual with a disability now and in the future. Our approach focuses on the assets of the individual and utilizes a paid network facilitator, a local person from the community who works with the individual and the family. Before a network is brought together, the facilitator spends time with the individual gaining a better understanding of the person's special gifts and interests. Then, with support from the FPN-NH, the facilitator works with the individual and the family to find people who will become part of an on-going network. In our process, the facilitator does the "asking" or the inviting of people to join an individual's network.

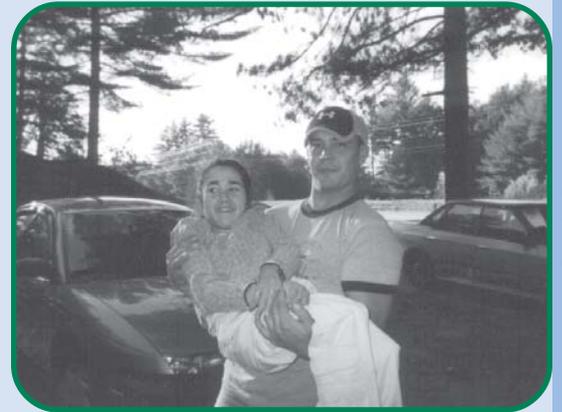
A strong personal network can provide an opportunity for growth and the infusion of new energy into the individual's life. Parents and families are able to relax knowing that their loved one's future is supported by a network of caring and responsible people. Future Planning Networks of New Hampshire makes a lifetime commitment to maintain the networks of its members. Over time, a personal network often takes on a life and direction of its own; the facilitator is responsible for providing support and making adjustments as an individual's network grows and changes.

Why is a personal network so important? What impact does it have on an individual who lives with a disability? Without a network, individuals may have an array of services, but still find that there is a void in their lives after "business hours." Too often we have seen our family members sitting at home in front of the TV because there is nothing else to do. Haven't we all wished that our family members had friends who would call and ask, "Want to go to the game tomorrow night?" or "Do you want to see the play on Saturday?"

Personal networks help individuals with disabilities to make connections outside their immediate families or paid staff. Through their personal networks, individuals are able to expand their relationships beyond those that have been organized by their families. Individuals with personal networks have increased opportunities to meet new people, try new things, and most importantly to have fun. We have found that individuals with strong personal networks have fuller lives and increased self-esteem.

In creating a personal network, the facilitator first gets to know the individual and then introduces the person to others who share common interests. With this approach, there are opportunities for *real* relationships to develop. People are able to establish mutually fulfilling friendships and experience the joy that comes

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Jocelyn Curtin and Dan Skoog on their way to a family picnic. The Skoog family is part of Jocelyn's personal network.

A Good Life for Cory

Cory B. Pierson



Cory Pierson gets ready to go horseback riding.

My son Cory Pierson describes himself as a “handsome, tall, lean, strong as an ox, intelligent young man of 25 years.” On any given day, you may find him working on his computer, taking photographs, horseback riding, sailing with me, hanging posters at the NHTI campus, or having a beer in a local watering hole. Cory has been using computers since he was two when he learned to use a voice synthesizer to assist his speech. Based on his experience Cory has written a book, complete with his own photographs, showing how leg braces are made. Concord Orthopedics supported this work and they still use Cory’s book to help their young patients who use braces.

Cory and his family have always expected he will have a good life. Because he has developmental disabilities, Cory depends on other people to assist him. Good quality services are essential for Cory to have a good quality life. Cory grew up in Bow and throughout his schooling he was included in regular classes. He had a wonderful time in high school, but with the transition to adult services, things got trickier.

Cory was on the waiting list for services from Community Bridges, the area agency serving greater Concord. In the meantime, Bow High School worked with the Department of Vocational Rehabilitation Services, to hire a vendor agency to help Cory find employment after graduation. When this was not successful, Cory and his supporters – including his family, his school team, and Vocational Rehabilitation (VR) – worked very hard to develop a creative plan for a small business for Cory. With funding and support from VR and his parents, Cory hired an assistant and opened his business, *e-Magine With Cory!* Together, Cory and his assistant developed a website, taught computer courses, provided workshops, operated a photography business in nursing homes, and helped seniors keep in touch with their families via e-mail. For a year and a half this was a very successful arrangement; then Cory’s assistant moved on. She proved irreplaceable, and the business slowly declined.

Due to a change in our family’s circumstances, developmental service funding became available and Cory started receiving “traditional” adult services from Visions, a spin-off of Community Bridges. The quality of Cory’s days went downhill. Support staff came and went. Some did not understand Cory and his needs; I later learned that one staff member had been verbally abusive to Cory. His days were mostly unproductive and unmotivated.

Setting Your Own Direction

Sue Fox, M.Ed., Institute on Disability

Individuals with disabilities often feel they have limited control over their lives and few opportunities to exercise choice in matters like how they spend their days, where and with whom they live, and how they spend their leisure time. Self directed services, those managed by the individual and/or his or her representative, significantly increase both the control individuals have over their services and the number of choices they can make in their day to day lives.

Self directed services not only enhance individuals’ choices in selecting their service providers, individuals and/or their representatives also can decide who to hire, how staff are trained, and where and when services are

provided. Individuals may hire friends, neighbors, or family members as long as they meet basic provider qualifications. In New Hampshire all area agencies for developmental services provide the option for self directed services and all services provided under the In Home Support Medicaid Waiver for Children with Developmental Disabilities must be provided through a self directed model. Some area agencies have embraced this model more strongly than others and offer a formal structure for individuals and families to direct their own services. The Area Agency of Greater Nashua has established a Customized Services Department within their agency and has found this to be the fastest growing segment of their business. Families and individuals are embracing the opportunity to self direct their services.

