

The New Hampshire Challenge

disability issues from a family perspective

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The Face of "Katie Beckett"



Sara Edgerly came home to her family two years after her accident because of the Katie Beckett Option. Photo- E.G. Stone

Dennis Powers Resigns

by: Janet M. Krumm

Dennis Powers has resigned from his position as director of the division of developmental services (DDS) effective October 31 to take a position as executive director of the Community Support Network, Inc. (CSNI), a nonprofit organization that works in support of the 12 area agencies throughout the state of New Hampshire.

Powers served as director of DDS since July 15, 2002, after having served as executive director of Region X's area agency. He leaves his position believing "We've really accomplished a lot this legislative session." The \$2.9 million in cuts in FY04 and the \$3.6 million in FY05 called for in the Governor's budget were almost completely restored by the Legislature and additional funds for the wait list were allocated.

"I think the legislators were intent on supporting families," he stated. The restoration of the cuts and the allocation of additional funds "also showed that the efforts of advocates have paid off."

Powers said that once the budget was approved, he sent an e-mail to the area agency directors suggesting that they use the restored funds to increase direct support salaries, provide stipends to home care providers and restore any cuts to family support councils. He also strongly suggested that the area agencies pass on a portion of the restored funds to the vendor agencies with whom they

A Lifeline of Hope for Families

by: Janet M. Krumm

The Katie Beckett Option is more than a line-item on a budget; it has been a lifeline to hope for many families in New Hampshire.

"I thank God that the Katie Beckett waiver was in place at the time of Sara's accident back in 1992," Ellen Edgerly said. "If it were not, we would not have been eligible for any other services because of our middle class income."

On February 2, 1992, Sara Edgerly fell through the ice into Merrymeeting Lake and remained submerged for almost 40 minutes before she was res-

cued. She was 11 years old at the time, and would be 13 before she returned home from what was supposed to have been a day of fun with her father, her brother and a friend.

Sara survived with a severe brain injury. Normal life for Sara and her family would never be defined the same way it was on February 1, 1992.

Because Sara's medical needs were so overwhelming, she would require nursing care in place 24/7 to come home. Unfortunately the Edgerly's insurance didn't

cover nursing care. "We had cream-of-the-crop insurance coverage," Ellen stated. "We didn't even reach our (lifetime) cap, but the insurance company refused to pay for long-term care nursing care."

In fact, it was the insurance company who recommended applying for Medicaid under the Katie Beckett Option. Though it was hard for Ellen to ask for help, she did whatever she had to do to bring Sara home.

"It was two years that we didn't have Sara under our roof, that we didn't have all our

children under our roof," Ellen remembered. "It was very hard. Without Katie Beckett, I wouldn't have been able to keep Sara home."

Ellen met Julie Beckett once at a conference. She went up to her and thanked her for all her efforts on behalf of her daughter. "If Julie Beckett hadn't worked as hard as she did to entitle her daughter to come home, we would have had to keep Sara in an institution," Ellen said. "And I just couldn't do that."

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John Stephen

newly-appointed Commissioner of the NH Department of Health and Human Services

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I know
no safe depository
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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A Generation of Students with Disabilities Transitions to Adult Life

What are their options for an inclusive future?

by: *Jamie Stephenson*

The Institute on Disability was established at University of New Hampshire in 1987 and the effort for school inclusion began.

Sixteen years later a generation of students who have been included since preschool is entering adult life. They have sat beside their typical peers for countless story times in elementary school, math quizzes and spelling bees in middle school, dissection labs and Shakespeare in high school.

They have sung in choruses, played in school bands, learned foreign languages, been elected to the National Honor Society, played soccer, served in student government, been called to the principal's office for cutting class.

In short, they have been seamlessly included in their school communities with the support and consensus of their peers, teachers, parents, and school administrators.

Sometimes the needed support was minimal and other times it was full. Sometimes a consensus was easily reached and at other times it required much deliberation and compromise.

The special education system was changed one child at a time and the effort has paid off. According to Jan Nisbet, director of the Institute on Disability, now there is an expectation of inclusion. But it wasn't always that way.

When first presented with the option of full inclusion many parents questioned the wisdom of thrusting their children into the rough and tumble world of public school.

The safety and seclusion of a segregated environment was attractive to families whose lives thus far had revolved around nurturing and protecting their children. The suggestion that a neighborhood school could offer the supports and educational opportunities that a "special program" allowed was suspect.

School administrators and teachers were often stymied when families began requesting inclusive placements. Many agreed that all students could benefit from inclusion but were sometimes less than enthusias-

tic when faced with the task of reworking the classroom environment.

The teachers worried how they would teach learners with significant challenges along with typical students.

The administrators worried how they would assure that IEP goals and objectives that were traditionally written for the segregated classroom would be carried out in the larger environment of the regular classroom, gymnasium, cafeteria, and playground.

Everyone was unsure about the outcome, but some very brave families jumped in with both feet anyway and began to advocate for supports to follow their children into the regular classroom.

The 1975 federal law mandating education for children of all abilities (P.L.94-142)

where inclusion is routine, rather than a rarity.

The next stage for inclusion is adult life. Now that their children with disabilities have studied and played alongside their typical peers in school communities, Families expect them to work and live alongside their typical peers in our local communities. Families want to see them as productive citizens in meaningful jobs leading satisfying lives.

After high school, typical students enter the workforce or attend college or technical school for further training and credentials.

Some of them move away from home to live in college dormitories or apartments near their workplaces. In the current economy many adult children choose to remain in their family home well past high

school, at age 18, was entitled to educational services for an additional 3 years. His same age classmates were headed to college and jobs and Andrew's parents were faced with the question, where is inclusion for Andrew now?

The notion of returning to Concord High School with no classes to attend and no classmates his age to support him didn't make sense. His high school classmates went to college and Andrew should, too.

Beth Dixon, Andrew's mother, describes the choice very matter-of-factly "Andrew liked going to visit his sister in college and it seemed logical to explore college as an option for him like we had for our other children." They found a small private college within commuting distance of home and negotiated a placement for Andrew

Club.

Because Andrew's last years of education were spent in the community doing meaningful work and personally satisfying activities the transition to adult services was smoother than usual. Andrew's family, with the support of the school district and the area agency had designed an inclusive entry into adult life for him.

According to the U.S. Department of Education the graduation rate nationally for students with disabilities has been steadily increasing.

From 1990 to 1995, the number of students with disabilities graduating with a diploma or certificate remained fairly stable and students with mental retardation and deaf-blindness were most likely to graduate with a certificate.

In 1997 and 1998, approximately 25% of students with disabilities graduated with a standard diploma but those least likely to graduate were students with mental retardation, autism, and multiple disabilities.

In 1999 and 2000, the standard diploma graduation rate for students with disabilities jumped to 52%. (Office of Special Education and Rehabilitative Services *Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*, Washington, D.C.: GPO, 1996, 1999, 2000, 2001, 2002)

These graduation numbers are encouraging but the question of transition into adult life remains. High school graduation is not an ending but a beginning for students with disabilities.

Transition planning and services for high school students has been part of IDEA since 1990.

As stated in the above report: "These transition statements are designed to provide instruction, related services, and community experiences that lead to positive post school results in postsecondary education and training, employment, adult services, independent living, and community participation."

The notion that the effort spent on the education of a

What about the students who have now graduated from inclusive school environments? Will they experience inclusion in adult life? Or are they destined to enter segregated adult life like the previous generation? The answer to both those questions is.... maybe.

included "least restrictive environment" to describe the placement entitlement for students with disabilities. The regulations went on to describe the regular classroom as the first placement choice with a continuum of more segregated placements ending with residential school.

However, in the beginning, students with disabilities were placed in separate classrooms, separate buildings, separate schools, and sometimes out of state. Over time, individuals with disabilities, their teachers, their families, and their schools have come to regard the least restrictive environment as the regular classroom with the supports and services necessary for academic success.

Now in New Hampshire often the first placement option is the regular classroom. Systems change has matured in the public schools to the point

school and even college or return when between jobs.

Students with disabilities have traditionally graduated from the segregated school environment into a segregated adult life of workshops, day rehabilitation, group homes, adult daycare, and sometimes, sadly, nursing homes.

But what about the students who have now graduated from inclusive school environments? Will they experience inclusion in adult life? Or are they destined to enter segregated adult life like the previous generation?

The answer to both those questions is.... maybe.

Andrew Dixon turned 21 this month. He has been included with his typical peers throughout school although he has significant behavior and attention challenges.

When his peers graduated from public school An-

in the student body. He would audit classes and not receive college credit.

In high school Andrew had a classroom aide all day and depended on others for transportation. These supports would need to continue in the college setting but the public school, although responsible for his services was not able to send personnel to private schools.

In collaboration with their area agency, where Beth serves on the Board of Directors, the Dixons and the school personnel were able to create a plan for Andrew to attend college classes, work in the college bookstore and volunteer at the Concord Boys and Girls Club.

Instead of spending his day back in the high school building, he was in the community spending time with his same age peers in class, working, and contributing to the programs at the Boys and Girls

Commissioner John Stephen

talks with The Challenge about the proposed cuts to Katie Beckett and the reorganization of DHHS

Interviewer: Janet M. Krumm

You've announced plans to re-organize the Department of Health and Human Services. There is a vacancy in the position of director of the Division of Developmental Services since Dennis Powers left. What are your plans regarding this vacancy?

Matt (Matthew Ertas) is serving as acting director. It was important for me to have someone to serve in that capacity to provide the information I need. I'm not making any decisions on placements of directors and positions until we can figure out what our reorganization team comes up with. They've been working with an analysis team- we have two outside auditors. We have folks that have been here for years looking and interviewing each division's area. We're interviewing employees; we're also interviewing providers. They're going to make some real detailed recommendations to me. I gave them a template of what I'd like them to start looking at. Right now, Matt is acting as director. We'll make a decision on what we're going to do at some point maybe in January. That's what I'd like to do.

There's always talk about merging the divisions of developmental services and behavioral health. There's 12 area agencies and 10 mental health centers. Is that something that would be on the table?

It's something we're considering, but it's not something we've made any definite plans on. Everything's on the table. That's the bottom line. Everything. We need to look at providing essential services to those in need and trying to consolidate where we can to be more efficient in many areas that affect direct care. Those are the needs of the community we must serve. And so when I say that, there are areas in this department where I feel consolidation is going to work and benefit those in need of our services. And so everything is being looked at right now. It may be that Behavioral Health and Alcohol and Drugs are a better fit, depending upon the services. But one thing I find here is that there are a lot of synergies. But there is duplication and there is some redundancy. So we need to just find those areas, minimize them, but also identity is important to our providers. I've heard that from the community that you're charged with working with. The community of...

People with developmental disabilities?

Well, the community of Alcohol and Drug Abuse as well. And the developmental disabilities community have expressed concerns about identity - making sure there's an identity here for those folks. I think that that's important. So we need to look at that. One thing I'm doing here is I want to have an open mind. I'm bringing a fresh view and also I'm charging a group that is responsible for looking at all these areas for me and coming up with some concrete recommendations. And I meet with them almost daily. So I have a sense of where they're starting to go but we're not even close to done our reorganization. And I want stability. I want stability for the employees of this department. And for the providers. So come sometime January or February, you will know from this point forward, under the administration I have - that this is going to be the structure that we're going to live with.

Once recommendations come in, and you have a sense of what it is that you want to accomplish based on those recommendations, what is the process? Does it have to be approved by the Legislature? Or can you just move ahead and do that yourself?

No. By law, I can do it myself. And I'm going to be providing the Legislature with input and reports. I've already told the Health and Human Service Committee that I'd come back and share with them some of the items and where we're going.

You talked about interviewing providers and employees. Do you have any mechanism to involve the people you serve?

Absolutely. It's already ongoing. Daily.

What is that mechanism?

Nick Toumpas is in charge of the reorganization team and has already been having those types of meetings and will continue to do so. I've identified certain providers and groups I want him to look at meeting with and he's working on that right now. I believe he's already met with Matt and some of his staff.

You've proposed a \$500,000 cut to Medicaid services to children with severe disabilities who are eligible under the Katie Beckett option, and you made several statements about the Katie Beckett program. For instance, that the cost of the program is \$20 million a year and there are 1,200 children being served by that program. I'm curious as to how you came up with the cost and whether that cost includes both the federal and state money or is that \$20 million representative of only the state money? And also, does that include Medicaid to Schools money as well?

It does include Medicaid to Schools, a small portion. And it does include the match.

So the \$20 million is federal and state funds?

Yes. That's just in that one area. There's other areas, too, that may provide services for children in need that are in the budget. So there are different programs. You're only talking about Katie Beckett service here.

Are you saying that children who may not be eligible for Katie Beckett after the cuts...

I don't look at it as that. I look at it as ... it's going to be a very comprehensive review, which is ongoing. I don't look at it as a cut. The issue is - and I've said this publicly - that the Department should not be extending eligibility by rules.

I'm not sure what you mean by that.

Because when you.... first of all, the whole area is being reviewed now and we're looking at it, very methodically and I have a staff that's putting together all kinds of information for me to review and I do not make decisions until I have all the information before me where I can make an intelligent decision. And I want to provide the NH Legislature the information so that they can tell me and make a decision of what the policy should be, as far as this particular area. Most all of the cases where you've heard stories about children that are impacted, in the scenarios that I've been looking at will not be impacted at all. And their services will not be affected.

What we're trying to do is look at it from a rules perspective. What are some of the eligibility rules we should have? And engage the Legislature so that they can make decisions on the policy. We're going to have public hearings. I've decided to have public hearings cause I want to hear from the community before we make any decisions.

