

The New Hampshire Challenge

disability issues from a family perspective

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Annie Forts
turns
stereotypes

Up side Down

Annie Forts has traveled the nation with her uplifting message on the power of a positive attitude. Now she has received a national award celebrating her leadership and perseverance. See articles beginning page 3.

Photo: E.G. Stone

Wait List Lawsuit Filed

by: Janet M. Krumm

The State of New Hampshire is once again facing a lawsuit over the services it provides - and does not provide - for its citizens with developmental disabilities. Nearly 25 years ago, parents organized and sued the State because of the terrible conditions at Laconia State School and Training Center, an institution which at the time provided essentially the only services the State offered. That lawsuit, Garity vs. Gallen, ultimately resulted in the closure of the institution and the concentration of resources into a newly-created community-based service system.

Harris vs. Shaheen, a class action lawsuit filed on January 16, 2002 in Hillsborough County Superior Court, charges that the State has failed its mandate to create a comprehensive array of community-based services, leaving many individuals with developmental disabilities with no services, and others with "grossly inadequate" services.

The lawsuit contends that in addition to the State's failure to develop a comprehensive array of services, it fails to deliver those services with "reasonable promptness" violating three laws: New Hampshire's *Services for Developmentally Disabled Act*, NH RSA 171-A, the federal Medicaid Act and the *Americans with Disabilities Act (ADA)*.

The suit was filed by Ron Lospennato of the Disability Rights Center and Erica Bodwell, of the lawfirm Backus, Meyer, Solomon, Rood and Branch of Manchester, NH.

"It's been a long time in coming," said Lospennato, referring to the lawsuit. "The wait list has been a problem for many, many years." Why a lawsuit now?

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Who Cares for the Direct Care Providers?

by: Janet M. Krumm

Direct support providers are key components of the adult service delivery system in New Hampshire. Adults with developmental disabilities receive services in their homes, out in the community, on the job. Direct care providers help with personal care, grocery shopping, doing laundry, managing money, support on the job, transportation - all the activities essential for living.

Without direct care providers, there is no system. Yet, agencies are having difficulties attracting and keeping people in these positions. This problem is not unique to New Hampshire; every other state is having similar problems. There are a number of reasons why.

The job of providing direct services to individuals is considered a low status job, despite the fact that the services provided are essential to the lives of the individuals they serve. Salaries hover around the minimum wage level, yet last year money for pay raises for these workers was initially cut out of the budget by legislators. It took strong lobbying to get

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Lawsuit

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"It really was a combination of factors that led us to file it at this time," explained Lospennato. "One is the relentless interest of many persons with developmental disabilities in getting services. Second, emerging case law around the country, particularly around the 90 day requirement for obtaining services under Medicaid. Thirdly, our capacity to do it became available. The situation just looked right for a number of reasons."

While encouraged by the success of similar lawsuits in other states, Lospennato explained this case differs somewhat from those lawsuits. "There are two issues that we are really looking at," Lospennato explained. "One is the quantity of services which are available.

People ought to be able to access the services they need and access them in a reasonable time because there's a sufficient array of services out there.

"And the second is the quality of services.

There are a lot of people who are ostensibly receiving services but they are, to say the least, thin."

The services as outlined in the suit include job training, education and habilitation, all services to help individuals become independent and self-sufficient. "Too many people are not getting those kinds of services," Lospennato declared. "And sometimes what's really going on for people is glorified baby-sitting. I hate to use that term when we are talking about adults, but that just sort of describes the relationship. People may be accompanied by somebody but very little is going on to increase their capacity to be independent, be productive.

"In some cases, in more extreme circumstances, (individuals need services) to be adequately protected," he added. "There are too many incidences where people have been neglected or abused because the support systems that are out there are, as I said before, thin.

"So this case also deals with the quality of services that

people are receiving," he explained. "There's no point in providing services to somebody if they're not going to benefit from it. Or worse, that they are harmed by it."

New Hampshire is renowned for closing its only state institution ten years ago, but Lospennato sees little reason for the State to congratulate itself on a job well done. "There's no more Laconia State School but that doesn't mean there are no institutions," Lospennato declared. "We have nursing homes. We have New Hampshire Hospital. Increasingly those kinds of facilities have been used over the years. Jail. There's all kinds of places where people end up that are really not appropriate and would be unnecessary if there were adequate services in the

credibly inappropriate situations for a very long time while they're developing a service for somebody. They're always behind the eight ball the way the funding mechanism works and they're always scrambling to address some crisis. And all these people who are not in immediate crisis get ignored until they're ignored so long they become in crisis themselves."

While the lawsuit names only five individuals, as a class action suit it includes all individuals with developmental disabilities in New Hampshire who are waiting for services, those who are eligible but not receiving services, and those receiving inadequate services.

The lawsuit names Governor Jeanne Shaheen, Donald Shumway, the Commissioner of New Hampshire De-

Responding to the allegation that many people end up in crisis situations because of the lack of services, Fox stated: "The Division has assured that all persons in critical need receive necessary services and, in fact, most people on the waiting list are receiving services and supports from the state."

According to Fox, funding for developmental services increased from approximately \$54 million in fiscal year '98 to \$62.8 million in fiscal year '01. \$68 million is authorized for fiscal year '02 and \$69 million for fiscal year '03.

During that same time, funding for the wait list increased from \$2.2 million in fiscal year '98 to \$3.9 million in fiscal year '01, with \$2 million authorized for fiscal year '02 and \$3 million authorized for fiscal year '03.

As for the allegations that New Hampshire has failed to build a comprehensive community-based system of services, Fox had this to say:

"The state made a decision years ago not to build more facilities such as Intermediate Care Facilities for the Mentally Retarded (ICF's-

MR) or group homes. All adult ICF's-MR and the majority of group homes in New Hampshire have been closed as people entering the system have not chosen to live in these settings.

"New Hampshire supports individual choice in determining the type of residential setting in which a person wants to live. It is discouraging that this lawsuit contends that New Hampshire does not have a comprehensive community based system because we have not built facilities to house persons with developmental retardation."

A preliminary hearing is scheduled for February 28.

"It's very important for families to stay involved with their family members, but at the same time I think the state is taking a good thing and stretching it beyond recognition."

***Ron Lospennato,
Director of Legal Services,
The Disability Rights Center, Inc.***

community."

One of the reasons for that is the lack of funding. Budgets have been inadequate to provide the services needed. Some of the adults represented in this lawsuit are living at home with their parents while they wait for services to become available.

"It's very important for families to stay involved with their family members," Lospennato acknowledged, "but at the same time I think the state is taking a good thing and stretching it beyond recognition. People are stuck living at home because there's nothing else even though it would be much more beneficial on many, many levels for them to be out of their home. There's nothing available."

The other result of the inadequacy of funding is that individuals end up in crisis situations before their needs are addressed. "Oftentimes, they wait for crises to happen before they do anything, which is usually too late," Lospennato said.

"That just requires people to suffer and be in in-

partment of Health and Human Services, and Susan Fox, the Director of the New Hampshire Division of Developmental Services as defendants in this case. Fox does not agree with the allegations made in the lawsuit.

"New Hampshire's developmental services system is a strong, comprehensive community-based system and is acknowledged both nationally and internationally as one of the best in the country," Fox stated.

"The state has made significant progress over the years to reduce the number of people waiting for services," Fox added, "as well as the time that people wait for those services.

"The Division of Developmental Services recently submitted a plan to the legislature to further reduce the waiting time to no more than 90 days over a five year period," Fox indicated. "The legislature has consistently supported waiting list initiatives and the legislative waiting list oversight committee is currently reviewing this waiting list plan."

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Annie's enthusiasm for life is evident in everything she does. Her rendition of the song *New York, New York* is as lively as if she were performing at Radio City Music Hall.

Photo: E.G. Stone



Ann Forts Is "Up" on Life

by: Janet M. Krumm

Annie Forts' prized possession is her karioke machine, a Christmas present from her parents. Eager to demonstrate its use, she chose the song "New York, New York" to sing. Annie belted the lyrics out in perfect time to the music, punctuating the climax of the song with a modified chorus line kick from a sitting position on her bedroom floor. Her energy is palpable; her enjoyment infectious. Watching her caught up in the moment, it is easy to see the gusto with which she approaches life.

The lyrics of the song are equally revealing. She sings of the desire to "live in a city that never sleeps"; to be the "top of the list" and the "king of the heap." She sings: "I want to make a brand new start of it/ New York, New York. ... If I can make it there/I'm gonna make it anywhere."

For a woman born with Down syndrome at a time when that diagnosis limited one's opportunities and expectations, Annie has single-mindedly climbed to the top of many a list not only in her hometown, but in the state she calls home, and beyond that, across this great country of ours. She has made a brand new start of raising the expectations for all people with Down syndrome. And if awards and accomplishments are any measure of success, Annie has truly "made it." She may not live in New York, but most people who know Annie Forts would say that whatever city she

is in is a place where she, at least, never sleeps.

Annie's life is full, and she says unabashedly, "I love my life!" Her smile brightens any room; her curiosity leads to unexpected opportunities; her friendliness engages even the most reluctant; her determination is unstoppable.

Annie's family learned that early on. Before Annie even knew what Down syn-

drome meant, she was crossing off the word "Down" on every newsletter her parents received and writing over it the word "Up." "Up" has become her trademark, the symbol of her approach to life. "Annie gets discouraged for about ten seconds," her father Bernie said. "Then she forgets about it and moves on."

When Annie was born, never did her parents Bernie and Shirley Forts dream that they would be spending their golden years accompanying Annie

around the country to her many speaking engagements. She averages about 20 a year, Bernie stated. She's visited California, Montana, New Mexico, Virginia, Massachusetts, Washington DC and Washington state, Wisconsin, Vermont, Connecticut, Missouri, New York, Florida, Tennessee and North Carolina. She's spoken to parents, young people with Down

people."

She tells people with Down syndrome to improve their lives. Go to school and get an education. Learn what you can to be successful. Live your life to the full.

Annie practices what she preaches. You might think that her speaking engagements take up all her time. Not so.

She also finds time to serve on the boards of various

part time at a video store and volunteers at a nursing home, two high schools (where she works in both their offices and their libraries), and a preschool (where she reads to and plays games with the children). She serves as an usher for her community's summer theater program, a greeter in her church and a "Tail Twister" at the Lions Club meetings (where she collects fines from members who are not wearing their Lions Club pins or name tags.)

Are you tired yet? Rest assured, Annie's not!