Cory started getting headaches and dreading getting up in the morning. Pretty soon, he was refusing to go to "work." He became depressed.

On several occasions, Cory, along with his mom and I, met with Visions and Community Bridges to let them know that he wasn't happy with his services. Nothing seemed to change. While I was discouraged, I was not defeated in my efforts to obtain good quality services for Cory. I learned about Planned Lifetime Advocacy Network, a group of families whose vision is "a good life for all people with disabilities and their families." With encouragement and support from Future Planning Network of New Hampshire, I traveled to Vancouver for a weeklong workshop and came back inspired.

Cory and I sat down and hammered out the document, "A Good Life for Cory." In this document, Cory described his vision of a good life and included photographs, quotes, interests, and strategies to guide those supporting his quest. He even drew up a typical week's plan of activities including social events and opportunities for personal growth and skill development. Cory clearly stated his intent to be a contributing member of his community.

In April 2006 we went back to Community Bridges with Cory's new plan. They eagerly agreed to support this plan under "Client Directed Services," an option that allows the family to directly manage their child's program and funds. It all sounded wonderful. But then we waited. And waited. Community Bridges kept promising the program would start next month. Cory, who lives with me, meanwhile had no program and I was missing a great deal of work in order to support him. I met with the director of Family Support and told her, "If you want to give this family 'Family Support,' then you get this program going."

At the 2006 Family Support Conference, I networked with other families, and learned that it was possible to switch Cory's services from one area agency to another. In August Cory and I began a dialog with the Area Agency of Greater Nashua and by September 1st this agency had in place a new Adult Custom Service plan for Cory. We were pleasantly surprised and pleased with the new plan. Nashua was completely open with us. They described the pros and cons of the various service plans, explained how their overhead is allocated, and showed us what we needed to do, which turned out to be minimal, as we had already done most of this work with the writing of "A Good Life for Cory."

Finally, Cory has the supports and services that he needs. When Cory was asked what he has learned from this journey so far, he replied, "What I would say is don't be afraid to speak up." We can all benefit from his spirit and words.

Area agencies offer an "Agency with Choice" model for those interested in self directed services. An Agency with Choice provides a wide spectrum of services including fiscal management and payroll services. An individual may choose to receive any range of services from the agency (with greater cost associated with greater support needs). These services might include person centered planning, assistance with developing and managing an individual budget, assistance with arranging for and monitoring formal and informal services, and support and training on how to be an employer. In addition, an Agency with Choice serves as the Employer of Record for all staff hired by the individual and provides a full range of payroll services, including withholding state and

federal taxes, issuing pay checks, filing IRS and Department of Labor forms, and providing worker's compensation insurance.

Self directed services provide greater choice and control to individuals and their families, but with this freedom and authority comes greater responsibility and accountability. In their role as key decision makers, individuals and their families must assure that they are utilizing federal and state funds appropriately and effectively. Research has consistently shown that individuals who self direct are highly satisfied with services, receive the services they need, and show positive health outcomes. Self direction is not for everyone, but it is an important and popular option for many.

Quality Matters in Mental Health – Better Days Ahead, Maybe

Ken Braiterman, NAMI NH Advocate for Recovery-Based Mental Health Services

In a year or less, Governor John Lynch will have the opportunity to nominate a new Health and Human Services Commissioner. New directions, ideas, and priorities in mental health services can start to emerge.

The current commissioner is reported to be considering a youth suicide prevention program. In New Hampshire, suicide is the second leading cause of death, after accidents, for people between 13 and 25. Data shows that involving whole communities in suicide prevention, not just the schools and mental health centers, saves lives. That would be a valuable legacy from a commissioner, who has presided over a mental health system that, on his watch, has gone from one of the best in the country to a grade of D in the 2006 State Ratings Report from the National Alliance on Mental Illness (NAMI).

The Bureau of Behavioral Health (BBH) is a demoralized shell compared to five years ago. "We used to think we were on the right track. We were aware of our frustrations and shortcomings internally, but we could hold our heads up when we went to other states. Today, there are nine vacant offices along the hall near my office," says one long-time employee speaking on condition of anonymity.

One of those vacant offices is the Office of Consumer Affairs. For years, passionate anti-bureaucrats promoted "radical" ideas that today's mental health professionals now consider mainstream. They helped create programs that gave people hope and taught them the skills they needed to achieve their goals, increase their independence and sense of self-worth, and improve the quality of their lives. The consumer-run peer support centers they created, and the "culture of recovery" they embedded in the state's mental health system, are the two things the NAMI report said New Hampshire could still be proud of.

For me, the test of new leadership in mental health will be how the bureau chief will resuscitate the Office of Consumer Affairs and deal with a state Mental Health Consumer Council that is re-emerging as a statewide advocacy group. Will BBH welcome creative tension to ensure New Hampshire continues moving towards a mental health system that helps people get well and stay well, instead of being maintained? Or will they expect consumers to know their place and accept whatever the system gives them?

In recent years, the ten community mental health centers (CMHCs) have gone through a generational change. Three new executive directors have replaced people who spent their lives creating a system other states envied, a system they tried their best to sustain intact even as resources dried up. Three new players in a group of ten hopefully will create opportunities for the out-of-the-box thinking the system needs now.

One positive move by the CMHCs' is their adoption of "evidence-based practices." Pioneered in the 1990s, this initiative was led in New Hampshire by the Dartmouth Psychiatric Research Center and this year is being phased into the state's mental health system. The practices – dual diagnosis treatment, medication management, supported employment, family psycho-education, and illness management and recovery – while imperfect, are more recovery-friendly than what the CMHCs offered before. This year, the system is implementing supported employment and illness management and recovery practices.

