

The New Hampshire Challenge

disability issues from a family perspective

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FRIENDS In The Making



James Owen, 21, goes up for 2 points at the Greenleaf Recreation Center in Portsmouth. James and his fellow players are members of the Basketball Club started by The FRIENDS Project.

Photo: E.G. Stone

See story on page 12.

House Budget Affects Medicaid Services

Advocates are concerned

by: Janet M. Krumm

The budget recently passed by the New Hampshire House of Representatives and sent to the Senate will affect Medicaid services to people with disabilities and the elderly, according to a report by NH CARES.

In it, rates to physicians are reduced by 5%, despite the fact that current rates cover only 60% of their actual costs. Rates for dental services have also been reduced by 5%. Current low reimbursement rates have discouraged doctors and dentists from participating in Medicaid, or forced them to limit the number of Medicaid recipients they treat, making it difficult for Medicaid recipients to get the medical and dental care they need. The cuts may compound that difficulty.

While the budget calls for a 5% reduction in services to people with developmental disabilities and acquired brain disorders, it anticipates recovering the 5% reduction by instituting a 6% assessment on those services and using the money it collects with this assessment to leverage more federal Medicaid dollars. The federal money it receives would be returned to those agencies based on the number of Medicaid recipients they serve, according to Fran Wendelboe, R, state representative from New Hampton.

Community mental health services will also be relying on the 6% assessment to funnel \$6.1 million into a budget that will then still be \$1.2 million less than the current budget.

Increases for nursing home ser-

vices for adults and children with chronic illnesses also rely on the 6% assessment revenues.

The budget also eliminates certain Medicaid services for adults that are optional by federal regulation but which the State has chosen to provide in its State Plan: ambulance and wheelchair van services, dental services, optometry services, physical, occupational and speech services, medical day care services and chiropractic services.

The State cannot eliminate services for children because early and periodic screening, diagnosis and treatment (EPSDT) services for children under 21 are federally mandated.

In addition, the budget reduced hospital payments by 5%, making Medicaid reimbursements only 66% of their actual costs. It also eliminates payments to hospitals for training of critically-needed staff, and all catastrophic costs payments to hospitals helping to cover high cost patients who are uninsured and can't pay themselves.

Almost \$2 million each year for the Healthy Kids Silver Health Insurance program is cut from the Governor's proposed budget and 12 of the 19 home visiting programs for children with special health care and other needs are

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I know no safe depository of the ultimate powers of the society but the people themselves;

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

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

Thomas Jefferson

In a letter to William Charles Jarvis September 28, 1820

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Budget moves to Senate

Revenues from 6% assessment not guaranteed

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eliminated in the budget passed by the House.

In addition to the reductions already outlined, there is a \$12 million fiscal footnote to the budget of the department of health and human services, with \$6 million of that targeted by the House to reductions in personnel costs. The remaining \$6 million cuts would be made at the discretion of the commissioner. If any of that \$6 million is used to reduce Medicaid services, the resulting 50% match in federal dollars would be lost.

Governor Benson included \$3 million (\$1.5 million in general funds, \$1.5 million in federal matching funds) for each year of the biennium for the wait list. That has not been changed in the House budget.

The House considered three options when voting for a budget: Plan A, Plan B or Plan C. Advocates lobbied for Plan B, but it was Plan C, recommended by the House leadership, which passed. According to Rep. Wendelboe, money for the wait list was in each of the

three options, and each of the options contained projected income from the 6% assessment which would compensate for the 5% cuts proposed by the Governor. "No matter which option passes" Rep. Wendelboe stated prior to the vote, "people with developmental disabilities are treated the same."

It was Rep. Wendelboe who suggested the assessment as a way to come up with more federal funds. Initially, she suggested a \$9.60 assessment per bed on nursing homes, following the example of several other states who have done this. The money collected from the assessment would be returned to the nursing homes who could use the money to provide additional Medicaid services, and thus receive matching federal dollars.

There were problems with that, however. Not all people in nursing homes are Medicaid eligible, and the money generated from the assessment could only be used for Medicaid patients. So the distribution of the money would be

uneven.

Instead, the Finance Committee decided to do a 6% assessment across the board of all Medicaid services provided in nursing homes and agencies that serve people with developmental disabilities, mental illness and acquired brain disorders. The revenue generated by the assessment would then be returned to them and used to provide additional Medicaid services for which the federal government would provide matching dollars.

Each of the agencies being assessed will have their budgets increased by the amount of money that will be collected from the assessment. Say, for instance, that an agency provides \$1 million dollars of Medicaid services. 6% of that is \$60,000. That agency's budget will be increased by \$60,000 so that the money they send to the State is essentially a wash. The \$60,000 will then be returned to the agency who will use it to provide \$120,000 of Medicaid services (because of the matching federal dollars).

This is the legislature's

strategy to generate new revenues in order to avoid the 5% cut in Medicaid provider payments proposed by the Governor's budget.

The ultimate success of this strategy depends upon whether the Centers for Medicare and Medicaid approve something that has not been tried before in other states (except with nursing homes), and may set a precedent. Their decision is not expected before August.

"We are hopeful," stated Senator Sylvia Larsen, "that this plan for an assessment will succeed in getting federal money." The budget passed by the House is, in her opinion, "irresponsible, and does not adequately address the very real needs of the State."

A public hearing is scheduled for April 28, after which the Senate Finance Committee will work on the budget. The three weeks in May during which the Committee will do its work are "critical weeks," Sen. Larsen said, for advocates to make known their concerns to their Senators. "There's a

strong momentum (for the Senators) to follow the leadership," she explained. "They are urging no changes in the budget."

The Senate Finance Committee will make a report to the full Senate, who will then debate the budget in less detail than did the House. "We will pull out the parts on which we agree and disagree," Senator Larsen explained.

A vote by the full Senate will be taken after this debate. If the resulting budget is different from the House's version, it will be sent to Conference Committee to work out the differences and come to an agreement. The deadline for a completed budget is June 18, but Senator Larsen believes that is ambitious. "A budget is required to be passed by July 1," she explained, "or we go to a continuing resolution," meaning a month by month allocation of funds to continue the operation of the government.

Once the budget is completed, it will be sent to the Governor, who will either sign, veto or allow it to become law without a signature.

How Will Cuts Affect DD Service System?

by: Janet M. Krumm

While New Hampshire can boast about the creativity of its service system for people with developmental disabilities, the system is feeling the strain of inadequate funding over the last decade.

The Legislature has flat funded the system since 1994, providing no increases despite the fact that costs have gone up, some exponentially. It is not only the area agencies who are affected; the many vendor agencies subcontracting with the area agencies have also felt the strain.

"We haven't been able to offer residential services for a couple years now," explained Sandy Pelletier, executive director of Region VI's area agency. "It's not even been an option. This is a serious crisis situation," she added, "an untenable situation."

Because funding for the wait list has not kept up with

need, filling vacancies has been done at the state level, not at the agency level. "We have parents whose sons and daughters are in their 40's and 50's," Pelletier stated, "who are in need of services." But the authority to decide who gets those services is not in her hands.

This year's budget process has been difficult. Agencies were told to build their budgets with reduced revenues when Governor Benson proposed 5% cuts in provider payments. Pelletier reported that her agency looked at "substantial reorganization. We took out from general management as much as we could," she stated. Reporting low general management already (because of previous flat funding), Pelletier's agency planned for a reduction of manpower and benefits.

"We cut our benefits program," she said. "It's not the best product now and we're ask-

ing for a higher employee match. This is the third year without raises for the employees."

General management cuts would not be enough, however. Services would also be affected. According to Pelletier, the board decided to differentiate between what she called "core" services and "value-added" services. Core services are those "we truly need to offer," she explained, such as case management, respite, vocational and residential services. Value added services would include camperships and recreational opportunities. "We will look more for family donations."

Each of the area agencies chose to deal with the imposed cuts in different ways. Bill Schofield is CEO of Residential Resources, a vendor agency serving approximately 100 people across the state. His

agency provides services for six area agencies.

Three of the agencies passed on the 5% cut to his agency. One agency asked for a 4% cut. One used a formula to determine what cuts would be made; Residential Resources ended up with a 1.4% cut. One gave them "very strict, very specific guidelines," Schofield reported, demanding a 7.9% cut in their management fees.

These cuts would not necessarily go away if the area agencies received the additional revenue generated by the 6% assessment, according to Schofield. "Most agencies have said 'no'," he reported.

"Obviously, we will try to minimize a direct impact on the day-to-day lives of people," Schofield said. "It's impossible, however, to absorb a 5% cut on a budget of \$60,000 without it having an ill effect on that person," he added.

What services will Schofield target? "We'll take a hard look at transportation costs," he replied. If an individual was coming into town every day, that frequency may decrease to two times a week. If two people who live together want to go different places - one, shopping, and one to the movies - they'll have to choose only one destination.

"We want to minimize changes in staffing," he explained. However, he would consider increasing the number of people with whom a staff person works from one to two, possibly three. He doesn't like it, though. "This is a regressive kind of direction," he stated. "We're going back to the early days of getting people back into the community. We're putting people in groups again."

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"What everybody is saying to us is, we want you to make these cuts but we do not want these cuts to make an impact on services," Schofield said. "We will do the best we can, but there is really nothing that is for us off the table for cuts. Desperation breeds desperation."

Despite the difficult situation he finds himself in, Schofield's agency is better off than many smaller agencies in the state, he explained. Schofield is the president of the Private Provider Network, an organization of private provider agencies in New Hampshire.

Because of the funding situation in New Hampshire, Residential Resources expanded its base into Maine and New York several years ago to increase its economic viability. "The general management fees we received from those services allowed us to absorb the cuts," Schofield explained. IPP, another provider agency, has had to absorb \$200,000 in cuts. He doesn't see the situation changing "until our legislature realizes that the revenue side has been exhausted, that there's no more blood to get out of the rock."

Agencies' choices are limited, according to Jay Haines, director of Community Services Network, Inc. (CSNI). They can look internally and they can ask vendor agencies to absorb cuts. But the size of the cuts pose significant challenges. "There's no way they could find a 4% cut in overhead," he stated, "without being irresponsible. It just doesn't exist."

He is concerned about the viability of the vendor agencies. "I am not going to be surprised to see

providers fold into other organizations," he said, "maybe even into the area agencies." He believes competition is healthy. With fewer provider agencies, consumers will lose choices and area agencies will lose options for the best providers, he believes.

When questioned about the possible consolidation of area agencies, Haines replied that question comes up repeatedly and the option has been examined in the past. "There have been a number of instances when area agencies came together to see if it makes sense to consolidate," he said. Their conclusion, he added, was that there would be some savings but those savings would not be meaningful enough to warrant the consolidation.

Until the funding situation improves, agencies find themselves facing unpleasant choices. If the 6% assessment is not approved by the federal government, agencies must absorb the 5% provider cuts proposed by Governor Benson and included in the budget passed by the House and now being considered by the Senate. Even if the 6% assessment is approved, the result, according to Pelletier, is "cost neutral."

"We are minimally back to flat, level funding," she explained.

Pelletier supports the 6% assessment. "The Legislature recognizes that the cuts are very severe," she stated. "They don't want to take resources away from people with developmental disabilities. They are struggling to find new revenues."

There has to be a solution to the problem, she believes. "We are willing to try anything."

The State of New Hampshire's Service System

The following information was excerpted from *The 2003 Report: Regional and National Perspectives on Developmental Disabilities Services in New Hampshire*, by David Braddock, Ph.D and Richard Hemp, State of the States in Developmental Disabilities Project, Department of Psychiatry, University of Colorado School of Medicine. The report was presented to the New Hampshire Legislature on March 25, 2003 by David Braddock.

Since 1984, New Hampshire has been a national leader in deinstitutionalization and community development. The State has had 12 years of experience in operating a completely non-institutional service delivery system. Based on empirical data, New Hampshire's transformation was achieved with an economy of resources when compared to other New England states and to the nation as a whole.

New Hampshire's utilization of Medicaid funding has been opportunistic and creative, both in terms of the level of reimbursement received from Washington and in the types of services that were supported by the federal government. Institutional reimbursement for Laconia was used to attain court-mandated institutional reform objectives and then terminated. The Waiver, the nation's more creative and individualized Medicaid program for supporting individuals in the community, now dominates the New Hampshire delivery system.

New Hampshire ranks 6th in per capita personal income. It also has virtually the nation's lowest "need index" - the smallest proportions of school-aged children and welfare recipients placing demands on state resources. New Hampshire has an educated population and the nation's lowest taxation as a percentage of personal income.

From 1977 to 2002, however, New Hampshire substantially lagged behind the five other New England states in its fiscal effort. A state's fiscal effort is a ratio measuring the proportion of a state's total statewide per-

New Hampshire's utilization of Medicaid funding has been opportunistic and creative, both in terms of the level of reimbursement received from Washington and in the types of services that were supported by the federal government.

sonal income devoted to financing developmental disabilities services. In 2000, fiscal efforts in Connecticut, Maine and Rhode Island exceeded New Hampshire's level by \$2.31 or more. Massachusetts and Vermont's effort levels in 2002 were substantially above New Hampshire's (by at least \$1.52). From 1996 to 2000, New Hampshire fell from 23rd to 33rd in its fiscal effort ranking in the country.

The projected FY 2004 fiscal shortfall for New Hampshire is 8.6% of the State's budget. Budget shortfalls across the states are impacting Medicaid enrollment, eligibility standards, and payment levels for a range of optional health care services. It remains to be seen whether there will be substantial Medicaid cuts that directly affect recipients with disabilities, although such cuts seem likely to occur in some states.

In the year 2000, an estimated 61% of the nation's 4.32 million children and adults with mental retardation/developmental disabilities in the U.S. resided with family caregivers, and 26% of those caregivers were aged 60 or more (an estimated 673,000 aged caregivers). In New Hampshire in 2002, there were an estimated 20,150 persons with MR/DD, of whom 12,351 (61%) were living with family caregivers. 3,036 were residing with caregivers aged 60 years or more, exceeding the total of 1,987 persons with MR/DD currently served in all types of supervised residential settings in the State.

Salary for direct care workers as of 2000 was \$8.67 an hour, which is 20% below the poverty level for a family of four. Turnover rate for direct care staff is 83%. The Bureau of Labor Statistics projects a 64% increase in demand for direct care staff for people with developmental disabilities through 2010, more than double the projected job demand for nursing aides, fast food workers, or across all occupations.

In 2003, New Hampshire's waiting list for priority one services is 351 individuals. The State ranks 17th highest among 30 reporting states in the number of individuals with developmental disabilities per 100,000 population waiting for community services. Rates ranged from 157/100,000 in Alaska to 2/100,000 in Arizona and Missouri.

Tidbits

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* In 1991, Laconia State School closed its doors and state reliance on federal ICF/MR funding dwindled.

* In 1992, the number of individuals receiving community based services was 1,274, all of which were funded under the federal Medicaid Home and Community Based Services Waiver.

* In 1995, New Hampshire ranked 3rd nationally in the number of persons with developmental disabilities in community settings of 6 people or less. The national average was 61%; New Hampshire's average was 95%.

* In 2000, New Hampshire ranked 25th nationally in the percentage of workers with mental retardation in supported/competitive employment.

* In 2002, the number of people in out-of-home residential services was 1,977, representing an increase (from 1992) of 55%. (The general population in the state increased 15% in the same period.) When those receiving partial services are included, a total of 2,800 people were served.

Spending for all services was \$152.5 million, 55% of which was reimbursed by federal funds.

* In 2002 federal-state Waiver funding in New Hampshire constituted 65% of family support spending, 70% of supported employment spending and 100% of supported living spending.