On Sundays, she goes through her rolodex of about 150 friends and begins calling them to set up luncheon dates, dinner dates, breakfast dates, shopping dates, a time to get together and drink tea and talk. When Annie says her life is full, she's not kidding.

Oh, and one other thing. Annie has started two separate funds. Ann's "UP" Fund raises money through the sales of items such as T-shirts, caps and sweatshirts imprinted with her Up syndrome design logo. All proceeds go to the National Down Syndrome Congress. She has raised nearly \$20,000 to date.

All the work is done out of her parent's home (where she lives part-time. She also has her own place in Meredith, an apartment attached to her sister's house.)

And as if that did not

"Be an Up person. An Up person makes other people feel good. Don't be a down person. Don't prejudge others with disabilities. Open yourself up to people."

Ann Forts

syndrome, junior high and high school students, college students, college professors, doctors, and members of service clubs. "We've never sent one letter out" soliciting these speaking engagements, her father explained. "They're all from word of mouth" referrals.

What does Annie say to these eager audiences? "Be an Up person. An Up person makes other people feel good. Don't be a down person. Don't prejudge others with disabilities. Open yourself up to

organizations. Among them have been the NH Developmental Disabilities Council, the Direct Support Professionals Association of New Hampshire, the New Hampshire Chapter of the American Association of Mental Retardation, the National Down Syndrome Congress and the President's Committee on Mental Retardation.

Does that sound busy enough? Hardly.

In between her speaking engagements and board and committee meetings, she works

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As Annie celebrates her 35th birthday this year, she can look back on her many accomplishments with pride.

She is the recipient of many prestigious awards:

- 1995** The 1st International Self Empowerment Award given by the Joseph P. Kennedy, Jr. Foundation at the United Nations in New York City, and
The Annual Down Syndrome Ambassador of Good Will Award presented by the Association for Children with Down Syndrome Inc.
- 1997** The Massachusetts Down Syndrome Congress Annual Dr. Allen Crocker Award,
The Lions International Community Service Award,
The ARC of Union County, NJ Spirit of the ARC Annual Award,
The ARC of New Hampshire Citizen of the Year Annual Award,
The National Down Syndrome Congress Exceptional Meritorious Service Award in recognition for all she has done to raise the nation's awareness of the abilities of people with Down syndrome.
- 2000** The Boston Celtics "Heroes Among Us" Award, given to salute her "courage, achievements and invaluable contributions" to the community.
- 2002** The Paul G. Hearne/American Association of People with Disabilities Leadership Award.

In 1990, Annie started Ann's "UP" Fund, a fund-raising project to benefit the National Down Syndrome Congress. She has raised over \$20,000 in profits from the sales of various items including T-shirts, caps and sweatshirts which use her "UP" Syndrome design logo.

In 1997, Annie started a new fund called the Annie Forts "UP" Syndrome Fund with the help of the Moultonboro Lions Club, of which she is a member. Approximately \$190,000 has been raised to date toward a goal of \$1 million.

Proceeds from this fund provide financial assistance to people with Down syndrome who wish to improve their lives by learning how to become more independent, building their self-esteem and learning how to become more effective self-advocates so that they might become respected members of their communities. Financial awards have been used by the recipients for camperships, travel assistance to the National Down Syndrome Congress, a scholarship to attend Leslie College, and participation in an 10 week Horsemanship Apprentice Program, to name a few.

The Fund also provides scholarships for Lakes Region area graduating high school seniors who are planning to major in Special Education or any field directly related to working with people with disabilities. In addition to four Lakes Region high school students, a scholarship was given to a

People First of New Hampshire

is proud to announce our Ten Year Celebration combined with a Performing Arts Event, April 20 - 21, 2002 at the HolidayInn, and, at the Capitol Center for the Arts in Concord, NH

Saturday, April 20: Various workshops with guest artists in preparation for next day's celebration - Your choice of one workshop to participate in. You can: act, dance, sing, play instrument, paint, write your story or poetry, more...Saturday evening: Ten Year Celebration, dinner, open mic, dance, and of course, a toast to mark the ten years!

Sunday morning, April 21: Rehearsal on and off stage at the Capitol Center For the Arts and displays of various art work, poetry, stories Sunday afternoon: The performance and more celebration More information and pre-registration information will be coming in the mail and online to you in January

The times, they are a'changin'....

Al Robichaud who served as the Executive Director of the NH Developmental Disabilities Council since 1994 left the DDC as of January 7, 2002. He is now the Executive Director for the Belknap County Citizens Council on Children and Families.

Clyde Terry has been appointed as the new Executive Director. Clyde has been at the NH Developmental Disabilities Council since 1994 where he most recently served as the Director of Policy and Planning.

Sue Fox, the Director of the Division of Developmental Services of the NH Department of Health and Human Services, has announced her departure as of March 15, 2002. Sue will assume the position of Project Director for the Real Choices/FLEX (Facilitating Lifespan Excellence) grant through the University of New Hampshire. The purpose of the grant is to create and implement improvements in community long-term care systems. The proposal was developed collaboratively by the disability and aging communities.

There has been no announcement to date as to her successor.

Bernie and Shirley Forts decided when Annie was young that they would not limit their expectations for her. Bernie says their life with Annie now is like "catching the tail of a comet."

Photo: E.G. Stone



Annie

Continued from page 3

take up enough time and energy, she has created another fund, The Annie Forts "UP" Syndrome Fund which provides funds for people with Down syndrome who want to improve their lives, as well as scholarship money for area high school students planning to major in Special Education. The Lions Club, of which she is a proud member, helped in the creation of the fund, donating \$10,000 to set it up. The wanted to honor their "most famous member" after her meeting with President Clinton. The fund has raised approximately \$190,000 toward its \$1 million goal.

That's quite a "heap" to be on top of!

How does Annie do this? With the loving support of her family. Her parents were determined never to limit her dreams. They allowed her to try to accomplish what she wanted to do, even when they themselves had reservations. Annie has written: "I have found that my disABILITY (sic) has not prevented me from reaching many levels of success that most people really do not expect me to reach. I surprise them - and "yes" - sometimes I surprise myself, too."

"Annie is a very strong person," Bernie admitted. "Shirley and I had it easy," he explained. "Annie is so social and easy going."

When Annie was ten years old, she was chosen as the Poster Child for the Union County Association for Retarded Citizens in New Jersey where she lived at the time. She was present in the state legislature when a resolution was passed commending her for her selection. A picture appeared in the local newspaper of Annie speaking confidently into a microphone, her arm extended and pointing to the senators. The heading for the photo read: "She'll be heard from." Little did they know!

Annie's family moved from New Jersey to New Hampshire as Annie was getting ready to enter high school. They had been vacationing in the Granite State for many years and had built a home in Moultonboro. The impetus for their move was to have Annie attend a regular high school in her hometown. The town in New Jersey where they lived would have bussed her out of town to go to school. "It was a wealthy town," Bernie explained. "It was easy for them to pay someone else" to educate their students with disabilities.

So Annie entered Moultonborough Academy in 1984, at a time when the word "inclusion" had not

entered our collective vocabulary. The high school "never had a child with Down syndrome," Bernie remembered. Even so, they accepted Annie into their program and provided her with the services of an aide to help her in her classes.

She did have some trouble with teasing. A few kids at the high school made things difficult for her, especially at the beginning, according to her father. A teacher alleviated that problem by assigning Annie a "Big Sister" - a student who was "well liked, good looking, and smart," Bernie said. With her Big Sister's help, Annie eased into the culture of the school and "by the time she graduated, she was pretty well accepted at school," Bernie remembered.

Annie's career as a motivational speaker had its beginnings with an invitation by Dr. Carl Cooley to speak to a group of 75 to 100 Dartmouth medical students. That turned into an annual invitation for about four or five years, after which she received an invitation to speak at the National Down Syndrome Congress conference. That speaking engagement led to others, which led to still others and now Annie has a business card which reads "Ann M. Forts, Self-Advocate and Motivational Speaker." And Annie is not shy about handing out those business cards.

She recounts an incident in which she was eating in an Atlanta restaurant (during one of her speaking engagements) when who does she see in the restaurant but Mark McGuire. This was during the time when he broke the long-standing home run record. She tried to get to meet him but was told that he was eating and did not want to have his meal disturbed. Annie's obvious disappointment, however, convinced McGuire to make the time to meet Annie after he finished his meal. "I grabbed my camera and two business cards," Annie said. She was rewarded with a picture of herself kissing a broadly smiling McGuire.

But Annie isn't one to let an opportunity pass. She told McGuire about her UP Syndrome Fund which would shortly be holding an auction as a fundraiser. She handed him her business card and asked him to please send her something that could be auctioned off.

"Two days after I got home, there was a big white box waiting for me," Annie recalled. Inside was a baseball hat autographed by Mark McGuire! That hat raised \$1,000 for the fund.

Annie has had occasion to meet many famous people: Michael Landon, Maria Shriver, Eunice and Sargent Shriver, John F. Kennedy, Jr., Chris Burke

(the actor with Down syndrome who starred in the television show *Life Goes On*, and President Bill Clinton. Her meeting with President Clinton left such an impression on him that he mentioned Annie in a speech the next day at the annual Democratic Leadership Council, broadcast by CNN. That resulted in an invitation by Katie Couric to appear on the NBC Today Show with her the next morning.

Annie's appearance the Today Show, which is broadcast nationally, was completely unrehearsed, a fact that make her parents a little nervous. "We didn't know what was going to come out of her mouth," her father admitted. But Annie was not perturbed. She handled herself with grace and style as she answered Couric's questions, even admitting to flirting with John F. Kennedy, Jr. who served with her on the President's Committee on Mental Retardation.

That was not Annie's only television appearance. Geraldo Rivera invited Annie to be on a show marking the 25th anniversary of the closure of Willowbrook, an institution for people with mental retardation in New York. Rivera's investigative work was instrumental exposing the horrendous living conditions there. Annie was invited to be a member of a panel of people, some of whom had lived in the institution before it closed. Rivera remarked on the many achievements of Annie Forts, highlighting for him the "utter waste of all that human potential" when people with mental retardation were "imprisoned" in institutions.

As evidenced by the Mark McGuire story, Annie not only takes advantage of opportunities; she creates them. The story of how Annie got her first job illustrates the strength of her determination as well as her fearlessness.

