

# The New Hampshire Challenge

disability issues from a family perspective

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## Down On The Farm

*Another option? Or a step backward?*



Deborah Gray wanted a different future for her son Andrew, who has autism, than what she saw offered by the service system. Her plans to create a farmstead for 40 people with autism and other developmental disabilities have sparked controversy within the disability community. Is she promoting an individual's right to self-determination, as she claims? Or is she setting the stage for a return to institutional living, as others fear? Read our interview with Deborah Gray and reactions from area agency directors on pages.....

**Photo: E. G. Stone**

**by: Janet M. Krumm**

When Deborah Gray's son Andrew was 8 years old, she started wondering what was going to become of him. "I sat down one night," she remembered, "and just started thinking and could see, even at that stage in his life, that competitive employment just wasn't going to be an option for him."

Andrew has a metabolic disorder that

causes severe mental retardation, according to Deborah, as well as autistic-like behavior. Now 19, Andrew experiences some significant challenges. "His gross motor skills are at the high end (as is his) receptive language," she explained, "but he's non-verbal and has very little expressive language in terms of signing or anything. He just uses some idiosyncratic gestures. And he's very easily over-

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## Budget Wish List Submitted

**Contains requests for what is truly needed**

**by: Janet M. Krumm**

Dennis Powers has submitted a "wish list" budget to the Department of Health and Human Services that includes all the funding that is actually needed to provide services.

Those proposed expenditures include:

\* \$17.8 million dollars of state funds for the wait list over the next two years. This money would be matched with \$17.8 million from the federal government.

\* \$800,000 increase for Early Supports and Services.

\* \$1.1 million increase in family support funds

\* 4.4% increase for area agencies and 1.6% increase targeted to home care providers

\* \$875,000 for the next fiscal year for ten individuals who will need forensic services

\* \$2.5 million for individuals with brain injuries on the wait list for services

The \$35.6 million for the wait list will serve the 345 people with developmental disabilities who are on the priority 1 wait list for services. Individuals on the priority 1 list are those whose needs are "pressing, immediate," according to Bob James, executive director of Community Developmental Services in Region VIII.

"There was no waiting list money last year," James stated, "and the year before, only 1/5 of the amount

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## Check out our new web site!

We have re-designed our web site to make it easier for you to access all the information we publish in each issue of our newspaper. It is easy to navigate and has links to all the resources listed in each issue. Visit us at [www.nhchallenge.org](http://www.nhchallenge.org). We think you'll like what you see.

### In this issue:

Peer support helps those with mental illness and their families

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# This is just the first step in a long process.



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#### Editor:

Janet M. Krumm  
(603) 742-0500  
(800) 758-6430  
Fax: (603) 749-0981  
email:

nhchallenge@attbi.com

#### Website:

www.nhchallenge.org

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that was needed was allocated." Allocated funds go to those individuals whose needs are life-threatening, James explained, so those individuals whose needs are not so acute end up on a waiting list. "Young adults out of high school, instead of coming out to an enhanced family system, are finding that there's nothing there," he added.

There are actually 3 priorities on the wait list, according to James. Priority 2 is a list of those individuals who are expected to need services in the future. It's a way to identify those individuals and plan for them, he explained.

Priority 3 includes those people who are now receiving some services, "people who live at home in a difficult family situation, but they are stable and okay right now," James said. "They're not in a good situation, but it's not life-threatening.

"Or people whose needs have increased, and we need to put more money into the situation. They're still holding together, but gradually things are becoming more stressful."

If these kinds of situations are not addressed, James continued, a crisis develops. "I've got Priority 3 people who are very frustrated," he acknowledged. "Their situations are inadequate but not life-threatening."

## ESS

Early Supports and Services (ESS) is a federal program that provides evaluation and services to children from birth to three who either have a disability or are at risk of developing one. "In the last two years" Powers explained, "there have been significant losses in the system primarily through ESS.

"It is a federal entitlement program," he added. "There's a relatively small amount, about a million and half dollars in federal supports that come into the state to support kids under Part C (of the Individuals with Disabilities Act), and that amount hasn't changed since the entitlement program

started." This is the reason for the increase requested by Powers.

The division is addressing this added cost in other ways, too. "We've been looking at other sources of revenue," Powers indicated. "This past July, we've raised the Medicaid rate that we pay area agencies for kids who are Medicaid eligible under ESS and we've also been encouraging them to use private insurance that families might have whenever possible."

The area agencies have seen a huge increase in the number of children eligible for ESS in the last few years, Powers explained, because of the successful efforts of Child Find "to make sure that families and practitioners understand that the service is there."

Recently, the division has proposed changes in eligibility for ESS "that would raise the delay threshold for children in early intervention from a 25%

the thought was that by raising the eligibility criteria, that we hopefully aren't going to be excluding any kids who have significant delays."

Those proposed changes are presently in the rules-making process.

## Family Support

The increase in family support funds is warranted by the increase in the number of families needing family support. "We put that in because we've had an increase of about 900 families statewide since the last family support allocation," Powers explained. Family support funds are flexible, providing support for families to keep their sons and daughters at home. These supports are crucial to families whose children are on the waiting list.

"We wanted to make sure that we acknowledged the fact that the area agencies and

cost for their services is typically much higher. Because their needs are so pressing, these individuals rise to the top of the waiting list very quickly, displacing others who may have been on the list for awhile.

And the expenditures for their services are high, reducing significantly the amount of money for those needing more typical community based services.

Every year, the legislature has failed to allocate additional money for forensic services, so the money for these services has come out of the money allocated for the wait list. "What we tried to do this year," Powers explained, "was to break out the people on the waiting list who have forensic needs from the general group of people on the waiting list."

"Our request was \$875,000 for the next fiscal year," he said. "We identified ten people who we felt had those kind of needs. Our hope is that by separating that out as a distinct group on the waiting list, that we can begin to educate legislators to the fact that there really are two distinct populations we're trying to serve."

I think the legislature understands on some level that this group of people

tends to rise to the top of the waiting list and get services quicker than other people," Powers stated, "and that the costs associated with people who have forensic needs are higher than someone typically on the waiting list.

"I don't think they've been able to figure out how to solve that particular dilemma," he added.

## Brain injury wait list

Last year, as the result of a class-action lawsuit filed by the Disability Rights Center, the State was ordered to provide services for individuals with brain injuries who were on the wait list for services as of De-

## Budget

*"I give (Dennis) Powers credit for putting down all the categories that are needed in the budget. People are going without services now."*

*-Bob James, executive director, Community Developmental Services*

to 33% delay," Powers stated. "It would be narrowing the eligibility for kids in ESS."

Prior to initiating the process to change the eligibility requirements, the division did a survey of other states' eligibility criteria. "We found that we had very liberal eligibility criteria, 25% delay," he said. "A lot of states have as high as 50%, you have to have 50% delay. So we felt that by going to 33%, we were hoping that we're not excluding any kids who really need those kinds of supports.

"What we're finding," he added, "is that a large percentage of kids who go through ESS are not eligible for area agency services because they don't have the level of disability necessary to make them eligible for services. What we're finding is that a large number of kids in ESS have somewhat mild language delays. And so

family support councils have been supporting a lot more families on the same amount of dollars."

## Providers

The 4.4% increase for area agencies represents an increase in the amount of money for existing services, which have seen no increase in the past ten years. In addition to that, the division asked for a 1.6% increase in funds for home care providers, which the division considers its most cost-effective residential service model.

## Forensic services

Individuals who pose a risk to themselves and/or the community need more specialized, forensic services. Typically, these are individuals who have had encounters with the criminal justice system and the

*Continued on page 3*

## Project Seeks Alternative to Guardianship

This 2-year pilot project is based on an alternative to guardianship used in several European countries, in particular Sweden, which has systematically replaced most of its existing 17,000 guardianships with “good men.” The model is based on the notion that many people don’t require a guardian so much as they need someone to help them make better, more self-directed decisions. Mentorship differs from guardianship in three critical respects. First, participants with mentors lose none of their civil rights. Second, the mentor model is voluntary. Third, and perhaps most important, the model assists persons to make more informed decisions which permit more control over how they live their lives.

Each of approximately 20 individuals in Rockingham County who meet the criteria for participation (see below) will be paired with a trained mentor who will provide suggestions and feedback about decisions facing that individual. The mentor’s goal will be to provide “assisted competence” that effectively eliminates the need for guardianship and its associated restrictions.

Staff from Area Agencies 8 and 10, the Division of Developmental Services, and guardianship agencies will identify individuals with developmental disabilities who are candidates to participate, namely persons who (a) are clients of an area agency and have a case manager from that agency, (b) have financial resources that can be managed adequately by the proposed individuals and/or with the assistance of a representative payee, (c) do not have an existing health condition that requires anything beyond routine medical decision-making, (d) need someone to offer advice and guidance rather than exercise directive powers, and (e) are amenable to a mentor relationship.

Mentors will be selected based on the following criteria: (a) passing a criminal record check, (b) willingness to work an average of 10 hours a month (two hours a week) with a person with a developmental disability to assist him/her in the process of developing independent decision-making skills, (c) commitment to each person’s right to self-determination, (d) being a member of the community in which the participant lives and works, (e) familiarity with the human service system, if possible, (f) not being the individual’s relative or residential provider, (g) willingness to assist the individual with his/her finances, (h) willingness to attend all required training, supervision, and peer support meetings; and to complete monthly progress reports, and (i) willingness to complete satisfaction surveys and other methods of project evaluations. Mentors will receive \$100 a month stipend to cover incurred expenses.

After the second year the plan will be to introduce mentorship into the rest of NH with the goal of establishing this model as the preferred choice over guardianship whenever possible.

**For more information about the project, including becoming a trained mentor, please contact:**

Robin Daning, Project Director  
Mentors for Informed Choice  
rdaning@email.com  
893-1299 ext. 334 (Region 10, Atkinson)  
224-5588 ext. 20 (Granite Bay Connections, Concord)

### Budget

*Continued from page 2*

December 10, 2001. The division anticipates that sixty additional people who came onto the wait list after December 10 will also need services. The \$2.5 million dollar request in the budget includes continued funding for services already being provided as well as funding for new services for those expected to need them during the next biennium.

### First step in a long process

“I give Powers credit for putting down all the categories that are needed in the budget,” James stated. “People are going without services now.”

Powers is quick to remind everyone, however, that this budget is not a final product. “I think it’s important for

people to understand that the budget we submitted now has a whole lot of hoops to go through,” he stated. “We’ve submitted this to the department of health and human services.

“The first Governor’s budget meeting was (the third week of November). The sense was that everybody’s talking about a 3% budget,” he explained. “Even though we weren’t given those specific marching orders, it appears that the Legislature and Governor-elect Benson are talking more in that range.

“So what will happen is that the budget will be revised numerous times, first by Governor Benson once he takes office. He’ll construct his budget based on what he sees as the state priorities, and then his budget will be submitted to the Legislature.

“What we’ve done,” he said, “is to make sure that in our

initial budget submission, we had everything that we think would be needed to fund the system. Then as it goes through the process, most likely that’ll be honed down.

“What I keep hearing from legislators is that they’re still struggling to solve the education funding crisis. Even at the waiting list oversight committee, when they were asked by a family member what they were proposing to do with our requests, they brought up the Claremont situation, and the fact that they’re still struggling to fund not only education but other competing human service needs.”

Given the changes in both the Governor’s office and the legislature, no one is willing to predict what will happen with the budget this year. One thing remains constant, however. Advocates need to make their voices heard.

## Project Will Support Youth with Disabilities Leaving the Juvenile Justice System

DURHAM – A four-year project at the University of New Hampshire will work to create a system of supports and services to help youths with disabilities whose school and community participation has been or would otherwise be disrupted due to delinquent behavior.

*School and Community Reentry for Juvenile Offenders with Disabilities* is a collaborative project of the Institute on Disability and Justice Works at the University of New Hampshire and the Alliance for Community Supports, funded by the U.S. Dept. of Education for \$180,000 per year for four years.

Guided by a Steering Committee of state and local agency representatives, the project will assist 60 participants in Nashua, NH, to complete high school, obtain initial work experience, develop a futures plan, and achieve a stable living situation and system of community supports.

Led by co-directors David Hagner, Ph.D., of the Institute on Disability and Michael Skibbie, J.D., of Justiceworks, the project will work to: increase the percentage of youth offenders with disabilities who progress satisfactorily to high school graduation; engage participants in a self-directed planning process to identify personal career plans, and; increase the capacity of schools and community organizations to provide effective supports to juvenile offenders with disabilities.

*The Institute on Disability’s mission is to promote the inclusion of people with disabilities into their schools and communities. 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 Center for Genetics and Child Development at Dartmouth Medical School; the Institute for Health, Law, and Ethics at Franklin Pierce Law Center; and the Center for Community Economic Development at Southern New Hampshire University comprise New Hampshire’s University Center for Excellence (UCE).*

*For more information, visit the Institute on Disability’s Web site at [www.iod.unh.edu](http://www.iod.unh.edu).*

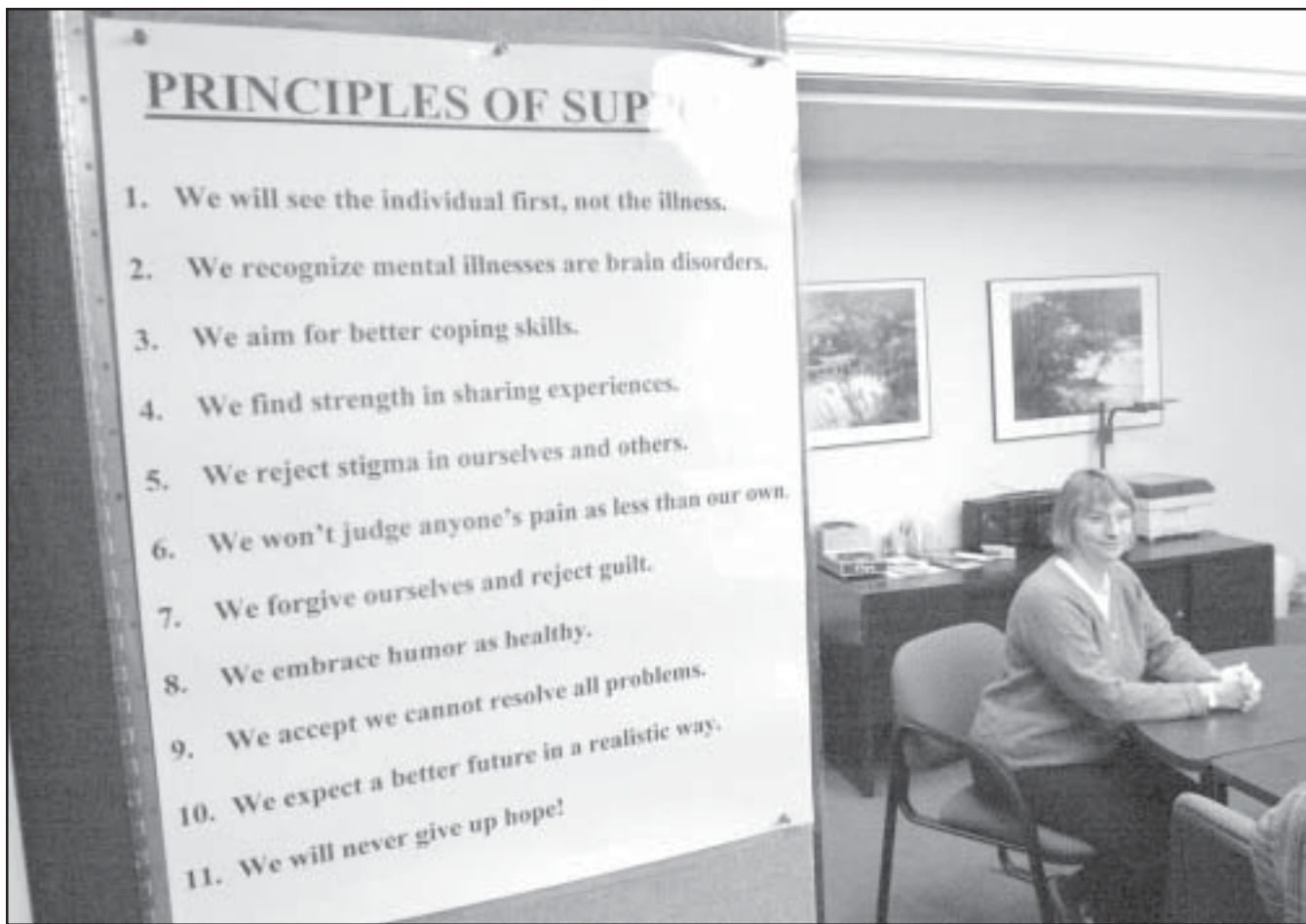
*Justiceworks is an applied research consortium of academics, criminal justice professionals, and policymakers who work collaboratively to address timely and pressing issues in crime and the administration of justice. Founded in 1999 at the University of New Hampshire to extend the institution’s land grant mission to the criminal justice system, Justiceworks has three main missions:*

§ *Provide accessible, timely, and affordable evaluations of state and local programs aimed at minimizing crime and delinquency,*

§ *Provide useful and current information about crime and crime control strategies to planners, policy makers, and those working within or interested in the field of criminal justice, and*

§ *Develop and provide new training opportunities in criminal justice to multiple audiences within the justice system in the region. Those opportunities include but are not limited to workshops, seminars, graduate coursework, and web-based distance learning in both real and asynchronous time.*

*For more information about Justiceworks, visit its Web site at: [www.justiceworks.unh.edu](http://www.justiceworks.unh.edu).*



**Jackie Ellis is a co-director of a regional support group for the New Hampshire chapter of the National Alliance for the Mentally Ill.**

**The group she facilitates meets on the second and fourth Thursdays of the month at Seacoast Mental Health Center on the Exeter Hospital grounds. Jackie Ellis can be reached at 431-1512.**

*Photo: E.G. Stone*

## Seacoast NAMI: What's it all about?

*Mental illness is a subject that not many people like to talk about, especially if it involves a member of their family. Jackie Ellis, a co-leader of S-NAMI (Seacoast National Alliance for the Mentally Ill), spoke with The Challenge about the importance of peer support for family members of those with a mental illness.*

*Interviewer: Shelley Fardelmann*

### **What is S-NAMI?**

It is a chapter of a national organization that provides support and education to families of people and people with major mental illnesses. NAMI is about 20 years old, its a grassroots organization that offers education, support and works as a lobbying group. It was started by a group of mothers who felt frustrated at not having help or support, and having to deal with the enormous stigma at the time. Peggy Straw, who was a leader of NH-NAMI, was one of the founding members.

### **What are its purposes and goals?**

Its purposes are to provide support to families and education—where you can go to get help when dealing with a family member with mental illness. It can direct you to resources in the community.