However, no new "practice" can help anyone unless the CMHCs act *NOW* to reduce turnover among their clinical staffs, without waiting for the Legislature to give them more money. There are CMHC clients who have had five therapists in two years and others who see a different doctor every time they go for a 15-minute appointment. Nobody can get well with an unstable therapeutic relationship. In a rapidly changing profession, the state has stopped providing continuing education, while clinicians' caseloads and billing quotas have increased – for insulting salaries.

The CMHCs absolutely need more money. But why do they need ten accounting departments, ten incompatible computer systems, ten offices to bill Medicaid, ten health and liability insurance policies, ten human services departments, and executives to manage each department? How can they afford one of the most expensive corporate lobbying firms in the state to tell the Legislature how poor they are? To get the money they need, they must show the Legislature that every new dollar will go to patient care, not corporate infrastructure.

New Hampshire's peer support centers offer a model for making the most of every dollar. Several peer support centers have merged their corporate functions; there are fewer executive directors and program directors, fewer state contracts to maintain, but their services have not suffered. Doctors have consolidated billing, accounting, and other administrative functions, networked their software, and actually seen services improve. Thoughtful, incremental movement in this direction is the kind of creative thinking CMHC directors should work on. BBH should encourage and facilitate it.

In another arena, New Hampshire must consider how it will handle offenders with mental illness. After choking community mental health services for years, we now find ourselves in a situation where one in five inmates in state prison (almost one in three if you count people with personality disorders) has a severe mental illness. About half the county jail population has mental illness. On a typical day at our Youth Development Center, more than half the children have a mental illness or an emotional disorder.

There is a growing consensus that we should be treating these people, not incarcerating them. Judges, corrections departments, and police are looking for ideas, money, and removal of bureaucratic obstacles. As NAMI NH's specialist on "courts, cops, and corrections," I see this ferment building.

One promising approach is "mental health court," where people arrested for minor crimes can – if they choose – be sent to treatment instead of to jail. In New Hampshire, Keene and Nashua currently offer this alternative. These programs raise human rights concerns because they can force a person to choose between invasive medicine and incarceration. Keene and Nashua are trying to address these concerns by keeping the defense attorney involved in every stage of the treatment. With these courts springing up fast around the country, many are calling for extensive studies and development of best practices. My opinion: We should not keep sending people to jail while we gather data and wait for Supreme Court rulings. Jail is too damaging to people with mental illness. We'll just have to learn to do this from experience.

Jail diversion for people with mental illness is a smart use of public money, not just a humane one. Early national data indicates these courts do reduce the expensive cycle of arresting, trying, and incarcerating the same people for petty crimes over and over again. Shoplifting, vagrancy, trespassing, threatening, simple assault, and vandalism – the main offenses mental health courts hear – cost society more than just the cost of law enforcement.

Another idea under discussion at our Department of Corrections, and at least one county jail, is a separate unit in the institution where people with mental illness can live and learn recovery skills, as well as take their medicine. Other programs would offer support and counseling to inmates after release. Many releasees need psychosocial help, but do not meet the strict qualifications for treatment at a CMHC. Other groups, like NAMI and peer support centers, will have to partner with the state to help keep these people out of prison. The state prisons are under court order to move in this direction.

These are just a few ways New Hampshire can make things better for people with mental illness. But if we do nothing, or just throw extra dollars into the existing system without new ideas and stronger leadership, it will continue to get worse.

The Need for Effective Employment Supports for New Hampshire Residents Living with Disabilities

Peter Antal, Ph.D., Institute on Disability, UNH

New Findings from the Access New Hampshire Project
(<http://www.iod.unh.edu/AccessNH/accessnh.html>).

New Hampshire citizens with disabilities have the potential to be valuable members of the state's workforce. Unfortunately, too many of these individuals are either shut out of the job market completely or do not receive the supports they need to maintain employment. According to the 2005 American Community Survey approximately 53,000 New Hampshire residents age 16-64 identify themselves as having some form of employment disability.¹ Among this group, only 24% were employed as compared to 81% of those who do not have disabilities. The 2006 Granite State Poll found one of every 25 New Hampshire residents has a disability² AND has left a job due to a lack of necessary support. In the North Country the likelihood of a person to have a disability and leave their job due to a lack of appropriate supports is one in eight.

A review of employment documentation from New Hampshire's Department of Vocational Rehabilitation Services (VR), the Bureau of Developmental Services in the Department of Health and Human Services, and the Social Security Administration (SSA) provide important background for better understanding the employment situation for New Hampshire citizens with disabilities.

(Continued from page 9)

from spending time with someone who knows you well and shares your interests. The relationships in a successful network – as is true of most relationships – may take several months to develop. It takes time for people to get to know one another and share the same level of comfort and ease.

Innovation Facilitators (IF) *is a technical assistance resource provided by the **Institute on Disability at the University of New Hampshire**. IF*

promotes excellence in person-centered planning through the support of practitioners, persons with disabilities, families, and personal support teams. For more information visit the Institute's website at:

www.iod.unh.edu/projects/if.html

While parents could provide the same "service" as Future Planning Networks and facilitate relationships, we have found that most parents are not comfortable inviting others to be a part of their sons' and daughters' lives. It also can be difficult for family members to provide the level of initial support that is needed for relationships to develop and become self-sustaining. During the critical early stages of the network, the facilitator keeps members connected and involved. FPN-NH supports these growing networks, provides training to the facilitators, offers ideas, and works behind the scenes to grow the network. We also provide parent training and workshops.

If you would like more information about Future Planning Networks of New Hampshire please email us at director@futureplannh.org, visit our website www.futureplannh.org, or telephone our office at (603) 271-8948.

