

The New Hampshire Challenge

disability issues from a family perspective

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Benefits Update

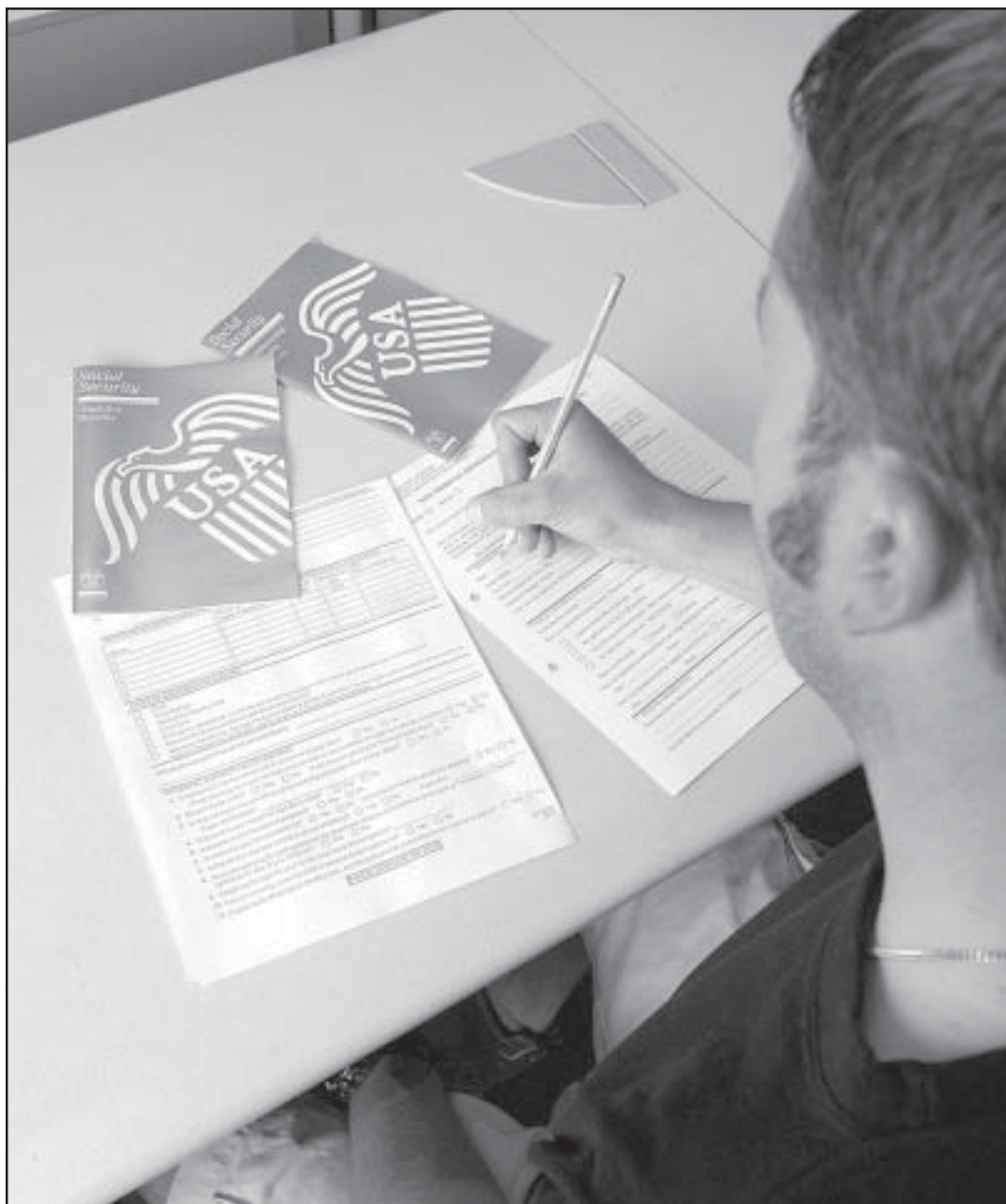


Photo: E.G. Stone

The last time The Challenge reported on Federal and State benefits programs was 1997. There have been a number of changes since then, including the introduction of new programs. In this issue, we present updated information on SSI, SSDI, APTD, ANB, Medicare and Medicaid. Turn to pages 10 through 21.

The State Budget and the Waiting List: What now?

There will be no money for the waiting list for the next three months. The 495 people who are on the Priority 1 and Priority 2 lists will have to wait until October to find out if there will be funding for the services they need. And that doesn't include people on the Priority 3 waiting list - those individuals in their 40s and older with aging parents whose current situations are tenuous because of the fading health or growing incapacity of their parents.

In the budget that came out of the Committee of Conference and was passed by the House and Senate, \$17.8 million was appropriated for the waiting list. This is the budget that was prominently vetoed by Governor Benson. When a Continuing Resolution was passed by the House and Senate and signed by the Governor to avoid a government shutdown, the level of funding approved until October 1 was the same level of funding as in the budget that was vetoed.

That's not the amount of money available to area agencies to spend, however.

"Right now, all we have are the contracts that were approved by Governor and Council in June," explained Bruce Pacht, executive director of United Developmental Services

(UDS), the area agency for Region 12. "And those contracts were all predicated on the Governor's original cut budget, with reduced amounts and no waiting list money. That's it. Until the division (of developmental services) tells us something different, we're not going to spend any other money."

Pacht doesn't expect the division to amend the contracts until a final budget is passed. "If this were your kitchen table," he explained, would you "spend like crazy for three months" if for "the following nine months, you only get to spend half" because the budget figures have been changed?

The effects of this budget have been felt long before the fiscal year began on July 1. Pacht's agency has already completed administrative reconfigurations to prepare for the expected cuts. "We dropped 4-5% of our direct support staff load," he stated, "and we closed the early intervention location and brought that staff into the Mechanic Street location where everybody else is. We think we're going to save on transportation and make some administrative savings."

It's the effects on the lives of people that disturb him.

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Yvonne Jenkins is one member of a group of parents in the North Country who are working together to create a transition program after graduation from high school for their sons and daughters. Working with their school districts and many agencies in their community, they have asked people to "think outside the box." Read about their efforts starting on page 6.

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of the ultimate powers
of the society but the
people themselves;

and if we think them
not enlightened enough
to exercise their control
with a wholesome discretion,

the remedy is not
to take it from them, but
to inform their discretion
by education.

Thomas Jefferson

In a letter to
William Charles Jarvis
September 28, 1820

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Waiting list still waiting

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"We started what we call doubling up," he explained. "Individuals with disabilities are not going out on their own one-to-one with staff anymore. Everybody has to pick somebody else, or you don't go out."

"It's a major change in philosophical approach to what quality of life means," he admitted. "In some cases, it's nice. People who like each other have a great time. But, you know, you don't like everybody every day. You're in the situation - if you have choice, life is great. You don't have choice, suddenly life is no good."

"So what do we do if today they feel like not being together?" he asked. "I still have only one staff assigned to supervise two people. What happens?"

Having choice in daily life situations is not the only quality indicator that has fallen victim to the budget situation. The requested cuts in spending have agencies "reducing services and recreating congregate things that look like sheltered workshops, but they're not calling them sheltered workshops, and pre-vocational training and all that crap that we threw out years ago," Pacht said.

UDS is a small agency which provides nearly all of its services in-house. Other agencies contract with vendor agencies to provide those services. Granite Bay Connections is a non-profit that has carved a niche for itself in the disability community.

Located in Concord, Granite Bay Connections provides a comprehensive range of residential and vocational programs, and specializes in working with individuals who are particularly difficult. "We've been very successful with extremely challenging individuals," stated Caroletta Alicea, founder and CEO. Those challenges include sexual offenders.

All of the staff at Granite Bay receive intense training specific to providing services to individuals with developmental disabilities who have committed or are at risk of committing sexual offenses. It's a training program that Alicea and Kasai Mumpini, her colleague, developed themselves after attending "any sexual offender training that we could get," she said.

What sets the agency apart, however, is that it also

provides temporary staffing to agencies around the state who have an emergency need for direct care workers.

Alicea, who contracts with a number of area agencies around the state, reported that funding to her agency was cut 5% across the board. As a result, she went from 72 employees to 47 in a month's time. Even with the layoffs, she was forced to reduce her employees' work week from 40 hours to 35, and accelerate the ratio of their health insurance contribution by 50% (after receiving a 28% increase in her health insurance costs). "And I'm only paying them \$8.75 to \$9 an hour," she added.

Her agency has enjoyed a very low turn-over rate - 1% - in the six years of its existence,

Governor Benson about how his emphasis on supporting business doesn't seem to include non-profit agencies, and how the bill in the legislature changing insurance regulations - which he supported - is detrimental to her business, and how the cuts in Medicaid provider payments mean people will not get served. "You can be out of paper," she told the Governor, "but you can't be out of help for persons."

Alicea had become such a familiar person to the Governor that he stopped to talk with her a number of times in the hallway of the Capital building. On June 30, just before the House took a vote on the Continuing Resolution, Governor Benson came out to Alicea and sat down next to her.

to be home care providers, according to Alicea. "Nobody wants to take care of our guys," she said.

She is continually looking for ways to reduce spending because the cuts she received were based on a budget that hasn't increased since 1993. "We're re-looking at our contracts for (maintenance) on our printers and copy machines," she said, "to reduce costs on that." She scrounges every nook and cranny of Concord to find goods that businesses or individuals no longer need but are serviceable. "They call me a professional beggar in Concord," she admitted. Area businesses know her so well that when she walks in she is immediately asked, "What do you need now?"

an individual with a developmental disability whose parents are unable to deal with his violent behavior. The other individual has an aging parent recently diagnosed with Alzheimer's disease. He's also keeping a watch on two individuals who will be turning 21 shortly and whose needs are significant. And he has no money available to provide services to any of them.

It used to be, he explained, that a person came off the waiting list when someone else died. "But we're keeping people alive," he said. "They're getting good care, more individualized care, access to specialists. Mortality rates have changed dramatically."

Linda Steir, parent of a daughter with a severe disability and the legislative coordinator for Community Support Network, Inc. (CSNI) has kept a close watch on the budget process this session. She believes that the budget coming out of this recently appointed joint legislative committee will not be drastically different from the one passed by the House and Senate.

"I say that," she said, "because I think Senator Green feels very committed to this budget, not for political reasons, but because it's a budget that meets the needs of people without creating new taxes and he intends, I believe, to meet the needs of the people."

"My sense is that people are his priority. And that that won't change in this next round of committee of conference. Obviously, if the Governor couldn't live with this budget and wants a budget that has less spending, then there will be cuts. But I'm optimistic that Senator Green and House Speaker Chandler are absolutely committed that a budget passes that meets the needs of people. And if cuts need to happen, I'm optimistic that they'll happen in places that won't be harmful to people."

She has been impressed with how hard legislators worked this session. "All politics aside, the fact of the matter is," she stated, "hundreds of legislators worked really hard this budget cycle to ensure that there was some funding for the waiting list, and despite their great efforts and their huge commitment to us, because we're un-

**"Governor Benson said, I don't want you to worry.
Your guys aren't going to suffer.
It's going to be okay."**

*Caroletta Alicea,
CEO of Granite Bay Connections*

according to Alicea. "My employees are very loyal," she said with pride. "They don't agency-hop." The employees who were laid off have asked to be put on the reserve list for temporary staffing around the state.

Still, she worries about her business. "We are a non-profit agency devoted to high standards of service," she said, "but I can't say or live those words with what Governor Benson's plan is."

She has told Governor Benson that herself. Her office is across the street from the State House and during lunch hour every day of the legislative session, she walked over to Governor Benson's office and asked to talk with him. Every day. "We have this long history," she said, laughing.

"Our Governor works for us," she stated. "Many people don't realize that this is one of the states where we have the ability as a community to access persons that work for us. So I take great advantage of that."

Alicea has talked with

"He said, I don't want you to worry. Your guys aren't going to suffer. It's going to be okay," she remembered. "The next time we went into (the gallery of) the House, that's when (Speaker of the House) Chandler came in and said that he (the Governor) would live with it. He was going to sign the budget."

"I took that very personally," Alicea said. "I took it like he really heard what I was saying. And I felt like I made a difference. That may not be true," she admitted, "but that was very emotional for me."

Emotions aside, Alicea, along with all the vendors in the state, face hard realities. Area agencies will no longer pay the costs of transporting individuals with disabilities to and from their day programs if the home care provider is not a family member. It will be up to the home care providers to provide (and pay for) the transportation, without receiving any increase in their funding. This will only increase the difficulty in finding people

Even if provider payments are increased from current levels in the final version of the budget, vendor agencies have been told by the area agencies the increases will not be passed along to them. "We'll never see that money," Alicea is convinced.

That doesn't mean that area agencies expect a surplus. "I'm projecting \$110,000 deficit for FY '04," Bruce Pacht stated, "and that's on a budget of less than \$6 million. If they raise the rates, all it's going to do for me is maybe cut down my deficit."

Pacht has eight individuals on the Priority 1 wait list in his region and one on the Priority 2 list, "and we're the smallest region in the state," he said.

Brian Collins, executive director of Behavioral Health and Developmental Services of Strafford County, Inc, the area agency for Region 9, reports he is facing two significant crisis situations in his region right now. Both are adults living at home. One concerns

Continued on page 4

At a press conference on July 3, Governor Craig Benson issued this proclamation declaring July, 2003 to be Independence Month for New Hampshire citizens with disabilities:

WHEREAS, all New Hampshire citizens, including individuals with disabilities, should be afforded choices, opportunities, and alternatives to live their lives as they choose; and

WHEREAS, New Hampshire employers need qualified workers, and thousands of qualified workers with disabilities are seeking employment in New Hampshire; and

WHEREAS, the State of New Hampshire aspires to be a model employer by setting high standards for hiring qualified people with disabilities; and

WHEREAS, July is an appropriate month to celebrate equality for all with Independence Day on July 4, and the 13th anniversary of the Americans with Disabilities Act on July 26; and

WHEREAS, it is fitting, in this month associated with independence, to recognize and celebrate independence, freedom, and equality for all Americans - including those with disabilities - by promoting equal employment opportunities for all;

NOW, THEREFORE, I, CRAIG BENSON, GOVERNOR of the state of New Hampshire, do hereby proclaim JULY 2003, as INDEPENDENCE MONTH in New Hampshire. I urge all citizens to celebrate independence and employment opportunities for all.

Given at the Executive Chamber in Concord,
this twenty-fifth day of June,
in the year of Our Lord two thousand and three,
and the independence of the United States of America,
twohundred and twenty-seven.

Craig R. Benson
Governor of New Hampshire

Continued from page 3

der a continuing resolution, there won't be any relief for those 400 families who are on that waiting list right now for a matter of three more months. And that's sad."

As a parent herself, she said, she feels for those parents - "the mothers who have already quit their jobs and are staying home with their kids because there's no programming, or parents who will have to quit jobs over the summer."

Steir urges families to continue their advocacy over the summer as the newly appointed joint Legislative Committee meets with the Governor to develop a new budget. It is important, she said, to remind the Committee members and the Governor that the waiting list needs to be funded.

Brian Collins noted that over 60% of the legislators voted to override the Governor's veto, demonstrating that there is legislative support for meeting the needs of our most fragile citizens. He remarked that he has heard legislators publicly speak about the "DD waiting list." This is significant, he believes. "We have penetrated their consciousness."

Did you know?

The New Hampshire Challenge published its first edition in the fall of 1988. Our front page featured Michael Dukakis and George Bush, Sr., candidates for President in the November election. The Challenge reported their answers to the question: Why should a parent who has a child with disabilities vote for you?

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Budget Advisory Group is Appointed

House Speaker Gene Chandler has appointed the House members and Senate President Tom Eaton has appointed the Senate members of the Joint Budget Advisory Group. They are:

Deputy House Speaker Michael Whalley, R-Alton
Rep. Neal Kurk, R-Weare
Rep. Kenneth Weyler, R - Kingston
Majority Whip Rogers Johnson, R-Stratham
Rep. Mary Jane Wallner, D-Concord

House Alternates are:

Rep. Robert Wheeler, R-Goffstown
Rep. Robert Giuda, R-Warren
Rep. Marjorie Smith, D-Durham

Senate Majority Leader Robert Clegg, R-Hudson
Sen. Dick Green, R-Rochester
Sen. Ted Gatsas, R-Manchester
Sen. Lou D'Allesandro, D-Manchester
Sen. Robert Boyce, R-Alton

This is the process the Legislature will follow to develop a new budget:

The Joint Budget Advisory Group will meet with the Governor during the summer to craft a new budget. Since it will technically be a "bill," it will go through the same process as other bills. Around the beginning of September, the House & Senate will come back. It will be a House bill, so it will go there first. Since the Legislature is not in session during September, there will have to be a 2/3rds majority vote to allow the bill in. Then there will be discussion about a public hearing (again, since it's a new bill, it should have a public hearing, but that's not a given). The bill will need a simple majority vote of the House to pass and then it will go to the Senate. Once passed by the Senate, it would go to the Governor where he will either sign it or veto it.

(Information on this process was provided by Linda Steir, legislative coordinator of CSNI)

Disability Access Issue Settled for Three Filene's Stores in NH

(St. Louis and Concord, NH) Filene's, a division of The May Department Stores Company, and the Disability Rights Center, Inc. announced in June that they reached an agreement in a lawsuit concerning three Filene's stores in New Hampshire - the Rockingham Mall at Rockingham Park in Salem, Pheasant Lane in Nashua, and the Mall of New Hampshire in Manchester. The lawsuit, originally filed by four persons who are members of the Regional Action Committee, a statewide advocacy organization composed of persons with mobility impairments, had alleged that those stores were not in compliance with certain accessibility requirements of the Americans with Disabilities Act (ADA).