Interesting tidbits from the history of NH's developmental services system:

(This information is a summary of *The 2003 Report: Regional and National Perspectives on Developmental Disabilities Services in New Hampshire* which was presented to the New Hampshire Legislature on March 25 by David Braddock, Ph.D, one of the co-authors of the report.)

* New Hampshire School for the Feeble-minded Children opened February 1, 1903. By 1904, there were 34 boys and 33 girls in residence and a waiting list of 80.

* By 1906, there were 80 residents and 117 applications on file.

* By 1910, the school's population reached 175. In addition to the population at the School, New Hampshire ranked second in the nation in the institutionalization of children in almshouses and orphanages. Professor Johnstone from the New Jersey Training School at Vineland consulted in testing children at the State School with the Binet system (which eventually became what is now known as the Stanford-Binet I.Q. test).

* In 1911, the trustees of the school instructed Dr. Baker, the superintendent, to place three children with families he deemed satisfactory.

* By 1914, the school was serving 183 children.

* In 1915, a census recorded 1,158 feeble-minded children and adults "at large" in the state. This constituted .95% of the state population of 430,572.

* By 1920, the average number served at Laconia reached 349. The school acquired 238 more acres of land, bringing the total acreage to 485.

* In 1924, the name of the school was changed from New Hampshire School for the Feeble-Minded Children to Laconia State School.

* In 1928, the population at the school reached 430.

* In 1932, a study of the 120 "parolees" who had left Laconia between 1925 and 1930 led to the conclusion that 94 of them were successful in their return to the community.

* In 1940, the U.S. Public Health Service surveyed Laconia State School, comparing it with institutions in other states and nationally. Laconia appeared to compare well with its relatively low admission rate, its relatively high discharge rate, and the lower death rate per 1,000 residents (7.9 compared with 20.6 nationally and 28.8 in Maine).

* The survey also examined the School's sterilization procedures, which included securing parental consent, a certificate by two outside physicians and a hearing held by the Board of the institution or the county commissioner. In 1940, 8 boys and 23 girls at Laconia State School were sterilized. (Sterilization, as a policy, was adopted across the country as a means to control the population of "defectives." It was recommended in a 1927 report as a "valuable adjunct to a system of parole for the mentally defective.")

* In 1950, the population at Laconia State School was 735 with 79 on parole or home visit. Capacity at the school was 720. The cost to maintain a child at the School was approximately \$10.50 a week and parents and relatives were requested to pay what they could afford toward those costs.

* In 1953, Richard H. Hungerford was appointed Superintendent. During his tenure, Hungerford invited parents to be partners in the administration of the school. "In order to be effective partners...you must have the facts," he stated. "Maintaining a parents' organization is your responsibility; giving you the facts is mine."



This picture of the former Laconia State School was taken in 1994 after its closing as an institution for people with developmental disabilities. It had been re-opened as a state prison. **Photo: E.G. Stone**

* In 1958, the Laconia Trustees asked for Hungerford's resignation. He was replaced by Arthur Toll.

* In 1961, the Board of Trustees was dismantled by the New Hampshire Legislature.

* In 1962, the resident population was 990.

* In 1969, the facility was renamed the Laconia State School and Training Center.

* In 1970, the population at the school peaked at 1,169.

* In 1975, state legislation was passed (RSA 171-A) which mandated individual service plans and the concept of the area agencies. No funding was provided for their administration.

* In 1977, Laconia State School was certified by the federal government as an ICF/MR facility allowing the State to receive federal Medicaid reimbursements of \$567,000.

* In 1977, Laconia's Association for Retarded Citizens decided to file a class action suit against the State of New Hampshire over the conditions at Laconia State School. They were joined by the state Association for Retarded Citizens.

* In 1981, *Garrity vs. Gallen* became the longest civil suit in New Hampshire's history. It resulted in a court approved plan called Action for Independence which outlined reforms at Laconia along with a multi-year plan for community service development. Funding for community spending was \$5.1 million. Laconia's budget that year was \$11.6 million.

* In 1984, the State was approved for a Medicaid Home and Community Based Services Waiver to fund its community services for people with developmental disabilities. The services included: assistive technology, specialty services, crisis response, consolidated developmental services, case management, personal care, community support and habilitation, supported employment, respite care and environmental modifications such as home adaptations.

* In 1985, federal Medicaid reimbursements amounted to over \$10 million.

* In 1987, Laconia's average daily population was 213 with a per diem rate of \$212, resulting in a total of \$17 million in spending. Community spending totaled \$38.8 million.

Nicholas Vailas Appointed Commissioner of DHHS

by: Janet M. Krumm

Nicholas Vailas brings a passion to his new job as commissioner of the NH department of health and human services. He has spent the weeks since his nomination was approved by the Executive Council in January visiting a number of the agencies and departments that collectively function as human services delivery systems. His goal has been, he said, "to feel the passion of those who deliver the care, and share their passion as well as their concerns so I have a better understanding of what I do overall, what decisions I make."

The focus of his efforts, he explained, will be to reduce the administrative costs of the department because "every dollar we improve upon is one dollar more we can give out in services."

Not that he thinks the department is "fat" and "inefficient." "Only ten cents of every dollar we spend is an administrative cost," he stated. "Ninety cents is actually (spent on) good care. But we've been given a challenge (by the Governor), and we have to step up to that challenge."

Commissioner Vailas praised the staff of the department. "We have great staff here," he said. "We really do. They work very hard and they're very compassionate."

He sees his job as "help(ing) these folks do their job in a way that is fulfilling to them and offers good care. And in a way that we can create environments where people can truly exercise their passion."

"People who enter this profession love what they do," he said. "They love it. It's never practical. They'd make more money and with less angst, if you may, outside this sector. But they find tremendous meaning and fulfillment with people

who are in need. Those are special people," he added. "So, given that, I feel for them. I want to help them."

But, he admitted, he must balance his desire to help "from a practical standpoint because passions are never practical. We've got to make sure the taxpayer in this state is getting the best bang for their dollar."

"We can find that balance," he emphasized.

What will his process for change and innovation be?

"The process is, first of all, to learn in a meaningful way what we do here as well as who is doing what," Commissioner Vailas said. "Then, try to conform the department to basic laws of business and nature."

"We have a huge breadth of a department," he

"I really believe that the more we realize self-determination," he stated, "two things will happen. I believe you will improve the cost and quality of care, and without getting too intellectual, you also improve people's ability to fulfill their lives. People want to go beyond just their existence."

"And with that, comes good health," he concluded.

The fact that each local agency provides services differently, however, has drawn his interest. "The model isn't the same when you go from location to location," he indicated. "We need to look at who's doing what better on a cost for client basis and maybe we can learn from one another."

He mentioned the fact that two area agencies (Region I and Region IX) provide both



Photo: Krumm

other commonality he noted was the pharmacology involved.

The Commissioner acknowledged the differences that exist, saying: "They are two different types of patients and therefore, there may be two different cultures." That does not negate the commonalities, he believes.

"In the cry for better outcomes and costs - and usually they go hand in hand," he

Other states are looking at reducing or eliminating optional Medicaid benefits as a way of dealing with budget deficits. When asked if he would consider this as a possibility, Commissioner Vailas acknowledged that it was an option he was considering.

"We want to get back to our core mission," he said. "These are difficult financial times that we're in. We just have to make sure that our core mission as a department is being fulfilled and we don't hamper that."

"The further you move yourself from the core," he added, "the more likely those programs are going to be in jeopardy."

Despite the passion Commissioner Vailas brings to his job, he realizes that his authority is limited by the Governor and the Legislature. The department "informs the Legislature and the Governor's office in a factual, meaningful way so that they can come up with the best possible solution given these times," he explained. "Then, once their decisions are made and voted on, then we have to carry that mission out."

"Which is difficult," he admitted. "But I understand that's why I'm here."

"But I'm hopeful we'll get through this okay," he added. "There will be some pain, but I believe we'll be okay."

"And in time, we'll get better."

Commissioner Vailas wants "to feel the passion of those who deliver the care, and share their passion as well as their concerns."

explained. "Could it be somewhat compressed laterally? Absolutely. Could it be compressed from a depth standpoint? Probably."

"And we need to do that," he stated. "Because, as you, by nature, get wider, if you may - - horizontal - you end up with duplication. And by nature, if you get a lot of depth, you have also redundancy of job responsibility."

What might that mean for the developmental services system?

First of all, Commissioner Vailas appears to be committed to local control. "Delivering care on a local basis is in the best interests of patients and families," he said.

He also supports the concept of self-determination.

mental health and developmental services under one administrative roof "to improve their costs." He calls this "getting back to the simple laws of business and nature, a business nature."

He visited Region IX and commented on the "high level of morale" he witnessed there, "as well as a reinforcement that common administrative purpose created a better continuity of care and improve(d) costs."

There is "a lot of common ground on these issues (mental health and developmental disabilities)," he stated. "They are not by and large mutually exclusive of one another. You'll find many of the physicians involved treat the same patients in both worlds." An-

explained, "you've got to defer to the commonalities. So my recommendation is to focus on commonalities, not differences."

That will be his focus on the entire department. "We're going to look at where we are and where we have similarities and commonalities, and combine divisions," he said.

This effort will not be orchestrated from the top, according to Commissioner Vailas. "This is going to be a bottoms-up management," he explained. "We cannot come up with any meaningful solutions unless we talk to the people who are actually doing the work."

"It's insane to think that I would know what's best for these people," he added. "They know what's best for them."

New Medicaid Waiver Approved

Provides personal care services for children with developmental disabilities

by: Janet M. Krumm

On December 16, 2002, New Hampshire celebrated its status as the first in the nation to offer a Medicaid Waiver In-Home Supports program. State and federal officials marked the event at Governor and Executive Council Chambers in the State House in Concord.

The In-Home Supports program will offer families more control over how the Medicaid money they are eligible to receive is spent to provide supports in the home for their children with developmental disabilities, according to Barbara Joyce Reed, program specialist for the division of developmental services (DDS) and Allita Paine, director of child and family services for DDS.

Until this Waiver was approved, families eligible for in-home supports under New Hampshire's Medicaid Home and Community-Based Waiver (HCBC) were restricted by its regulations. Supports were limited to home-health care services. Caregivers had to be Certified Nursing Assistants (CNAs), and reimbursement rates were set by regulation. Support services were limited to the home only - no excursions into the community were allowed.

The In-Home Supports program provides more flexibility. Families can hire caregivers other than CNAs, and for less money than the set CNA rate. If their child has challenging behaviors, families can use some of the funds for a behavior consultant. Therapists (speech, occupational and physical) can be hired as consultants to work with paraprofessionals at schools. Caregivers can accompany children in the community for excursions with their peers. Funds can be used for respite for the families, and for necessary home and vehicle modifications.

"We're pretty excited that we have something to offer families," stated Paine. "We've never supported families (with these kinds of needs) well since the institution closed."

In the 90s, according to Reed, families whose children

had autism or pervasive developmental delay (PDD) complained that the home health care benefits did not serve their needs well. CNAs often did not have a background in the behavioral supports their children needed and the services they provided were not allowed outside the home. At that time, however, home health care was the only option available to families.

The In-Home Supports program is a response to that unmet need. The flexibility of this program would allow these families to hire a behavioral consultant to work with their child's caregiver at home and, perhaps, coordinate with the school so that the services their children were receiving were

will be added as funding allows.

The important aspect of this program is that services for each child will be individualized. The services provided will be "family-directed as much as the family wants to do that," Paine explained. "What will be provided is dependent on what the family prioritizes." The process is "not unlike what happens for adults," she said. "Negotiations happen at the local level."

When the family applies to their area agency for services under the In-Home Supports Waiver, the area agency will begin the process of determining if their child is eligible. "They fill out

"they have to have met that in-patient level. So we do what we call presumptive eligibility." Even though there are additional eligibility requirements, Reed thinks "it would be pretty hard to conceive that a child who got approved by Medicaid administration as Katie Beckett they didn't make those individual factors as well."

"But it's possible," she added.

While the goal of the Waiver is to offer families greater choice, control and responsibility for the services their child needs, area agencies will play an important role. Caregivers may be chosen by the family, but the area agency will be their employer of record, paying their salaries and ben-

will not be required, according to Reed.

"We feel in that case, between the agency negotiating with the family, they're going to look pretty thoroughly at the competencies of that individual," she said. "Since it's family-directed, the families are really going to be sure of who they have come in. But ultimately the area agency is going to be the employer of record, so they're going to be scrutinizing things as well."

Costs for consultant services and home modifications are also included in the budget. In addition to these costs, a general management fee of between 9% or 10% for the area agency must be included. "That percentage will vary," explained Reed, depending on how much administrative responsibility families take on themselves. The area agencies, however, are tasked with the oversight responsibilities for individual Waiver plans.

Once the service plan and budget are decided upon by the family and the area agency, it then goes to the division to be reviewed and approved. According to the terms of the Waiver, budgets for services must average \$20,000 a year, with an absolute cap at \$30,000. "Over \$20,000, it gets a little sticky," Paine admitted.

"Families who need these services should go their area agencies and make themselves known," Paine said.

Now, families have a choice between the benefits allowed under the HCBC Waiver and those allowed under the In-Home Supports Waiver. There are advantages and drawbacks to each and families must weigh those and decide which would better serve them.

"If the medically-oriented benefits under the HCBC Waiver are meeting their needs," Paine said, "families should stay with them." One of the advantages of these benefits is that there is no monetary cap. The disadvantage is the lack of flexibility in the use of the funds.

If the child's needs are not medically oriented and the

The goal of the In-Home Supports Waiver is to offer families greater choice, control and responsibility for the services their child needs.

consistent.

"We wanted to get at the deeper end of families that have things going on that make care giving particularly difficult," Reed stated.

This Waiver program was two years in the making, according to Paine. "Because this was the first Waiver in the country under the Independence Plus initiative, we spent many hours on the phone this past spring and fall," she said. "The Centers for Medicaid and Medicare Services (CMS) required a lot more detail than usual."

Because this is a model Waiver, regulations stipulate that no more than 200 families can be served. Initially, the Waiver will serve families who are already receiving services under the home-health benefits of the HCBC Waiver but whose needs can be more appropriately met under this new Waiver. There has been no new allocation of funds by the NH Legislature for this Waiver, so the division plans to "redeploy" funds already allocated under the HCBC Waiver. New families

forms," Reed explained, "and then they have to submit a cover sheet that shows the individual and family factors, indicating which ones apply. Then they have to submit the service agreement and the budget that goes along with that."

The service plan is developed by the family and area agency, specifying which services the family needs, how often the family will receive the services and over how long a period of time each of those services will be delivered. The budget is developed reflecting the cost of the services a family chooses.

While the final determination for eligibility is made at Concord, Reed believes that the area agencies will already have a good idea about whether a child will meet the level of care requirement.

Children who became eligible for Medicaid through Katie Beckett will have less need to prove their eligibility. "By virtue of having come through Katie Beckett in the first place," Reed explained,

efits, all of which must be included in the budget.

Families may choose to be their own service coordinators, or they may use the services of the family support coordinator at the area agency or subcontract with another agency to provide service coordination. The cost for the service coordination must be included in the budget. The standard rate for service coordination under the HCBC Waivers is approximately \$250 per month, but there will be some flexibility in determining that rate, according to Reed.

Caregivers chosen by the family may include neighbors, extended family or people in the community. If over the age of 18, they must meet certain state requirements and must consent to background criminal checks which will be paid for by the area agency at no cost to the family. Families may choose caregivers who are between the ages of 15 and 17 with the agreement of their area agency. Criminal background checks for them are impossible, so they

Waiver

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Medicaid Made Simple

(well, as simple as possible)

by: Janet M. Krumm

Talking about Medicaid can be very confusing because its regulations are complex. Medicaid is a joint Federal-State funded insurance program for very low income and certain needy people. Applicants are determined to be financially eligible (because of low income and resources), medically eligible (because of a disability or need for long-term care services) or eligible through receiving foster care or adoption subsidies.