The rules process involves a public hearing.

No. This is going to be different. We're going to go out to the community before we even file the rules.

Oh, so the rules won't be filed?

We're going to go out and listen to the community before these rules are filed.

Do you have any time line?

They're going to be in January. Public hearings. They're being scheduled now.

But the rules will not be filed until after?

That's correct. After the public hearings. Nothing will happen in the year '04 as far as any of these changes. FY'04.

So what will people be reacting to?

I as Commissioner want to hear from the community about examples of services that we've provided that have helped them, that have made a difference in their lives, that have helped families and that have contributed to the health and independence that we're all about. And I want to be able to hear those examples, to the extent I can.

And also, I'm making arrangements to visit a few homes where we provide these types of services. I care about this area. My wife has a sister whose son is a quadriplegic after a neck injury when he was 11 years of age. And David is now in his 30's. But I've witnessed first hand some of the effects in the community.

We need to make sure we do everything we can to help the community but yet we have limited resources and we need to make sure that we are in fact complying with the legislative intent and policy. That's the issue here.

My understanding of the process is that, a piece of legislation is passed, which it was in 1988, and then the Department comes up with rules which then go through a public hearing and then are presented to a Joint Legislative Rules Committee. So the Legislature has a role in the process of all this. Is that correct?

Yes. It has a role. However, the Policy Committee does not get involved. The Legislature doesn't vote on it as a block. The departments end up dictating, with the assistance of some of the rules attorneys basically what the rules are going to look like.

My concern has always been that departments may have a tendency to engage in the rule making process and not clearly establish rules that follow clear legislative intent. That's all I want. I want to make sure we're following clear legislative intent.

And in fact, Janet, the New Hampshire Legislature recognizes this issue and there's a study committee currently ongoing in a bi-partisan way and they're going to be reforming their rules process. Because they feel that the Policy Committee doesn't get involved in



Commissioner Stephen, addressing the Joint Legislative Fiscal Committee, presents his plan for \$20.9 million in cuts.

Photo: Ken Williams, courtesy of the Concord Monitor

the making of rules and they want that type of involvement. And so that's all we're talking about.

In that particular area, there are many issues that will be determined in the future. We'll hear from people. We'll be able to make our plans known. And then we'll look back and on some of the issues, we may come up with a different recommendation that we thought originally after hearing from some of the folks in the community. That's important.

So you are planning to have the hearings in January to hear from folks and then come up with a set of regulations based on the outcome of those hearings, based on the information you gathered at those hearings?

It will help us in determining the type of rules that we want to propose. And again, I've already asked the Legislature to also be involved. We're going to have an audit, as you know. And the Legislature can define the policy for us.

And in my opinion, it's going to be up to the Legislature to define the guidelines and the policy. And when we have that information and present it to the Legislature, I'm hopeful that they will determine that they need to do something in one way or other, to clearly define the guidelines here for us as a department.

But asking the Legislature to do that would be asking them basically to pass a piece of legislation? Is that what you're saying?

When we look at the positions and are able to obtain all the information, they'll be provided with more information to make those decisions. And we'll have to wait and see what information we have. The audit, the findings of the audit, we may find other things we need to do.

So the Legislature, I'm hoping, is involved as an active participant. We engage them to make policy decisions. Like I said, I committed to Sen. D'Allessandro that we're going to do

whatever we can to educate the Legislature and provide them with every piece of information they need to help guide this policy.

But in the meantime, I think the rules have to clearly define the law. That's what I'm talking about. Or they have to clearly follow the law. And follow well-established legal principles. That's all.

Do you have a sense that right now they're not following the law? Or following established legal principles?

I believe that we have extended the rules beyond the clear legislative policy.

Which was?

When I say clear legislative policy, we have extended the eligibility guidelines and requirements. Over the past few years, by rulemaking, rather than by legislative statute.

I looked over the rules from '89, and the rules that were passed in '94 that expired in 2002, and the only significant difference in my...

With the 1994 rule change.

...was the language, not so much the eligibility requirements.

If you look at the language changes. And I listen, again, the clinicians here and the experts are the ones I rely on for advice. The language changes in the rules have loosened some of the requirements in terms of eligibility, or in terms of the guidelines as far as criteria for program eligibility. These are issues I'm looking at right now.

Interview with Commissioner Stephen

Continued from page 5

Would you care to give an example of the ones that you..?

Again, I'm reviewing them and I have some specific ideas and examples but I want to be able to look at it very detailed and methodically before I'm able to comment. Because I want to make sure it's entirely accurate. You sometimes, Janet, hear one thing; you hear another. So it's a very complicated process.

But I think that when it's all said and done. I have no question in my mind that the children in need of our services that are truly in need based upon the intent of this program from the very beginning of the law, back in the 80s are absolutely going to continue to receive those services. And if there's going to be any changes, or any additions or any type of rule updates, then I would look to the Legislature to give us that clear guidance.

In February, the Department presented a proposed set of rules for Katie Beckett and at that time made a statement that they felt that only 10-15 children might lose eligibility with the new proposed rules. Given that you are quoted as saying there are 1200 children right now eligible for Katie Beckett, do you have a sense of how many children might be affected by a change in eligibility?

Right now I'm reviewing that issue currently as we speak. I'm having meetings almost on a weekly basis. I'm reading a number of impact statements. All that information is being assembled currently. I'm going to go out in the field as well and listen to people, see what the real effects are, what the impacts are.

How will you find the people that you're going to listen to?

Well, what I'm saying is, I'm hopeful that through the public hearing process we'll be able to identify some of these issues. But the legislative audit is going to be able to identify some of the financial fiscal issues there. All of that combined is going to give me more information and then we'll be in a much better position to provide that information to the Legislature.

I understood that this was to be a performance audit. What do you mean by performance, as opposed to a financial audit? Is there a difference?

I'm not sure... I don't..... It's not ringing any bells.

The Medicaid eligibility will affect money that comes into early intervention programs for children 0-3 and also for Medicaid to Schools. Right now there's a big problem funding early intervention as it is. If children lose eligibility for Medicaid or the eligibility requirements are more restrictive than they are right now, that could significantly affect the amount of money coming in for early intervention and Medicaid to Schools. That would appear to be cost-shifting - either to the families to pick up their costs, because they're typically not covered by private insurance for these services or to local towns and cities because they have to pay the school budget. How do you feel about that sense of cost-shifting?

I want to know more about it. And I'm going to review it. And we're going to look at all these issues. And I'll be able to hopefully when we review this matter, at least be able to educate the Legislature on what the implications are going to be. But these are issues I currently am reviewing. So we'll look at it and it might possibly well be that it does not result in any cost-shifting when we're done our review.

Will there be a copy of the review made public?

I'm going to put on the website a list of public hearings, locations, dates.

Has that been determined?

We're working on it now so hopefully we'll be done by the end of the

week. I'm going to have our staff available, and they're continuing to work on it now, to review the issues. They're looking at files and cases and the audit is going to take place as well. So it's an ongoing process.

But I mean once this process is finished, and you come up with a report that says these are the fiscal repercussions, these are whatever repercussions to services, when that report is finished, will a copy of that report be available to the public?

I'm not sure in what form there will be a report, per se. But we'll definitely provide the public with information through our rule-making process.

As you know, when we propose the rules, the rules are made public. And there's ample time for comment, even at that point. So that public hearing process happens again. So there will be plenty of information. So I'm sure that during that discussion, those issues will come out.

In fact, Senator Larsen asked me in a letter she sent me a number of questions that I want to make sure I can provide her with detailed answers. And some of these questions she's asked me you're asking me. I want to be able to do that. So I'm sure that we'll be able to provide more information as we are able to obtain it. In what form I'm not sure yet - we're still working on identify-

"I have no question in my mind that the children in need of our services that are truly in need based upon the intent of this program from the very beginning of the law, back in the 80s, are absolutely going to continue to receive those services. And if there's going to be any changes, or any additions or any type of rule updates, then I would look to the Legislature to give us that clear guidance."

John Stephen, Commissioner
NH Department of Health and Human Services

ing the issues. Right now, as far as how, our public hearing process is going to be determined. But it's going to be determined so that we can have significant information and there will be ample time for the public to comment. As well as provider community and anyone who feels a need to comment.

As Commissioner, I need to make sure that I hear from folks that are affected and also make a decision that I feel is within the ambit of law, clearly consistent with law and in a responsible way and make sure the Legislature is determining the policy.

When you say clearly consistent with law, you're talking about the federal and the state law?

I'm talking about federal and state law. Correct. Correct.

One of the things that I'm discovering in looking at this issue is that families are very nervous about this, as you can imagine, and are reluctant to speak publicly about it for fear of bringing attention to themselves and possibly putting their case in the spotlight and endangering their eligibility. So in a public hearing, in an atmosphere of apprehension, which is what people are experiencing right now, there may be some reluctance to be open. How are you going to encourage people to be open at a public hearing if they're feeling that being open may be detrimental to their own situation?

I'm hopeful that it's an open dialogue, an open process. I feel that.... I'm trying to obtain information and to make the right decision here as Commissioner.

We may end up finding information where we can provide more services for someone in need. And maybe they're not receiving all the services that they should. Or that they have available. We may find that out. We may be able

Continued on page 7

to provide even more assistance through this process. It could end up being quite beneficial for some of the folks that may not be aware of certain optional services. So, no matter what, I think that we have to make sure that we are provided with as much information as possible in order to make an intelligent decision.

But then when the decision is made on where we want to go, that there's even more time for comment and review. And obviously, the Legislature makes the final decision. That's all I want - the Legislature to be involved and to set the policy, to set the guidelines, to establish the criteria. That is not what we have today. We have that by rules and you mentioned it yourself, Janet. There's a Rules Committee. That Committee vote doesn't get voted on by the General Court.

So you think that every rule and regulation should be...?

No, I don't. But there's no clear legislative policy or guideline or law that's established. And the Department has general rule-making. I have a concern in that area. Because I want to make sure we establish rules that are absolutely consistent with clearly defined policy, Legislative policy. That's what I'm looking for.

It would seem to me, though, almost what you'd be asking for is an incredible amount of detail in legislation.

In some cases, maybe. In others, maybe not. It's going to be a case by case approach. Right when I got here, one of the first things I saw was a rule that established food protection or food safety certification process for every restaurant, with the exception of a few. And I looked at the statute. The statute is a general licensing statute - that the Department has licensing function and may establish rules consistent with the policy of licensing. Well, it didn't say anything about a certification process for food establishments that have to go through a certification for food safety.

So I decided that I was going to withdraw that rule. Because the rule established a criteria where you go through a certification process. Some here said well, it wasn't real clear, but you have licensure responsibilities so you can do it. Well, as soon as I withdrew that rule, I found out after the fact that a bill to allow this was in front of a House committee, Policy committee, and they voted 13-4 inexpedient to legislate. The same bill. Same issue. But yet one of the Senate committee members said, oh, you can do this by rule-making. So our Department was getting mixed messages and decided to go through the rule-making.

The reason I'm raising that is because that's a big issue with me. To make sure that rules are written in such a way that they clearly define the legislative intent and policy. That's all.

You mentioned earlier that you've been getting advice from clinicians and experts about Katie Beckett. Who are the people you consider clinicians and experts?

The ones that work at the Department that do...

Dennis Powers

Continued from page 1
subcontract.

Nearly \$9 million was added to the budget for the waiting list over two years. "We told the Legislature that we could serve 160 people with that money," Powers said. "We anticipate that we'll be able to serve from 180 to 190 people, however, because the area agencies sent us very cost-effective proposals."

Referring to the budget footnote requiring the Commissioner to make an additional \$20 million in cuts over the next two years, Powers admitted that "every division is going to have to be contributing to the cuts." He anticipated DDS's contribution would be the savings from not starting some programs right away. The ABD waiting list is made up of individuals with acquired brain injuries who will need services in the next

biennium. Not all programs will start at the beginning of the biennium. "It takes longer to set up services for people who are coming from nursing homes or rehab centers," Powers explained.

"The savings from services not starting up right away will not hurt services," Powers said, adding "once services for individuals start, they will carry over into the next year."

(Note: At the time of the interview with Dennis Powers, the Commissioner had not yet announced his plan to cut \$500,000 from the Katie Beckett program.)

The division itself has made administrative changes to realize savings as well, Powers said. All vacant positions have been frozen, meaning there are seven positions not filled at DDS. For the several months prior to his departure, the division engaged in a process of re-

organizing how it operates. In order to use the remaining employees' skills more effectively and provide more support to the community, program specialists - the liaisons between the division and the area agencies - will assume responsibility for an additional area agency.

Those who had responsibility for two area agencies would now serve as program specialists for three. Those employees who had responsibility for other programs (such as family support or Medicaid to Schools) would add program specialist for one area agency to their responsibilities. "This is our response to a tight budget," Powers said.

Powers looks forward to returning to the private sector. "I want to contribute to the system," he said. "I plan to work collaboratively with the area agencies on policy issues and best practices."

Readers, Please note....

On pages 8, 9, 10 are presented the text of the Federal law, and the text of the New Hampshire regulations: those that were implemented in 1989 after the NH Legislature passed a state law in 1988, and those implemented in 1994 which expired in December, 2002. It is the change in the regulations that is causing the concern expressed by Commissioner Stephen in our interview with him.

Do the review?