Marlyn Curtin is President of the Board of Directors Future Planning Networks of New Hampshire, her daughter, Jocelyn, is a lifetime member and is enjoying the benefits of a growing network.

Joyce Johnson Ninness, M.Ed. is the executive director of Future Planning Networks of New Hampshire and would love to discuss your child's future, contact her today.

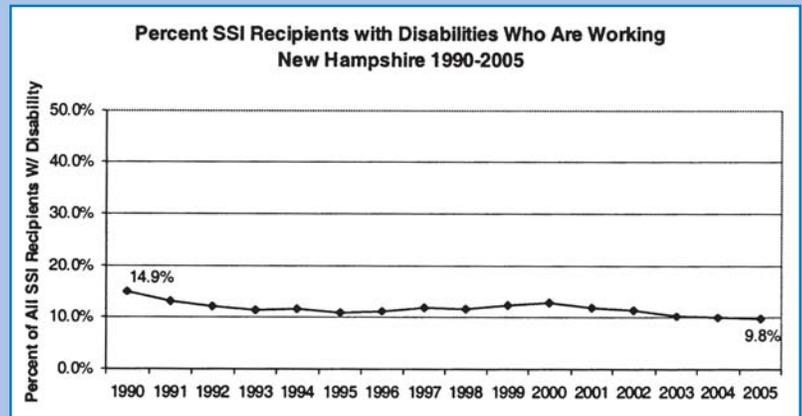
"The disparity in life experience between Americans with and without disabilities may be greater in the area of employment than in any other sphere of life."

— National Disability Policy

1) Work participation among individuals with disabilities receiving Supplemental Security Income (SSI) has dropped over time. Information from the Social Security Administration for New Hampshire shows that the percent of individuals receiving SSI who are working has dropped substantially from 15% in 1990 to 10% in 2005. In spite of support from MEAD (Medicaid for Employed Adults with Disabilities) and other innovative programs, individuals with disabilities receiving SSI are less likely to be employed than they were four years ago. It is critical to gain a better understanding of this situation and develop strategies to reverse this disturbing trend.

2) Length of employment has decreased. The state's Bureau of Developmental Services has found that, while a strong majority of individuals with developmental disabilities who receive services through the area agency system have been able to sustain employment for at least 12 months, this majority has been dropping over the last few years from 89% in 2003 to 81% during the first half of 2006.³

3) Reliance on the welfare system continues to be a major challenge. VR regularly collects information on the proportion of participants who indicate a shift in their source of income from a primary reliance on welfare support to primary reliance on wages. While some success has been shown in this area, change has been slow with only 48% of VR participants in FY 01 and 54% in FY05 indicating that wages



are their primary source of income. Reasons for this include the lack of access to information about work incentives offered by disability programs, the highly individualized nature of each person's benefits profile, inconsistency of employment, absence of a benefit "safety net," and financial disincentives that are built into some benefit programs.

4) Average income received by individuals with disabilities falls far short of a livable wage. New Hampshire residents receiving VR services have seen their average weekly wages drop from \$342 in FY01 to \$318 in FY05. Earnings for individuals with developmental disabilities are significantly lower, with average wages amounting to only \$5.91 per hour for individuals served by the Bureau of Developmental Services as of June, 2006. Fifty-eight percent of New Hampshire residents receiving these services are working ten hours a week or less with an average wage of \$59 per week. Based on the 2006 New Hampshire's Basic Needs and Livable Wage study, the estimated livable wage⁴ in New Hampshire for a single person is \$10.42 per hour or \$417 per week. For a person supporting even just one family member, the average hourly and weekly wage necessary for the family's well being jumps to \$16.95 per hour and \$678 per week.

Clearly, New Hampshire needs to be doing more to ensure that people with disabilities have the opportunity to become productive members of the workforce. The state's system of employment supports would benefit greatly from innovative approaches for job placement and support for workers with disabilities. Establishing a public policy that makes long-term employment of individuals with a disability a priority is long over due.

¹ In the 2005 ACS, employment disability is defined as "Because of a physical, mental, or emotional condition lasting 6 months or more, the person has difficulty working at a job or business"

² In the 2006 Granite State Poll, employment disability is defined as "Do you have a condition or disability that affects your ability to find employment?" About one in ten across the state and one in five from the North Country agreed with this statement.

³ Similar information from VR is not available due to legislative restrictions which caps the amount of time a person can be followed up on to three months post employment.

⁴ The amount an individual would need to pay for the basic necessities of life such as: food, rent, utilities, basic telephone services.

STILL AT HOME

Julia Freeman-Woolpert, Disabilities Rights Center

Joyce Provencher is part of a large and close family. Now 49, she lives at home with her parents Lucille and Gerard in West Manchester. She has known the neighbors for years and with their church and stores nearby, it's easy for Joyce to get out on her own. Joyce is happy where she is living.

Twenty years ago for a period of two years Joyce lived away from home. Except for that time she has always lived with her parents. Even though the Provenchers are getting older, the family has made no definite plans for the day when they can no longer care for Joyce. She may go live with her sister in Maine or perhaps with another sister who lives in Windham.

Joyce received services from the Moore Center in the past. Joyce's guardians, her mother and sister Teri, have not contacted the Moore Center recently for help with services or to plan for Joyce's future living arrangement. The family's earlier experiences working with the service system to find a program where Joyce could learn independent living skills were not successful. "Whenever I've looked they've never had anything that worked for her. They used to tell me that she falls between the cracks. She's too smart for this and not enough for that." Joyce, herself, isn't keen on receiving services from the Moore Center, which she sees as stigmatizing.