### **What drew you to S-NAMI? Why did you get involved?**

Because I have an adult child with a major mental illness.

### **How old is he? How well does he function in the world?**

He is 23. He does pretty well. He has an associates degree in culinary arts and he works. He lives with his dad.

### **Do you have a good relationship?**

Yes, a very good one.

### **When did he become ill?**

Midway between his freshman year in college in 1997.

### **Did you know where to go to get help?**

Yes and no. I knew to get him to the Ports-

mouth Pavilion. Beyond that it was all new territory.

### **How long was he hospitalized?**

Many months. At New Hampshire Hospital for the most of it. It was horrible.

### **How has it been helpful for you and your family to be involved with S-NAMI?**

For a lot of reasons. When I first went to the meetings I was in the information gathering stage. I'd get information on meds, lawyers, doctors, books, reference books.

### **Did you get emotional support?**

Yes, definitely.

### **When did you decide to become active in the group?**

After a couple of years of regular meetings, I had the opportunity to take a teacher training program to teach a course called Family To Family which is a NAMI sponsored 12 week course for family members. David was very sick at the time. I was doing it to help myself. So I took the course. It covers 5 major mental illnesses and talks about coping with family members, learning to empathize, how to take care of your own needs. I took the course to become a teacher—it is a commitment to teach two 12 week sessions. Then NAMI offered training to become a support group leader. And so I took that. After I took the training I agreed to co-lead our twice monthly meetings.

### **What services do you provide to families and the public?**

We meet twice a month in Exeter for caring and sharing. At this point we are not offering regular outside speakers but we have had them on such topics as Social Security, housing, legal matters, such as setting up special needs trusts, and nutrition. We do have a psychiatrist who speaks at least twice a year on such topics as medications and research. People enjoy the caring and sharing. We also do support over the phone and have a small library of vid-

eos, books, and brochures. It's all open to the public.

### **What has S-NAMI and NH NAMI accomplished for people with mental illnesses and their families?**

Our group at this point doesn't do much lobbying. National NAMI does send us e-mails in the form of action alerts to let us know to contact elected representatives about benefit issues or pending legislation. One of the things NH-NAMI does is quality control of N.H. Hospital—informal walk throughs to insure that people are treated appropriately and that the facilities are clean. NH-NAMI organizes the Family To Family course. Probably sixty people have or are taking this course. Its been a great educational arm of the organization.

### **Looking to the future, what are the short and long term goals of S-NAMI?**

The short term goals are to get more regular guest speakers, at least once a month. The long term goals are more visibility in the community as an advocacy and stigma busting force.

### **What is being done to eliminate stigma?**

I think a big piece of it is education — letting people know that just because a person has schizophrenia doesn't mean that they are dangerous. The statistics show that people with major mental illnesses are no more likely to commit a crime than anyone else as long as they are on proper medications.

# Support Groups Make a Difference

by: Shelley Fardelmann

In a sunny storefront at 148 Front Street in Exeter, people's lives are quietly changing. This is the home of the Exeter Consumer Alliance. Years ago, its clients would be housed at New Hampshire Hospital or wandering on the streets. Yet today they have a place to come together with friends to hang out, take self-improvement classes, and learn to expand their life possibilities.

Peer support centers, of which the Exeter Alliance is a relatively new one, have been around for about 15-20 years. According to Shery Mead, a consultant on peer support and recovery in the mental health field, peer support evolved after the deinstitutionalization of the mid-sixties.

It was a reaction to human rights issues—people who had been in institutions were reporting human rights violations, shock treatments, restraints, seclusion and forced medication. The goal of the peer support movement was to help consumers advocate for themselves, and to develop a network of peer-to-peer support, said Mead.

The center in Exeter is a satellite of the Seacoast Consumer Alliance in Portsmouth, which opened about 10 years ago. Before the Alliance opened, many area mental health consumers were in a day program at Seacoast Mental Health Center. With Medicaid funding cutbacks projected at that time, the day program, called the Lighthouse, was predicted to close. Daniel Herring and Sharon Helps wrote the initial grants and got funding for the Portsmouth Alliance.

Eight years later, the center in Exeter has been opened for two years. A non-profit, it gets its funding through the Seacoast Alliance, according to Natalie Reid, who manages the center.

The center is roomy and comfortable, with a large living room and kitchen. There are a T.V. and two computers. The center is open now from 10:00 a.m. to 2:00 p.m. Monday, Tuesday and Thursday. It offers a number of groups to

help consumers make the bridge to recovery.

There are self-esteem groups, where people talk and encourage each other, life skills workshops that help people with socialization, hygiene and nutrition, self growth groups that teach G.E.D. and computer skills, and groups just for fun, such as crafts and creative writing. Charlotte Duquette, the manger of Seacoast Alliance in Portsmouth, commented that people who want to go to college, or get a job, can learn how to use a computer, or how to interview well.

The Alliances, both in Portsmouth and Exeter, are consumer-run, meaning that the people in charge also have a mental illness. At the present time, the managers have to have some college education, but according to Duquette, the job description is being changed to require experience instead. The good thing about having consumers as managers is, as Duquette put it, "It's their place."

Natalie Reid works at both Alliances, on different days of the week. She opens up, makes the coffee, and starts the groups. Sometimes she cooks lunch, other times people get take-out. Reid finds a lot of fulfillment in her job. "It's good for your self-esteem to have a pay-

ing job. It gives you something to look forward to each morning," she said.

The Alliance members have many activities to keep them busy. They go on day trips, such as to the White Mountains, have a weekly dinner in Portsmouth on Wednesdays, have picnics in the summer and seasonal holiday parties year round.

The Alliances are also a place where the homeless can come for companionship. Duquette said, "That's why I'm here at 6:00 in the morning. We give them a cup of hot chocolate."

Mary Hoyt, who has also worked at the Alliances, ob-

## When Someone You Love Has A Mental Illness A Handbook for Family, Friends, and Caregivers

By Rebecca Woolis, M.F.C.C

Reviewed by: Shelley Fardelmann

This book offers a practical approach to help families deal with the issues that come up when coping with a loved one who has a serious mental illness. The first two chapters provide information on understanding major mental disorders. The following chapters offer suggestions on how to handle daily problems that can crop up in the life of someone who is mentally ill.

The Quick Reference Guides throughout the book are especially helpful in dealing with the many difficult situations that can arise on a day-to-day basis. The book is easy to read and comes well recommended. The forward is written by Agnes Hatfield, Ph.D., a past president of the National Alliance for the Mentally Ill. E.Fuller Torrey, M.D., an expert in the field and author of *Surviving Schizophrenia*, says, "Ms. Woolis has produced a handbook which is both practical and accessible, eminently useful for all of us who have a family member with a serious mental illness."

served that the life skills classes are very important for consumers who are on the streets. "They often lose the ability to take care of themselves. Many peer support centers offer toothpaste, soap, and food, as well as the help with re-learning social skills," she said.

The long term goals of the Satellite center in Exeter are to be open every day, and to get more people in. Reid commented, "We want to reach more people in the community; we need to reach more people with mental illness."

The Exeter Consumer Alliance is still small, but it can grow to be as active as the Portsmouth center. For now it offers

a place where consumers can call home. As Hoyt observed, "People with mental illness have in many cases suffered the indignity of forced hospitalization, been locked on wards, had to deal with medication side effects, and the stigma of being different."

"In a peer support center you aren't different. The others have been where you've been. The shame is lessened, you can talk about it, and move forward with your life."

**For a list of support groups and community mental health centers, see pages 6 and 7.**



Photo: E.G. Stone

# Statewide NAMI meetings

## Area 1

### Berlin

Richard Laflamme  
MH Clinic#3 12<sup>th</sup> Street  
Berlin  
752-1005  
1st Weds. of month  
6:00-8:00 PM

### Littleton

Annette Carbonneau  
All Saints Parish House  
Littleton  
823-5374  
1st /Support & 3rd/Education  
Thursday  
7:00-9:00 PM

### Wolfeboro

Sandra Troendle  
Maplewood House, Bay St.,  
Wolfeboro  
569-4962  
3rd Weds. of month  
7:00-9:00 PM

## Area 2

### Claremont

Bud Ross  
West Central Services  
40 North St.  
Claremont  
543-3118  
3rd Monday of month  
6:00-7:30 PM

### Upper Valley

Ruth Bleyler  
RivermillComplex  
Mechanic St.  
Lebanon

795-9912  
ruth.bleyler@valley.net  
3rd Thursday of month  
5:30-7:30 PM

## Area 3

### Winnepesaukee

Tylaine Guariello  
Genesis  
111 Church St.  
Laconia  
293-8853  
tywho1@metrocast.net  
3rd Monday of month  
6:30-8:30 PM

## Area 4

### Concord

Patricia Nelson  
United Way  
46 South Main St.  
Concord  
228-1160  
2nd & 4th Monday of month  
7:00-9:00 PM

### PAMI

### Concord

Helen Guilderson  
NH State Hospital-Library  
Room  
224-5162  
2nd Sat. of month  
10:00AM-Noon

### Franklin

Temporarily not operating  
(Was Betty Bouchard, 286-7756)

## Area 5

### Keene-Cheshire

Sara Webb  
Monadnock Family Services,  
Room #117  
93rd Street  
Keene  
835-2890  
1st Monday of month  
6:30-8:30 PM

### Keene -Cheshire

Patti Szydlo  
MacMillian Building  
Elm St.  
Keene  
924-6540  
2nd Tues. of month  
7:00-8:30 PM

Nancy Bolton  
352-1067

### Peterborough

Rebecca Lawrence  
Monadnock Community Hospi-  
tal  
Old Street Road  
Peterborough  
563-9946  
2nd & 4th Thurs. of month  
7:30-9:00PM

## Area 6

### Nashua

Rita Moyer  
883-6919  
St. Francis Xavier Church Par-  
ish Meeting Rm  
41 Chandler St.  
Nashua

Sharon Murray-Block

N A M I N H -  
Nashua@attglobal.net  
2nd & 4th Tues. of month  
6:30-8:00PM

1st & 3rd Monday of month  
7:00-9:00 PM

Leo/Ellen LeBouthillier  
332-5433

## Area 7

### Manchester

Greater Manchester Mental  
Health  
401 Cypress St.  
Manchester  
Nancy Maguire  
644-6192  
maguire@grolen.com  
2nd & 4th Thurs. of month  
7:00-9:00PM

Gloria Johnson  
656-9081

## Area 8

### Seacoast

Ed Stewart  
Seacoast Mental Health Center  
bevvy@ttlc.net  
on Exeter Hospital Grounds  
772-4537  
2nd & 4th Thursday of month  
7:00-9:00PM

Jackie Ellis  
431-1512

## Area 9

### Dover

Shirley Varney  
Wentworth Douglas Hospital  
789 Central Ave.  
Dover  
742-7669

Fran Reynolds

332-1064  
[erafranr@msn.com](mailto:erafranr@msn.com)

## Area 10

### Salem

Candy McLaughlin  
Marion Gerrish Community  
Center  
39 W. Broadway  
Derry  
362-4407  
[candym@tiac.net](mailto:candym@tiac.net)  
Every Mon. of month  
6:00-7:30 PM

Salem Public Library  
234 Main St.  
Salem  
Every Thurs. of month  
10:30-Noon

### Additional Resource Group

### Bipolar Support Group

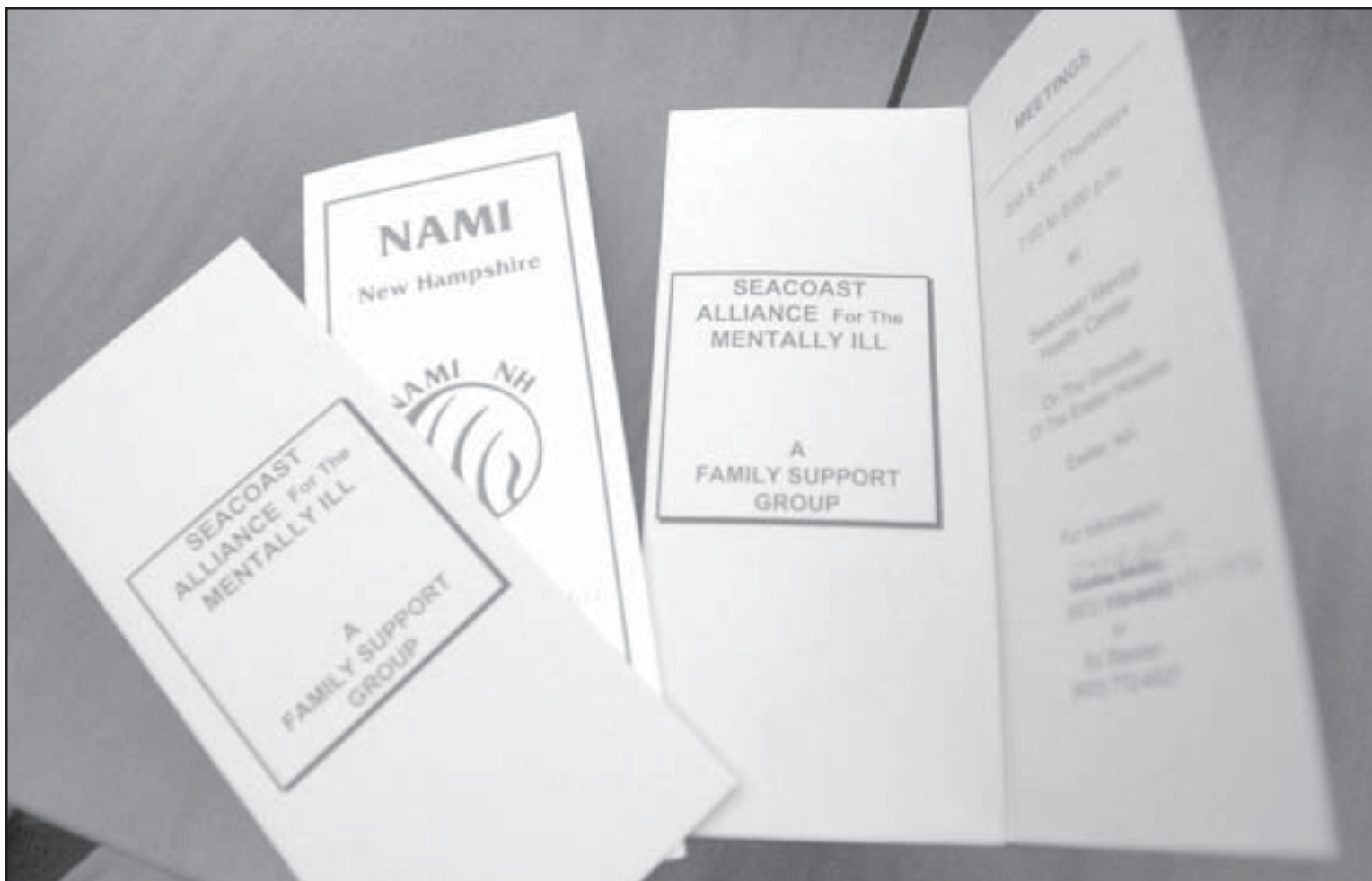
Community Campus  
Portsmouth  
Portsmouth, NH 03801  
Diane Cyr  
431-6703 x 3167  
2nd Mon., of month  
6:30-8:30PM  
[dianecyr@attbi.com](mailto:dianecyr@attbi.com)  
[dianec@cmhc.seacoastmentalhealth.org](mailto:dianec@cmhc.seacoastmentalhealth.org)

### Main Office for AMI-NH

10 Ferry Street, Unit 314  
603-225-5359  
Concord, NH 03301  
1-800-242-NAMI (6264)  
603-228-8848 Fax  
[www.naminh.org](http://www.naminh.org)  
[naminh@naminh.org](mailto:naminh@naminh.org)

**AMI-NH is a  
source of  
information and  
support for  
families and  
individuals with  
mental illnesses.**

Photo: E.G. Stone



# NH Community Mental Health Centers

## Region I

Northern NH Mental Health and Developmental Services

Main Office: 447-3347  
 Conway : 447-2111  
 Berlin : 752-7404  
 Groveton : 636-2555  
 Wolfeboro : 569-1884  
 Colebrook : 237-4955  
 Littleton : 444-5358

## Region II

West Central Community Mental Health Services

Main Office: 448-0126  
 Claremont : 542-2578, also 542-5449  
 Lebanon : 448-1101  
 Newport : 863-1951

## Region III

Genesis, the Counselling Group

Main Office : 524-1100  
 Plymouth : 536-1118

## Region IV

Riverbend Community Mental Health

Main Office : 228-1551  
 Henniker : 428-3336  
 Franklin : 934-3400

## Region V

Monadnock Family Services

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

## Region VI

Community Council of Nashua

Main Office : 889-6147

## Region VII

Mental Health Center of Greater Manchester

Main Office: 668-4111

## Region VIII

Seacoast Mental Health Center

Main Office: 431-6703  
 Exeter : 772-2710

## Region IX

Behavioral Health and Developmental Services of Strafford County

Dover : 742-0630

## Region X

Center for Life Management

Main Office (Salem)  
 893-3548  
 Derry : 434-1577  
 Windham : 434-9937

John Rawls, political theorist and Harvard professor, died November 24, 2002. His book "A Theory of Justice" is an essential text for legal scholars, economists, political scientists and philosophers, according to his obituary in The Boston Globe. Dr. Rawls wrote: "Justice is the first virtue of social institutions as truth is of systems of thought." "This has two fundamental consequences," wrote Mark Feeney. "First, all people are entitled to the greatest amount of liberty compatible with all others having the same degree of liberty. In effect, this simply reaffirms the Bill of Rights. The second consequence is far more radical. It is what Dr. Rawls called 'the difference principle.' Inequalities in society and the economy are allowable only to the extent they are beneficial to the least well off. Equal liberty and a fair distribution of society's resources are thus the fundamental principles of a just society."

<p><b>Need Information on...</b>                  disabilities                  special education &amp; related services                  behavioral interventions                  IDEA 97                  IEPs                  transition                  working with parents</p>	 <p><b>NICHCY</b></p>
<p>The National Information Center for Children and Youth with Disabilities</p>	<p>Call today or visit our NEW Web Site same address!                  1-800-695-0285                  www.nichcy.org</p>

# Progress? Yes, but.....

*Richard Cohen is a lawyer who has recently taken the helm of the Disability Rights Center (DRC) after a fifteen year absence from the state. He shared with The Challenge his reflections on the changes in the disability community – both good and bad – he sees upon returning to New Hampshire.*

by: Janet M. Krumm

“My interests in the disabilities movement goes beyond the framework of legal rights,” he explained. “I’m interested in service delivery, public administration, best practices, quality assurance – a number of different areas.”

