

The New Hampshire Challenge

disability issues from a family perspective

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Preschool Challenges School Districts



Photo: E.G. Stone

Dashel waits his turn in circle time as he sits on the lap of Judi Ryner at The Montessori School in Keene. Preschoolers have many options in some school districts; very few in others. The Challenge examines the preschool programs in two New Hampshire school districts in this issue - Keene and Dover. To read the stories of four families and the choices they are presented, turn to pages: 10 - 19.

Commissioner Donald Shumway

announced his resignation effective July 31 to take the helm at Crotched Mountain Foundation as its president and chief executive officer. We interviewed Commissioner Shumway about his decision to leave state service and go into the private sector. To read what Commissioner Shumway has to say, go to pages 6 - 9.



Photo: Krumm

Court Orders Services for People with Brain Injuries on Waitlist

by: Janet M. Krumm

Individuals with brain injuries who were on the waiting list as of December 10, 2001 will receive services as a result of a court order by Judge Steven McAuliffe of the US District Court for the District of New Hampshire. The State is appealing the decision to the US First Circuit Court of Appeals.

The Court ordered the State "to fund the waiver services within twelve months absent extraordinary circumstances," explained Suzanne Gorman from the Attorney General's office. Services will be provided through the area agencies, according to Matthew Ertas, Acting Director of the Division of Developmental Services (DDS). "We have already started providing services to those people who are on our ABD waiting list as of December 10," Ertas stated.

There were 46 individuals on the waitlist as of December 10, 2001, according to John Capuco, Psy.D. Administrator of Brain Injury Services in the Division of Developmental Services. Of those 46, twenty have been provided services since the court order. The Attorney General's office is in the process of preparing a request for \$1.23 million from the State for its 50% match share of the Medicaid funding needed to provide services for the remaining 26.

In the current biennium, the Legislature allocated a total of \$3 million for services for individuals with brain injuries, Capuco explained. That money has already been allocated, he added. "We don't have the funds needed," stated Ertas. The \$2.46 mil-

Court Order

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State provides services, waits for appeal

Continued from page 1

lion represents the amount of money determined to be necessary to provide services during FY '03 for the 26 individuals remaining of the 46 who were on the waitlist as of December 10.

That will not eliminate the wait list, however, according to Capuco. "As of now, there are 16 people who have been added to the waiting list since December 10," he pointed out. If the First Circuit Court of Appeals upholds the District Court's decision, the state will be mandated to provide services for them as well.

Sheila Zakre, an attorney from the Disability Rights Center (DRC) who is representing the plaintiffs in this case, believes she has a really strong case. "The law is really clear, the Medicaid statute itself is really clear that waiver programs that are adopted by the states cannot limit to less than 200 persons the number of people on a particular waiver," she explained. "The (individuals eligible for services under the) ABD waiver, even with the persons who are waitlisted, were not going to exceed 200 persons. So we think that we have a very strong case on that issue."

Gorman disagrees. "The state's position is that (the Medicaid) statute does not provide a minimum," she said, "that there is no minimum 200 person requirement. That is really the crux of the issue on appeal."

Both sides have already filed legal briefs indicating their positions and oral arguments are scheduled sometime in the fall, perhaps as early as September, according to Zakre.

The lawsuit has not yet gone to trial. "The court has the option of deciding, what does the law say about the rights of the individual?" explained Zakre. "Once the court makes a declaration - this is what it says - then the defendants are supposed to conform their conduct to the law. If they don't, the plaintiffs have the right to come back in court and say, 'they are violating the law and the rights you have articulated the law protects'."

In this case, Judge McAuliffe's declaratory judgment order was based on "what the law in fact does say," ex-

plained Zakre. "The law does in fact say that services have to be provided with reasonable promptness in a waiver program at least up to the 200 limit that is set in the statute. And given that order, the state was then able to appeal to the First Circuit."

There are several possible outcomes for the appeal, according to Zakre. "The First Circuit may simply uphold the district courts' decision. The First Circuit may remand to the district court. And the Circuit could do this for a number of different reasons. One could be that the Circuit believes that the judge's reasoning was incorrect but the case required further factual development.

"The case never went to trial," Zakre continued. "The district court judge declined to rule on our ADA integration claim, which essentially argues that segregation in facilities is a violation of the Americans with Disabilities Act. The judge

didn't rule on that claim in the District Court because the judge felt like all of our claims could be heard under the Medicaid statute which requires that Medicaid funded services be provided with reasonable promptness.

"But if the court disagrees with the judge on that, the court could remand that to the district court for consideration of the ADA claim. And in that case, it would go to trial."

Gorman stated that even if the case gets remanded to the District Court, there is still the possibility that there would be no trial. "It may depend on the circumstances at that time," Gorman explained, "as to whether the trial goes forward or not. The facts may be substantially different by the time it goes to trial, so it's a little hard to articulate at this point what our position will be, depending on what the facts are at that time"

When asked what facts

could be different, Gorman responded: "Some of these plaintiffs may no longer be on the waiting list. So if that changes, then that renders the whole issue moot."

Even if the First Circuit does not agree with the District Court's decision, Zakre thinks it's unlikely that the State would stop providing services to those individuals who were on the waiting list and are currently or will be getting services as a result of the court order.

What is at greater stake is the fate of those individuals who came or will come onto the waiting list after December 10. The number of people with brain injuries on the waitlist fluctuates, stated Zakre, but "the number is generally below 50." If the First Circuit Court upholds the District Court's decision, then the State will be obligated to provide services to anyone with a brain injury eligible for Medicaid up to the 200 person limit.

Court Order Establishes Important Policy

"It's very important policy," stated Don Shumway, Commissioner of the Department of Health and Human Services, referring to the court order in the ADB waiver lawsuit, known as *Bryson vs. Shumway*. "People cannot be kept on a waiting list more than a year. And while it is under appeal in terms of some of the particular details of the court order, I think it's very important that it has been settled in the way that it has. I think it's good for persons with head injuries, will help them get the services that they need."

Shumway doesn't think it will be easy to achieve, however. "It'll be a challenge for the State and providers sometimes to deliver the services in the time frames that are set up," he commented, "particularly as human resources problems become more challenging. It is going to get very hard to hire people as you look out a few years and as the economy reheats and as unemployment goes down."

Because the case has not gone to trial, "providing an educational opportunity," Shumway added, "the basic problem's not well known; therefore, the court order was not really paid attention to. I think it merited two or three paragraphs of coverage".

While largely unknown to the general public, the problem the lawsuit addresses is familiar to the legislature. "I think legislative leaders generally have a good understanding of it," Shumway said. "They know what the State's obligations are but it's a small lawsuit compared with the school funding one from a policy and finance point of view. The DD wait list one, while still in an evolving legal status, is also relatively small compared to Claremont.

"If you take the head injury one plus the DD wait list, plus the children's dental lawsuit that we're hopefully in the final stages of mediating the settlement to, eventually the numbers of discrete cases add up and build up to having a significant financial obligation that the State must undertake during a time of ongoing fiscal crisis.