Children become eligible if their family income (including assets and resources) is below the level set by the state. A child with a severe disability may be determined eligible despite his or her family income through what has become commonly known as the Katie Beckett Waiver, but is actually called Home Care - Children with Severe Disabilities (HC-CSD Medicaid). The child must be living with a parent and must need a certain level of care to be eligible, but the income of the parents is discounted. Only the income of the child and his or her assets and resources are counted.

Once determined eligible, the Medicaid recipient is entitled to all the services Medicaid offers under the State Plan. The federal Medicaid program mandates certain services and allows states to choose from a list of optional services. Once a state chooses to provide certain optional services, however, the state is mandated to provide them to all Medicaid-eligible recipients. Those choices are listed in the State Plan.

Federally mandated Medicaid services are the following:

- * Inpatient hospital services
- * Outpatient hospital services (12 visits per year)
- * Nursing home care
- * Physician services (18 visits per year)
- * Home health care
- * Federally qualified health center (FQHC) and rural health clinic (RHC) services
- * Laboratory and x-ray services (15 x-rays per year)
- * Early and periodic screening, diagnosis and treatment (EPSDT) services for children under 21
- * Family planning services and supplies
- * Nurse midwife and nurse practitioner services

New Hampshire has chosen to offer the following services in its State Plan:

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

Medicaid also pays for long-term care and supports offered in the home and other community settings. These services are available under Waiver programs (for which the State must apply and receive approval from the Centers for Medicare and Medicaid).

The Waiver programs currently in effect are:

- * Home and community based services (including case management services) for the elderly and chronically ill (HCBC-ECI waiver)
- * Home and community based services (including case management services) for the individuals with developmental disabilities (HCBC-DD waiver)
- * Home and community based services (including case management services) for individuals with traumatic brain injury or acquired brain disorders (HCBC-ABD waiver)
- * In-Home Support Waiver for children with developmental disabilities

Each of the waivers has a list of services that are provided to eligible recipients and include (depending on the terms of the particular waiver):

- * case management services
- * personal care services
- * respite services
- * environmental modifications
- * day habilitation/adult day services
- * supported employment services
- * nursing services
- * home health aide services
- * homemaker services
- * emergency response system services
- * adult medical day care services
- * in-home day care services
- * nursing home respite services

Medicaid recipients cannot receive Waiver services under two Waivers at the same time. The list of basic Medicaid services (both federally mandated and the services chosen by the State in its State Plan) are available to every Medicaid recipient. Recipients should not confuse Waiver services with the term "Katie Beckett Waiver." Technically, Katie Beckett is not a waiver; it is a means to determine eligibility for Medicaid services. Waiver services have their own added eligibility criteria.

(Information for this article was taken from the Program Guide published by the NH department of health and human services.)

Waiver

Continued from page 7

family can benefit from the flexibility of the In-Home Supports program, then the family should apply for the benefits under that Waiver, realizing that there is a monetary cap.

A choice must be made. "A family can't be on two Waivers at once," Paine stated.

There are situations, however, where a family who chooses the In-Home Supports Waiver may also need home health services for their child. Home health (medical) services, as part of the State Plan, are available to all Medicaid recipients.

"There would be cases where that could happen," Reed admitted. "What we've said is that we most likely wouldn't approve that if a family tried to get CNA service plus personal care."

"The way this program is working," she explained, "is by being able to take transfer dollars from the CNA line item and use it to match the waiver."

However, if it could be demonstrated that a child needed some nursing (RN or LPN) services, Reed conceded, "then there wouldn't be a problem getting the nursing under the state plan and the personal care under the waiver."

"(But) you'd really have to be able to show the child really does need that more medical component," she emphasized.

The model program has been approved for three years and can be extended beyond that time after a review. For more information about

When someone loves you, the way they say your name is different. You know that your name is safe in their mouth.

A child's definition of love

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Eligibility criteria for the In-Home Supports program

- * Must be a child birth to 21 years of age
- * Must be found eligible for area agency services
- * Must be found eligible for Medicaid
- * Must agree not to receive services under any other Medicaid Community Care Waiver
- * Agrees to make payment toward cost of care, if applicable (see note below)

AND

The individual must require *one* of the following:

1. Services on a daily basis for:

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

2 Services on a less than daily basis:

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

AND

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

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

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

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

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

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

Annie Forts "UP" Syndrome Fund Invites Grant Requests



The Annie Forts "Up" Syndrome Fund is non-profit fund created in honor of Ann Forts by the Moultonboro Lions Club to provide money for enrichment opportunities to persons with Down syndrome and to help support individuals interested in pursuing a career in special education.

Ann Forts is a nationally recognized motivational speaker who annually travels over 20,000 miles speaking at meetings and conferences all over the United States. The primary focus of her speeches is to help people understand there definitely is an "UP" side to life with Down syndrome. She speaks from first-hand knowledge.

Ann has served seven years as a member of the President's Committee on Mental Retardation, an advisory committee in Washington, D.C. She has been a guest on "The Today Show" and "The Geraldo Rivera Show."

Ann has received numerous regional and national awards, including the 1st International Self-Empowerment Award by the Joseph P. Kennedy, Jr. Foundation at the United Nations and the Paul G. Hearne/American Association of People with Disabilities 2002 Leadership Award. She donated the \$10,000 she received as part of Paul G. Hearne award to the Fund.

For information about the Fund, contact Donald Brown, President of the Fund at (603) 253-9527, or go to the web site at www.anniefortsupfund.org.

Guide Dogs Available Free of Charge For People Who Are Blind

The Guide Dog Foundation provides guide dogs free of charge to people who are blind or visually impaired and need the increased mobility and independence that a guide dog provides. The Foundation breeds and trains Labradors and Golden Retrievers for this very important job. It provides transportation to its New York campus, the guide dog, a comprehensive training program, and a lifetime of aftercare services all free of charge to the consumer.

There are many benefits to training with a guide dog at the Guide Dog Foundation in Smithtown, N.Y. Among them:

- * Small class sizes for personalized attention
- * Long history of excellence in dog breeding
- * Highly skilled, professional training staff
- * Comfortable, family-like environment
- * Diverse training areas, from country walks to city subways
- * Newly renovated and expanded student residence hall and student union

Can you or someone you know benefit from a guide dog? People interested in applying for a guide dog should contact the Guide Dog Foundation Admissions Office. For an application and cassette tape describing the Foundation, call toll-free (866) 282-8047 or visit the web site at www.guidedog.org.



"Somebody started a place like yours in Rhode Island. "It grew and grew and grew until it turned into an institution."
 Roberta Gallant

"I won't let my son live in an institution, and he'll be there."
 Deborah Gray

Photo: Krumm

People First Share Their Stories with Deborah Gray

by: Janet M. Krumm

When the members of People First heard about Deborah Gray's plans to build a farmstead for people with disabilities, they were concerned. They worried that this farmstead would be the beginning of another Laconia State School.

People First is a statewide self-advocacy group composed of people with cognitive disabilities. Started with a grant from the Developmental Disabilities Council in 1992, the group celebrated its tenth anniversary last year. A number of individuals in the group grew up at Laconia State School and have no intention of ever returning to institutional life.

The group discussed how they would respond to the news about Gray's plans. They decided to invite Deborah to a board meeting so that they could "share their stories and questions," according to Tammy Mill of Plainfield, NH, co-chair of the board of People First.

Deborah accepted the invitation and on March 15, a day that defied any hint of spring, she met with about 40 members of People First at Community Bridges in Bow, NH. Seated around tables arranged in a square, members welcomed Gray and presented

their stories and thoughts according to a structured agenda.

The five individuals who spoke emphasized the opportunities each now has to live a full and satisfying life, contrasting that with the horrors some of them experienced during their residence at Laconia State School.

Bob Getchell proudly produced a picture in his high school yearbook of himself donating blood during a school blood drive. Brian Ridley who lived in a group home until he was 15, spoke about his experience working on a farm where he learned how to operate farm machinery. He moved to a farm in 1993, but emphasized that he doesn't have to be on a farm forever. "I may choose to live somewhere else," he stated. He would like to start his own business and his future dream is to be a truck driver.

Mike Theriault who was committed to Laconia State School at the age of nine and was discharged at the age of 34, lives in an apartment in Concord. He can frequently be seen riding his bike around the city. He and Frank Vinciguerra, who lives in an apartment in Manchester, are both fourth degree Knights in the Knights of Columbus, a Catholic fraternal

organization.

Tammy Mills spoke about her love for music and her pride about learning skills a teacher once told her she could never learn.

Roberta Gallant, a former resident of Laconia State School, talked proudly of her apartment in Concord, where she has her own "kitchen and bathroom, TV room, refrigerator, stove, microwave oven, and personal computer." Her sister Jocelyn, who also lived at Laconia State School, now lives in Salem, making it difficult for the two to get together often. They take advantage of technology to keep in touch. "I have a web camera," she explained. "I talk with my sister live on camera."

The lives these individuals described are ordinary, created out of simple pleasures and accomplishments - which is exactly the point they wanted to make. Their journey to the ordinary was not easy; many had to prove their abilities to those unable or unwilling to believe in their capacity.

Tammy's mother refused to send her to a school for the blind, resisting teachers' adamancy that Tammy would never learn otherwise. "They thought I couldn't learn," Tammy remembered, "that I couldn't catch up with people.

They were wrong!"

Bob recounted his many difficulties at school, which he finished through sheer persistence. "My parents have more respect of me" because of that, he said.

Mike, Roberta and Miriam Wesi all spent a good part of their lives at Laconia State School, a place they do not recall fondly. Mike ran away many times. Roberta described the horror they lived through in the institution.

"That place was so horrible," Roberta stated. "Other people and I were physically, verbally and sexually abused. People never treated me right. They stole my belongings without asking me. I was very angry about that.

"I worked for 5 cents an hour. Staff people made good pay. We earned nothing but a nickel an hour.

"I did not like living there," she said. "Those dorms - we had no privacy. No stalls in the toilets, no curtains in the showers. The buildings really stunk terribly. They smelled like urine and stool and vomit. People went to the bathroom all over the floor.

"We were put in straight jackets. We were made to kneel down in columns if we misbehaved. Staff poured cold water on us to calm us down.

"We were made fun of, laughed at, talked about behind our backs. I was absolutely angry - I hated other people talking behind my back.

"They pulled my hair, slapped my face, punched my nose, eyes and ears, threw me to the floor."

As she related her experience, Roberta spoke calmly, her nervousness showing occasionally when she lost her place in the notes she held in front of her, but the smile on her face never wavered, belying the horror of the words escaping her lips. The room was utterly silent during her presentation - those who lived the horror with her acknowledging her honesty with their silence, those who escaped the horror silently supporting their friend.

In contrast, Miriam Wesi described the emotions washing over her when she returned to the site of Laconia State School for the first time to give a presentation. "I was afraid to go there," she remembered. "I didn't like my life at Laconia State School." She had a knot in her stomach as the cab pulled up to the property. "It hasn't changed," Miriam added. "There's barbed wire up, but nothing else has changed."

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Their journey to the ordinary was not easy.

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Miriam's account mirrored Roberta's. "I saw staff hitting people with rubber hoses," she stated. "You can't imagine the moaning and groaning. And you can't jump in (and help). Your own life was in jeopardy.

"I learned to keep my mouth shut and do what I was supposed to do."

Miriam made it very plain that she did not support Gray's plans. "A person who starts this (farmstead) needs their head examined," she stated.

When Bob invited Deborah to speak, she thanked People First for their invitation and for sharing their stories with her. "I know you're worried that

I'm starting a new Laconia (State School)," she said. "That's the last thing I want to do."

Deborah spoke about her son and her concern for his future. "I thought that a farm would be a good place for him," she explained. "I didn't want him to be in a situation where he wouldn't be able to tell someone if bad things were happening to him."

The idea grew to include other people with disabilities, she added. "I'm giving people who are interested in farming an opportunity for people who want to be in the country to be in the country. No one will be

forced to be there," she emphasized.

Roberta responded with some reservation. "Somebody started a place like yours in Rhode Island," she said. "It grew and grew and grew until it turned into an institution."

That won't happen, Deborah assured Roberta. "I won't let my son live in an institution, and he'll be there."

Others questioned the range of choices people who lived on the farm would have. How many people would live there. "No more than 24," Deborah answered. People could just come for the day if

they live close by, she added.

Would the apartments on the farm have Section 8 housing? "I think that the answer is yes," she replied, but added that she would have to get more information about it.

If people wanted to go shopping, could they do it themselves? "There will be staff people who will take everyone to the store," Deborah said.

A concern was expressed about the farm having an institutional environment. "I don't want it to be an institution," Deborah stated, "or feel like an institution. There will be two safeguards," she added.

"It will not be owned by the state and we can't be forced to take people if there is no room.

"This is a different world," Deborah offered. "People have choices. If they're not happy, they can leave.

"There's no need to worry about this turning into a new Laconia."

The meeting was concluded with a thank you from Tammy to Deborah for coming to spend a part of her day with the group. She expressed the hopes of everyone in People First: "that our stories have made a clear picture of how we created a future for ourselves."

"We hope our stories have made a clear picture of how we created a future for ourselves."

Tammy Mills,
Co-Chair,
People First of NH



Frank Vinciguerra poses a question about Section 8 housing funds to Deborah Gray.

Photo: Krumm

Law Makes Abuse by Caregivers a Felony

As of July 16, 2002 a law went into effect which imposes criminal penalties on caregivers who abuse or neglect individuals 60 or older or adults who are disabled. The law calls for jail terms up to 15 years for people convicted of purposely injuring individuals in their care and up to seven years when negligence results in an injury.

Caregivers are defined by the law to be "any persons who have been entrusted with, or have assumed the responsibility voluntarily, by contract, or by order of the court, for frequent and regular care of or services to an elderly, disabled, or impaired adult, including subsistence, medical, custodial, personal or other care, on a temporary or permanent basis. A caregiver shall not include an uncompensated volunteer, unless such person has agreed to provide care and is aware that the person receiving the care is dependent upon the care provided." The law, however, makes exception for those who have made a good faith effort to provide care but have been unable to do so through no fault of their own. It also makes exception for those caregivers following the lawful directives of an elderly person or an adult with a disability who is legally competent to make his or her own decisions.

To report suspected abuse, contact the local Division of Adult and Elderly Services district office, or call 1-800-351-1888, ext. 4384. (TDDY: 1-800-735-2964).

"Hope has two beautiful daughters - their names are anger and courage; anger at the way things are, and courage to see that they do not remain the way they are."

St. Augustine



(From left) Liz Malone provides supervision while James Owen, 21, Darrell Gate, 20, and Patsy Brinkley, 21, enjoy an afternoon of pick-up basketball. The basketball club was started with the help of The FRIENDS Project in Portsmouth.

Photo: E.G. Stone

FRIENDS in the making

by: Janet M. Krumm

Parents, teachers and school administrators in Portsmouth have joined together to address what they see as the biggest problem children with disabilities face - loneliness.

"We knew that after years of including kids with disabilities in regular classes," Bruce Boley, former special education director in the Portsmouth School district, stated, "that they did not have actual reciprocal relationships with other students. With anybody.

"For a number of kids with disabilities, their chief problem was that they were lonely, not only in school," he added, "but after they graduated, it got worse."

What could parents, teachers and school administrators do to address this problem?