When she was 30, Joyce tried moving out of her parents' home. Though it was the era of group homes, the Moore Center advised the family that Joyce was too capable and wouldn't fit into a group home. Instead she went to a transitional residence run by Easter Seals, to learn how to live independently. She was going to learn how to cook, do laundry, and grocery shop; none of those things happened. Lucille believes that the program was too advanced for her daughter and that Joyce's skill level had already peaked. With the program's constant staff turnover, Joyce actually lost skills.

From the transitional residence she moved to Washington Manor, a boarding house for elders and people with disabilities. The Provenchers



Joyce Provencher with her parents, Lucille and Gerard.

were hopeful that it would be a good fit for their daughter, but that situation also deteriorated. Lucille remembers Joyce coming home for a family gathering. "She wasn't herself," said Lucille. Joyce who is usually gregarious and fun loving sat off by herself, avoiding the rest of the family. When Lucille asked her what was wrong, Joyce replied, "I'm used to being alone now." With Joyce lonely and unhappy, her parents brought her back home, where she has been ever since.

While Joyce is friendly and enjoyable to be around, she does not have many friends or take part in many activities. For many years she worked as a dishwasher, but an arm injury three years ago put an end to that. She now receives Social Security benefits and volunteers at the VA Hospital with her father. That injury along with the subsequent surgery, left Joyce much more fearful and preoccupied about her health. Joyce also becomes very anxious and concerned if her mom is unwell, even if she only has a simple cold. Lucille finds it hard to get any privacy or time to herself.

One of the few breaks Lucille gets is when Joyce volunteers at the VA. "The VA is a Godsend," Lucille said. The Provenchers tried using respite services in the past, but their workers kept leaving and Joyce constantly had to adjust to new people. Ultimately, the family decided it wasn't worth the effort.

Lucille Provencher would like to say something positive and encouraging to other parents who have a child with a disability. She would like to be able to say that it gets easier with time, but that hasn't been the reality for her family.



Why I Am Moving

Kathy Bates

I love my house. I live in a great neighborhood and have wonderful neighbors, but I am moving because I don't always have reliable personal care services. There are times I don't feel safe in my own home. I'm moving back to my hometown to be closer to my family. I know that in an emergency my family will be there for me.

I have been in a situation where my care attendant failed to show up for her evening shift. I had to go to my neighbor, who at the time was a complete stranger, and ask for help. I had not been able to go to the bathroom for 12 hours and I would not have been able to go to bed. I was lucky that my neighbor had some experience in personal care assistance and was able to help me. This was not the only time that something like this has happened to me.

I have always been a strong, articulate advocate for myself and others, but at times my life is consumed with just trying to get my personal care needs met. Basically my life stops until I can get out of bed and that doesn't happen without personal care attendants. I work for People First and the Institute on Disability, when my personal care attendants don't show up it means I'm unable to be the reliable employee that I have always been. How can I do any job if I'm stuck in bed? I want to work like everyone else. I really want to teach again and to be able to work every day. I want to be able to say, "Yes I can do the job." and mean it. But that hasn't always been possible.

I know that I am not the only one in this situation. There are many reasons why employment is a tough issue for people with disabilities. One of the main reasons is that people are afraid that they will let potential employers down if they are unable get to work. It is not at all like calling in sick, because you're not. You just cannot get out of bed. It's frustrating.

Direct support is not like other work, it's not like punching a cash register; almost anyone can do that. It's about giving the person who needs assistance dignity and independence. A personal care assistant helps you with what you cannot do; for me that is bathing, toileting, and getting dressed. Most attendants do this work part time and the hours are inconvenient. People need assistance really early in the morning and late at night. It is not a typical job where employees work an eight hour shift. This makes it difficult to find personal care attendants. There is not often overtime work and because the pay is so low, most attendants need more than one job to survive. In most cases attendants are paid less than \$10 an hour and do not receive benefits.

New Hampshire needs a statewide back up system for direct supports, a place that people who have disabilities can call if their support worker fails to show up. It would be a dream come true to have all the organizations that provide direct support come to the table to figure out this critical issue. We need to create a system where you could call a toll free number and talk with a real person who could connect you with an attendant in your community who could provide direct support when it is needed. Developing a personal care provider network that is similar to New Hampshire's transportation collaborative could be the solution. It would be good for everyone; workers could get more hours and people with disabilities would get their needs met.

Even though my family is there and willing to help, I feel it is a strain on them to have to be my backup support. I want my family to be my family, not my caregivers. I just want to be Kathy, not the one who always needs something.

**The RAP Sheet is a free quarterly publication; to subscribe please contact
the New Hampshire Council on Developmental Disabilities
603-271-3236**

When I Call, Who Will Answer?

Terry Lochhead, Coordinator NH LEADS (Leadership, Education, and Advocacy for Direct Care and Support Staff),
a program of the NH Community Loan Fund

After Mary Lea Kendall's mother, Katherine, had a stroke, the family's life began to revolve around direct-care workers. Three days a week, just after Mary Lea and her husband leave for work in one car, a health aide drives up in the family's van to help Katherine get out of bed, bathe, dress, and get to physical therapy. On alternate days, a personal care services provider from another agency provides backup.

"Without these direct-care workers, Mom would not be able to exercise and maintain her mobility," says Mary Lea. "But it all unravels pretty easily. One of them has to hold down several jobs to make ends meet and the other has a lot of car problems. It's not easy to find someone to fill in for them."