"So, while any one of the lawsuits may not hit the threshold of particular legislative concern, I think collectively they will. That will pose a real challenge for the incoming governor".

Budget Cuts Will Not Affect Services

but there will be no new allocations for the DD waiting list this year

by: Janet M. Krumm

On June 12, the \$15.2 million in budget cuts recommended by Governor Shaheen was approved by the Legislative Fiscal Committee. \$9 million of that was targeted to come out of the budget for the Department of Health and Human Services.

Matthew Ertas, Acting Director of the Division of Developmental Services, stated that the \$9 million in cuts would have "very minimal" impact on developmental services. "The Commissioner has made some decisions that have been helpful to us in terms of our system," Ertas stated, "and it's not going to affect the services that we provide at all."

He had one caveat to that assurance, however. "I say that with the realization that there is going to be a new commissioner sometime in January or February," he added, "and so I interpreted what has been decided to mean that we are okay for the first six months."

Commissioner Don Shumway has announced his resignation effective July 31,

and Kathy Sgambati has been appointed by Governor Shaheen as Acting Commissioner. A new Commissioner is not expected to be named until after a new governor assumes responsibilities in January. Ertas does not anticipate any significant changes under Sgambati's leadership.

Still, even without programmatic cuts, there will be no new allocations for people on the waiting list during the fiscal year beginning in July. "When we received waiting list dollars last time around, we used all of them," Ertas stated. "We assigned all of the dollars that we received from the legislators."

In the budget approved last year, the legislature allocated \$2 million dollars for the first year of the biennium and \$3 million for the second year. The \$3 million for the second year includes \$2 million to continue the services from the first year and an additional \$1 million new dollars.

Typically, allocation of the waiting list money is a two-

step process, Ertas explained. Decisions are made each year of the biennium. This time, "we didn't follow a two-step process," Ertas stated. "We had a situation where we had a lot more people on the waiting list than we had money for," he explained. "So, because there was a need for it, we assigned all of the dollars. There is no more money to give out."

Ertas explained the process used last year. The area agencies "submitted all of the names that they had for '02 and '03, but the needs are so dramatic that we really had to respond to some of the people who were on the '02 list.

"And so by the time we assigned all the dollars to all of the people who were in critical situations, in other words, some people were coming out of the DCYF system who could not go home. Some were coming out of the school system who could not go home. All of those people had to have residential service and so forth, and that really took quite a bit of the

money.

"Then there were also individuals who were graduating in '02 and '03. All those people got money. By the time we addressed the needs of those folks, all the money was gone. It was really a modest sum of money."

In all, 99 people received services, at a per person cost of about \$30,000.

There is little room to address crises that arise unexpectedly, Ertas admitted. "Once the waiting list dollars are used," he explained, "the system's capacity to respond to some new crisis is very, very limited these days. Because the fact that the system in general has not received cost of living increases over the years, meant that whatever flexibility that we had has disappeared.

"All the new monies we get are all waiting list dollars," he continued. "So area agencies have not really had an opportunity to address the regular cost of living increases.

"So whatever flexibil-

ity we had in the budget has been plugging all those holes as a result of (rising costs). Rents have gone up. Gasoline prices have gone up. Food prices. Insurance. Not to mention wage increase and so forth.

"Right now there's a nursing shortage all across the country and we're having a hard time recruiting. Area agencies are having a hard time recruiting nurses which means that they have to offer more money to be able to get nurses. So all of that is creating a very tight financial situation."

That tight financial situation could have been made worse by the announced budget cuts. "We were asked to give up a very small amount of money," Ertas stated, "and it's really going to have no effect whatsoever on the services. That's really the bottom line.

So I think we came out okay from this whole episode. Both the Governor and the Commissioner had tried very hard to have the least amount of impact on services, and I think they were able to achieve that."

Legal Route in DD Waitlist Lawsuit Bumpy

by: Janet M. Kumm

At a preliminary hearing, Judge James Barry, Jr. of the Hillsborough County Superior Court surprised Ron Lossennato of the Disability Rights Center with his ruling. The purpose of the hearing was to petition the court for preliminary relief. Essentially, that means that the plaintiffs were asking the court to mandate services for them immediately, instead of waiting for the outcome of the trial.

There are four tests that have to be met for a judge to grant preliminary relief, explained Sheila Zakre, an attorney with the Disability Rights Center. The plaintiffs would need to show 1. irreparable harm; 2. the likelihood of success on the merits of the case; 3. no alternative administrative remedy; and 4. whether it's in the public interest to grant preliminary relief.

Judge Barry denied that

petition.

In addition, Judge Barry said there couldn't be a class action, effectively limiting the lawsuit to the five individuals named.

He also denied attorney's fees.

The decision surprised him, admitted Lospennato, the DRC attorney who, with Erica Bodwall of the law firm Backus, Meyer, Solomon, Rood and Branch of Manchester, NH, are the attorneys who filed the suit.

Upon receiving the decision, the plaintiffs' attorneys filed a motion for reconsideration. "Essentially, on reconsideration, he reversed himself," explained Lospennato, "on all of the issues, except for the preliminary relief issue."

The reversal of the decision about the class action does not mean that the judge has declared the lawsuit a class action; only that he would delay

his decision regarding that until more information and evidence was provided him.

This lawsuit, Harris vs. Shaheen, argues that the State of New Hampshire has failed its mandate to create a comprehensive array of community-based services, leaving many individuals with developmental disabilities with no services and others with "grossly inadequate" services.

"We feel as though what we really need to do is a process of educating the judge," Lospennato said, "which requires getting discovery, getting the facts before the judge in a way that's comprehensive and clear and hopefully, at that point, he'll see the light. And we'll be able to get a more favorable decision."

Lospennato believes the process of discovery and trial could take anywhere from six to twelve months.

Section 8 Vouchers Available for Nursing Home Residents

Section 8 Rental Assistance Vouchers are immediately available for eligible persons currently living in a nursing home who would prefer to live in a community.

The New Hampshire Housing Finance Authority announced that there is no waiting list for these vouchers.

The Section 8 Voucher Program is a subsidy to help eligible participants pay for the cost of renting or, in some cases, paying a mortgage. Many landlords throughout the state accept these vouchers and there are a variety of organizations that help participants find housing.

Persons living in a nursing home who interested in returning to the community may contact Patricia Vincent at the Institute on Disability by calling (800) 238-2048 or e-mailing pvincent@cisunix.unh.edu or Anda Tubalkain at the New Hampshire Housing Finance Authority at (800) 439-7247 Ext. 9297 or by e-mailing atubalkain@nhhfa.org.

The New Hampshire Challenge has a new email address:

nhchallenge@attbi.org

Dennis Powers Appointed Director of Division of Developmental Services

by: Janet M. Krumm

Dennis Powers has been appointed Director of the Division of Developmental Services by Kathy Sgambati, Assistant Commissioner of the Department of Health and Human Services, filling the position vacated by Sue Fox March 15. Powers will assume responsibilities on July 15.