First, Boley and Heidi Chase, then a special educator at the high school, held focus groups with typical kids from the high school and middle school. The overwhelming message they received from those focus groups was that the most significant interpersonal connections for kids happened after school, through sports, phone calls, jobs and extra-curricular activities.

"We knew that having kids in regular classes was not enough," Boley stated. "We can't just be in the position of handing out money to people to babysit kids with disabilities after school," he added. "We didn't want to do that."

So Boley convened a task force. Initially small - five parents, three teachers and Boley - the group defined two goals:

- to support individual students in activities of their choosing, and
- to look at the systemic issue of why students with disabilities or exceptional students are isolated, and identify what the group could do and what the community could do about that.

Their efforts became The FRIENDS Project.

"We literally made up the project as we answered the questions," said Chase, who has since been hired as coordinator.

The overriding question for some parents early on was: what can we do now to create opportunities to bring all kinds of kids together and foster real friendships? Greater efforts were channeled into addressing immediate needs. "Nathaniel and kids like him

were sitting home alone after school watching movies and listening to CDs," said Nancy Beach, one of the parents in the group. While Nathaniel likes to do those things, "is that really a part of getting him into the community?" she asked.

There were discussions and disagreements in the beginning, according to Beach. "Parents tend to be quite emotional," she admitted. The administrators would "just roll their eyes," she laughed. As time went on, "it became kind of an emotional support group, too."

The group tried different activities. Some worked; some didn't. In the three years since it began, however, the Project has successfully created a number of opportunities to bring kids together to have a good time.

There's the girls group that meets Wednesdays at the high school. "The girls club is the most successful activity as far as bringing girls with disabilities together with girls without disabilities," Beach commented. "They go out to dinner once a month at a local restaurant, and they go to the movies. They do a lot of things together."

There's Friday Night!, a social gathering for young people. "We have an average of 20 kids there," Chase said. "They range in age from 15 to 24 years old. They spend a couple hours of social time together," playing basketball and other recreational games, listening to music and doing craft.

There's a video club where individuals 18 and over get together to watch videos. "That's mostly guys," Nancy said. They meet the first and third Tuesdays of the month at the Greenleaf Recreation Center.

There's a basketball club on Tuesdays and Thursdays after school, where anyone is welcome to come to the Greenleaf Center to play pick-up games. Transportation is provided from the high school.

As the number of activities increased, Amanda Price, a UNH student, was hired to assist Chase. She has been instrumental in coordinating these events and getting students from UNH to participate, according to Chase and Beach. "I was there one Friday night,"

Beach remembers, "and in walks the UNH girls swim team. Well, needless to say, Nathaniel and some of his guy friends were quite happy."

A number of the students from UNH who participate in the activities belong to sororities and fraternities who emphasize community service. Beach acknowledges some ambivalence about that. "A part of you says, well they have to be here," she admitted. But she believes that it opens doors to opportunities for students to get to know people with disabilities as people first.

The FRIENDS Project sponsors a community drumming event once a month. "About 35 people come to that event," Beach stated, mostly adults with disabilities who reside at two local group homes.

In addition to the activities that FRIENDS has organized and facilitated, they also have money available to provide supports for students with disabilities to participate in after-school activities of their own choosing.

Beach has experienced

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some personal revelations as the Project has evolved. "In getting the kids out into the community and getting the community involved, what I found out was that it didn't really bother me that Nathaniel wanted to hang out with kids like himself," she said. "Sometimes I think we strive so hard to have out kids completely out there with people without disabilities that we forget that what we're doing is like reverse discrimination."

For instance, most of the kids in the basketball club have disabilities, Beach explained. "But you know what? They're out after school and they have a great time. And they really have gotten to know each other really well and slowly but surely, other kids are starting to get involved."

The hope the parents have, Beach added, would be that the rec department take over programs like that and open them up to everyone as non-competitive programs, de-emphasizing the participation of kids with disabilities. In fact, FRIENDS has been reaching out to the larger community, offering through collaboration to better train recreation centers about how to support children and adults with disabilities.

The Project recently put on a fashion show as a fundraising event. They invited prominent people in Portsmouth to join individuals with disabilities modeling clothes that local specialty retail shops donated for use at the event.

The fashion show was a huge success, selling 300 tickets at \$35 each and raising \$2,500 at a silent auction held the same night.

But the most amazing thing, according to Beach, was "that our kids were just a part of it. I was standing back there dumbfounded," she remembered, "saying, this is what it's all about. Our kids are part of an activity."

Even students with severe disabilities not living at home have benefitted from the FRIENDS Project. The Edgewood Center Club was born out of the desire of a middle school student who decided that she wanted to visit her classmates who lived there. Chase helped her make that happen. Other students joined her and together they are turning a sun room into a "fun" room, where they visit once a week and hang out with their classmates. FRIENDS applied for a

grant to make the redecorating possible.

Beach and other parents involved in the group beam their excitement about FRIENDS. They also frankly admit that it's been difficult to get high school students without disabilities involved. "We've not had as much success with kids at the high school," Beach stated. "What we found is that kids are really busy. There are kids that are great during the school day with kids that are the same class. But then, they have sports; they have academic stuff; they have their own friends they want to do things with.

"Again, it goes back to, why should I expect somebody Nathaniel's age to want to hang out with him if they have nothing in common?" she said. "It goes back to our initial goal. We want to create opportunities that could possibly help forming friendships - real, natural friendships for our kids."

FRIENDS is not only about creating activities; it's about systemic change. Even though he is retired from the school district, Boley continues to meet with a small group to look at what the community can do to prevent people with disabilities from being so isolated. "It's a 'think' group," Boley said.

"I'm a lot more concerned with people with disabilities who are in their 20s and 30s and what happens with them," he stated. Boley grew up next door to his aunt who had a significant disability. His aunt lived with his grandmother. "She grew up not going to school, and we grew up thinking that's the way it was." He has learned otherwise.

Boley's concern is not limited to people with disabilities, but embraces all people he calls "exceptional - people who are overweight, have eating disorders, are not appealing in their appearance. There's a lot of desperate kids and people," he said, "more than we realize."

He has an opinion why this is so. "The world is run by extroverts who are successful," he stated, "and they think that's okay. They don't know who's living next door to them."

The FRIENDS Project is trying to introduce them to each other.

For more information on the FRIENDS Project, contact Heidi Chase at (603) 436-7100, ext. 284 or e-mail her at h.chase@portsmouth.k12.nh.us

Crotched Mountain Responds to Community Needs

GREENFIELD, NH. In a recent report submitted to the Charitable Trusts Unit of the New Hampshire Attorney General's Office, Crotched Mountain Rehabilitation Center (CMRC) has calculated that it spent \$2,585,754 during its 2001-02 fiscal year to address community needs. The report is submitted annually, as required by state law, and is posted on the organization's web site: www.crotchedmountain.org/CommunityBenefitsPlan.htm.

"This amount reflects the total value of free and subsidized services for 29 specific 'community benefits,'" states president, Donald L. Shumway. Community benefits include a range of programs and services designed to meet the health needs of the communities Crotched Mountain serves - principally people with disabilities throughout New Hampshire and beyond, as well as families living in local communities in the Monadnock region. (more)

Of the 29 different community benefits rendered last year, 88 percent of the total valuation was used to support top 10 activities: 1) Brain Injury Center, enabling community reintegration for 27 inpatient adults daily; 2) Dental Clinic & Health Center, which delivered more than 900 inpatient appointments combined annually; 3) Outpatient Clinic, which provided more than 4,000 appointments for over 1,000 people of all ages; 4) Aquatics, which rendered more than 26,000 individual therapeutic and recreational uses; 5) Internship Program, which supported 47 medical, clinical, and international students throughout the year; 6) Children's Specialty Hospital, which provided skilled nursing care for 34 respite and short-term inpatients; 7) Wonderworks, which provided child care for up to 71 children of employees and local families on a daily basis; 8) the School Partnership Program, which strengthened the capacity of local schools to educate 75 students with disabilities throughout New Hampshire; 9) Driver Evaluation & Training, which served 176 individuals with disabilities; and 10) Media Center & Library, which served more than 9,600 after-school visitors from the local community.

"Our community benefits address a number of identified needs in our communities, including access to dental care and nutrition; fitness and safety; specialty medical services, such as physical and occupational therapy, speech/hearing, and assistive technology; mental health; professional and community education; child care and early intervention; family support; and transportation," continues Mr. Shumway. These community needs were identified through a series of comprehensive assessments conducted in November, 2000 which, by law, must be updated every three years.

Because it serves two distinct communities, Crotched Mountain conducted its own independent research to survey the needs of people with disabilities and also teamed up with a group of local health and human service organizations, led by Monadnock Community Hospital, to determine the health needs of the general population living in the greater Peterborough area.

"This year we estimate Crotched Mountain will deliver \$2,646,725 worth of community benefits, distributed throughout 26 specific programs and services," stated Mr. Shumway. We invite interested members of our communities to review our community benefits plan, which is posted on our web site, and offer us their input."

Crotched Mountain employs approximately 800 people who assist children and adults with disabilities throughout New Hampshire and the northeast to achieve optimal growth and independence in their own community. For further community benefits information, please contact Tracy Messer, Manager, Market Research & Community Services at: (603) 547-3311, ext 480; or by e-mail: communitybenefits@crotchedmountain.org.



Audiologist Margaret Glover meets with an outpatient.

Courtesy Photo



When a cultural organization contacts VSAarts of NH for help in making its program more accessible, the first step is an access survey. Rebecca Bruns, director of cultural access, (left) talks with Rodney Rowland, collections manager at Strawberry Banke Museum. Next to Bruns (out of sight) is Maureen Hall, site survey coordinator. Janice Hastings, executive director of VSAarts is at the far right.

Photo: E.G. Stone

VSAarts Helps Cultural Programs Become Accessible

by: Janet M. Krumm

How does a local arts program make itself accessible to everyone? That's the question the people at Strawberry Banke Museum in Portsmouth were struggling with when VSA arts stepped in to offer help.

Strawberry Banke Museum is New Hampshire's oldest seacoast neighborhood. Visitors can experience what life was like for those who lived in Puddle Dock from the early 1600's to the 1950's by entering and viewing the many historical homes on this plot of land by the Piscataqua River. The historical authenticity of the buildings, however posed access problems for people with disabilities. For them, entry was not guaranteed.

Efforts had been made to render the Museum accessible, but not all were successful. For instance, Rodney Rowland, collections manager of Strawberry Banke, recounted the attempt to build an accessible bathroom in one of the houses. A location inside the building was identified and an architect was hired. The layout of the bathroom was created using universal design.

But the project was not a success. No one had thought about how someone would get to the bathroom using a wheelchair. Access to the bathroom was down a long ramp that was too steep for people using wheelchairs to navigate safely.

The Museum now had a beautifully designed bathroom - that was not accessible!

Enter VSA arts. Rebecca Bruns, director of cultural access for the organization, offered to help the folks at Strawberry Banke explore ways in which the museum could become more accessible, both physically and programmatically.

The cultural access program of VSA arts started out in 1996 as an idea of Janice Hastings, present director of the organization. Hastings approached the State Council on

it had as its mission the creation of opportunities for people with disabilities to experience and participate in the arts. "The arts raised the bar on expectations for people with disabilities," Hastings explained, "not just for individuals with disabilities, but for their parents and teachers as well." It was a way for people who had no voice to find their voice, she added.

In education, the arts provide a way for students with disabilities to learn and to demonstrate what they were learning. An artist's approach is to ask "what can everyone do

New Hampshire reflect their communities, are typically governed by volunteer boards and have few resources. "Cultural organizations can't afford major projects," Bruns added. The challenge was to create a means for systems change that was not threatening and was doable.

The process starts with a site survey. Bruns and VSA arts board member Maureen Hall visit the site of the organization or program. They spend time looking at the physical site and talking with the people who run the program. "We involve the volunteers (of the program)

them) to ask the right questions," she added.

A report is generated based on the site survey and given to the organization. It is then up to the organization to decide what they want to do.

Rowland outlined how the report was helpful to Strawberry Banke. "We took the report apart piece by piece," he said. They developed an access plan, identified particular goals they wanted to accomplish, prioritized them and created a time line, assigning responsibility to different departments for each goal. "That's the best way," Rowland stated. "It's not just one person's responsibility; it's everybody's."

Some goals were small and simple; others involved more work and planning. For instance, it was decided that a grip rail was needed in one building. That was assigned to the maintenance department. Communication, however, presented a more complex issue.

"Communication was our biggest issue," Rowland admitted. Communication encompassed developing a pamphlet to articulate the Museum's accessibility policy, and training the volunteers to ask questions when someone called about accessibility to make sure that

"We are not an enforcement agency. We are interested in identifying access issues and implementing improvements."

the Arts and Granite State Independent Living with the idea, where she received support to explore it further. In 1999, a business plan was created, funding was secured and Bruns was hired in 2000.

Accessibility was not a new concept for VSA arts, but the enlargement of their focus was. Fifteen years ago, when the organization was called Very Special Arts of New Hampshire,

here?" Hastings added. "We are missing opportunities if we're not hearing the voices of everybody," she stated.

But participating as artists was only the beginning. Hastings wanted to create ways in which people with disabilities could participate as audience members, too.

"New Hampshire is rural, small and historical," Bruns explained. Arts programs in

as team members," Hall explained. Their purpose is to learn about the program and also to learn what the organization means by accessibility, as well as to identify the ways the program is already accessible.

Bruns and Hall very consciously try to put everyone at ease. "Comfort level is the key to success," Bruns explained. Hall agreed. "You have to make it comfortable (for

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person's particular needs could be accommodated, to name just two concerns. Others included providing the role players (volunteers who donned costumes and played the roles of historical figures) and other volunteers with information about accessible entrances and bathrooms, the operation of a lift on the property, and the use of transfer chairs by people with walking disabilities.

Discussing together as a team all the aspects of an issue, "makes everybody think," Rowland explained. "It's that very shift in thinking we're after," Hastings stated. "It improves the whole program."

While VSA arts provides technical assistance based on the Americans with Disabilities Act (ADA), Bruns, Hall and Hastings emphasize that they are not an enforcement agency. "We are interested in identifying access issues and implementing improvements."

Bruns does not overwhelm the organizations with which she works. "We go in backwards," she said, explaining their approach. "We start with the program." Hastings calls it the "oh, by the way..." method.

VSA arts of New Hampshire has grown in its mission and its scope over the years. In 1988, its first year of existence, Very Special Arts worked with 500 people in the Granite State. In 2002, that number reached 10,249. VSA arts is changing attitudes and giving voice to people with disabilities. With its cultural access program, it is helping arts organizations to be accessible and welcoming to all, not from a "place of fear," Hastings explained, but from "wanting to do the right thing and having the tools to do it."

June Event Kicks Off Project for Theater Accessibility

On June 5, 2003, The Music Hall in Portsmouth and VSA arts of New Hampshire will kick off a project that will help make theater accessible to people who are blind or have low vision. *Project 3D - Audio Description, Audience Development, New Directions* came out of an access site survey conducted by VSA arts with the staff and board of the Music Hall.

As explained in *Perspective*, a publication of VSA arts of New Hampshire: "Audio description is a prepared and rehearsed narration of the visual aspects of a production and is presented concisely between the spoken dialogue of the performance. The describer narrates those visual elements that convey meaning or insight into the story line, character

development, and the relationship among characters. In addition, visual effects unique to a theater experience are described, such as the physical attributes of the theater."

At the June 5 kick-off event, The Music Hall will host workshops for organizations and individuals who want to learn more about Audio Description. Workshops will begin at 9AM and continue until 5:30 PM. The day will culminate with a public performance of *JazzArtSigns* at 8:00

in the evening. A dinner option is available from 5:30 to 7 PM.