...do the review and work on a daily basis in this area, are obviously providing me with a great amount of resources and advice. In the field, I've been talking to people weekly. At the state hospital, physicians I've been talking to about this issue. I've been talking to people in the community, when I go and speak to them about the issue. Absolutely.

So you're talking to some of the family support coordinators...and people like that in the area agencies who work with this on a daily basis with these families?

Yes, I am. Some of them have come up to me and talked to me on their own. And I'm listening. And I've also spoken to a couple of the psychiatrists who work at the state hospital, and Dartmouth and other areas. Because the experts are the ones I'm relying on to give me advice that I need to make that decision. We'll continue to have that dialogue.

How accessible do you want to be to the average person receiving services?

I receive phone calls here and I'm calling them back. Yesterday I received a call from someone that has a developmentally disabled child that requires 24/7 nursing care and I'm actually going to go visit that person at home, that family. And I'm setting that up now, Kathleen (Henderson, executive assistant to Commissioner Stephen) is setting that up. I've got another call. And I would welcome them to call 1(800) 852-3345 or Kathleen (603) 4334, and I'll get back to them. Because I don't want folks to unnecessarily be alarmed.

It is a process, Janet, that we need to go through. It's not just this particular area. It's an issue of rule-making that needs to be reviewed here, throughout the whole Department. And then figure out, again, what the policy is.

FEDERAL LAW – KATIE BECKETT

(1902(e)(3))

At the option of the State, any individual who—

(A) is 18 years of age or younger and qualifies as a disabled individual under section 1614(a) [42 USCS § 1382c(a)];

(B) with respect to whom there has been a determination by the State that—

(i) the individual requires a level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded,
See He-W 508.03

(ii) it is appropriate to provide such care for the individual outside such an institution, and
See He-W 508.02(d) & (e)

(iii) the estimated amount which would be expended for medical assistance for the individual for such care outside an institution is not greater than the estimated amount which would otherwise be expended for medical assistance for the individual within an appropriate institution; and
See He-W 508.02(g)

(C) if the individual were in a medical institution, would be eligible for medical assistance under the State plan under this title [42 USCS § § 1396 et seq.],

Effective January 1, 1989

ELIGIBILITY FOR CHILDREN WITH SEVERE DISABILITIES (NH regulations)

Chapter He-W 500 MEDICAL CARE

Section He-W 502.07 Medical Assistance for Children with Severe Disabilities

(a) Recipient eligibility:

Medicaid services shall be available to children with disabilities who:

- (1) meet the financial requirements outlined in He-W 641.04;
- (2) are under 18 years of age;
- (3) are chronically ill or severely impaired whose illness or disability requires 24-hour inpatient care or may not require 24-hour inpatient care, but in the absence of family centered community-based care may precipitate admission to or prolong stay in a hospital, nursing facility or other long-term care facility.
 - (a) family centered community-based care shall mean the following:
family centered is a philosophy which recognizes the pivotal role of families and supports families as partners and collaborators in all aspects of decision making with respect to the provision of services for their children.
 - (b) Community-based is an organized network of integrated and coordinated services delivered at the local level which promote normal patterns of living.

Medical criteria

In addition to the requirement in 502.07 (a), a severely disabled child shall meet one of the following medical criteria:

1. Children who have chronic ventilation problems:
 - (a) who need ventilator assistance for some portion of the day. These children shall require ventilator care, bronchial suctioning and may require cardiopulmonary monitoring and gastrostomy feeding;
 - (b) who are ventilator-dependent. These children shall require constant ventilator care, bronchial suctioning, cardiopulmonary monitoring, and may require gastrostomy feeding; or
 - (c) who require daily dependence on other device-based respiratory or nutritional support. These children shall require tracheostomy tube care, suctioning, oxygen support, or tube feeding.
2. Children who have a chronic medical problems with long-term requirements for nursing care or monitoring in conjunction with a medical device to compensate for the loss of a life sustaining body function. These children shall require complex alimentation, medications, suctioning, catheterization, intravenous therapy, tracheostomies, equipment monitoring, prescribed therapy regimens and/or ostomies.
3. Children who have central nervous system (CNS) problems, either the result of trauma or CNS disorders. CNS disorders shall mean an injury to the skull, brain or its covering or to the spinal column resulting from anoxia, anatomic malformations, trauma, infection, genetic syndrome or intraventricular hemorrhage which produces severe damage to the motor or cognitive centers of the brain including alterations in levels of consciousness. These children may require assistance in physical positioning, feeding, toileting and display an inability to participate in age appropriate activities.
4. Children, who as a result of an illness, trauma, congenital anomaly or hereditary disease, are severely intellectually disabled so that they cannot and will not in the future be able to care for themselves. These children shall be profoundly or severely mentally retarded, or have two or more serious handicapping conditions, such as: deaf/blind, mentally retarded/blind, cerebral palsy/mental retardation, or mental retardation with difficult to control convulsive disorder. Children who have not been diagnosed as having one of the above shall have experienced severe speech, language, or perceptual-cognitive deprivations through evidence of abnormal behavior such as: failure to respond to social stimuli, severe self-abuse, severe self-stimulation, or manifestation of intense and prolonged temper tantrums.
5. Children with a pervasive developmental impairment as the result of a severe mental illness or autism, and who have major impairments in functioning in the family, in school or with peers. Such illnesses shall be characterized by the following symptoms: a severe behavior disorder; extreme withdrawal from family, friends, and peers; recurring episodes of aggression; recurring hyperactivity which significantly impairs normal functioning; self-destructive behavior; extreme compulsiveness, severe anxiety; or the need for daily supervision, care and monitoring.

HOME CARE FOR CHILDREN WITH SEVERE DISABILITIES (KATIE BECKETT)

(NH regulations – expired December 2002.)

He-W 508.01 Definitions.

(a) ‘Active treatment program’ means an aggressive, consistent implementation of specialized and generic training, treatment, health and related services directed toward:

- (1) The acquisition of the behaviors necessary for the child to function with as much self determination and independence as possible; and
- (2) The prevention or slowing of deterioration of the ability to function.

(b) ‘Family centered community-based home care’ means an organized network of integrated and coordinated services delivered at the local level which promotes normal patterns of living and which recognizes the pivotal role of families with respect to the provision of services for their children.

(c) ‘Cost effective’ means the estimated medicaid cost of care outside an institution is no higher than the estimated medicaid cost of appropriate institutional care.

(d) ‘Degree of care’ means the level of intensity or extent of medical care, treatment or intervention required by the child as determined by the medical setting in which the child is being evaluated.

He-W 508.02 Recipient Eligibility.

(a) The purpose of family centered community-based home care shall be to support but not supplant the child’s family as the primary caregiver.

(b) To be eligible for medical assistance for home care of certain children with severe disabilities, the child shall:

- (1) Reside with at least one parent;
- (2) Be able to receive services in the home as defined in 45 CFR 233.90(c)(1)(v)(B);
- (3) Meet the program criteria as described 1902(e)(3) of the Social Security Act;
- (4) Meet the recipient criteria of He-W 641.04, except that, pursuant to the prohibition in 1614(f)(2)(B) of the Social Security Act on the deeming of parental income, the criteria of He-W 641.04(c)-(g) shall not apply;
- (5) Meet the medical criteria as outlined in He-W 507.03;
- (6) Require the same degree of care that is typically provided in a hospital, nursing facility or intermediate care facility for the mentally retarded as specified at He-W 508.03.

(c) In addition to the eligibility requirements described in (b) above, the services proposed for the child shall be:

- (1) Medically appropriate, as determined by the joint medical review team in accordance with (d) and (e) below; and
- (2) Cost effective as determined by OMS in accordance with (f) and (g) below.

(d) The joint medical review team, upon certification by the child’s physician, shall determine if it is **medically appropriate**, in accordance with (e) below, for the child to receive family centered community-based home care as opposed to institutional care.

(e) The joint medical review team shall determine that family centered community-based home care is **medically appropriate** if the following conditions are met:

- (1) The care can be provided in the home without jeopardizing the medical needs of the child;
- (2) Medical and psychological support services are available in the community;
- (3) The child’s treating physician recommends home care and certifies the safety of home placement;
- (4) The child’s family or guardian have expressed a willingness and desire to assume responsibility as the primary caregiver(s) for the child in order to maintain the child at home; and
- (5) The family and household members have been trained to support the child’s needs in the home and have the ability to be primary caregivers.

(f) In order to maintain cost effectiveness, nursing care shall be allowed only up to 16 hours per day for at-home support, except as specified in (g) below.

(g) **Cost effectiveness** shall be determined to be maintained if nursing hours exceed 16 hours per day if the nursing care is provided:

- (1) On a time-limited basis as documented in a medical plan of care; and
- (2) For the purpose of the following:
 - a. To stabilize acute conditions; or
 - b. To transition a child from institution to home placement.

He-W 508.03 Degree of Care.

(a) In order to determine the most appropriate degree of care under which to evaluate the child, the joint medical review team shall review:

- (1) The child’s medical condition; and
- (2) The child’s community care needs.

(b) The joint medical review team shall determine that the degree of care provided by a **hospital** is appropriate for the child if the following criteria are met:

- (1) The child requires hospitalization for an indefinite period of time; and
- (2) Either of the following are met:
 - a. The child requires a complex care schedule and the use of sophisticated equipment designed to alert caregivers to potential life-threatening problems; or
 - b. The child has the constant potential for aspiration, respiratory obstruction or arrest, and/or other life threatening complications requiring the need for prompt, recurrent, skilled interventions to sustain life.

The Challenge is pleased to announce the debut of a new column:

Ask Jan!

Are you confused about how the system works? Jan Larsen has worked in the developmental disabilities service system for 20 years. She brings a wealth of knowledge and understanding about how the system works, particularly benefits - both State and Federal - and can answer questions that would stymie anyone else. At work, whenever someone needs information, the common refrain is "Ask Jan." Now you can ask her questions, too.

Dear Jan,

I just retired and now my son, who has a disability, has lost his Medicaid. How come no one at Social Security told me?

Unhappy mom

Dear Unhappy Mom,

In New Hampshire the Social Security offices and our State Welfare offices are not combined in any way, as they are in other states such as Massachusetts. So the technician at Social Security wouldn't be able to tell you how your retiring would affect your son.

When a parent is entitled to Social Security for any reason, the parent's children (and possibly spouse) are entitled to benefits under Social Security. This is automatic because these benefits are an entitlement. The children's (even adult children) and spouse's benefits are based on the amount of the worker's retirement amount.

Many times this changes the child's benefit from Supplemental Security Income (SSI) to Social Security Disability Income (SSDI). This new check is usually higher than what the child was receiving, changing the child's unearned income for Medicaid calculation and in many cases resulting in the loss of regular Medicaid.

Since there are other ways to qualify for Medicaid, your son may be able to qualify for Medicaid under the In and Out program or under a new program called Medicaid for Employed Adults with Disabilities (MEAD).

If your child has ongoing monthly medical expenses, those expenses will offset the spend-down amount, possibly making him eligible for In and Out Medicaid.

If your son works, he can pay a monthly premium for Medicaid, based on both earned and unearned income, making him eligible for MEAD.

If he has insurance at work the cost of his company insurance is deductible for both these programs.

If your son isn't working but has a program from an area agency or mental health agency, the cost of these services changes his standard of need, making him eligible for regular Medicaid. Contact your agency provider for the cost of the services being provided to your son, and then give that information to Medicaid.

To avoid surprises regarding benefits, you can call before making changes to ask questions about Social Security at 1-800-772-1213 from 7am to 7 pm. For State benefits, call your local office of Health and Human Services, department of Family Assistance case technician.

Please note:

Benefits programs are complex, with intricate rules and regulations. Consult your local government offices for complete details.

Readers may write Jan with a question for this column at: ASK JAN, P.O. Box 579, Dover, NH 03821-0579
or e-mail her at: askjannhchallenge@verizon.net

Katie Beckett regulations

Continued from page 9

(c) The joint medical review team shall determine that the degree of care provided by a **psychiatric hospital** is appropriate for the child if the following criteria are met:

- (1) The child meets the criteria in He-M 401.06 (a)(2), He-M 401.06(a)(3) and He-M 401.06(b);
- (2) The child has specific symptoms and functional impairments that require professional and community interventions; and
- (3) The child has problems of a chronic and severe nature requiring an intensive amount of professional supervision which are determined by an inability to function in the following major life areas:
 - a. Family relations;
 - b. Interpersonal and or social skills; and
 - c. Educational and or vocational skills.

(d) The joint medical review team shall determine that the degree of care provided by a **nursing facility** is appropriate for the child if any of the following criteria are met:

- (1) The child is dependent on technologically sophisticated medical equipment such as, but not limited to ventilators, gastrostomy tubes, or central venous lines to sustain life;
- (2) The child requires observations or judgments more than once per hour throughout a 24 hour period or continuously, to maintain health status;
- (3) The child requires direct interventions from skilled nursing or skilled rehabilitative professionals to maintain health status;
- (4) The child is dependent daily on less sophisticated medical equipment such as, but not limited to catheters, nebulizers, or oxygen to sustain life;
- (5) The child requires observations and judgments less often than once per hour and not less often than once every 3 hours throughout the 24 hour period to maintain health status; or
- (6) The child requires basic nursing and rehabilitative interventions under the direction and supervision of skilled nursing or skilled rehabilitative professionals.