"I think that the next two years are really going to be critical in New Hampshire in terms of the system's future," Powers said when asked what excited him about his new position. "I think there are a lot of decisions that are going to need to be made about funding and the waiting list and all of the issues that we face here day to day in the regions. I felt a need to be in a position where I could help make some of those decisions that will affect our future."

Powers' name surfaced several times as the Division sought out potential candidates. His 12 years experience as executive director of Region 10 Community Support Services, Inc. gives him a good perspective on the needs of the developmental services system in the state as well as its strengths. "One of the strengths of the whole system," he explained, "it that there have been so many people who have been around for a long time."

Powers assumes responsibility at a time of great uncertainty, what with a gubernatorial election in the fall and a soon-to-be vacancy in the office of Commissioner of Health and Human Services. "I think anytime you have so many unknowns, there's a certain level of risk in assuming a position like this," Powers admitted. "But I also think that the families and the people who have been advocating for the system over the past few years aren't going to let

things happen to bring down all the hard work people put into it.

"So I know it's going to be critical who the governor is and who the commissioner is, but I think they're going to be taking over at a time when this system still has a lot of needs, but it has a lot of people who are interested in making sure it continues to be what we've all been proud of developing over the years."

It is uncertain as to who will fill Powers' position at the area agency during the search for a new executive director. "We have a very strong management team here at the agency," Powers stated. "One possibility is that the group would continue to manage the agency until a permanent director was named. If it looks like (the board) is going to do an extended search, then they may decide they want to appoint an interim director."

It will not be easy for Powers to leave the agency he has directed for the past twelve years. "I always have regrets leaving someplace," Powers admitted. "I told the board that this has been like my second family. You know, the people who work here at the region, the board of directors, the family support council, they've just been tremendous to work with over the years. And so in that respect, it's tough to leave just because of those relationships that have all developed."

But the board should take consolation in one thing, Powers added. "I keep telling them that I'm not going that far away. I still live here in the region. "So I think it's just taking on a different set of challenges."

Court Orders Clear Criteria for Katie Beckett Eligibility

by: Gretyl Macalaster

An agreement has been reached between the Disability Rights Center (DRC) and the New Hampshire Department of Health and Human Services (NH DHHS) regarding a lawsuit filed by the DRC in June of 2001.

In the lawsuit, the NH DHHS was found in violation of implementing Home Care-Children with Severe Disabilities (HC-CSD), also known as the Katie Beckett option, consistently and fairly. The lawsuit cites four cases of children who were deemed ineligible to receive Medicaid under HC-CSD because they would not otherwise be institutionalized but for this option.

HC-CSD is a family centered community-based home care program to support but not supplant the child's family as the primary caregiver. It is meant for children with severe disabilities who may otherwise require institutional care.

HC-CSD or the Katie Beckett option was implemented in July of 1989. This option includes families whose income exceeds Medicaid requirements but who would otherwise be eligible to receive

benefits.

The Katie Beckett option takes into account only the income and resources of the child during the financial eligibility process, not the income and resources of the child's parents.

Systemically, NH DHHS will now be required to establish quality assurance practices for review. This will include revising forms so that clients send in the appropriate information for reviewing. According to Amy Messer at the DRC, "it is not just medical needs that are important in deciding an ICF-MR [Intermediate Care Facility-Medical Review] level of care".

Another change will be that the Divisions of Behavioral Health and Developmental Services will be involved in the initial review as well as in the appeals process. This is a considerable change from the original process, which involved only medical reviewers from the Department itself.

Perhaps the biggest triumph in this case is that a group of four specialists in the field of developmental disabilities will be convening to develop a

policy statement looking at the four criteria under He-W 508.03(e), which establishes an ICF-MR level of care. Two of these specialists are to be chosen by the Plaintiff.

The four criteria under He-W 508.03(e) that determines whether an individual meets the ICF-MR standard of care are:

1. The child has a developmental disability as defined by RSA 171-A:2,V
2. The child requires a continuous and pervasive active treatment program throughout the child's daily routine.
3. There is a need for continuity of treatment to and from all home and community-based settings and
4. Either of the following are met:

- a. The child requires continuous medical monitoring for a chronic severe health problem or
- b. The child requires continuous supervision, monitoring, and redirection of behavior associated with any condition, related mental retardation, that results in impairment of general intellectual functioning or adaptive behavior.

Although these are sup-

posed to be the only standards by which NH DHHS determines eligibility, they were requiring clients to demonstrate that without HC-CSD the child would be institutionalized. These standards determine that an intermediate care facility may be appropriate for individuals but do not stipulate that a client must be institutionalized if HC CSD is not implemented.

The suit claims that the state must set "reasonable standards that are consistent with the objectives of [the Medicaid Act]."

The policy statement this group produces will provide guidance for reviewers insuring consistency and fairness in eligibility determinations.

The standards by which one meets HC-CSD are very

high. This case does not change any of the rules by which children are deemed eligible. What it does is insure that each case will be reviewed consistently and fairly with all others and that the NH DHHS is properly applying the rules.

Amy Messer says that she is "hopeful that this will help improve consistency and fairness in which determinations are made. It will be good for the Department to take a good hard look at their requirements and improve the process for eligibility reviews".

The DRC is pleased with the outcome and glad to have input on these policy decisions. The systemic changes will set a precedent for all future applicants and individuals up for redetermination.

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Families Find Katie Beckett Inaccessible

Inconsistencies in Eligibility Led to Lawsuit

by: Janet M. Krumm

Linda Stier witnessed firsthand the inconsistencies that led to the Katie Beckett lawsuit. Around 1989, Linda had applied for Medicaid for her two year old daughter Marika under the Katie Beckett waiver. "I was first encouraged to apply," Stier remembered, "because it was believed that her disability was severe enough to meet home care for children with severe disabilities." Marika was determined eligible and began receiving Medicaid benefits.

Not long after that, Stier began working for family support in Region 10. She encouraged other parents to apply for Medicaid benefits for their children under the Katie Beckett waiver. "You can get access to medical services and developmental screenings and additional therapies and help with the cost of wheelchairs," she told them. So parents applied.

Because the waiver was so new to the Heath and Human Services caseworkers in the district offices, family support coordinators would accompany parents when they applied. "One of the reasons we did that," Stier explained, "was what we found was fairly frequently the intake workers were asking for the family's income. And of course, you know it's only the child with a disability who's applying for services, so the family's income is not counted (under the Katie Beckett waiver). And so we had to be there to remind technicians of that frequently."

Eventually, as more families applied and caseworkers became more familiar with the requirements of the Katie Beckett waiver, eligibility determinations became more routine. "It became almost second nature that when we met children with certain diagnoses at early intervention or somewhere in those early years when kids were identified with a severe disability, that we suggested to families that they apply," Stier remembered. "And in terms of labels, kids who had Down syndrome, cerebral palsy, mental retardation - because those are

the developmental disabilities that we worked most with - those kids routinely were found eligible."

That changed, however, in the latter half of the 1990s. Eligibility became more "sporadic," Stier stated.