This one day event will be only the beginning of this project, however. During the coming year, the play *Knights of the Square Tables* will be presented in six locations around the Granite State with Audio Description. A "colorful dance and theater interpretation of the story of King Arthur and the Knights of the Round Table," the performance is being promoted as family entertainment.

The sites chosen for the performance will receive technical training, use of the AD equipment, marketing and program outreach consultation, an access site survey of their venue, and disability awareness training for their staff, according to VSA arts.

"Audio Description will provide a new 'welcome' to children and adults who are blind and their families and friends into cultural centers across the state," VSA arts states.

For more information about Audio Description, the kick-off event in June at The Music Hall in Portsmouth, or the cultural access program contact Rebecca Bruns at VSA arts at 603-228-4330 (V/TTY) or e-mail her at rebecca@vsaartsnh.org.

Familiar Faces, New Responsibilities

Clyde Terry is the executive director of Granite State Independent Living in Concord, NH. His most recent position was executive director of the NH Developmental Disabilities Council, where he authored state and federal legislation on issues impacting the lives of people with disabilities. Some of these include HMO reform, Medicaid reform, employment assistance, civil rights enforcement and other issues. Terry spearheads a national coalition of disability organizations on election reform and accessibility for people with disabilities. He is co-author of the 2002 publication: *Voters Denied Equal Access at the Polls: A Status Report of the Accessibility of Polling Places in the United States*.

Gordon Allen is the executive director of the NH Developmental Disabilities Council. His experience includes six years as director of the first developmental services provider to bring Laconia State School residents back to the community, 14 years as the founding director of the Granite State Association of Nonprofits and two years as senior health policy analyst for the NH department of health and human services. Allen also served three terms in the NH Legislature, where he served on the Finance Committee.

Registering for Selective Service a Must

by: Janet M. Krumm

Is a young man with a developmental, physical or emotional disability exempt from registering with the Selective Service System when he turns 18? NO!

Registration is just that - a means for the government to build a database of potentially eligible men in case a draft is ever reinstated. (A draft can be reinstated only if legislation is passed by Congress and signed by the President.) There is no classification system in the database, so there is no way that a young man registering could identify himself as having a disability. "We have nowhere to put that information," Alyce Burton, public affairs spokesperson for the Selective Service System stated.

Burton explained, however, that any physical or cognitive disability that would prevent a young man from volunteering in the Armed Services would likely eliminate him from the draft. The classification process begins with the Armed Services.

Sgt. Troy Hall, recruiter for the U.S. Army, outlined the process for entering the Armed Services. First, a potential recruit would be required to take the Armed Services test. A young man with a high school diploma would have to get a score of 31. A young man with a G.E.D. would be required to

get a score of 50. "We've had people with bachelor's degrees fail the test," Sgt. Hall commented.

If the potential recruit passes the test, then he is sent to a Military Entering Process Station for a physical exam. "It's a generalized sports physical," Sgt. Hall explained.

Only one out of twenty men who apply to the Armed Services actually qualify, according to Sgt. Hall. Even if the draft were reinstated, he added, there would still be an elimination process. "The Army's not like it used to be. Tanks are fully computerized, they weigh 50 tons and travel 75 miles per hour," he explained. Operation of sophisticated weaponry demands certain qualifications.

If the draft were reinstated, some men wouldn't even get to the point of having to take the test, according to Burton. "There would be a lottery," she explained, "which would determine the order that men are called. Those with very high lottery numbers may not even be called to report for testing."

Regardless of the improbability of a young man's being determined fit for military services, it is still the law that he register when he turns 18. In fact, any man who fails to register within 30 days of his 18th birthday may be fined up to \$250,000, imprisoned for up to five years, or both. (Women are

not required to register.) Failing to register is a felony.

Registration is important in other ways, as well. It is required for employment with the federal government and the U.S. Postal Service, student financial aid and job training. In New Hampshire, young men must be registered to be eligible for state employment and state enrollment in post secondary institutions, including financial aid for this schooling.

A man can register by mail or on-line at www.sss.gov. Registration forms can be found at the local Post Office.

Within 90 days of registration, a person will receive in the mail a Registration Acknowledgment Card from the Selective Service which provides a copy of the individual's registration record. It is important to safeguard that document because it serves as proof that a person is registered.

Once an individual is registered, the law requires that the Selective Service be informed of any address changes within 10 days. Change-of-Information Forms (SSS Form 2) are available at the local Post Office. On-line change of information is not yet available.

For more information about the Selective Service System and registration requirements, go to www.sss.gov, or call 1-847-688-6888.

Men have been inducted into military service through the Selective Service System since the time of the First World War, 1917. President Roosevelt signed legislation in 1940 to create the country's first peacetime draft and formally establish the Selective Service System as an independent Federal agency. The draft ended in 1973, when the U.S. reverted to an All-Voluntary military.

Law mandates release of student into to Armed Forces

In the No Child Left Behind Act of 2002, there is a provision that requires public secondary schools to release student directory information to military recruiters. Parents wishing to keep their son's personal information private must actively opt-out of the information release by a deadline early in the school year. To opt-out, write a formal letter to the high school principal informing him or her that you do not want your son's personal information released to the military. Mention in the letter that the school must honor the request under the No Child Left Behind Act, and sign the letter.

(This information was extracted from an article by Luc Davidson Schuster in *Quaker Witness*, January 2003.)

National Council on Disability Wants Information about College Experiences

The National Council on Disability (NCD) is seeking information from parents and students about how they finance college. NCD is inviting letters about financial aid and disability experiences in an effort to understand how disability and financial aid affects the college experience.

Parents and students may share a brief, informal note about their experiences by e-mailing NCD at youthfeedback@yahoo.com. Individuals are invited to share as much of their story as is needed to explain their circumstances and the relationships between their disability expenses, college financial aid, vocational rehabilitation services, and other sources of support.

A few questions that may help individuals organize their thoughts are:

1. If you disclosed your disability to your college, did this information affect your financial aid package? To what extent did your financial aid increase or decrease as a result of disclosing your disability?

2. What stories or suggestions could you share about how you have paid for school?

3. What stories or suggestions could you share about these concerns and their effect on your financial aid?

* Are you physically and mentally able to attend school at least half time?

* Can you meet your school's requirements for satisfactory academic progress?

* If you must take a reduced course load because of your disability, will you run out of eligibility for Pell Grants before you finish school?

* Are you physically and mentally able to participate in your college's work-study programs?

4. From where have you requested financial assistance for college? For example, do you have stories about working with resources such as any of the following:

* Offices at your college (financial aid office, disability services, student support services, etc.)

* Your state vocational rehabilitation agencies

* Supplemental Security Income (SSI) or Social Security Disability Income (SSDI)

* SSA Plan to Achieve Self-Support (PASS)

* The SSA Ticket to Work Program and its rehabilitation agencies

* Educational Opportunity Programs (EOPs)

* TRIO outreach, retention, and student support programs

New Software Opens Library to People with Vision Impairments

by: Jessica D'Avanza, Goffstown Public Library

The Goffstown Public Library has made it easier for the blind and visually impaired to access the library's volumes.

Two new software programs - Magic a screen magnification program, and Jaws, a screen reading program from Freedom Scientific - have been installed on one of the libraries computers.

Library Director Dianne Hathaway is thrilled with the new software. "It has opened up the world to them. Think of the access they didn't have before."

Magic can be used by anyone with impaired vision, colorblindness by magnifying the text on the screen from two to 16 times. With text smoothing, mouse enhancements, screen locators and inverse colors for contrast reading, Magic can allow someone with impaired vision user to fully experience a computer.

Jaws, the other software program, makes it possible for blind people to use the library's card catalog and databases, the Internet, e-mail, Instant Messenger, Real Player, America Online, word-processors, Microsoft programs such as Word, Excel, PowerPoint, Access and Outlook.

"We're hoping to have other libraries to do this," said Michael York, State Librarian. Ross Doerr, a certified Jaws trainer of the New Hampshire Association for the Blind introduced the new Jaws software to the Goffstown public on October 16. Doerr, an attorney, became blind as an adult, but the Jaws software allowed him to stay in touch with his kids through e-mail. Jaws, has become his windows to the world, he said.

"I think it's amazing," said Amy Lapointe, Assistant Library Director. "It's exciting as a librarian because we connect people with resources."

While using Jaws a

voice reads out loud the text on the screen, and keystrokes take place of a mouse. As the computer reads, a higher-pitched voice is heard to stress a capital letter. Settings that control the speaking voice, pitch, and typing echo are all options the user can use. The keystrokes are a combination of Microsoft Windows and Jaws commands.

A Jaws dictionary allows the user to specify how a word is spoken. Doerr's last name is pronounced, "deer" by Jaws. Typing in the word "door" identifies to the computer the correct pronunciation.

With a price tag of \$800 to \$1100 for the Jaws software, Doerr believes it is not an option for a person living on disability to afford a computer and the software.

"It's expensive to be blind," Doerr said. "These are my mechanical eyes, it's doing for me what doctors can't."

Jaws will not read pictures that are not labeled. This can cause some

minor problems while using the Internet, as not all Websites are Jaws functioning. Jaws will read a picture if it is labeled which helps the blind person to "see" the picture.

Lapointe found the music group U2's Website to be hard to navigate while using Jaws because of the high graphic content, which Jaws cannot read to its user.

Hathaway and Lapointe attended the Adaptive Technology Consulting seminar in Massachusetts for personal one-on-one training of the software. "I'm still learning it," Lapointe said. "It's a lot to learn. It would be difficult for someone who was not familiar with a computer."

The Goffstown Public Library was the only library to apply for the LSTA grant money to purchase Jaws and Magic made available through the New Hampshire State Library.

The New Hampshire Association for the blind is aware of 51 legally blind or vi-

sually impaired individuals in Goffstown and an additional 22 in nearby communities.

Basic Jaws training is available through the New Hampshire Association for the Blind. "I think it is unrealistic for any member of this library to train someone to use the Jaws program," Doerr said.

The library purchased a monitor of 19 inches for the computer after they had been accepted for the grant. An enlarged character keyboard will be a future purchase. "Hopefully now that this is in place we'll have people who will use it," Lapointe said.

The Jaws and Magic software were made possible through funds administered by the New Hampshire State Library and provided by the Institute of Museum and Library Services.



You have the right to remain silent....



....but it can be used against you.



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5. Have concerns about your disability affected your decisions about student loans? For example, some students are reluctant to borrow money for school because they wonder if they will be able to work and repay their loans.

6. What additional expenses did you face as a student with a disability?

* Please describe services or accommodations that your college funded. Examples: TTYs, speech recognition software, screen reading software, note takers, readers, sign language interpreters, transportation, personal assistants

* For what disability-related expenses have you *not* been able to receive funding from your college, vocational rehabilitation agency, or health insurance provider?

7. How do all of the support services you utilize work together? For example, what is the relationship between the assistance you receive from your college and the help available from vocational rehabilitation agencies?

8. If you are considering attending graduate school, from where will you seek financial support?

Sending just one paragraph about a particular issue or concern will help this effort. Please return your comments by October 30, 2003. Send them to:

Dr. Gerrie Hawkins
Youth Advisory Committee
National Council on Disability
1331 F St., NW, Suite 850
Washington, DC 20004
Fax: (202) 272-2022 or E-mail: youthfeedback@yahoo.com.

The Youth Advisory Committee (YAC) is made up of young adults with disabilities who advise the National Council on Disability (NCD) about issues faced by children, adolescents, and young adults with disabilities.

Members of the YAC know how important it is for people with disabilities to succeed in college and are considering ways that the federal government can address related concerns. Advice from the YAC helps NCD to make recommendations to the President and Congress on disability issues such as special education, the transition to adulthood and independence, independent travel, rehabilitation, higher education, employment, health care, and other topics.

There is little information from people with disabilities about their higher education experiences, including financial challenges, barriers, and level of success. Their stories will help expand what is known about these issues, so the support services provided to students with disabilities can be improved.

Concerns About I.D.E.A.

**A letter from:
The New Hampshire Department of Education,
Parent Information Center,
State Advisory Committee,
New Hampshire Developmental Disabilities Council,
and NAMI-NH**

The United States House of Representatives has just released its proposal, HB 1350, for the reauthorization of the Individuals with Disabilities Education Act (IDEA), which they have titled the Improving Education Results for Children with Disabilities Act of 2003. It is critical that you familiarize yourself with this bill and respond immediately (by the end of March).

There are many areas in this bill which align it with the No Child Left Behind law, providing greater emphasis on reading skills, including early intervention for children experiencing difficulty with reading, enhanced personnel standards, performance goals and indicators, and including children with disabilities in assessments to ensure schools effectively meet the needs of children with disabilities.

Because of the belief that many children who have been identified as having learning disabilities would not have needed special education had they been provided appropriate, scientifically-based instruction practices and programs that contain the essential components of reading instruction, this bill allows a school district to use up to 15% of its IDEA funds to provide pre-referral educational support services for students who have not been identified as needing special education or related services but who need additional academic and behavioral support to succeed in a general education environment.

This will undoubtedly help children who are having difficulty in school, but unless the funds come from another source (for example No Child Left Behind funds), the money available to serve identified children with disabilities will be reduced.

The Improving Education Results for Children with Disabilities Act of 2003 includes several initiatives to re-

duce the paperwork burden on teachers, related services providers and school administrators. One of those requirements is that, "Each State that receives funds under this Act shall - (2) minimize the number of rules, regulations, and policies to which the State's local educational agencies and schools are subject relating to this Act, and (3) identify in writing to its local educational agencies and the Secretary any such rule, regulation, or policy as a State-imposed requirement that is not required by this Act and Federal regulations."

Further, the Federal agency will then determine which requirements result in excessive paperwork completion burdens for teachers, related services providers and school administrators. There is no requirement, however, to consider whether any of these additional requirements benefit children with disabilities.

New Hampshire's special education law and regulations do include some additional protections for children with disabilities and they clarify Federal requirements (ex: we have determined that a "reasonable time" to complete an initial evaluation is "45-days"). This may lead to New Hampshire lowering our standards to the Federal level.

The philosophy of IDEA has always been that it sets the minimum standard for States to follow when providing a free appropriate public education to children with disabilities. This reauthorization should not result in a reversal of that standard.

One area in which the requirements for the Individualized Educational Program have been reduced is by removing the phrase, "including benchmarks or short-term objectives" from the IEP component regarding measurable annual goals. This would make it more difficult for schools and parents to monitor a child's

progress towards his/her annual goal.

Additionally, new language has been added requiring that special education, related services and supplementary aids and services provided to a child, or on behalf of a child, are to be based on peer-reviewed research.

This is a commendable standard, but peer-reviewed research may not exist for every related service a child may need (ex. Special transportation), and it is important that the law does not inhibit the IEP team's ability to be creatively responsive to the needs of children with disabilities.

The process by which children suspected of having specific learning disabilities are to be evaluated and determined eligible for special education has been radically revised.

First, the school district does not have to consider whether the child has a severe discrepancy between achievement and intellectual ability in the areas typically considered for learning disabilities. Instead they may "use a process which determines if a child responds to scientific, research-based intervention."

This means that IQ testing would no longer be part of the evaluation for a child suspected of having LD. Then, when the decision is made about the child's eligibility for special education, the determinant factor cannot be a "lack of scientifically-based instruction practices and programs that contain the essential components of reading instruction, lack of instruction in math, or limited English proficiency."

In the absence of readily available, scientific, research-based interventions that maybe used evaluate children suspected of having learning disabilities; it would be premature to abandon current assessment practices. A concern is whether this might result in a substantial delay in a child be-

ing determined to have a learning disability and receiving appropriate special education services.