Ronald K. Lospennato,

the legal director of the Disabilities Rights Center, the Protection and Advocacy program for the State of New Hampshire, commended Filene's for its efforts under this agreement. Commenting on the settlement, Thomas A. Kingsbury, president and chief executive officer of Filene's said: "All of us at Filene's are committed to providing every customer with full access to the merchandise and services offered in our stores. We are pleased to have reached this agreement."

According to Carol Williams, one of the plaintiffs; "Filene's has been synonymous with retail in New England for decades. This (settlement) shows the importance and good business sense of making their stores accessible and in helping

to fulfill one of the central goals of the ADA - the integration of all persons with disabilities into the fabric of American society." She also added that "This is a win-win for us and Filene's; we look forward to bringing our business to Filene's."

Under the agreement, which will remain in effect for at least two years, Filene's has agreed to make enhancements to the aisle widths within these three stores to assure that persons with physical disabilities have access to most of its merchandise. It has also agreed, among other things, to make minor changes where necessary to its bathrooms, fitting rooms, and cash register counters to assure compliance with the ADA.



File photo: E.G. Stone

DRC Attorney Named Recipient of Prestigious Award

On Thursday, May 22, 2003, Ronald K. Lospennato, legal director of the Disability Rights Center, Inc. received the Frank Rowe Kenison Award from the New Hampshire Bar Foundation.

The Kenison award was established by the Bar Foundation in 1998 to recognize an individual (or individuals) who make a substantial contribution to the betterment of New Hampshire citizens through the administration of

justice, the legal profession, or the advancement of thought.

Lospennato has spent nearly 30 years in public interest law and 24 years at the Disabilities Rights Center in Concord, NH. He is respected throughout the state for his tireless and dogged representation of people with disabilities, including people confined in mental health and correctional facilities. Lospennato has been involved in a variety of high impact cases that have changed the lives of many New Hampshire children and individuals for the better.

The disability community has much for which to thank Lospennato. He has helped define education with the Timothy W. case, assured the educational rights of school-age prisoners with disabilities, challenged the State to eliminate its wait list for services, and just recently reached a settlement with Filene's to make their stores more accessible to people with physical disabilities.

Public interest law is not a lucrative field. There are no huge financial awards to fill a lawyer's pockets, especially

when that lawyer works for a nonprofit agency. Lospennato has worked quietly but consistently to secure and protect the rights of those in our society who often cannot speak for themselves. Every person with a disability in this state owes Ron Lospennato a debt of gratitude, for he has touched the life of every individual with a disability, young and old, with the quality of his work and the deep compassion and drive for righteousness that compels him to sit at his desk every morning and continue the seemingly never-ending struggle for civil rights.

Truly his career lives up to the ideals reflected in Frank Kenison's words when he said: "The Supreme Court and Judiciary of this state will continue to maintain and guard its house of justice for the humble as well as the powerful, for the poor as well as the rich, for the minority as well as the majority, and for the unpopular as well as the popular."

Ron Lospennato, the disability community of New Hampshire salutes you!

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with a tax deductible donation today.
Thank you.



These parents have been meeting every month to plan for their children's futures. Sitting around the table in the library of Berlin High School are (from left, clockwise) Yvonne and Larry Jenkins, Rita and Andre Belanger, Dorothy Ouellette and Eric Van Leuven. **Photo: Krumm**

What Happens After They Graduate?

by: Janet M. Krumm

The old adage "It's not what you know; it's who you know" is only half true when applied to a group of parents from the North Country who are working to create a transition program for their sons and daughters at Berlin High School.

The fact that they live in small communities where everyone knows just about everyone else is a definite plus. The people who work in the agencies, schools and organizations servicing the six young men and women have watched them grow up. Most of the teachers, service coordinators, counselors and administrators have worked for years in their jobs and have long-standing professional relationships amongst themselves.

The parents have known each other a long time, some since before their children with disabilities were born.

They are an educated group, and include a teacher, a psychiatrist, an artist, a cabinet maker, a nurse practitioner, a library reading specialist, a stay-at-home mom who helps with her husband's business, a rehabilitative assistant, and a former fireman who now works as a carpenter. Friendships have developed over the years among the parents who share interests beyond special education and IEPs. Two performed in the community theater together. Two worked together in the schools.

Their sons and daughters have gone to school with each other all their lives. They hang out with each other all the time. Two of them went to the prom together.

It was "what you know" or rather what they didn't know that propelled this group of parents to get information and ask hard questions.

The catalyst was a simple question. Could Daniel Pigeon graduate with his class

and still receive services from the school district?

The answer his mother was given was "no." Once he graduated, the school district's job was done.

"Mr. Michaud (the special education director at Berlin High School) had said that we'd done so well including our children that they've done everything," Dorothy Ouellette, Daniel's mother explained. "They've participated in all the things at high school and they're ready to leave high school sooner than students with disabilities used to be."

This came as a shock to Dorothy. "I always assumed Daniel was just going to just graduate," she said, "because that's what he wanted and that's what I wanted for him. But reality set in," and she remembered thinking, "What am I going to do with that time in between, before the supports kick in?"

Her friends Yvonne and Larry Jenkins, Andre and Rita

Belanger, Eric and Norine Van Leuven and Bob and Lorraine Dumoulin were in the same boat. They each had a son or daughter who was nearing graduation and who was facing the same uncertain future.

Daniel, who is 18, and his friends - Lily May Jenkins (20), Craig Eichler (20), Alex Van Leuven (18) and Danielle Dumoulin (19) - were all active in their school and their communities. All attended Berlin High School, were in class together, participated in extra-curricular activities; some had part-time jobs in the community.

"Alex is incredibly happy," his father Eric stated. "because he hangs out with Craig, and Lily May, and everybody. He serves the students at the cafeteria and the teachers in the teachers' lounge. He's going to be just starting at the florist. He works two days for an hour at Top Furniture and then comes back and does his reading. He's like, everywhere.

"And it suddenly be-

came like really, scarily, frighteningly obvious that when he's finished, even if you have a place for him to live, every bit of that's gone. Every bit of it."

The parents had been meeting together to talk about housing possibilities for their sons and daughters when the graduation question forced them to change gears. Yvonne Jenkins, who was pursuing her Master's degree, was researching post-secondary opportunities for students with developmental disabilities.

"I found a really great article about a program in Kentucky that does exactly what I wanted to hear," she said, "and I thought, why can't we do this?" She brought the information to the group and together they created a task force to discuss ideas and possibilities. "We just said, let's just invite everybody and we sent a copy of the article to everyone

Continued on page 7

ahead of time and had this meeting.”

The meeting was held in February. Approximately 25 people came together: sped teachers, sped directors from both Berlin and Gorham, agency people from the Community Services Council (an office of their regional area agency), a counselor from the Department of Vocational Rehabilitation, the disability coordinator from the Community Technical College in Berlin. “All the principal ingredients that could make it work came together,” Larry Jenkins recalled, “and it was really a very dynamic meeting.”

The parents presented their concerns about their sons and daughters who were technically ready to graduate, but who still needed services and supports. How could this group address their predicament?

That initial meeting ignited a spark of creativity that has resulted in the formation of a program offered through the school with the collaboration and assistance of the area agency, Voc Rehab and the Community Technical College which has allowed the students to graduate with their class and continue services.

The rationale behind this is that the students’ IEPs are not complete because they are not ready to transition into the community, Larry explained. “The special ed people came up with that,” Yvonne added. “Not us.”

“Steve (Michaud) said that his portion, the academic portion has been completed,” Dorothy said. “Their responsibility for Daniel’s academics has been completed. But they can support the vocational

piece.

“But that’s where Voc Rehab picks up,” she added. “Because they will support him as long as he’s doing some sort of a job training.”

But Voc Rehab has limitations. They can provide support for a limited time, about three or four months, according to Jill Blunden, a team leader at the area agency who also works with students transitioning from high school. And it has to be around a specific job.

The parents aren’t happy about the limitations. “You have a kid and you’re supposed to try to plug him in so that he knows exactly what he’s going to do,” Dorothy explained with frustration, “and work and train this kid in this job, and you can only support him if he’s going to do this job.” Her son Daniel wanted to go into culinary arts, but did not have the skills to take the class at the Community Technical College.

“So all of a sudden, your kid is told, oh sorry, you can’t do what you want to do,” she said, “you’ve got to pick something else now, that you think you might want to do for the rest of your life. So people sit around the table and say, what could we have Daniel do now for the rest of his life?”

No other high school kids are expected to say they know exactly what they want to do with the rest of their lives, Yvonne added. “They don’t know. They shouldn’t have to. But (our kids) do.”

Eric thinks his son might be happier with several part time jobs. “I know a lot of adults now who have 3 part-time jobs,” he said. “Because it just fits them better. And that may fit Alex better.”

But Voc Rehab won’t support that kind of preference. They will support an individual in one job, which must be long-term but for which the individual will not need long-term supports.

“We said, what if it doesn’t work out?” Yvonne remembered asking. “What then?” The answer, she reported, was to contact them again.

“Help them out again?” Andre Belanger repeated. “What does that do morally to a human being?” Andre takes exception to what he calls “shoving someone into a position and categorizing them. Haven’t our children gone through enough?” he asked.

Despite the limitations of Voc Rehab services, the parents are looking forward to the opportunities this transition program will offer their sons and daughters. “Next year, they’re going to have 20 hours of support to get them using public transportation, take them to the college for courses, take them shopping, teach them cooking,” Yvonne explained.

The students will be taking courses at the Community Technical College. Deb Stewart, who until recently served as the college’s disability coordinator, said: “A lot of people don’t know what colleges can do, as far as with students with disabilities. They think high school is the last route. All colleges by law are expected to provide accommodations and modifications to students who are identified with disabilities. That’s the ADA.”

She sees college as a time of exploration for the students. “They’re going through the same decision making that

all students at that age go through,” she explained, “and we’re just trying to provide, as an educational facility, not necessarily degrees but exposure.”

The students in the transition program have many options at the college, she stated. If they take a course and cannot finish it in one semester, they have the option of getting an extension. “You set up a time line so it’s not like a full year,” she said.

Another option is to officially withdraw but stay in the course and take it again the next semester for a grade. “We actually have a withdrawal period that’s quite long without getting your money back,” Stewart explained. “You can get almost three quarters of the way through and withdraw and not fail,” she added.

“If you want to get your money back, it’s within the first week.

“And then we have an academic withdrawal, too, which is when the professor can withdraw them. It’s a later time period.”

Students can also audit courses.

There is a process that Stewart initiates when a student with a disability enrolls in the college to explain to everyone involved what the expectations are. “It’s all up front,” she explained. “Everyone at the table, students, parents, faculty, will be fully aware of the student, the accommodations and modifications and also the students are aware of our curriculum, our outcomes.”

While the college provides a number of accommodations, there are very few modifications they can provide. “We can’t modify the outcomes,” she

stated. “At this level, you have to meet those outcomes.” So it is important to match the courses the students take with their competencies. “I take a good look what they’re reading level, writing level is at and then, also what their interests are,” she said. Then she suggests courses.

There are one credit courses, like Technology and Computers, and basic skills courses in math, reading and writing which might be suitable. Stewart brings the faculty into the process from the beginning.

When Daniel wanted to take a culinary arts class, the professor who taught the class came to her and asked how he would measure Daniel’s competence to take the course. Stewart suggested that he set up a pre-test, which he did. That test helped both the teacher and Daniel see that Daniel didn’t have the skills necessary to take the class. “That was a perfect example of not exposing these kids to failure,” she said. “They could have easily gone in there, not being able to do a lot.”

One factor that is critical for success is the drive of the student. In college, students must do the work and advocate for themselves. “We write out a whole plan,” Stewart pointed out, “but if they don’t follow through themselves, we’re not running after them. That’s a big step.” If it is not the student’s choice to be there, he or she will not have the drive, the motivation to succeed.

The goal, according to Stewart, isn’t a degree necessarily. “I’m not real positive in this, but I don’t foresee them getting degrees. I do foresee them tak-

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“And it suddenly became like really, scarily, frighteningly obvious that when he’s finished, even if you have a place for him to live, every bit of that’s gone. Every bit of it.”

Eric Van Leuven, Berlin



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ing courses like any high school student would come to college and decipher what they want to go for. I see that whole process occurring."

What the ultimate outcome for the students will be is unknown. "Maybe they will be successful," Stewart said. "Maybe they won't. But they'll make that decision on their own."

"And that's the nice thing. The college isn't making that decision. We're providing the opportunity for them, but as I said to you and as I continually say to them and their parents, the competencies that they have to meet are no different from any other student. Whether or not they're successful is unknown, but they have the opportunity."

It's opportunities that the parents are seeking for their sons and daughters. They want to continue the kinds of opportunities offered during high school but tailor them to the changing needs of their children. They see the academic opportunities in high school leading to academic possibilities in college. They see the summer jobs offered by the school in collaboration with the area agency as stepping stones to adult working life.

Berlin High School, in collaboration with the area agency, provides job opportunities during the summer for students with developmental disabilities. Jill Blunden and Steve Finnigan-Allen are employees of the area agency who work with students in high school. Blunden's primary focus is the vocational program. She works closely with Finnigan-Allen who develops jobs in the community.

"Usually, we're invited to attend the IEPs sometimes as early as 14," Blunden explained. "We start looking at vocational goals. Provide summer jobs. Sometimes with financial support from the schools; sometimes with financial support from Voc Rehab. We're a vendor agency for Voc Rehab."

The summer jobs the students work last all summer, she explained. Some do volunteer work; some do job shadowing; some are paid, and the students who are paid get starting wages. Community integrators - who are either full-time employees of the area agency or college students working for the summer - support the stu-

dents in their jobs.

This vocational program for high school students offered by the area agency "is unique," said Finnigan-Allen. "It's evolved tremendously."

With the support of their program director and the area agency director, both Blunden and Finnigan-Allen have been working as a team with the school district and Voc Rehab "helping people match jobs, match experiences."

This involvement with the high school started a number of years ago when the school had a couple of students who were very challenging, with behavior issues. They contacted the community mental health agency, which is part of the area agency in Region I, when they had exhausted their resources, according to Denise Gagnon, program director at the area agency. "We all know each other," Gagnon explained.

The area agency became involved and after that, the school district continued to use them as a resource.

For Finnigan-Allen, the turning point was a summer job experience years ago at Story Land. "We had four or five people work as a crew at StoryLand," he explained. "Since then, these guys have all found jobs on their own. But rather than relinquish that work, what we did was we worked with VR, helped them become more involved with the schools, with IEPs, as did we. And we recruited more high school age kids to do that work, which is really age appropriate. "Since then, a lot of doors have opened for these kids," he added. "They were able to do summer jobs that weren't in special programs like the Youth Corps groups, which are good programs, but after two years, it's nice to do something that your peers are doing, too. We've been doing it for close to 10 years"

In addition to the obvious benefits to the students, Finnigan-Allen sees benefits of working in the high school for



Rita and Andre Belanger of Berlin, NH

Photo: Krumm

"I have this horrible axe to grind with the State. That axe is this: I have a human being in my house with the inalienable right to be happy. And New Hampshire - like other states - make an exception for people with mental disabilities with a waiting list. They should all be put in jail. What's the legal right that people can make those decisions to cut care from people? I have a right to be happy. So does my son. Period.

"And this waiting list is dictating - blatantly, just standing out in focus to the world - that they want a certain, particular section of people in the state to live in poverty. It's a mandate. It's written. The legislation is such that these people have to wait. Too bad. What about the kids who don't have parents?"

Andre Belanger, Berlin, NH

the area agency, too. "What's nice about it," he explained, "is that you get to see these kids before they graduate. You don't really know where their strengths are. All you see are these reports and they can be helpful, but they don't really tell you if a person can sweep. It's nice to get some practical reality skills so you can know where to go, where to start."

He's excited about what this group of parents are doing. "This year is kind of a neat year," he said, "because we have a group of families who are much more outspoken with what they want for their kids. They want their kids to graduate, but they didn't want to lose services."

Lena Parent, the family support coordinator at the area agency agrees. "This is something entirely new to our community," she said. "We've

never seen any families get together and organize like this in trying to support one another, in trying to see what they can do for their kids. Not waiting for someone else to do it."

Parent has been working with the parents individually on transition and advising them as a group. "Working with those families was phenomenal - all of them," she stated. "They were very knowledgeable. They did their homework. They researched. They did what they had to do, and I was just there to support them, if they had any questions."

The parents are pleased with the opportunities being offered to their sons and daughters, but they know that the future holds no certainties. When their sons and daughters reach the age of 21, all the supports stop and they will be put on a waiting list for services. "It

could be eight to ten years on the waiting list," Andre said.

"I have this horrible axe to grind with the State," he admitted. "That axe is this: I have a human being in my house with the inalienable right to be happy. And New Hampshire - like other states - makes an exception for people with mental disabilities with a waiting list. They should all be put in jail. What's the legal right that people can make those decisions to cut care from people? I have a right to be happy. So does my son. Period.

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What If Beethoven Could Hear?

By: George W. Fellendorf and Tom Sidebotham

Ludwig van Beethoven became severely hard of hearing in the middle of his adult life. Today he is revered as one of the foremost composers of classical music the world has ever known. If Beethoven had not begun to lose his hearing in the middle of his career as a piano virtuoso, would the world of music have been better or worse?

Beethoven was born in 1770 in Bonn, Germany. His father, Johann, and grandfather, Ludwig, were both well-recognized musicians so young Ludwig was directed toward a musical career from his earliest years. Before his son had reached the age of seven, Johann van Beethoven had recognized his son's talent. He is said to have falsified his son's birth certificate to create the impression that Ludwig was two years younger and therefore an infant prodigy in the same league as the already famous Wolfgang Amadeus Mozart. Bad tempered and perhaps mentally unbalanced, Johann was a hard and demanding teacher who would often haul his child

out of bed in the middle of the night to practice on the harpsichord.