Cohen sees “a lack of progress in many areas, and positive developments in others,” he admitted. He cited the emergence of the Institute on Disability at UNH as a positive development, and the family leadership training as another. Despite these positive developments, however, there are still shortcomings, he said. “The state universities as a whole have not exercised the type of roles and responsibilities to help advance the full integration of individuals in society,” he explained, “and the parent/family movement has made great strides, but not enough to penetrate the barriers many schools and other institutions have put up to real parent involvement.”

Despite the legislation of the last 25 years, people with disabilities are still struggling with issues of access, inclusion and adequate supports. “We have obviously made tremendous strides from the days of Laconia (State School) and the old NH Hospital,” he said, “but in terms of what expectations were and what the law requires now, I think we have a ways to go.”

Children with disabilities, for example, are not getting an adequate education, Cohen contends, despite the Individuals with Disabilities Act (I.D.E.A.) and corresponding state law.

“I think that the vast majority of students with disabilities are still getting a very mediocre or poor education,” Cohen stated, “and aren’t being helped to reach their potential, nor are they being equipped to become full, productive citizens to meet the demands of society, whether that’s in employment or in housing, or in independent living. In other words the very purpose of education which

forms the cornerstones of the Claremont II decision and I.D.E.A. and other federal laws are not being afforded students with disabilities.” Neither public schools nor private placements are meeting these kids’ needs in the same way it is meeting other kids’ needs.”

That is not just his personal opinion, Cohen insists. “There are a lot of very specific indicators,” he adds. “When you look at standardized test scores among kids with disabilities - even kids with orthopedic handicaps or learning disabilities - they perform much, much worse than other kids without disabilities. This is a national

problem, but our gap seems to be worse in this state than in some other states.” New Hampshire schools also place students with disabilities in private segregated facilities at a much higher rate than the national average—over five times the national average,” Cohen added.

One source of the problem, Cohen believes, is attitude - the attitude of society at large, which still does not value people with disabilities in the same way people without disabilities are valued. This attitude is reflected in the schools and much of the education establishment, including institutions of higher learning. He adds. “While there have been great strides in terms of access and on related fronts, in general schools and these other entities

don’t have the same commitment toward students with disabilities achieving excellence as they do for most other children.”

Cohen recounts an incident in Minnesota when, in his capacity as a federal court monitor, he spoke with a sixteen year old young man in a state institution. The young man had a mild to moderate cognitive disability. Cohen asked him what he wanted to be when he grew up, “which is sort of a typical question one frequently asks of a kid,” he said.

“I was the first person to ever ask him that question,” he remembered. “I mean, no one ever thought of this kid as

institutions.”

Cohen believes this situation is due to a combination of a lack of will and/or capacity. “There are a lot of excellent schools or individual classrooms,” he acknowledged, “but in general there is kind of a lack of will and capacity and they feed on each other and the result is that kids who remain in the regular schools aren’t getting educated to the degree of (kids without disabilities).

“And then there are other manifestations,” he added. “In addition to an increase in suspension/expulsion, restraint, and ultimately drop out rates, schools and others inappropri-

ately use or encourage the use of the abuse and neglect, juvenile delinquency or CHINS (Children in Need of Services) systems to get kids out of school.” There are rarely good outcomes when these systems are used, surely not the outcomes when schools and communities have the capacity on the local level to properly serve kids with disabilities. The inappropriate use of these ‘alternative’ systems also unnecessarily stigmatizes the parents or the children.”

“The lack of political leadership is also to blame here”, Cohen reflected. “Kids with disabilities, both those with formal educational disabilities and those with more general disabilities, make up at least 20% of the student population. However, most political leaders are failing to step up to the plate on the issue of the adequacy of education to this population. This is particularly the case in New Hampshire.

“On the federal level, Congress and recent Presidents have for the most part demonstrated a commitment to a quality education for students with disabilities. This can be seen in the continued re-authorization of the federal special education law, IDEA, as well as the attention being paid to students with disabilities and other disadvantaged groups in No Child Left Behind, (the new federal education reform law).

“Key legislative and executive branch leaders in this state have been shamefully silent about the crisis in education of students with disabilities, have failed in legislation and policy to help school districts build the necessary local capacity, and then failed to enact even the mildest accountability measures to address the problem of will. It seems in this state ‘local control’ rather than educating kids is the goal of education,” Cohen concluded.

The problems he sees are not limited to education, however, but are pervasive throughout the adult service system as well. A number of laws - both on the national and state level - have been passed to ensure the rights of individuals with disabilities, but the purpose for which they were passed is still largely unrealized, according to Cohen.

“The underlying purpose of the RSA 171-A (the state law) and the various federal laws (Section 504 of the Rehabilitation Act, the Developmental Disabilities Act, the Americans with Disabilities Act), is to assure that people with disabilities have the same right to live in the community and the same benefits and privileges that all people have: independent living, employment, etc.,” he explained. “So clearly, in terms of the underlying purpose of these laws, and the state’s prom-

***“Key legislative and executive branch leaders in this state have been shamefully silent about the crisis in education of students with disabilities, have failed in legislation and policy to help school districts build the necessary local capacity, and then failed to enact even the mildest accountability measures to address the problem of will. It seems in this state ‘local control’ rather than educating kids is the goal of education.”***

***Richard Cohen***



*Continued from page 8*

ise in the downsizing or elimination of its two major institutions for persons with disabilities, New Hampshire Hospital and Laconia (State School), the State is not meeting its commitment."

As illustrations, Cohen cited increased waiting lists for services for persons with developmental disabilities, traumatic brain injury, and very likely individuals with mental health needs. "Even for persons receiving services, New Hampshire is falling behind from its position of leadership," Cohen added, citing statistics from Braddock's 2000 State of the States report, showing that from 1992 to 1998, supported employment dropped 25% for individuals with developmental disabilities in New Hampshire while it increased nationally at a rate of 37%.

"It is probably not a coincidence that there has been flat funding for developmental services (from the State) during almost all of those years," Cohen added.

The numbers reflect more than a decrease of prevalence in supported employment, however. Cohen wonders whether there is a change in fun-

always been there," he stated. "Unfortunately, we aren't tapping it, in significant part because the educational system and then the adult system and the link (or lack thereof) of informal and legally mandated transitions are holding people back."

The systemic problems Cohen wants to address are interlinked, he asserts. "If you're an employer," he explained, "you don't want someone who is undereducated. You don't have the time or whatever to provide elements the schools should have been providing during a child's early school and then transition years. Train yes, educate no."

"And if you have someone who is undereducated with a disability then you are dealing with both educating that person and possibly accommodating that person. So it's critical for the education system to really prepare the person."

"That's why I love the whole idea of transition to make the link, so that for the future employer, the accommodation and the transition occur in a natural way. For the student, during that period from 14 to 16

***"To create real change and then to sustain it over time is the biggest challenge. Can change be sustained? This is a problem I have now with the lack of progress and, in some instances, the backsliding compared with the period of the 70's and 80's. Are the gains being sustained? I'm not sure many are."***

***Richard Cohen***

dream," especially for people with developmental disabilities, Cohen concluded.

"What we see are people languishing, maybe a little trip to the park or just watching TV," he added. "We've come a long way from Laconia (State School) and the inhumane way in which people were treated in facilities like that. But in terms of productive, meaningful activity there are a lot of people with developmental disabilities who just aren't leading really productive, meaningful and quality lives."

Cohen wants more than a dream - he wants a reality of excellence and success for

neglect petition was filed against the mom which in Cohen's view "was the irony of all ironies, or family support going awry."

Yet despite his legal background, he does not see the solution as being strictly legal. "One of the things I emphasize in the office," he explained, "is that litigation alone rarely, in and of itself, can create change for people. To create real change and then to sustain it over time is the biggest challenge."

"Can change be sustained?" he questioned. "This is a problem that I have now with the lack of progress and in some instances, the backsliding compared with the period of the 70's and 80's. Are the gains being sustained? I'm not sure many are."

In addition to the real limitations of litigation, Cohen is well aware of how the limitation of resources affects the ability of his organization to do its job. "We can't meet all the legal and other needs of individuals with disabilities," he admitted. "So the challenge is how do we maximize our resources to have the greatest impact possible?"

"That means not just maximizing DRC's resources," he continued, "but influencing other groups, the private bar and lay advocates, and educating parents and consumers so they can be self advocates. How do we increase the ability of people to address their own legal problems and also address underlying problems? Both our litigation, where possible, and are other advocacy activities must attack the underlying systematic causes of the problems our clients face."

There's a difference, Cohen believes, in way legal solutions work for people with disabilities and they way they work for people without disabilities. "When a person with-

out a disability or who is otherwise a more typical citizen comes into a law office with a legal problem," he explained, "the lawyer hopefully addresses it and the person can go back to living a fairly normal life. There are exceptions to that but it's basically how the system works."

"Here, if a person comes in with a disability and has a legal issue - let's assume its special education for example - and we address that problem, they still go back to a host of other problems and in fact the problem that we addressed may reappear in some other form the next year."

"Using a traditional legal model of dealing with a legal problem a person with a disability is faced with, doesn't mean that we are solving the problem for that individual in a lot of other spheres," he added. "So the challenge for us is to make sure that a lot of our effort is to address underlying problems in a way that's comprehensive and again that it's sustained over time."

The big question is, how?

Cohen believes the private sector has a lot to teach us about effecting change. "Advocacy and change in the private sector is much more than litigation," he said. "In fact, that's probably only a small piece of it. Change occurs through a variety of ways and through the use of a number of tools. Advocates and self-advocates need to use all of those tools on behalf of people with disabilities."

"When you think of what major institutions or businesses do when they seek to promote or cause change," he observed, "they educate, influence, use the media, change the political climate." The zero tolerance practices of schools and police came about not because

***From 1992 to 1998, supported employment dropped 25% for individuals with developmental disabilities in New Hampshire while it increased nationally at a rate of 37%.***

***Source: 2000 Braddocks' State of the States Report***

damental expectations or we are not doing a good enough job in education both developmental service staff, employers and the public.

"Twenty-five years ago, the notion was that a vast majority of people with disabilities could do productive work and get good remuneration in competitive employment," he said. Cohen cites testimony given during the Garrity vs. Gallen trial nearly 25 years ago as an example.

"We put Mark Gold on the stand," he remembered, "who was one of the leading people in the country in what we then called Semi Competitive Employment. He showed videos of people with very profound mental retardation performing vocational tasks independently."

"The technology and the will and the capacity of people with disabilities have

to the time that he or she achieves adulthood, systematic and vigorous preparation should be occurring. This makes which then makes it much easier for the employer to hire the individual, because the student or really incoming employee is a.) prepared well; and b.) transitioned well."

"Unfortunately this is hardly happening," he pointed out.

In the adult service system, this problem is exacerbated by the lack of good job development and job coaching available to people with developmental disabilities, Cohen added. "The area agencies are in a double bind," he explained, "because they're dealing with people who may not be as prepared for the job market as well."

As a result, supportive competitive employment is becoming "more and more of a

individuals with disabilities. As the director of a protection and advocacy organization, the DRC, Cohen believes the overall mission of his organization" is to address any barrier that might be an impediment to an individual leading a quality life or any thing that prevents an agency from doing its role."

The cases that the DRC litigates involve both individual and class action suits, and reflect the systemic problems facing people with disabilities. "We had a case," Cohen said in illustration, "where the parent couldn't deal with the incredible behavioral challenges of her teen age daughter, there weren't a lot of good supports from either the school or the area agency and then the area agency reported the mom as neglectful to DCYF (Division of Children, Youth and Families) even though the mom was heroic." A

**Progress**

*Continued on page 11*

# Richard Cohen

*returns to New Hampshire, his commitment to people with disabilities as strong as ever.*

Courtesy photo



by: Janet M. Krumm

As a proponent for change, Richard Cohen brings many skills honed over the years in a variety of job experiences.

Cohen's introduction to people with disabilities issues was in Boston as a legal services attorney, but it was the Garryty v. Gallen lawsuit that proved to be his real immersion into disability issues.

He came to New Hampshire a young attorney in 1973, working for New Hampshire Legal Assistance in Keene. Two years later, the position of Managing Attorney opened up in Concord, and Cohen took the job. "Because the institutions for persons with mental illness, institutions for persons with disabilities, and the prison as well were in the Concord area, a lot of our clientele were institutionalized, captive, or disabled," he remembers. He would soon get to know more than he imagined about the service system for people with developmental disabilities.

In 1976, after winning a major case against the state prison regarding conditions of confinement, New Hampshire Legal Assistance was approached by the Association for Retarded Citizens to address the deplorable conditions at Laconia State School. "We were being lobbied heavily, and rightly so, by Freda (Smith) and

others," Cohen recalled. "They had gone to the U.S. Justice Department, private firms, (and then) came to us. So the Laconia law suit became the #1 priority for New Hampshire Legal Assistance, a priority that all of our clientele agreed with as well (because of) the horrendous conditions at that institution.

"We were the closest office to Laconia," Cohen added, "and I had a little experience in the area. We went and visited Laconia and couldn't believe that people were still being treated that way. I was horrified - an understatement.

"Given our own ideological thinking - here we were young, civil rights attorneys - and based not only on the law, but on what we were beginning to read in terms of cutting edge literature about persons with developmental disabilities we saw that it made no sense and there was no reason, even for people with the most severe disabilities, to be living in an institution."

So Legal Assistance took the case, filed suit and Cohen was lead trial counsel in what became the longest civil trial to date in the history of the state.

The trial "was a tre-

mendous battle of experts," Cohen explained. "And what we made up for in lack of skill we made up with in energy and zeal. The last year prior to trial, John MacIntosh (Legal Assistance's other attorney) and I were working seven days a week, incredible hours. The trial itself was ten weeks and then the post trial - it was about a year and a half of just total commitment. We need more of that today"

Cohen and his team of lawyers prevailed, and the rest is history. The Court's decision in the Garryty vs. Gallen suit set in motion what would eventually result in the closing of Laconia State School, the State's only institution for people with developmental disabilities. New Hampshire became the first state in the nation to close its institution.

Cohen's path was set. "I think in a way I was already beginning to lean in that direction," he admitted, "and I think I already considered myself a disability rights advocate, but

major mental retardation consent decree out there. "There were six institutions under court order," he said, "and the purpose of the decree was both to improve institutional conditions and place large numbers of people into the community. The case had gone on for twelve years when I accepted the appointment in 1984. I was able, along with the parties, to bring it to a successful conclusion by 1988."

From Minnesota, Cohen returned to Massachusetts to become a state court monitor over the Boston Public Schools. "They were under a court order to improve their special ed services," he explained. "I think we did some good work there," he added. "It was an incredible learning experience because of how political the environment was there."

What were his guiding principles as a court monitor? "My philosophy as court monitor in both places was: the decree says X, this is what it requires. If you start allowing the

was preferred as long as it did not cause undue delay. However, if that did not work, I used whatever enforcement authority I had to obtain compliance. That was my responsibility. If you start allowing an exception here and there, you are going to have a very long slippery slope.

"My philosophy was to use these decrees as what they were intended to be, an order to get the parties into compliance."

He stayed in Massachusetts, becoming the Director of Investigations for abuse and neglect in the state Department of Mental Retardation in 1993. "Both experiences (as court monitor and director of investigations) were interesting," he stated, "in terms of learning and dealing in a highly politicized culture in Boston and Massachusetts."

The unit Cohen headed was new, having been established as the result of an expose by the Boston Herald and the Inspector General on the way investigations were being done by the department of mental retardation. "The allegations

***The Garryty vs. Gallen trial "was a tremendous battle of experts. And what we made up for in lack of skill we made up with in energy and zeal. The last year prior to trial, John MacIntosh and I were working seven days a week, incredible hours. The trial itself was ten weeks and then the post trial - it was about a year and a half of just total commitment. We need more of that today."***

***Richard Cohen***

that whole experience and the aftermath got me hooked in a broader way."

He remained in the state, doing disability work until 1984, even serving on the board of directors of the then newly created Disability Rights Center for a brief time as a Legal Assistance representative.

From 1984 to 1988, Cohen became a federal court monitor in Minnesota over a

parties to deviate from the letter, or the spirit of what is required in the court order or consent decree, you start going down a very slippery slope. The parties, can if they choose, negotiate something different, but my job was to monitor, to make sure that people complied with the letter of the law, with the spirit of the law. When there were ways to do that collaboration or negotiation, fine, that

were that the Department was sort of investigating itself previous to my coming on," Cohen explained, "and investigations were being whitewashed."

Phil Campbell, appointed commissioner at the time, had a background in the ARC, and hired Cohen to set up

*Continued on page 11*

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an independent unit which reported directly to the commissioner. Cohen's investigative staff came both from law enforcement and human services, some of whom had no experience with people with developmental disabilities.

As a result, "there was a lot of training," Cohen acknowledged, "both in values training, and interviewing of persons with developmental disabilities, and individuals with verbal skills who had cognitive impairments or processing problems as well as people who were totally non-verbal where other modes of communication had to be used."

"I took my charge that we were to independently investigate abuse and neglect wherever it occurred, very seriously," Cohen said.

"So when we found abuse or neglect or related problems in the institutions or the community, my charge to the investigators was not only to look at what happened around the particular incident, but why it happened.

"We looked at whether there were systemic problems in management, licensing, whatever, that led to this incident being investigated? We also were very candid and truthful with regard to some very popular community providers who served individuals who were very challenging. If we found abuse and neglect there, we took no prisoners, so to speak."

Cohen learned an important and powerful lesson from his experiences there. "I think one of the things I learned," he said, "is that you need to do your job, you need to be really vigorous in what you do, whether its investigations or legal advocacy, if you're in a political environment, in order to sustain you need to have a constituency, a group behind you."

Cohen decided to leave his position when his boss was removed due to political pressure, leaving him with no backing to continue hard-hitting investigations.

He has no regrets. We started a new unit which continues to function today in Massachusetts. "I learned a lot about investigations," he said. "Previously as a lawyer and a court monitor, I had done a lot of investigative work, but this was much more formalized investigation.

"Because of my legal background, experience in the

disabilities rights field, and in investigations in Massachusetts, I have had the opportunity to consult or train in several states on their abuse and neglect investigations, and have just completed a chapter in a book on the subject that is due out shortly."

He also learned about the sorts of things that caused abuse and neglect. "What is it that caused people to either abuse or neglect folks? Is there a certain type of person that is a predator that is neglectful, are there conditions of employment, for example that creates, foster or contribute to that?"

"I think all of those things are true, those things happen," he admitted. "There are people who are absolute predators, who actually seek out these jobs to then prey on people who are more vulnerable.

"There are other situations in which a person may be prone to abuse, and when conditions aren't right, they may become abusive. For example when there is a shortage of staff."