Another area where major changes have been included has to do with children with behavioral issues. The requirement that a manifestation determination review be held when a child is removed to an interim alternative educational placement as a result of his/her violating school rules (when that removal constitutes a change in placement) has been eliminated from this bill.

Also removed are protections for children whose behaviors are a manifestation of their disabilities. In addition, the situations for which a child can be removed to an interim alternative educational setting for up to 45 days have been expanded, and their time in such a setting can be extended for a variety of reasons, including if their behavior would interfere with the school's ability to maintain an appropriate educational atmosphere.

The current IDEA provides a process by which the IEP team may consider what re-evaluations they need to understand a child's educational needs and make decisions regarding his/her eligibility for special education, present levels of educational performance and to write the IEP.

This bill weakens that process by allowing parents and the school district to simply agree that a 3-year reevaluation is unnecessary. It also offers parents the option of having the IEP team develop a comprehensive multi-year (3-year) IEP, instead of reviewing and revising the

IEP on an annual basis.

While this is currently only an option and not a requirement for all parents, there are fears that it may eventually lead to the 3-year IEP becoming mandatory.

The last major area that has been changed has to do with dispute resolution. This bill puts a positive emphasis on parent/school collaboration and early dispute resolution, including a requirement that States provide voluntary binding arbitration as one means to resolving disagreements.

It has removed, however, the section of the current IDEA having to do with parent reimbursement for attorney fees (including limitations) when a parent files for a due process hearing and they prevail.

Additionally, if parents refuse to give their consent for an initial evaluation or for the provision of special education services, the school district is freed from the obligation to evaluate, develop an IEP or provide services to such child.

Previously, a disagreement in any of those areas could have been resolved by either informal means or by either party filing for a due process hearing. This was an important protection for children who the district felt needed special education services.

Even though this letter includes a great deal of information, and the proposed bill is complicated, please take this opportunity to inform your Senators and Congressmen of your thoughts on this proposal. Thank you in advance for your involvement - it truly is important.

**Advocacy is a right
and a responsibility.**

National Parents Group Issues Position Paper on Discipline Issues and I.D.E.A.

The National Committee of Parents Organized to Protect IDEA represents millions of parents and families who are unified across the country to protect the educational guarantee required by the Individuals with Disabilities Education Act.

The National Coalition of Parent Centers and the National Down Syndrome Society are spearheading the effort to organize and communicate strong parent support to protect this most important law. This effort is based on the belief that our children's lives depend on this law.

As Congress contemplates the reauthorization of IDEA this year, consideration is being given to changing the language of the Act with regard to school discipline procedures for students with disabilities. The National Committee of Parents Organized to Protect IDEA urges Congress to refrain from making such changes because the changes made to the law in 1997 are working and the need for further change does not exist.

Following the adoption of the changes to the law in 1997, the General Accounting Office (GAO) was asked to assess the discipline provisions in IDEA. In a report released in January 2001, the GAO found that IDEA discipline provisions do not hinder school officials in disciplining students.

In the study, principals generally rated their school's special education discipline policies under both IDEA and local policies as having "a positive or neutral effect on school safety and orderliness." The report also refuted concerns about the so-called "double-standard" between students with and without disabilities or, what we refer to as "the safety net."

Under IDEA, behavior of students with disabilities is required to be addressed as an education matter so that all children, including those who have behavior issues or whose disabilities involve behavioral manifestations, are able to learn in the least restrictive environment. When a student's disability-related needs include behavior challenges, special education and related services must be provided in a manner consistent with the child's IEP to address the student's unique

needs. As clarified by the IDEA Amendments of 1997, when a child's behavior impedes the learning of him/herself or others, the IEP team must consider strategies, including positive behavioral interventions and supports, to address that behavior.

The experience of thousands of parents affiliated with The National Committee of Parents Organized to Protect IDEA indicates that these types of interventions have worked well to help students with disabilities meet their behavioral needs in school. Teachers, administrators and parents, working to-

gether, have been successful in assessing when behavioral or other interventions are necessary and in providing ways to address inappropriate behaviors.

This does not mean that students with disabilities cannot be disciplined. On the contrary, regulations promulgated by the U.S. Department of Education currently permit schools to suspend students protected by IDEA for up to 10 school days in a given school year without providing educational services or placing them in alternative educational settings. The regulations further permit students with IEPs to be suspended for *more* than 10 days or expelled if their infractions are not deemed manifestations of their disabilities. However, in such instances, they must continue to be provided their right to free appropriate public education.

This means there must be no cessation of the education programming and services they receive, or may need additionally to receive, to participate fully in a preschool, elementary or secondary curriculum that is consistent with state education standards and their IEPs.

Provisions added to the law in 1997 state that school personnel can remove students with disabilities for up to 45 days to an alternative setting

who possess or carry a firearm to school or knowingly possess, sell or distribute illegal drugs in school or at a school function. In addition, the school, through a hearing officer, may seek to remove for up to 45 days a student who exhibits behavior that "is substantially likely to result in injury to the child or others."

As Congress reviews the discipline issue, The National Committee of Parents Organized to Protect IDEA, ask that it consider the following:

* Through its own investigation, the GAO finds that no problem

exists. The burden should be on those advocating for change to show that a pervasive national problem exists that cannot be effectively addressed under current law, including working with parents through the IEP process;

* Any proposed statutory change that permits teachers/school administrators to unilaterally remove students with disabilities from their educational placement for such subjective determinations as "disruptive behavior" is overly broad and will punish students for behaviors that are disability-related, in violation of their civil rights under section 504 and the Americans with Disabilities Act, and;

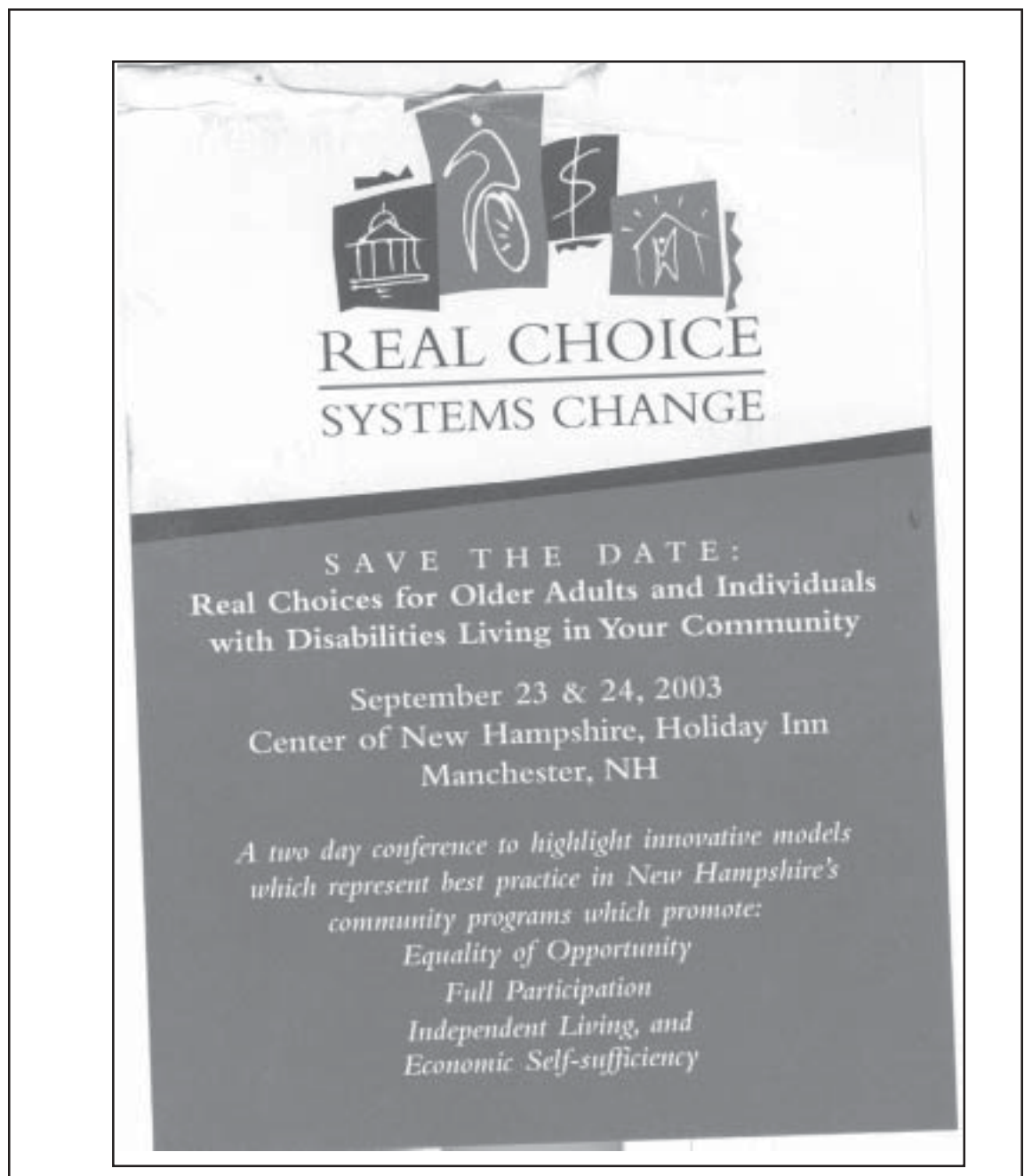
dren with disabilities – including those with mental retardation, autism, and mental illness. Some of these children may have behaviors that interfere with their ability or the ability of other children to learn. These behaviors must, under the law, be addressed as education issues. These children were the intended beneficiaries of Public Law 94-142, the predecessor of IDEA; they must not be excluded from school based on a subjective determination of a school administrator, teacher or administrative hearing officer.

The National Committee of Parents Organized to Protect IDEA strongly concur that the current discipline provisions in IDEA are sufficient to ensure school safety. On behalf of the thousands parents who are affiliated with our organizations, we urge Congress not to amend the current IDEA discipline provisions in the next reauthorization.

(This material was prepared with private funds.)

* IDEA ensures a free appropriate public education for *all* chil-

Our children's lives depend on this law.



Assessment or tax?

Opinion

Once again the Legislature is wrangling over a budget. Once again, advocates are pleading the case for those whose voices are less strong and less financed than the nursing home industry, for example. Once again, citizens are hearing the New Hampshire mantra of "No new taxes."

But is this really true?

You need to read between the lines.

Governor Benson has clearly threatened to veto a budget that contains a tax of 36cents on cigarettes. This, while he remains silent on a 6% "assessment" on services provided to people with developmental disabilities, mental health, acquired brain disorders, and infants - birth through 3 - who have disabilities or are at risk for disabilities. Curious!

Some have claimed the "assessment" is merely a scam to leverage more federal dollars for our state. It is likened to the old MEDISCAM trick, long protested by our own GSCPA activists. Those federal dollars come out of our income taxes, not our property taxes, so there is no local cry about the drain on NH taxpayers. In other words, there will be no political repercussions statewide.

And these same federal dollars (A.K.A. "assessment") will provide the Legislature acceptable political cover to help those people in our state who are the most vulnerable and fragile. It's politically safe and viable, precisely because it is FEDERAL.

It even has the support of the service providers. We understand this. Service providers have been living in an economy of scarcity the last decade, despite the booming economy and having "our friend" Governor Shaheen in office. New Hampshire was frugal to the point of being stingy even in the good times, when revenues are rolling in and a perceived friend was in control. According to the research of David Braddock of the University of Colorado, New Hampshire's spending for services to people with developmental disabilities ranked 23 in the country in 1996, when the economy was hot. Now, it is dropping to 33 in 2000 when it is ice cold - *even though half of the money spent was matching federal dollars!*

The silence from the Corner Office on this "assessment" (no one dare call it a tax!) is notable. The Legislature can feel good that it is doing something on behalf of people with disabilities. The area agencies nervously breathe a little easier for a while, hoping this new band-aid will let them see at least as much money as they had last year. The taxpayer ignores the whole scheme because it's FEDERAL, and not coming out of their property taxes.

The facts remain the same. New Hampshire is not taking a long term solution, but milking Medicaid for what is a state responsibility. Meantime, Medicaid is one of the fastest growing line-items of the federal budget. President Bush has proposed a plan to decrease Medicaid spending by giving states several years of block grants with fewer strings attached in exchange for steadily decreasing amounts in the future. The conservative ethic currently thriving in Washington will make the kind of new loophole New Hampshire is eyeing in Medicaid evaporate, if the Centers for Medicare and Medicaid Services even approves it at all.

We all should be honest about this. In the end, it all comes down to taxes, no matter what euphemism is used, and no matter what political expediency seems attractive. There are no good guys or bad guys here in this situation. There is only a lack of will and a fear of the word "tax."

In the end, it is a matter of will. New Hampshire has not the will to pay for its responsibilities. Taxing people with disabilities - young and old - is a safer bet politically than taxing cigarettes. These are the very bad choices before us.



Letters to the Editor

Readers' Reactions to "Down on the Farm"

To the editor:

I am writing in response to the New Hampshire Challenge article concerning Deborah Gray wanting to put her son in a Farm House with 50 people with disabilities.

I do not agree with Deborah Gray. I believe that even though people have good intentions, sooner or later (because of financial and other reasons,) the population at a place like this will continue to increase. Putting a son or daughter in any type of institution (and this seems to me to be a mini-institution) is not the way to solve the problem. I know firsthand from my own experience how it feels to be denied opportunities. I spent 23 years of my life at the Laconia State School and Training Center. I received no formal education. I was always slapped and kicked around by attendants at Laconia State School and Training Center. The food was not cooked the way it should be have been. It affected my health along with the health of my sister Roberta and many other residents as well.

The death rate was very high at Laconia State School and Training Center. The sanitary conditions were poor. We were thrown together in big wards with no privacy. We took cold showers, and used the same sink to wash our hands (that's why we caught so many germs.)

Families and the people of New Hampshire worked hard to close the institution. Anyone who had ever been a part of the institution knew how positive that was for our state and our people. Allowing people with developmental disabilities back into their communities was the first step. There is still a lot that needs to be done to move persons with disabilities forward. To me, bringing back institutional type settings is moving backwards, not forwards.

I worked hard to become independent, especially when I was told all my life that I never would be. It bothers me that other people with disabilities may end up back in the surroundings that I fought so hard to leave.

There are other options for Deborah Gray's son. I know she wants what's best for him and I hope that she will look into all the other alternatives before she makes such an important decision.

**Jocelyn C. Gallant
Concord, NH**

To the Editor:

I have a disability and I live in the community here in New Hampshire. I lived at Laconia State School for four years before it was closed down. I had no life there. Residents

lived in large dormitories with no privacy. They threw cold water on you when you didn't wake up. Sometimes residents were locked in a room and put in straight jackets. Sometimes there was not enough food and we went hungry. We couldn't go to the store to get food. We had to wait until the next day. We didn't even have the freedom to tell people that we didn't like how we were being treated.

Students who didn't have disabilities went to regular schools and got an education. Even though we were supposed to learn how to live independently, they didn't teach us any skills at Laconia. They only wanted to teach people without disabilities. It wasn't until I got out that I learned how to live on my own and get a job.

An article in the newspaper said Governor Benson wants to cut the budget for Health and Human Services. Cutting the budget would hurt people with disabilities because it would cut the services they receive. People with disabilities need those services to stay in the community, learn the skills they need, get training and support for jobs, and be independent. Right now I have staff working with me in the community to help me learn how to cook, shop, and find a job.

Continued on page 17

Letters to the Editor

Continued from page 16

Without the staff and services, some people with disabilities would not be able to function in the community.

There is already a waiting list for people who need services who aren't getting any services at all. We need funding so people can get off the lists and so that people with disabilities who are in the community can keep receiving services. Please do not cut services for people with disabilities.