At age nine, Beethoven wrote his first compositions. He auditioned with Mozart in Vienna and by the year 1796 at age 26, he was an accomplished piano virtuoso. He was widely recognized throughout Europe for his improvisations and could demonstrate his outstanding ability to repeat such improvisations from memory over long periods of time.

In 1796, however, Beethoven began to experience a buzzing noise in his ears. At first it was an annoyance to be tolerated as are many oncoming physical disabilities, but soon it became a major problem. In the spring of 1801, for example, he was invited to play at the house of friends in Vienna. One of the ladies in the audience reported that as Beethoven played a piano concerto pianissimi, his hands hardly touched the keyboard. "The Maestro imagined that the keys were releasing delicate sounds, but in fact there were none." At that moment, they all realized the unbelievable, that Beethoven was already deaf.

After a number of similar experiences, Beethoven felt compelled to stop playing and gave himself up completely to composition. His physician, Dr. Schmidt, ordered him to seek a quiet environment where he could relax and rest his hearing. From the small village of Heiligenstadt outside of Vienna in 1802, he wrote in a moving letter to his two brothers, which he never mailed, that he was contemplating suicide. "What humiliation if someone near me heard a distant flute, and I heard

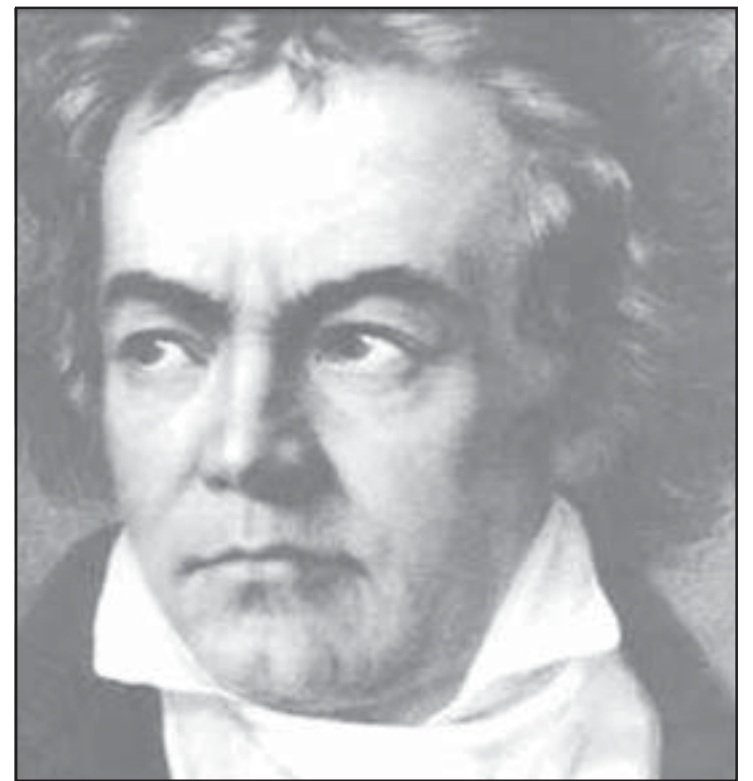
nothing. If someone heard a shepherd sing and I heard nothing. These events led me to despair. I almost took my own life."

As one reviews Beethoven's life experiences with deafness, a question emerges: What if Beethoven had been born in 1970 instead of 1770? In the 1970's, doctors of medicine and science conceived the idea of implanting electrodes in the inner ear of adults with acquired hearing loss. These implants restored the sensation of sound to ears that had lost this capability through disease or injury.

Parents of deaf children, and deaf people themselves, initially had many concerns with this surgery. Many questioned the quality of the sound heard, and the psychological impact of restoring a sense of hearing, but not totally normal hearing. Today cochlear implants are common among both children and adults who have met the medical criteria for this surgery.

What if Ludwig van Beethoven had received a cochlear implant at the age of 30 years? Would that have increased the number and quality of the magnificent compositions for which he is now world acclaimed? Would he have lived a longer and more harmonious life with his family and his colleagues?

Beethoven changed his career from that of a performer to a composer when he finally accepted his deafness as a permanent condition. He tuned his attention to the sounds he could hear in his head and placed the notes on paper. Had he been given a somewhat different au-



Ludwig van Beethoven

ditory sensitivity through a cochlear implant, would Beethoven's music composed in later life have changed? We will never know the answer to this question.

A review of Beethoven's career challenges us today to confront both the positive and negative potential of a cochlear implant. We can only surmise its impact on his work as a composer. A cochlear implant, however, might well have dramatically improved his social contacts with his two brothers, with his nephew, Karl, whom he loved as his own son, and with other artists of his time. He was considered by many as irritable, caustic, and opinionated when in fact much of this may have been a cover up for his inability to hear. It is said that Karl became so distressed with his uncle's behavior that he attempted to take his own life, an attempt which failed only because of his faulty aim with a pistol.

The cochlear implant is not a cure for deafness. No one claims it can restore perfect hearing. It does have promise to bring a new type of sensitiv-

ity to sound that can be trained under the guidance of a qualified speech and language specialist. In time a person can become more relaxed in the company of both hearing and hearing impaired individuals, hear on the telephone, and respond to environmental sounds again. Beethoven sorely missed hearing a distant shepherd's song and the sound of a flute. Perhaps for a hearing impaired mother today, it would be the sound of her baby's cry or a father's first experience in hearing "Daddy".

Those of us who were born in 1900's rather than the 1700's, including those with one or more disabilities, have been blessed with new technologies and new medical interventions to help us ease our way through life. We can confidently expect also a growing attitude of tolerance and acceptance of those with disabilities that was unknown to Ludwig van Beethoven. Perhaps the next such creative genius to come on the world scene will have an easier time in fulfilling his or her destiny than did maestro Beethoven.

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tion is such that these people have to wait. Too bad. What about the kids who don't have parents?"

It is this anger and frustration, coupled with their love for their sons and daughters that strengthen this group's determination to make a future for their children. They will continue to research, to advocate, to lobby their legislators, to dream that one day, their sons and daughters will be a part of the community, doing work they enjoy, living as independently as is possible and be surrounded by a network of loving support.

So, for these parents, it's not only who they know, it's what they know that has made their efforts so far successful. And they aren't finished.

Authors: George W. Fellendorf is the former Executive Director of the Alexander Graham Bell Association for the Deaf (1962-1967) and lives in Keene, NH. Tom Sidebotham has an Masters in Journalism and Music, Keene State College, and is an enthusiastic student of Ludwig van Beethoven's life and works.

Editor's note: Five references were cited as research sources for this article. Readers who wish to know more about Beethoven, and the impact of deafness on his work are referred to the following books:

The Story of the Symphony, Vol. II, Ludwig Spohr (1784-1859)

Let your deafness no longer be a secret even in art; Self-portrait and the Third Movement of the C Minor Symphony: Fifth Beethoven Forum, Owen Jander (2000), University of Nebraska Press, Lincoln, NB

Great Composers: Beethoven, Robin May (1990), London, Octopus Publishing Company

The Life and Times of Beethoven, Enzo Orlando, Editor (1867), Philadelphia. Curtiss Publishing Company

Beethoven, Maynard Solomon (1998), New York, Schirmer Books



Photo: E.G. Stone

Benefits 101:

An easy to understand (we hope!) explanation of Federal and State cash and medical benefits

by: Janet M. Krumm, with assistance from Jan Larsen

SSI. SSDI. Medicaid. Medicare. PASS plan. APTD. Acronyms abound in any field, and the disability field has its share. When a parent hears these acronyms, however, the reaction can range from hope to frustration.

Each of these acronyms represents a benefits program available to people with disabilities (some are available to others as well). The programs vary in benefits available and eligibility and can cause otherwise sane and intelligent people to collapse in a heap of frustration. It is not impossible to apply for and receive benefits on one's own, but it is always wise to enlist the assistance of someone who "knows the system," such as a family support coordinator, a regional benefits planner from your area agency, or a Bureau of Special Medical Services coordinator.

Cash Benefits

Social Security Disability Insurance

Social Security Disability Insurance (SSDI) is a Federal insurance program. The basic idea behind Social Security is a simple one. You pay taxes into a trust fund during your work years, and you and members of your family receive monthly benefits when you retire or die or become disabled. Social Security, then, is based on a worker paying into the system before benefits can be received.

There are three categories of Social Security benefits: Retirement, Survivor, and Disability. Each of these categories has family benefits, which are available to spouses and/or children. In this article, we will be concentrating on the Disability category, which is known as Social Security Disability Insurance, or SSDI.

A person becomes eligible for SSDI if he or she has worked, paid FICA taxes, and becomes disabled. The benefit eligibility is based on the number of working "quarters" that the individual has paid into Social Security. Once the disabled former worker becomes eligible for SSDI benefits, his or her family members may also be eligible, based on the record of the former wage-earner. For instance, the worker's spouse is eligible if he or she is 62 or older, or at any age if he or she is caring

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for a child under 16, or a child of any age who is disabled. Children receive SSDI dependents' benefits up to the age of 18. However, a child (even an adult son or daughter not living with the parent) with a disability may continue to receive SSDI-Childhood Disability Benefits (CDB) as long as that child remains disabled (according to Social Security definition of disability).

More individuals with disabilities are now in the work force and they are paying into the Social Security system. The younger a worker is, the fewer working 'quarters' he or she needs to be eligible for SSDI. So it is possible that young men or women with disabilities could receive SSDI benefits before their parents retire.

All recipients of SSDI receive monthly cash payments (see chart). People receiving SSDI will not lose their benefits automatically when they begin to work. There are work incentives to encourage people to return to or enter the work force. These incentives were created so that people could "keep the safety net of their full benefits while attempting the sometimes fearful process of returning to the workforce," according to Herbert Salls, District Manager of the Manchester office of Social Security.

Supplemental Security Income

Supplemental Security Income (SSI), is another Federal benefit program that provides monthly cash payments. The SSI program was established in 1972, and implemented in January, 1974. It provides cash assistance to low income children (and adults) with disabilities.

SSI, however, is not paid through the Social Security Trust fund, but through general revenues. So, benefits are not based on paying into the system first.

SSI is designed for individuals with disabilities and people 65 and older who don't have much money. The amount of a person's monthly check is based on his or her income, which includes such things as SSDI, wages, and Veteran's Administration (VA) benefits. For children under the age of 18, the family's income level is used to determine eligibility, based on the number of people in the family. For adults, the individual's income level is used even if they are still living with their family.

In some states, a person who is determined eligible for SSI is automatically eligible for Medicaid, a federal and state health insurance program. In New Hampshire, however, that is not true. Even if a person is determined eligible for SSI, that person or the individual's parents or guardians must apply separately for Medicaid.

To apply for SSI, contact the Social Security Administration at 1 (800) 772-1213, your local SSA office listed in your telephone directory, or visit their web site at: www.socialsecurity.gov. Your local office may be in another state if you live in a border town. To begin with, the application requires basic information including parents' or the individual's pay stubs (to establish income eligibility), proof of the person's birth and citizenship, and the person's social security number. Every person must have a social security card

A report on how the child or adult functions is also needed, to include information from teachers, doctors, and therapists, as well as the parent's or guardian's impressions of the person's disability. This report is critical for the SSA reviewers to get a complete picture and assesses whether the disability is severe and how it affects the person's ability to function. The staff at the local SSA office will give you help filling out the applications if you need it. A decision on your application will be made with all due haste (but may take several months). Monthly payments will be retroactive to the date of the first application.

Because SSI is based on income and resources, one way to go to work, still keep your benefits and maximize your SSI is to develop a Plan to Achieve Self Support (PASS). A PASS plan allows an individual to work and "set aside" money for training, equipment and other job-related expenses. This "set aside" money is not calculated in a person's earnings, so it will not affect his or her Social Security benefits, and at the same time may allow a person to receive the maximum amount of SSI.

Individuals with disabilities who need certain items or services in order to work may be able to subtract part of the cost of these items or services from their work income, resulting in a higher payment from SSI. These Impairment Related Work Expenses (IRWE), such as the cost for a cab for someone whose disability prevents that individual from driving, must be approved by Social Security.

Aid to the Permanently and Totally Disabled (APTD)

This is a State program that awards twice-a-month cash payments. These payments may be received by check but are also now in the form of an Electronic Benefits Card (EBT). To be eligible, a person must be disabled (according to the State's definition of disability), be between the age of 18 and 64, meet the income and resources limits set by the State, and must apply for SSI. Monthly payments can be small and may discourage people from applying. However, there is a major incentive to applying for this benefit. Eligibility for APTD automatically makes one eligible for Medicaid, and potentially eligible for Food Stamps.

Note: A person who had been receiving both SSI and APTD and who loses his or her SSI eligibility for medical reasons, automatically loses his or her APTD eligibility as well. This is because, under federal regulation, states may not have medical eligibility criteria that are less restrictive than SSI.

Also, it is important to know that one of the requirements for receiving APTD is signing a paper by which the recipient agrees that if he or she comes into money in the future that person may be required to pay back the State for the services received. For those receiving medical assistance only, the State's right to recover is applicable only after age 65. The State also has a right to place a lien on any property owned by anyone receiving assistance. Estate planning, then, becomes crucial. Parents would be wise to consult an estate planner knowledgeable about benefits to protect their sons and daughters from any of these possibilities.

Aid to the Needy Blind (ANB)

This is another state program, similar to APTD, which provides cash payments twice a month for eligible applicants. Unlike APTD, eligibility for ANB is not based on ability to work. The eligibility criteria for this program is the diagnosis of blindness according to the state's definition. There is no age criterion; anyone from an infant to an adult is eligible based on the diagnosis of blindness. However, the income criteria are the same as APTD. Like APTD, this benefit is for people who have limited income and assets.

Once eligibility for this benefit is established, the applicant is automatically eligible for Medicaid and potentially eligible for Food Stamps, as with APTD. And, similar to SSI, recipients can "work themselves off" this benefit.

Additional Information

Anyone whose life circumstances change, such as a parent either retires, become disabled or dies, should contact Social Security immediately. What is important to know is that the amount of monthly income, including Social Security benefits a person receives affects his or her SSI payments and Medicaid eligibility. One of the most frustrating problems for SSI recipients is that Social Security bases benefits on monthly income but only looks at income every three months. Underestimating income can result in having to pay back money to Social Security.

If an individual knows his or her income will vary, (because of a five- week month or because of more hours in a particular month), it is advisable for the individual to report a higher amount to the local Social Security office before the three month period. Otherwise, benefit payments may be received that are more than that to which the person is entitled. When Social Security checks its records for the actual income received by the individual in prior months and finds it was greater than reported, it will calculate an overpayment of benefits.

When that occurs, letters are sent out that explain the overpayment and set out a payback schedule. This can be a hardship for the individual and his or her family. Contacting the local Social Security office as soon as the letter arrives can make it easier to make payback payments. Contacting them as soon as there is a change may prevent this from happening and/or ensure this doesn't happen again. Generally, it is better to receive a lower monthly check initially and then have Social Security add the extra amount owed than have a bigger check and have to pay money back.

(NOTE: It is important to understand that such calculations are done by the Social Security office in Baltimore, not the local office.)

Additionally, once a person turns 18, that person becomes a "family of one." What this means is that, prior to 18, a person's benefits are based on the income

and assets of the parents as well as the individual. After 18, benefits are based on the individual's income and assets only. Because a person with a disability generally has limited income and assets, he or she is typically eligible for benefits upon turning 18.

Another consideration for families during this process is the issue of guardianship. When a person with a disability turns 18, that person is automatically considered an adult, whether or not the person is capable of handling his or her own affairs. Parents who are used to signing all documents for their sons and daughters suddenly find that they no longer have any legal say. Parents should explore guardianship (it can be limited) or power of attorney when appropriate to enable them to continue to have legal rights in the decisions affecting the lives of their sons and daughters. This is done through a court process. Contact your regional family support coordinator for more information.

Medical Benefits

Medicare

Medicare is a federal health insurance program administered by the Social Security Administration. A person becomes eligible for Medicare at age 65, or by receiving SSDI or SSDI Childhood Disability Benefits (CDB). Children who receive SSDI-CDB after age 18 become eligible at 20, because a disabled recipient must wait two years after SSDI or SSDI-CDB cash payments begin before the Medicare coverage begins. Part A of Medicare coverage is at no cost and covers hospitalization and related costs. Part B includes a monthly premium and covers physician's charges, therapies, outpatient visits and some equipment. Medicare does not cover such things as routine physical exams, prescription drugs, eyeglasses, and hearing aids.

Individuals who are just above Medicaid limits and who qualify for Medicare may be eligible for the "Qualified Medicare Beneficiary" (QMB) program, administered by the Centers for Medicare and Medicaid Services (CMS) and the Department of Health and Human Services. A person eligible for this program may have the Medicare Part B premium paid by the State. For more information, contact your local office or call the CMS QMB office at 1 (800) MEDICARE.

If a recipient loses SSDI payments because his or her earnings have increased above the set limits, it is still possible to "buy into" the Medicare program so as not to lose medical benefits.

Medicaid

Medicaid is a combined Federal and State program providing medical benefits. Created by Federal legislation in the 1960's, Medicaid was originally designed to provide basic health care to the poor. It was small in design and scope. Since, then eligibility has been expanded to include long term care for the elderly and people with disabilities. These changes created what is known as categorical eligibility, which means that people must fit into well-defined categories in order to be eligible. Once you are eligible, you receive the same benefits as the next person.

While Medicaid may seem like a maze requiring cleverness, persistence, and patience on the part of the applicant, it can also be compared to a large building with a lot of different doors. The services are basically the same, but each door has different restrictions. The one qualifier is that children get more and different services than adults.

Getting through those doors is called eligibility.

Typically, eligibility is determined solely by a family's or an individual's income and resources. (See chart). That is the door through which most Medicaid recipients enter.