"The two areas I saw the greatest shift," she said, "were kids who had Down syndrome and kids who had PDD/autism. In those instances, it was so inconsistent. Some kids with Down syndrome applied and got on. Others kids with Down syndrome applied and were denied."

Stier became more and more frustrated as she witnessed children - who in the past would typically be found eligible - denied Medicaid benefits. "I watched some kids with Down syndrome get on and some kids not get on. I saw kids with autism who got on regularly. Then all of a sudden, a wave of kids come along and they get denied

"We do know that kids with mental retardation and cerebral palsy and autism often do get on," Stier admitted, "but there isn't a consistent application. And there really aren't clear interpretations."

It got to the point that Stier, in frustration, started asking the workers at DHHS: "Will you just tell me which ones can get on and which ones can't?" She was working with families to whom she was recommending that they apply for Medicaid, only to have the children be denied. When those families would come back for further help, Stier advised them to appeal.

Initially, Stier accompanied families to the appeal hearing, but then began recommending that they hire a lawyer to represent them. "Now they have to hire a lawyer and pay out of their pockets to fight for something that the kid next door got without the blink of an eye four years ago," Stier commented.

When asked if it was necessary to hire a lawyer to file an appeal, Stier stated: "You don't have to, but they do. Medicaid brings their lawyer." She

continued to offer to accompany parents to the hearing, but told them: "I'll come to the meeting with you, but I can't throw around the language about the statute like they do. And that's what their lawyers were doing, and you had to have a way to respond that goes above and beyond your family support person sitting there."

No longer a family support coordinator, Stier remains a strong advocate for families and for children with severe disabilities. She has strong feelings about the inconsistencies in Medicaid eligibility determinations, particularly regarding children with Down syndrome.

"In lay terms," Stier explained, "what they were saying was (in the case of) kids, especially young children, who are born with Down syndrome, having Down syndrome in and of itself is not a severe disability. I heard almost those exact words more than a number of times - that just because a baby is born and has mental retardation and Down syndrome doesn't mean that child rises to the level of having a severe disability. And I would disagree."

"I think that a baby with Down syndrome has significant challenges," Stier continued, "if not today than the very near future. Certainly by elementary school we see the gap that's there between this kid and a typically developing kid. And some people at Heath and Human Services have said to me, well then it's at that point that those kids should apply."

"It's like, please, we know what the future holds for these kids. I mean, we can predict a lot of things about these kids and we know that they're going to need supports and interventions, so start when they're young. I mean, that's the whole point of early intervention."

Linda Stier presently works as a Policy Coordinator for the Community Support Network, Inc. (CSNI)

Ron Lospennato Wins Prestigious Award

Ronald Lospennato, Esq., a 1978 graduate of Franklin Pierce Law Center, and a member of the New Hampshire Bar since 1978, became the third recipient of the Bruce Friedman Award given by the New Hampshire Partners in Service (NHPS) at their annual meeting in Concord on May 9. Ron has been with the Disabilities Rights Center (DRC) since 1979, and has been DRC's legal director since 1987.

NHPS is a private, nonprofit organization united in action to strengthen and promote services for less fortunate children and families in New Hampshire. The award, which is annually given to one person in New Hampshire, was established to honor the memory of Bruce Friedman. Bruce founded the Civil Practice Clinic at Franklin Pierce Law Clinic in 1978, directed it, and taught at the Law Center until his untimely death in 1997. Past honorees include the Honorable Judge Edwin Kelly and Representative Mary Jane Wallner.

In a statement released by NHPS, this year's award was given to Ron Lospennato because of "his countless hours of hard work and undying commitment to children over the years has propelled NH service delivery away from institutions and toward community based care."

The Disability Rights Center has been in existence for almost 25 years and is part of a nationwide protection and advocacy system created by Congress to pursue legal and administrative remedies to insure the protection of the rights of individuals with disabilities. The organization is dedicated to removing barriers existing in New Hampshire and to the full and equal enjoyment of civil and legal rights of people with disabilities.

Attorney Lospennato has represented individuals in the areas of special education, right to services in the least restrictive environment, social security, housing, employment discrimination, right to treatment and right to refuse treatment, guardianship, health insurance and Medicaid issues. He has handled all aspects of litigation and advocacy, including practice before Federal and state trial and appellate courts. His efforts have improved interagency planning and service delivery for children between the education and court systems, established that all children have a right to an education, resulted in major improvements to the child welfare protection system and ensured that schools provide and fund educational services to children placed by juvenile courts.

Summer Institute Offered

The fourth annual Summer Institute on Educating Students with Autism/PDD in General Education classes will be held July 29 through Aug. 1 at The Center of New Hampshire at Holiday Inn in Manchester.

The four-day conference, sponsored by the University of New Hampshire's Institute on Disability/UCe and the New Hampshire Department of Education, is designed to answer questions related to effective support strategies for students with autism/PDD and their families, teachers, paraprofessionals, related service providers, and school administrators.

Keynote presenters will address effective ways to educate students with autism/PDD in general education classes. A variety of workshops will also be offered, including topics such as facilitated communication, movement differences, developing social stories, supporting sensory sensitivities, and alternative and augmentative communication.

Space is limited and participants are encouraged to register early. The registration fee is \$325 per person. For more information, visit <http://iod.unh.edu> or call 228-2084.

An Interview with Commissioner Don Shumway

Don Shumway has tendered his resignation as commissioner of the department of health and human services, effective as of July 31, after which he will become the president and chief executive officer of the Crotched Mountain Foundation in Greenfield, NH. We were able to spend some time talking with Commissioner Shumway about his tenure as commissioner and his plans for the future.

Interviewer: Janet M. Krumm

Why are you leaving early?

I don't see myself exactly as leaving early. That sounds strange, but it's a four year term. It comes up immediately after the next governor's elected and the chance of being reappointed is low. Quite low, probably.

I've been through the experience in the past where I served under individuals whom I had a lot of policy disagreement with and sometimes they actually like you to stay and they use you under those conditions to validate things you don't want to do, don't believe in. And I swore I'd not do that again.

So, basically, my plan was to go through the legislative session, stabilize the policy setting, get the budget squared away. We did get an additional \$14.8 million, plus two litigation related expenses on the side appropriated, so that stabilizes us for '02, puts much of what we need in place for '03 in the budget. We still have one area to work on. I'm working on the 3% budget reductions that we're having to do now, and working on the process of filing the '04 - '05 budget, which goes in early to mid August.

So basically, those were the milestones that track the work that I do. Those milestones are either complete or wrapping up at this time.

It's funny. I found a bunch of scrap paper last night, which was my resume. I had just printed in early April a whole bunch of updated resumes. I planned on beginning a job search right now, essentially, first of May and searching through the summer and probably accepting something, hopefully if I found it, in the fall and starting up late fall. That basically was my window.

As it turns out, I didn't search at all. They (Crotched Mountain Foundation) came to me and asked me. I pushed them back time-wise: Don't talk to me right now, I've got a legislative session to survive. So they came in right after the session was over and I went down and talked with them and believed it was something I really, really wanted to do. So, I didn't use any of my resumes.