Frank Vinciguerra
Concord, NH

Article promotes accessibility awareness

To the Editor:

I would like to thank you for the excellent articles by Mr. Sean Raymond about his personal experiences as a young man with a disability. I was particularly struck by his recent article "Shopping is Rough On Wheels". It was timely, with the holiday shopping season in full swing, and was also written in an engaging, yet serious style that gave a full picture of what it is like to shop from a wheelchair.

His criticisms are very valid, and should make any retail store manager look at his or her store in a new light. I can personally attest to this fact, as I am both the father of a six-year old girl who depends on the use of a wheelchair, and a retail manager.

I look forward to more of Mr. Raymond's articles in the hope that they will continue to heighten awareness on the subject of handicap accessibility in public places.

Glenn Noblock
Dover, NH

Roommate needed

To the Editor:

My name is Frank and I live in Concord on the Heights. I am looking for a male roommate to share a two bedroom apartment. I am interested in an individual who does not smoke, drink alcohol, with no police record and has an income. If

you are aware of anyone interested in sharing an apartment, please contact me at 226-1998. Thank you.

Frank Vinciguerra
Concord, NH

Budget Inadequate

To the Editor

I am so angry I could spit! I read with horror the results of the NH House of Representatives budget vote.

I can't believe that once again the poor, elderly and disabled get to carry the budget on their backs. People who qualify for services by the state's own criteria will have to wait another 2 years for another budget that hopefully (but most likely won't) will fund services.

For 8 years now the Area Agencies (AA) that provide services to persons with Developmental Disabilities (DD) has been level funded. Over these same 8 years the cost of housing rents, heating oil, salaries health insurance, liability insurance, fleet insurance, etc. have all gone up.

There are employees that qualify for food stamps, section 8 housing and welfare programs. What a shame!

There are more and more people every year who qualify for services but can't get them because our state legislators won't pass funding.

Every year the AA system has to find ways to service someone experiencing an emergency such as the very elderly parent who cares for them dying. Whenever another person is served without additional funding another person's services must be cut back.

A week or so ago several parents got together to talk with legislators about our children's (some adult) needs. It is always hard to beg but that's what the NH legislature has done to us..... Turned us into beggars. Of the 15 legislators invited only 2 showed up. That's okay I thought, the other 13 already know enough about our needs to make an intelligent budget vote and fairly fund the DD system..... Holy smokes, you guys 'n gals really stuck it to the disabled again!

In a newspaper article on 1-24-03 Governor Benson and his (then) new commissioner of DHHS were quoted as saying "..... Advocates for the poor, elderly and disabled need not fear Republicans,". Well governor, I ask you, is it Republicans that control the state? I submit that Republicans (party in general) should be feared unless you are prosperous enough to not need state services. That is not the case with many poor, elderly and disabled through no fault of their own.

I hope the Senate will do better.

Sincerely,
Pete Eldredge
Somersworth, NH

Foster parents needed

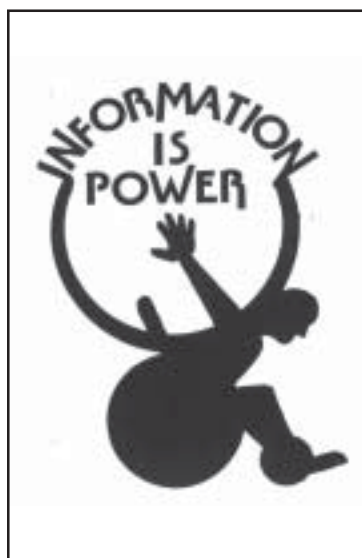
To the editor:

Have you ever thought about foster parenting? Please do! Foster homes are needed for children of all ages, particularly older children. If you can help or would like more information, call your local Department of Health and Human Services' Division for Children, Youth & Families foster care worker at 1-800-862-5300.

Jan Feuer
1-800-624-9700, ext. 789
NH DHHS Division for Children, Youth and Families

www.nhfapa.org
www.dhhs.state.nh.us/DHHS/FOSTERCARE/default.htm

E-mail:
jfeuer@dhhs.state.nh.us



Need Legal Advice? Can't Afford an Attorney?

This article is reprinted from The Granite Slate, November, 2002, a publication of Granite State Independent Living

If you need legal advice and cannot afford a lawyer, there are several programs that may help. It depends on your issue and ability to pay something. This network of providers uses volunteer and staff attorneys and relies on a variety of grant funding sources and contributions of services by lawyers. They assist or represent low-income people with critical legal needs.

Legal Advice and Referral Center (LARC) - for issues related to family law, such as divorce or child custody disputes, welfare or government benefits, housing, bankruptcy or consumer law. The telephone number is (800) 639-5290 or visit larcnh.org

New Hampshire Legal Assistance (NHLA) - covers a broad range of matters including subsidized housing, property tax relief, housing discrimination, unemployment compensation, domestic violence, Social Security, and other state and local government benefit programs. Offices are located in Manchester, Portsmouth, Claremont, Littleton and Berlin. Their web site is nhla.org.

Pro Bono Referral Program - families and individuals are screened by LARC for eligibility. The pro bono program refers cases of eligible clients to volunteer attorneys in the client's area of the state.

Reduced-Fee Referral Program - for people whose income exceeds the limits of eligibility for pro bono or NHLA. Attorneys agree to accept cases at reduced hourly rates.

Lawyer referral staff match eligible individuals with attorneys who practice in the area of law they need. For more information, call (603) 229-0002

Senior Citizens Advice Line - this free telephone advice line is exclusively for people age 60 or older - regardless of income. It is available between the hours of 9:00 AM and 4:00 PM, Monday through Friday. Calls are answered live (not voice mail driven). For more information, call (800) 353-9944.

Disabilities Rights Center, Inc. (DRC) - this is an independent non-profit agency which is the federally designated "protection and advocacy" agency in New Hampshire to represent individuals with disabilities. Depending on the individual's income, the service may be free or have a cost. For more information, call (800) 834-1721 or visit www.advocacy@drcnh.org.

Civil Practice Clinic - legal services provided by students of Franklin Pierce Law Center, with guidance from lawyers and faculty.

Free information can be obtained from the NH Bar Association or LARC. To read or obtain a list of pamphlets, check out the bar's web site at nhbar.org. The state Attorney General's Consumer Protection and Antitrust Bureau also has a free publication titled "NH Consumer's Sourcebook." That office can be reached at (603) 271-3641..

The Challenge needs your support.
Please make a tax-deductible contribution today.

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@nnhmds.org **website:** nnhmds.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@nnhmds.org

Developmental Specialists:

Berlin/Groveton: Stacia Losier Phone: 752-3009, (800) 862-8634 slosier@nnhmds.org
Littleton: Peg Roy Phone: 444-1742 x4 mroy@nnhmds.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@nnhmds.org
Respite coordinator: Same
Benefits Technician: Sharon Kolinsky 752-1005 x 3307 skolinsky@nnhmds.org

Colebrook/Groveton -

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

Respite coordinator: Same

Legislative Liaison: Same

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

Littleton -

Family support coordinator: Diana Flick 444-1742 x6 dflick@nnhmds.org
Respite Coordinator: Same
Benefits Technician: Susan Beauchamps 444-5358
Family Support Council Chair: Cecile Fillion 752-5704 cecilefi@ncia.net

REGION II Sullivan County

Developmental Services of Sullivan County, Inc.
R.F.D. #3, Box 305, Claremont, New Hampshire 03743
Mark Mills, Exec Director
Phone: 542-8706
Case Management: 542-8706
Adult Services: 542-8706e-mail: mmills@dsscofnh.org
Family support coordinator: Kristina Allen 542-8706
Kallen@dsscofnh.org
Respite coordinator: Jean Sorrell 542-8706
Jsorrell@dsscofnh.org
Early Supports and Services: Dora Maxwell, 542-8706 x135
Dmaxwell@dsscofnh.org
Benefits Technician: Rhonda Desmaris 542-8706 x114
Rdesmaris@dsscofnh.org
Legislative Liaison: Jean Sorrell 543-1618 x121
jsorrell@dsscofnh.org
Family Support Council Chair: John Milliken 826-436
rollingthunder@madscape.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 **Website:** www.lrcsc.org
Family support coordinator: Christine Santaniello 524-7755
chriiss@lrcsc.org
Respite coordinator: Susan Tolcser 524-7755
susant@lrcsc.org
Benefits technician: Lisa Richardson 524-8811
richardson@lrcsc.org
Legislative Liaison: Chris Collier 536-1884
chriscollier@earthlink.net
Family support council chair: Susan Gunther 293-7371
smgunther51@juno.com

REGION IV Capitol District

Community Bridges
525 Clinton Street, Bow, New Hampshire 03304-4609
Roy Gerstenberger, Exec. Dir.
Phone: 225-4153 or 800-499-4153
E-mail: rgerstenburger@communitybridgesnh.org
Website: www.communitybridges.org
Family support coordinator: Jo Edwards 225-4153 (800)499-4153, ext.224 jedwards@communitybridgesnh.org
Respite coordinator: Renee Carlisle 225-4153 (800) 499-4153, ext.215 rcarlisle@communitybridgesnh.org
Benefits Technician: Rebecca Spinney 225-4153 ext. 222
rspinney@communitybridgesnh.org
Family support council chair: AnnetteKowalczyk 224-1524
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 **Website:** www.mds-nh.org
Family support coordinator: Bob Barrows 352-1304 (800) 469-6082 bob@mds-nh.org
Respite coordinator: Carol Burns 352-1304
carolb@mds-nh.org
Benefits technician: Sue Raymond 352-1304 sue@mds-nh.org
Early Supports and Services: Anna Lake 352-1304
Anna@mds-nh.org
Legislative Liaison: Becky Thompson 225-4546
sandb1990@aol.com
Family support council chair: Cameron Tease 827-3538 c
tease@marken.com
Family support council co-chair: Debra Napsey 924-0972
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

Partners in Health Family Support Coordinator: Karin Harvey-Olsen
882-6333 x373 Fax: 889-5460 karinh@region6.com

Respite coordinator: Carole Smith 882-6333 x 325 caroles@region6.com

Benefits technician: Diane Luszey 882-6333 dianel@region6.com

Intake Coordinator: Sue Rockwell 882-6333 suer@region6.com

Legislative Liaison: Bob Mackintosh 882-6333 Bobm@region6.com

Family support council chair: Peter Marcoux 888-5894
pmarcoux@verizon.net

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

Family services resource manager: Joe Rojek 206-2855
joe.rojek@moorecenter.org

Respite coordinator: Joy King 206-2743 joy.king@moorecenter.org

Early Supports and Services: Susan Sakowicz 206-2804
susan.sakowicz@moorecenter.org

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

Legislative Liaison: Ilene Wheeler 668-5423
ilene.wheeler@moorecenter.org

Family support council chair: Donna Nicholaidis 624-1592
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
Resource coordinator: Judy Sadler 436-6111, x334 judy@cdsregion8.org
Respite coordinator: Geoff Simons 436-6111 geiff@cdsregion8.org
Benefits technician: Denise Larsen 436-6111 denise@cdsregion8.org
Legislative Liaison: Sabrina McKenna 430-8386
Sabrina.mckenna@verizon.net
Family support council chair: Kathy Ennis 964-9740
Kennis@northeastrehab.org

REGION IX Strafford County

Behavioral Health and Developmental Services of Strafford County, Inc
Forum Court. 113 Crosby Road, Suite #1,
Dover, New Hampshire 03820-4375
Brian Collins, Exec. Director
Phone: 749-4015 **Fax:** 743-3244
E-mail: bricol@concentric.net **Website:** www.dssc9.org
Family support coordinator: Deirdre Watson 749-4015 dwatson@dssc9.org
Respite coordinator: Karen Juckett 749-4015 kjuckett@dssc9.org
Early Supports and Services: Suzanne Iverson 740-4015 siverson@dssc9.org
Benefits specialist: Julie Batchelder 749-4015 jbatchelder@dssc9.org
Legislative Liaison: Hugh Philbrick 749-4015 hphilbrick@bhdssc.org
Family support council chair: Chuck Raymond 743-3909 chuckray@ttlc.net
Family support council vice-chair: Karen Salter 692-2088 ksalter@aol.com

REGION X Atkinson/Salem

Region 10 Community Support Services, Inc.
8 Commerce Drive, Atkinson, New Hampshire 03811
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
Respite coordinator: presently vacant
Early Supports and Services: Aleece Pappas 893-1299
apappas@region10nh.com
Benefits technician: Deanna Johnson 893-1299 djohnson@retion10nh.com
Legislative Liaison: Terri Cadorette 893-1299 tcadorette@region10nh.com
Family support council chair: Carol Ingram 893-1129 carol-ingram@rcn.com

REGION XI Carroll County

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626 Eastman RoadCenter, Conway, New Hampshire 03813-4219
Peter Blue, Exec Director
E-mail: pblue@centerofhope.org
Margie Matthews, Associate Executive Director
E-mail: mmatthews@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
Respite coordinator: Tina Wallace 356-6921 x 29 twallace@centerofhope.org
Benefits technician: Lindelle Gorham 356-6921 x26
lgorham@centerofhope.org
Legislative Liaison: to be identified - legislativeliaison@centerofhope.org
Family support council chair: Frances Hyslop 539-5429 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: KathyMarshall@uds.org

Family support coordinator: Tara Mullen 443-4109 tara@uds.org
Respite coordinator: Melissa Eastman 443-4113 melissa@uds.org
Benefits technician: vacant
Legislative Liaison: Philip Eller 1-800-698-5465 p2pnh@VALLEY.NET
Family support council chair: Elizabeth Larson 448-5302
elizabeth.s.larsen@hitchcock.org
Upper Valley Support Group (UVSG) (provides emotional support & info)
Phone: 448-6311UVSG
Respite Program coordinator: Leona Ryder 448-1268



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.
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
website:

www.neatexchange.org
Sale of quality refurbished equipment; Rentals, service & repair; Information & referral services; Inventory on website

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

Autism Society of NH
898-0916 or 679-2424
website: www.geocities.com/SV2833
Statewide organization provides information, advocacy and support to individuals with Autism and Pervasive Developmental Disorders (PDD), and their families.

Brain Injury Association of

New Hampshire
225-8400, or (800) 773-8400
e-mail: mail@bianh.org
www.bianh.org
Statewide organization provides resource information to survivors of brain injury and their families.

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

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
email: pclarke@dhhs.state.nh.us
Website: www.ccachc.org
Information and advocacy

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

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

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

Early Education and Intervention Network of N.H.
228-2040

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

Family Resource Connection
271-7931 or 1-800-298-4321
e-mail: FRC@library.state.nh.us
Website: www.state.nh.us/nhsl/frc/
Free, statewide program of NH StateLibrary providing materials on all aspects of raising, caring for and educating children, especially children with special needs; free lending library of books and videos mailed to your home with postage paid envelopes for return; free research and reference service.

Family Support Coordinator, DDS (Kris Bregler)
271-5057
1-800-852-3345 x 15057
kbregler@dhhs.state.nh.us
Can direct you to services available through the Division of Developmental Services (DDS), the 12 Regional Area Agencies and Regional Family Support Programs

Governor's Commission on Disability
271-2773 (Voice),
271-2774 (TTY)
1-800-852-3405 (Voice)
Fax: 271-2837
www.state.nh.us/disability
Information and referral. Provides information about the many services, laws, and regulations that affect citizens with disabilities. Implement and operates the federally funded Client Assistant Program designed to work out problems that may arise between persons with disabilities and the Division of Vocational Rehabilitation

Granite State Guardianship Services Phone: 837-9561
Fax: 837-2613
e-mail: info@gsgs.org
website: www.gsgs.org
Provides legal guardianship services to people with developmental disabilities and mental illness.