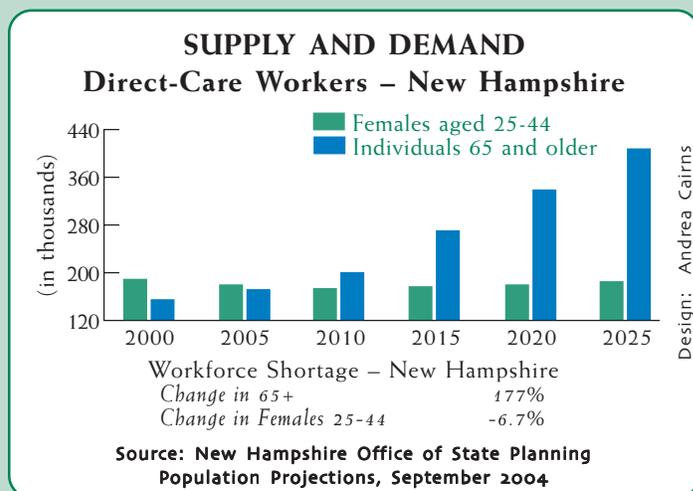
Direct-care workers provide 8 out of every 10 hours of direct support services to people who are elderly or have disabilities. They also form a crucial support system for families who provide hours and hours of unpaid support to loved ones. But many families are beginning to ask, "When we call for assistance in the future, who will answer?"

Annual turnover among direct support professionals in New Hampshire's Developmental Services System approached 50% in 2003. In its 2006 report on eldercare, New Hampshire Employment Security predicted there may be a supply and demand problem if nothing is done.

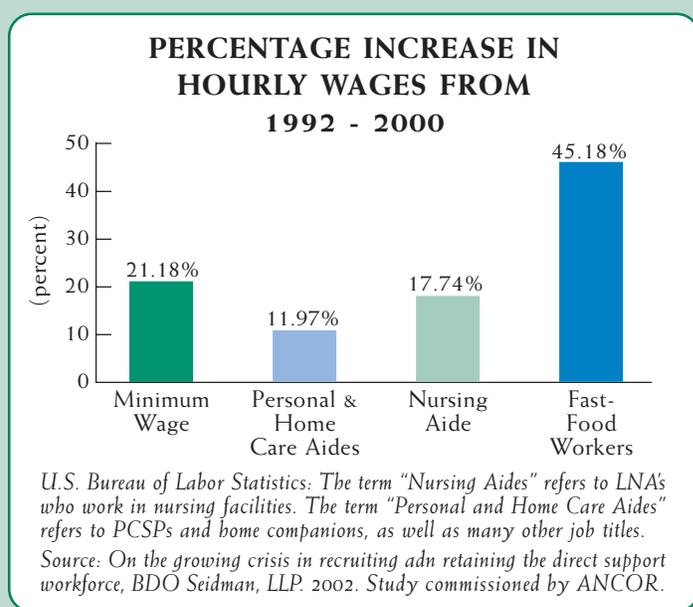
Part of the challenge is demographic. The number of persons with disabilities is growing in New Hampshire. Due to medical advances, more children with disabilities are living longer. More people with disabilities are also living at home. And more children are born with autism.

At the same time, older New Hampshire residents will soon need more direct care workers. Over the next two decades, the number of people in the state who are 65 years old and over will nearly triple. By 2030, the number of citizens 85 and over will double. Simultaneously, the New Hampshire Office of Energy

and Planning projects a 6.7% decline in the age group that has traditionally produced direct care workers – women 25-44 years old.



Another part of the challenge is pay, benefits, and career options. It is difficult to attract today's worker for a field with low pay, few benefits, unstable hours, and isolated, demanding work environments. According to a 2002 study by BDO Seidman, LLP for the American Network of Community Options and Resources (ANCOR), wages for fast food workers in the United States are rising faster than wages for home and personal care aides and their benefits are worth three and a half times more than those for personal care aides.



Employment Security reports that wages for New Hampshire's home and personal care aides are among the lowest in New England. For 2004, average wages for these New Hampshire workers were \$9.03 an hour. Crossing guards make more.

Direct-care workers are leaving their jobs because they cannot live on \$9.03 an hour. This is especially true of employees who are not their client's relative. UNH's Office of Economic Initiatives and the North Country Council just released a study, *New Hampshire's Basic Needs and Livable Wage, 2006*, which estimates \$10.42 an hour is a livable wage for a single person. When there are two working adults in a three-person family, the livable wage drops to \$10.10 an hour, but that is still about a dollar higher than the average wage for a home or personal care aide in New Hampshire.

Even if aides make a "livable wage," the term is a misnomer, according to Michael Hill, president of the New Hampshire Hospital Association. The "living wage" quoted in the UNH study is actually a subsistence wage, he says. It does not include any savings for further education or a rainy day. The "living wage" is the bare minimum needed to survive day-to-day.

Wages are not the only factor involved in recruiting and retaining workers, according to the Paraprofessional Healthcare Institute. For experienced workers to commit to a career in direct care and support, they must have training, support, and career options available.

Consumers not only want an experienced workforce; they also want and need a consistent and reliable service. Consumers repeatedly state that they want to know who is coming into their home, and they want to be able to depend on that person arriving at a set time. Reliability means the person the consumer trained shows up every time they need assistance; it is not a round robin of strangers coming through the door.

In Nashua, 94-year old Edith has dimming eyesight due to macular degeneration, but she is still living independently. Jenn Craigie is the Home Health Aide who assists Edith with bathing, dressing, exercise, and housework. The two have forged a firm partnership. They are in the middle of creating a window garden for Edith, and they share many memories. At home, Jenn reads the newspaper so she can keep Edith

in touch with current events. As the beneficiary of growth opportunities provided by her employer, Quality Care Partners, Manchester, Jenn considers direct care her career and has no plans to leave.