Annie and her mother Shirley were shopping in the local supermarket in Moultonboro one day when Annie was in high school. Suddenly Annie disappeared. She went to find the store manager and asked for an interview; she wanted to work at the supermarket. After talking briefly with Annie, the store manager came to Shirley and told her Annie could come in for an interview. "She got the job," Bernie said.

It was a job bagging groceries, an ideal way for her to meet a lot of people in the community, according to her father. She started making friends and hasn't stopped since. Her oft-stated goal is to make as many friends as there are stars in the sky. She's convinced she's getting pretty close. Who would disagree?

Ann Forts Named as Recipient of AAPD Leadership Award

Annie Forts has been named one of seven recipients of the first annual Paul G. Hearne/American Association of People with Disabilities (AAPD) Leadership Award. She was chosen from a highly competitive field of 400 applicants from across the country.

Paul G. Hearne, a tireless advocate who spent his life opening doors and removing barriers for people with disabilities, was the visionary founder of AAPD. Although not permitted to enter school physically until age 15, he went on to achieve remarkable success as a lawyer, nonprofit executive, foundation president, federal agency director, and mentor to countless people with disabilities.

The Paul G. Hearne Award recipients emulate Paul G. Hearne's leadership and perseverance by making a positive impact in the disability community.

As a recipient, Annie will receive a \$10,000 cash award and a crystal sculpture representing the passing of the torch of leadership. Annie will be given membership in AAPD, and have the opportunity to build relationships with fellow awardees and national disability leaders through the awards' mentorship program.

The awards are being presented at the AAPD Leadership Gala, held on February 27, 2002 at the Washington Court Hotel in Washington, D.C. Congressman John Sununu will present the award to Annie the night of the gala. The next day, she will meet with Senator Bob Smith and Senator Judd Gregg at their offices in the Capitol Building.

AAPD is a national, non-partisan, non-profit membership organization promoting political and economic empowerment for the more than 56 million children and adults with disabilities within the U.S.



Photo: E.G. Stone

Al Robichaud, formerly Executive Director of the NH Developmental Disabilities Council, was one of the people who nominated Ann for the Paul G. Hearne/AAPD Award. This is what he has to say about Ann Forts.

"I've been an admirer of Ann's for a number years. It's pretty hard to know her and not be. I've never seen anybody work a room like she does. And she does it very deliberately, I suspect. As soon as you meet her, you become caught up in her enthusiasm and excitement for life.

"The wonderful thing about Ann is that she doesn't carry any of the stigma of disability with her. She's a very vivacious young woman who enjoys life to the hilt and looks for ways to get other people encouraged about their own lives, overcoming adversity by paying attention to what's really positive.

"She brings people along. I've seen her interact with her fellow Lions Club members. Never once did I ever get a sense that there was a level of tokenism. Quite the opposite. In fact, I saw a lot of Lions Club members working really hard to take on her characteristics and become as avid a supporter of their events as she was. She is very much an active member of that organization to the point that her enthusiasm was the drive behind their wanting to start the Annie Forts Up Syndrome Foundation to make sure that other people have access to the same opportunities that Ann has had.

"Certainly, we can all look at Bernie and Shirley Forts as being wonderful parents with certain resources that many families don't have. And that has certainly been an advantage to Ann. But beyond that, she has so been able to interpret what life means for people that I have seen the Lions Club just generate around what some of those members would call the Annie fever. She is contagious, as Bob Purdy would say. She elevates everybody's enthusiasm and spark for life to the degree they have to do something to give back.

That kind of epitomizes Ann's life, that she's constantly giving back. For anybody who would look at her and give her accolades for all that she's achieved, in her own way she is always out there serving as the ambassador of happiness and good will and forcing people to take a look at the way life ought to be lived. Whether you're a person with a disability, a family member of a person with a disability, or just Joe citizen, look for those positives in life that will make you happy and live them.

"She's an amazing young woman. To have traveled around this country as often as she has, to stand before literally thousands of people in any given audience and do a keynote speech which can at once bring you to tears and bring laughter to your voice just by her presence and her vivacious attitude. She's very compelling and offers wonderful hope for families of young kids with disabilities that this is the way life is to be lived. And does so again in a way that is not token.

"She has lived what she expresses. She has gone through inclusionary public school; she has been a valued member of her community; she's been a productive, contributing member of her community by holding as many as three simultaneous part-time jobs. She has the freedom to come and go throughout that community and know as many people as anyone else would and probably more than most. To have gone to the Oval Office and influenced the President of the United States and have known as a friend, John F. Kennedy, Jr., to have appeared on national talk shows and to have been admired by millions of people is an accomplishment that many of us will never experience in our life. But to also be a young woman with Down syndrome and accomplish that is to serve as that role model for all of us, not just people with disabilities.

"I consider Ann a friend and I think that everyone that Ann meets she considers a friend as well. I just see that for the rest of her life she's going to continue to influence the way people think about people with disabilities."

**Do you have a story to share?
Call The Challenge at
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1 (800) 758-6430
Or e-mail us at
nhcjmkn@nh.ultranet.com**



Life Is A Gift - Don't Waste It!

by: Sean Raymond

This is another in a series of articles written by Sean Raymond about his person experience as a young man with a disability. Sean has Spinal Muscular Atrophy.

We all go through changes in life. Some of the changes are for the better and others, as we all know, are not. I've recently been going through some changes and not for the better.

Since the middle of September I have gotten much weaker in both of my hands, my arms and even my neck. I've started having difficulty chewing because jaw muscles are fatiguing easily.

I don't eat steak anymore because I'm afraid I might choke on it. I can only write for a short period of time before my wrist gets so tired that I can't write and I have to stop and rest. Even now as I type this very article, I need to stop and rest my hands every couple of minutes.

I never thought I would get this weak and for the first time in my life I am afraid.

I've gone through periods like this before, when I would slowly lose some of my strength in my arms, hands, legs, neck, jaw, and almost any other muscle you can name. The difference then was that the little bit of strength I had left was still enough to go about my daily life in pretty much the same fashion.

For instance, I used to be able to lift my arms above my head, and slowly I lost the strength to do that. But, lifting my arms above my head was not something that I needed in order to write, type, hold a book to read or unscrew a cap.

When I was finally too weak to walk and gave up trying, I got to use my wheelchair and I was very relieved that I would never have to struggle walking 10 feet again. Walking wasn't a useful ability for

me because it was so difficult and I could still get around using my wheelchair.

It wasn't until now that I started losing useful abilities, like the ability to write, type, hold my head up, chew my food, lift up a book or feed myself. As hard as it is for me to type, write and do everything else I've mentioned, I still do it. I am not going to give up on these abilities I've mentioned like I gave up on walking because I've learned where there's a will there's a way.

I may not be able to type the standard way with my left hand over keys 'a', 's', 'd', and 'f' and right hand over 'j', 'k', 'l' and ';' but I can still type 20-30 words per minute using only my index finger on my right hand and my thumb, index finger and middle finger of my left hand.

Unfortunately, though, my typing days are numbered

one hand and arm gets tired I can switch my fork over to my other hand and continue eating while the other hand rests.

Sometimes, when my neck gets tired I have to support it using my arms and hands. It is getting increasingly harder to do so since my arms are getting weaker and my neck is too, but I'm still managing to do the best I can. I can't make as much eye contact as I used to, but the people I talk to are aware of this and understand.

The greatest loss I have suffered due to the weakness in my neck is my ability to publicly speak. It is so hard to make frequent eye contact and read from a page or book because my neck muscles tire so quickly now. I can no longer speak with the same force and power I once did as a result of these weakening muscles. This above all has brought me great

"I've found so much beauty in life that my spirit is nearly unbreakable."

Sean Raymond

and I will be getting voice-activated software because typing for a long period of time is just too hard for me. I will still be able to dictate the thoughts I have typed for nearly 10 years because of the great advancements in technology. I am very thankful for these advancements that will allow me to dictate my articles faster than I can type them.

Eating has become a big problem for me, but I have learned to adjust. I am a very slow eater now because of the time it takes me to chew and swallow my food and feed myself, but I can still do it. I will continue to do it as long as I can and continue to find new ways to do it. I've learned how to feed myself using both hands ambidextrously, so that when

sadness, but I am still thankful for the abilities I have and for the time I was able to use my ability to publicly speak to reach people. I will never forget the kind comments of how well I spoke at church, or on TV, or the telethon, and it is memories like these that I am thankful for.

I've talked about all the physical weakening I have gone through, but I haven't mentioned the intangibles that I have that cannot be weakened by my disease. If there's one aspect of me that has gotten stronger as a result of my physical weakening it is my spirit. I've found so much beauty in life that my spirit is nearly unbreakable.

I have spent a lot of time with my family and friends and because of them I have seen past my disability. If I were to



spend every day thinking about all the things in life that I couldn't do, I'd never get around to all the things in life that I can do. It is because of my family and friends that I have gotten the most out of life and it is because of them that my spirit will stay strong through the toughest of times.

I believe that everyone has a special ability, whether it is to tell jokes, run fast, jump high, cheer people up, do math, remember facts, perform magic tricks or even draw. The list of abilities can go on and on, but the point is that everyone has some ability or abilities that he or she can excel in. Not everyone has discovered his or her own abilities, but I worked hard to find mine. I discovered that my abilities were mental abilities. I pushed myself to do well in school and because I did I strengthened my mind.

I didn't start out on such a good note. I had to go to summer school in order to pass the first grade because I couldn't read well. It wasn't until I discovered math in third grade that I really enjoyed school.

Math gave me the fuel for my intellectual fire and opened the doors for me to expand my interests. I loved the feeling when I got my tests back and I did well, and I wanted to feel it all the time, so I worked hard in school. If anyone had

asked me in elementary school if I thought that I would graduate sixth in my class I would have laughed, but through hard work and dedication I strengthened my intellectual abilities and became a well-rounded student.

Math and English were always my favorite subjects but I gave my all to every class I ever took no matter how trivial it may have been. It was this work ethic that pushed me to excel and allowed me to graduate sixth in my class.

I never once allowed my physical disability to get in the way of my mental abilities. Sometimes I would get really sick and miss a week of school, but my mind stayed healthy during those times and I was still able to learn while I was out. I never wanted to have that feeling that I didn't try my hardest.

I never wanted to let myself down and to me if I didn't do my absolute best at school I would have let myself down. If my best would have made me a 'C' student instead of an 'A' student I would still be happy knowing that I did my best. It just so happened that through my hard work at school I found my abilities.

I could have easily used my wheelchair as an excuse to

Sean

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Have equipment you don't need? Give it to REM!