I set the latest date I could with it, which was the end of July. It was time. In terms of the leaving part, it was time. I wasn't sure if it was a good idea to stay through the end. I think it would have made for a more difficult transition for the Department.

Under a new governor, you mean?

Under a new governor. I think getting out with a little advance probably is a better idea than staying through the last day. I think it puts the Department in a much better position to transition. I'm less the issue of who's *not* going to be Commissioner, and I'm getting them focused on who *is* going to be. I think that's a very healthy, good thing. The next governor gets a clear playing field of thinking about Health and Hu-

man Services issues - which is important - not what will Shumway be fighting or agreeing with or whatever. My tenure is up. It's a tenured, specific time period position. This really is more or less the end of it.

So it's a natural kind of transition, really.

Yes. At least it was in the way I was thinking about it.

Why Crotched Mountain?

There are a series of successive reasons that moved me towards a "yes" to Crotched's interest in me. The first was I wanted to find a community non-profit agency to run. That was what I wanted to do. That was where I wanted to go.

Did you want to stay in the area?

Yes. Definitely wanted to stay in the area.

I wanted to find an agency that had diverse capability, diverse interests. Crotched provides senior citizen programs, provides DD programs, programs for people with head injuries, programs for children with special health needs, developmental pediatrics clinics, a large child care center, a host of different types of populations, but with a central interest in disability and related interests.

That's where I come from. That's who I am. That's what I do, what I love to do.

Second, it's got an interesting geography. It's got programs from Portland to Albany, and in the Boston area. Again, it's a large organization, a complex organization, has diverse and challenging finances, tremendous challenges in work force issues and the like. So, it was of the scale and type that I was really interested in. What I'll call intellectually interested in.

It was also emotionally what I was interested in because it has, I think, great potential that is not yet realized. It has the potential to do enormous good for a whole lot of people in a whole lot of different ways.

And it has the potential for allowing me to become much more engaged with family members, persons with disabilities, direct care workers. And I get almost none of that at this level. The sole engagements I tend to have is with what I'll call representatives of families or persons with disabilities. They might be advocates; they might be family members who are advocates, but they're representatives of the families.

They're not the family on Friday night saying, "What do I do with my son's needs or my daughter's problems?" I used to get a lot more of that



in the Division of Mental Health and Developmental Services and loved working with the Alliance for the Mentally Ill, Special Families, United ..

You really bond with people. You establish relationships. They get to know you. You get to know them. But I'm an abstraction here. They're an abstraction for me. I mean, I know them, they know me, but we never see each other.

I get a lot of my energy off of those relationships. The emotional connection with individuals is what makes me enjoy tackling the more difficult parts of the work that I do.

Here, in the role that I'm in now, I really enjoy the competitive struggling, but I don't like it as much, because it's not as connected with people. Or it is, only in the abstraction. That's good, and I have a lifetime of base to build on in this state, but it's just not as much fun.

I'm looking to have that more emotional, fun aspect to what I do. So Crotched seemed to represent that for me, very specifically.

It also has specific challenges that I like. It is financially challenged.

The fact is that it, like all providers, is substantially underpaid for what it does, and in fact it has extended itself somewhat more than other providers, even at a time when the contracts that they have are way below their cost. So it is operating way below break even in its program service delivery.

So its operating margin is negative; its investment margins have been very negative because of the stock market with the endowment that it does have. So it's now on several years of net losses.

That's a serious challenge to the organization and its ability to deliver care.

Yet, at the same time, it seems to me to have a serious investment in its workforce. It wants to pay more for its direct care roles; it wants to provide a really good benefit structure for people to have health benefits, dental health, retirement plans, things like that. That's a really responsible corporate set of values for it to have, and I wanted to find a corporation that was going to try to have those employment values to it. Crotched does have that.

It's viewed as being somewhat out of step in some of its services. Well, I love that. That's the kind of thing I love to deal with, I love to figure out, I love to kind of head-on engage in. What I don't know is: where's this all going to go? How's this going to end?

But then I never know that about the things that I've started. It's the journey that's the fun part.

When I interviewed with the board, there's several parents on the board and they really dominated the interview. And they asked great questions. We had an extraordinary amount of fun in the interview. That was, I think, the thing that made me feel like this is the right thing to do.

I think the first question they asked me was, In the field of disabilities, where would you see yourself on the philosophical continuum of highly conservative to way far out radical side? I said, Well, I'm generally seen as being on the pretty far out end of this. They laughed hysterically, because of course Crotched, for some, represents a place that is not exactly way far out on the radical end.

So, they laughed and I laughed, because here we are sitting and talking about me coming in. They said, Well, how do you feel then about dealing with critics who would criticize your being here and the things Crotched might be providing for services? And it led to a series of wonderful exchanges that, for me, represented what I want to be dealing with other than what I call partisan politics and "gotcha" elections, electoral behavior.

What I said was that what I think is important is less where one is on a philosophical continuum and more whether or not one is ready to absolutely commit oneself to a meaningful dialogue with family members about their dreams and aspirations for their sons and daughters, when one's really willing to say, let's try to do this. And whether one is willing to sit down with individuals with disabilities and, using the most thoughtful and considered individual planning, say, what is the future that you would like to pursue?

I don't know whether that's conservative or liberal. All I know is that's real and the rest of it's budgets and buildings and stuff. My job is to make the budgets and buildings follow the people and their dreams. And if you want someone to try to help you figure that all out, I want to do this.

It's what I want to do. It's all I ever really wanted to do but you get caught in these responsibilities that bring you to other places. For me, I feel very much like I'm returning to something that I cherish much more in my life. That's what I want to do.

I've been hearing that Dr. Carl Cooley has become persona non grata among a lot of people since he joined Crotched Mountain as their Medical Director in 1998.

There are people who were practically best friends who have not spoken with him in years. I don't respect that.

Most of those people I would say, first of all, are newcomers. They weren't around here when we were trying to figure out what we were going to do with Baker, Felker, Keyes, Powell, and other buildings at Laconia State School. They are people who entered the picture when it was all over and we could worry about what I'll call 'how to make very good better.'

But what I've always respected more were people who were willing to say, how do I take things that are really difficult and pick them up and move them and do whatever it takes to move them? To me that's a far more important job.

I asked Rich Crocker to go to Laconia State School to be superintendent not because I was trying to do something wrong to Rich, or wrong to the world, but rather you ask your best people to go take on your most difficult tasks.

I loved the work and I so respected what Jack Melton did at Laconia State School. Anyone who knew Jack respected him for his values. But he was superintendent of Laconia State School! Was he bad for

being superintendent? No, he was not. And to the people who are the come-latelies, who say: "It's not pure. It's not pure. They're doing something wrong. It's not pure," my answer is: "Oh, go gossip to someone else. I'm too busy."

Most people have the best interests of their children in mind.

Except under extraordinary conditions, which even then are often driven by poverty, addiction, chronic illness, things like that. If you find the way to support people in their decision-making, you find extraordinarily powerful commitment within families. That is what you have to tap into.