(e) The joint medical review team shall determine that the degree of care provided by a **intermediate care facility for the mentally retarded** is appropriate for the child if the following criteria are met:

- (1) The child has a developmental disability as defined in RSA 171-A:2, V;
- (2) The child requires a continuous and pervasive active treatment program throughout the child's daily routine;
- (3) There is a need for the continuity of treatment to and from all home and community-based settings; and
- (4) Either of the following are met:
 - a. The child requires continuous medical monitoring for a chronic severe health problem, or
 - b. The child requires continuous supervision, monitoring, and redirection of behaviors associated with any condition, related to mental retardation, that results in impairment of general intellectual functioning or adaptive behavior.

Public forums on the Katie Beckett Option will be held in January.

(The schedule had not been decided as of press time.)

Families will have an opportunity to provide the Department of Health and Human Services with information about what the Katie Beckett Option has meant in the lives of their children and their families. Anecdotal evidence is important. It is just as important, however, to address the fiscal concerns expressed by the Commissioner and the Legislature. These questions, taken from a survey developed and used by the Minnesota Department of Health, may suggest the kind of information the Commissioner and Legislature could find helpful in making a decision about the Katie Beckett Option. Eligibility and cost-effectiveness are important issues in this decision. Testimonies from families will be more effective if they address the purse as well as touch the heart.

1. What is your child's disability? Does your child have more than one diagnosis?
2. How does your child's disability affect your family?
3. Does your child depend on you for activities of daily living? (Eating, toileting, dressing, bathing, speaking, understanding others, getting around the home and/or community)
4. How is caring for your child different from caring for children of comparable age?
5. Does your child exhibit any behaviors that are disruptive, violent, uncontrollable?
6. What level of supervision does your child need? How many days of pre-school/school did your child miss because of his/her disability?
7. Does your child need a special diet?
8. Does your child use prescription drugs? How many, and at what cost?
9. Does your child need medical services that are specialized? Who pays for that? (Do you have private insurance that pays for medical visits, etc.?)
10. Has your child used emergency medical care in the last twelve months? What kind and who paid?
11. Does your child need specialized equipment and/or supplies? (Wheelchair, braces, adaptive equipment, assistive technology, diapers that would not normally be used at his/her age, disposable supplies such as tubing, syringes, etc.) Who paid?
12. What kinds of expenses have you incurred that are directly related to your child's disability? (Additional phone usage, need for cell phone for emergencies, home or vehicle modifications, extra charges for utilities)
13. Is your child authorized to receive home care? Has he/she received home care in the last year? What kind of home care? (Nursing, home health aide, direct support worker) Who paid?
14. Has your child or your family received counseling because of your child's disability? Who paid?
15. Do you coordinate your child's care or does he/she have a care coordinator? Who paid?
16. Does your child need mental health services? Are you able to obtain the services he/she needs? Who pays?
17. Do you need respite? Who provides the respite? (Family member, friends, provider) Who pays?
18. Estimate your out-of-pocket expenses in the last year for your child with a disability. Were those expenses greater than for other family members without a disability? How do they compare?
19. Is your employment and/or the employment of your spouse affected by the special needs of your child? (Need to: leave job, work part-time, refuse job opportunity for fear of losing benefits, take a second job, increase work hours)
20. Have you missed any work time because of the needs of your child? How many days and for what reasons?
21. Has your child's needs influenced where you live? Why?
22. Is your child covered by private health insurance? Is there a lifetime maximum benefit? Are there any limitations or exclusions because of your child's disability? Is there a deductible that must be met before benefits are paid? What is that deductible? Is there a co-pay? What is it?
23. Have you ever lost health insurance coverage because of your child's special needs?
24. How much does your family pay a month for private health insurance?

Region IX's Area Agency Changes Name and Recognizes Long-time President

On Tuesday, November 25th, Behavioral Health & Developmental Services of Strafford County held its Annual Board Meeting. The evening included recognition of long-time board president John McCooey and the announcement of the agency's new name: Community Partners.

John McCooey, member of the Board of Directors since 1995 and Board President since 1996, was recognized for his long-standing commitment

to the organization and the people it serves. Dover Mayor Alex Nossif attended the event to present Mr. McCooey with a commendation for service from the City of Dover, and fellow Board Member Constance Slater read a signed commendation from Governor Benson regarding Mr. McCooey's years of dedicated service to the people of Strafford County.

Under Mr. McCooey's leadership, Developmental Services of Strafford County ex-

panded its existing services to individuals and families with developmental disabilities to include community mental health services, following the closure of Strafford Guidance Center in 2001. The name was changed to Behavioral Health & Developmental Services of Strafford County to include these new services.

The new name, Community Partners, reflects the agency's success in partnering two organizations with one solid

mission. Community Partners recognizes the needs of the community and the significance of partnering with the members of this community to serve them and the people they care about.

The agency's new name and logo was developed with the assistance of consultants Watson Communications Group, and was funded in part through a grant from the Partnership for Effective Nonprofits, an initiative of Foundation for Seacoast Health,

Greater Piscataqua Community Foundation, and United Way of the Greater Seacoast. The aim of the Partnership is to coordinate the resources of local funders to assist non-profit organizations to strengthen their management, programs, and sustainability.

For more information about Community Partners and the services they provide, call (603)749-4015.

Special Medical Services Bureau

Another resource for some families

by: Janet M. Krumm

1. Where does a family go when their child has special nutritional needs?
2. How does a child who has been receiving pediatric cardiac care since birth - including surgeries - find an adult cardiologist with knowledge of pediatric conditions?

These are some of the questions that concern Special Medical Services Bureau (SMS) in the Department of Health and Human Services.

Some answers they can give readily; some need more time and work.

1. SMS contracts with 14 pediatric nutritionists geographically dispersed across the state to assist families with the nutrition, feeding and swallowing problems of their children. There is no cost to the family for this service, but there is a waiting list of 60 families due to budget cuts.

motor clinic, a child may see a pediatric orthopedic surgeon, an orthotic professional, a physical therapist, a developmental pediatrician, and a durable medical goods provider.

This provides an opportunity for all the professionals a child needs to talk with each other, problem-solve and write a report with joint recommendations. In addition, a care coordinator meets with the family prior to their visit, is present during the visit and continues contact with the family afterwards to help with follow-up care.

This interdisciplinary model of care is not supported

for expenses not covered by Medicaid or other public programs.

"We're the insurer of last resort," Bumbalo explained. "We pay mostly for medically related things Medicaid doesn't pay for." There is an annual cap for hospital costs - \$2,500.

The role of Special Medical Services Bureau (SMS) has changed radically since it was created in 1935, not only in what it provides, but in the philosophy that guides it.

Originally created to provide medical specialty services to "crippled children" because such services didn't exist, it now focuses on community-based, comprehensive, culturally competent, family-centered care for children with special health care needs. Those needs are defined as "chronic physical, developmental, behavioral or emotional conditions which require health and related services of a type beyond that required by children generally."

SMS receives federal funds in the form of a Maternal and Child Health block grant. The State must provide matching funds, but the match ratio is different from Medicaid. Instead of a 50-50 match like Medicaid, the federal government provides funding for one-third of the budget for SMS, and the State provides for two-thirds from the General Fund.

"We're slated to get a bit of an increase from the federal government this year," Bumbalo said, "because the poverty rate in NH as gone up." She expects the increase to be about \$80,000.

Budget cuts from the State, however, have forced SMS to cancel three contracts for services. The nutritional network will see a significant impact. There is now a waiting list of 60 families for this service.

In addition to the

3. How do children with a neuro-motor disability get all the professionals they need in the same room at the same time to discuss their medical problems and make joint recommendations?

4. Where does a family get the money to pay for overnight stays for themselves when their child is in a specialty hospital a long way from their home and they can't afford the expense of a motel for an extended period of time?

Special Medical Services has a nurse on duty during working hours to answer parents' questions about services, their child's condition or any concern they have. To reach the nurse on duty, call:

**603-271-4488, or
1-800-852-3345, ext. 4488.**

"We're the insurer of last resort. We pay mostly for medically related things Medicaid doesn't pay for."

Judy Bumbalo Bureau Chief Special Medical Services

2. A current initiative of SMS is to work with families and medical professionals to help create a smooth transition from pediatric cardiology care to adult care.

They are looking at how families find adult providers, how much time it takes, and how big a problem it is for families to provide the adult cardiologist with all relevant medical records.

They are also addressing how to educate adult cardiologists about the particular needs of former pediatric patients.

"Children with cardiac problems are living longer," explained Judy Bumbalo, RN, Ph.D, and bureau chief of SMS. "Adult cardiologists don't know how to deal with a child who has had four heart surgeries by the time he or she is 18."

3. SMS supports two neuro-motor clinics - one in Concord and one in Manchester. During a visit to the neuro-

by the private sector, Bumbalo stated. "Insurers determine the cost per hour for each service and bill for that," she explained. "No insurance is going to pay for all those professionals in one clinic at one time for one visit."

Instead, families would have to make six different visits. "That's very difficult and expensive for families," Bumbalo said. Not to mention an inefficient way to provide care.

4. When a child has special medical needs, families inevitably incur out-of-pocket expenses. Care for the child in a specialty hospital may be covered by private insurance or Medicaid, but a family's stay in a nearby motel is an out-of-pocket expense.

(SMS encourages and will help eligible families to apply for Medicaid.)

When a family is determined financially eligible (income at 185% of poverty), SMS will provide financial assistance

Neuro-motor clinic, SMS supports two other clinics: Amputee/Limb Deficiency, and Child Development clinics (one in Lebanon at Dartmouth-Hitchcock Medical Center, one on the Seacoast at UNH, and one in Manchester.) All clinics use the interdisciplinary model of service.

The shift from direct services to enabling, population-based, and infrastructure-building services reflects a philosophical shift in the service system, and a change in their mandate from the federal government.

In 1988, SMS provided diagnostic evaluations by a multidisciplinary team regardless of family economic status for the following: Amputee, Cardiac, Child Development Clinics, Cleft Lip and Palate, Epilepsy, Cystic Fibrosis, Genetics Clinics (Children and Adult), Myelodysplasia, and Neuromotor.

Now, they work with families and community-based providers to ensure that children needing those services and supports will have access to them in the community. The Clinics they continue to offer provide services and supports not supported in the private sector.

One of the most visible signs of SMS' focus on family-centered care is their continued support of NH Family Voices, an organization run by parents having children with special

health care needs, multiple disabilities and mental health conditions.

Family Voices 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. Family Voices also distributes a free newsletter, Pass It On.

A current project of Family Voices that is being supported by SMS is the creation of a "tool box" for use by medical providers to help them assist families in accessing supports and services for their children. The tool box will contain information about existing resources as well as helpful hints on how to, for example, write a letter to ensure that a particular service will get paid for by private insurance or Medicaid.

Special Medical Services is not just a payment program, Bumbalo concluded. "Our mandate is much broader. SMS helps families obtain specialty health care services for their children and health information and support services for themselves." They must be doing something right - they have a patient satisfaction rate of 94%.

The Child Health Assurance Program

Coverage lasts until age 21

by: Janet M. Krumm

Every child up to the age of 21 who receives Medicaid - no matter how the child became Medicaid eligible - is automatically enrolled in the Child Health Assurance Program (CHAP).

This can be confusing because the age when a child is considered an adult for Medicaid purposes varies among the different Medicaid programs. Health Kids Gold, for example, covers a child until the age of 19. A child becomes eligible for Healthy Kids Gold because the income and resources of their parents are below an established level or through the Katie Beckett option if he/she has a severe disability.

A person applying for Medicaid as an adult can do so at the age of 18. (In fact, a child on Healthy Kids Gold

must apply again as an adult between the ages of 18 and 19, although coverage will continue under Healthy Kids Gold until the age of 19.) Medicaid for Employed Adults with Disabilities (MEAD) is available at age 18.

While it is necessary to receive Medicaid to be eligible for CHAP, CHAP is not a Medicaid program. CHAP is the State's name for a federally mandated program called Early and Periodic Screening, Diagnosis and Treatment (EPSDT). CHAP provides screening, diagnosis and treatment for children. It's emphasis is on prevention, education and healthy life styles.

The screenings covered by CHAP include: dental, medical, developmental, nutritional, and vision and hearing assessments. Eyeglasses and hearing

In the past, every district office of the Department of Health and Human Services had a CHAP worker available to help families and answer questions. This is no longer the case. For questions about the benefits available in the CHAP program, contact the following DHHS employees at Concord.

Call: **1-800-852-3345**

and ask for:

**Diane Boucher, ext. 5454, or
Pat Bowen ext. 7703, or
Lynn Ellis ext. 7517, or
Kurt Kaltenborn ext. 5722**

aids are covered if needed by the child. Immunizations are covered, as well as transportation costs for doctor visits.

Any treatment recommendations which result from a CHAP screening must be paid for by Medicaid if the treatment plan is approved by the Department of Health and Human Services. By federal regulation, there is no cap on the services

recommended in an approved CHAP treatment plan.

Non-traditional treatment may also be covered if the child's physician believes it may reduce the child's disability. For example, if a doctor recommends expanded physical therapy services and the plan is approved, Medicaid will pay for it.

NH ATEC/ ASSETT Workshops That Come to You!!!

If you can gather 5-15 teachers, paraprofessionals, parents or therapists, we are offering a variety of presentations to better serve your students. Choose the workshops that best suit your needs!!!