The Refurbished Equipment Marketplace, a division of ATECH Services, was established in 1994 through funding from the New Hampshire Technology Partnership Project and with support provided by the Judson Fund, the Belle Peabody Brown Fund, and the Charles & Arlene B. Greenfield Fund of the New Hampshire Charitable Foundation.

The REM receives and refurbishes donated assistive technology equipment such as wheelchairs, walkers, scooters, hospital beds, bath equipment, lift chairs, portable ramps, communication aids and more. The donations are tax deductible.

The equipment is then redistributed statewide to people of all ages through a net-

work of participating durable medical equipment dealers and through direct sales from the showroom at 84 A Ironworks Road, Concord, NH.

For those finding out about the REM for the first time, or for those trying the REM again for the first time, here's an introduction to the staff. Please feel free to call: Julie Williams, the REM Office Manager for equipment availability, pricing and to schedule donation pick-ups and deliveries.

For service and repairs, please call: Phil Dresser, the REM Technician/Service Manager. Phil has recently completed both Invacare and Sunrise Medical (Quickie) Tech School Courses.

Please call: Paul Luff, the REM Coordinator, for more information or to schedule a presentational overview of the REM at your organization.

In an effort to serve more people during the past year and a half the REM has undertaken several initiatives to increase both donation and sales. These include sending out stickers that can be placed right on the equipment; reminding consumers to consider donating the equipment as soon as they no longer need it.

This addresses one of the key factors for the ongoing success of the program. By shortening the length of time equipment sits unused, its useful life is increased for the next person. Also, parts are more

readily available for current equipment.

The REM is expanding target-marketing efforts, through exhibits, shows, and presentations, especially to organizations that provide support and services to people of all ages with short or long-term disabilities. Hospitals, nursing homes, assisted living homes, schools, senior centers and continuing care companies can all benefit from the products and services provided at the REM.

Anyone can donate or buy equipment at the REM; ideal equipment is less than 6 years old and in good working condition. Call the REM directly at **1-800-427-3338 (NH Only)** or **(603) 224-7630** and arrange a tax-deductible dona-

tion. They can even pick up the equipment if you cannot drop it off.

To purchase equipment call the number above to see if they have it.

Or visit their web site: www.neatexchange.org and search the current inventories. An "equipment wanted" list is maintained if they don't have what you're looking for at the time of your call.

For more information please contact Paul Luff at the number above or email at pluff@nhaat.mv.com

Sean

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isolate myself from my peers. The majority of the students that I hung out with were active in all sorts of school activities. Some were into sports others were into acting and most of them were into some form of student government. I found myself active in student government and the math team. I couldn't play baseball, but I could do math!

Student government gave me a forum to express my ideas and publicly speak to my peers. When I was elected treasurer in consecutive years I was on top of the world. It was through an active role in school that I felt like an equal.

If I had been silenced by my disability and let my high school years pass me by I could have blamed it all on my disability, but I decided to be a part of the student community. I spent time with my peers and enjoyed every minute of it. My disability can't stop me from having fun with other people. I will not allow it to segregate me from my peers.

Even outside of school I could have been a hermit, but that's no fun. "Have wheels will travel" is my motto! I love the mall and electronic stores are my favorite places to go shopping.

I love working and the

people I work with. I could have been a passive worker and kept to myself, but I love people in general. I enjoy talking to people and making friends. I've met a few people that can't get over my wheelchair, but I've met so many more that don't even see it. With all the people and activities in the world how could I let my disability get me down?

All you can do is take a look at yourself and find the good within. Once you find something to be thankful for exploit it.

Don't let a day go by without being grateful for what you have. If you can walk then be grateful and walk while being grateful. If you are smart then be grateful and use your intelligence to the best of your abilities. If you can play baseball then be grateful and just swing the bat.

I can't walk and I can't play baseball, and there is always going to be something that I can't do. There's always going to be something that you can't do, but if you look hard enough you'll find other things that you can do.

Use all the gifts you have and be thankful for each and every one of them. Life is a wonderful gift; don't waste it.

UNH's Institute on Disability Offers Mentoring and Community Employment Training

HAMPTON – A mentoring and employment training seminar for individuals with disabilities will be held in March to provide on-the-job training methods, creative problem-solving, service quality improvement, and an ongoing network for peer support.

Adults with developmental disabilities have historically been relegated to second-class status in the workforce. The U.S. Census Bureau estimates that about 33.1% of adults with disabilities are unemployed. But the rate of unemployment for individuals with severe disabilities — those who require multiple supports over an extended period of time — is a staggering 74%. And many of those who are employed work not in the regular labor force but in segregated sheltered workshops.

Fortunately this picture has begun to change. In New Hampshire, employment for individuals with developmental disabilities has been steadily improving, says Dr. David Hagner of the University of New Hampshire's Institute on Disability. "Young adults are saying that they are interested in real jobs with real futures." New admissions to sheltered work have virtually ceased. The Bureau of Vocational rehabilitation refers only about three individuals, on average, for sheltered employment statewide per year. The federal Rehabilitation Services Administration revised its policies so that starting this year sheltered workshop placements are no longer considered legitimate vocational rehabilitation outcomes.

"Finding the right job and making sure the business receives any help it might need

to successfully employ an individual requires trained staff with skill and experience," Dr. Hagner explains.

The Institute on Disability offers an annual series of training seminars to service providers throughout New England who provide these employment services. Particularly effective is the Mentor Training seminar, whereby experienced staff members are trained to serve as mentors for other staff and take on a leadership role within their organization.

This year's Mentor Training seminar, led by Dr. Hagner, will be held at the Ashworth-by-the-Sea Hotel at Hampton Beach from March 27 through March 29. For information, contact the Institute at 862-0556 or visit its Web site at iod.unh.edu.

Dr. Hagner, Rehabilitation Projects Director with the University of New Hampshire Institute on Disability, is a Certified Rehabilitation Counselor with more than 20 years' experience in teaching, research, evaluation and direct service. In addition to coordinating the community employment seminar series and mentorship project, he currently conducts research about employment supports for individuals with autism and homeownership for individuals with significant disabilities.

Dr. Hagner has published 5 books and over 35 chapters, monographs and journal articles related to employment and rehabilitation. He frequently lectures at regional and national conferences and has also been involved in training and consultation in Australia, New Zealand and Scotland. He also serves as Consulting Editor for the journal [Mental Retardation](http://www.mentalretardation.com).



Zachary Taylor's family: (from left) Justin, Tom, Zachary, Sue, Nick, Josh, Ashley Beznoska and Tasha the cat.

Photo: E. G. Stone

Support that makes a difference

by: Janet M. Krumm

Zachary's father Tom was the first to suspect. His son's behavior reminded him of a friend's son who was diagnosed with autism.

Sue at first dismissed Tom's suspicions. But in the summer after he turned two, Zachary was evaluated, and Sue was told by doctors at Dartmouth that "he's quite significantly autistic."

All Sue knew at that point was that she was overwhelmed. There were three other children in the house - Justin, who was three, Nick who was 10 and Josh 12. Sue had quit work and gone back to school to become a Registered Nurse (she was at that point an Licensed Practice Nurse) when Zach was a baby. To pick up the slack financially, Tom worked 80 hours a week as a contractor.

But it was Zach and his needs that demanded most of her time.

"When I first found out that Zachary had autism," Sue remembered, "with the three other kids, it was really, really difficult for me because he was very, very clingy and he required one-on-one 24/7.

Zachary at first would not go to anybody except for me. My husband would look at him and he would cry."

His sleeping patterns didn't help either. "He would wake up at one in the morning and be up til five and then be up all day," Sue said. "It was horrible."

Zach was also "a big safety risk," Sue explained. "He would run out into the street and just keep running. One time Justin had fallen, and when I went to tend to him, Zach of course sees that my back's turned and goes diving for the street. By the time I realized it, he was like halfway down the road. It was at that point that I decided that I needed someone to come and help me out."

Help came in the form of the Lakes Region Community Services Council, (LRCSC) the area agency for Region III.

Sue was told about respite services, and began the search for a respite provider. "I had looked for someone just so that I could do something with my other kids even if Zachary was with me," Sue explained. "At first, LRCSC didn't have

anybody available. They have paraprofessionals that work for them but (there were) only like three of them."

So Sue called local colleges searching for early childhood education students who might be interested in part-time work. "Some of them never even responded," Sue said in puzzlement.

Since Zachary was Medicaid-eligible, Sue was told that Medicaid money was available for CNA (Certified Nursing Assistant) services. She called a nursing agency and explained her needs. The nursing agency assured her that they could provide her with a CNA who had experienced with children with autism.

"They sent a nurse over," Sue recounted. "They did an extensive background on Zachary. I gave her a whole bunch of information on what his needs were."

They did find a CNA to work with Zachary, "but she had no experience with people with autism," Sue said. "So I ended up training her for a month, just as to what Zach's quirks were, because he's got a

lot of behavioral stuff and he's non-verbal. It takes a long time for Zach to warm up to people and for people to know how to read Zachary, because of his non-verbal status."

Attempting to augment the training she was giving the CNA personally, Sue informed the nursing agency that there were formal training programs available and that if the nursing agency would send the CNA to such a program, the area agency had offered to pay for it. They never took up the offer.

"So I signed her up for one myself," Sue said.

After about a month, Sue decided that she would have to leave Zachary alone with the CNA. "I had left one day and said, I gotta run a couple of errands. So I ran a couple of errands. I come back and she's got soap operas on, sitting in front of the television watching soap operas and Zachary is just like running around, going crazy in the house.

"I was really, really upset," Sue recalled, "because I had spent a month trying to work with this person."

If that was not enough to upset her, a staffing decision by the nursing agency stunned her.

"The nursing agency ended up sending her to another assignment after I had told them I need someone long term because Zachary is autistic and he gets used to one person." The nursing agency sent the CNA Sue had trained to work one-on-one with Zachary to work with a student with autism as a one-on-one aide in school. "So she ended up not working with Zachary after I trained her," Sue declared. "I was very, very upset."

"After I expressed my extreme disappointment in the fact that I had trained her the whole summer and then they ended up planning to send her with someone to school in September after I told them I wanted someone long-term, they said, 'Oh, no problem, we're gonna have someone come in for two weeks and she's gonna show her what to do'."

The Joy of Zachary

(clockwise) Sue holds Zach to calm him down when he gets overstimulated.

(top right) Ashley plays hide and seek with Zach in his bedroom.