"There are others who are fine, but they lack the training from the provider. They just don't know what is or neglectful and they think that what they are doing is totally appropriate."

Because of this experience and the knowledge he gained from it, he urges caution in certain situations. "Sometimes providers are too quick to fire someone where most of the fault may not lie with the individual; it may be just a lack of training," he explained.

"And given our human resource shortage and all of that, the blame game can sometimes be self defeating. Obviously, when you have someone who is very or willfully abusive you need to get rid of them, but there is a lot of grey area in many of these situations."

In 1997, Cohen wasn't sure exactly what he wanted to do professionally - whether he wanted to stay in the disability arena or go back to the traditional practice of law as a disabilities rights advocate. So took a part time job at the Disability Rights Center in the policy area and, at the same time, took a job prosecuting and doing investigations in the environmental area for an agency within the department of environmental protection in Massachusetts.

After a couple of years, two things happened. Cohen got tired of commuting from Massachusetts and the Disabili-

ties Rights Center had received an increase in funding to enable the organization to fund Cohen's position full time. So he came on board as their "full-time policy person."

Donna Woodfin began talking about retiring after more than 20 years as the director, and Cohen was interested in succeeding her. "Ron (Lospennato) had been there many years, but was more interested in staying in strict legal work," Cohen explained, "and I certainly had an interest in it."

So now Cohen finds himself back in the fray. "I really like, at this stage of my career, mentoring and leading and managing and taking an organization like this and maximizing our ability to serve its clientele which are people with disabilities," Cohen admitted.

The new director of the DRC brings formidable skills and rich experience to the disability community in New Hampshire. He is a leader who has come full circle, from being lead counsel in a lawsuit over conditions in the State's institutional service system to being the director of a protection and advocacy organization which is suing the State over the conditions of its community-based service system.

New Hampshire, pay attention!



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## Progress

*Continued from page 9*

kids are any more dangerous today than ten or twenty years ago, but because groups changed the political climate. We need to be honest, but we need to get the message out there."

Collaboration figures prominently in this effort, according to Cohen. "The purpose of collaboration is to get things done," he emphasizes.

"If you're looking at organizational behavior, human dynamics, and the way change occurs it usually occurs with a number of people collaborating, either externally or internally, to pursue a common mission or a common interest. So I see working very closely with the DD Council, the people with disabilities, families, state and private agencies and the university system as a whole."

Yet, he recognizes that he must be vigilant in any collaborative effort. "The one thing that I believe in and this organization believes in," he emphasized, "is you have to keep your eye on the ball; that is, that you can't be collaborating to death with no results. If the collaboration isn't producing an outcome and producing it in a reasonably urgent manner - urgency is a word that doesn't seem to exist amongst a lot of people - you need to be forthright with folks. You then need to use your other strategies, which can be litigation, can

be public pressure, etc."

Cohen feels a real tension in acknowledging both the remarkable progress that has been made for people with disabilities and the pressing need to change the seemingly intractable problems that still remain. "We have come so far," he acknowledges, "but I sometimes wonder - I say this partly tongue-in-cheek - at least in the DD system, I can't say so much about the special ed system, whether we peaked around the early '90s and we've kind of gone downhill. Not only in terms of the waiting list, but in terms of supported employment, and what's happening out there both in terms of serving people and empowering people to be more independent. I sense stultification, that there is not the zeal and creativity that existed and, that, coupled with lack of resources, we are going down hill."

Cohen is not a man to sit still and allow that to happen. He is passionately committed to "action and implementation and change that is comprehensive and sustained over time."

"That commitment is not one that DRC has a monopoly on," he added. "It is a commitment shared by all persons who seek to remove barriers to full integration and equal opportunity for people with disabilities."

# Shopping Is Rough On Wheels

## A look at accessibility in Filene's Department Store



Photo: E.G. Stone

by: Sean Raymond

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

One of the most frustrating aspects about being in a wheelchair is accessibility. There are so many places I can't go because of steps at the entrance, narrow doors, narrow aisles, and other location factors.

My biggest problem, even with so-called accessible businesses, is the entrance doors because several of the businesses I go to have no electronic door openers. I'm not physically able to open the doors, so for me to go alone to a store, a movie, or even a restaurant requires the assistance of strangers.

Imagine having to wait outside of a store door for someone to walk by just so you can ask him or her to help you in. Let me say that it doesn't help boost your self-esteem.

I've said it before, in earlier articles, I love movies, and if I want to go alone to see a movie at the Newington 12 movie theater it is a struggle. I can't open the outside doors of the facility that lead into a kind of waiting area, and then to get into the actual lobby from this area there is another set of doors

that I can't open either.

Of course, then there's the actual door to the theater that plays the movie, which I can't open. Now, reverse this process for leaving the facility and that doesn't make for a good night out at the movies.

This hasn't even taken into account the fixed seating arrangement for wheelchairs once

I get into the theater. In some theaters at the Newington 12 facility I have only 2 places to sit: the front row or 5 rows back from the front row.

I love movies too much to let this stop me from going, but it would be so much nicer if going to the movies was as easy for me as it is for the majority of able-bodied people.

This is just one personal example of a business lacking accessibility. The Dis-

ability Rights Center has recently filed a lawsuit against a large department store concerning the overall accessibility of the store. When I saw the name of the store I was not surprised because I go to one of their branches at the Newington Mall approximately two times a month and for me to get around the store and shop is a nightmare!

The store is Filene's and the lawsuit is against three of their branches: Salem, Manchester, and Nashua. The actual complaint alleges that the Filene's stores in the locations mentioned fail to provide people with mobility disabilities "full and equal access to merchandise," and other services such as payment counters. That these stores "routinely arranges their merchandise racks so that people with mobility disabilities, such as individuals who use wheelchairs, are unable to independently obtain access to much of the merchandise within store departments."

In short, the Filene's in Salem, Manchester and Nashua discriminate against people in

Again, the door was a little tricky to get open, but I did it and once I got in I was fine. The handicapped stall was spacious and easy to get in and out of.

The sink, however, was impossible to utilize. The handles for controlling the water were too far away and the counter was too low. There was also an obstruction below the counter that made it impossible for me to reach the sink.

Ironically, the men's bathroom is located in the bra and panty section, so as I went to the bathroom I noticed how the space between bra racks was ridiculously small. Anyone in a wheelchair who wanted to shop for a bra would not be able to get around that section of the store.

Next, I went to look at winter bed ensembles and that section was decent. There were a couple of aisles obstructed by the bulky bed ensemble packages, so I couldn't look at the inner-aisle packages available. On my travels to the men's clothing I passed all varieties of children's clothing. The guys' 8-20 section was horribly configured. I could get around the

the aisle I almost always came to a dead end with blocked aisles on my left and right.

The clothing racks were so close together that it was impossible to squeeze my wheelchair through. Even when going through aisles that I could squeeze through I was constantly worried that the clothes would get hooked on my wheelchair since there was such little room.

This is what I call *perimeter shopping*, which is looking at the items in view from the main aisles without actually moving in to look at all of the items. I would like to be able to look at everything in a section.

The Izod, Claiborne, and Nautica clothing sections were not very good either. This is what I really wanted to look at because these are the styles of close I wear. I was upset when I found out it was so difficult to get around these sections.

There was a little more space to get around, but I still couldn't get around all of the racks and stands they had assembled. I could circle the sections from the main aisle with no problem, but to get to the center part of each section and really check out the clothes was not possible in most cases.

After my discouraging experience in the Izod, Claiborne, and Nautica sections, I moved over to the men's dress clothes to check out the button-down shirts and ties.

This was the first section that I could really check out without too much trouble. A couple of racks were too close for me to get between, but overall it was the best section I went through. The blazer and coat sections were tragic, however. The bulkiness of the clothing only subtracted from my ability to get through the aisles.

The **biggest** problem that plagued me while shopping at this store were boxes and portable moving racks. I couldn't

***"There were numerous boxes stacked throughout the store that appeared to be strategically placed to make my shopping experience as hard as possible. I don't think this was done intentionally, but there was an obvious lack of thought and sensitivity when the employees just scattered and stacked big, heavy boxes all around the store."***

***Sean Raymond***

wheelchairs, and people with other mobility disabilities.

I've been to the Filene's in Salem, located in the Rockingham Park Mall, and the accessibility is certainly questionable. My first problem was the entrance door that connects directly to the parking lot. I couldn't open it, so I went around through the accessible mall entrance.

My first visit in the store was the men's bathroom.

perimeter and into some aisle ways but it's like a labyrinth once I attempted to get in. There's little room to turn around, so fortunately it wasn't a busy shopping day and I was able to clumsily retreat from constant dead ends.

This pattern of dead ends was common throughout the store. First, I had to circle the perimeter to find an aisle way that appeared to be accessible, and then once I got down

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even see the men's socks, let alone get to them, because of boxes stacked in front of the aisle ways that led to the socks.

There were numerous boxes stacked throughout the store that appeared to be strategically placed to make my shopping experience as hard as possible. I don't think this was done intentionally, but there was an obvious lack of thought and sensitivity when the employees just scattered and stacked big, heavy boxes all around the store. I have never gone shopping and seen so many boxes just stacked up in the middle of main aisles and aisles within individual sections. This problem was awful.

As I made my way around the store I couldn't help but notice the layout of the women's clothing sections. It appeared that the women's clothing sections were much harder to negotiate than the men's. It looked like there were many more clothing racks all squished together than in the men's sections.

I would imagine that the majority of shoppers at Filene's are women, which accounts for the added clothing racks in the women's section, but the added clothing racks to a space already nearly impossible to navigate is only going to make what little accessibility there is into completely inaccessible areas.

Throughout my shopping experience at the Salem Filene's store, I have mentioned several of the problems that I encountered; however, there was one good aspect of the store that I would like to mention.

I was asked several times by employees if I needed help. This is good because I did need help. I do appreciate the effort but during a busy time with a full store, who knows if I would have even been noticed. Not to mention the attention I would bring to myself if I had someone move an entire row of racks so that I could get to a rack all the way in the back.

On my next shopping trip I may actually have someone move an entire row of racks so that I can get to the back just for the sake of seeing what happens.

I also must add that in my overall shopping experiences of life, this store wasn't the worst. It was actually pretty good, only in comparison to other experiences. The men's clothing and apparel was de-

cent, in comparison to other stores, but the women's sections looked really bad.

The Filene's in the Newington Mall is much smaller and because of that I find it to be comparatively worse than the one in Salem. There is less room to maneuver and more racks crammed into a smaller space.

The jewelry department in the Newington location is far worse than the Salem one. The table coverings are so long that they touch the floor and my wheels catch them as I squeeze between tables.

There are some sections in the Newington location that I can't even find one aisle

to get down, which leaves me stuck to the main aisle. So, the Salem Filene's in comparison to the Newington Filene's is much better, but it is still not at a standard that it should be at.

Unfortunately, the Newington location was built before the three Filene's locations in the lawsuit, so, "legally speaking," they were off the hook because the particular laws involved in this lawsuit don't apply to older buildings, like the one in Newington.

It is a shame that the Filene's in Salem isn't better laid out for people in wheelchairs and people with other mobility disabilities. It is better laid out than other stores that



Photo: E.G. Stone

I hope that everyone becomes aware of disabled people and the injustice that we suffer every day because we are a minority that has been ignored for far too long.

Part of the reason why we have been ignored and have suffered inequality is because we don't always say or do anything about the problems that plague us. Some people make it their life effort to fight for accessibility and equality for disabled people and I commend them for their efforts, but not everyone is like that. For some disabled people it is hard to make a difference because they don't have the ability to effectively communicate, but I do and it is time that I stopped being quiet. It is time that I notify the right people when I feel like I have been a victim of discrimination. I am so used to being inconvenienced that I may not even recognize discrimination when I see it!

It takes a lot of time to do the right thing, but isn't it worth it? I know it is tough to speak up and declare injustice, but it is necessary. I have done it in the past, some of the time, when I felt the cause was worthy of my time, but I need to think about the big picture and make sure I let no act of discrimination towards me go unnoticed. I need to realize that if it comes down to a choice of writing a letter to the Newington 12 cinema about my problems or watching "Survivor: Thailand," I need to write the letter. If I have to write one letter to the Newington 12 cinema every week until I get a response that pleases me I need to do it.

Now imagine if everyone in a wheelchair wrote one letter a week to the same cinema, or any place for that matter that discriminates. This is just one approach toward achieving equality. Going to UNH as a full-time student limits the amount of time I have to fight these battles, but I pledge I will do more. This lawsuit was an eye-opener for me and I hope it is an eye-opener for others too. I hope my article inspires others to make a difference by doing what they can. This is a battle that is far from over and if we work together I know we will win.

I have been to, but it still fails to satisfy me as a shopper. I

only hope that this lawsuit makes a step towards equality and accessibility.

Please support our  
annual appeal.  
The Challenge  
depends on your help.



Candace Cole-McCrea

Photo: E.G. Stone

I, Candace Cole-McCrea, am currently Chair of the Department of Human Services at New Hampshire Community Technical College at Stratham and Pease. I reside in Milton with the younger of my two sons, Kestrel, age 8. My first son is biological; my youngest is adopted as a special needs child. I was labeled retarded, myself, as a child and young adult. I have been institutionalized, raped and battered, spent many earlier years in a wheelchair and over a decade blinded by a pharmacy's mistake. I received my G.E.D. when I was in my 30's, went through college and graduate schools to become a transformational psychologist. I have regained much of my sight without medical intervention over the years, and am currently seeking to overcome severe infectious rheumatoid arthritis/deformities caused by rape and medical errors. I am relying on crutches etc. once again.

Besides working full time as a professor, I home school my youngest son, own and care for my own home and have published professional articles and poetry, some about disability and some about my native American Indian experiences. I also counsel and mentor others at no charge to them, but I do accept donations and help with yard work.

After meeting with Janet Krumm, the editor and publisher of The New Hampshire Challenge, it was agreed by us both that I should offer chapters of my life story to unfold within the newspaper, hopefully to increase awareness and to help and encourage others. Therefore, in future editions, I will submit pieces of my life in a series of installments...some brutal, some joyful and full of beauty.

This issue of The Challenge features a chapter of my life in which I highlight my experience at age 11, when I was hospitalized on a pediatric ward for nearly a year, wherein I met a little infant girl, disabled and also labeled retarded. This was one experience, among many, positive and negative, that was to empower and transform the value and meaning of my life. With it, I wish to communicate that no one ever should decide the prognosis of another's life as valueless and without quality. We do not know the future. My license plate, even though it is a handicapped plate, says the same thing everyone else's does....that I get to "Live Free (til I) Die".

To those who wish to communicate with me, I can be reached at [snowyowl@metrocast.net](mailto:snowyowl@metrocast.net), phone 603 652-7594. I will so gratefully and joyfully respond as quickly as my energy and strength allow me. Thank you each so much.

# Jody

Her Name was Jody and they had placed her in the crib next to my bed on the ward because, as they said, we had so much in common, she and I.

So much in common... I cried inside. I had never seen another child like me. I watched her day and night as she cheerfully entertained herself with her hands, lying unnaturally flat on her back already swaddled in physical restraints they thought were therapeutic. So much in common, she and I...I cried inside.

So much in common... I watched her parents come and visit—her father always firmly escorting her tearful mother away, down the corridor after each short visit of looking at, but never holding, Jody. Her father escorting her away...leaving Jody alone without her mother, without her father...I cried inside.

So much in common... the big, grown up people who were supposed to be so smart, talked of Judy needing the "special care"

of other institutions and hospitals far from home, of how any loving parent or professional would do the same. (It was 1960 and few people realized...)

So much in common... they wondered if she could be intelligent enough to be able to learn enough for any quality of life...and they put her in the crib next to my bed because, as they said, we had so much in common, she and I.

I'll never forget those few days with Jody near me, playing happily with her hands, trusting us all. I watched her day and night. I cried inside.

I had never seen another child like me before and my heart broke. Until then, I thought maybe I was such a horrible child that it had to happen to me (God's will?) and that no one else could possibly be treated like I was because no one else could possibly deserve it...then I saw Jody and she was such a happy, bubbly baby girl.

There was nothing terrible or ugly or horrible about her. Just her legs did not work...and they assumed her mind did not either. She was, like me, born premature.

Maybe I wasn't terrible or ugly or horrible either. I watched her day and night. I cried inside. My heart broke...and my heart broke again, as I sat there silently watching her parents one day, sitting so close to me, sign the papers...so much in common...

And, now years later, I still remember those few days better than I remember this morning's coffee. I look back and see myself so clearly, an eleven year old disabled, tiny, scrawny girl, all cheekbones and eyes, living in a world of fear and socially imposed and self imposed isolation.

I had withdrawn from the world of people the way a small animal withdraws from predators. I was silent, hidden, trying to shelter myself somewhere

deeply away from others, deeply under my own skin, so deeply I hoped not to feel the relentless psychic and physical pain.

Maybe, if I could only withdraw deep enough...even if I could not stop them from torturing my body and shattering my feelings...maybe, at least I could stop them from torturing my soul. I wanted something of me that was mine, unhurt...that they did not control or reach. I stayed hidden, even from myself. No tears, ever. No one ever got through...no one...until Jody.

Jody. I lay on my little grey bed and watched sweet, cheerful Jody and learned a truth about American cultural life—THEY WERE GOING TO DO IT AGAIN. They were going to hurt, neglect, abandon another child and they really called it "Love" and "Science" and "Medicine". THEY WERE GOING TO DO IT AGAIN.

Something in me changed that

day that has never seen people the same way since.

I realized that we, as humans, often do things just because we are taught to, told to, or do not have any other ideas of what else to do and not because we have worked together to find good, life respecting solutions for ourselves, for other peoples, for life on earth. THEY WERE GOING TO DO IT AGAIN. THOUGH JODY WOULD REMAIN PHYSICALLY ALIVE, THEY WERE GOING TO TAKE AWAY HER LIFE.

Her parents were already questioning how it was the God could have given them such a child. I watched their pain, saw their tears, felt their grief and wanted to cry out to them, to the professionals, to everyone:

*Continued from page 14*

WHAT IS SO HORRIBLE ABOUT HAVING A CHILD LIKE ME?

WHY IS A CHILD LIKE ME A CURSE TO BEAR?

WHY DOES MY BEING ALIVE MAKE YOU SO UNHAPPY?

WHY DO OTHERS PITY YOU AND WHY DO YOU PITY YOURSELVES?

ARE ONLY PERFECT BABIES TRULY HUMAN—TRULY PEOPLE?

WHY CAN'T JODY AND I BE PEOPLE TOO?

WHY DO SO MANY OF YOU EVEN LIKE MEAN PEOPLE BUT YOU WILL NOT EVEN LOOK AT US?