That is what Edith's daughter, Jeanne Holt, of Hollis, wants to hear. "It works better for Mom if it's the same [direct-care worker]. It's exhausting for her to explain [to a series of strangers] where to put the laundry or how to find the broom. Mom would rather stay home alone than tell a stranger what to do."



Jeff Forester

Jean Holt of Hollis, and her 94-year old mother Edith, share a laugh as they describe the good times Edith has had with her direct-care worker, Jenn Craigie.

The road to enabling older citizens to age in place and people with disabilities to live at home must be built on a strong direct-care workforce. Senior citizens and people with disabilities are counting on such a workforce, but they are not alone. A growing number of families are also counting on it and business assumes this strong support system will be available to help retain experienced employees, as the total workforce grows older and leaner. Creating a quality direct-care workforce is important for us all, but to be effective, we need to start now.

Do you have a story about your experience with direct-care workers? Please write Terry Lochhead at the Direct Care Workforce Initiative (NH Community Loan Fund) at tlochhead@nhclf.org or mail it to her at 7 Wall Street, Concord NH 03301. To read more stories, visit www.nhclf.org and go to Programs/Economic Opportunity/Direct Care Workforce Initiative.



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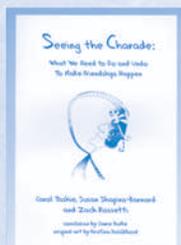
The Institute on Disability celebrates its 20th anniversary in 2007 with its annual outreach calendar, highlighting a shared dedication to community, diversity, and inclusion. Along with original artwork created by individuals who are connected to our mission, each month features inspirational quotes as well as projects and organizations that seek to increase inclusive community supports for people with disabilities and their families.



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SEEING THE CHARADE: WHAT WE NEED TO DO AND UNDO TO MAKE FRIENDSHIPS HAPPEN

By Carol Tashie, Susan Shapiro-Barnard, and Zach Rossetti

Price: \$25 (Book – 186 pages)

For too many students with disabilities, loneliness is their most common complaint. Despite our recognition of the importance of relationships and belonging, many students still do not have real friends and many of the strategies we use to solve this problem, not only fail, but actually make the situation worse. This book looks at the reasons why real friendship is such an elusive goal for so many students with disabilities and offers some suggestions and specific strategies on how to overcome these obstacles and how we all can support students to have the kinds of social lives they want and deserve.



LITTLE ONES HAVE BIG DREAMS TOO: A GUIDE FOR FACILITATORS

By Ann Donoghue Dillon, M.Ed., OTL

Price: \$10 (Booklet – 27 pages)

Person-centered planning begins with a committed group of people gathering to engage in an ongoing and creative process of planning for someone who needs extra support in the coming months or years. Person-centered planning is attractive to people who are seeking an innovative, informal, person-centered, community engagement approach to change as opposed to a more system-directed, formalized and regulated approach to planning for change. The targeted age group for the maps in this publication is children and youth through their early teens. Facilitators, parents, developmental services agencies, school systems, positive behavioral support teams, mental health teams, Head Start agencies, wrap-around teams and early intervention teams will find this publication helpful.

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Educating Students with ASD in General Education Classes: Fostering Academic Learning

Cheryl M. Jorgensen, Ph.D.

January 10 & April 11, 2007 4:00 pm - 6:00 pm

Educating Students with ASD in General Education Classes: Fostering Communication

Rae Sonnenmeier, Ph.D., CCC-SLP

February 12 & May 7, 2007 4:00 pm - 6:00 pm

Challenging Behaviors at Home and School

Ann Dillon, M.Ed.

February 13, 2007 3:00 pm - 5:00 pm

PECS & Augmentative Communication

Michael McSheehan

March 14 & June 13, 2007 4:00 pm - 6:00 pm

FACILITATED COMMUNICATION (FC): INTRODUCTORY TRAINING

In this workshop for new and beginning level facilitators, presenter Pascal Cheng, of Howard Community Services in Burlington, VT will cover topics that include: the history of FC, basic FC techniques, determining FC candidacy, and current research and best practices. Registration Fee: \$95

March 13, 2007

9am to 3:30pm

Institute on Disability, 56 Old Suncook Road, Suite2, Concord, NH 03301

METHODS, MODELS & TOOLS

Patty Cotton, M.Ed., Director, Innovation Facilitators and Pam McPhee, MSW, Director of the Browne Center lead an intensive, interactive 5 day course, designed to develop the competencies needed to facilitate consumer and family directed career, education, and life planning.

Registration Fee: \$800

March 23 & April 6, 13, 20 & 27, 2007 9:00 am - 4:00pm

April 6th & 20th will be held at The Browne Center in Durham, NH. All other dates will be at Community Campus in Portsmouth, NH

2007 SPRING SYMPOSIUM: RAISING EXPECTATIONS

Including ALL Children in Education

Workshops include:

- ◆ The Classroom Assistant's Role in General Education Classrooms
- ◆ Literacy Instruction for Students with Disabilities
- ◆ Asperger Syndrome and Social Inclusion
- ◆ Inclusive Recreation

Registration Fee: \$99

March 27, 2007

9:00 am to 3:00 pm

Center of New Hampshire, Radisson Hotel, Manchester, NH

WHOSE DECISION IS IT ANYWAY?

Training on legal issues for those who work with seniors Mary McGuire, Esq. presents a workshop to help those who work with seniors to understand the rules and laws around decision making. Participants will be able to describe who can, and cannot, make their own decisions as well as the legal documents that are required to give others decision making authority. Registration Fee: \$12

Two Dates and Locations to Choose From:

January 30, 2007

8:00am - 12:00pm

Best Western Hotel, Portsmouth, NH

March 29, 2007

8:00am - 12:00pm

E.F. Lane Hotel, Keene, NH

Resources

If you have concerns about services, the following advocacy organizations can help.