(center right) Justin likes playing with his brother, but knows how to follow Zach's lead

(bottom right) Ashley directs Zach during play. Her attention to Zach frees Sue to tend to her other sons' needs.



Photography by: E.G. Stone

(bottom center) Tom built a huge family room to give Zach plenty of room to run around and play.

(upper left) It took Zach awhile to be comfortable with adults other than his mother. Ashley and Zach spend 4 hours a day, five days a week together at home.







Photo: E.G. Stone

Another CNA came, but did not show up the second day and ended up on medical leave for six months. Another CNA was sent, but by this time, the first CNA who had been trained was gone. That, it turned out, was irrelevant because that CNA never showed up.

"So I said, you know what, I'm done with the nursing agency staff," Sue said. "It left a very bad taste. I know not all nursing agencies are like that, but I spoke to CNAs later and they told me that they were sent to homes with autistic kids and they didn't know what to expect. They just had no training whatsoever. Medicaid is paying them, I know, a lot of money and they have no experience whatsoever. It's disappointing."

Fortunately for Sue, one of the paraprofessionals at LRCSC became available and came to work with Zach for about 12 hours a week. "She was experienced with kids with autism," Sue said, "and she was very, very good."

That arrangement lasted about ten months, and Zachary made definite progress during this time. Because Zachary was not comfortable with anyone but his mother, the early intervention team wanted to get him into a group setting. Thus Zachary was enrolled in an Early Head Start program. The paraprofessional accompa-

nied Zach to the program. "She was already trained. She was going there, not to do anything structured, but just to have him around other kids," Sue explained. "He did okay there."

When it was time for Zach to transition into the school system, the paraprofessional decided to return to school for her degree so she was not available to accompany him. Bill White from Zachary's early intervention team gave the school district a list of qualifications to use in selecting the paraprofessional who would work with Zack one-on-one.

"After the meetings, the school went and hired a person and they told me she had no experience with autistic kids," Sue remembered. "And they were expecting me to just go there and drop him off. I said no. I'll come in. So I went in for like 3 months and I showed the girl everything about Zachary myself. I basically trained her myself."

Because their school district did not offer a preschool program, Zachary was enrolled in The Whole Child Center in Tilton. "After his first day," remembered Sue, "I came home and I was like crying. (I said to myself) Oh, my God, she has no idea."

"Zachary threw himself on the floor and started pounding himself in the head. You should have seen the girl's face.

"This whole program has given me a lot of flexibility."

I didn't think she was going to last a minute. She goes, "Oh my God, I didn't know that they did that'."

When she came home that day, Sue called the Special Ed Director in her district. "I said, 'Look, Bill White told you the specifications, and this girl doesn't even know what the meaning of autism is.' And she said, 'Oh, quit whining!' I was totally mortified."

Sue's solution to the problem was, once again, to train the paraprofessional. In addition to coming into school every day, Sue signed her up for a training series offered by SERESC. When the paraprofessional hesitated out of concern for transportation, Sue enrolled herself and drove them both to the training. All of this effort paid off. "She's been with him since he started last April," Sue stated, "and she's wonderful."

Even with the training, however, there were still prob-

lems. Because the preschool program was outside the district and the nearest special education teachers and support personnel were at least eight miles away, there was no support for the paraprofessional in the preschool, and no resources available for Zachary's unique needs.

his own pictures, his own schedule book, provided all the pictures."

Sue complained to the school district. "This was ridiculous, I said. (There are) no resources. What's the purpose of sending him to preschool if I'm there with him everyday? To send my other son to a babysitter while I was there? It was ridiculous."

Sue said she "kicked and screamed" until the school district provided the funds for The Whole Child Center to hire a liaison between their program and the school district. That liaison works three mornings a week to make sure that the paraprofessional working with Zachary has the resources she needs and that Zach's IEP is being met. "That person is key," Sue emphasized.

While Zach's needs were finally being met at school, Sue still had needs at home. Once Zach came home,

"And I'm allowed to determine what she's being paid. Zachary has a certain budget a year and they said (I could) pay her up to \$10 an hour. Well, you know what, I wanna pay her \$10 an hour," Sue told them, "because these people are seriously underpaid. I mean you can go to Burger King and make \$9 an hour."

"This whole program has given me a lot of flexibility," Sue explained, "being able to hire this person, and be in the interviewing process and really determining how Zach's budget is going to be used and what she's being paid. That has worked out very, very well."

Ashley comes to the Taylor house five days a week for about 4 hours a day. She works on discrete trial trainings with Zach as outlined by the early intervention team. The service she offers the Taylors is very flexible. "Now I have time to sit down and do homework

"He wakes up and laughs for the first half hour of the day. I think that's the greatest thing in the world."

Tom Taylor

lems. Because the preschool program was outside the district and the nearest special education teachers and support personnel were at least eight miles away, there was no support for the paraprofessional in the preschool, and no resources available for Zachary's unique needs.

"I was bringing my own toys," Sue said. "I brought in all Zach's toys from home because the school district didn't (supply any). They paid the Whole Child Center a tuition and they expected that's it."

"The Whole Child Center had stuff, but not the stuff that Zach needed - cause and effect toys with music and lights and sound. The paraprofessional couldn't even find half the pieces to half the stuff if she did find something, because it's a preschool with tons of kids. So I brought in all his own toys,

he needed constant supervision and attention, making it difficult for Sue to attend to her other children's needs or even make supper. Once again, the area agency came to her help.

A pilot program was being started, she was told. "(The agency) did some creative financing through Medicaid," Sue explained. "They created a new position for respite and home supports and this girl is not a respite provider that comes in the afternoon to my house. She is a paraprofessional, but it's a family support aide."

Sue was involved in her selection and hiring. "LRCSC let me in on the interviewing process with this person," Sue explained. "It took me a few people to interview before I found one. She is working out very, very well."

with my other children where before Zach was pulling on my leg, or pulling a fit, or whatever," Sue said. But Ashley's services are not focused exclusively on Zach. If Sue wants to spend some time with Zach, Ashley can take over with the other children for awhile.

The schedule Ashley works has allowed her to go back to school and take classes in the morning. "It works out very good for the both of us," Sue admitted.

As a result of her experience, Sue has strong opinions about paraprofessional services. When asked what factors have the most impact on those services, Sue does not hesitate. Lack of training and pay are paramount. "CNA's have to go

Zachary

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What do you mean, certification?

The demand for paraprofessionals in our schools becomes greater every year. There were a total of 5,391 special education paraprofessionals working in New Hampshire school districts in the school year 2000-2001, the latest date for which figures are available. In that same year, there were 127 vacancies. (These figures are for special education paraprofessionals only.)

Carol Davis, Coordinator for the Comprehensive System of Personnel Development in the NH Department of Education, stated that "the number of paraprofessionals employed grows dramatically every year."

Qualifications to be a paraprofessional are few. New Hampshire does not require certification, although the Department of Education offers a certification that is optional. The one exception is a Medicaid re-

quirement that for a school district to receive reimbursement for "rehabilitative assistance" to a Medicaid-eligible student, the paraprofessional providing those services must be certified. The services provided must be health-care related, not academic, and a certified health care professional must sign off on the services each week.

Fulfilling the Medicaid requirement for certification, however, does not mean that the paraprofessional need actually be certified by the Department of Education. If the school district can document that the paraprofessional meets the equivalent of the requirements for certification, that paraprofessional is considered "certified" for Medicaid reimbursement purposes.

The Department of Education reports that of the 5,391 paraprofessionals work-

ing in the 2000-2001 school year, 4,732 of them were either certified or met the equivalency requirements for certification. There is no distinction in the data between the two categories.

The optional certification now offered by the NH Department of Education is good for a three year period and comes with a fee of \$80. To renew certification, a paraprofessional must complete 50 hours of CEUs (Continuing Education Units) within a three year period and pay the \$80 fee.

There are several programs in the state offering training for paraprofessionals. The College for Lifelong Learning (CLL) offers a Basic Paraprofessional Training Program and an Advanced Paraprofessional Training Program.

The Basic course is a 42 hour college level course offering instruction in six competency areas: Educational Professionalism, Special Education Services, Child Development, Communications, Behavior Management, and Health and Safety Issues.

Applicants must have a high school diploma and must currently be employed in a New Hampshire school.

Upon completion of the course, a participant receives a CLL certificate which is authorized by the State of New Hampshire and is good for three years. The CLL certificate also provides the certification necessary for schools to receive Medicaid reimbursement. At the end of three years, the paraprofessional must apply for certification from the State Department to retain certification as a paraprofessional. According to

Jean Shlager, Project Coordinator at CLL, 1600 people have completed the Basic course since 1995.

The Advanced course consists of three 4 credit courses. A paraprofessional would take this course for additional professional development as a paraprofessional or to work toward special education teacher certification. These courses can be applied to appropriate degree programs in the College for Lifelong Learning.

Judith Fillion, Director of the Division of Program Support in the NH Department of Education, considers the career ladder provided by the CLL program to be "more and more important." It provides "quite a pool of candidates for general and special education teachers." Those who complete the Advanced program can then use the Alternative 4 option towards certification as a teacher.

Davis agrees with Fillion. "Having a strong career ladder is wonderful for the profession as a whole," she said. "It's good for the profession; it's good for the students and the families they serve."

New Hampshire Technical Institute in Concord offers two additional programs: the Certificate Program in Special Education, which is a one-year program and an Associates Degree in Education, a two year program. The certificate program, created four years ago, consists of 6 courses for a total of 20 credits. Ellen Dokton at NHTI was instrumental in creating these programs in cooperation with the NH Department of Education. According to Dokton, recent legislation indi-

cates a trend which will make programs such as the one at NHTI important.

After January 8, 2002, all Title I paraprofessionals newly hired must have the equivalent of an associate's degree. Anyone who is currently working as a Title I paraprofessional has three years to meet the new requirement. This is a new standard created by Bush's Leaving No Child Behind legislation. Referring to the new standard for Title I paraeducators, Dokton said, "I.D.E.A. is going through the exact same process, and it's going to follow suit." What that means, according to Dokton, is that special ed paraeducators will need a minimum of an associate's degree for certification.

Still another training program is offered by SERESC. Developed in 1998 with a grant from the NH Department of Education and in cooperation with the NH Department of Health and Human Services and the Autism Society of New Hampshire, SERESC offers workshops for parents who are working with children with autism. There are now introductory and advanced sessions which are offered regionally. SERESC reports that 2,000 people have received training through these workshops.