Augmentative Communication Related Workshops:

Workshop Titles:

- * Where to Begin with Augmentative/Alternative Communication (AAC)
- * The How- To's of Scheduling Systems
- * The Myths of Yes/No Questions
- * Every Move Counts- Assessment and Intervention
- * Beginning Dynavox, Dynamite, or Dynamo Training

Other Assistive Technology Workshops That Come to You:

Workshop Titles:

- * Basic Switch Making
- * Creative Problem Solving and Worksite Accommodations
- * Santa's Workshop- Adapting Toys in Time for Christmas
- * Assistive Technology Solutions for Home, School, Work and Play
- * Electronic Memory and Prompting Aids for Home, School and Work
- * Basic Switch Making, Modifying and Mounting
- * Overview of Assistive Technology Fabrication Tools, Materials and Resources
- * Electronic Aids for Daily Living
- * Computer Access Hardware and Software for Physical Disabilities
- * Computer Access Software Training

Contact ATECH Services/ASSETT to discuss times and dates that would best accommodate your group and to customize the workshop. If you have any questions please call 603-226-2900 V/TDD or fax at 603-226-2907

* *These workshops are \$225 and include a take home tools & materials kit and advanced CEU approvals.*

Details available at www.nhassistivetechology.com

ATECH Services/ ASSETT Announces Workshop Schedule

Who should attend: Professional development opportunities are being offered for educators, paraprofessionals, OT, PT, SLP, ATP, special educators, parents, students, consumers & others.

Workshop Strand Themes: This year, we offer workshops in three different strands. Participants can choose one or more of these workshops if they wish to focus their professional development in one area, or can mix and match from among the strands to meet their own professional development needs.

Strand #1: Designing Classrooms that Work for All Learners will focus on instructional strategies that teachers can use to better support all learners, including those with sensory impairments.
Strand #2: Assistive Technology: Obtaining Positive Outcomes offers several workshops on a variety of assistive technology solutions, strategies, —both high and low tech— that exist to support people with disabilities achieve desired outcomes in school and work.

Strand #3: Transitions will offer workshops on best practices in transition— from early intervention to school, and from school to work or college.

Location: Workshops are offered this Fall in the **ASSETT Conference Room, 2nd floor of the Dolloff Building, 117 Pleasant Street in Concord, NH.** In addition, we are available to come to your school with these or other related topics (see page 3)...call us to design the specific training you need!

Registration Fees:

Schools Receiving ASSETT Services: \$35 per person or \$70 for up to three people from one school for a full-day workshop and \$20 per person or \$40 for up to three people for a half-day workshop, unless otherwise noted.

Schools not affiliated with ASSETT: \$60 per person for a full-day workshop and \$40 per person for a half-day workshop.

Parents and Students: NO COST.

Workshops that come to you: www.nhassistivetechology.com.
\$100 per hour, minimum of 2 hours (for 5-15 people)

Hands on All Day Assistive Technology Fabrication Workshops: \$225 per person, which includes all take home fabrication tools, materials and video, as well as the cost for OT and ATP CEUs.

CEUs: AOTA and ATP CEUs applied for for all Assistive Technology Workshops. CEU certificates will also be provided for all other disciplines.

Cancellation policy: Due to inclement weather, workshops can be canceled and rescheduled for another date. All participants have the option to attend the future date or receive a full refund. In addition, if the participant is not completely satisfied with the training received, they can receive either a complete refund or a coupon to attend a future CEU activity at no cost.

For more detailed information regarding these workshops: Please call (603) 226-2900 or visit our website at

www.nhassistivetechology.com.
ATECH Services/ ASSETT

Workshops at a Glance

* Switch Making, Mounting and Modifying

T. Willkomm

Date: December 5, 2003

Time: 8:00am - 4:00pm

Strand 2

* DynaVox: Information Management: Backing Up and Sharing Pages

G. Weisel

Date: December 11, 2003

Time: 8:45am - 3:15pm

Strand 2

* DynaVox: Getting Started

G. Weisel

Date: January 4, 2004

Time: 8:45am - 3:15pm

Strand 2

* Assistive Technology and School-to-Work

T. Willkomm

Date: February 24, 2004

Time: 9:00am - 3:00pm

Strand 3

Continued from page 1

That determination would have enacted a heavy price. "We would have lost our house, and our marriage," Ellen admitted.

The Challenge has reported on several children over the years whose families depended on the Medicaid services and supports available to them because of the Katie Beckett Option.

In 1996, we told the story of Breana Mainville, six years old at the time. Breana had survived six surgeries, five of them open-heart, and a month-long coma.

With a several hundred dollar specially designed bath seat paid for by Medicaid, Breana could be bathed. She slept on a specially designed bed that cost Medicaid nearly \$7,000. Medicaid paid for the wheelchair Breana used, allowing her to go to school and participate with other five and six year old children. Medicaid paid for the feeding bags and liquid nourishment needed to keep her alive. Medicaid paid for the paraprofessional assisting her at school and the speech and physical therapies she received as well as the medical equipment needed at the school.

Breana's mother Harley had calculated the cumulative costs of all the equipment and services paid for by Medicaid and it came to nearly \$900,000. "Without Medicaid," Harley was quoted as saying, "I'd be more stressed out. I'd be worrying about bills." Even so, Medicaid did not provide for all of the needs associated with caring for Breana. At the time of the article, Harley and her husband Gary were mounting a campaign in the community to raise funds for a wheelchair accessible van so that they could take Breana with them in the car.

Breana had such complex medical needs that if it were not for the Katie Beckett Option, she would not be able to live at home. For Harley, that was inconceivable. "It would be over my dead body that she went into a state home," she was reported saying.

But children have a variety of disabilities, and thus, a variety of needs. Children with mental illness may not need braces and wheelchairs, feeding bags and bath chairs, but that doesn't diminish the severity of their disability.

The most effective treatment for children with mental illness is early intervention, explained Michael Cohen, executive director of the New Hampshire chapter of the National Association for the Mentally Ill (NAMI-NH). The earlier mental health services are provided to a child, the fewer "systems" will be involved in his or her care. Unfortunately, coverage under private health insurance plans is limited.

New Hampshire has a law mandating parity in insurance coverage for physical and mental illnesses. But the parity law includes only nine major mental illness diagnoses, according to Cohen, none of which apply to children. So parents who have insurance coverage typically face higher co-payments and deductibles along with limited mental health services.

Compounding this is the reality that only three hospitals in the State offer in-patient mental health services for children - two are private hospitals and one is the State hospital. This makes it a challenge to get into residential treatment programs. Getting admitted to the State Hospital, for instance, requires an involuntary commitment, according to Cohen.

Medicaid pays for mental health services for children, and Katie Beckett may be the only way a family can access those services. The alternative is to wait until a child is in crisis, but then the Division for Children, Youth and

The many faces of Katie Beckett



Photography by E.G. Stone

Top left: Sue Taylor's life changed when she was able to get in home supports to help her with her son Zachary who has autism.

Bottom left: Cassandra Janvrin helps her sister Breaua Mainville eat dinner in this file photo from the Winter, 1996 issue. Breaua's needs were so complex that her mother, Harley Janvrin said, "If I lost Medicaid, I don't know what I'd do."



Top right: Sara Edgerly (left) and her mother Ellen. As Sara fought to get her life back, Ellen fought for the supports to make it possible to bring her home.

Bottom right: The supports Sara Edgerly needs to live in the community are paid for by Medicaid.



Families (DCYF) and perhaps even the Juvenile Justice system may become involved. Some parents are faced with giving up their parental rights in order to access services under the DCYF program Children In Need of Services (CHINS). Ultimately, the costs are great - financially for both the State and the family, and emotionally for the family.

Children with autism pose a different set of challenges. In our Winter, 2002 issue, The Challenge reported on Zachary, a three year old with autism. Medicaid paid for the home supports that allowed them to be a family. Before the supports, Zachary's mom Sue was feeling overwhelmed by his need for constant one-on-one attention. She couldn't work; she had no time to attend to the needs of her other three children, and her husband Tom was working 80 hour weeks to pick up the slack financially.

Zachary not only demanded constant attention during the day; his sleep patterns were horrendous. "He would wake up at one in the morning," his mother said, "and be up 'til five and then be up all day. It was horrible."

Having a support person come every day for a four hours in the afternoon gave Sue time to give full attention to her other children and help them with their homework. It relieved the enormous stress Sue felt trying to do it all alone. And Zachary had the one-on-one supervision and attention he needed to work on the skills outlined in a program developed by his early intervention team.

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

For these families, and families like them across the state, Medicaid provides the supports they need to keep it together. For them, Medicaid is the difference between disaster and survival.



Donna Woodfin

Photo: Krumm

by: Janet M. Krumm

She never expected it to become a career; after all, how could she count on a position in a newly-created organization with no guarantees for longevity as a way to support herself and her children? Donna Woodfin had a teaching degree when she was hired as the first executive director of the Developmental Disabilities Advocacy Center (D.D.A.C.) in October, 1978. In her early years as director, she coupled her professional duties with school part-time to get her Masters in Administration in preparation for the day that her job at the D.D.A.C. would end.

Fast forward to 2003. Despite having formally "retired" in 2002 after a 24 year tenure as executive director, Donna still comes into the office part-time several days a week to continue the advocacy work she loves.

Donna's introduction to the disability community came with the birth of her daughter Ellen in 1966 who was diagnosed with Williams syndrome at 20 months. There were no

laws guaranteeing the rights of children or adults with disabilities in the late 60's and early 70's. The Laconia State School was the center of New Hampshire's service system, such as it was. Educational opportunities for children with disabilities were dependant upon the willingness of school officials.

What's a parent to do? Donna's solution was to get involved in advocacy efforts. She joined the local ARC, then known as the Association for Retarded Children, a parent advocacy group, even serving as president. She also joined the Coalition for Handicapped Citizens (which later became the Parent Information Center) and became involved in the state ARC in the late 60's.

Donna was fortunate to find schools in Concord that were willing to accept Ellen, who "was very social" Donna remembered. Ellen attended pre-school at Emerson School and went on to attend elementary school in Concord at two different schools, one a long-time special education school

and the other a community school.

As she grew older, however, the heart condition with which Ellen was born - aortic stenosis - became more of a problem, requiring surgery when she was seven years old. Ellen did not survive.

It was a difficult time for Donna. The loss of her daughter was compounded by the loss of her father whose love for his granddaughter was boundless. And in the midst of this emotional trauma, she became a single mother caring for small children. "I had to go back to work," she said.

The route she traveled to the D.D.A.C. took her into schools as a substitute teacher and to Head Start providing training to Head Start personnel statewide. She wrote a grant for the Community Action Center to begin a Senior Companion program which matched low-income seniors with other seniors. "I got to meet a whole bunch of other people," she said.

Her life turned with a phone call from a friend who

told her about an ad in the paper for a position at the D.D.A.C. In 1975, Congress had passed legislation mandating the creation of and providing funding for a protection and advocacy (P&A) organization for people with developmental disabilities in every state.

In New Hampshire, the Governor's Commission on Disability received initial implementation funds of \$10,000. The Commission created a publication called The Blue Sheet to inform people about their civil rights.

In 1977, funding was increased to \$20,000, half of which went into the publication of The Blue Sheet and half of which was given to the ARC as a subcontractor.

It was around this time that the ARC became lead plaintiff in the Garrity V. Gallen lawsuit over conditions at Laconia State School. Politically, it became clear that the ARC would not be designated as the State's protection and advocacy organization. In order not to lose the funding, the Developmental Disabilities Advocacy Center was founded and Donna was hired as its first executive director in October of 1978.

"I was not aware of the controversy," Donna admitted. "I was so naive at the time; I didn't understand the politics."

Donna was the only employee initially. Help was provided by a student from the Franklin Pierce Law Center, and a subsequent C.E.T.A. grant provided the funds to hire a secretary. It wasn't until 1979 that a staff attorney was hired - Ron Lospennato.

In 1986, legislation was passed mandating protection and advocacy services for people with mental illness. Existing P&A organizations were authorized to implement this

legislation. Reflecting its expanded responsibilities, the D.D.A.C. changed its name to the Disability Rights Center, Inc. Over the years, the DRC has added responsibilities for P&A work for people with a wide range of disabilities. The number of staff has grown to about 20 (many part-time) and funding grew from the start-up of \$20,000 to the present \$1.4 million.

The DRC has made a difference in the lives of people with disabilities. The most dramatic moment in Donna's mind was the Timothy W. case. Timothy was a young boy with severe disabilities who was being denied an education in Rochester because the school district considered him too disabled to benefit from an education.

"This was an incredibly important case," Donna remarked. The District Court ruled in favor of the Rochester School District. The DRC appealed the case to the 1st Circuit Court of Appeals, which ruled in favor of Timothy W. Rochester appealed the case to the US Supreme Court, which refused to hear the case, letting stand the ruling of the 1st Circuit Court of Appeals.

"If it hadn't gone our way, it would have made very bad law," Donna explained. "It would have been the beginning of a very slippery slope. We were incredibly thankful for that outcome. And it wasn't even a class-action suit; it was an individual case."

Legal advocacy can have a powerful impact on people's lives. "But it's very lonely," Donna explained. "You feel like you're all alone. You

An Unexpected Career

Continued on page 17

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feel just like the client feels - like everyone's against you. That can be difficult for relationships outside," she admitted.

Donna remembers a director of a state agency once saying to her, we hate the fact that you're there, but we always know where we stand. "I took that as a real compliment," she said.

"For people who have not been around very long - who have not been through (the) Laconia (lawsuit) and other movements - it may feel like a battle," she said. "Hopefully, in the end, it makes it better for everybody. People who have been around for a long time understand that."

There was a young mother with whom Donna worked early in her career. Every year she helped this mother advocate for her child with the school district. About six years after her last meeting with the mother, Donna heard from the woman. She told Donna the

good things that were happening for her child. "She said to me, 'Without you, this never would have happened.' It was very gratifying years later to get that," Donna admitted.