When a person is found eligible for Medicaid coverage, a Medicaid card is issued. Having this card does not ensure eligibility. Medicaid eligibility is based on a person's monthly income and other factors. It is possible for a person to lose eligibility in one month, and regain it the next

Once an adult with a disability (or a family) has an income too high to meet the limits set by Medicaid, he or she can still be eligible under different programs. Medicaid compares an individual's income with the Standard of Need (SON) set by the State. This difference is called a spend down. When a person's income is higher than the Standard of Need, medical expenses can offset that difference or spend down. Under the Medicaid In and Out program medical costs to meet the spend down can be based on monthly medical costs or on a three month basis. The individual must incur these costs before being eligible. This means that the dates of eligibility can differ from one month to another depending on the spend down amounts and the date the medical cost happens.

Each month (or on a three month basis), the applicant will bring in all the medical bills he (or the family) has incurred during that period. (It is not necessary that the bills be paid.) If the amount of those bills exceeds the spend down amount, that person or family will be eligible for Medicaid that month (or during that three month period). NOTE: The three month period equals a month's spend down amount times three. Medicaid will then pay all the medical bills incurred that month or during the three month period.

It is advisable for a person or family who is eligible for Medicaid In and Out to bring proof of their incurred expenses to their local DHHS office as early in the month as possible to avoid dealing with the hassles of billing with their health care provider(s). So, for instance, if an individual is taking medication regularly and the cost of that medication is more than the spend down amount, the cost of filling the prescription(s) on the first day of the month will provide the Medicaid case worker with proof of eligibility for that month. The individual can then give his or her health care provider(s) that information and avoid the hassle of having to go back and correct insurance information with the provider(s).

An individual whose circumstances would ordinarily preclude eligibility for Medicaid In and Out might consider applying to cover the costs of a catastrophic illness or accident. The costs of the bills incurred because of that illness or accident may be large enough to make that person eligible. (Remember: the bills only need be incurred. They do not have to be paid.)

While it is advisable to bring the bills in as early as possible, it is not necessary. Application for Medicaid can be made for up to three months retroactively.

Another Medicaid door through which a person can enter is Medicaid for Employed Adults with Disabilities (MEAD). Many people with disabilities work part-time and are not eligible for health insurance coverage from their job. Medicaid pays for services not often covered under private insurance. It used to be crucial to investigate the impact of increased income on Medicaid eligibility. In the past, income from work made some individuals ineligible for Medicaid. This is no longer necessarily true. Now, individuals with disabilities can work and even receive medical benefits from their employer and still buy into Medicaid by paying a monthly premium based on their net income (which is approximately half of their gross income).

To be eligible, a person must be between the ages of 18 and 64, have a disability (as defined by the State), be working, and meet the income and resource requirements (which are larger than those otherwise used to determine Medicaid eligibility). Monthly premiums range from \$0 to \$210 until the person's annual adjusted gross income exceeds \$75,000. Then, the full premium is calculated as 7.5% of the person's gross income (which includes the income of the person's spouse, if married). If a person is covered by private insurance through an employer, the amount of the monthly premium paid for the private insurance may be deducted from the monthly MEAD premium.

Medicaid case technicians make the determination of eligibility and do re-determinations on a regular basis.

Medicaid coverage for children

Medicaid for children under the age of 19 is called Healthy Kids Gold. Children typically receive Medicaid coverage when their parents are deemed eligible because of low income and resources. Children with disabilities, however, may enter the Medicaid house through a different door.

Home Care for Children with Severe Disabilities (HC-CSD)

A change in the Federal rules for Medicaid has allowed families caring for a child with a severe disability to enroll that child in the program regardless of the family's income.

The Home Care - Children with Severe Disabilities (HC-CSD) Program (also known as the Katie Beckett Option) came about because of one family's experience. Katie Beckett had complex medical needs and was being cared for in a hospital. Her parents could not bring Katie home because she would lose her Medicaid eligibility once she lived at home with her family due to her family's income. Her parents' income and assets would be counted in determining her eligibility for Medicaid. This family's plight was broadcast on national TV.

In response to that situation, the Federal Government offered states an optional program based on the disability of the child. This option for children with complex medical needs and other severe disabilities allows children to live at home with their families and still receive Medicaid. Parents' income is not counted. This saves states thousands of dollars in hospital costs.

The criteria for HC-CSD are as follows:

1. the child is under 18 years of age,
2. the child is chronically ill or severely impaired requiring a level of care normally provided in a hospital or other medical institution,
3. the child can be cared for at home,
4. the cost of home care does not exceed the cost of institutional care, and
5. the child must live with at least one parent.

Although the parents' income is not one of the criteria for HC-CSD, the child's income and resources are counted. The New Hampshire regulations for HC-CSD have recently changed. The State now uses the same eligibility categories as the Federal Government uses for Social Security eligibility. The eligibility requirements for Medicaid are so complex that sometimes the only way to find out if a child is eligible is to apply.

The application process for HC-CSD requires filling out many forms (that are used only for this program) to document the child's disability. These forms need to be filled out by a variety of professions. It is wise to have all the forms filled out and together before applying because there is a 10 day limitation to return any required documentation. Failure to do so can result in the application being denied just because all the documents haven't been returned.

It is crucial that the medical information describing the child in detail is worded properly. A family should begin by finding someone to assist them with the process. Individuals who have expertise in this area include a case coordinator at an Early Supports and Services Program, a family support coordinator at an area agency, a nurse at a well child clinic, a hospital social worker, and staff of the Bureau of Special Medical Services in Concord.

Some families have successfully applied on their own, but it helps to have advice from someone who knows the system. The Office of Medical Services Review Team must make a decision within 90 days of the application, and coverage can be retroactive for up to three months from the date of application. A family who is turned down can appeal the decision through the DHHS district office within thirty days. It is always advisable to appeal the decision.

A child who is found eligible will receive a letter of acceptance and a Healthy Kids Gold Card which will entitle the child to all the services covered by Medicaid.

Children with Severe Disabilities (CSD)

This little known program is for children whose disabilities are not severe enough to meet the criteria for HC-CSD. It does count parental income, but only counts a portion of parental assets.

To apply for either HC-CSD or CSD, it is necessary to go to the local district office of the Department of Health and Human Services. This office is listed in the phone directory under "New Hampshire State of."

Note: Medicaid for children is called Health Kids Gold. Applications for Healthy Kids Gold should not be confused with applications for HC-CSD or CSD, even though all three are Medicaid programs for children. Parents whose income and resources are low enough for their children to be eligible for Medicaid should fill out a Healthy Kids Gold application. This application is not taken to the local district office; it is mailed to the address in Concord listed on the form. Parents of children with disabilities, whose income and resources might otherwise disqualify their children from eligibility for Medicaid should go to their local district offices to apply for HC-CSD or CSD.

Child Health Assurance Program (CHAP)

Every child who is eligible for Medicaid is automatically enrolled in the Child Health Assurance Program (CHAP). For CHAP, "child" is defined as a person birth to 21, even though for every other program, a person is considered an adult when he or she reaches the age of 18. This is important to know because children receive more benefits than adults under Medicaid.

This program ensures that a child who is on Medicaid will have periodic screenings and immunizations. The screenings consist of dental, medical, developmental, nutritional, and vision and hearing assessments. Any treatment recommendations which result from a CHAP screening must be paid for by Medicaid if the treatment plan is medically necessary and approved by the Division of Health Planning and Medicaid. There is no cap on services which are medically necessary and approved in a CHAP treatment plan.

Also, the treatment plan can include non-traditional treatment which the doctor believes to be medically necessary to reduce the child's disability. It must also be approved, however, by DHHS.

CHAP workers are no longer available in the local district office of the Department of Health and Human Services. For information about CHAP, contact the Concord office at 603-271-7703, or 1-800-852-3345, ext.7703.

Healthy Kids Gold and Silver

Despite having similar names, Health Kids Gold and Healthy Kids Silver are two different types of health care coverage. Health Kids Gold is Medicaid for children under the age of 19. Medicaid will cover more than just medically related services and may be used to pay for such services as respite, service coordination and case management, rehabilitation and personal care. Medicaid will also reimburse school districts for medically necessary services (as outlined in an Individualized Education Program - IEP) provided to students with disabilities.

Healthy Kids Silver is for families with children who do not have health insurance. The child does not have to have a disability. Healthy Kids Silver is not Medicaid. It is offered through Anthem Blue Cross and Blue Shield and is strictly medical insurance. Healthy Kids Silver does not cover the extra services provided under Medicaid.

Applications for both Healthy Kids programs are sent to the same place: New Hampshire Healthy Kids, 25 Hall Street, Suite 303, Concord, NH 03301. Assistance is available toll free at 1-877-4NH-CHIP (1-877-464-2447). TDD Access: Relay NH, 1-800-735-2964.

Continued from page 9

Conclusion

Benefits programs provide needed resources for people with disabilities. Each program is governed by Federal and/or state rules and regulations, which are complex and can be confusing. It is possible to apply for these benefits on your own, and The Challenge offers this information to help you get started. To receive benefits, families must take the initiative and apply for them at the appropriate agencies (see charts).

For Social Security benefits, (such as SSDI and SSI), you may call a toll-free number (1-800-772-1213) and apply by phone. This number will reach one of 34 tele-service centers across the country. At certain times of the month, or even certain times of the day, the tele-service centers are busier. If you call at one of the busy times, a recording will let you know how long it will be before a representative can speak with you personally. This will give you a choice of waiting or calling back at another time.

You may also apply over the internet. Visit www.socialsecurity.gov and click on "Disability and SSI."

Whether you apply in person, by phone or over the internet, it is better to be prepared. There are specific kinds of information and certain documents that are required in the application process. If you are prepared with that information, the process will be shorter and smoother.

For State programs (APTD, ANB, and HS-CSD/CSD Medicaid), you need to apply at your local district office of the NH Department of Health and Human Services.

There are people who can help families with this process. Family support coordinators will offer information and assistance, as will benefits planners in the area agencies. Of course, case technicians in each of the appropriate agencies are available to answer questions as well. It is important to remember, however, that Social Security and the Department of Health and Human Services can only give you information about the programs they administer. Changes reported to one program may make a big difference in another program, but staff in one office may not know how this impacts eligibility for a program they don't administer. Family support coordinators and benefits planners will generally have knowledge of both Federal and State programs.

** This article discusses only a portion of the many benefits that are available for individuals and families. For instance, Social Security has spousal benefits that we only mentioned briefly. If you are a spouse of a worker who is now retired, disabled or deceased, then you should contact your local Social Security district office for more information about available benefits.*

In addition, while the information presented in this article has been checked and reviewed for accuracy, The Challenge is unable to present all the information relevant to the rules and regulations of these programs. For complete information, contact your local district offices.

Work Incentives for SSI and SSDI

Individuals receiving SSI and SSDI cash benefits will not automatically lose those benefits if they return to work. Each program allows deductions and disregards from a recipient's earned income. This is what happens.

SSI

When an SSI recipient becomes employed, the Social Security Administration (SSA) will disregard the first \$20 of unearned income and the first \$65 of earned income. After that, every \$2 you earn, you lose \$1 in benefits. As you earn more, your benefit amount decreases. In order to lose benefits completely, you would have to make twice the amount of the benefit you receive, plus \$85. So, for instance, if you are receiving the maximum benefit of \$552 for an individual, you would have to earn \$1,189 in a month to lose your benefits completely. SSA will continue to keep your records on file even if you no longer receive cash benefits. If you lose your job, or your job situation changes so that your earned income decreases, report the change to the local SSA office so that your benefits can begin again.

An SSI recipient who is a full-time student in good standing may have wages up to \$1,340 a month and \$5,410 a year not counted as earned income for SSI purposes. Any wages earned above the caps will be considered earned income and may affect the student's eligibility.

SSDI

SSDI regulations are different. If you are receiving SSDI cash benefits, you may work without losing those benefits as long as you do not earn more than \$800 a month. The \$800 limit is what defines "Substantial Gainful Activity" (SGA). When you are averaging \$800 a month or more of wages, SSA considers your disability to have "ceased."

The months that a recipient earns between \$570 and \$800 are part of what the Social Security Administration calls a trial work period. After nine months of receiving over \$570 but less than \$800, SSA will review a recipient's eligibility to determine if they are performing SGA. (What may be confusing is that the nine months do not have to be consecutive months. So, for instance, if a person earns \$600 one month, \$400 the next, \$500 the next, and \$750 the next, that person will have accumulated two months of the nine months allowed.)

A recipient's benefits will not stop, however, until he or she earns more than \$800 for nine months in a five year period. (Again, these need not be consecutive months.) Once a person has worked and earned \$800 or more for nine months, that person has demonstrated the ability to work, according to SSA regulations. The individual will be given a three month

grace period before benefits end. There is no gradual tapering off of benefits. They just stop.

It is also important to keep in mind that the amount of earned income may be reduced by the cost of Impairment-Related Work Expenses (IRWE). IRWE are those items and services that a person needs in order to work and that are paid for by the individual, and for which the individual receives no reimbursement. Cab fare for someone who cannot drive, for instance. The cost of these items and services should be reported to the local SSA office and may be deducted from the individual's monthly earned income. If a person is making \$800 a month, but has IRWE amounting to \$150, the earned income in that month would be \$650. So it is important to keep track of IRWE - it could mean the difference between keeping and losing your benefits.

Subsidy Deduction

A person with a disability who is performing a job but needs more supervision or is doing fewer tasks than other workers doing the same or similar job, and is receiving the same pay, may be eligible for a subsidy. If the individual's employer fills out a subsidy form from SSA outlining what percentage of the job the employee is actually performing, SSA may determine that the difference between that percentage and 100% is a subsidy by the employer and deduct that percentage of the monthly wages from the recipient's earned income. For instance, if an employer determines that an individual is actually performing only 75% of the job, SSA may determine that 25% of the wages the individual earns may be deducted and not counted as part of the individual's earned income. If a person's wages or self-employed income is at or near the cap, a subsidy could allow the individual to retain his or her eligibility and benefits.

This subsidy deduction applies to both SSI and SSDI.

Ticket to Work

The Ticket to Work program is a national initiative to help people with disabilities have greater choice in what rehabilitation and employment services they can use to get into the workforce and achieve their employment goals. It also removes one of the greatest obstacle to work - health care coverage - by allowing Medicaid coverage for individuals who are working. (See MEAD in previous benefits article.) It is a voluntary program. For more information, call toll-free 1-866-YOURTICKET (1-866-968-7842), toll free TDD: 1-866-833-2967, or visit the web site: www.yourtickettowork.com

Cash Benefits - A Simplified, Non-Official Guide for Families

Benefit programs are complex, with intricate rules and regulations. The Challenge offers this guide as a snapshot. While we have worked hard to provide accurate information, it is not possible to include all the facts relevant to each program, or guarantee 100% accuracy. Consult your local government offices for complete details

Title	SOCIAL SECURITY DISABILITY INSURANCE (SSDI)	SUPPLEMENTAL SECURITY INCOME (SSI)	AID TO PERMANENTLY AND TOTALLY DISABLED (APTD)	AID TO NEEDY BLIND (ANB)
Apply At	Social Security office or call 1-800-772-1213	Social Security office or call 1-800-772-1213	Department of Health and Human Services office	Department of Health and Human Services office
Based On	The Insured paying FICA for a specific number of quarters depending on age, and being blind or disabled.	Being disabled or blind, and income and resources not exceeding set limits.	Disability of applicant (state definition of disability differs from Social Security), and income and resource levels not exceeding set limits.	Being blind, and income and resources not exceeding set limits.
Resource Criteria	.Call SSA office	Needs based resource test. Individual cash assets not to exceed \$3,000. Can own the home that is lived in. May own a car worth \$4,500 excluded if used for doctors visits. Burial account and plot must be irrevocable. Whole life insurance w/face value or \$1,500 or more/cash surrender value is counted. Household belongings valued at more than \$2,000 are counted.	\$1,500 cash assets	\$1,500 cash assets
Monthly Income Limits for Eligibility	\$800 gross monthly earnings test. If earnings are in excess of \$800 monthly, SSA will not consider individual disabled. Different rules for blind people...call SSA office	Income must be less than maximum benefit after deductions. Max benefit limits depend on the person's living arrangements. Limit - \$552 per month as of 1/03 (limits change every January). Limits decreased by 1/3 when living in household of another and not paying fair share of expenses (as defined by SSA)	Benefit amount based on living arrangements. Net income can not be higher than: \$ 566 for individual living arrangement. Applicants in group living arrangements have higher income levels.	Same as APTD
Waiting Period	Full five calendar months from date of disability. Payments begin on seventh month.	None. Benefits based on date of application, or date of phone call to make appointment. For children applying at age 18, the first full month after 18th birthday.	None. Benefits based on date of application.	Same as APTD
Age Criteria	None, but must have paid into FICA the required number of working quarters for age.	Can apply at any time. Under age 18, income criteria based on family income. Over age 18, income criteria based on disabled individual's income only.	18 years to 64 years	None
Additional Concerns	After nine months of earning more than \$800 gross per month (need not be consecutive months), eligibility will be reviewed.	Can "work yourself off" - gradual decrease of benefit as earnings increase.	Can "work yourself off" - earned income deductibles are more restrictive than SSI.	Can "work yourself off" - earned income deductibles are the SAME as SSI.
Other Benefits?	After two years of cash benefits, can become eligible for Medicare	Nothing	Automatic eligibility for Medicaid and potential eligibility for food stamps.	Same as APTD
Date Received	For new applicants, may be any day in the month. Benefit is for the month previous.	1st of the month, for that month.	2 times a month -Recipients may receive their benefits by check or have an Electronic Benefits Card (EBT) issued (works like a debit card).	Same as APTD

Medical Benefits - A Simplified,

Benefit programs are complex, with intricate rules and regulations. The Challenge offers possible to include all the facts relevant to each program, or guarantee

Title	MEDICARE	MEDICAID (for adults)	MEDICAID IN & OUT
Apply At	Social Security office, or call 1-800-772-1213, or visit the web site: www.socialsecurity.gov	NH Department of Health and Human Services district office	NH Department of Health and Human Services district office
Based On	Receipt of SSDI disability benefits for 2 years. Children who have received SSDI benefits before age 18 get Medicare coverage at age 20.	Disability/blindness and/or income. Automatic if receiving APTD or ANB. If not receiving APTD/ANB, based on Net Income Limit.	Same requirements as Medicaid (for adults) except is over income limit. Difference in income determined as "spend down."
Resource Criteria	None	Asset limit for individual in community is \$2,500. For individual in group home, contact DHHS office for details.	\$2,500 for one person
Monthly Income Limits for Eligibility	If SSDI cash benefit not longer received, Medicaid remains in effect for 39 months with "buy in" option.	Monthly eligibility of Net Income Limit as of 1/03 is \$566 for an individual in the community. If individual is in group home, contact DHHS for details. SSI not counted as income.	Same as Medicaid (for adults). Difference between individual's income and Net Income Limit is the "spend down" amount. Eligibility is month-to-month (or a 3 month period and depends upon whether the individual's medical bills for that month (or 3 months) exceed his or her "spend down" amount.
Waiting Period	SSDI recipients - 2 year waiting period if under 65.	None. Benefits based on the date of application; can apply for 3 months retroactive.	None, once DHHS verifies individual's medical expenses exceed "spend down" amount for one or three month period.
Age Criteria	Age 65, or receiving SSDI for 2 years.	APTD: 18 to 64 years ANB: no age limit	Same as Medicaid (for adults)
Additional Concerns	Can "buy into" Medicare if ineligible for SSDI as benefits end.	N/A	An ineligible individual may apply for coverage for incurred catastrophic medical expenses if the monthly medical bills exceed the monthly "spend down" amount, and the asset limit is not exceeded.
Other Benefits?	N/A	Ages 18-21, Child Health Assurance Program (CHAP). For information, call 603-271-7703. If working, see MEAD.	N/A
Date Received	Red, white and blue permanent card issued when first eligible.	Permanent plastic card issued when first eligible. (Having card does not ensure continued eligibility).	Permanent plastic card issued when first eligible. (Having card does not ensure continued eligibility).