To instead sit on the sidelines and play the role of the critic and judge the decisions that others have to make when one doesn't know their circumstance and one hasn't been part of the problem that they've been (dealing with) fails to recognize how you in fact are contributing to the problem where you didn't provide solutions.

I've been in the business of trying to provide solutions all my life. I just feel myself still being in the business of trying to provide solutions and that's what we're going to do.

"What I think is important is less where one is on a philosophical continuum and more whether or not one is ready to absolutely commit oneself to a meaningful dialogue with family members about their dreams and aspirations for their sons and daughters, when one's really willing to say, let's try to do this. And whether one is willing to sit down with individuals with disabilities and, using the most thoughtful and considered individual planning, say, what is the future that you would like to pursue?"

Donald Shumway

I have to admit when I first heard the news, my initial reaction was shock. But then when I thought about it some, I thought that your decision made a lot of sense.

When they called me up, I didn't return the phone calls through the first week. But I knew why they were calling. I had this gut feeling.

I'm a very lucky person in many different ways. When Jeanne Shaheen called, I knew why she was calling. And I knew I'd say yes. And as soon as I saw their message, I also knew I'd say yes. I'm blessed with having this pathway of opportunities kind of laid out in front of me, and I'm a very lucky person in that regard.

You probably don't like to hear a lot of accolades....

I'm sick of it.

I know.

I'm sorry, but I really am.

You've made it possible for a lot of other people to do good things, too. That's a wonderful thing.

We've had some absolutely wicked teams, haven't we? Just great, great groups come together

and do great things. I've got David King's picture over there and I've got Dick Lepore's picture up there. You know, there's a whole lot of people that basically were unbelievable. Mentors and colleagues I've been blessed to learn from, watch, be corrected by, but mostly to join with in a common cause and beat the living daylights out of the barriers we've encountered. So I've been very fortunate in those regards.

Do you have any ideas about where you want to go with the job at Crotched?

It's actually not the formula with which I work. What I try to bring is who I am to a job and the people that are connected with that job - the board of directors, the management team, the people that work at and run the different programs, the parents, the individuals with disabilities - and to sit down and build a sense of direction.

I think it's wrong to step into an organization believing that you know best and everything you do is going to be right. Because you don't and it's not.

What I like to do is to go in and establish a connectedness, to really soak up the story that people bring, and to deal with sometimes the smaller problems, but use them as a way of establishing, a way of working and thinking about things so that people can build trust and take on bigger problems.

So the first problem I'm interested in working with is the problem of not having dishes.

I had an individual, a disabled individual, come up to me in a group meeting with Crotched staff and parents and clients. And he asked, "What about dishes?"

I, in my usual kind of social work sets, said, "Oh, absolutely. Knives and forks, too."

He told me, "No! I'm talking about a satellite dish. I want to have a satellite dish!"

Oh, ah, yes, right. So the first problem I want

to work on is the problem of dishes.

And of course, that's a problem both of my interpretation of his question and a problem of another level of communication, which is communication with the culture at large.

So what we gotta figure out is the problem of dishes. That's where I'm going to start.

I love that story.

But I can't tell you any of those stories from around here. That's the problem.

When you came in here, I remember one of the things that you talked about was wanting to establish a connectedness with the people who worked for you, and helping to create a different atmosphere here because there was such a sense of fear and looking-over-your-shoulder from Terry Morton's tenure here. Do you feel that you've done that?

I do. It didn't happen in one day. But I think over time we've healed a lot of wounds and helped people understand that they work in an environment of mutual respect and collegial support.

I know I would say that I've bonded with them

Shumway

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man services in the state. I did not.

The work that we can be proud of is that we established both within the department and across state government under Governor Shaheen a true sense of collaborative work on behalf of meeting the legislative goals that were put in front of us at a time of tremendous fiscal austerity. We really worked together. We've pulled off some incredible things. That's a good thing.

Again, what most people seem to strive for in big jobs, so to speak, is to have their name on the building that got built, the particular major change that occurred.

I think it's more important to be able to say that despite enormous complexity and obstacles, we were able to provide great services to 80,000 Medicaid recipients each year.

We were able to greatly improve our child support timeliness and amount of payments to single parents and to kids. We were able to put in place the basics of a long term care system that has the potential for allowing seniors to make lots of new choices, and have tremendous opportunities to stay in their own homes and in their communities.

We were able to beef up the front lines of the child protective social workers, the juvenile probation parole officers, and the people who do the basic protection of our children.

All of those things, all at once, we were able to improve, stabilize, and literally make it look easy, a lot of the time. That's what the legislature charged us with. That's the job we are assigned.

All too often, the legislature, much like the rest of us, has eyes bigger than our pocketbooks. We're able to recommend very good policies but not be able to produce the resources to carry them out. But we've been able to make do and carry out these policies. That's great. That's what we should be doing.

What do you think is the biggest challenge to your successor?

Being able to deal with the fact that people ask one's predecessor, "What's the biggest challenge to your successor?" I'm going to pass on that. I'm not cursing my successor with that answer. They're on their own.

There will always be a tremendous need for the work of the Department of Health and Human Services. It will always be controversial in that it involves representing people who are often the least successful, sometimes least attractive, sometimes stigmatized members of our society. That work will always be challenging. I will respect anyone who steps up to try and make it happen in a meaningful and dedicated way.

What do you think will be your biggest adjustment?

The commute.

Leaving government financing and entering private financing. I've really got to learn a lot of new financial skills.

Working with a board of directors will be different. Again, I'm used to working in a much different decision-making authority-based system.

Putting together a strategic plan with the Crotched Mountain community - all the stakeholders - that does justice to the combination of needs of individuals and mission that the organization has carved out for itself. That will be fun, but very challenging.

That's kind of the first month.

Do you see yourself working with the community services network, the area agency network?

I hope so. Yes, Crotched is a major provider of community services to the state and has programs from Littleton to Salem and over to Keene, so it's spread out across the state. My hope would be that we could find ways to be very good collaborative partners with other organizations, both within the disability community and also beyond, in other service sectors. See what kind of joint undertakings we might be able to engage in, see what Crotched can bring to the table to join with them to do different, good things.

Have any of them been in contact with you?

Actually, they have. It's been interesting, but I've gotten several notes from folks. What they're saying is that they're looking forward to an early opportunity sit down and talk about how we can put together some good strategies to bring to our communities.

It's going to be very interesting to see all the dynamics of this.

I know. Isn't it? It's so funny.

You've just turned some people's worlds upside down.

That's part of the fun of it.

I'm sure it is. It's going to be interesting to watch. I've had some conversations just in the last month about Crotched Mountain, and some people don't even want to talk about it. It seems there are more families who are looking to place their children at Crotched Mountain instead of in the public schools because the public schools have just been so dismal for them.

It's a real problem. Certainly, with our son we had problems in having any possibility of successful experience for him in public schools when we pulled him out and enrolled him in a private school. It was amazing to see the situation go from black to white, from night to day.