DO YOU REALLY THINK A GOD HAS PUNISHED YOU AND US?

WHY ARE OUR LIVES SEEN AS WORSE THAN DEATH...WHY DO YOU THINK WE ARE BETTER OFF DEAD?

I wanted to know but I did not ask. I never asked. I had learned. They didn't know so very much and couldn't tell me. They didn't know. They just thought they knew. I didn't ask.

But Jody changed my life. I vowed that morning at the age of eleven that I would grow up and speak...I vowed that early morning when I first awakened and saw Jody's crib empty. They had taken her away to a new facility while I slept. I cried inside and since no one was around, I cried outside. But I screamed on the inside. (I did not want to face their anger by bothering them in any way). I screamed on the inside:

THIS HAS TO STOP...SOMEONE HAS TO STOP THEM. SOMEONE HAS TO TELL THEM...SOMEONE HAS TO TELL THEM THAT THERE ARE REAL PEOPLE INSIDE OF BROKEN BODIES...INSIDE OF BROKEN MINDS...INSIDE OF BROKEN HEARTS...INSIDE OF BROKEN SOULS...THERE ARE REAL PEOPLE INSIDE...SOMEONE HAS TO TELL THEM...THAT IT IS NEVER SMART OR RIGHT

OR INTELLIGENT TO SAY OR DO WHAT HARMS SOMEONE DEPENDENT UPON YOU. FOR WISDOM, FOR GUIDANCE, FOR SUPPORT, FOR HELP...THIS HAS TO STOP. ALL OVER THE WORLD, THIS HAS TO STOP...

For the first time in my life I truly prayed, from my heart, from the center of my being, "Dear God, whoever you are, if you are, please help me not to hate them or hold it against them ever, no matter what. Help me to grow strong, to show another way, to forgive, as I have heard someone said once before, 'They know not what they do'."

Years and years and years have gone by. As I approach closer to age 60, I realize there has never been a day when I have not thought of Jody and held her in my heart. And as I have lived within this gift of time-life, I have wondered so about Jody...

Jody... Did they rape you too, Jody? Did they Beat you with belts? Encase you in plaster to prevent you from being trouble? Treat you like you were too stupid or retarded to understand? To love? Yell at you when you cried?

Did they hate looking at you and did it show in their faces when they did?

Did they light candles and say prayers hoping you would change and become someone else?

Did they leave you in body excrement and bed bugs and bed sores day and night for months never ending?

And worse... Did they try to make you pretend with them that all this was all right and that it was God's will?

Jody... Did you live to grow up? Did you ever get free of walls, restraints, pain and fear? Do you have memories of your mother and father beyond that they left you there?

Jody...

Did you ever go to school and get treated like a real person there?

Did you ever find people who did not look at you in disgust or shame or as an inferior form of life?

Were you ever touched by a man that did not hurt you?

Jody...

Did you ever get to eat what you wanted, to wear what you chose, to go where you chose, to say as you will?

Did they ever let you grow up?

Did you ever get to live long enough to know aging?

And Jody...

Were you ever loved?

Did you ever get free of walls, restraints, pain and fear?

I DID,

I DID, JODY.

I DID.

AND I AM KEEPING MY PROMISE.

JODY, I GOT TO BE FREE.

I NEVER EXPECTED IT, BUT, JODY, CAN YOU IMAGINE...DID YOU EVER GET TO KNOW WHAT IS OUT HERE IN THE BEYOND.....

I DID, JODY.

HERE IS WHAT THE WORLD TRULY IS...HERE IS WHAT I HAVE FINALLY BEEN ALLOWED TO LIVE...HERE IS WHAT IT IS TRULY LIKE BEYOND...

Jody, do you hear me? Jody...

I got to see Balloons and flowers and sunsets and goldfish and dirt and tadpoles and oceans and mountains and sidewalks and movies and butterflies and aeroplanes and grocery stores and hurricanes and kite tails.

I got to hear Trumpets and whispers and parakeets and car engines and music boxes and window fans and sparrows and vacuum cleaners and neighbors and singing and laughter and raccoons and drums and motor boats and teachers and swing sets and winter winds.

I got to do House cleaning and piano playing and flower gardening and

snow balling and tub bathing and husband loving and belly laughing and heart crying and flirt playing and school learning and pencil drawing and poetry writing and Sunday cooking and laundry washing and car driving and friend talking and bill paying and money earning.

I got to feel

Walking and back rubs and snowburns and summer sun and morning showers and shampoo and toothbrushes and kitty casts and exhaustion and icy chills and overworked and flu aching and lonely-angry, and grief stricken, and happy hugging and friendship sharing and joy and love and forgiveness and goodness and Grace. I got to feel my son being born, Jody...and I have known a man's love...can you imagine, Jody....can you imagine?

And then, Jody, As if that were not more than enough... I finally was allowed to think, Jody.

They finally let me think... And no one punishes me for it, or treats me like I have hurt or offended them with my thinking... Can you imagine, Jody?

Did you ever get to know How it is to finally be Free to think and to say what you think...and to be respected for it, even if what you say is different than what everyone else in the room thinks or wants to hear?

Free to think and to speak with no one trying to take that away, medicate it away or change it in any forceful or authoritarian way...

Freedom to think and to speak...Freedom to have my experience, my life, my work treated with respect...Freedom to live (til I) die...

# Jody

But even more important, to have been given the Grace, the life in which to learn, to remember, with every breath, with every difficult step...to always hold in my heart the truth of the past, of what people have taught, dictated and believed themselves to be...the history of the past...but always also...the truth of the present, the truth of the future, everywhere, in all nations, nooks and crannies of Earth...

That all people...

The bent, broken, mindless, soul hurt, black, brown, white, red, man, woman, child, addicted, unborn, old, educated, ignorant, right, wrong, violent, gentle, believer and unbeliever, the rich, the poor, the authority, the client, the boss, the worker...

All people...

All People...

A L L

PEOPLE

Truly have

"so much in common".

(Thank you, Jody, and to all other Jody's other there, to include my niece, Jayln, who struggles with Fredrick's Ataxia. You have each been a great teacher. Thank you for giving me and so many others a reason to believe in self determination and to find our own humanness.) Because of you, I can offer my young son, my aging mother and father, my niece, my students, my neighbors

The Freedom to Live (til we) Die...

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**Deborah Gray in her office at Farmsteads New England. The office is presently located in Epping. Gray is waiting to see if the purchase and sale agreement on a farm in southwestern New Hampshire will be finalized. If so, she hopes to open the program in the early part of next year.**

*Photo: E.G. Stone*

## **“Farming’s a good idea but being isolated on a farm is not a good idea.”** - Deborah Gray

*Continued from page 1*

stimulated,” she added.

When he was about twelve, Andrew came home from school covered in bruises and abrasions, according to Deborah. “We took him to a doctor to make sure there were no internal injuries,” she said. “The doctor filed an abuse report against the school, which nothing ever came of. They decided the school had done the best they could.

“Obviously, he never spent another day in that school,” she added.

With a Bachelor’s in elementary education, a Masters’ in special education, and Doctoral studies in special education administration, Deborah is no stranger to the needs of children with disabilities. In addition to raising a son who exhibits behaviors on the autism spectrum, she has completed the Leadership Series on Autism.

Deborah taught at the Seacoast Learning Collaborative, taught special education at Boston University and served as a special education consultant and educational examiner at Pinkerton Academy. Deborah is a well-educated woman with first-hand experience in her field.

Still, she was at a loss when it came to imagining a future for her son in a system

with which she was well-acquainted.

“I knew he was never going to wash tables at McDonald’s or stock shelves in Walmart,” she said. “It just wasn’t going to happen.

“And I didn’t want to see him in a sheltered workshop where he’d be forced to sit somewhere and sort nuts and bolts or do some activity that he didn’t understand the meaning of. Even if it was a purposeful activity, if he was putting something together that a factory was going to use in some other product, those activities have meaning, but he wouldn’t have understood the meaning for it.

“And he is physically very active. He likes to be up and around and I didn’t want him in a place where he wouldn’t be able to get up and around and move, and have to sit there for another half an hour before he could get up, and end up being restrained and other things. You picture all the negative things that could happen.

“But in looking at what’s out there, I just felt that’s what would end up happening,” Deborah admitted.

So Deborah started to take stock of the things that Andrew could do, activities that Andrew liked to do. “I thought, well, he likes open spaces. He

likes to roam around outside. He likes anything that gives him motion, whether it’s riding in a car or riding on a horse. He’s got the gross motor skills to do gross motor sorts of tasks.

“And I thought a farm would be a perfect environment for him,” she remembered.

Deborah has had no experience on farms. But not long after the idea of a farm began to take root in her mind, Deborah happened to visit her aunt in Nova Scotia. That visit helped shape her vision a little more.

Deborah’s aunt lives out in farm country. During her visit, Deborah saw a man come down the road and stop by the house. This man, who had a cognitive disability, was working on a neighboring farm. Deborah discovered that he came to visit her aunt periodically just to talk.

“We talked to him for a while,” Deborah remembered, “and it became evident that he was so incredibly lonely. He told us that he had run the haymaking machine by himself that day for the first time. And my aunt said, oh, isn’t that wonderful. Did so-and-so - who was the owner of the farm - tell you you’d done a good job? And he said, no.

“And I just thought, this is so sad. He’s walking a

mile down the road to visit an elderly woman because he knows she’ll sit and talk with him. He’s not getting the support he needs.”

Deborah since learned that he has been moved from the farm because of “improper behavior in the community.” and placed into an institution.

“This just never should have happened,” she insisted. “He just wasn’t getting the support he needed.”

That experience didn’t deter Deborah from her inclination for Andrew, but it did make her think: “Okay, the farming’s a good idea but being isolated on a farm is not a good idea.” So the idea of supports took on importance.

That led her to consider the possibility of a few people with disabilities living on the farm with staff to support them. At this time, Deborah was working on her doctoral thesis (which, she is quick to point out, she hasn’t finished) and was researching rural opportunities for people with developmental disabilities when she discovered Bittersweet Farms in Ohio. This was a program which had been around for twenty years and specifically served people with autism.

As she read the book describing their program, Deborah became excited. “It

was my vision already up and running somewhere,” she realized. “So I did go out and visit their program and liked what I saw.”

At the time of her visit, Bittersweet Farms had a waiting list of 100 people and no openings for the previous seven years. At the present time, the waiting list has increased to 150. “So I said, okay, well the model obviously works,” she recalled. “Successful out there, anyhow.

“So I said, I’m just gonna do it.” Andrew at this time was sixteen years old. “He’s got five years to go,” she realized. “It could take me five years to get this thing up and running and I want it ready for him when he turns 21. So I quit my full-time job and started working on this.”

While she was at Bittersweet Farms, she asked for advice on how to proceed and was encouraged to create an advisory board. So that was her first step.

She put out a couple press releases and held several informational meetings in different libraries. Soon she had a core group of four - three volunteers and herself.

The initial commitment was short-term - to set up

**Farm**

*Continued on page 19*



# An interview with Deborah Gray

*The Challenge invited Deborah Gray to talk about her farmstead program. In this candid interview, she describes her plans.*

Interviewer: Janet M. Krumm

## Why a farm?

I'm well aware that the philosophy today is to have everyone placed individually - in individual job sites, individual housing arrangement, and such. Most of the area agencies have a vested interest in continuing that model.

We just believe that people are entitled to a choice if they want to work on a farm. If they're happy working on a farm that also has other people with disabilities working on it, then they ought to have that choice available to them. And we think that this program is - I guess I can speak for my own son anyhow - is more appropriate than the currently prevailing model.

## How many people do you envision working and/or living on the farm?

When we start off, with ten people or 20 people as we build, we will be somewhat dependent on fundraising and grant writing to make the budget. When we hit 30 people, that's kind of the break even point. And by going to 40 people, that gives us a cushion and it will allow us to provide things like an extended day program.

## Your plan indicates that you intend to offer both a day program and a residential program. Will both be available when the farmstead opens?

It's probably going to depend on the property that we obtain. Originally, the thought was to start with a day program, assuming there would be no place for them to live and then we'd build some residences. Now the property that we almost bought actually had what had been a caretaker's cottage that would have served very well as a home for two people until we could get the other things built. And the zoning ordinances in the town actually made it easier for us to open if we had people in residence right away.

## What kind of residences do you envision and how much choice

## will individuals have about their living arrangements?

As much as it's possible to give people a choice, we'll give them a choice. What we would like to do, zoning regulations permitting, is have three bedroom staffed homes for people who need 24 hour staff.

We're looking at basically three levels, assisted, supervised and independent. And then one and two bedroom apartments for people at the independent living level.

For those people, there obviously is more choice because they can live by themselves in an apartment. If they want to live by themselves or they've got a good friend or they meet someone who they think they'd really get along with and like to room with, then there'll be a couple two bedroom apartments available.

But obviously, there isn't an unlimited number of homes available, so it's going to be somewhat where we have spaces and where they want to

Obviously, it depends on how challenging a person with disabilities is. My son is very challenging so I always have him in the back of my mind. I would never put him in a position with one person. Because I think someone would end up getting hurt. He's too frustrating.

## Will the residences be co-ed?

I've thought about it. I haven't thought to the point of making a decision about it. I think that in the assisted and supervised levels, probably it'll be co-ed. I don't really see any reason not to. When it comes to apartment living, it opens up a can of worms. Personally, I'd prefer people not live together if they're not married. But I think that's something the board of directors is going to have to discuss. I guess that's probably all I can say on the matter at this point.

## How will you protect against the possibility of abuse? What

the only two people who are ever there.

I haven't thought in terms of putting two adults in each home overnight. But what I have certainly thought of is video cameras, two-way windows, or one-way, what's the term?

I basically figured that those will be options that will be offered to the family. If someone wants a camera installed in their child's room to

I will also, in terms of safety measures, have the little walkie-talkie intercom things so that if a staff member is out hiking with someone and someone gets injured or sits down and says, I'm too tired, I can't walk back, that they'll be able to communicate with the rest of the staff and say, hey, I need help out here.

I'm certainly thinking in terms of policies that would safeguard against one-on-one situations. I'm not to the point yet of having formalized those, but if someone's got to go back to their house during the day, then maybe two people have to go with them. Or maybe they've got to turn the camera on or maybe they've got to have the walkie-talkie on. I'm just not to the point of deciding how we're going to handle that but we certainly have thought about it and will do whatever we need to do to make people feel safe.

*You indicate in your business plan that the farmstead program will be funded both with Medicaid money from the Community Care Waiver and the individual's SSI funds. Will the residents have any money of their own or will all their needs be met on the farm?*

***We just believe that people are entitled to a choice if they want to work on a farm. If they're happy working on a farm that also has other people with disabilities working on it, then they ought to have that choice available to them.***

be. We'll give them as much choice as we can.

## Do you plan to have live-in staff?

We're looking at a rotating shift of workers rather than live-in staff and we're doing that for a couple of reasons. My initial reason for doing that was because I don't want my staff to burn out and I think that live-in positions are burn-out positions.

## kinds of safeguards do you intend to implement for the protection and safety of the individuals living and working on the farmstead?

That's another reason that I prefer a group situation, because those kinds of things are less likely to happen when there are other people around, than if you've got somebody just living with a paid room mate and who knows what goes on in the apartment? They're

run continuously or to run every evening, or something, I'm willing to do that.

That's one of the things, in fact, that we've put into the philosophy statement. That we'll go the extra mile in terms of providing peace of mind. If you just want a pane of glass in the door that's covered by a curtain that people can take a quick peek anytime, I'm willing to do whatever makes people comfortable.



Photo: E.G. Stone

***“So there will be opportunities (to go into the community), but it will be whatever kind of naturally needs to be done. We won’t be looking for reasons to bring people into the greater community during the day.”***

*Continued from page 17*

I think certainly the majority of their needs will be met on the property. I think that pocket money is more important to people who are more able. For instance, my son, money means nothing to him. He has no use for it. To give Andrew pocket money, it’s not important.

***What about for those individuals who are more independent, who will be living in the apartments, for example?***

I think that we will work that out somehow. I would like to be able to pay people for the work that they’re doing on the farm, once they get through the vocational training stage. I think that we have to start things slowly and to begin with, it’s going to be vocational training.

When a person gets to the point that they’re able to do some tasks with minimal supervision, it makes sense to pay them for those tasks. Whether we pay piecemeal or hourly, we haven’t worked that out. But I think we can accommodate that need and that will give them a little spending money.

***What kinds of activities will you have available on the farm?***

There will be a dozen jobs or activities available, feeding the animals, cleaning up after them, petting them - that’s going to be a job, to play with the animals, because we don’t want animals that are spooking, nervous around people, that sort of thing. They’ll be working in the greenhouse during warm weather, working in the fields. There’ll be crafts, there’ll be baking, there’ll be therapeutic horseback riding and taking hikes in the woods, all sorts of things.

***Will individuals be able to choose which activities they want to do?***

Certainly, there’s opportunity for someone to say, “I really want to work with animals, but I don’t give a hoot about planting anything,” So, fine. They work with animals and they don’t work in the greenhouse. Someone else

might want to do cooking and crafts and never walk into the barn. That’s fine. Whatever activities they like.

We’ll ask people at the beginning to kind of try out all the different things because there might be an activity they don’t think they’d like but once they try it they find that they do like it. But once they’ve kind of made a choice and decided this is what their schedule is going to be, for the first two hours of the day, they’re going to working in the barn, for the next two hours, they’re going to..whatever, we’re going to strongly encourage them to stick to the schedule. Because that’s their responsibility.

plenty of opportunities to go out into the community evenings and weekends, just like most of us do. Most of us work during the day, and that’s what we do. We don’t go to the mall 11 in the morning. We work. So it’s that normal kind of routine. Even though our work will be a combination of work and recreational activities. It’s not just going to be work all day. There will be recreational activities, too.

For the most part, people will be on the farm during the day. And people who are in the residential program will have their chance to go to the movies or to the mall in the evenings or on weekends, just

looking for reasons to bring people into the greater community during the day.

***In your business plan, you indicate your staff will include an executive director, a secretary, a bookkeeper, a dietician/cook, a nurse/mentor, a day program director/teacher, ten mentors (direct care providers), speech and language, OT, PT and behavioral specialists/consultants, but only one farm manager and a lead craftsperson. Will you be requiring that your mentors have farm experience?***

No. The farmer will

***care providers in the area agencies are approximately \$8.50 an hour. What will allow you to pay your mentors more?***

To some extent, it’s the numbers, I think.

***Because of having a group and having the need for fewer direct care providers?***

Fewer one-on-one, certainly. Because everyone doesn’t need a one-on-one. The system now requires an enormous number of one-on-one people because everyone’s going in a different direction. Nobody’s going to the same spot at the same time. If we were in a situation where there were hundreds of people out of work and everybody looking for a fairly low-paying job, maybe that wouldn’t be an issue. But that’s not the case. People are having a hard time finding direct care workers.