Non-Official Guide for Families

this guide as a snapshot. While we have worked hard to provide accurate information, it is not 100% accuracy. Consult your local government offices for complete details

	MEDICAID FOR EMPLOYED ADULTS WITH DISABILITIES (MEAD)	HEALTHY KIDS GOLD (Medicaid for Children)	CHILDREN WITH SEVERE DISABILITIES (CSD-Medicaid)	HOME CARE - CHILDREN WITH SEVERE DISABILITIES (HC-CSD Medicaid) Katie Beckett Option
	NH Department of Health and Human Services district office	Get application at NH Department of Health and Human Services office, or call 1-877-464-2447, or download application from the NH DHHS web site: www.dhhs.state.nh.us . Completed application is mailed to address on form.	NH Department of Health and Human Services district office	NH Department of Health and Human Services district office
	Disability, age, employment status. Monthly premiums are based on net income limit (as defined by state) and range from \$0 to \$210. When adjusted gross income (AGI) reaches \$75,000, premiums are 7.5% of AGI.	Income and resources * <i>This is the typical way children become eligible for Healthy Kids Gold. Parents whose income is greater than the limits established and whose child has a severe disability should consider applying for HC-CSD Medicaid.</i>	Disability (less restrictive than HC-CSD) and income level - income, resources & expenses - of applicant and parents are counted. (Note: for ANB, parental income and assets not counted.)	Disability - child MUST live w/parent & meet state-defined level of care (not to exceed federal level of care). Parents income and resources do not count.
	\$20,560 for one person \$30,840 for two or more persons Resources must be in a special MEAD account.	None	\$2,500 in assets; a portion of parents' resources are counted	\$2,500 in assets for applicant only (parents' assets not counted)
	Net income limit (approximately 1/2 of gross income) cannot exceed \$3,323 for one person, \$4,478 for two or more persons. Certain resources are excluded: retirement plans, medical savings accounts, accounts for goods and services which will enhance employability but not paid for by Medicaid.	Income limit based on family size. For children age 1 - 19: 2 \$1,841 3 \$2,316 4 \$2,791 For children birth to 1, the income levels are higher: 2 \$2,985 3 \$3,755 4 \$4,525	Net combined monthly income for: 2-person household is \$642; 3-person household, \$652; 4-person household, \$662. SSI benefits not counted as income.	Child's gross monthly income cannot exceed \$1,159. SSI benefits not counted as income.
	None. Benefits based on date of application; may apply for 3 months retroactive.	None. Benefits based on date of application. Can be applied 3 months retroactively.	None. Benefits based on date of application. Can be applied 3 months retroactively.	None. Benefits based on date of application. Can be applied 3 months retroactively.
	Age 18-64	Children birth to age 19	Children birth to age 19	Children birth to age 19
	Monthly premiums may be reduced by premiums paid for private health insurance. Individuals who become unemployed for good cause and plan to return to work retain eligibility for 12 months.	N/A	Child must apply for APTD by 19th birthday, may apply after 18th birthday, to continue to receive Medicaid coverage as an adult.	Child must apply for APTD at age 18 to continue to receive Medicaid coverage as an adult.
	N/A	Child Health Assurance Program (CHAP) For information, call 603-271-7703	Child Health Assurance Program (CHAP) For information, call 603-271-7703	Child Health Assurance Program (CHAP) For information, call 271-7703
	Permanent plastic card issued when first eligible. (Having card does not ensure continued eligibility).	Permanent Healthy Kids Gold plastic card issued when first eligible. (Having card does not ensure continued eligibility).	Permanent Healthy Kids Gold plastic card issued when first eligible. (Having card does not ensure continued eligibility).	Permanent Healthy Kids Gold plastic card issued when first eligible. (Having card does not ensure continued eligibility).

<p style="text-align: center;"><u>Medicaid State Plan Services</u></p> <p style="text-align: center;">available for <u>all persons</u> who are eligible for Medicaid. <i>Note: Certain limits, and/or</i></p>	<ul style="list-style-type: none"> * Doctor's office visits * Hospital care (inpatient and outpatient) * Outpatient Rehabilitation Center visits <ul style="list-style-type: none"> * Medication/drugs * Therapy (OT, PT, Speech, etc.) * Durable Medical equipment (i.e., braces, prosthetics, wheelchairs, adaptive equipment) * Medical supplies and prosthetics (includes ear molds, hearing aids, orthopedic shoes, back braces, specialized formulas) <ul style="list-style-type: none"> * Chiropractic care * Podiatrist * Optometric services * Psychological and psychiatric services <ul style="list-style-type: none"> * Case management * X-rays * Transportation (for medical visits) <ul style="list-style-type: none"> * Dental services (children) * CHAP/EPSTD (for children - screening, diagnostic and treatment services, with emphasis on preventive medicine - service limits may not apply, <u>with prior authorization</u>) <ul style="list-style-type: none"> * Early intervention services * Community Mental Health services through local mental health centers <ul style="list-style-type: none"> * Organ transplant services * Nursing services
<p style="text-align: center;"><u>Long Term Care Options</u></p> <p style="text-align: center;">for persons who are eligible for Medicaid, <u>and who are:</u></p> <ul style="list-style-type: none"> * elderly, or * have a severe disability, or 	<p style="text-align: center;">A. Home and Community Based Care Waivers</p> <p style="text-align: center;">for persons who:</p> <ul style="list-style-type: none"> * have a developmental disability, or * have a traumatic or acquired brain disorder, or * are elderly, or chronically ill <p style="text-align: center;">B. Nursing Home Services</p> <ul style="list-style-type: none"> * Cedarcrest ICF/MR (pediatric)

Some Medicaid Facts You Might Want To Know:

* You must apply separately for Medicaid and SSI benefits. Federal determination of disability supersedes the state determination. However, if the State makes a determination of eligibility, and the Federal Government decides that you are not eligible, you will continue to receive the State Medicaid benefits until you have exhausted the Federal appeal process (which can take up to three years). It is definitely in your best interests to apply for both.

* The age of maturity for benefits is 18. While your son or daughter will receive educational services up to the age of 21, he or she is considered an adult at the age of 18. If your child is receiving Medicaid benefits (for instance, under the Katie Beckett Option) before the age of 18, he or she must reapply between the ages of 18 and 19. If your child is not receiving Medicaid benefits, he or she may be eligible at the age of 18, when the applicant is considered an adult. That means that the parents' income and assets are not counted. Some parents have encountered problems applying for APTD for children at age 18 who are still eligible for HC-CSD. The local district office cannot enter the application; it must be sent to the State office in Concord.

* When applying for Medicaid, applicants will be asked to fill out a self-determination form, which will ask them to explain why they think they are disabled. If

there is medical information already available, applicants can request that their doctors send the information. (To expedite the process, doctors may dictate the information over the phone to the Office of Health Planning and Medicaid.) If a medical evaluation must be done, the Office of Health Planning and Medicaid will help the applicant to find a doctor, if needed, and will pay for the evaluation.

* In every other program, a child is considered an adult at age 18, except for CHAP, where that age is extended to 21. Every child (age 0 to 21) who is deemed eligible for Medicaid will automatically be enrolled in the CHAP/EPSTD program. Medicaid service limits do not apply when a medical necessity is documented and prior authorization is given.

* Transportation costs for medical visits are reimbursable. Recipients must use the form available at the district office. A physician must sign the form for each date a recipient is transported.

* The cost of disposable diapers for school age Medicaid-eligible children may be covered. A prescription is needed and must be brought to a pharmacy, or medical supplier who can bill Medicaid.

Mental Health Management Services (MIMS)

MIMS are direct face-to-face service interventions delivered in a natural environment which has as its purpose and objective the reduction or management of the symptoms of a client's mental illness so as to allow the client to develop, utilize and/or maintain the skills and supports he or she needs to successfully live, learn, work and play within the environments of his or her choice.

In order to receive MIMS services, a person must be Medicaid eligible and meet the eligibility requirements for state supported services. (For further information about eligibility requirements, contact your child's case manager or therapist.)

MIMS services include:

* **Group therapeutic intervention** - the development and maintenance by a client of skills needed to live with other persons as roommates and neighbors. These skills include conflict resolution, personal responsibility, and communication.

* **Medication education** - development by the client of skills necessary to comply with physician prescribed medication

* **Symptom management** - the identification and minimization of the negative effects of psychiatric symptoms which interfere with a client's daily living, financial management, personal development, and community integration

* **Individual psychotherapeutic intervention** - the development by a client of interpersonal and self-care skills and an understanding of his or her mental illness to enable the client to adapt to community settings in which he or she lives and functions

* **Supportive counseling** - includes interactions with a client and/or persons in the client's immediate support system, with the goal being the development and/or maintenance of client growth and supports necessary for that client to manage his or her mental illness

* **Crisis management** - includes client training regarding management of a psychiatric crisis, with the goal being the ability of the client to identify a psychiatric or personal crisis, implement the crisis management plan identified in the client's individual service plan (ISP), if appropriate, and/or seek needed support from either residential or clinical staff, and

* **Family support** - includes family education and consultation, with the goal being the development and maintenance of family support systems and/or better management by the client of his or her mental illness.

The purpose of MIMS is to help individuals with mental illness to learn to manage the symptoms of their illness that get in the way of doing the things they want to do.

What is important to know about MIMS is that the services offered **must be delivered in the person's natural environment**, meaning that service deliverers come to the home, the school, the basketball court, the mall, wherever the person with the mental illness needs assistance. Also, services are offered **any time of the day they are needed**, not just during office hours.

Individuals who deliver services must meet experience and educational requirements as defined by the state of New Hampshire, and are employed by a Medicaid provider. The level of expertise of the providers ranges from those people who have personally experienced mental illness to those with a more clinical background.

NH Department of Health and Human Services District Offices

Berlin

219 Main Street
Berlin, NH 03570-2463
(603) 752-7800, or
1(800)972-6111

Claremont

17 Water Street
P.O. Box 870
Claremont, NH
037432280
(603) 542-9544, or
1(800)982-1001

Concord

40 Terrill Park Drive,
Unit 1
Concord, NH 03301-
7325
(603) 271-6200, or
1(800)322-9191

Conway

73 Hobbs Street
Conway, NH 03818-
6188
(603) 447-3841, or
1(800)552-4628

Keene

809 Court Street
Keene, NH 03431-1712
(603)357-3510, or
1(800)624-9700

Laconia

65 Beacon Street West
Laconia, NH 03246
(603) 524-4485, or
1(800)322-2121

Littleton

Lisbon Road
80 North Littleton Road
Littleton, NH 03561-
3814
(603) 444-6786, or
1(800)552-8959

Manchester

361 Lincoln Street
Manchester, NH 03103-
4976
(603) 668-2330, or
1(800) 852-7493

Nashua

19 Chestnut Street
Nashua, NH 03060
(603) 883-7726, or
1(800) 852-0632

Portsmouth

30 Maplewood Avenue,
Suite 200
Portsmouth, NH 03801-
3737
(603) 433-8300, or
1(800)821-0326

Rochester

150 Wakefield Street, Suite
22
Rochester, NH 03867-1309
(603) 332-9120, or
1(800)862-5300

Salem

154 Main Street, Suite 1
Salem, NH 03079-3191
(603) 893-9763, or
1(800) 852-7492

TDD Access; Relay NH

1(800)735-2964

Benefits Related Acronyms

APTD - Aid to the Permanently and Totally Disabled

ANB - Aid to the Needy Blind

CCW - Community Care Waiver

CHAP - Children's Health Assurance Program

CMS - Centers for Medicare and Medicaid

CNA - Certified Nursing Assistant

CSD Medicaid - Children with Severe Disabilities

DHHS - Department of Health and Human Services

EBT - Electronic Benefits Transfer

EPSDT - (Federal name for CHAP) Early Periodic Screening, Diagnosis and Treatment

ESS - Employment Support Services

HCBC/ABD - Home and Community Based Care for Acquired Brain Disorder

HCBC/DD - Home and Community Based Care for Developmentally Disabled

HCBC/ECI - Home and Community Based Care for Elderly and Chronically Ill

HC-CSD Medicaid - Home Care-Children with Severe Disabilities (Katie Beckett)

IRWE - Impairment Related Work Expenses

MEAD - Medicaid for Employed Adults with Disabilities

MIMS - Mental Illness Management System

OAA - Old Age Assistance

PASS - Plan to Achieve Self Support

PCA - Personal Care Assistant

QMB - Qualified Medicare Beneficiary

SGA - Substantial Gainful Activity

SON - Standard of Need

SSA - Social Security Administration

SSDI - Social Security Disability Insurance

SSI - Supplemental Security Income

TANF - Temporary Aid to Needy Families

Medicaid Home and Community Based Care Waivers

Home and Community Based-Care Waiver - Developmental Disability HCBC - DD

Must:

- * be Medicaid eligible
- * have a developmental disability
- * require 24 hour support services or supervision

Determination of eligibility is made by :

Regional Area Agency and the Division of Developmental Services

* Funding is limited to the number of persons approved by the Division of Developmental Services and the Centers for Medicare and Medicaid Services (CMS) and the amount approved by the Governor and the NH Legislature.

Home and Community Based Care Waiver - Acquired Brain Disorder HCBC - ABD

Must:

- * be Medicaid eligible
- * be between the ages of 22-65
- * have an acquired brain disorder, which occurred before the age of 60, requiring skilled or long-term rehabilitative care on a 24 hour basis, and whose disability is the result of:
 - 1) traumatic brain injury from a car accident or related trauma; or
 - 2) anoxia, stroke, or other occurrence limiting oxygen flow to the brain; or,
 - 3) demyelinating disease, such as Multiple Sclerosis; or
 - 4) infectious disorder, such as encephalitis or meningitis;, or
 - 5) other related neurological disorder (Huntington's Disease, etc.)

Determination of eligibility is made by :

Regional Area Agencies and Division of Developmental Services

* Funding is limited to persons who are currently in long term skilled or rehabilitative facilities in order to provide community alternatives, and to persons who are at imminent risk for placement in a long term care skilled or rehabilitative facility. The Governor and the NH Legislature approve the amount of funding available for services.

Home and Community Based Care Waiver - Elderly and Chronically III HCBC - ECI

Must:

- * be Medicaid eligible
- * be 18 or older
- * be chronically ill
- * must require 24 hour nursing care

Determination of eligibility is made by :

Local office of the Department of Health and Human Services, and Division of Elderly and Adult Services

* Funding for this waiver must be approved by the Governor and the NH Legislature.

Note: spousal income is not counted when determining Medicaid eligibility for this waiver, and the resource cap is \$1,500 not \$2,500

Also, in order for a person to be eligible for this waiver, he or she may need to have in place a community support system for a least part of a day

Medicaid Home and Community Based Care Waivers

In-Home Support Waiver for Children with Developmental Disabilities

Must:

- * Be a child birth to 21 years of age
- * Be found eligible for area agency services
- * Be found eligible for Medicaid
- * Agree not to receive services under any other Medicaid Community Care Waiver
- * Agree to make payment toward cost of care if applicable

AND

The individual must require *one* of the following:

1. Services on a daily basis for:

- * performance of basic living skills
- * enhancement of developmental or behavioral skills
- * medication administration or instruction/supervision of self-medication by a medical professional
- * medical monitoring or nursing care by a licensed professional person

2 Services on a less than daily basis:

- * as part of a planned transition to greater independence
- * to prevent circumstances that could lead to more intrusive and/or costly services

AND

Has *one of the following combinations* of factors which complicate care of the individual or impede the ability of the care-giving parent to provide care:

1. Has a combination of 2 or more of the following individual factors:

- * lack of age-appropriate awareness of safety issues so that constant supervision is required
- * destructive or injurious behavior to self or others
- * condition that significantly impedes the ability of the care-giving parent to provide care
- * inability to participate in local community childcare or activity programs without support
- * inconsistent sleeping patterns or sleeping less than 6 hours per night and requiring supervision when awake

2. Has a combination of 1 of the preceding individual factors and 1 or more of the following parent factors:

- * age of either parent being less than 18 years or above 59
- * physical or mental condition that impedes the ability of the care-giving parent to provide care
- * care responsibilities for other family members with disabilities or health problems
- * founded child neglect or abuse
- * availability of only one parent for care giving.