There has been criticism over the years that the focus of the DRC has been "too legal," according to Donna. "But if you need (legal services) and you come here and we're able to do something for you, man, are you a supporter!"

"It's very satisfying to see the results of what we do," admitted Donna. "It's the greatest satisfaction, because when people come to us, they have no hope. They've usually been everywhere, and tried everything before they got here."

"The law works," she emphasized.

"But laws are not self-enforcing," she added. "They don't work automatically, but ultimately they work, or they're made to work because they get altered or changed."

Donna has experienced both highs and lows in her 24

plus years with the DRC. She admits to stepping into her role with little knowledge or foresight about what she was getting herself into. "I'm not sure I'd want to step into this now," she said, laughing, referring to the number of different programs for which the DRC presently has responsibility.

"This has turned into a career," she acknowledged. "I didn't realize it at the time (I started)." When she responded to that employment ad, she knew the work was important, but didn't think the job would last. "I'll enjoy it," she remembers thinking. "It'll get me there until I can get a teaching job."

Fortunately for the New Hampshire disability community, that teaching job never materialized. Instead, Donna Woodfin brought her skills and her experience to a generation of families and individuals with disabilities whose lives are forever changed because of her untiring efforts.

To honor Donna Woodfin for her 24 years of service,

The Donna D. Woodfin Disabilities Rights Center Scholarship Fund

has been created to provide financial assistance for students with disabilities to attend college or other post-secondary programs.

Contributions may be sent to:
The Disabilities Rights Center
P.O. Box 3660
Concord, NH 03302-2077

Did you know.....?

that the first issue of The Challenge (1988) featured responses from the Democratic and Republican candidates for President - Michael Dukakis and George H. Bush?

Want to know which candidate for President will best represent your interests in the upcoming Presidential Primary?

Look for the candidates' positions on disability issues in our Winter, 2004 issue, coming out in early January.



Exercise your power -

Read The Challenge!

(And please give generously to this year's annual appeal.)



Are you or a family member living with a brain injury or stroke? Do you find yourself asking questions about how to explore financial resources, where you can get long term care, how to set up various therapies or how and when you can go to work? If these or any other questions and are frustrated by a lack of information, the new **Resource Facilitation Program** might be right for you. The Brain Injury Association of New Hampshire, in partnership with the NH Division of Developmental Services, is offering this new program to brain injury and stroke survivors and their families free of charge.

Resource Facilitators will present the best available service options to enable:

- ◆ Informed decision making
- ◆ Consumer choice
- ◆ Maximized independence
- ◆ Continuous quality of life

Resource Facilitators will provide:

- ◆ An Intake Assessment
- ◆ Training and Education
- ◆ Resource referrals
- ◆ On-going monitoring and advocacy
- ◆ Life planning

To see if Resource Facilitation is right for you, contact the Brain Injury Association of New Hampshire office at 800-773-8400 (NH only) 225-8400 or erin@bianh.org.

NH SPED Bureau Offers Public Input Sessions

The New Hampshire Department of Education, Bureau of Special Education, wants to hear from interested parties regarding how they might like to see the special education process regulations changed. Public input sessions are scheduled around the state during the 2003-2004 school year.

Every aspect of the provision of special education in New Hampshire is open for input at each session. In order to give focus to the input, the following general categories will be covered at each session:

1. Child Find (finding children who might need special education), referral, evaluation, determining eligibility ("coding")
2. The child's IEP (Individualized Education Plan)
3. Placement of the child for receipt of special education and related services
4. Operation of special education programs, both public and private.

Sessions are scheduled as follows:

January 29, 2004 3-5 PM and 6-8 PM NH Department of Education 105 Pleasant Street, Room 15 Concord, NH	April 8, 2004 3-5 PM and 6-8 PM Seacoast area (place to be determined)
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March 15, 2004
3-5 PM and 6-8 PM
SAU Office (Board Room)
196 Bridge Street
Manchester, NH

For more information, call 603-271-3741 or e-mail braymond@ed.state.nh.us

Southeastern Regional Education Service Center (SERESC)

is offering the following workshops

Sensory Integration the Next Step-

With Traci Gilman, OTR/L.

This workshop will go beyond the AIDeIng information and give hands on strategies and training.

Date: Dec 10, 2003

Time: 9 - 12pm

Where: SERESC, Bedford, NH .

Disorders of Regulation & Social Interaction in Young Children

With Teresa Bolick, Ph.D.

Date: January 13, 2003 with snow date of January 2003

Where: SERESC, Bedford, NH and Videoconference to NCES in Gorham, NH.

More information to follow.

If you would like further information on any of these events, please contact Robin Knight, Project Assistant at (603) 206-6816 or rknight@seresc.net.

"Like the Golden Rule, advocacy is a wonderful concept. But in a fashion, advocacy goes beyond the Golden Rule. While it's one thing to do for others as you would have others do for you, it's quite another thing to work for another as you would work for yourself. In the first instance, you are guided to treat other people as you expect to be treated by them. That's only decent and reasonable. If you're an advocate, you have agreed to treat another person as you would treat yourself - to "buy" into his or her viewpoints, to rationalize his or her behavior, to be as selfish concerning his or her needs as you are concerning your own."

Burton Blatt

NH Department of Education Offers New Service to School Districts - Facilitators for Difficult IEP Meetings

The Bureau of Special Education is pleased to announce the availability of a new service to school districts: a cadre of people trained to facilitate a Special Education Team meeting in the place of the "Case Manager," or other district person who customarily conducts the Team meetings.

A facilitator is available for situations where the working relationship between the parents and the school has become unproductive.

The purpose is to assist the Team in working through the discussion and decision-making for one of the steps/meetings in the Special Education Process.

Who?

A trained facilitator

What?

Conduct a Special Education Team meeting* for the district using facilitation techniques

Where?

In the district, where the district

would ordinarily conduct its own Team meeting (the facilitator will travel to the district)

When?

With the same 10 days' notice the district gives parents for a Team meeting**

Why?

Assist districts to have Team meetings with parents where parties are having difficulties working together and reaching Team decisions.

How?

Contact Jackie Teague*** in writing, at the Bureau with the information in the 10 day notice:

- Purpose of the meeting
- Date
- Time

- Identification of the participants [by name, title, Team member role]

- Location

Please also provide the name, title, phone number and e-mail address of the person making

the request for the district so Jackie may respond immediately regarding details and availability of a facilitator.

* Facilitators are available for any of the types of meetings the IEP

Team/Special Education Team has:

- o Disposition of referral
- o Evaluation planning
- o Determination of eligibility
- o IEP writing and revision (including ESY, transition or vocational planning, and graduation)
- o Placement selection
- o Manifestation determination

** requires a 5 day notice to the parent and Bureau

***Jackie Teague may be contacted by email: jteague@ed.state.nh.us, fax 603-271-1099, or phone 603-271-3741.

TDD Access: Relay NH 1-800-735-2964 or 711

Note to families:

According to Jackie Teague, the Bureau of Special Education must receive a request for a facilitator from a school district, not a parent. It is the school district who controls who runs the meeting.

The Bureau chooses the facilitator from their list of available trained facilitators.

Facilitators receive intense training in mediation and group dynamics from experienced facilitator/mediator trainers.

If the issues are not resolved to the parent's satisfaction, the parent still has the right to go due process or request mediation.

Disability Awareness Mini-Seminars Offered

The Governor's Commission on Disability and the Statewide Independent Living Council (SILC) are jointly sponsoring a series of two-hour Disability Awareness Mini-Seminars to be held monthly in the Commission's office at 57 Regional Drive in Concord.

The purpose of the series is to develop and increase an understanding of various disabilities, and to increase awareness of the many organizations and programs serving people with disabilities. The series also provides opportunities for individuals with disabilities, parents, advocates, professionals and others interested in disability-related issues.

The Mini-Seminars scheduled for December and January are:

Claimants Disability Services, December 10, 2003
Sight Services for Independent Living, January 14, 2004

For more information, or to register, contact Becky Emery or Karen Geary at 1-800-852-3405 (V/TTY) or 603-271-2773.



National Down Syndrome Congress Presents President's Award to UNH's Institute on Disability

DURHAM – The Institute on Disability at the University of New Hampshire was presented with the National Down Syndrome Congress President's Award during its annual convention, held Aug. 22-24 in Philadelphia. The award was presented to the Institute on Disability for pioneering leadership in creating and advancing best practices and for its commitment to parents and self-advocates as equal partners.

The Institute on Disability's mission is to promote the inclusion of people with disabilities into their schools and communities and to advance knowledge about disability and best practices. The Institute works with students and faculty, conducts statewide training, participates in grant-funded model demonstration projects, conducts research and engages in collaborative partnerships with other statewide organizations that are committed to improving the lives of persons with disabilities and their families.

The Institute on Disability, together with the Division of Genetics and Child Development Children's Hospital at Dartmouth, and the Department of Pediatrics at Dartmouth Medical School; the Institute for Health, Law, and Ethics at Pierce Law Center; and the Center on Community Economic Development and Disability at Southern New Hampshire University comprise New Hampshire's University Center for Excellence on Disability (UCED).

Transition

Continued from page 3

student with disabilities should lead to employment and a place in the community is reasonable. But the reality is very different.

During the 13 years that transition planning has been required, there has been little progress in formulating a viable plan for entry into adult life.

Most individuals with disabilities in New Hampshire are placed on a waiting list for services at age 21. After all of their school inclusion and daily involvement in their communities, they are go home to wait for months or years.

"We do so much and it's sad to see the funding drop off so completely at 21" observed Colleen Bovi, Director of Pupil Personnel at Timberlane Regional School District.

According to Charlene Mayo of the Parent Information Center, transition planning in New Hampshire schools has been weak and many transition plans simply refer to vocational rehabilitation.

"The educators are not trained to do it (transition planning) and more self advocacy is needed," she explains.

Sean Dunham is a study in self-advocacy. His mother, Bonnie, describes him as having "a level of self esteem that many of us only dream of. He knows that he is wonderful and he completely believes in his right to be involved in absolutely everything."

While in high school he attended all the dances, was a manager on the basketball

team, and went on all the field trips. After school he chose to volunteer for many community organizations and causes including Habitat for Humanity and the Gore Campaign.

Now that he is out of school he is working part-time at Wendy's and campaigning for Howard Dean. He goes out with a friend on Friday nights to sing karaoke. He has even traveled to Kenya without his family.

Bonnie admits that Sean's community inclusion hasn't been easy. "It takes a lot of effort by our whole family," she says. But the result has been worth the work.

His school inclusion and subsequent community inclusion have been the result of constant planning and support from his parents and community in collaboration with their area agency.

Obviously there are a lot of pieces to assemble for transition to be successful. It is no wonder that educators, parents and service providers struggle to create transition plans.

"Families expect inclusion and you need good community connections for it to work," states Jan Nisbet. The next level for individuals with disabilities will be what the community can do.

The school boards ensure inclusion in education and there should be town organizations to oversee community inclusion. When that happens, according to Nisbet, there will be real possibilities for individuals with disabilities to live independently.

Transition resources in New Hampshire

Paul Leather, Director
Division of Vocational Rehabilitation
NH Department of Education
78 Regional Drive Building 2
Concord, NH 03301
603-271-3801

Mary Ford, Director
Division of Instruction
NH Department of Education
101 Pleasant St
Concord, NH 30001
603-271-6693

Cate Weir, Transition Consultant
Institute on Disability
University of New Hampshire
10 Ferry St
Concord, NH 03301
603-228-2084

Transition resources nationally.

Sarah Menlove
State Improvement Planning Division
Office of Special Education Programs
U.S. Dept of Education
Mary E Switzer Building
330 C Street SW
Washington, D.C. 20202 2640
202-205-8952

Career Voyages
(information about jobs)
www.careervoyages.gov
1-887-872-5627

National Center for Secondary Education Transition (NCSET)
Institute on Community Integration
University of Minnesota
6 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455
612-624-2097
www.ncset.org

Institute for Community Living
Inclusion/UCEDD
Umass Boston
100 Morrissey Blvd.
Boston, MA 02125
617-287-4300
TTY: 617-287-4350
www.communityinclusion.org

When you receive our annual appeal letter, please respond generously. We're counting on your support.

Opinion

A Granite Myth

“For the great enemy of truth is very often not the lie—deliberate, contrived and dishonest—but the myth—persistent, persuasive, and unrealistic.”

John F. Kennedy, Commencement Address at Yale, 1962

As anyone in New Hampshire knows, the Katie Beckett waiver is taking a serious scrub down at the Department of Health and Human Services in Concord. Nameless “clinicians and experts” have carried a myth to Commissioner Stephen. The myth is this... that New Hampshire families who have children with severe disabilities desire Medicaid so that they can live at taxpayers’ expense while they preserve their own substantial personal income. “The Legislature never intended this with the Katie Beckett legislation,” is the outcry. “These families are sticking it to the State!”

WRONG! We were there... we covered this story since 1988.

The facts are these.

The Katie Beckett legislation was passed by the New Hampshire Legislature during the administration of a very – VERY - conservative Governor, John Sununu. The first regulations were written during the administration of Governor Judd Gregg, another well-known conservative. Indeed, during the Gregg administration, family support legislation was passed (and signed by the Governor) creating Family Support Councils which provided a grassroots control on regional area agencies. Most significant of all, during the Gregg administration New Hampshire closed the doors forever to the Laconia State School, and institutionalized care.