His leaning first of all, just took off. His self-confidence soared. Our regret was that we didn't do it sooner. We had this what I'll call kind of blind faith in "the public school will do this right." And "this next IEP will be the one that fixes it." It just wasn't our experience.

I don't want to have the public schools not succeed. I've only wanted the public schools to succeed. I hope there are ways Crotched can help public schools succeed.

But I also want to make sure that no one gets flushed down the toilet either. There's a whole lot of kids who through lack of choices and chances get flushed and that's an unforgivable thing for any one child. It's unforgivable.

Does that mean that Crotched is THE answer, or is going to do things right and everyone else is going to do things wrong? It doesn't say that.

But can we be part of the creative solution? Can we step in at times and say, we got something to offer here? I hope so.

Is there anything you want to say to people as you leave?

I hope to continue to have a very active voice in representing social justice issues at a state policy

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and I feel very strongly that they are a truly great team that does incredible things that are enormously difficult in a fashion that is largely transparent for people, so that the enormous complexity of what we're dealing withjust the financial complexity alone!

Just take that dimension of how we've balanced these budgets, how we've glued together the finances of the Department with chewing gum and paper clips through this period of time. It's an incredible thing - a huge accomplishment by unbelievably talented and skilled, experienced people, many of whom no one would ever stand up and applaud, thanking them for what they've done, yet who've worked incredibly hard and given up all kinds of opportunities that they could have had to do more lucrative work in settings that would have given them cars and accolades and so forth. And instead have been able to outsmart federal cost allocation systems and do the work of carrying resources through very technical processes to be delivered, put up against case load growth that we've seen just spiral enormously as the recession has hit. Things like that, that unbelievable talent. I will miss them greatly.

What has the reaction been around here to your announcement?

Well, some have said they understand that commissioners are basically the Christmas help. They come, they leave. I like that one a lot, actually.

The reaction has been what I would hope it would be. On the one hand, I have a great deal of personal support to me for the work that we've done, the environment we've created, things like that. But also a clear understanding that a lot of the work that we've done was designed to strengthen them in their jobs and make it so that they could handle the demands that are placed on them in the context that we're in.

Some people said they were surprised, but a lot of the time what they said was they were surprised but not at all surprised at the same time. That is, from day one, I've been telling them that this is what we're going to do and be ready to stand on your own two feet during times of adversity. They're really good at that. They're very strong, very capable, and stable and they're where they gotta be.

It sounds like you would consider that your greatest accomplishment.

Yeah. I think so. I'm not going to claim that as commissioner, I changed the basic paradigm of hu-

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level through both advocacy work that Crotched Mountain would engage in as well as in my own personal commitments. But I also hope to work at a somewhat more personal level than I had in the past, get my skate park built in town, things like that. I'll be around.

Do you anticipate having more time at Crotched Mountain?

Probably not more time but a somewhat different use of time. I have to spend an inordinate amount of time on technical preparation in this job, paying attention to an enormous array of federal fiscal challenges that come at us.

With Crotched I hope to spend a little more of my time out working with organizations and individuals and family groups and community groups and trying to bring together different issues. So it'll feel different and look different.

I don't know that it's more or less time. I think it's the same amount of time; it's just spent differently.

But it might be more energizing?

Definitely more energizing, but also a little more social, and a little less technical.

Do you anticipate a rapid increase in the number of people who are applying to Crotched Mountain for services now that you're going? Had you thought about that?

Not until this moment.

There's a lot of families who are going to look at Crotched Mountain differently, I think, or look at it more closely than they might have previously, knowing that you'll be involved. I think you should recognize that'll be true.



“Refrigerator Mothers,” Airs on PBS in July

If anything could be more devastating to a mother than having her child succumb to autism, it might be having to shoulder the blame for the affliction. That's what happened to a generation of mothers in the 1950s and '60s, when medical orthodoxy blamed autism on the mother's failure to bond with her child. Though wholly discredited today, the “refrigerator mother” diagnosis condemned thousands of autistic children to questionable therapies, and their mothers to a long nightmare of self-doubt and guilt.

In *Refrigerator Mothers*, the new film by David E. Simpson, J.J. Hanley and Gordon Quinn, and a Kartermquin Educational Films production, these mothers tell their story for the first time.

Refrigerator Mothers airs Tuesday, July 16, 10 p.m., ET (check local listings) on PBS. *Refrigerator Mothers* is the fourth program in the 15th anniversary of P.O.V., television's longest-running series of independent, non-fiction films. P.O.V. continues on Tuesdays through August 27, with additional Fall and Winter specials.

Today, we know autism as a mysterious, even frightening neurological disorder that affects more than one in 500

people. Typically, babies seem to begin life as normal and active only to slip into varying states of mental isolation, marked by speech difficulties, self-imposed isolation and obsessive, ritualistic behavior. In the '50s and '60s, however, an entirely different view held sway.

In retrospect, it seems incredible - and not a little disturbing - that the medical establishment should have based its understanding of autism on a sweeping comparison made by one man. Bruno Bettelheim was one of the first child development specialists to focus on autism, but his explanation for its origin was breathtakingly wrong. Bettelheim, who had spent time in a Nazi concentration camp, believed he saw parallels between the behavior of some camp prisoners and autistic children. This led him to posit that autism was a psychological disturbance arising from detached and “frigid” mothering - something akin to how prisoners reacted to the cold authority of camp guards.

The shock is not so much that Bettelheim could be so wrong as that it took decades before anyone in the medical community listened to the few lone voices, such as Bernard Rimland, Eric

Schopler and the mothers themselves, who had been challenging the unfounded theory of mother-blame since the early 1960s.

Refrigerator Mothers shows that many of the women branded “refrigerator mothers” had successfully raised other children. Deeply shaken to be told they were the cause of such a nightmare in one of their children - a judgment driven home by the fact that one popular therapy was to remove the child from the mother - many of these women, over time, resisted the verdict of medical authority. Most tellingly, these mothers continue to care for and advocate for their children with autism today - a dramatic demonstration of a bond that has outlasted scientific error and unfounded accusation and blame.

Refrigerator Mothers compels us to closely examine how we understand the role of the medical establishment in our lives. It opens the door to an intimate, moving account of life with an “invisible” disability - one that isn't immediately obvious. Finally, the film serves as a striking cautionary tale about the tragedy that misdiagnosis can cause, and a dramatic portrait of women whom society rejected as mothers but who never stopped being mothers to their children.

P.O. V. Interactive (www.pbs.org/pov)

P.O.V.'s award-winning Web department creates a web site for every P.O.V. presentation. The web sites extend the life of P.O.V. films through community-based and educational applications, focusing on involving viewers in activities, information and feedback on the issues. In addition, pbs.org/pov houses the unique Talking Back feature, filmmaker and viewer resources, and information on the P.O.V. archives as well as a myriad of special sites for previous P.O.V. broadcasts. P.O.V. also produces special sites for hire, specializing in working closely with independent filmmakers on integrating their content with their interactive goals.