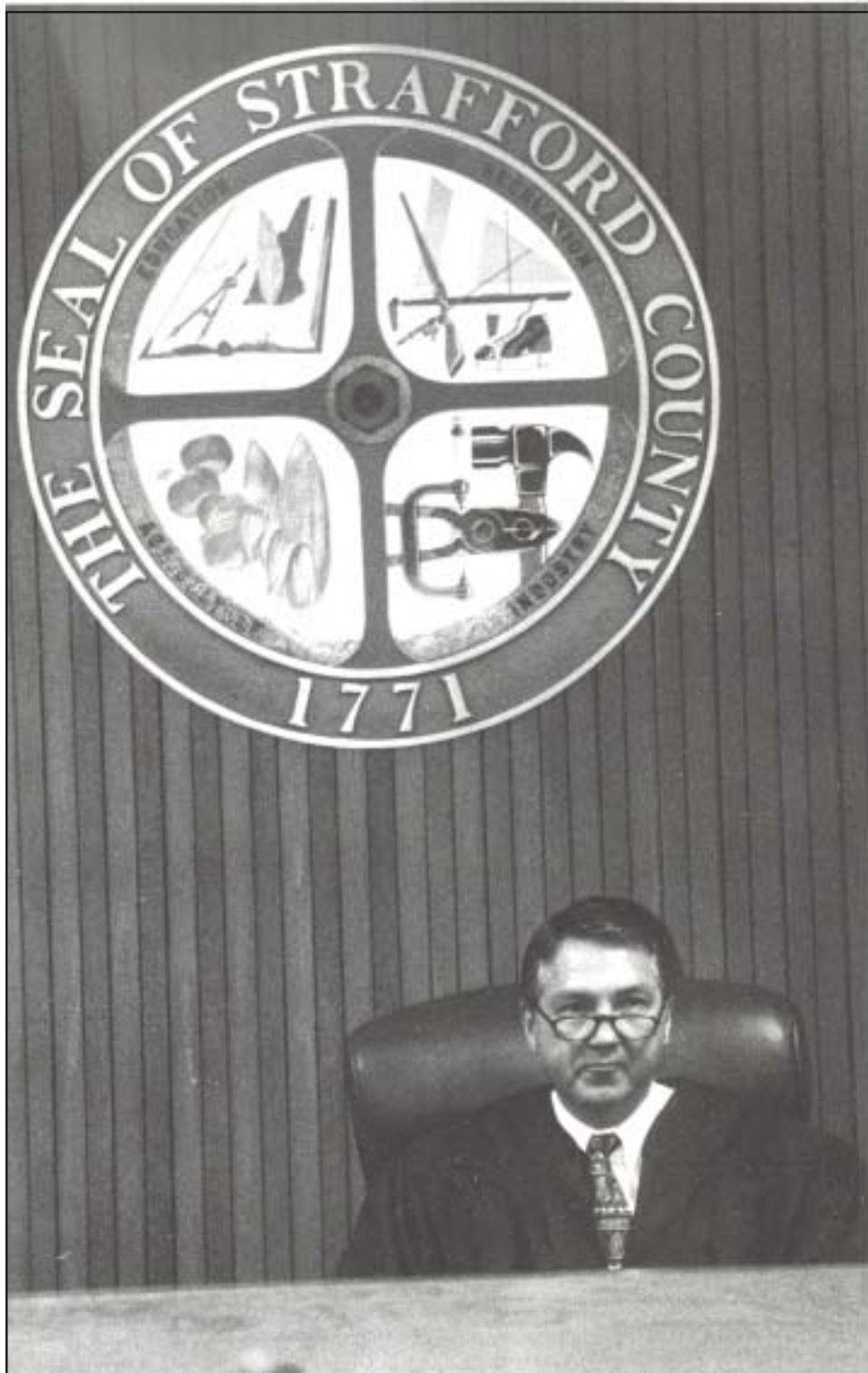
Note: This is a Federal requirement for all services provided under a community care waiver. The requirement states that if an individual has any net income left over after receiving services, the individual must make a payment for those services, after certain deductions have been made. The division of developmental services has reached an agreement with the Center for Medicaid and Medicare Services that they could deduct \$1,250 per month of the child's net income before requiring payment. Since DDS considers only the income of the child, they do not anticipate having to bill anyone for services under the In-Home Supports program.

Determination of eligibility is made by :

Regional Area Agencies and Division of Developmental Services

* Funding is limited to 200 children with priority given to children whose families are using (or would use) CNA services, but for whom CNA services are not meeting the needs of their child. Families may have more than one child eligible. Individual annual budgets must average \$20,000, but may not exceed \$30,000.

New E-mail address for The New Hampshire Challenge:
Contact us at: nhchallenge@comcast.net



Honorable Gary R. Cassavechia, Probate Court of Strafford County

File photo: E.G. Stone

by: Janet M. Krumm

I had been dreading this for a year. My son's 18th birthday was looming ever larger in our lives, marking a significant milestone for him - and for us. There was a lot to be done.

I was not ignorant of what needed to be done. I had done research on this for past articles in *The Challenge*. I knew that Joe should apply for Supplemental Security Income (SSI) benefits through the federal government because as an adult with an established disability, he would most likely be eligible. I knew that even though Joe had already been deemed eligible for Medicaid through the Katie Beckett option, his eligibility under that option ended with his childhood. He would have to re-apply as an adult.

There was a lot of paperwork - appointments to be

made, forms to fill out, information to be gathered - but I was no stranger to paperwork. One of the skills I've honed since Joseph's birth is how to fill out paperwork correctly - give them the information they want the way they want it. True, paperwork is a pain in the, um, neck, but it's doable.

No, I wasn't looking forward to all that, but that isn't what I was dreading.

I was dreading guardianship.

New Hampshire law states that once a person turns 18, that person is considered a capable adult with legal rights. Once Joe turned 18, I could not legally sign his IEP anymore. I had no legal status to demand the services to which he was entitled by law. The school district would be well within its legal rights to present an IEP to

Joe and have him sign it without consulting me at all.

It's not just the IEP I was worried about, it was also being able to act on his behalf regarding medical procedures. Given the new HIPPA regulations, the medical world is being very careful about privacy issues. I would have no legal standing there anymore.

I knew that I had to petition the court for the legal right to make decisions on Joe's behalf so that I could protect his interests.

Sounds simple, doesn't it?

Fill out the paperwork, meet with the lawyer appointed by the court to represent Joe, gather information in support of our petition, and show up at court at the specified time and date to present our testimony to the judge. That's all we had to

Guardianship

Personal reflections on the reality

Five years ago, The Challenge published an issue that was focused on guardianship: what is it and how you do it. We provided practical information on the law itself, the forms to be filled out, the location of the courts. This article will focus on my personal experience with applying for guardianship over my 18 year old son Joseph this past spring.

do.

I knew how to do this. I had interviewed the very judge before whom we would be testifying for an article on guardianship several years ago. I knew the kind of testimony he was looking for. I was familiar with the law.

So why this feeling of dread?

All I could picture in my mind was testifying to the judge about Joe's incompetency in a courtroom as Joe sat listening to my testimony. What would he think? How would that make him feel? How would I explain all this to him?

For all of his life, I have been emphasizing Joe's competencies. All my advocacy has centered around what he can do. (The only exception has been the application for Medicaid when he was younger, which was focused on what he couldn't do.)

I am not blind to Joe's difficulties. I know that his reading level is basic. I know that math is as easy for Joe as a foreign language is for my husband (yeah, that bad!). I know that he needs short, concise verbal directions or else he gets confused. I know that he doesn't like to be left alone for very long, especially at night. I know that he never checks the vacuum cleaner bag when he vacuums unless reminded to do so. (Now that might not seem like a problem. After all, we all forget that at times. The problem is, Joe loves to vacuum so

our vacuum cleaner gets a lot of use. When the bag hasn't been changed after many tours of duty, it affects the motor adversely.)

So I'm not blind to these things. It's just that I've lived with them for 18 years now and that's become "normal" for me. As with my other two children, I look at Joe's accomplishments and celebrate them, no matter how seemingly small or insignificant.

But now I would have to stand in court and explain why Joe's rights should be taken away from him - in front of him! I wasn't looking forward to that.

As the day loomed larger, the amount of stress I felt increased. My jaw started to bother me. It ached in the morning when I woke up. It hurt every time I opened my mouth. The Saturday after we filed our petition with the court, I developed such a severe headache that I had to go to the emergency room in our local hospital. After one shot and two pills, I spent the next two days in a drug-induced zombie-like state.

Every time my husband Jack and I sat down to discuss our upcoming testimony, I broke down in tears.

The two nights before the court date, I tossed and turned all night. I couldn't sleep. The day before the hearing, the tension in my shoulders and neck was creating a dull throbbing in the back of my head. To ward off another visit to the emergency room, I called a therapeutic massage practice

and scheduled a last minute appointment. I was a stress train-wreck waiting to happen.

Because I couldn't talk about the guardianship without crying, we decided that Jack would present our testimony in court. He, however, urged me to give a short statement before his testimony. Knowing full well that my composure was likely to crack, I wrote the statement and printed it so that I could read it to the judge.

On the day of the hearing, we picked up Joe from school early and drove together the short distance to the court. Hugh Philbrick, the transition coordinator from our area agency who had been capably helping us through this process, joined us there. Our daughter Kate, who is a teacher, left school early to join us in court.

As we were waiting for court to convene, we spoke with Joe's attorney briefly. After a short wait, we were summoned into the courtroom. Joe's attorney invited Joe to sit with him at the table to the right. Jack, Kate and I sat at the table to the left. Judge Cassavechia's presence was announced and we all stood as he entered and took a seat. Then we sat, and the hearing began.

Judge Cassavechia asked who was representing Joe and then asked Jack and me if we were being represented pro se (meaning, were we representing ourselves). We responded yes. The judge then asked if this petition was being contested and Joe's attorney said, "No." Then, the judge invited us to testify. I stood and walked to the podium situated in between the two tables. With my paper in front of me, I began to read.

"Your honor, it is with some reluctance and with great trust that I approach the court today. My husband and I are here to petition for guardianship over our son Joseph. We are here with one purpose only: to do what is in the best interests of our son.

"We have advocated for him for 18 years now" At this point, my voice cracked and all the emotion I had been harboring for the last year overwhelmed me. I didn't know if I could go on. I took a few deep breaths, trying to gain my composure. The court bailiff walked over and put a box of tissues on the podium for me. After what seemed a very long moment, I began to speak again, my voice wavering but (I hope) intelligible.

"We have advocated

that he be given every opportunity possible for him to succeed, to learn, to participate in our community in meaningful ways," I explained.

"Joseph is a responsible, caring adult, who treats everyone with respect. He is a capable adult and we are very proud of him. We intend to nurture his desire for independence and provide the supports he needs to achieve that independence."

The courtroom was silent. I could feel everyone's attention on me. I could feel the support of Jack and Kate to the left of me. I was aware of Joseph to my right, but I blocked out any concern about what he might be feeling or thinking.

"I come here today with mixed emotions," I admitted to the judge. "I come with reluctance because I do not want to taint my son's belief in himself, in his capabilities." The tears were flowing and my control was becoming more and more tenuous, but I continued. "And yet I come, paradoxically, because I want to safeguard his

My statement concluded, I turned and sat down at the table, where my daughter grabbed my hand and held on tight as I wiped my eyes.

It was Jack's turn. He walked to the podium, taking his notes with him and presented our testimony as to why we were petitioning for guardianship.

The judge asked Jack questions during his testimony. There are 19 specific rights listed on the petition and a box marked "Other." We did not ask the court to remove all of Joe's rights, but we were required to present the court with factual instances that occurred within the last six months demonstrating why we were petitioning for a particular right to be removed.

At the end of Jack's testimony, Joe's attorney was invited to speak. He testified that he had spoken with Joe's doctor and with Jack and me and Joe, and reviewed information he had received. It was his opinion that the petition for guardianship was appropriate and he

hesitation in addressing the court. As his "testimony" began to range farther and farther afield from the issue at hand, the judge finally interrupted by throwing his hands in the air and saying (with a chuckle), "Okay, Joe, you win."

At the conclusion of all the testimony, Judge Cassavechia ruled, approving our petition for guardianship. He then outlined our responsibilities as guardians, reminding us that we were required to file an annual report to the court which should evaluate Joe's continuing need for guardianship. Guardianship is a legal role, he explained, and should be considered separate from our role as parents. Our responsibility as legal guardians is to encourage Joe to be as independent as he can and to make as many decisions as he is capable of making. "Just because you have the right to make decisions for him doesn't mean that you should make all his decisions," the judge instructed.

Joe has not lost all his rights. He can vote. He has the

choose? Will he keep his grades up at the end of the year when senioritis hits?

I have been spared the terror inspired by a teenage driver who just got his license and is out past his curfew.

I haven't as of yet had to be careful what kind of impression I make for a new girlfriend, or worry about his being out too late with her.

My parenting experience has - and will be - different because Joe has one extra chromosome. Petitioning for guardianship brought that into sharp focus. That's the real reason, I believe, that I struggled with such powerful emotions as Joe's 18th birthday approached. It was easier to focus on whether Joe's feelings would be hurt during this guardianship process than to examine if I were hurting and why.

It's been over a month since the hearing. We've received a copy of Judge Cassavechia's ruling in the mail. My jaw doesn't hurt anymore, and I'm sleeping much better. I haven't had a headache in a while.

Life goes on, much as it did before. The issue of guardianship has been confined to a folder in my file cabinet. Our energies are now directed to creating an IEP that will help Joe make a smooth transition from school to adult life and work over these next three years. Once again our focus is on Joe's capabilities and the promise of his future.

This experience taught me one thing, though. Information isn't always enough. I had all the information I needed. It took the understanding of my husband, the support of my daughters, the kind and gentle encouragement of Hugh Philbrick, the willingness of my friend Jan Larsen to answer questions to which she knew I knew the answers, the respect given to my son by his attorney Gregory Wirth, the considerate attention as well as patience of Judge Cassavechia, and the unconditional love of my son to get me through this process.

"Poor Mom," Joe said. My son may need help navigating life's arena, but he needs no help navigating the human heart. I am so blessed.



**My son may need help navigating life's arena,
but he needs no help navigating the human
heart.**

rights and prevent his exploitation. I come with great trust in the Court's wisdom to create a balance between those two concerns.

"My husband and I have spoken with Joe's attorney, Mr. Wirth. We indicated in our petition that we were interested in guardianship of the person for Joe, and we marked most of the rights indicated on the form. Because of our discussion with Mr. Wirth we have reconsidered that initial assessment. We are asking for guardianship over less, with one caveat. We are not clear on several issues and we are asking the Court's guidance in these particular matters. My husband will further explain our position."

I was nearly finished. "I would like to thank the Court for your careful consideration of this matter before you today.

"This is about the life of my son," I said, "whom I love very much." I looked at the judge, my voice wavering once again. "I want only what is best for him."

supported our petition.

When Mr. Wirth finished speaking, he sat down, turned to Joe and asked if he had any questions for the judge. Joe smiled, nodded a yes and began to speak. He talked about his family, mentioning each of us by name - even our dog. He spoke of school and how much he loves haunted houses. He spoke about relatives who had died. And as he spoke, I realized that my worries about testifying in his presence were groundless.

As Joe spoke, he revealed his happiness, his contentedness with his life. He never addressed any of the limitations we outlined in our testimony. It was as if what we had said wasn't really important. The only concern he expressed was for me. Referring to my being upset in court, Joe turned to me and said, "Mom sad." He then turned to the judge and added, with sympathy, "Poor Mom." This elicited a smile from the judge.

Unlike me, Joe felt no

right to hold or obtain a motor vehicle operator's license (if he can pass the test). He has the right to make gifts and possess property or income, though he has no right to make contracts or grant power of attorney.

Joe's life has not essentially changed. Jack and I will continue to advocate that he be given every opportunity to participate in the life of his community. We will continue to teach him and encourage him. We will continue to feed him and clothe him and house him. We will continue to love him.

But something has changed. I have been yanked out of the "ordinary" in my life. In a moment of singular clarity, I have been reminded (once again) that parenting Joe is not like parenting other young men his age.

I will be spared the tension that typically accompanies senior year: Has he filled out his college applications? Has he filled out scholarship applications? Where will he be accepted? What college will he

Opinion

A veto and lost ground

Many readers remember a time when children with disabilities were not allowed into a regular classroom in New Hampshire. Some even remember when they were not allowed into any public school! Another unhappy memory is the Laconia State School. Laconia was an institution founded with good intentions, but it ultimately turned into a house of terror for its captive residents. In the not-so-distant past, it was easy to separate family members with disabilities from society – there were pitifully few options. Now, it's not as easy to separate them, but it **IS** easy to ignore them.

The failure of our Governor and Legislature to provide adequate resources for a growing number of citizens with developmental disabilities is causing hard-fought ground to be lost. The trends in New Hampshire are changing. About fifteen years ago, the State moved boldly out of institutions and into the community. The former residents of Laconia speak eloquently about the choices and freedom they now have. Now, however, the State is forcing movement backward - to segregation from the community, and congregation of people, because resources are so paltry. A parent from Berlin, Andre Belanger, stated quite frankly the obvious: the waiting list blatantly dictates that our State government wants a certain segment of our population to live in poverty.