In New Hampshire, the Katie Beckett Option was viewed as a tool to provide community-based support to parents who no longer had access to institutional care. By the way, which President personally created the Katie Beckett Waiver? President Ronald Reagan. Who would challenge his credentials as a conservative? And why was it created? As a cost-savings measure. It’s cheaper to support children in their homes than in institutions.

It’s true that Governor Merrill and former Commissioner Morton gave the disability community a strong challenge to prove that community based services were working, and we did. In the first “reorganization” the disability community stood up, demanded its own identity and lived. By the way, myths and assumptions back then promised \$32M in savings from HB-32. That myth faded into oblivion quickly.

Then came the Shaheen Administration. The disability community felt safe because we had a Governor who understood our issues. Fact is, we did not gain one inch, and the disability community went to sleep based upon the myth that “a friend” would look out for us. This provided fertile ground for new myths and assumptions to grow.

And here we are! We covered the news from Sununu to Bensen. We know the spirit, the origins and the motivations behind the legislative intent of the Katie Beckett waiver. It was conservative in origin, and meant to support children in the community, not institutions. To have some state bureaucrats peddle a myth to our new Commissioner, and tempt him back to the 1940s is to break with the conservative wisdom of President Reagan, and Governors Sununu, Gregg and Merrill.

The disability community must CHALLENGE the myth. The State’s fiscal situation is problematic. Legislators want to be sure that State money is spent wisely. It is up to the disability community once again to dispel the myth and shine a light on the reality of our lives. Lies are easily revealed. Do not allow this myth to grow or persist. It can easily weaken the foundations of a community-based service system that is desperately needed. It’s time to stand up and be heard.

At the end of this struggle, we’ll find either “compassionate conservatives” or hypocrisy. Which title will the State House choose?



Guest Commentary

I am a fifty-two-year-old
 “Child Left Behind.”

Many other adult citizens and I lack some basic math, reading, and writing skills. While they and I were children living at the Laconia State School and Training Center (a residential placement located in Laconia, New Hampshire), New Hampshire deprived them and me of opportunities to receive proper elementary-and-secondary grade school education. The Laconia State School and Training Center there also never offered private tutoring which we needed.

On April 12, 1978, residents’ parents filed a class-action lawsuit against Laconia State School and the state of New Hampshire to correct problems at the institution. However, the settlement left no entitlement-funding resources available for us uneducated-and-undereducated adults to finish school as full-time students.

New Hampshire still owes those people and me an appropriate education in math, reading, and writing because the State stole it from us. A few other persons and I have had to hire personal tutors to recoup some of that missing instruction. This cost Lakes Region Community Services Council in downtown Laconia and Community Bridges in Bow, New Hampshire, too much money and has been unfair.

New Hampshire’s **RSA 186-C** and the United States’ **Individuals with Disabilities Education Act (I.D.E.A.)** are guilty of age discrimination!

RSA 186-C and **I.D.E.A.** protect children’s educational rights but do not apply to people currently age 21 and over.

Regarding age, every American citizen should now be entitled to an elementary-and-secondary grade school education. Therefore, this type of academic service is very important to adults - not only children.

The State and Federal Legislatures must remove the age restrictions from **RSA 186-C** and **I.D.E.A** allowing everyone the opportunity to earn a diploma or its equivalency. By eliminating such ridiculous restrictions, we will finally be able to obtain the education New Hampshire initially denied us during our childhoods spent at the former Laconia State School and Training Center.

Written by Roberta Gallant, a former resident of the Laconia State School and Training Center. Roberta is an activist in the disability field, and will no doubt be an important part of the upcoming election season. She acquaints with most of those who represent her at the state and national levels. Roberta, thank you for reminding us about those who were first left behind!

This is the time for our annual appeal. When you receive a letter from us asking for your support, please be generous.
 We’re counting on you!

UPCOMING EVENTS

December

IEP Clinic

Sponsored by: Parent Information Center
Date: December 6, 2003
Time: 9:00-12:00 noon
Where: Chester, NH
Cost: Free
For more info, contact: PIC at 603- 224-7005 or 1-800- 232-0986 or at www.parentinformationcenter.org.

Understanding and Participating in the NH Special Education Process

Sponsored by: Parent Information Center
Date: December 8, 2003
Time: 6:00-9:30 pm
Where: North Conway
Cost: Free
For more info, contact: PIC at 603- 224-7005 or 1-800- 232-0986 or at www.parentinformationcenter.org.

Educational Surrogate Parent Training

Sponsored by: Parent Information Center
Date: December 8 & 9
Time: 6:00-9:30 pm
Where: North Conway
Cost: Free
For more info, contact: PIC at 603- 224-7005 or 1-800- 232-0986 or at www.parentinformationcenter.org.

Positive Supports for Children with Autism in Preschool Classrooms

Sponsored by: University of New Hampshire's Institute on Disability
Presenter: Ann Donoghue Dillon, Institute on Disability
Date: December 10, 2003,
Time: 1:00 pm – 4:00 pm (registration starts at 12:30)
Where: College for Lifelong Learning, Bow, NH
Cost: \$25.00
For more Information: Call 603-228-2084

January

Presidential Awareness Forum

Sponsored by: CAUSE (Communities Actively United for Social Equality)
 Presidential candidates have been invited to answer questions from CAUSE members.

Date: January 12, 2004
Time: 7 –9 pm
Where: St. John Evangelist Church 72 Main Street Concord, NH
Cost: Free
For more Information: Contact Mary Trinkley, Director of CAUSE, at 225-0999 or email nhcause@aol.com.

Effective Writing and Reading Instruction for Young Children

Sponsored by: Institute on Disability/ UCED UNH
Presenter: Ruth Wharton-McDonald, Ph.D.
Date: January 15, 2004
Time: 9 am – 3 pm
Where: Highlander Inn – Manchester, NH
Cost: \$60
For more Information: Call 228-2084 or 1-800-238-2048

Positive Behavioral Interventions

Sponsored by: Parent Information Center
Date: January 22, 2004
Time: :00-9:00 pm
Where: Plymouth
Cost: Free
For more info, contact: PIC at 603- 224-7005 or 1-800- 232-0986 or at www.parentinformationcenter.org.

Upper Valley Regional Winter Games

Sponsored by: Special Olympics NH
Date: January 24, 2004
Where: Dartmouth Ski Way and Garipay Field Hanover, NH
For more Information: Call 1-800-639-2608

Literacy Supports for Students with Learning Disabilities

Sponsored by: Institute on Disability/ UCED UNH
Presenter: Gretchen Hanser, M.Ed. OTR-L
Date: January 30, 2004
Time: 9 am – 3 pm
Where: Highlander Inn – Manchester, NH
Cost: \$60
For more Information: Call 228-2084 or 1-800-238-2048

February

27th Annual Winter Games

Sponsored by: Special Olympics NH

Date: Feb. 1-4, 2004
Where: Waterville Valley Ski Resort, Waterville Valley, NH
For more Information: Call 1-800-639-2608

What it Means to Presume Competence: Lessons from Research on Autism

Sponsored by: Institute on Disability/ UCED UNH
Presenter: Douglas Biklen, Ph.D.
Date: February 5, 2004
Time: 9 am –3 pm
Where: Highlander Inn – Manchester, NH
Cost: \$60
For more Information: Call 228-2084 or 1-800-238-2048

Developmental Disabilities & Sexuality: Working with Groups

Sponsored by: Planned Parenthood of Northern New England
Date: Wednesday, Feb 11, 2004
Time: 9 am – 4 pm
Where: Concord, NH
Cost: \$90
For more Information: Call 1-800-488-9638 or EDUCATION@PPNNE.ORG

March

Central Regional Ski Marathon

Sponsored by: Special Olympics NH
Date: March 7, 2004
Where: Ragged Mountain, Danbury, NH
For more Information: Call 1-800-639-2608

Positive Supports for Children with Autism in Preschool Classrooms

Date: March 25
 (See December 10 for description.)

State Basketball Tournament

Sponsored by: Special Olympics NH
Date: March 27-28, 2004
Where: Portsmouth NH
For more Information: Call 1-800-639-2608

April

Seacoast Regional Swim Meet

Sponsored by: Special Olympics NH
Date: April 17, 2004
Where: Portsmouth and Dover, NH
For more Information: Call 1-800-639-2608

May

Positive Supports for Children with Autism in Preschool Classrooms

Date: May 11, 2004
 (See December 10 for description.)

June

Positive Supports for Children with Autism in Preschool Classrooms

Date: June 3, 2004
 (See December 10 for description.)

35th Annual Summer Games

Sponsored by: Special Olympics NH
Date: June 11-12, 2004
Where: University of NH Durham, NH
For more Information: Call 1-800-639-2608

Access '04

Sponsored by: Granite State Independent Living
Date: June 18 & 19, 2004
Where: Whittemore Center at UNH, Durham NH
Cost: Free
For more Information: Call 1-800-826-3700

Education "Boot Camp" Offered

Education-A-Must, a NH-based education advocacy agency, is proud to host the founders of Wrightslaw.com, Peter and Pamela Wright, for their only 2004 workshop appearance in New Hampshire. Parents, teachers, attorneys, advocates and special education professionals, will have access to the best minds in the field of special education law in a two-day intensive 'boot camp' program.

Conference participants learn how to use special education statutes and regulations to get answers to questions; how to use tests and measurements to measure educational progress and graph out test scores; how to write SMART Individualized Education Plans (IEPs), goals and objectives; and how to use tactics and strategies to get appropriate special education services.

Attorney Peter Wright, and his wife, Pamela Wright, who is a licensed clinical social worker and psychotherapist, have written two special education law books, titled "Wrightslaw: Special Education Law" and "Wrightslaw: From Emotions to Advocacy". Their well-visited website, www.wrightslaw.com, has a bounty of information intended to demystify the complexities of education law and teach parents how to advocate for their child.

The Wrightslaw Boot Camp session will be held on March 26 & 27, 2004 at the Best Western Executive Court Inn and Conference Center in Manchester, NH.

To register for this event, contact Education-A-Must at: www.education-amust.com. The registration fee for this conference is \$225 per person, or \$205 per person, if the registration is received prior to January 15, 2004. The conference also provides 12 CLE & CLU credits for professional certifications.

Educational Surrogate Parent Training Program

If you would like to make a real difference in the life of a child with a disability, please consider becoming an Educational Surrogate Parent. Volunteers are **urgently** needed to represent the special education interests of children with disabilities who do not have parents to serve in the capacity. Surrogate Parents are only responsible for representing their assigned child in the special education process, not for the child's daily care, maintenance or support. All participants will be provided with a FREE training and an extensive resource manual. For more info, contact: Parent Information Center at 603- 224-7005 or 1-800- 232-0986 or at www.parentinformationcenter.org.

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

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/Respite coordinator:

Lena Parent 752-1005 x 3343 lparent@nnhmhds.org

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

Colebrook/Groveton -

Family support /Respite and respitality coordinator/Legislative liaison/Parent to

Parent coordinator: Stacey Bilodeau 636-6193 x 3558, or

(800) 862-8634 x 3558 sbilodeau@nnhmhds.org

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

Littleton -

Family support /Respite coordinator:

Diana Flick 444-5358 x 3460 dflick@nnhmhds.org

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 **e-mail:** mmills@dsscofnh.org

Case Management: 542-8706

Adult Services: 542-8706

Family support coordinator/Respite coordinator/Legislative liaison:

Jean Warner 542-8706 jwarner@dsscofnh.org

Early supports and services: Kathie Sarles, 542-8706 x135 ksarles@dsscofnh.org

Benefits technician: Rhonda Desmarais 542-8706 x114 rdesmarais@dsscofnh.org

Family support council chair: Lilly Barton 835-2523

Q/A complaints: Mark Mills (as above)

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@lrcsc.org

Website: www.lrcsc.org

Family support coordinator: Christine Santaniello 524-7755

chriss@lrcsc.org

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

Benefits technician: Lisa Richardson 524-8811 richardson@lrcsc.org

Legislative liaison: Chris Collier 536-1884 chriscollier@earthlink.net

Family support council chair: Susan Gunther 528-1713

smgunther51@juno.com

Complaint investigator: Peter Bacon 524-8811

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.communitybridgesnh.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

Legislative Liaison and Parent-to-Parent coordinator:

Becky Thompsom 225-4153 or (800) 499-4153, ext. 241

bthompson@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

Director of service coordination: Sheila Mahon 352-1304

julie@mds-nh.org

Director of childrens' service coordination: Julie Cashin 352-1304

julie@mds-nh.org

Director of adult service coordination: Beth Staudt 352-1304

beth@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/Family support council chair:

Larry Butcher 357-8383 lgbutcher@aol.com

Family support council vice-chair: Danette Downing 355-0152

ddowning@co.cheshire.nh.us

REGION VI Nashua

The Area Agency of Greater Nashua, Inc.