***Do you anticipate having similar difficulties?***

No, I really don’t. When an article went out in one of the papers in the Monadnock area recently - I don’t think it was something I wrote; I think it was someone who had gone to a zoning board meeting and was taking notes and put an article about what we were doing - I got three calls and/or e-mails like within two days from direct care workers working out there who said, oh, this sounds really interesting, can you send me information?

I don’t think I’m going to have a problem. I think we’re creating a program that’s going to be an interesting place to work for everybody. Yes, for everybody.

***Have you had any interest on the part of families?***

I’ve had numerous calls from people interested in sending their child to the program. We did an annual drive last fall that brought in probably \$15,000 by sending an envelope out to our mailing list, which is made up basically of people who have called up and asked for information.

**Interview**

*Continued on page 19*

***“I don’t know if people are threatened by what we’re doing or why we upset people so much because I’m not going to force anyone to come to the farm. It’s a choice and if someone wants to make this choice, then they make it and if they don’t, then they don’t.”***

like most of us do.

Now that isn’t to say that we will never bring someone in the day program out into the community. There’s a birthday coming up in their family and their parent says, do you suppose you could get them to the mall to go shopping? Yes, we can make accommodations now and then.

There will be trips that we need to make into the community when we’ll bring people with us. Maybe we’ve got to go to Sam’s Club to stock up on paper plates or whatever we buy at Sam’s Club. Well, someone will come along.

If we need to go get the oil changed in one of the cars, then someone who enjoys doing that kind of thing will go along for the ride, walk around and look at the cars while the oil is being changed. So there will be opportunities, but it will be whatever kind of naturally needs to be done. We won’t be

be expected to teach a little bit, in terms of letting the mentors know what needs to be done next. We probably will have one mentor assigned as sort of assistant farmer so that if the farmer’s not there, somebody knows what needs to be done.

***Given that, do you think only one person with farming experience is adequate?***

We’re going to have to take it a piece at a time and if we find that we need a second person, one in charge of animals, one in charge of plants and greenhouse, then we’ll work things around to accommodate that need.

***You indicate that your salaries for your direct care providers (or mentors as you call them) will be an average of \$10 an hour plus benefits. Starting salaries for direct***

***What about the choice to take a day off?***

All of us go to work whether we feel like going to work that day or not. It’s the responsible thing to do. People take mental health days. Well, people shouldn’t take mental health days, but they do. So, you know, we’ve got to be reasonably accommodating. If someone’s in the day program and they’re refusing to get out of bed and their parent or guardian says, I don’t want to fight with them, they’re going to take the day off, well, so be it. They take the day off and they don’t come. We want to encourage people to follow through with their responsibilities.

***What choices will individuals have about going into the community?***

Certainly people in the residential program will have

# Area Agencies not enthusiastic about farm program, say it lacks choice.

by: Janet M. Krumm

In order to receive Medicaid funding for individuals in its proposed day and residential programs, Farmsteads of New England (FNE) must be certified by the Bureau of Health Facilities Administration. State regulation HEM-1001 sets the standards by which community residences are either certified or licensed, according to Matthew Ertas of the division of developmental services. Community residences which have three or fewer people must be certified; those residences of more than three must be licensed.

"The certification process looks at safety, staffing and training," Ertas explained. The larger number of people

served, the more emphasis there is on safety, he added.

In addition to the requirements of the Bureau of Health Facilities Administration, the Division of Developmental Services has a provision that requires an organization to apply for a waiver if it serves more than three people in a community residence.

Because Farmsteads of New England plans to build residences for no more than three people, they will not need a license nor a waiver, explained Ertas. But they will need a contractual relationship with an area agency to receive Medicaid funding.

"A vendor agency has to have a relationship with an area agency," Ertas said. "All funding for individuals comes

through an area agency. The vendor and the area agency enter into a contractual relationship to access funding through the system. (Gray) will not get certified until she has demonstrated that she has a contractual relationship with an area agency."

That may not be easy to do.

Roy Gerstenberger, executive director of Community Bridges, Region IV's area agency, reported that Gray had approached his agency to introduce her program and seek support. "A few months ago, she stopped by with materials her board produced," Gerstenberger said, "fliers describing the organization and a copy of the management plan.

"Our reaction," he said,

"was to explain the process in which we assist people identifying what they need or want. I told her this was a model unlikely to gain support for a lot of reasons. It's a congregate setting and people are not asking for congregate settings. The agency does not support congregate settings."

There's also the issue of choice, he added. "It's a narrowly defined living arrangement which requires a lot of people choosing the same thing at the same time, which is not very likely.

It's a choice-driven system," he explained. "Her project appears to be narrowing down choices rather than increasing them."

In recent years, the developmental services system has emphasized self-determination, giving individuals with developmental disabilities and their families more choices and more control over the services they receive. Once an individual receives funding (from newly allocated waiting list funds), the area agency meets with the individual and his or her family to decide what kind of services the individual needs and wants. A list of vendors who contract with the area agency is made available from which the individual and family can choose. These vendors

all have contractual relationships with the area agency, some with more than one agency.

"This is a new kind of presentation," Gerstenberger said. "To have 30 people together - it's a very unique set up. There would not be 30 people in one region who would want to do this," he added, "for one region to hold a contract with the state."

If only one area agency entered into a contractual agreement with Farmsteads of New England, only those families living within that region would be able to use them as a vendor.

Should a family outside of that region want to use FNE as their vendor, they would either have to move into the region which held the contract or prevail upon their agency to enter into an interagency agreement with the area agency who had the contract with FNE, thus allowing the Medicaid funds to flow through their area agency into the other area agency.

There is not a lot of support among the area agency directors for the farm program. Alan Greene, executive director of Monadnock Developmental Services, Region V's area

*Continued on page 21*

## Interview

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**What happens if someone wants to come and there's no money in the area agency - they're on a waiting list?**

I don't know how we can accommodate that unless the people want to come up with the money privately. There aren't too many families who can afford that. I think that initially, it's going to be people who are already funded whose parents hear of this and say, ooh, that sounds better than wiping tables in McDonald's for two hours and wandering around doing nothing for the rest of the day.

**There's a lot of controversy in the disability community about your plans. How do you feel about all that?**

I simply heard that there's controversy. But I certainly understand that we're going against the tide.

**Have you had any phone calls from people who are opposed to what you are doing? Have you gotten any kind of feedback directly?**

I've gotten no phone calls. I've gotten a couple e-mails. And there were people at the zoning board meeting who spoke up, who were philosophically opposed to it. Not that the zoning board meeting

was the appropriate place for that conversation.

I don't know if people are threatened by what we're doing or why we upset people so much because I'm not going to force anyone to come to the farm. It's a choice and if someone wants to make this choice, then they make it and if they don't, then they don't.

**People are saying this is *deja vue* - that Laconia State School started out from the County Farm concept. In the early days, there was a lot of farming, and sewing, and basket making. There were all kinds of activities going on for people and it eventually degenerated into an extremely unpleasant and unfortunate place to be. I think that's why people are concerned. There's that fear that this has the possibility of eventually becoming that. I think they have the sense that we have to stop it now before it can become something completely unmanageable.**

I think that we address those concerns by saying, number one, Laconia turned into what it turned into because it was state owned. And the state was in a position of having to accept people whether they had room or not. People would get dropped on the doorstep and

they had to open their door and take in yet one more.

We're not state owned. We're not going to accept people that we don't have room for. And we're putting a cap. We're saying a maximum of 24 people in residence.

There's also the safeguards just in the system today. Everyone has a team of people who are working with them to make sure they're in a place where they're happy, that they're doing things that are fulfilling to them.

And there are other choices available. If someone comes to our program and after a year, isn't happy there, they don't have to stay. So they get a job coach and go back .....or whatever else they want to do. It's a different world than it was when Laconia started.

So I think that those fears are needless. It's not going to happen, because no one going to let it happen. Even if we wanted to pack people in like sardines, which of course is ludicrous, but even if we wanted to, nobody's going to let us because nobody's going to keep their child with us, if that's what's happening.

## Farm

*Continued from page 16*

an incorporation. Legal documents had to be signed and articles of incorporation had to be created and submitted to the state. Once the incorporation became legal, a board of directors was formed. Only one member of the original advisory board is now on the board of directors. The organization applied for and received a non-profit designation by the IRS. Farmsteads of New England was born.

The next step was to raise money to buy property. Nearly \$200,000 has been raised to date, most from a single large donation, Deborah reported. A recent dinner and silent auction raised \$27,000 - after expenses. Deborah was ready to look for a piece of land.

The goal seemed within reach in late September when

Deborah signed a purchase and sale agreement for a farm in Antrim. However, at a zoning board meeting in Antrim, Deborah found herself surrounded by advocates who opposed her plans. She won the board's approval but discovered later that the owners had withdrawn from the agreement. Undeterred, she began the search anew.

As of late November, she has entered into a purchase and sale agreement for a property in southwestern New Hampshire, but is reluctant to reveal the location until the sale is firm. If all goes well, she expects to close on the property by the end of the year and begin operating her program early in 2003.

## Editorial

### Time for "CAN"

Governor-elect Benson is a man of possibilities. Throughout his successful campaign, we heard over and over "It's time for 'can't' to be over with. It's time for 'can'." We like that attitude.

There's been too much of "can't" in New Hampshire toward our disability community. Even in the corner office these last six years, we've heard: "Can't find money to eliminate the wait list; we can't increase money for existing services." Legislators said: "We can't pay our direct care providers a living wage." When our state coffers ran over with surplus, we heard "can't." Now the coffers run red, we still hear the same message: "Can't."

We agree – it's time for "CAN." Benson has the mandate, and the majority in the House and Senate to make CAN happen. Benson's words to the disability community during his campaign were reassuring – he acknowledged our needs. So, we think CAN should happen.

And this is why.

Since 1989, New Hampshire has remained solvent because of a Medicaid loophole, labeled "Mediscam" by our own disability activists who followed the money. Since the Gregg Administration, our activists can lay a line to state-claimed Medicaid services which was paid to New Hampshire at fifty cents to the dollar. This money gave our state a windfall of free federal Medicaid money totaling over \$1B dollars. For some perspective, a billion dollars equals one thousand million.

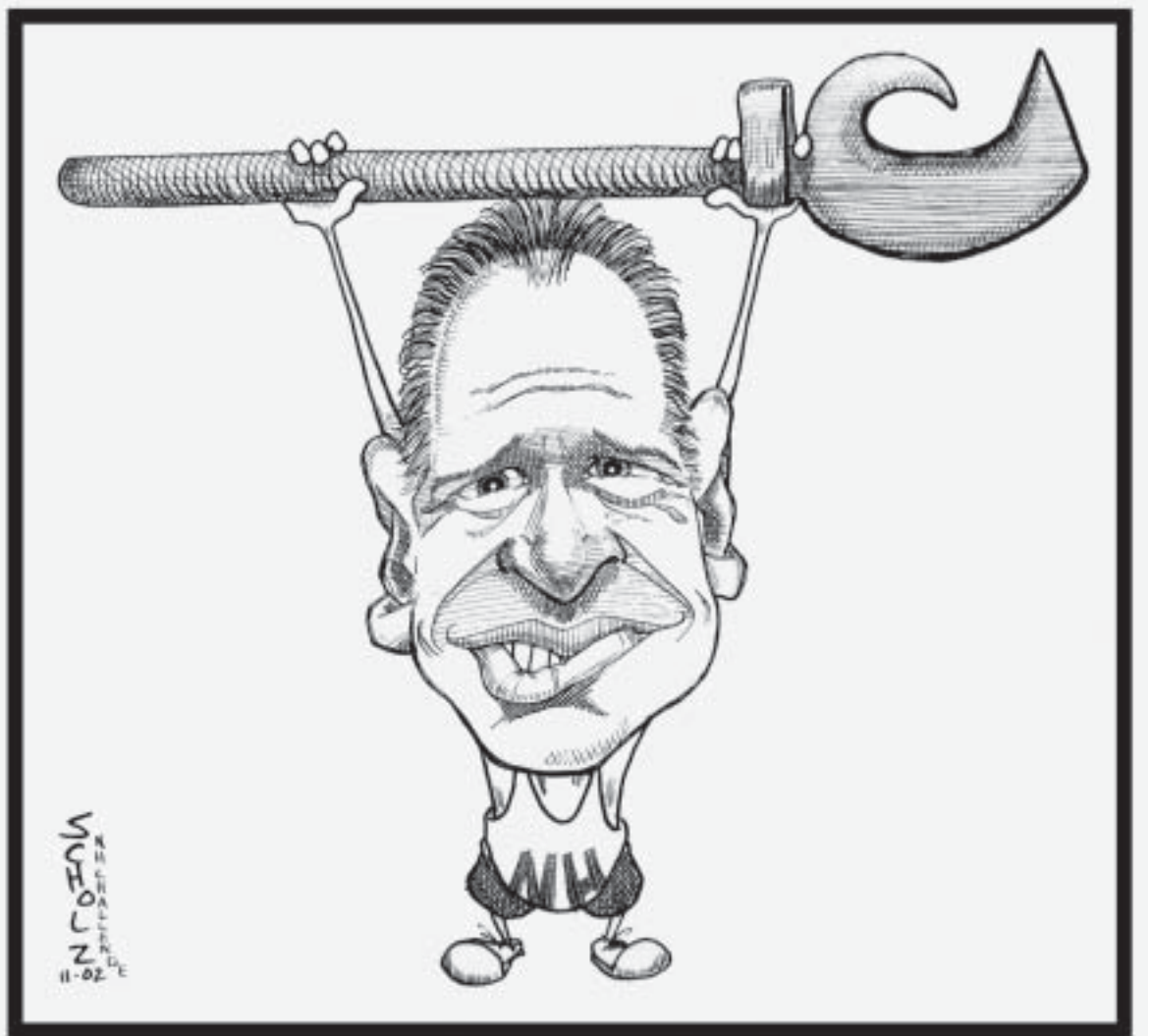
This money was taken in, and cynically placed by our legislative leadership and every Governor (remember the "can't" people) since that time back into the General Fund. There, it was divided up and given to many agencies having absolutely nothing to do with the health and welfare of the fragile New Hampshire citizens against whom the money was claimed. Among the beneficiaries of this money were the State police, the Tourism bureau and the Liquor Commission.

Yes, this was legal. But it is un-ethical, and it stinks. And we are not apologists for Democrats - they did it too. Democrats and Republicans share the responsibility for this scam. MEDISCAM has no party affiliation - the General Court of New Hampshire and every corner office since 1989 together accomplished this sleight-of-hand.

Meanwhile, heaping insult on injury, state agencies during this same time frame, re-defined the critical levels of citizens with disabilities in need. They re-defined some citizens off the wait list, and totally eliminated others. Creating new definitions and categories of need do not cost a cent, but can indicate "improvement" on paper. If anyone asks the families involved who support their loved ones, you will get the same answer... "We are still waiting for services for our family members over 21."

Dennis Powers just submitted a budget to the department of health and human services that contains the money necessary to actually fund services for our adults on the wait list. The cost is \$17.8M of state funds, to be matched (ETHICALLY) with \$17.8M of federal funding over the next two years. If we CAN do this, New Hampshire would use Medicaid money for legitimate Medicaid services, not as a back door to balancing our budget. It CAN happen - "can't" attitudes will continue to shamefully fund the Liquor Commission, State Police and tourism.

Governor-elect Benson, we appeal to you to keep the money in health and human services where it was intended by the U.S. Congress. Use the money ethically, and eliminate the wait list. It's time for CAN!



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or his creative, dedicated and diligent work as our web master these last six years.

With his technical knowledge and his generosity,

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Ken continues to serve The Challenge as the President of our Board of Directors.

Thank you, Ken.



# "We know exactly how this works. There are serious drawbacks about this idea." - Roy Gerstenberger

*Continued from page 19*

agency, did not offer a lot of hope. "Would the area agency enter into a contractual agreement with Farmsteads of New England?" he asked rhetorically. "Possibly. **IF** people wanted to live there. That doesn't mean it's probable," he added.

He agrees with Gerstenberger about the unlikelihood of thirty people in his agency wanting to go to FNE. At the same time, he admitted that "area agencies can not sit in a closed room and made decisions about who gets to live where. It's a market-driven system in which persons with disabilities and their families can choose."

Mark Mills, executive director of Developmental Services of Sullivan County, the area agency in Region II, knew nothing about the project when asked. "Anything that's going to support people with disabilities I would want to learn more about," he said.

He shied away, however, from giving definitive support to the program. "I would definitely want my board involved in that," he said. "This would be a new sort of thing. They've been working to make the organization responsive to families and a resource to the community."

While FNE "doesn't necessarily fit with that view," he added, he would be looking to his board for direction. "Ultimately," he admitted, however, "it's a decision that gets made by our consumers."

"We certainly have always promoted individuals to have choice over their services," Jane Dichard, executive director of Region 10 Community Support Services, Inc. "What is being proposed, however, is not what families are asking for typically," she admitted. But, she added, "We would contract as long as the program's services fulfill the expectation of the (Medicaid) community care waiver. These expectations include: opportunities for individual growth, promoting independence, and providing opportunities for community integra-

tion."

Bob James, executive director of Community Developmental Services, Region VIII's area agency, was more sympathetic, though still wary. "I am understanding of any option a parent wishes for their son or daughter," he said. "We have a strong commitment to community-based services and inclusion, but there are times when families find something else that they think is appropriate.

"I can't say at this point whether we will fund (or not),

gated program. "I will not support a segregated model," he insisted. But, "would I prohibit it? I don't know."

There are other reasons to be wary about this model, James added. "There is a 'security of place' that is seductive," he suggested. But that security may be an illusion.

Even people living on a farm "are still going to be beholden to the legislative process of the allocation of Medicaid dollars," Gerstenberger stated. "They will have to worry about the next commissioner and Gov-

Gerstenberger insisted. "If there is a large number of people, the staff need to tend to those whose needs are demanding, leaving the others without assistance."

Another myth is that a group of people with disabilities will learn from each other. "You have marked diminishment in teaching new skills," he said. "In this model, the individual is with people who are similarly struggling. He or she doesn't have models who are experienced. It makes it difficult to learn absent any effective demonstration. You don't surround

idea when we gave it a good shot

"It didn't turn out to be a good idea," he added. "We were working with phenomenally dedicated people to make the model work, and it didn't. Our fears should not lead us to go back to old models. They should lead us to explore new models.

"All we can do is rely on the very real experience that we've all had," he concluded.