Why is that?

Doesn't the Governor realize that by refusing supports to individuals with disabilities, he is forcing parents to quit their jobs? Does he want to force even more people into poverty? Isn't that counter-productive? Doesn't sound like good business sense to us.

Recently, Governor Benson made quite a splash by smiling broadly while he forcefully banged an oversized veto stamp on a state budget for which hundreds of legislators had worked very hard. A smile of victory had no place at such a somber event. That vetoed budget actually had increased funding for our family members on the wait list. Perhaps he thought that by accepting the very same budget as part of a Continuing Resolution, he was providing the help needed. If that is so, then he's still learning his job. And people will suffer because of the length of his learning curve.

It is rumored that some legislators are tired of hearing stories about the plight of people with developmental disabilities and their families, tired of seeing advocates in the halls of the Capitol and State Office buildings. Well, here's a thought. Families are tired, too. Tired of telling the same stories over and over, stories in which the names may change but the story lines are essentially the same. Tired of making another trip to Concord - sometimes with very little notice – to keep their family members visible to those who have power over their lives.

It is rumored that one legislator responded to a concern about the lack of supports for people with developmental disabilities in the community who have or are at risk of sexually offending by saying they should all be locked up. Out of sight, out of mind? (But not out of pocket, we assume.)

The Governor and some of his supporters seem unaware of our recent sad history. It is critical that we do not forget, lest history repeat itself. Make no mistake; people are suffering and will continue to suffer until our State government makes decisions that are both financially and morally sound.

People's lives are the issue here. No more, no less.

Facing the future.....



....together

Optional Medicaid Services at Risk

The Federal Government mandates that the State provide certain services to all Medicaid recipients, but allows the State to choose from a list of optional services. Once the State has chosen which optional services it will provide, it must provide these services to all Medicaid recipients. The State can, however, change its State Plan and eliminate any or all of the optional services. These are the Medicaid services that were at risk during the budget process this last session.

Optional Medicaid services which New Hampshire has chosen to offer in its State Plan are:

- * Prescription drugs
- * Psychotherapy (12 visits per year)
- * Community mental health centers
- * Chiropractic services (6 visits per year)
- * Podiatrist services (12 visits per year)
- * Durable medical equipment (prior authorization required)
- * Physical-occupational-speech therapy (80 15-minute units per year)
- * Dental care for adults (for acute pain or infection)
- * Vision care and hearing aid services
- * Adult medical day care
- * Therapeutic foster care services
- * Ambulances and wheelchair van transportation

State Department of Ed Seeks Parents for Partnership Team

A State Family-School-Community Partnership Team is seeking parents to join them, or names of parent groups who would be interested in networking.

The Team wants to invite parent leaders from throughout the state who will contribute from their local parent groups, in addition to paid state leadership professionals who will listen intently to the parents, and share information about current programs that may be of interest. Most importantly, parents and professionals are coming together in a spirit of equal footing, knowledge, respect and, most importantly, with the desire to meet the best possible expectations and needs of children.

The Team is being careful to be non-exclusive, but wants to keep a relatively equal balance of unpaid parents and professionals.

The Participation Team is co-led by Heather Thalheimer, the Director of the Parent Information Center and Catherine Brown-Herman, Educational Consultant in the Bureau of Special Education, and meets on a quarterly basis. The meeting place varies mainly between PIC and the Dept. of Education.

For more information, contact:

Catherine Brown-Herman, Coordinator

NH Special Education State Improvement Grant (SIG)

101 Pleasant St., Concord, NH 03301-3860

cbrown-herman@ed.state.nh.us

603-271-3863, Fax: 271-1953, TTY Access: 711

An Institution by Any Other Name is Still an Institution

By: Zach Rossetti

All people are people first.

It's a simple statement, short, direct, most people would agree with it. Yet many students with disabilities still endure separate "special" classes and many adults with disabilities suffer in institutions of all shapes and sizes. The general public may talk the talk of inclusion and disability rights, but few actually walk this walk. The message is still heard loud and clear- "If you have a disability, you are broken and need to be fixed." Separate schools, "special" education, resource rooms, inclusion students, small buses, behavior programs, community-based instruction, stairs rather than ramps, narrow aisles that don't fit wheelchairs, "accessible" restaurants with only one accessible spot in the far corner away from the bar, dance floor, or main dining room, Christopher Reeve wiggling his fingers and hoping for a cure rather than supporting accessibility issues, Jerry Lewis and the MDA telethon, and the continued existence of institutional living all combine to form a definitive statement that disability is deficiency and those with disabilities do not belong.

All people are people first.

Burton Blatt said it the best: "If there is hope in what we have learned in our examination of institutionalization, it is not in any improvement of institutional life- imprisonment and segregation can be made more comfortable, but they can never be made into freedom or participation." An alternative living community, as many new institutions now call themselves, is emphasized as one option among others open to people. Well, not all people. In this sense, people have tried to justify the existence of alternative living communities for people with autism or other disabilities, stressing the personal choice factor. This is laughable. First, it is still based on an institutional model, which is disrespectful at best and abusive at worst. Second, it perpetuates the model of disability as deficiency. Third, most people with disabilities still are not allowed to have the freedom to make their own choices, so, realistically, they are *sent* to an alternative living community by families, friends, and guardians who have internalized the common stereotypes that say having a disability means "you can't live in our community but we set one up for you far away from us." Sounds like segregation to me.

All people are people first.

If people with disabilities were supported to live lives of their choosing in their communities, to work real jobs for real wages, and to develop reciprocal and meaningful friendships- basically, if all people really were people first- then it would be easier to tolerate the continued existence of the so-called alternative living community. If someone chose to live there then with a full life completely open to them, it would be a true choice, one that would have to be respected. Until then, alternative living communities must be outed for what they are: institutions. Institutions are not helpful. They are dictated by numbers, money, and programs. They are oppressive and often abusive. They start out with good intentions and quickly regress into the numbers game, exacerbated by prejudice against disability and the least common denominator. "Meaning well is not an excuse."

All people are people first.

Like with most things, if you lived in an institution or know someone who lived in an institution, you know what I am talking about. For the uninitiated (dare I say ignorant), it may seem like a cost-effective way to ensure rehabilitation, safety, and happiness. The only way this makes sense is when you inherently view disability as deficiency or tragedy, resulting in the drive for cures and justification of segregation. Imagine the message that your loved one with a disability receives when you dedicate your life to curing her or tell him through actions and emotions that you will only love him when he is more like you, more "normal."

All people are people first.

During *Good Morning America's* recent three-part series on autism, *Unlocking the Mystery*, Diane Sawyer consistently referred to autism as a "devastating disease" and "tragic fate" for which the only hope was a new program/miracle cure (supposedly potentially found by Tito and Soma Mukhopadhyay) or yet another separate school (Magnolia School). This narrow focus is both disrespectful to people with autism and limiting in the development of appropriate supports needed in inclusive classrooms and for community living. This deficiency model prevents an understanding of the bigger picture that autism is a valued difference like many other human characteristics and that children and adults with autism are usually more similar to those without these labels. The complete disregard for facilitated communication (FC) and for research validating it shown in the third installment of this series is further proof of the narrow scope and, even, prejudice of this deficiency model. The dedicated push for a cure combined with the belief that people that "retarded" could not author messages of their own has closed minds to research validating FC, guidelines regulating the use of FC, and the now independent communicators once receiving facilitation.

All people are people first.

It is this same type of deficiency model thinking that leads to the development of places like Farmsteads, Inc., a residential farm (alternative living community) for people with autism envisioned by Deborah Gray. I understand that the differences of autism can be extremely difficult and that most schools and communities still fall far short of inclusion, but in addition to concerns raised above, this shows to those who would reopen huge institutions that parents, loved ones, and advocates support segregation. It is just a short hop from Farmsteads to Crotched Mountain to Laconia State School. Ms. Gray makes a valid point about the shortcomings of the school system, but just imagine the positive changes that could have been made with the time, effort, passion, money, skills, and intangibles she has brought to the table for the creation of another institution. There are farms already out there. We can develop appropriate supports. Inclusion needs a real chance.

All people are people first.

It is the year 2003. We need to listen to people who have suffered and endured "special" classes, segregation, stigmatization, and abuse. We need to listen to those who have had their lives stolen away, locked up in institutions where physical punishments were the norm and head banging was the subject of ridicule rather than recognized as a call for help. We need to listen to all of the ways that kids and adults try to tell us that they just want to belong. We need to listen to independent communicators. We need to listen to communicators who still benefit from support. We need to listen to frustrated parents and frustrated teachers. We need to listen to friends, siblings, lovers, neighbors, colleagues, family members, and students with disabilities saying in so many ways that all people are valued and valuable. We need to listen.

All people are people first.

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, operations manager

Phone: 447-3347 **Fax:** 447-8893 1 (800) 439-3347

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

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

Director: Kelly Desilets. OTR/L

Developmental Specialists:

Berlin/Groveton: Stacia Losier Phone: (800) 862-8634 x 4551 slosier@nnhmhds.org

Developmental Services:

Community Services Center

69 Willard Street, Berlin, New Hampshire 03570

Art Froburg, area director

Phone: 752-7404

Common Ground

headquarters for day service & case management

29 Maple Street, Box 599, Littleton, NH 03561

Phone: 444-5358

Vershire Center

39 Colby Street, Colebrook, NH 03576

Phone: 237-5721

Berlin area -

Family support coordinator: Lena Parent 752-1005 x 3343 lparent@nnhmhds.org

Respite coordinator: Same

Benefits technician: Sharon Kolinsky 752-1005 x 3307 skolinsky@nnhmhds.org

Colebrook/Groveton -

Family support coordinator: Stacey Bilodeau 636-6193 x 3558, or (800) 862-8634 x 3558 sbilodeau@nnhmhds.org

Respite and respitality coordinator: Same

Legislative liaison: Same

Parent to Parent coordinator: Same

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

Littleton -

Family support coordinator: Diana Flick 444-5358 x 3460 dflick@nnhmhds.org

Respite coordinator: Same

Benefits technician: Susan Beauchamps 444-5358 sbeauchamps@nnhmhds.org

Family support council chair: Cecile Fillion 752-5704 cecilefi@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

Case Management: 542-8706

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

Family support coordinator: Jean Sorrell 542-8706

jsorrell@dsscofnh.org

Respite coordinator: Same

Legislative liaison: Same

Early supports and services: Dora Markwell, 542-8706 x135

dmarkwell@dsscofnh.org

Benefits technician: Rhonda Desmarais 542-8706 x114

rdesmarais@dsscofnh.org

Family support council chair: John Milliken 826-436 1

jdmilliken@adelphia.net

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: riche@lrsc.org **Website:** www.lrsc.org

Family support coordinator: Christine Santaniello 524-7755

chriss@lrsc.org

Respite coordinator: Susan Tolcser 524-7755 susant@lrsc.org

Benefits technician: Lisa Richardson 524-8811 1

richardson@lrsc.org

Legislative liaison: Chris Collier 536-1884

chriscollier@earthlink.net

Family support council chair: Susan Gunther 293-7371

smgunther51@juno.com

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: rgerstenburger@communitybridgesnh.org

Website: www.communitybridges.org

Director of family support: Jo Edwards 225-4153 (800)499-

4153, ext.224 jedwards@communitybridgesnh.org

Respite coordinator: Renee Carlisle 225-4153 (800) 499-

4153, ext.215 rcarlisle@communitybridgesnh.org

Benefits technician: Rebecca Spinney 225-4153 ext. 222

rspinney@communitybridgesnh.org

Family support council chair: Annette Kowalczyk 224-1524

akowalczyk@comcast.net

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: Julie Cashin 352-1304 (800)

469-6082 julie@mds-nh.org

Respite coordinator: Carol Byrnes 352-1304 carolb@mds-nh.org

Benefits technician: Sue Raymond 352-1304 sue@mds-nh.org

Early supports and services: Anna Lake 352-1304

anna@mds-nh.org

Legislative liaison: Larry Butcher 357-8383 lgbutcher@aol.com

Family support council chair: Cameron Tease 827-3538

ctease@markem.com

Family support council co-chair: Debra Napsey 924-0972

brianlogan@aol.com

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

144 Canal Street, Nashua, New Hampshire 03064

Sandra Pelletier, exec. dir. Beth Raymond, assoc. dir.**Phone:** 882-6333 **Fax:** 889-5460**E-mail:** spelletier@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:** kshottes@region6.com **Website:** www.thepluscompany.net**Adult day service program**

200 Derry Road, Hudson, NH 03051-3398

Deb Wall, director Phone: 883-0994 **Fax:** 886-1238**E-mail:** dwall@alvirnehs.org**Early Intervention and Pediatric Therapy**

144 Canal Street, Nashua, NH 03064

Nancy Dowey, Prog. Coord. Phone: 882-3434 **Fax:** 889-5460**E-mail:** ndowey@region6.com**Family support coordinator:** Nzenalu Obinelo 882-6333, ext. 372nobinelo@region6.com**Partners in Health family support coordinator:** Nancy Lucci882-6333 x373 **Fax:** 889-5460 nlucci@region6.com**Respite coordinator:** Carole Smith 882-6333 x 325 csmith@region6.com**Benefits technician:** Diane Luszey 882-6333 dluszey@region6.com**Intake coordinator:** Sue Rockwell 882-6333 srockwell@region6.com**Legislative liaison:** Bob Mackintosh 882-6333 bmackintosh@region6.com**Family support council chair:** Peter Marcoux 888-5894pmarcoux@verizon.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:** bcollins@bhdssc.org **Website:** www.dssc9.org**Family support coordinator:** Deirdre Watson 749-4015 dwatson@bhdssc.org**Respite coordinator:** Karen Juckett 749-4015 kjuckett@bhdssc.org**Early supports and services:** Suzanne Iverson 749-4015 siverson@bhdssc.org**Benefits specialist:** Julie Batchelder 749-4015 jbatchelder@bhdssc.org**Legislative liaison:** Hugh Philbrick 749-4015 hphilbrick@bhdssc.org**Family support council chair:** Chuck Raymond 743-3909chuck.raymond@comcast.net**Family support council vice-chair:** Karen Salter 692-2088ksalter643@aol.com**REGION X Atkinson/Salem****Region 10 Community Support Services, Inc.**

8 Commerce Drive, Atkinson, New Hampshire 03811

Jane Dichard, exec. director**Phone:** 893-1299 **Fax:** 893-5401**E-mail:** jdichard@region10nh.com **Website:** www.region10nh.com**Family support coordinator:** Kathy Waterson 893-1299kwaterson@region10nh.com**Respite coordinator:** presently vacant**Early supports and services:** Aleece Pappas 893-1299apappas@region10nh.com**Benefits technician:** Deanna Johnson 893-1299 djohnson@region10nh.com**Legislative liaison:** Terri Cadorette 893-1299 tcadorette@region10nh.com**Family support council chair:** Carol Ingram 893-1129 carol-ingram@rcn.com**Family support council co-chair:** Janice Brown 382-1925MrsBto3@hotmail.com**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:** 206-2746 **Fax:** 206-2706**Family services resource manager:** Joe Rojek 206-2855joe.rojek@moorecenter.org**Respite coordinator:** Joy King 206-2743 joy.king@moorecenter.org**Early supports and services:** Celeste D'Innocenzo 206-2791celeste.d'Innocenzo@moorecenter.org**Benefits technicians:** Linda Lawrence 206-2768linda.lawrence@moorecenter.org

Audrey Mason 206-2770

audrey.mason@moorecenter.org**Legislative liaison:** Ilene Wheeler 206-2754ilene.wheeler@moorecenter.org**Family support council chair:** Keith Foster 624-9471 kfoster@earthlink.com**REGION VIII Seacoast****Region VIII Community Developmental Services Agency, Inc.**

Parade Office Mall, Suite 40, 195 Hanover Street, Portsmouth, NH 03801

Bob James, exec director Cathy King, associate executive director**Phone:** 436-6111 **Fax:** 436-4622 **E-mail:** bob@cdsregion8.org**Family support and early supports and services:** Lenore Sciuto 436-6111lenore@cdsregion8.org**Children's support coordinator:** Mary Dawn Corey 436-6111mary@cdsregion8.org**Adult support coordinator:** Pam Raley 436-6111 pam@cdsregion8.org**Resource coordinator:** Judy Saddler 436-6111, x 334 judy@cdsregion8.org**Respite coordinator:** Geoff Simons 436-6111 geoff@cdsregion8.org**Benefits technician:** Denise Larsen 436-6111 denise@cdsregion8.org**Legislative liaison:** Sabrina McKenna 430-8386Sabrina.mckenna@verizon.net**Family support council chair:** Kathy Ennis 964-9740Kennis@northeastrehab.org**REGION XI Carroll County****Center of Hope, Inc.**

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

Margie Matthews, exec director**E-mail:** mmathews@centerofhope.org**Phone:** 356-6921 or (800) 290-0905 **Fax:** 356-6310**Director of adult and family services:** Christine MacDonald 356-6921 x 52or (800) 290-0905 cmacdonald@centerofhope.org**Respite coordinator:** Tina Wallace 356-6921 x 49 twallace@centerofhope.org**Benefits technician:** Lindelle Gorham 356-6921 x26lgorham@centerofhope.org**Legislative liaison:** to be identified - legislative@centerofhope.org**Family support council chair:** Peg Cade 539-7869**Family support council co-chair:** Dana Pearson 284-6463blumlrp@worldpath.net**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:** Kathy Marshall 448-2077Kathy@uds.org**Family support coordinator:** Tara Mullen 443-4109 tara@uds.org**Respite coordinator:** Melissa Eastman 443-4113 melissa@uds.org**Benefits technician:** vacant**Legislative liaison:** Philip Eller 1-800-698-5465 p2pnh@VALLEY.NET**Family support council chair:** Roberta Gross bobbgross@earthlink.net**Upper Valley Support Group (UVSG)** (provides emotional support & info)**Phone:** 448-6311 **E-mail:** p2pnh@valley.net **website:** www.uvsg.org**UVSG respite program coordinator:** Nicole Demers 448-1268respitcare@valley.net



Where to Find Help Statewide Resources

AMI-NH - Alliance for the Mentally Ill of NH
15 Green Street
Concord, NH 03301
603-225-5359,
or (800) 242-NAMI
E-mail: info@naminh.org
www.naminh.org

Statewide organization and affiliates offer information and support to people with serious mental illnesses and their parents, children, spouses, siblings and friends.