The topics covered in the workshops include: Sensory Processing, Communication Development, Community Supports, Parent Perspectives, Play, and Behavior Management. Scholarships are offered for those who cannot afford the price.

Zachary

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through a course. Why don't paraprofessionals?" she asked. "Why aren't they licensed? It makes it a more dignified profession and maybe they can be recognized and get paid (more) because of that."

The paraprofessional who works with Zach at his preschool "makes \$8 an hour," Sue stated. "She works with Zach one-on-one half the day and then she works just at the regular preschool the rest of the day and she only makes \$6 an hour. That's pathetic." And, she added, the reason she works the additional hours is for the benefits the school district doesn't provide.

Sue is equally dismayed over the lack of qualifications for paraprofessionals. "There should be a standard that schools have to go by in hiring these people," she stated. "You don't just hire a teacher off the street. You're working with a special ed child. These people should even be more highly trained. Joe off the street with no teaching experience is going to go into a classroom and know how to educate my child? It's crazy.

"(The paraprofession-

als) are responsible primarily for their (the kids with disabilities) education, the way I see it. It's scary, sometimes."

The Taylors just want to be a family. They go to soccer games, skateboarding activities, baseball games, where Zach is recognized and accepted. They are a part of the community and try to make sure that Zach is as much a part as the rest of them.

When asked what challenges Zach presents to him as a father, Tom shakes his head not understanding. He doesn't see Zach as a challenge. He's just his son and his autism is just the way things are. "He wakes up and laughs for the first half hour of the day," Tom remarked. "I think that's the greatest thing in the world."

"Zachary is just a joy and he's so funny and he's cute," Sue enthused. His brothers "are awesome with him," she added. "They see him as a little brother who does funny stuff, just like any other 3 year old.

"They've all had to make adjustments as far as my attention and time, but now that I have this person at home, it makes a very big difference."

Resources for Paraprofessionals:

The National Resource Center for Paraprofessionals in Education and Related Services

Offers articles and information, training materials and other resources

www.nrcpara.org/

The National Clearinghouse for Paraeducator Resources

www.usc.edu/dept/CMMR/Clearinghouse.html

A Guide for Direct Support Professionals

A publication of the NH Developmental Disabilities Council, providing information detailing an overview of the developmental services system, regulatory references, grievance processes, self-advocacy, and family support and a listing of often-used acronyms. For information, call the NH Developmental Disabilities Council at 271-3236.

For information on the training programs, contact the following:

Jean Shlager
Project Coordinator
College for Lifelong Learning
447-3970

Ellen Dokton
NHTI
271-2722

Carolyn Woodman
SERESC
434-0552

Direct care workers need support and respect

Continued from page 1

those funds reinstated.

Janet Williamson, a parent of an adult receiving services, has served on many boards where this issue has been discussed. "Everybody recognized the fact that direct care people in the adult care delivery system are at minimum wage, entry level," Williamson stated. "But when you talk about raising the salaries, because of the numbers of people we employ at that level, it's a huge thing."

Williamson doesn't have the answer to this issue but says: "Until we figure out a way to compensate people fairly, we're not going to get people to stay on board. We're not going to get people to buy into values and expectations when they're just trying to stay above water personally."

"In the group home environment," she explained, "it's not uncommon for people to be working 60, 70, 80, 100 hours a week to provide for families. So what energy level, then, do they bring to those jobs? How can we sit down and say, oh and by the way we want to sit down and talk about having greater expectations for the people you support, and put all this energy into figuring out the dynamics of increasing opportunities for people. How can we expect that?"

Michelle Mayo, a home care provider for her cousin who has a developmental disability, says that while money is important, it's not the only issue. While acknowledging the need to have enough money to meet her expenses, she emphasized: "For me, it was never about the money. Okay, I have to have a living. I have to have enough money to survive. But it wasn't that all these 10 years. It was lack of respect."

Mayo has been a home care provider for about 10 years, ever since she took her cousin Mildred out of the NH State Hospital where she had lived for nearly 30 years. Once Mildred came to live with her, Mayo re-

alized she had a lot to learn. "It's one thing to have a big heart," Mayo said, "but then reality set in. I realized I had to learn the system."

What she learned spurred her to co-found an organization for direct care providers - Direct Support Professionals Association of New Hampshire (DSPANH - pronounced D-Span). With the support of the NH Developmental Disabilities Council and legal help from DDC board members, DSPANH became a 501(c)(3) nonprofit boasting at one point 145 members.

Membership recently has dwindled, Mayo said, "in

One of the big issues Mayo sees system-wide are contracts that home care providers sign with vendor agencies. Typically, the contracts include language prohibiting home care providers from talking directly with families or guardians about the individual living with them. Once she realized this, she took a look at her own contract, saying "I was appalled!" Instead of speaking with families, home care providers are directed to come to the vendor agency with any concerns.

Language like that only emphasizes an attitude that Mayo says is prevalent throughout the system - direct care

alized their whole life," Mayo said, referring in part to her cousin. And, because agencies are so desperate, she continued, staff who are not seasoned are put into situations with not some enough training, making it very difficult for them.

Williamson received similar feedback in the process of working to create different living arrangements for her son. "I interviewed a lot of the group home staff," Williamson said. "I talked to them and tried to figure out what was going on here."

"Salary, yeah, was an issue. Supervision was another key factor. Being able to access

from DSPANH, vendor agencies, area agencies, and the Department of Health and Human Services came together to discuss the issues. Out of that task force came a list of best practices for direct support professionals (DSP):

1. Provide DSPs with adequate education and training;
2. Trust DSPs and treat them with respect;
3. Give them fair and equitable compensation;
4. Expand the benefits given to them;
5. Provide a mechanism for communication so that information about state laws and regulations will be disseminated among the DSPs;
6. Develop fair and equitable grievance procedures.

"There is no relief in the system for us," stated Mayo. "We can be let go for any reason. There are no rules and regulations to protect us. There is no grievance process in place."

As the system incorporates the concepts of self-determination and self-directed services, the direct support professional becomes more important, Mayo said. "The way the system is going, the next step is that families and individuals can now take their money and shop around and do what they want. And that makes us even more important as DSPs, because they need us whereas they don't necessarily need a manager."

Speaking for all DSPs, Mayo says: "We love working with (individuals with disabilities). We love enriching their lives. They enrich ours, also. It's a give and take thing."

Until the concerns of DSPs are met, however, agencies will continue to have problems recruiting and keeping good, qualified people. Families have a role to play in this arena, Mayo believes. "You as a family member are our best ally in getting our needs met right now at this point in time," she stated.

"Until we figure out a way to compensate people fairly, we're not going to get people to stay on board. We're not going to get people to buy into values and expectations when they're just trying to stay above water personally."

Janet Williamson

part because people do not have the time to go to meetings." There are several reasons for that, according to Mayo. "There is no replacement staff available" to allow them to take the time off, and some of the vendor agencies for whom people work consider the organization to be composed of "troublemakers who will come back with new-found information and tell (other workers) what's going on."

Mayo wants to make families aware of the issues that face direct support professionals, as she prefers to call them. "We realized that we have to start educating families and the Office of Public Guardian (OPG) about this system that we're in," she stated, "because they just don't know. They haven't a clue."

workers are not respected. According to her, they are not asked information when it is they who know the individual best. They are not included in developing the individual's Individual Service Plan (ISP). "I should have a part in forming (an individual's) program," Mayo asserts, "a program that (the agency) expects me to do." Not being valued causes a great deal of frustration among direct care workers and home care providers, Mayo stated.

Other issues are the ratio of direct care workers to the individuals they serve. Because of the difficulties in finding people to work, direct care workers are often responsible for two to three people, according to Mayo. "That's too much, especially when you have somebody who has been institution-

management or supervision right away when they needed help was a problem.

"Co-worker support was another factor they either did or didn't have that made a job really good or not good, depending on who they were working with for co-workers. So it wasn't just dollars that they were talking about."

"Training was another thing they didn't feel they got enough of. They would get some general training at the area agency but training around individuals, specific to what's going on with that person, they didn't feel they received adequate resources for some of those things."

Mayo participated in a task force that was created by the DD Council to address issues facing direct support professionals. Representatives

Hold the date!

The Direct Support Professionals 8th Annual Conference will be held on October 25 and 26, 2002 at the Center of New Hampshire, Holiday Inn. This year the conference will be held in conjunction with the Northeast Region 10 AAMR Annual Conference to provide direct support professionals opportunities to network with families and with other professionals. For more information, call the NH Developmental Disabilities Council at (603) 271-3236, or Michelle Mayo at (603) 433-0012.

Upcoming Events

Special Olympics New Hampshire Regional Basketball Tournaments

Dover March 9
 Salem March 17
 Keene March 17

Basketball Tournament

(Unified and Traditional)
 Portsmouth April 6 & 7

Seacoast Regional Swim Meet

Dover April 13

Regional Summer Games

Great North Woods May 19
 Monadnock & Conn. River May 19
 Lower Merrimack May 11
 Central May 11
 Seacoast May 19
 For info, call 1-800-639-2608

The Ethics of Touch

Helping individuals with developmental disabilities understand physical boundaries
 Facilitator: David Hingsburger
 March 13, 2002
 9 AM to 3:30 PM
 Portland, ME
 For info, call 1-800-488-9638

The State of Education in NH

Forums conducted by the NH Department of Education to listen to families' concerns

"IEPs. What's Working? What's Not?"

March 14, 2002 6-8 PM
 Dept of Ed, 101 Pleasant Street, Concord, NH

"Special Education: What's Working? What's Not?"

May 7, 2002 6-8 PM
 Littleton, NH
 For info, call 271-3494

7th Annual Autism Spectrum Disorders Symposium

March 15 & 16, 2002
 Rhode Island Convention Center
 Providence, Rhode Island
 For info, call 508-677-9239, x 41

2002 New Hampshire Family Support Conference

May 3, 4, & 5, 2002
 The Grand Summit
 Bartlett, New Hampshire
 Scholarships are available.
 For info, call your regional family support coordinator (see listings on page 17 & 18)

Need help with costs for recreational activities?

There's another source for help besides your area agency. CRA/DD is an organization formed to fund recreational activities for individuals with developmental disabilities.

Coalition for Recreational Activities for the Developmentally Disabled (CRA/DD) is a nonprofit organization staffed by volunteers, negating the need for administrative costs. All funds go directly to the mission of the organization: assisting individuals with developmental disabilities access recreational programs.