144 Canal Street, Nashua, New Hampshire 03064

Sandra Pelletier, exec. dir. Direct Phone line: 459-2701

E-mail: spelletier@region6.com

Beth Raymond, assoc. dir. Direct Phone line: 459-2704

E-mail: braymond@region6.com

Phone: 882-6333 **Fax:** 889-5460

Website: www.region6.com

REGION VI Nashua (continued)

Family support coordinator: Nzenalu Obinelo 459-2749
nobinelo@region6.com
Partners in Health family support coordinator: Nancy Lucci
 459-2744 **Fax:** 889-5460 nlucci@region6.com
Respite coordinator: Christie Arnold 459-2705 carnold@region6.com
Benefits technician: Diane Luszey 882-6333 dluszey@region6.com
Intake coordinator: Sue Rockwell 459-2730 srockwell@region6.com
 Ramona Burgess 459-2712 rburgess@region6.com
Director of QI - service coordinator supervisor: Jennifer Boyer 459-2715
jboyer@region6.com
Legislative liaison: Bob Mackintosh 459-2746 bmackintosh@region6.com
Family support council chair: Peter Marcoux 888-5894
pmarcoux@verizon.net

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

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 206-2855
joe.rojek@moorecenter.org

Community Liaison/Respite coordinator:
 David Johnson 206-2743 david.johnson@moorecenter.org

Early supports and services: Celeste D'Innocenzo 206-2761
celeste.d'innocenzo@moorecenter.org

Benefits technicians: Linda Lawrence 206-2768
linda.lawrence@moorecenter.org
 Audrey Mason 206-2770
audrey.mason@moorecenter.org

Legislative liaison: Ilene Wheeler 206-2754 ilene.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 **E-mail:** bob@cdsregion8.org
Cathy King, associate executive director
Phone: 436-6111 **Fax:** 436-4622
Family support and early supports and services: Lenore Sciuto 436-6111
lenore@cdsregion8.org
Children's support coordinator: Mary Dawn Corey 436-6111
mary@cdsregion8.org
Adult support coordinator: Pam Raley 436-6111 pam@cdsregion8.org
Resource coordinator: Mandy Thibodeau 436-6111, x 334
mandy@cdsregion8.org
Respite coordinator: Geoff Simons 436-6111 geoff@cdsregion8.org
Benefits technician: Denise Larsen 436-6111 denise@cdsregion8.org
Legislative liaison: Sally Weiss 463-7104 sallyaweiss@hotmail.com
Family support council chair: Kathy Ennis 964-9740
Kennis@northeastrehab.org

REGION IX Strafford County**Community Partners**

Forum Court, 113 Crosby Road, Suite #1, Dover, New Hampshire 03820-4375
Brian Collins, exec. director **E-mail:** bcollins@bhdssc.org
Phone: 749-4015 **Fax:** 743-3244
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 Picard 749-4015 jbatchelder@bhdssc.org
Legislative liaison: Hugh Philbrick 749-4015 hphilbrick@bhdssc.org
Partners in Health coordinator: Sarah Small 749-4015 ssmall@bhdssc.org
Complaint investigator: Lee White 749-4015 lwhite@bhdssc.org
Family support council chair: Chuck Raymond 743-3909
chuck.raymond@comcast.net
Family support council vice-chair: Karen Salter 692-2088
ksalter643@aol.com

REGION X Atkinson/Salem**Region 10 Community Support Services, Inc.**

8 Commerce Drive, Atkinson, New Hampshire 03811
Jane Dichard, exec. director **E-mail:** jdichard@region10nh.com
Phone: 893-1299 **Fax:** 893-5401
ebsite: www.region10nh.com
Family support coordinator: Kathy Waterson 893-1299
kwaterson@region10nh.com
Respite coordinator: presently vacant
Early supports and services: Aleece Pappas 893-1299
pappas@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 382-1925
MrsBto3@hotmail.com

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 52
 or (800) 290-0905 cmacdonald@centerofhope.org
Respite coordinator: Lindelle Gorham 356-6921 x26
lgorham@centerofhope.org
Benefits technician: Same
Legislative liaison: Marti Shedd 447-4723 mshedd@centerofhope.org
Family support council chair: Peg Cade 539-7869
Family support council co-chair: Dana Pearson 284-6463
blumlrpd@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 443-4132
Kathy@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 bobbigross@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 448-1268
respitcare@valley.net
Partners in Health coordinator: Katie Ouelette 603-448-7108 pih@uvsg.org
Human Rights complaints: Andrew Forbes 443-4124 andy@uds.org



Where to Find Help Statewide Resources

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

NH-ATEC
67 Communications Drive
Laconia, NH 03246
1-800-932-5837
Lorraine Halton, Clinical Director
E-mail: lorraineh@atechservices.org
Provides highly specialized evaluations and consultations in the area of assistive technology: Seating & wheeled 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
Donna Furlong, Admin. Assist
E-mail: dfurlong@nhaat.mv.com
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
603-224-7630 or
1-800-427-3338
Paul Luff, Coordinator
E-mail: pluff@nhaat.mv.com
website:
www.nhassistivetechology.org
Sale of quality refurbished equipment; Rentals, service & repair; Information & referral services; Inventory on website

TEC Exploration Center
117 Pleasant Street
Dolloff Bldg.
Concord, NH 03301
603-226-2900
Lee Benoit, Technician COTA/L
E-mail: lbenoit@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
603-225-8400, or
1-800-773-8400
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
603-271-4488, 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
78 Regional Drive, Bldg. 2
Concord, NH 03301
603-271-3471 (V/TTY)
or 1-800-299-1647
Fax: 603-271-7095
E-mail: dlebrun@ed.state.nh.us
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 Dartmouth-Hitchcock Medical Center
603-650-7884

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
603-271-4991 or
1-800-852-3345 X4991
Fax: 603-271-5166
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
603-271-3741
Fax: 603-271-1953
E-mail: braymond@ed.state.nh.us
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 (V/TTY)
Fax: 603-225-2077
E-mail: advocacy@drenh.org
website: www.drenh.org

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 & support to promote best practices in early intervention and early childhood/special education

Family Resource Connection
603-271-6826 or
1-800-298-4321
E-mail: FRC@library.state.nh.us
Website: www.state.nh.us/nhsl/frc/
Free, statewide program of NH StateLibrary 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 guardianship, protective and fiduciary services to incapacitated residents of NH

Granite State Independent Living (GSIL)
21 Chenell Drive
Concord, NH 03302-9680
603-228-9680, (V, TTY)
1-800-826-3700(V/TTY)
Fax: 603-225-3304
E-mail: erica.marden@gsil.org
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, accessibility services, and deaf and hard of hearing services.

Institute on Disability/UCED (Concord office)
Phone: 603-228-2084 or
1-800-238-2048
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.

NAMI-NH - Alliance for the Mentally Ill of NH
15 Green Street
Concord, NH 03301
603-225-5359,
or 1-800-242-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.

NH Association for the Blind
603-224-4039 or
1-800-464-3075
E-mail: services@sightcenter.com
www.sightcenter.com

Provides information and gives direct services to people of all ages who are blind and visually impaired 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
603-271-4525, 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



Where to Find Help Statewide Resources

Continued from page 22

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 Hewitt Hall
4 Library Way
Durham, NH 03824
603-862-0070
TTY-NH 1-800-735-2964
TTY-ME 1-207-955-3323
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
10 White Street
Concord, NH 03301
603-224-8041
E-mail: info@opgnh.org
website: www.opgnh.org
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
12 Flynn Street
Lebanon, NH 03766
1-800-698-5465
www.parenttoparentnh.org
E-mail: contact@p2pnh.org
Specializes in networking parents of children with special needs; support and information

People First of NH
4 Park Street, Suite 201
Concord, NH 03301
603-568-2128,
or 1-800-566-2128
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 IOD/UCED
312 Morrill Hall
Durham, NH 03824
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
650 Elm Street
Manchester, NH 03101
603-624-1250
or 1-800-639-2608
Fax: 603-624-4911
website: www.sonh.org
Provides sports opportunities for athletes with developmental disabilities.

"Talking Books"
NH State Library Services to Persons with Disabilities
117 Pleasant Street
Concord, NH 03301
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
44 South Main Street
Concord, NH 03301
603-228-4330 (V/TTY)
Fax: 603-225-7240
E-mail: info@vsartsnh.org
website: www.vsarts.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:
Community Partners
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

New Parent Group Forms in Lakes Region

A newly formed parent group, PAUSE - (Parents Actively United for School Excellence), will be meeting on the 2nd Thursday of every month in the Sun Room at The Memorial Hospital in North Conway from 6:00 PM to 8:00 PM.

PAUSE is a group of parents organized to promote understanding and awareness throughout the community and within the public education system for individuals with special needs or differences in learning.

If you have interest or would like to learn more, please join us, refreshments will be served. If you have any questions or would like to be on our mailing list please contact: Marti Shedd at 447-4723; Penny Richards at 447-2615; Jennifer McPherson at 447-6397; Jane Stacey-Merrill at 447-6566 or Lisa Ingemi at 447-6511.

*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*

NH Community Mental Health Centers

Region I

Northern NH Mental Health and Developmental Services

Dennis McKay, executive director
Eric Johnson, deputy director
CMHSA Contact: Joan Galbraith
87 Washington Street
Conway, NH 03818

Phone: 603-447-3347

Fax: 603-447-8893

website: nnhmds.org

Region II

West Central Behavioral Health Services

Jesse Turner, executive director
CMHSA Contact: Chris Wagner
2 Whipple Pl., Suite 202
Lebanon, NH 03766

Phone: 603-448-0126 or

1-800-540-0126

Fax: 603-448-0129

website: www.wcbh.org

Region III

GENESIS Behavioral Health

Michael Coughlin, executive director
CMHSA Contact: Dawn LaCroix
771 N. Main Street
Laconia, NH 03246

Phone: 603-524-1100

Fax: 603-524-0760

website: genesishb.org

Region IV

Riverbend Community Mental Health Center

Dale Klatzker, executive director
Bret Longgood, chief operating officer
CMHSA Contact: Mary Lee Carley
70 Pembroke Road
Concord, NH 03301

Phone: 603-228-1551 or

1-800-852-3323

Fax: 603-225-2803

website: riverbendmhc.org

Region V

Monadnock Family Services, Inc.

Kenneth Jue, executive director
CMHSA Contact: Diane Freitas
64 Main Street, Suite 301
Keene, NH 03431

Phone: 603-357-6678

Fax: 603-357-6896

website: mfs.org

Region VI

Community Council of Nashua, Inc.

Zlatlo M. Kuftinec, MD, executive director, medical officer
Carol Farmer, deputy director
CMHSA Contact: Patty Prince
7 Prospect Street
Nashua, NH 03060

Phone: 603-889-6147 or 1-800-762-8191

Fax: 603-883-1568

website: ccofnashua.org

Region VII

The Mental Health Center of Greater Manchester

Peter Janelle, executive director
William Rider, chief operating officer
CMHSA Contact: Debbie Campo
401 Cypress Street
Manchester, NH 03103

Phone: 603-668-4111

Fax: 603-669-1131

website: mhcgm.org

Region VIII

Seacoast Mental Health Center, Inc.

Jay Couture, executive director
Erik B. Johannessen, deputy director
CMHSA Contact: Tammy Spear
1145 Sagamore Avenue
Portsmouth, NH 03801

Phone: 603-431-6703

Fax: 603-430-3753

Region IX

Community Partners

Brian Collins, executive director
CMHSA Contact: Patricia Turner
(749-3244)

113 Crosby Road, Suite 1

Dover, NH 03820

Phone: 603-749-4015

Fax: 603-743-3244

website: www.dssc9.org

Region X

CLM Behavioral Health Systems

Victor Topo, executive director
CMHSA Contact: (information not available)

Salem Professional Park

44 Stiles Road

Salem, NH 03079

Phone: 603-893-3548

Fax: 603-898-4779

website: centerforlifemanagement.org

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 Dr., 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



Lovely Embroidered Golf, Denim & Sweat Shirts
Embroidered Canvas Book / Tote Bags
Embroidered Autism Awareness Holy Bears
Autism Awareness Ribbons ~ Golf Towels
WE DO SPECIAL ORDERS
GOLF TOURNAMENTS, SPECIAL EVENTS OR PERSONALIZING
Helping Raise Autism Awareness ... One Stitch At A Time

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>

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.cms.hhs.gov

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

www.csni.org

Community Support Network, Inc.

www.dhhs.state.nh.us

NH Department of Health and Human Services - information on benefits programs

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.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

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

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

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 \$17.50 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

For Sale:

Jet 3 motorized wheelchair; excellent condition; 1 1/2 years old; \$4,500 new, asking \$2,000 or best offer. Call Phyllis at 603-679-2909 and leave message.

Support People First of NH While You Shop!

The website of People First of NH now features online shopping to support their non-profit organization. Shop online from the People First website to Amazon and Current Fundraiser. In addition, they are offering a new site where shoppers can purchase from a variety of shops. This new site has daily deals and discounts. It will provide shoppers with lots of opportunities to shop online at their favorite stores while People First of NH will receive up to 40% of the purchase. Visit their website at www.peoplefirstofnh.org for a shopping spree, or, go directly to their Green Page at www.peoplefirstofnh.org/online_fundraising_for_people_fi.htm

All-ways  Accessible supports the New Hampshire Challenge!

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Friday January 16, 2004
 10:00 a.m. to 3:00 p.m.
 Wayfarer Inn
 Bedford, New Hampshire

Disability Town Hall Meeting

Breaking Down the Barriers to Employment of Persons with Disabilities

Who will be there: Governor Criag Benson
 Other Statewide Policy Makers

Who should attend: People with Disabilities
 Policy Makers
 Providers of Employment Services
 Employers

The candidates for President are invited to attend.

For more information about this meeting, please contact Granite State Independent Living at:
 603-228-9680
 1-800-826-3700 TTY 888-396-3459



Spread the Word!

Do you know someone who could use The Challenge?

Name _____

Street address _____

City _____

State _____

Zip _____

Phone _____

Please send this form to:
 The New Hampshire Challenge
 P.O. Box 579
 Dover, NH 03821-0579

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