ATECH Services
603-528-3060 V/TTY,
or 1 (800) 932-5837
Website:
www.nhassistentechology.org
ATECH is an umbrella organization under which the following organizations function:

NH-ATEC
67 Communications Drive
Laconia, NH 03246
1-800-932-5837
E-mail:
lorraineh@atechservices.org
Seating & mobility
Augmentative & alternative communication
Computer access
Home & worksite modifications

ASSETT - Assistive Services to Schools for Education, Technology and Training -
117 Pleasant Street
Dolloff Building
Concord, NH 03301
603-226-2900
E-mail:
cwein@cisunix.unh.edu
Consultations & Technical assistance; Loans of specialized equipment and materials; Training for educators, parents & children; Library for families & educators

REM (Refurbished Equipment Marketplace)
84 A Iron Works Rd.
Concord, NH 03301
224-7630 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

TECH-LAB
117 Pleasant Street
Dolloff Bldg.
Concord, NH 03301

603-226-2900
E-mail:
mpeabody@nhaat.mv.com
Hands-on technology exploration; loans of assistive technology; training; technical support

Autism Society of NH
P.O. Box 68
Concord, NH 03302
603-679-2424
E-mail:
nhautism@yahoo.com
website: www.geocities.com/SV2833

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

Brain Injury Association of New Hampshire
109 N. State Street, Suite 2
Concord, NH 03301
225-8400, or (800) 773-8400
E-mail: mail@bianh.org
www.bianh.org

Statewide organization provides resource information to survivors of brain injury 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

Bureau of Vocational Rehabilitation
603-271-3471
or 1-800-299-1647
Fax: 271-7095
www.ed.state.nh.us
Provides individualized guidance, counseling and placement services to eligible consumers; also provides family services around needs of individual

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

Council for Children and Adolescents with Chronic Health Conditions and their Families
105 Pleasant Street
Concord, NH 03301
Peter Clarke
271-4991 or
1-800-852-3345 X4991
Fax: 271-5166
cell: (603) 396-9238
E-mail:
pclarke@dhhs.state.nh.us
Website: www.ccachc.org

Information and advocacy

Department of Education Bureau of Special Education
101 Pleasant Street
Concord, NH 03301
603-271-3494 Fax: 271-1953
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.

18 Low Ave. P.O. Box 3660
Concord, NH 03302-3660
603-228-0432, or 1-800-834-1721 Fax: 225-2077

E-mail: drc@totalnetnh.net
Provides legal services and other advocacy assistance to persons with disabilities; information/referral

Early Education and Intervention Network of N.H.

10 Ferry St. #416
Concord, NH 03301
603-228-2040

E-mail: info@eeinnh.org
website: www.eeinnh.org
Information/referral; early intervention and pre-school programs for children with developmental disabilities or at risk for developmental delay.

Family Resource Connection
271-6826 or 1-800-298-4321

E-mail:
nyea@library.state.nh.us
Website:
www.state.nh.us/nhsl/frc/
Free, statewide program of NH State Library providing materials on all aspects of raising, caring for and educating children, especially children with special needs; 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 15057
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
57 Regional Drive
Concord, NH 03301
271-2773 (Voice),
271-2774 (TTY)
1-800-852-3405 (Voice)

Fax: 271-2837

www.state.nh.us/disability
Information and referral. Provides information about the many services, laws, and regulations that affect citizens with disabilities. Implements and operates the federally funded Client Assistant Program designed to work out problems that may arise between persons with disabilities and the Division of Vocational Rehabilitation

Granite State Guardianship Services

34 Jefferson Road
Whitefield, NH 03598-1221
Phone: 603-837-9561
Fax: 603-837-2613

E-mail: info@gsgs.org
website: www.gsgs.org

Provides legal guardianship services to people with developmental disabilities and mental illness.

Granite State Independent Living (GSIL)

603-228-9680, (V, TTY)
1-800-826-3700(V/TTY)
website: www.gsil.org

Information and referral, peer support and counseling, skills training, advocacy, interpreter and personal care attendant services, transportation, social and recreational programs and accessibility services.

Institute on Disability/UCED (Concord office)

Phone: 603-228-2084
Fax: 603-228-3270
(Durham office)
Phone: 603-862-4320
Fax: 603-862-0555
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

Dartmouth-Hitchcock Medical Center
603-650-7886
Genetic testing and counseling, information and referral

M.I.C.E. (Multi-sensory Intervention through Consultation and Education)

603-228-1028(V)
603-228-5755 (TTY)
Statewide program for educational and developmental services for children with visual or hearing impairments and their families.

NH Association for the Blind
603-224-4039 (800) 464-3075
E-mail:

services@sightcenter.com
www.nhbvi.com
Provides information and gives direct services to visually impaired people of all ages to enable them to maintain their independence.

N.H. Developmental Disabilities Council

10 Ferry Street
Concord, NH 03301
603-271-3236
1-800-852-3345, x 3236
E-mail: nhddcncl@aol.com
www.nhddc.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

UNH/Recreation
862-0070
E-mail:
northeastpassage@unh.edu
website: www.nepassage.org
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

603-224-8041
Provides legal guardianship services for people with developmental disabilities and mental illnesses.

Parent Information Center

603-224-7005 V/TTY
1-800-232-0986
E-mail: picinfo@parentinformationcenter.org
website: www.parentinformationcenter.org
Information, support and training around educational issues and advocacy

Parent to Parent of NH

1-800-698-5465
www.p2pnh.org
E-mail: contact@p2pnh.org



Where to Find Help

Continued from page 22

Specializes in networking parents of children with special needs; support and information

People First of NH
603-568-2128,
or 1 (800) 225-2125
E-mail: janet.peoplefirstofnh@verizon.net
website:

www.peoplefirstofNH.org
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
603-862-0561 (Voice/TDD)
603-862-0034 (fax)

www.seacoastclinic.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.

Special Olympics NH
603-624-1250
or 1-800-639-2608
Fax: 624-4911
website: www.sonh.org
Provides sports opportunities for athletes with developmental disabilities.

"Talking Books"
(NH Bureau of Services to Persons with Disabilities)
603-271-3429,
or 1-800-491-4200
website:
www.state.nh.us/nhsl/talkbks
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
E-mail: info@vsaartsnh.org
website: www.vsaarts.org
Provides opportunities in the arts for people with disabilities and technical assistance for programmatic and cultural access

Partners in Health

New Hampshire Partners in Health (PIH) is a comprehensive community-based program designed to address the needs of children with chronic health conditions and their families. The program is currently available in 13 regions of the state through the efforts of Council for Children and Adolescents with Chronic Health Conditions and the Department of Health and Human Services.

PIH offers families the services of a Family Support Coordinator, respite funds, a resource library and the opportunity to participate in community health care planning. Families can also receive help accessing resources, and solving problems with insurance, finances, and education. As of FY ending June 20, 2001, PIH served 500 families, made 2,900 child contacts, 1,140 of which were contacts with children on Medicaid.

Partners In Health Locations

REGION 1: Berlin, NH
Family Resources Center
123 Main Street
Gorham, NH 03581
603-466-9027 or
1-800-640-6486, x 406

REGION 2
Developmental Services
of Sullivan County
RFD #3, Box 305
Claremont, NH 03743
603-542-8706

REGION 3:
Community Health & Hospice
780 N. Main St.
Laconia, NH 03246
603-524-8444

REGION 4:
Community Bridges
525 Clinton St.
Bow, NH 03304
603-226-3212

REGION 5:
Monadnock Developmental
Services
121 Railroad St.
Keene, NH 03431
603-352-1304

REGION 6: Area Agency of
Greater Nashua, Inc.
144 Canal Street
Nashua, NH 03064
603-882-6333

REGION 7:
VNA Home Health & Hospice
Services, Inc.
1850 Elm St.
Manchester, NH 03104
603-641-1090

REGION 8:
Families First of the Greater
Seacoast
100 Campus Drive, Suite 12
Portsmouth, NH 03801
603-422-8202 ext. 146

REGION 9:
Behavioral Health and
Developmental Services of
Strafford County
Forum Court,
113 Crosby Road, Suite 1
Dover, NH 03820
603-749-4015

REGION 10: Derry, NH
Child and Family Services
48 W. Broadway
Derry, NH 03038
603-432-8362 or
1-800-640-6486, x 404

REGION 11
Center of Hope, Inc.
626 Eastman Road
Center Conway, NH 03813
603-356-6921

REGION 12:
Upper Valley Support Group
12 Flynn St.
Lebanon, NH 03766
603-448-6311

REGION 13:
Ammonoosuc Community
Health Services
25 Mt. Eustis Road
Littleton, NH 03561
603-444-5962

Additional information about
PIH can be found on the
CCACHC website:
www.ccachc.org

NH Community Mental Health Centers

Region I

Northern NH Mental Health and Developmental Services
Main Office: 447-3347
Conway : 447-2111
Berlin : 752-7404
Groveton : 636-2555
Wolfeboro : 569-1884
Colebrook : 237-4955
Littleton : 444-5358

Region II

West Central Community Mental Health Services
Main Office: 448-0126
Claremont : 542-2578, also 542-5449
Lebanon : 448-1101
Newport : 863-1951

Region III

Genesis, the Counseling Group
Main Office : 524-1100
Plymouth : 536-1118

Region IV

Riverbend Community Mental Health
Main Office : 228-1551
Henniker : 428-3336
Franklin : 934-3400

Region V

Monadnock Family Services
Main Office : 357-4400
Peterborough : 924-7236
JAffrey : 532-4291
Winchester : 239-4376

Region VI

Community Council of Nashua
Main Office : 889-6147

Region VII

Mental Health Center of Greater Manchester
Main Office: 668-4111

Region VIII

Seacoast Mental Health Center
Main Office: 431-6703
Exeter : 772-2710

Region IX

Strafford Guidance Center
Dover : 742-0630

Region X

Center for Life Management
Main Office (Salem)
893-3548
Derry : 434-1577
Windham : 434-9937

*If you would like to have a resource listed in The Challenge,
contact us at: (603) 742-0500, or 1 (800) 758-6430,
or e-mail us at: nhchallenge@comcast.net*

We want to take a moment and thank all our loyal supporters whose financial assistance helps make each issue of
The New Hampshire Challenge
 possible. Without your generosity, our task would be far more difficult.

Thank you

in particular to the following individuals and organizations who have recently contributed to
The Challenge:

Barbara Banley-Bill of New Hampshire
 Ruth Bleyler of New Hampshire
 Sr. Ruth Ann Brighton of New Hampshire
 Pete Macalaster of New Hampshire
 Michael Riley of New Hampshire
 The Robin Hill Farm of New Hampshire
 The Plus Co. of New Hampshire

ADA Anniversary Dance and Celebration

July 26 at 8 PM at Union Station
 Washington, D.C.

(VIP Auction starts at 7 PM)

This event will help support the work of three national disability organizations:

ADA Watch/National Coalition for Disability Rights
 Disability Rights Education and Defense Fund
 National Council on Independent Living

**For more info, contact Natalie Shear Associates
 at 202-833-4456**

*The following information is reprinted with permission from:
 Monday Morning in Washington, DC,
 (Inclusion Research Institute, 2002)*

IEP Meeting Tool (2003)

The National Center on Low-Incidence Disabilities has developed an IEP Pop Up tool that helps families learn the laws and find good responses to challenges that may arise in an IEP meeting. The tool suggests 16 statements that a parent might hear at a meeting, suggestions of possible helpful responses, and links to the section of IDEA that relate to the answer.

1. <http://www.nclid.unco.edu/Hvoriginals/Advocacy/Popup/popup.html>

Upcoming Events

August

11

SONH Unified Sports State Golf Tournament

Where: Mojalaki Golf Course, Franklin, NH

For more information: call 603-624-1250 or 1-800-639-2608 or visit the web site at www.sohn.org

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SONH Unified Sports State Softball Tournament

Where: Philips Exeter Academy and Exeter Parks Recreation Fields, Exeter, NH

For more information: call 603-624-1250 or 1-800-639-2608 or visit the web site at www.sohn.org

22-24

Families, Friends, Freedom, Philadelphia National Down Syndrome Congress Annual Convention

Location: Adam's Mark Hotel, Philadelphia, Pennsylvania

Cost: \$85 Individual fee;

\$125 Family fee for members;

\$115 Individual fee;

\$180 Family Fee (for non-members)

Registration deadline is 7/31

For more information: call 1-800-232-6372 or register online at: www.ndscenter.org

September

23 - 24

Real Choices for Older Adults and Individuals with Disabilities Living in Your Community

Where: Center of New Hampshire, Holiday Inn, Manchester, NH

Cost: Unknown

For more information, call Janet Williamson at 603-228-2084 or 1-800-238-2048 or E-mail her at jgw@cisunix.unh.edu

October

5

Buddy Walk

A one mile walk to promote acceptance and awareness of individuals with Down syndrome. There will be food, entertainment and FUN! Christopher Burke, star of the hit series, "Life Goes On," will be leading the walk this year with Annie Forts! (We are looking for sponsors of this year's walk.)

Time: 12 - 3 PM.

For more information: contact Sarra Dennehy at 603-715-2450, or e-mail her at: dennehys@comcast.net

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SONH Fall Games

Bowling (Candlepin and Ten Pin), Unified Sports Volleyball, Cross Country Running

Where: Manchester, NH

For more information: call 603-624-1250 or 1-800-639-2608 or visit the web site at www.sohn.org

Toll Free Hotline for air travelers with disabilities

The U.S. Department of Transportation is calling on all disability organizations to promote public education about its Toll Free Hotline for air travelers with disabilities through their organization newsletters, list-serves and sponsored events. The Toll Free Hotline for disabled air travelers has been in operation since August 2002 and is available for callers from 7 a.m. to 11 p.m. Eastern Time, seven days a week. It is currently not being fully utilized. The Hotline serves two main purposes: (1) education and (2) assistance in resolving disability-related air travel problems.

Air travelers who want information about the rights of persons with disabilities in air travel or who experience disability-related air travel service problems may call the Hotline to obtain assistance at: 1-800-778-4838 (voice) or 1-800-455-9880 (TTY).

Did you know?

The New Hampshire Challenge published a book celebrating its first ten years of existence. The book, *It's About Families - A ten year retrospective of The New Hampshire Challenge*, presents a history of the disability community in the Granite State from the perspective of the lived experience of families. Copies are still available for \$15. To order a copy for yourself or as a gift to a friend, call 1-800-758-6430 or e-mail us at nhchallenge@comcast.net.

Additional Resources

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

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

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

www.benefitscheck-up.org

A nonprofit initiative led by the National Council on Aging which features a database of roughly 1,000 federal and state programs for the elderly and people with disabilities.

www.csni.org

Community Support Network, Inc.

www.dot.gov/accessibility

The US Department of Transportation's site for information about air travel for people with disabilities

www.dredf.org

Disability Rights Education and Defense Fund, founded in 1979 by people with disabilities and parents of children with disabilities, is a national law and policy center

www.emerginghorizons.com

Consumer oriented magazine about accessible travel. Available in print and on-line.

www.eseals.org

Easter Seals NH

www.cms.hhs.gov

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

www.dhhs.state.nh.us

NH Department of Health and Human Services web site. Information on benefits programs.

www.dredf.org

Disability Rights Education and Defense Fund - a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities

www.hhs.gov/newfreedom/

US Department of Health and Human Services' New Freedom Initiative

www.inclusionresearch.org

Inclusion Research Institute - a nonprofit organization whose activities include education, research and dissemination of information promoting inclusion

www.nhhelpline.org

New Hampshire Help Line

www.nhspinal.org

NH Chapter of the National Spinal Cord Injury Association

Publications of Interest

Disability Solutions

FREE

A resource for families and others interested in Down syndrome and related disabilities. Published six times a year.

For information on subscriptions, call (503) 244-7662

www.disabilitysolutions.org

subscription@disabilitysolutions.org

Exceptional Parent Magazine

Paid subscription \$39.95 a year

(201) 489-4111 1 (877) 372-7368

website: www.EParent.com

Feature articles; extensive listing of national organizations for specific disabilities/conditions

New Developments

Benefit of membership

(301) 652-2263

E-mail: devdelay@mindspring.com

website: www.devdelay.org

(cost of membership - \$48 for families; \$85 for professionals)

Published quarterly by Developmental Delay Resources, a nonprofit organization that connects parents and professionals, disseminating to them the most current information about causes, interventions, and preventions for developmental delays by seeking healthy options for the whole child.

Family Voices

FREE

800-852-3345 x 4525

e-mail: nhfv@yahoo.com

website: www.nhfv.org

Resources and information for families with special health care needs; quarterly

Ragged Edge

Paid subscription \$17.00 a year

Fax: (502) 899-9562

e-mail: circulation@raggededgemagazine.com

website: www.raggededgemagazine.com

Magazine written by and for people with disabilities with information on issues pertinent to the disability movement; bi-monthly

www.nichcy.org

National Information Center for Children and Youth with Disabilities

www.nod.org

National Organization on Disability

www.sath.org

Society for Accessible Travel & Hospitality

www.skimhs.org

Maine Handicapped Skiing - offers year-round recreation for people with physical disabilities free of charge

www.socialsecurity.gov

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

www.yourtickettowork.com

Information on the Social Security Ticket to Work program

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