Granite State Independent Living (GSIL)
228-9680, (V, TTY)
1-800-826-3700(V/TTY)

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

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

Medical Genetics Dartmouth-Hitchcock Medical Center
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 with visual or hearing impairments and their families.

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

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

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

It On

Northeast Passage UNH/Recreation
862-0070
e-mail: northeastpassage@unh.edu
website: www.nepassage.org
Provides (for a fee) equipment and expertise to individuals, schools and companies to ensure access to educational outings and recreational activities.

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

Parent Information Center
224-7005 V/TTY
1-800-232-0986
website: www.parentinformationcenter.org
Information, support and training around educational issues and advocacy

Parent to Parent of NH
1-800-698-5465
www.p2pnh.org
email: 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
e-mail: jhhpfnh@LRnet
website: www.peoplefirstofNH.org
Self-advocacy group of people "working together to help each other take charge of our lives"; help team available for new or existing groups; 24-hour answering service

Seacoast Child Development Clinic at UNH
862-0561 (Voice/TDD)
862-0034 (fax)
www.seacoastclinic.unh.edu
An interdisciplinary clinical consultation service, assisting families of children with developmental disabilities by using a team approach. Evaluation may include home and/or school visit, depending on needs of child and family. The program is affiliated with Dartmouth Center for Genetics and Child Development and the Institute on Disability, UNH.



Where to Find Help

Continued from page 22

Self-Determination for Persons with Developmental Disabilities -

Institute on Disability/UAP

862-4320 Fax: 862-0555

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

Provides sports opportunities for athletes with developmental disabilities.

"Talking Books"

(NH Bureau of Services to Persons with Disabilities)

271-3429, or 1-800-491-4200

website:

www.state.nh.us/nhsl/talkbkks

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

email: info@vsaartsnh.org

website: www.vsaarts.org

Provides opportunities in the arts for people with disabilities and technical assistance for programmatic and cultural access

The Challenge
wishes to thank
MJO
Enterprises
for their invaluable
and generous
assistance with our
annual campaign.



Partners in Health

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

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

Partners In Health Locations

REGION 1: Derry, NH
Child and Family Services
99 Hanover Street
Manchester, NH 03105
603/668-1920

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

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

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

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

REGION 6: Area Agency for
Developmental Services
144 Canal Street
Nashua, NH 03064
603/882-6333

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

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

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

REGION 10: Berlin, NH
Child and Family Services
99 Hanover Street
Manchester, NH 03105
603/668-1920

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

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

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

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

NH Community Mental Health Centers

Region I

Northern NH Mental Health and Developmental Services

Main Office: 447-3347

Conway : 447-2111

Berlin : 752-7404

Groveton : 636-2555

Wolfeboro : 569-1884

Colebrook : 237-4955

Littleton : 444-5358

Region II

West Central Community Mental Health Services

Main Office: 448-0126

Claremont : 542-2578, also 542-5449

Lebanon : 448-1101

Newport : 863-1951

Region III

Genesis, the Counseling Group

Main Office : 524-1100

Plymouth : 536-1118

Region IV

Riverbend Community Mental Health

Main Office : 228-1551

Henniker : 428-3336

Franklin : 934-3400

Region V

Monadnock Family Services

Main Office : 357-4400

Peterborough : 924-7236

Jaffrey : 532-4291

Winchester : 239-4376

Region VI

Community Council of Nashua

Main Office : 889-6147

Region VII

Mental Health Center of Greater Manchester

Main Office: 668-4111

Region VIII

Seacoast Mental Health Center

Main Office: 431-6703

Exeter : 772-2710

Region IX

Strafford Guidance Center

Dover : 742-0630

Region X

Center for Life Management

Main Office (Salem)

893-3548

Derry : 434-1577

Windham : 434-9937

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

Upcoming Events

May

5 & 6

New England Symposium on Community Economic Development and People with Disabilities

Sponsored by: Project Dollars and Sense, University of New Hampshire/Institute on Disability

Location: Sheraton Harborside Hotel, Portsmouth, NH

Time: All day Seminars

Cost: \$175.00

For more information: call (603) 271-8349

6

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

7

Special Education Laws & the Process

Sponsored by: Parent Information Center

Location: Durham

Time: 5:30 PM - 9:15 PM

For more information: call (603) 224-7005 or 1-800-947-7005

Legal and Financial Planning

Sponsored by: Future Planning Networks of New Hampshire.

Presenter: Attorney John Kitchen

Location: Good Shepard Lutheran Church, 2238 Parade Rd, Laconia, NH.

Time: 6:00PM - 8:00PM

Cost: \$5.00 per person (couple). Registration required no later than one week before the session.

For more information: call Mary Beshta (603) 524-7755 or (603) 744-9301, or email her at: MaryB@lrcsc.org

Children and Young Adults: Finding Hope for Survival

Third annual Erik Cogswell Memorial Conference

Sponsored by: Erik Cogswell Memorial Fund, NAMI-NH, NAMI Family of York, Maine, Seacoast Bipolar Support Group and Seacoast Mental Health Center

Presenter: Peter S. Jensen, M.D.

Location: The Inn of Hampton, in Hampton, NH

Time: 10 AM to 4:15 PM

Cost: \$30 for family members and consumers, \$45 for professionals

For more information: call (603) 225-5359 or 1 (800) 242 NAMI

7 & 14

Educational Surrogate Parent Training

Sponsored by: Parent Information Center

Location: Durham

Time: 5:30 PM - 9:15 PM (must attend both sessions)

For more information: call (603) 224-7005 or 1-800-947-7005

8

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

Positive supports for Children with Autism in Preschool Classrooms

Sponsored by: University of New Hampshire's Institute on Disability and the New Hampshire Department of Education.

Presenter: Ann Donaghue Dillon, Institute of Disability

Location: College for Lifelong Learning, Bow, NH

Time: 1:00PM - 4:00PM (Registration starts at 12:30 PM)

Cost: \$25.00

For more information: call (603) 228-2084

8-9

Transition: Adolescence and Early Adulthood

Sponsored by: SERECS and Crotched Mountain Services

Presenters: Dr. Jack Agati, Tom Benjamin, M.S., David Hackett, M.Ed., Cate Weir, M.Ed.

Location: Live at The Meeting Place, SERESC, Bedford, NH By videoconference at North Country Education Foundation in Gorham and Crotched Mountain Rehabilitation Center in Greenfield

Time: Thursday and Friday, 9:00 AM to 3:30 PM

Cost: At Bedford location: \$185 per individual, \$145 per parent or paraprofessional

At NCEF or CMF location: \$165 per individual, \$145 per parent or paraprofessional

For more information: Contact Robin Knight at (603) 206-6816 or e-mail at rknight@seresc.net

13 & 14

20th Annual Brain Injury & Stroke Conference

Sponsored by: Brain Injury Association of New Hampshire

Location: Courtyard Marriott & Grappone Conference Center, Concord, NH

Time: 8:30 AM - 3:30 PM both days

Cost: Professional Fee: \$189.00, Survivor/Family Fee: \$94.00

For more information: call (603) 225-8400.

14

Literacy

Sponsored by: Parent Information Center

Location: Manchester

Time: 6:00 PM - 7:30 PM

For more information: call (603) 224-7005 or 1-800-947-7005

20

NH Achieving Results with Special Education: What's working? What's Not?

Sponsored by: New Hampshire Department of Education & Bureau of Special Education

Presenter: Facilitated Discussion Groups for both parents and STUDENTS

Location: Oyster River Middle School, Multi-Purpose Room, 1 Coe Drive, Durham, NH

Time: 6:00 PM - 8:30 PM

Cost: none

For more information: call (603) 271-3494

Real Choice and Control for Employment

Sponsored by: Institute on Disability, NH Dept. of Ed.

Presenters: Heidi Cloutier, Karl Honsaker, Peg Healy and JoAnne Malloy

Location: College for Lifelong Learning, Bow, NH

Time: 9AM - 3 PM

Cost: \$60 per person; \$55 per team member (3 or more)

For more information: call (603) 228-2084

21

IEP Clinic

Sponsored by: Parent Information Center

Location: Peterboro

Time: 5:30 PM - 7:30PM

For more information: call (603) 224-7005 or 1-800-947-7005

29

Educational implications for students with cochlear implants

Sponsored by: ATECH Services / ASSETT

Presenter: Donna Blain, M.A., CCC-A

Location: Southeastern Regional Educational Service Center (SERESC), 29 Commerce Road, Bedford, NH.

Time: 9:00AM - 4:00PM

Cost: \$60.00 for up to three professionals participates from the same school, and a family rate of \$20.00 per family.

For more information: Contact ATECH Services/ASSETT, 117 Pleasant St, Concord, NH 03301 or fax to (603) 226-2907. Telephone number (603) 226-2900.

June

3

Legal and Financial Planning
Sponsored by: Future Planning Networks of New Hampshire.

Presenter: Attorney John Kitchen

Location: Community Bridges 525 Clinton St., Bow (Annex)

Time: 6:30PM - 8:30PM

Cost: \$5.00 per person (couple). Registration required no later than one week before the session.

For more information: call Micky Shoemaker at (603) 228-3284 or email at: nhshoes@aol.com

5

Audio Description "Kick-off" Event

A day of workshops to learn about and experience Audio Description, followed by a public performance of *JazzArtSigns* in the evening

Sponsored by: VSAarts of New Hampshire and GSIL

Location: The Music Hall in Portsmouth, NH

Time: Workshops 9 AM to 5:30 PM; Performance begins 8 PM

Cost: \$60, plus \$20 dinner option

For more information: call Rebecca Bruns at (603) 228-4330 (V/TTY) or e-mail: rebecca@vsaartsnh.org

6 - 8

34th Summer Games

Sponsored by: Special Olympics New Hampshire

Location: UNH, Durham

Time: Friday 7:30 AM to 9:00 PM; Saturday 7:00 AM to 9:00 PM; Sunday 8:00 AM (breakfast)

For more information: contact SONH at (603) 624-4911 or web site: www.sonh.org

8

FUN DAY

Sponsored by: Brain Injury Association of New Hampshire

Location: Camp Mi-Te-Na, in Alton, NH

Time: 9:00 AM - 3:00 PM

Cost: \$10 per person

For more information: call (603) 225-8400 or 1-800-773-8400

21

Special Education Laws & the Process

Sponsored by: Parent Information Center

Location: Bedford

Time: 9:00 AM - 12:30 PM

For more information: call (603) 224-7005 or 1-800-947-7005

21

Educational Surrogate Parent Training

Sponsored by: Parent Information Center

Location: Bedford

Time: 9:00 AM - 4:30 PM

For more information: call (603) 224-7005 or 1-800-947-7005

26-28

Building on Family Strengths, A National Conference on Research and Services in Support of Children and Their Families.

Additional Resources

Helpful Websites:

www.aapd.com

American Association of People with Disabilities

www.access-able.com/

Access-Able Travel Resource

www.adanet.org

American Disability Association

www.albinism.org

The National Organization for Albinism and Hypopigmentation

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

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

www.benefitscheck-up.org

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

www.csni.org

Community Support Network, Inc.

www.dot.gov/accessibility

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

www.dredf.org

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

www.emerginghorizons.com

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

www.eseals.org

Easter Seals NH

www.cms.hhs.gov

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

www.dredf.org

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

www.hhs.gov/newfreedom/

US Department of Health and Human Services' New Freedom Initiative

www.nhhelpline.org

New Hampshire Help Line

www.nhspinal.org

NH Chapter of the National Spinal Cord Injury Association

www.nichcy.org

National Information Center for Children and Youth with Disabilities

www.nod.org

National Organization on Disability

www.sath.org

Society for the Accessible Travel & Hospitality

www.skimhs.org

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

www.ssa.gov.SSA_Home.html Information on Supplemental Security Income (SSI), disability and related benefits

Publications of Interest

Disability Solutions

FREE

A resource for families and others interested in Down syndrome and related disabilities.

Published six times a year.

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

www.disabilitysolutions.org

subscription@disabilitysolutions.org

Exceptional Parent Magazine

Paid subscription \$39.95 a year

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

website: www.EParent.com

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

New Developments

Benefit of membership

(301) 652-2263

E-mail: devdelay@mindspring.com

website: www.devdelay.org

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

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

Family Voices

FREE

800-852-3345 x 4525

e-mail: nhfv@yahoo.com

website: www.nhfv.org

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

Ragged Edge

Paid subscription \$17.00 a year

Fax: (502) 899-9562

e-mail: circulation@raggededgemagazine.com

website: www.raggededgemagazine.com

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

Continued from page 22

Sponsored by: Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute for Human Services, Graduate School of Social Work, Portland State University
Location: Hilton Portland, Portland, Oregon

Time: All Day Seminars

Cost: \$305.00

For more information: contact: www.rtc.pdx.edu

**July
11-13**

National Down Syndrome Society National Conference

Location: Adam's Mark Hotel, St. Louis, Missouri

For more information: visit www.ndss.org or call 1-800-221-4602

August

22-24

National Down Syndrome Congress Annual Convention

Location: Adam's Mark Hotel, Philadelphia, Pennsylvania

For more information: call 1-800-232-6372

Adams, Keith & Lorraine of PA
 Adams, Ruth and Bill of PA
 Akins, Caroline of NH
 Alexander, Marty of NH
 Allen, Gordon of NH
 Allen, Janice K. of NH
 All-Ways Accessible, Inc of NH
 Aultman, Shirley of NH
 Autism Society of NH
 Barden, Mr. & Mrs. Andrew of NH
 Bart, M/M Costa of NH
 Belmont, Joseph T. of NH
 Bergeron, Brenda T. of NH
 Beshta, Mary of NH
 Birnie, Elizabeth of NH
 Bishop, Pamela of NH
 Blodgett, Ray, Priscilla & Brian of NH
 Boucher, Mr. & Mrs. Edward of NH
 Bowman, Peter and Suzanne of ME
 Broad, Muriel & Ed of NH
 Brown, Catherine & Robert of NH
 Brown, David & Barbara of NH
 Buckley, Michael & Shirley of, NH
 Burdick, Arnie of NH
 Burgon, Karen of NH
 Burke, Thomas/Marjorie of NH
 Burtner, Jim of NH
 Cagle, Thomas of NH
 Cameron, Mary Ellen of NH
 Cassidy, Frank & Theresa of NH
 Chabot, Paul & Simone of NH
 Chaput, Roland & Nancy of MA
 Connelly, David & Colette of NH
 Connors, Margaret J. of NH
 Cooper, Daryle & Mary Ann of NH
 Covert, Susan of NH
 Crocker, Allen of MA
 Cunis, MD, David of NH
 D'Angelo, Rich & Patty of WA
 Dennis, Robert and Nancy of NH
 Dillon, Colleen & Dave of NY
 Dixon, Beth of NH
 Doucet, Mr. & Mrs. Normand of NH
 Dow, Sylvia & David of NH
 Downing, M/M Delbert of NH
 Drabinowicz, Theresa of NH
 Drexel, Kathryn of NH
 Durkee, Judith of NH

Eastman, David G., MD of NH
 Emrich, Mary of NH
 Fair, Patricia of NH
 Fardelmann, Shelley of ME
 Flockhart, Eileen of NH
 Ford, Ruth of NH
 Forgit, Cathy & Fran of NH
 Forry, Katy of NH
 Foss, Carrie of NH
 Fowler, Betsy of NH
 Fraize, Donna of NH
 Frink, Jane M. of NH
 Gagne, Colleen A. of NH
 Gaudet, Joseph & Lucy of NH
 Gherardi, Catherine & Gerald of NH

Kaplan, Sue of NH
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