Autism Society of New Hampshire

PO Box 68, Concord, NH 03301

603-679-2424

Email: info@nhautism.com

Web: www.autism-society-nh.org/

Parent organization providing education, awareness, and advocacy

Brain Injury Association of New Hampshire

109 North State Street, Suite 2

Concord, NH 03301-4464

603-332-9891

Web: www.bianh.org/

Creating a better future through brain injury prevention, education, advocacy and support

Disabilities Rights Center

18 Low Avenue

Concord, NH 03301-4971

603-228-0432

Email: advocacy@drcnh.org

Web: www.drchn.org

The Krempels Brain Injury Foundation

Community Campus, 100 Campus Drive, Portsmouth, NH 03801

603-430-7668

www.krempelsfoundation.org/

The Foundation operates Steppingstones, a post-rehabilitation, community-based program for people living with brain injury from trauma, tumor or stroke.

NAMI New Hampshire

15 Green St., Concord, NH 03301

603-225-5359 or 1-800-242-6264

Email: info@www.naminh.org

Web: www.naminh.org

New Hampshire's voice on mental illness

Parent Information Center

P.O. Box 2045

Concord, NH 03301

603-224-7005

800-947-7005

Email: picinfo@parentinformationcenter.org

Web: www.parentinformationcenter.org

People First of New Hampshire

4 Park Street, Suite # 201

Concord, NH 03301

1-800-566-2128 or 603-568-2128

Email: peoplefirstnh@verizon.net

Web: www.peoplefirstofnh.org/

A statewide self-advocacy group

INTERNET RESOURCES:

THE AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES has a webpage with tips on how to complain about all sorts of things, from disability-related issues to lemon cars to telemarketers.

www.aapd.com/docs/complaints.php

APSE, formerly the Association of Persons in Supported Employment, provides technical assistance and education about supported employment, encourages service delivery based on sound values and ethics, and is actively involved in legislative and policy change for supported employment.

www.apse.org/

THE BEACH CENTER ON DISABILITY AT THE UNIVERSITY OF KANSAS, a rehabilitation research and training center on policies and families.

www.beachcenter.org/

THE DISABILITIES RIGHTS CENTER offers an online brochure "When you have a complaint about your Community Mental Health Center or Area Agency"

www.drcnh.org/aacmhcfq.htm

FUTURE PLANNING NETWORKS OF NEW HAMPSHIRE

website www.futureplannh.org

Rolling Gourmet Seeking Diners – Get Paid to Rate Restaurant Accessibility

The Christopher Reeve Foundation (CRF) has awarded the Disabilities Rights Center and the New Hampshire Chapter of the National Spinal Cord Injury Association a Quality of Life grant to expand the *Rolling Gourmet*, New Hampshire's guide to restaurant accessibility.

With the CRF grant, the *Rolling Gourmet* is able to offer a \$25 debit card, good anywhere, to encourage diners with disabilities to rate New Hampshire's restaurants for accessibility. It also will allow the *Rolling Gourmet* to provide direct feedback to restaurants on their accessibility as experienced by individuals with disabilities.

Launched in 2005 on the 15th anniversary of the Americans with Disabilities Act, the *Rolling Gourmet* is a guide to accessible dining with reviews provided by diners with disabilities. It has proved to be a popular program with more than 175 New Hampshire restaurants rated so far. While the ratings focus on physical access, there is room for comments about accommodations and friendliness. This is not only a guide for accessible dining, but also serves as encouragement for restaurants to become fully accessible.

To find out more, call Julia Freeman-Woolpert (1-800-834-1721) or visit the *Rolling Gourmet* on the web at: <http://www.drcnh.org/restaurant.htm>.

Quality of Life grants, conceived by the late Dana Reeve, are given to programs or projects that improve the daily lives of people living with paralysis, particularly spinal cord injuries. Funding is awarded twice yearly to programs in thirteen categories, including: accessibility, advocacy, arts, assistive technology, children, counseling, education, employment, health promotion, independent living, practical services, sports and recreation, and therapeutic riding.



Resources, Continued

THE MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES offers "Parallels in Time II," a free, easy-to-use online resource, with photos, videos, and information about the history of services to people with developmental disabilities.

www.mnddc.state.mn.us/parallels2/

NEW HAMPSHIRE INSTITUTE ON DISABILITY is a source for information, research, and training on a wide variety of disability issues. www.iod.unh.edu

PLANNED LIFETIME ADVOCACY NETWORK (PLAN) The goal of this Canadian organization is "to ensure a safe and secure future for your relative with a disability and, in the

process, to provide you and your loved ones with peace of mind."

www.plan.ca/homepage.php

QUALITY MALL, FROM THE UNIVERSITY OF MINNESOTA, source for free information about person-centered supports for people with developmental disabilities

www.qualitymall.org/main/

SOCIAL ROLE VALORIZATION website: www.socialrolevalorization.com/

THINKCOLLEGE.NET a website for youth with intellectual disabilities who are interested in the benefits of a postsecondary education. www.thinkcollege.net/

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 ♦ Website: www.drcnh.org

"Protection and Advocacy System for New Hampshire"

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

INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH

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

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

Institute on Disability/UNH – Concord

56 Old Suncook Road, Suite 2

Concord, NH 03301

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

Institute on Disability/UNH – Manchester

250 Commercial Street, Suite 4107

Manchester, NH 03101

Phone: (603) 628-7681

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

NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

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

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

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NH COUNCIL ON DEVELOPMENTAL DISABILITIES

21 South Fruit Street, Suite 22, Room 290

Concord, NH 03301-2451

RETURN SERVICE REQUESTED

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