An Annual Classic Golf Tournament is held yearly at Campbells' Scottish Highlands Golf Course in Salem, New Hampshire as a fundraiser for the organization. In 1999, the group raised \$12,500, enabling them to fund 45 applicants in the year 2000. In 2000, the money raised increased to \$23,000, allowing funding for 105 requests in 2001.

Examples of recreational opportunities funded by CRA/DD are: swimming lessons, horse-back riding lessons, karate, membership in an athletic club, bowling, and attendance at a summer camp.

Interested individuals must fill out an application. Grants are capped at \$250 per individual or family. Once an application has been approved, a check is sent directly to the program, not to the individual.

The deadline for applications is April 1. For more information, call (603) 893-8597.

Respite Fund Request 2002 Application

Please print or type all information.

Date _____

Applicant's name _____ age _____ phone number _____

street address _____ city _____ state _____ zip _____

name and phone number of person completing this form _____ relationship to applicant _____

Please state type of disability _____

Please describe the activity for which you are requesting funding:

Attach a brochure or pamphlet or other supporting documentation which includes the cost and description of the activity. Please submit a brief explanation about how the activity will benefit the applicant.

Date(s) of planned participation in activity _____

*This grant has a cap of \$250 per individual or family. The check is sent directly to the activity location. It is **not** sent to the applicant.*

Total cost of the activity _____ Amount requested _____

Has the applicant received grant funding from CRA/DD in the past two years? _____

I certify that the information provided on this application is true, complete and accurate to the best of my knowledge. I will submit to CRA/DD a brief summary of my experiences upon completion of the activity. Failure to do so will jeopardize future requests for funding. I agree to allow CRA/DD to use any pictures I send back for publication.

 applicant's signature, or signature of person filling out this application

Applications must be received by April 1, 2002.

Incomplete applications will be automatically denied.

Area Agencies

for Developmental Services

REGION I

North Country

Northern New Hampshire Mental Health and Developmental Services, Inc.

87 Washington Street, Conway, New Hampshire 03818
Dennis MacKay, Exec Dir., Eric Johnson, Assoc. Director

Phone: 447-3347 **Fax:** 447-8893

e-mail: dmackay@nnhmhds.org **website:** nnhmhds.org

Area Offices:

Upper Connecticut Valley Mental Health and Developmental Services(MH)

Charlie Cotton, Area Director

34 Colby Street, Colebrook, New Hampshire 03576

Phone: 237-4955

White Mountain Mental Health and Developmental Services (MH) outpatient MH

29 Maple Street, P. O. Box 599, Littleton, New Hampshire 03561

Jane MacKay, Area Director

Phone: 444-5358

Family Centered Early Supports and Services

31 Brooklyn Street, Groveton, New Hampshire 03582

Phone: 636-2555 or 1 (800) 862-8634

Developmental Services:

Community Services Center

69 Willard Street, Berlin, New Hampshire 03570

Art Froburg, Area Director

Phone: 752-1005

Common Ground

headquarters for day service & case management

29 Maple Street, Box 599, Littleton, NH 03561

Phone: 444-6894

Vershire Center

39 Colby Street, Colebrook, NH

Phone: 237-5721

Family Resource Center - Parent to Parent services: providing support and connections for parents of children with developmental disabilities and special or chronic health care needs

123 Main Street, Gorham, NH 03581

Phone: 466-9011, or 1 (800) 771-8531

Region I:

Berlin area -

Family support and Respite coordinator: Lena Parent 466-9010
parent@nnhmhds.org

Benefits Technician: Sharon Kolinsky 752-1005 kolinskysg@landmarknet.net

Colebrook/Groveton -

Family support Respite coordinator: Stacey Bilodeau 636-1090, or 636-2555
sbilodeau@nnhmhds.org

Benefits Technician: Lynda Biron 237-5721 lbiron@nnhmhds.org

Littleton -

Family support and Respite coordinator: Diana Flick 444-1742
dpelletier@nnhmhds.org

Benefits Technician: Terri Paige 444-5358

Family Support Council Chair: Cecile Fillion 752-5704 cecilef@ncia.net

REGION II

Sullivan County

Developmental Services of Sullivan County, Inc.

R.F.D. #3, Box 305, Claremont, New Hampshire 03743
Mark Mills, Exec Director

Phone: 542-8706 **e-mail:** mmills@dsscofnh.org

Case Management: 542-8706

Adult Services: 542-8706

Family support coordinator: Laura Herrin 542-8706
lherrin@dsscofnh.org

Respite coordinator: Kristina Allen 542-8706
Kallen@dsscofnh.org

Benefits Technician: (there's no one currently in this position)

Family Support Council Chair: Lilly Barton 835-2523

REGION III

Lakes Region

Lakes Region Community Services Council

(Serves all of Belknap & 12 towns in southern Grafton Co.)

P. O. Box 509, Laconia, New Hampshire 03247

(Residential, vocational, quality assurance, business, case management, family support, & enhanced family care)

Rich Crocker, Exec. Director

Phone: 524-8811 **Fax:** 524-0702

e-mail: richc@lrsc.org **website:** www.lrsc.org

Family support coordinator:

Christine Santaniello 524-7755 chriss@lrsc.org

Respite coordinator

Denise Sleeper 524-7755 denises@lrsc.org

Benefits technician: Lisa Richardson 524-7755

Family support council chair: Tracy Mansfield 528-1713

REGION IV

Capitol District

Community Bridges

525 Clinton Street, Bow, New Hampshire 03304-4609

Roy Gerstenberger, Exec. Dir.

Phone: 225-4153 or 800-499-4153

e-mail: roy@comm_bridges.mv.com

Family support: Jo Edwards 225-4153 (800) 499-4153, x 224
jo@comm-bridges.mv.com

Respite coordinator:

Renee Carlisle 225-4153 (800) 499-4153, ext.215

Benefits Technician: Rebecca Spinney 225-4153 ext. 222

Family support council chair: Annette Beaudet 224-1524

Family support council co-chair: Becky Thompson 225-4564

REGION V

Monadnock

Monadnock Developmental Services, Inc.

121 Railroad Street, Keene, New Hampshire 03431

Alan Greene, Exec. Director

Phone: 352-1304 **Fax:** 352-1637

e-mail: alan@mds-nh.org **website:** www.mds-nh.org

Family support coordinator:

Bob Barrows 352-1304 (800) 469-6082 bob@mds-nh.org

Respite coordinator:

Carol Byrns 352-1304 carol@mds-nh.org

Benefits technician: Sue Raymond 352-1304

Family support council chair: Cameron Tease

ctease@marken.com

Family support council co-chair: Debra Napsesy 984-0972

REGION VI**Nashua****The Area Agency for Developmental Services of Greater Nashua, Inc.**

144 Canal Street, Nashua, New Hampshire 03060

Sandra Pelletier, Exec. Dir.

Beth Raymond, Assoc. Dir.

Phone: 882-6333**Fax:** 889-5460**e-mail:** sandyp@region6.com **website:** www.region6.com**Affiliate Agencies:****The PLUS Company, Inc.**

240 Main Dunstable Road, Nashua, NH 03062

Kim Shottes, Exec. Dir.

Phone: 889-0652**Fax:** 880-8938**e-mail:** kims@region6.com **website:** www.thepluscompany.net**Adult Day Service Program**

200 Derry Road, Hudson, NH 03051-3398

Deb Wall, Director

883-0994

No Fax

e-mail: dwall@alvirnehs.org**Early Intervention and Pediatric Therapy**

144 Canal Street, Nashua, NH 03064

Nancy Dowey, Prog. Coord. **e-mail:** nancyd@region6.com**Phone:** 882-3434**Fax:** 889-5460**Family support coordinator:** Nzenalu Obinelo 882-6333, ext. 372

nzenaluo@region6.com

Respite coordinator: Carole Smith 882-6333 x 325

caroles@region6.com

Benefits technician: Sue Rockwell 882-6333 suer@region6.com**Family support council chair:** Peter Marcoux 888-5894

peter@coftab.net

REGION IX**Strafford County****Behavioral Health and Developmental Services of Strafford County, Inc.**

Forum Court, 113 Crosby Road, Suite #1, Dover, New Hampshire 03820-4375

Brian Collins, Exec. Director

Phone: 749-4015**Fax:** 743-3244**e-mail:** bricol@concentric.net**website:** www.dssc9.org**Family support coordinator:** Deirdre Watson 749-4015 dwatson@dssc9.org**Respite coordinator:** Karen Juckett 749-4015 kjuckett@dssc9.org**Benefits technician:** Julie Batchelder 749-4015 jbatchelder@dssc9.org**Family support council chair:** Chuck Raymond 743-3909 chuckray@ttlc.net**Family support council vice-chair:** Karen Salter 692-2088 ksalter@aol.com**REGION X****Atkinson/Salem****Region 10 Community Support Services, Inc.**

8 Commerce Drive, Atkinson, New Hampshire 03811

Dennis Powers, Exec Director

Phone: 893-1299 **Fax:** 893-5401**e-mail:** dpowers@region10nh.com **website:** www.region10nh.com**Family support coordinator:** Kathy Waterson 893-1299

kwaterson@region10nh.com

Respite coordinator: presently vacant**Benefits technician:** Maureen Monahan 893-1299 monahan@region10nh.com**Family support council chair:** Cathy Forgit 382-7791 ccathyf@attbi.net**REGION XI****Carroll County****Center of Hope, Inc.**

626 Eastman Road, Center Conway, New Hampshire 03813-4219

Peter Blue, Exec Director **e-mail:** pblue@centerofhope.orgMargie Matthews, Assoc. Exec. Dir. **e-mail:** mmatthews@centerofhope.org**Phone:** 356-6921 or (800) 290-0905 **Fax:** 356-6310**Family support coordinator:** Christine MacDonald 356-6921 x50

(800) 290-0905 cmacdonald@centerofhope.org

Respite coordinator: Tina Wallace 356-6921 x49 twallace@ceterofhope.org**Benefits technician:** Lindell Gorham 356- 6921 x26

lgorham@centerofhope.org

Family support council chair: Frances Hyslop 539-3599exe4me@metrocast.net**Family support council vice-chair:** Dennis Parcels 539-6674**REGION VII****Manchester****Moore Center Services, Inc.**