Despite the reluctance they expressed, all the area agency directors admitted that families may see in this model an alternative to services that are not working for them. "Our community based system of services and inclusion - we promised a great deal but we've fallen short in a lot of ways," James admitted. "People have days that are very boring. We don't have high enough expectations."

"There's a void in getting people involved in the community," Mills agreed. "Our system has failed. We've failed to do that."

"I would agree completely with the description that many things are not what they should be," Gerstenberger admitted. "But we should begin somewhere else, have a different starting point. Invest more time in planning, imagining a real life for a person's son or daughter. What's available for support? What can be activated to build support for all their life?"

Referring to the idea of establishing the farm for people with autism, Gerstenberger stated: "A diagnosis provides a key to services. It has nothing to do with who they ought to be with." He sees the task of the area agencies to "activate what we would hope to be a varied and multi-faceted support system throughout their life."

***"I would agree completely with the description that many things are not what they should be. But we should begin somewhere else, have a different starting point. Invest more time in planning, imagining a real life for a person's son or daughter. What's available for support? What can be activated to build support for all their life?... Our fears should not lead us to go back to old models. They should lead us to explore new models."***

***Roy Gerstenberger, director  
Community Bridges***

but we will not because of ideology take anything off the table."

James has had serious health problems in recent years and has two children who are receiving special education services. "I really hate it when officials beforehand make decisions about my life."

Gray met with James a while ago to talk about her plans. "In our talk, I encouraged her to develop it more inclusively," he said. Her plan "harkens back to a time when we put people with disabilities on farms; it has bad connotations," added. "A fully integrated model would be a good option."

James expressed admiration for Gray. "She's an interesting person. I applaud her," he said. "I think it's great when somebody takes the initiative to do something new. More options for people are good."

Still, he has concerns about the farm being a segre-

gated program.

Past experience has lessons to teach as well. "There are a lot of people in a lot of organizations in the state providing services who have experience with congregate living," Gerstenberger stated. "We know exactly how this works. There are serious drawbacks about this idea.

"I have not run a 30 bed home, but I did run an operation with eight people," he stated. "As director, I would have the responsibility to speak with people about the drawbacks, give voice for the hundreds of people who are currently involved in our system who know the downfalls."

What are those downfalls?

One is the illusion that the ration of staff to individuals will go down in a larger congregate setting. "One to three or one to four is a false representation of the reality,"

people with disabilities only with other people with disabilities when you are trying to advance skills."

Turnover rates in group settings are just as high as anywhere else, Gerstenberger asserted, "and the consequences are just as devastating. It's an artificial environment by definition. In a staff-dependent home, staff create the nature of the home. When they leave and new staff come in, the nature of the home completely shifts.

"We're not talking about something new here," Gerstenberger emphasized. "Conceptually, congregate living was a good idea. It was good

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# Upcoming Events

## December

10

### Positive Approaches to Managing Difficult Behaviors –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenters:** Derek Wilson and Colin Newton, co-founders of Inclusive Solutions, Nottingham, England

**Location:** Society for the Protection of NH Forests, Concord, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

11-14

### Our Quest: Opportunity, Equality, Justice

#### 2002 TASH Conference

Co-sponsored by: TASH New England, The Institute on Disability/UCE, UNH [www.iod.unh.edu](http://www.iod.unh.edu), The Center for Community Inclusion, University of Maine/UCE

[www.ume.maine.edu/~cci](http://www.ume.maine.edu/~cci), Center on Disability & Community Inclusion of Vermont [www.uvm.edu/~cdci/](http://www.uvm.edu/~cdci/), and the Autism National Committee [www.autocom.org](http://www.autocom.org)

**Location:** Sheraton Boston and Hynes Convention Center

**Cost:** \$89 (family member or person with a disability), \$164 (student), \$244 (individual registration), \$154 (one day – Thursday or Friday), \$59 (Saturday only)

**For more information,** call 1-800-482-TASH (8274)

E-mail: [registration@tash.org](mailto:registration@tash.org)  
Website: [www.tash.org](http://www.tash.org)

## January

9

### Providing Individualized Support to Young Children with PDD/Autism and Related Issues:

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Ann Donoghue Dillon, Institute on Disability, UNH

**Location:** College for Lifelong Learning, Bow, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

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### Upper Valley Regional SONH Winter Games

hosted by the Dartmouth Club of the Upper Valley  
Location:

Alpone skiing - Dartmouth Skiway, Lyme, NH

Cross country skiing & snow shoeing - Garipay Field, Hanover, NH

**For more information,** contact Games Director Pete Bleyler at 795-9912

## February

2-4

### 6<sup>th</sup> Special Olympics NH Annual Winter Games

**Location:** Waterville Valley, NH

**For more information,** call 603-624-1250 or 1-800-639-2608

Website: [www.sonh.org](http://www.sonh.org)

5

### Using Functional Assessment to Create Effective Support Plans –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenters:** Cathy Apfel, Institute on Disability, UNH

**Location:** Elms Conference Center, Highlander Hotel,

Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

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### Life as a Paraprofessional: Strategies for Working with Students with Challenging Behaviors –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cathy Apfel, M.Ed., Institute on Disability, UNH

**Location:** Elms Conference Center, Highlander Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

## March

5

### Beyond Inclusion 101: Using Reflective Practice to Enhance Students' Participation & Achievement

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cheryl Jorgensen, Ph.D., Institute on Disability, UNH

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

### Supporting Students with Autism/PDD in General Education Classes –

Sponsored by the University

of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cathy Apfel, M.Ed., Institute on Disability, UNH

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

### Standards, Assessments, and IEPs: Planning for Success in the General Curriculum –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Michael McSheehan, Participation ETC, Providence, Rhode Island

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

### Difference Between High School and College –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cate Weir, Institute on Disability, UNH

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

### Promoting Responsible Student Behavior: A School-Wide Disciplinary Approach

Sponsored by the University

of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Jon Udis, Consultant, Upstream Educational Services, Montpelier, Vermont

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

### The Role of the Classroom Assistant in General Education Classrooms: Promoting Independence

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenters:** Frank Sgambati, Institute on Disability, UNH

**Location:** Center of New Hampshire Holiday Inn, Manchester, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

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### Physical Education and Wellness for All Students –

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Michelle Grenier, UNH

**Location:** Morning - New Hampshire Hall, UNH Afternoon - The Brown Center, Durham, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more

**For more information,** contact 603-228-2084

# 2002 TASH Conference Held in Boston

UNH's Institute on  
Disability is a Proud  
Sponsor

*It's not too late  
to attend.....  
Register onsite!*

BOSTON – When goals and visions are shared, community ties increase in strength. That is why the Institute on Disability at the University of New Hampshire is proud to be a Gold-level sponsor of this year's International TASH Conference, set for Dec. 11-14, 2002 at the Sheraton Boston and John B. Hynes Convention Center.

The 27<sup>th</sup> TASH Conference showcases innovative "how-to" strategies, research, empowering stories and more than 350 breakout sessions that include cutting-edge, practical information about changing images, attitudes and systems to empower individuals with disabilities and their families.

Individuals with disabilities and families play an important role in this conference, making it a diverse and rich environment to exchange strategies and stories.

Keynote speakers include Jamie Burke, a 16-year-old sophomore at Westhill High School in Syracuse, NY, who is fully included in a Regents Academic track program. Burke has used facilitated communication since age five and recently wrote and narrated a documentary video entitled "Inside the Edge: A Journey to Using Speech Through Typing," produced by Syracuse University. Burke is a frequent speaker at conferences and enjoys reading, bowling, the Syracuse Symphony, and is a member of the Young Actors Workshop of Syracuse Stage.

Robert Hayman, Jr. will also join the conference as a keynote speaker. Hayman is a Professor of Law at Widener

University of Law in Delaware where he teaches and writes in the areas of Constitutional law, civil rights, equal protection law, and jurisprudence. In his recent book *The Smart Culture: Society, Intelligence, and Law*, Hayman explores pervasive American cultural assumptions of natural inequality. Interweaving engaging narratives with dramatic case studies, *The Smart Culture* is a history of intelligence that challenges our notions about who is smart and who is not.

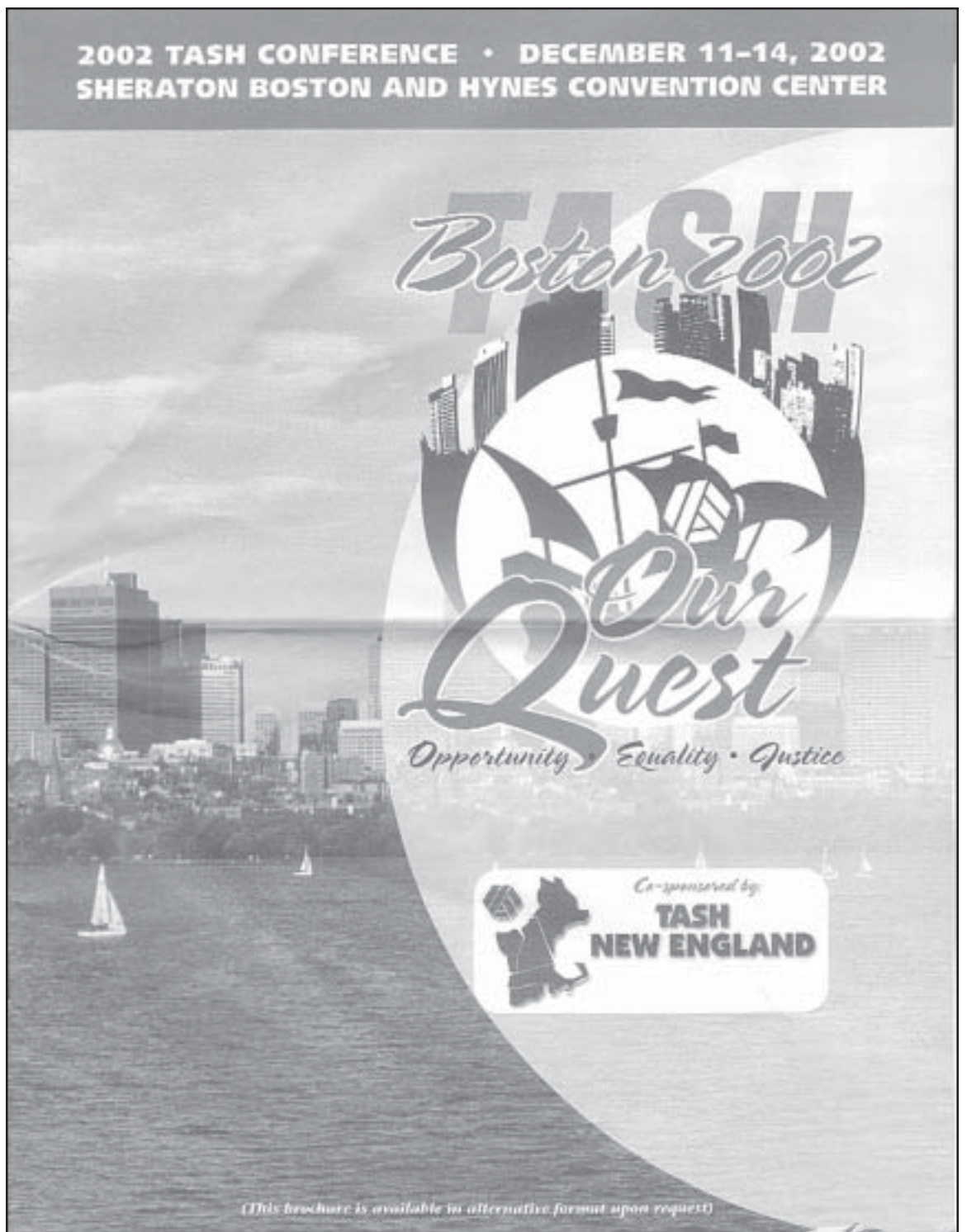
More than 30 topic strands offer participants a variety of lectures and sessions to choose from, including:

- Self-Determination with Laurie Powers: Exploring multiple perspectives on personal, community, and systems approaches for promoting self-determination.

- Voices of Friendship with Carol Tashie: If everyone agrees friendship is important, why do so many kids still not have real friends?

- Removing the Barriers to Full Inclusion with Cheryl Jorgensen: Why is the realization of "full inclusion" so difficult when we know its benefits?

The Institute on Disability supports TASH's belief that all people, regardless of their label or perceived level of disability, should have the supports they need to direct the course of their own lives, and to live and participate successfully in the community.



## Upcoming Events, continued

### April 8

#### **The Evolving Role of the Inclusion Facilitator: Skills for Addressing "Second Generation" Inclusion Barriers**

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cheryl Jorgensen, Ph.D., Institute on Disability, UNH

**Location:** Society for the Protection of NH Forests, Concord, NH  
**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more  
**For more information,** contact 603-228-2084

### May

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#### **Tools and Materials for Constructing Low Cost Assistive Technology Solutions for Students with Disabilities –**

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Therese Willkomm, Ph.D., ATECH Services

**Location:** Doloff Building, ASSETT Conference Room, Concord, NH  
**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more  
**For more information,** contact 603-228-2084

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#### **Breaking Down the REAL Barriers to Full Inclusion –**

Sponsored by the University of New Hampshire's Institute on Disability/UCE and the NH Department of Education

**Presenter:** Cheryl Jorgensen, Ph.D., Institute on Disability, UNH

**Location:** Society for the Protection of NH Forests, Concord, NH

**Time:** 9:00 am – 3:00 pm (registration and coffee begins at 8:30 am)

**Cost:** \$60.00/per person for individuals, \$55.00/per person for teams of three or more  
**For more information,** contact 603-228-2084

# Area Agencies

## for Developmental Services

### REGION I

#### North Country

#### Northern New Hampshire Mental Health and Developmental Services, Inc.

87 Washington Street  
Conway, New Hampshire 03818

**Dennis MacKay, Exec Dir.**

**Eric Johnson, Assoc. Director**

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

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

#### Area Offices:

#### Upper Connecticut Valley Mental Health and Developmental Services(MH)

Charlie Cotton, Area Director  
34 Colby Street

Colebrook, New Hampshire 03576

**Phone:** 237-4955

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

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

Jane MacKay, Area Director

**Phone:** 444-5358

#### Family Centered Early Supports and Services

31 Brooklyn Street Groveton, New Hampshire 03582

Director: Pat Arneson

**Phone:** 636-6193 or 1 (800) 862-8634

**E-mail:** [parneson@nnhmhds.org](mailto:parneson@nnhmhds.org)

#### Developmental Specialists:

**Berlin/Groveton:** Stacia Losier Phone: 752-3009, (800) 862-8634 [slosier@nnhmhds.org](mailto:slosier@nnhmhds.org)

**Littleton:** Peg Roy Phone: 444-1742 x4 [mroy@nnhmhds.org](mailto:mroy@nnhmhds.org)

#### Developmental Services:

Community Services Center  
69 Willard Street

Berlin, New Hampshire 03570

Art Froburg, Area Director

**Phone:** 752-1005

#### Common Ground

headquarters for day service & case management

29 Maple Street, Box 599

Littleton, NH 03561

**Phone:** 444-6894

#### Vershire Center

39 Colby Street

Colebrook, NH

**Phone:** 237-5721

#### Berlin area -

**Family support coordinator:** Lena Parent 466-9010 x 3343 [lparent@nnhmhds.org](mailto:lparent@nnhmhds.org)

**Respite coordinator:** Same

**Benefits Technician:** Sharon Kolinsky 752-1005 x 3307 [skolinsky@nnhmhds.org](mailto:skolinsky@nnhmhds.org)

#### Colebrook/Groveton -

**Family support coordinator:** Stacey Bilodeau 636-6193, or (800) 862-8634  
[sbilodeau@nnhmhds.org](mailto:sbilodeau@nnhmhds.org)

**Respite coordinator:** Same

**Benefits Technician:** Lynda Biron 237-5721 [lbiron@nnhmhds.org](mailto:lbiron@nnhmhds.org)

#### Littleton -

**Family support coordinator:** Diana Flick 444-1742 x6 [dflick@nnhmhds.org](mailto:dflick@nnhmhds.org)

**Respite Coordinator:** Same

**Benefits Technician:** Susan Beauchamps 444-5358

**Family Support Council Chair:** Cecile Fillion 752-5704 [cecilefi@ncia.net](mailto:cecilefi@ncia.net)

### REGION II

#### Sullivan County

#### Developmental Services of Sullivan County, Inc.

R.F.D. #3, Box 305, Claremont, New Hampshire 03743

**Mark Mills, Exec Director**

**Phone:** 542-8706

**Case Management:** 542-8706

**Adult Services:** 542-8706e-mail: [mmills@dsscofnh.org](mailto:mmills@dsscofnh.org)

**Family support coordinator:** Kristina Allen 542-8706

[Kallen@dsscofnh.org](mailto:Kallen@dsscofnh.org)

**Respite coordinator:** Jean Sorrell 542-8706

[Jsorrell@dsscofnh.org](mailto:Jsorrell@dsscofnh.org)

**Early Supports and Services:** Dora Maxwell, 542-8706 x135

[Dmaxwell@dsscofnh.org](mailto:Dmaxwell@dsscofnh.org)

**Benefits Technician:** Rhonda Desmaris 542-8706 x114

[Rdesmaris@dsscofnh.org](mailto:Rdesmaris@dsscofnh.org)

**Family Support Council Chair:** John Milliken 826-436

[rollingthunder@madscope.com](mailto:rollingthunder@madscope.com)

### REGION III

#### Lakes Region

#### Lakes Region Community Services Council

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

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

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

**Rich Crocker, Exec. Director**

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

**E-mail:** [richc@lrcsc.org](mailto:richc@lrcsc.org) **Website:** [www.lrcsc.org](http://www.lrcsc.org)

**Family support coordinator:** Christine Santaniello 524-7755

[chriiss@lrcsc.org](mailto:chriiss@lrcsc.org)

**Respite coordinator:** Susan Tolcser 524-7755

[susant@lrcsc.org](mailto:susant@lrcsc.org)

**Community Builder:** Denise Sleeper 524-7755

[denises@lrcsc.org](mailto:denises@lrcsc.org)

**Benefits technician:** Lisa Richardson 524-8811 1

[richardson@lrcsc.org](mailto:richardson@lrcsc.org)

**Family support council chair:** Susan Gunther 293-7371

[smgunther51@juno.com](mailto:smgunther51@juno.com)

### REGION IV

#### Capitol District

#### Community Bridges

525 Clinton Street, Bow, New Hampshire 03304-4609

**Roy Gerstenberger, Exec. Dir.**

**Phone:** 225-4153 or 800-499-4153

**E-mail:** [rgerstenburger@communitybridgesnh.org](mailto:rgerstenburger@communitybridgesnh.org)

**Website:** [www.communitybridges.org](http://www.communitybridges.org)

**Family support coordinator:** Jo Edwards 225-4153 (800)499-

4153, ext.224 [jedwards@communitybridgesnh.org](mailto:jedwards@communitybridgesnh.org)

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

4153, ext.215 [rcarlisle@communitybridgesnh.org](mailto:rcarlisle@communitybridgesnh.org)

**Benefits Technician:** Rebecca Spinney 225-4153 ext. 222

[rspinney@communitybridgesnh.org](mailto:rspinney@communitybridgesnh.org)

**Family support council chair:** AnnetteKowalczyk 224-1524

[akowalczyk@attbi.com](mailto:akowalczyk@attbi.com)

### 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](mailto:alan@mds-nh.org) **Website:** [www.mds-nh.org](http://www.mds-nh.org)

**Family support coordinator:** Bob Barrows 352-1304 (800)

469-6082 [bob@mds-nh.org](mailto:bob@mds-nh.org)

**Respite coordinator:** Carol Burns 352-1304

[carolb@mds-nh.org](mailto:carolb@mds-nh.org)

**Benefits technician:** Sue Raymond 352-1304 [sue@mds-nh.org](mailto:sue@mds-nh.org)

**Early Supports and Services:** Anna Lake 352-1304

[Anna@mds-nh.org](mailto:Anna@mds-nh.org)

**Family support council chair:** Cameron Tease 827-3538 c

[tease@marken.com](mailto:tease@marken.com)

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

[brianlogan@aol.com](mailto:brianlogan@aol.com)



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

144 Canal Street, Nashua, New Hampshire 03060

**Sandra Pelletier, Exec. Dir. Beth Raymond, Assoc. Dir.****Phone:** 882-6333 **Fax:** 889-5460**E-mail:** sandyp@region6.com **Website:** www.region6.com**Affiliate Agencies:****The PLUS Company, Inc.**

240 Main Dunstable Road, Nashua, NH 03062

**Kim Shottes, Exec. Dir.****Phone:** 889-0652 **Fax:** 880-8938**E-mail:** kims@region6.com **Website:** www.thepluscompany.net**Adult Day Service Program**

200 Derry Road, Hudson, NH 03051-3398

**Deb Wall, Director****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:** nancyd@region6.com**Family support coordinator:** Nzenalu Obinelo 882-6333, ext. 372[nzenaluo@region6.com](mailto:nzenaluo@region6.com)**Partners in Health Family Support Coordinator:** Karin Harvey-Olsen 882-6333 x373 Fax: 889-5460 [karinh@region6.com](mailto:karinh@region6.com)**Respite coordinator:** Carole Smith 882-6333 x 325 [caroles@region6.com](mailto:caroles@region6.com)**Benefits technician:** Diane Luszy 882-6333 [dianel@region6.com](mailto:dianel@region6.com)**Intake Coordinator:** Sue Rockwell 882-6333 [suer@region6.com](mailto:suer@region6.com)**Family support council chair:** Peter Marcoux 888-5894[pmarcoux@verizon.net](mailto:pmarcoux@verizon.net)**REGION IX****Strafford County****Behavioral Health and Developmental Services of Strafford County, Inc**

Forum Court. 113 Crosby Road, Suite #1,

Dover, New Hampshire 03820-4375

**Brian Collins, Exec. Director****Phone:** 749-4015 **Fax:** 743-3244**E-mail:** bricol@concentric.net **Website:** www.dssc9.org**Family support coordinator:** Deirdre Watson 749-4015 [dwatson@dssc9.org](mailto:dwatson@dssc9.org)**Respite coordinator:** Karen Juckett 749-4015 [kjuckett@dssc9.org](mailto:kjuckett@dssc9.org)**Early Supports and Services:** Suzanne Iverson 740-4015 [siverson@dssc9.org](mailto:siverson@dssc9.org)**Benefits specialist:** Julie Batchelder 749-4015 [jbachelde@dssc9.org](mailto:jbachelde@dssc9.org)**Family support council chair:** Chuck Raymond 743-3909 [chuckray@ttlc.net](mailto:chuckray@ttlc.net)**Family support council vice-chair:** Karen Salter 692-2088 [ksalter@aol.com](mailto:ksalter@aol.com)**REGION X****Atkinson/Salem****Region 10 Community Support Services, Inc.**

8 Commerce Drive, Atkinson, New Hampshire 03811

**Jane Dichard, Exec. Director****Phone:** 893-1299 **Fax:** 893-5401**E-mail:** dpowers@region10nh.com **Website:** www.region10nh.com**Family support coordinator:** Kathy Waterson 893-1299[kwaterson@region10nh.com](mailto:kwaterson@region10nh.com)**Respite coordinator:** presently vacant**Early Supports and Services:** Aleece Pappas 893-1299[apappas@region10nh.com](mailto:apappas@region10nh.com)**Benefits technician:** Deanna Johnson 893-1299 [djohnson@region10nh.com](mailto:djohnson@region10nh.com)**Family support council chair:** Carol Ingram 893-1129 [carol-ingram@rcn.com](mailto:carol-ingram@rcn.com)**REGION XI****Carroll County****Center of Hope, Inc.**

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

**Peter Blue, Exec Director****E-mail:** pblue@centerofhope.org**Margie Matthews, Associate Executive Director****E-mail:** mmathews@centerofhope.org**Phone:** 356-6921 or (800) 290-0905 **Fax:** 356-6310**Director of Family Support:** Christine MacDonald 356-6921 x 52(800) 290-0905 [cmacdonald@centerofhope.org](mailto:cmacdonald@centerofhope.org)**Respite coordinator:** Tina Wallace 356-6921 x 29 [twallace@centerofhope.org](mailto:twallace@centerofhope.org)**Benefits technician:** Lindelle Gorham 356-6921 x26[lgorham@centerofhope.org](mailto:lgorham@centerofhope.org)**Family support council chair:** Frances Hyslop 539-5429 [ece4me@ttlc.net](mailto:ece4me@ttlc.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**

104 Lyme Road, Hanover, New Hampshire 03755

**Kathy Marshall, Coordinator****Phone:** 643-5439 **Fax:** 643-6223**E-mail:** [Kathy@uds.org](mailto:Kathy@uds.org)**Family support coordinator:** Tara Mullen 443-4109 [tara@uds.org](mailto:tara@uds.org)**Respite coordinator:** Melissa Eastman 443-4113 [melissa@uds.org](mailto:melissa@uds.org)**Benefits technician:** vacant**Family support council chair:** Elizabeth Larson 448-5302[elizabeth.s.larsen@hitchcock.org](mailto:elizabeth.s.larsen@hitchcock.org)**Upper Valley Support Group (UVSG)** (provides emotional support & info)**Phone:** 448-6311 UVSG**Respite Program coordinator:** Leona Ryder 448-1268**REGION VII****Manchester****Moore Center Services, Inc.**

132 Titus Avenue, Manchester, New Hampshire 03103

**Paul Boynton, CEO****Phone:** 668-5423 **Fax:** 206-2706**E-mail:** paul.boynton@moorecenter.org **Website:** www.moorecenter.org**Family support coordinator:** Jan Larsen 206-2744[jan.larsen@moorecenter.org](mailto:jan.larsen@moorecenter.org)**Respite coordinator:** Joy King 206-2743 [joy.king@moorecenter.org](mailto:joy.king@moorecenter.org)**Early Supports and Services:** Susan Sakowicz 206-2804[susan.sakowicz@moorecenter.org](mailto:susan.sakowicz@moorecenter.org)**Benefits technicians:** Linda Lawrence 206-2768[linda.lawrence@moorecenter.org](mailto:linda.lawrence@moorecenter.org)

Audrey Mason 206-2770

[audrey.mason@moorecenter.org](mailto:audrey.mason@moorecenter.org)**Family support council chair:** Donna Nicholaides 624-1592[donna.nicholkildes@yahoo.com](mailto:donna.nicholkildes@yahoo.com)**REGION VIII****Seacoast****Region VIII Community Developmental Services Agency, Inc.**

Parade Office Mall, Suite 40195 Hanover Street

Portsmouth, New Hampshire 03801

**Bob James, Exec Director Cathy King, Associate Executive Director****Phone:** 436-6111 **Fax:** 436-4622**E-mail:** bob@cdsregion8.org**Family Support and Early Supports and Services:** Lenore Sciuto 436-6111[lenore@cdsregion8.org](mailto:lenore@cdsregion8.org)**Resource coordinator:** Judy Sadler 436-6111, x334 [judy@cdsregion8.org](mailto:judy@cdsregion8.org)**Respite coordinator:** Geoff Simons 436-6111 [geiff@cdsregion8.org](mailto:geiff@cdsregion8.org)**Benefits technician:** Denise Larsen 436-6111 [denise@cdsregion8.org](mailto:denise@cdsregion8.org)**Family support council chair:** Kathy Ennis 964-9740[Kennis@northeastrehab.org](mailto:Kennis@northeastrehab.org)



# Where to Find Help

## Statewide Resources:

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

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

**NH-ATEC**  
1-800-932-5837  
Seating & mobility  
Augmentative & alternative communication  
Computer access  
Home & worksite modifications

**ASSETT - Assistive Services to Schools for Education, Technology and Training -**  
226-2900  
Consultations & Technical assistance; Loans of specialized equipment and materials; Training for educators, parents & children; Library for families & educators

**REM (Refurbished Equipment Marketplace)**  
224-7630 or 1 (800) 427-3338  
**e-mail:** [pluff@nhaat.mv.com](mailto:pluff@nhaat.mv.com)  
**website:**  
[www.neatexchange.org](http://www.neatexchange.org)  
Sale of quality refurbished equipment; Rentals, service & repair; Information & referral services; Inventory on website

**TECH-LAB**  
117 Pleasant Street  
Dolloff Bldg.  
Concord, NH 03301  
226-2900  
Hands-on technology exploration; loans of assistive technology; training; technical support

**Autism Society of New Hampshire** 898-0916  
Statewide organization provides information, advocacy and support to individuals with Autism and Pervasive Developmental Disorders (PDD), and their families.

**Brain Injury Association of New Hampshire**  
225-8400, or (800) 773-8400

**www.bianh.org**  
Statewide organization provides resource information to survivors of brain injury and their families.

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

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

**Council for Children and Adolescents with Chronic Health Conditions and their Families**  
**Peter Clarke**  
271-4991 or 1-800-852-3345 X4991  
**Fax:** 271-5166  
**cell:** (603) 396-9238  
**e-mail:**  
[pclarke@dhhs.state.nh.us](mailto:pclarke@dhhs.state.nh.us)  
**Website:** [www.ccachc.org](http://www.ccachc.org)  
Information and advocacy

**Department of Education Bureau of Special Education**  
271-3494 **Fax:** 271-1953  
[www.ed.state.nh.us](http://www.ed.state.nh.us)  
Responsible for ensuring that school districts provide a free and appropriate education to all educationally handicapped students

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

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

**Early Education and Intervention Network of N.H.**  
228-2040 [www.eein.org](http://www.eein.org)  
**e-mail:** [eeinnh@earthlink.net](mailto:eeinnh@earthlink.net)  
Information/referral; early intervention and pre-school programs for children with devel-

opmental disabilities or at risk for developmental delay.

**Family Resource Connection**  
271-7931 or 1-800-298-4321  
**e-mail:**  
[FRC@finch.nhsl.lib.nh.us](mailto:FRC@finch.nhsl.lib.nh.us)  
**Website:**  
[www.state.nh.us/nhsl/frc/](http://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](mailto:kbregler@dhhs.state.nh.us)  
Can direct you to services available through the Division of Developmental Services (DDS), the 12 Regional Area Agencies and Regional Family Support Programs

**Governor's Commission on Disability**  
271-2773 (Voice),  
271-2774 (TTY)  
1-800-852-3405 (Voice)  
**Fax:** 271-2837  
[www.state.nh.us/disability](http://www.state.nh.us/disability)  
Information and referral

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

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

**Institute on Disability/UCE**  
228-2084 **Fax:** 228-3270  
862-4320 **Fax:** 862-0555  
[www.iod.unh.edu](http://www.iod.unh.edu)  
Training, technical assistance and resources with the goal of improving the quality of life and level of participation of people

with disabilities in schools, the community and the workplace

**Medical Genetics** 650-7886  
Genetic testing and counseling, information and referral

**M.I.C.E. (Multi-sensory Intervention through Consultation and Education)**  
228-1028(V) 228-5755 (TTY)  
Statewide program for educational and developmental services for children birth through three with visual or hearing impairments.

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

**N.H. Developmental Disabilities Council**  
271-3236  
1-800-852-3345, x 3236  
[www.nh.ddc.com](http://www.nh.ddc.com)  
Monitors services; promotes policy; advocacy

**NH Family Voices, a Family to Family Health Information and Resource Project**  
271-4525, or 1 (800) 852-3345 x 4525  
**e-mail:** [NHFV@yahoo.com](mailto:NHFV@yahoo.com)  
**website:** [www.nhfv.org](http://www.nhfv.org)  
Assists families in finding their way through the maze of services by providing information and emotional support, identifying resources available within the community, and making available a lending library of books, videos and audio tapes; distributes free newsletter, *Pass It On*

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

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

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

**Parent to Parent of NH**  
1-800-698-5465  
[www.p2pnh.org](http://www.p2pnh.org)  
**e-mail:** [contact@p2pnh.org](mailto:contact@p2pnh.org)  
Specializes in networking parents of children with special needs; support and information

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

**Seacoast Child Development Clinic at UNH**  
862-0561 (Voice/TDD)  
862-0034 (fax)  
[www.iod.unh.edu](http://www.iod.unh.edu)

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

**Self-Determination for Persons with Developmental Disabilities - Institute on Disability/UAP**  
862-4320 **Fax:** 862-0555  
[www.iod.unh.edu](http://www.iod.unh.edu)  
Provides information, referral and technical assistance

**Special Olympics NH**  
624-1250 or 1-800-639-2608  
**Fax:** 624-4911  
**website:** [www.sonh.org](http://www.sonh.org)  
Provides sports activities for athletes with developmental disabilities.

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

**VSA arts of New Hampshire**  
228-4330  
**e-mail:** [info@vsartsnh.org](mailto:info@vsartsnh.org)  
**website:** [www.vsarts.org](http://www.vsarts.org)  
Provides opportunities in the arts for people with disabilities



# Where to Find Help

## 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](http://www.disabilitysolutions.org)

[subscription@disabilitysolutions.org](mailto:subscription@disabilitysolutions.org)

### **Exceptional Parent Magazine**

Paid subscription \$39.95 a year (201) 489-4111 1 (877) 372-7368

website: [www.EParent.com](http://www.EParent.com)

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

### **New Developments**

Benefit of membership (301) 652-2263

website: [www.devdelay.org](http://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.

### **Family Voices**

FREE

800-852-3345 x 4525

e-mail: [nhfv@yahoo.com](mailto:nhfv@yahoo.com)

website: [www.nhfv.org](http://www.nhfv.org)

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

### **Ragged Edge**

Paid subscription \$17.00 a year Fax: (502) 899-9562

e-mail: [circulation@raggededgemagazine.com](mailto:circulation@raggededgemagazine.com)

website: [www.raggededgemagazine.com](http://www.raggededgemagazine.com)

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

***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@attbi.com](mailto:nhchallenge@attbi.com)***

How important is The Challenge to you and your family?  
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Phone number \_\_\_\_\_

E-mail \_\_\_\_\_

Send your donation to:  
The New Hampshire Challenge  
P.O. Box 579  
Dover, NH 03821-0579

## Helpful Websites:

**[www.aapd.com](http://www.aapd.com)**

American Association of People with Disabilities

**[www.access-able.com/](http://www.access-able.com/)**

Access-Able Travel Resource

**[www.adanet.org](http://www.adanet.org)**

American Disability Association

**[www.albinism.org](http://www.albinism.org)**

The National Organization for Albinism and Hypopigmentation

**<http://aspe.os.dhhs.gov/cfda>**

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

**[www.assistguide.com](http://www.assistguide.com)**

Assist Guide - National resource for disability and long term care

**[www.csni.org](http://www.csni.org)**

Community Support Network, Inc.

**[www.disabilityresource.com](http://www.disabilityresource.com)**

The Disability Resource

**[www.disabilitynews.com](http://www.disabilitynews.com)**

Disability News Service

**[www.eseals.org](http://www.eseals.org)**

Easter Seals NH

**[www.essential schools.org](http://www.essential schools.org)**

Coalition of Essential Schools

**[www.cms.hhs.gov](http://www.cms.hhs.gov)**

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

**[www.hhs.gov/newfreedom/](http://www.hhs.gov/newfreedom/)**

US Department of Health and Human Services' New Freedom Initiative

**[www.newhorizons.org](http://www.newhorizons.org)**

New Horizons for Learning

**[www.nhhelpline.org](http://www.nhhelpline.org)**

New Hampshire Help Line

**[www.nichcy.org](http://www.nichcy.org)**

National Information Center for Children and Youth with Disabilities

**[www.nod.org](http://www.nod.org)**

National Organization on Disability

**[www.ppcd.org](http://www.ppcd.org)**

People to People Committee on Disability

**[www.sath.org](http://www.sath.org)**

Society for the Accessible Travel & Hospitality

**[www.skimhs.org](http://www.skimhs.org)**

Maine Handicapped Skiing

**[www.ssa.gov.SSA\\_Home.html](http://www.ssa.gov.SSA_Home.html)**

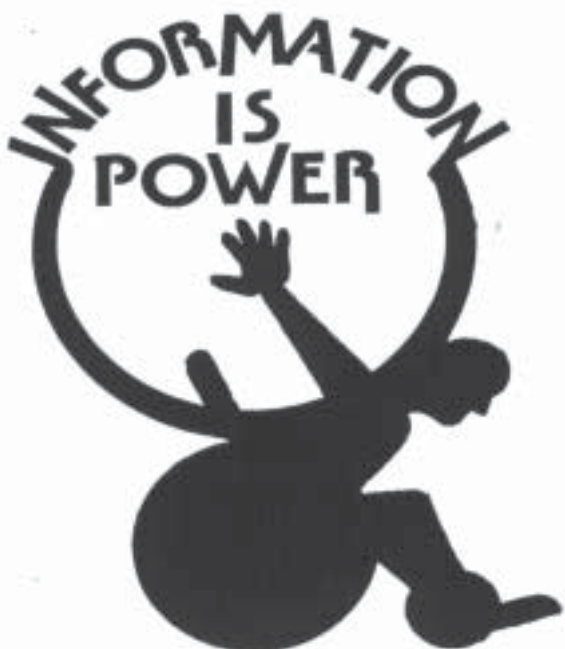
Information on Supplemental Security Income (SSI), disability and related benefits

# It's elementary!



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Dover, NH 03821-0579

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