132 Titus Avenue, Manchester, New Hampshire 03103

Paul Boynton, CEO

Phone: 668-5423**Fax:** 206-2706**e-mail:** paul.boynton@moorecenter.org **website:** www.moorecenter.org**Family support coordinator:** Jan Larsen 206-2744 jan.larsen@moorecenter.org**Respite coordinator:** Joy King 206-2743 joy.king@moorecenter.org**Benefits technicians:**

Linda Lawrence 206-2768 linda.lawrence@moorecenter.org

Audrey Mason 206-2770 audrey.mason@moorecenter.org

Family support council chair: Donna Nicholaides 624-1592**REGION XII****Grafton County** (serving Grafton, Canaan, Enfield, Lebanon, Hanover, Lyme and Orford)**United Developmental Services**

85 Mechanic Street, Suite 300, Lebanon, New Hampshire 03766

Bruce Pacht, Exec Director

Phone: 448-2077**Fax:** 448-1841**e-mail:** bruce@uds.org**Family Centered Early Supports and Services**

104 Lyme Road, Hanover, New Hampshire 03755

Kathy Marshall, Coordinator

Phone: 643-5439**Fax:** 643-6223**e-mail:** Kathy@uds.org**Family support coordinator:** Tara Mullen 443-4109 tara@uds.org**Respite coordinator:** Melissa Eastman 443-4113 melissa@uds.org**Benefits technician:** Elaine Campeau 443-4103 elaine@uds.org**Family support council chair:** Elizabeth Larson 448-5302

elizabeth.s.larsen@hitchcock.org

Upper Valley Support Group (UVSG) (provides emotional support & info)**Phone:** 448-6311**UVSG Respite Program coordinator:** Leona Ryder 448-1268**REGION VIII****Seacoast****Region VIII Community Developmental Services Agency, Inc.**

Parade Office Mall, Suite 40, 195 Hanover Street

Portsmouth, New Hampshire 03801

Bob James, Exec Director

Cathy King, Associate Executive Director

Phone: 436-6111**Fax:** 436-4622**e-mail:** bob@cdsregion8.org**Family support:** Lenore Sciuto 436-6111 lenore@cdsregion8.org

Mary Dawn Corey 436-6111 MaryDawn@cdsregion8.org

Respite coordinator: Geoff Simons 436-6111 geoff@cdsregion8.org**Benefits technician:** Denise Larsen 436-6111 denise@cdsregion8.org**Family support council chair:** Kathy Ennis 964-9740



Where to Find Help

Statewide Resources:

AMI-NH - Alliance for the Mentally Ill of New Hampshire
225-5359, or (800) 242-NAMI
Statewide organization and affiliates offer information and support to people with serious mental illnesses and their parents, children, spouses, siblings and friends.

ATECH Services
528-3060, or 1 (800) 932-5837
Website:
www.nhassistivetechology.org
ATECH is an umbrella organization under which the following organizations function:

NH-ATEC
67 Communications Drive
Laconia, NH 03246
1-800-932-5837
Seating & mobility
Augmentative & alternative communication
Computer access
Home & worksite modifications

ASSETT - Assistive Services to Schools for Education, Technology and Training -
117 Pleasant Street
Dolloff Bldg.
Concord, NH 03301
226-2900
Consultations & Technical assistance; Loans of specialized equipment and materials; Training for educators, parents & children; Library for families & educators

REM (Refurbished Equipment Marketplace)
84A Ironworks Road
Concord, NH 03301
222-2384, or 1 (800) 427-3338
e-mail: pluff@nhaat.mv.com
website:
www.neatexchange.org
Sale of quality refurbished equipment; Rentals, service & repair; Information & referral services; Inventory on website

Technology Exploration Ctr.
117 Pleasant Street
Dolloff Bldg.
Concord, NH 03301
226-2900
Hands-on technology exploration; Loans of assistive technology; Training; Technical support

Autism Society of New Hampshire
898-0916
Statewide organization provides

information, advocacy and support to individuals with Autism and Pervasive Developmental Disorders (PDD), and their families.

Bureau of Special Medical Services 271-4488, or 1-800-852-3345 ext. 4488
Division of Public Health; broad range of health programs for diagnosis and treatment of children (0-20) who have physical disabilities, chronic illnesses or developmental delays

Child Development Center
650-7884
Assessment, diagnosis, follow-up; information and education

Council for Children and Adolescents with Chronic Health Conditions and their Families
1-800-656-3333
Information and advocacy

Department of Education Bureau of Special Education
271-3741
www.ed.state.nh.us
Responsible for ensuring that school districts provide a free and appropriate education to all educationally handicapped students

Disabilities Rights Center, Inc. 228-0432, or 1-800-834-1721 Fax: 225-2077
Provides legal services and other advocacy assistance to persons with disabilities; information/referral

Bureau of Vocational Rehabilitation
271-3471 or 1-800-299-1647
Fax: 271-7095
www.ed.state.nh.us
Provides individualized guidance, counseling and placement services to all eligible consumers; also provides family services around needs of individual

Early Education and Intervention Network of N.H.
228-2040 www.eein.org
Information/referral; early intervention and pre-school programs for children with developmental disabilities or at risk for developmental delay.

Family Resource Connection
1-800-298-4321
Free, statewide program of the

NH StateLibrary that provides materials on all aspects of raising, caring for and educating children, especially children with special needs; also free lending library of books and videos mailed to your home with postage paid envelopes for return; free research and reference service.

Family Support Coordinator, DDS (Kris Bregler)
271-5057
1-800-852-3345 x 5057
kbregler@dhhs.state.nh.us
Can direct you to services available through the Division of Developmental Services (DDS), the 12 Regional Area Agencies and Regional Family Support Programs

Governor's Commission on Disability
271-2773 (Voice),
271-2774 (TTY)
1-800-852-3405 (V, TTY)
website:
www.state.nh.us/disability
Information and referral

Granite State Guardianship Services Phone: 837-9561
Fax: 837-2613
Provides legal guardianship services to people with developmental disabilities and mental illness.

Granite State Independent Living Foundation
228-9680, (V, TTY)
1-800-826-3700(V/TTY)
website: www.gsil.org
Information and referral, peer support and counseling, skills training, advocacy, interpreter services, personal care attendant services, transportation, social and recreational programs and accessibility services.

Institute on Disability/UAP
228-2084 Fax: 228-3270
862-4320 Fax: 862-0555
www.iod.unh.edu
Training, technical assistance and resources with the goal of improving the quality of life and level of participation of people with disabilities in schools, the community and the workplace

Medical Genetics 650-7886
Genetic testing and counseling, information and referral
M.I.C.E. (Multi-sensory In-

tervention through Consultation and Education)
228-1028(V) 228-5755 (TTY)
Statewide program for educational and developmental services for children birth through three with visual or hearing impairments.

NH Association for the Blind
224-4039 (800) 464-3075
Provides information and gives direct services to visually impaired people of all ages to enable them to maintain their independence.

NH Brain Injury Association
225-8400, or (800) 773-8400
www.bianh.org
Statewide organization provides resource information to survivors of brain injury and their families.

N.H. Developmental Disabilities Council
271-3236
1-800-852-3345, x 3236
www.nh.ddc.com
Monitors services; promotes policy; advocacy

NH Family Voices, a Family to Family Health Information and Resource Project
271-4525, or
1 (800) 852-3345 x 4525
e-mail: NHFV@yahoo.com
website: www.nhfv.org

Assists families in finding their way through the maze of services by providing information and emotional support, identifying resources available within the community, and making available a lending library of books, videos and audio tapes; distributes free newsletter, *Pass It On*

Northeast Passage
862-0070
Provides (for a fee) equipment and expertise to individuals, schools and companies to ensure access to educational outings and recreational activities.

Office of Public Guardian
224-8041
Provides legal guardianship services for people with developmental disabilities and mental illness.

Parent Information Center
224-7005, or 1-800-232-0986
Information, support and training around educational issues

including Individual Educational Plans (IEP's) and advocacy

Parent to Parent of NH
1-800-698-5465
www.p2pnh.org
Specializes in networking parents of children with special needs; support and information

People First of New Hampshire
536-9797, or 1 (800) 639-6172
Self-advocacy group of people "working together to help each other take charge of our lives"; help team available for new or existing groups; 24-hour answering service

Seacoast Child Development Clinic at UNH
862-0561 (Voice/TDD)
862-0034 (fax)

www.iod.unh.edu
An interdisciplinary clinical consultation service, assisting families of children with developmental disabilities by using a team approach. Evaluation may include home and/or school visit, depending on needs of child and family. The program is affiliated with Dartmouth Center for Genetics and Child Development and the Institute on Disability, UNH.

Self-Determination for Persons with Developmental Disabilities -
Institute on Disability/UAP
862-44320 Fax: 862-0555
www.iod.unh.edu
Provides information, referral and technical assistance

Special Olympics NH
624-1250 or 1-800-639-2608
Provides sports activities for athletes with developmental disabilities.

"Talking Books"
(NH Bureau of Services to Persons with Disabilities)
271-3429, or 1-800-491-4200
FREE service for people with visual, physical, and reading disabilities. Supplies (by mail) cassette books and records and equipment needed to use them. Fiction, non-fiction and popular magazines available

VSA arts of New Hampshire
228-4330
Provides opportunities in the arts for people with disabilities



Where to Find Help

Helpful Websites:

www.aapd.com

American Association of People with Disabilities

www.access-able.com/

Access-Able Travel Resource

www.adanet.org

American Disability Association

www.albinism.org

The National Organization for Albinism and Hypopigmentation

www.allsupinc.com

Healthcare and Disability Reimbursement Services

http://aspe.os.dhhs.gov/cfda

Hundreds of publications on disability-related subjects available on-line

www.assistguide.com

Assist Guide - National resource for disability and long term care

www.csni.org

Community Support Network, Inc.

www.disabilityresource.com

The Disability Resource

www.eseals.org

Easter Seals NH

www.essential schools.org

Coalition of Essential Schools

www.hcfa.gov/

Information from the US. Centers on Medicare and Medicaid (formerly the U.S. Health Care Financing Administration)

www.hhs.gov/newfreedom/

webpage of US Department of Health and Human Services announcing activities conducted as part of President Bush's New Freedom Initiative

www.newhorizons.org

New Horizons for Learning

www.nhhelpline.org

New Hampshire Help Line

www.nod.org

National Organization on Disability

www.ppcd.org

People to People Committee on Disability

www.sath.org

Society for the Accessible Travel & Hospitality

www.ssa.gov.SSA_Home.html

Information on Supplemental Security Income (SSI), disability and related benefits

Publications of Interest

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