Therapeutic Riding Program Needs Volunteers

Upreach Therapeutic Riding Center, a 501(c)(3) organization dedicated to improving the physical, emotional, and psychological development of children and adults with disabilities through progressive therapies centered around the horse, is in need of helpers.

Each six week term, approximately 120 volunteer hours are required to assist the riders during their riding session. With the leadership of the instructor, volunteers help riders groom and tack their horse. During the session, volunteers either sidewalk, which involves walking and jogging beside the rider, or participate as the leader, which involves leading the rider's horse. Each program volunteer must attend a two-hour training session prior to their participation in the program. During the training session, volunteers learn about the program, how to groom, tack, sidewalk, and lead the horse.

For more information, call (603) 497-2343

Preschool: Problem? Or Opportunity?

When a child with a disability is born, the parents enter a whole new world. The vocabulary they use to navigate these new waters include such words as: services, benefits, early intervention, respite, family support, special education, evaluation, placement. At the same time as they are adjusting to a new life in their family, parents are adjusting to a new landscape which they may never have known existed before.

Not too many years ago, the birth of a child with a disability meant a wrenching decision to sever him or her from the family. The only "help" offered to the family was a bed in an institution. If the family refused this offer of help, they were pretty much on their own. Children with disabilities did not participate in the many activities that typical children did. They didn't go to school. They weren't allowed to participate in many of the community activities available for children. They lived lives isolated from the larger community.

Things have changed a great deal in the last 50 years. Instead of removing a child with a disability *from* the community, efforts are made to better include the child *in* the community.

Those efforts start with early intervention services and are now seeping into the preschool services children receive. Best practices in the field of early childhood education for children with disabilities, according to Debra Nelson of the Institute on Disability/UAP, UNH, are based on the guiding principles that:

- all children and families belong in communities,
- supports and services should be only as special as necessary,
- children with disabilities and families should be supported with a family-centered approach and a "whatever it takes" attitude on the part of providers.

Another guiding principle, according to Bruce Mallory, vice-provost and dean of the Graduate School at UNH, and professor of Early Childhood and Special Education, is the principle of "natural proportions".

"It's a best practice principle," explained Mallory, that there shouldn't be a disproportionate number of children identified with disabilities in any classroom, preschool through secondary school. That as much as possible classrooms should be diverse and represent the diversity in the communities in which they exist."

These best practices are based on the foundation laid by the Individuals with Disabilities Act (IDEA). IDEA mandates that: "Unless the IEP of a child with a disability requires some other arrangement, the child is educated in the school he or she would attend if nondisabled"

It further states: "A child with a disability is not removed from education in age-appropriate regular classrooms solely because of needed modifications in the general curriculum."

New Hampshire's Rules for the Education of Children with Disabilities, based on IDEA, state: "Each LEA (local education agency) shall ensure that, to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who do not have disabilities and that, consistent with 34 CFR 300.550(b), special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

Some school districts in New Hampshire are incorporating best practices into their programs as they comply with both IDEA and New Hampshire's Rules. But preschool services differ from district to district. We will look at two districts, one on the eastern border, and one on the western, that demonstrate very different philosophies about the delivery of services to young children.

These are the stories of five children: Ryan, Tomi, Oliver, Alex and Brian in two school districts, Keene and Dover. All five are in preschool. All five have been identified as having disabilities. All of their parents are happy with the services they are receiving. But there's a significant difference in the way services are offered to families in each of the two districts.

Ryan (Keene)

Three and a half year old Ryan was diagnosed with PDD/NOS just as he was turning three. Already wearing glasses and having had ear tubes inserted, he was experiencing some delays. As a result, for about a year he had been receiving early supports and services through Monadnock Developmental Services (MDS), the area agency for Region V, and Rise, an early intervention service and community daycare program.

But his mother Terri Ylitalo suspected something more. "I knew he wasn't autistic, but he had some of the symptoms of being autistic - you know, being obsessed with something to the point where he's totally engulfed. Totally. He doesn't even know the rest of the world exists. He does do that. And that's what was making me nervous."

So, at the suggestion of the early supports and services specialists at Rise, she took Ryan to see Dr. Carl Cooley, Medical Director at Crotched Mountain Rehabilitation Center, who diagnosed him with PDD/NOS. "I was a little uncomfortable about getting him



Ryan (right) tries to balance some blocks while his classmate Paul chooses another activity. Both preschoolers attend The Montessori School in Keen.

Photo: E.G. Stone

diagnosed,” Terri remembered. “I didn’t want to put a tag on him. But at the same point, I realized that it was imperative for him to have some type of diagnosis once he entered the school system.”

Ryan’s speech therapist from Rise began to prepare Terri for Ryan’s transition, as did the coordinator from MDS. “They made me realize I needed to be the advocate as the parent,” Terri said. “They didn’t direct me which way to go, but they just let me know you should really do your homework, kind of get a good idea of what’s out there.” So Terri began to look. “I spent time before meeting with the school and visited the preschools, the ones that I thought I’d like him to attend,” Terri remarked. “And actually spent a couple hours at each one. And came to the decision that I wanted him to attend (The) Montessori (School). I liked the way Montessori presents things and (I like their) organization. I knew that would be a good place for Ryan to grow, knowing his personality.”

The first meeting with the Keene preschool team was the day of Ryan’s evaluation. “Initially, it was pretty overwhelming,” Terri remembered. “Cause you have four or five different professionals working with Ryan and asking you questions and then kind of observing him while kind of separating him while asking you questions.” During the evaluation, Ryan’s speech therapist from Rise was there with Terri. After the evaluation, Terri was sent a report, which she was encouraged to “mark up.” At the team meeting following, Terri was accompanied by Ryan’s speech therapist from Rise and the coordinator from MDS.

Terri acknowledged some anxiety on her part about her first interactions with the Keene preschool team. “Initially, I was concerned that they would be more concerned about the dollar than Ryan,” she admitted. “But I learned early on that was not the case. They’ve always had Ryan’s interests first and foremost.” Still, Terri found herself in disagreement with the team’s placement recommendation. “I felt that they wanted him to go to Jonathan Daniels,” Terri stated. The Keene district preschool is housed at the Jonathan Daniels Elementary School. “And basically ...it just wouldn’t work for me. ‘I’m single mom and I work and Jonathan Daniels doesn’t provide any pre-care,’ she explained. “Montessori does. And I like the whole philosophy of Montessori better. I basically had my argument down as to why I thought Ryan should go there, and after stating my case, I think it was agreed that we would try this and if it did not work, that we would re-evaluate it.”

Terri said that the team’s objection to The Montessori School was that “they thought it was too structured. And I thought being structured is what he needed. So we were at a little - I wouldn’t call it a tug of war, but they had a specific place in mind and then I had a specific place in mind.”

Ryan started at The Montessori School on his third birthday. His progress since he entered the program has been significant. “Since then, I’ve seen and grandparents have noticed the same, and the same with his father (Peter Zukowski) his vocabulary has almost tripled,” Terri stated. “He’s talking now. He’s expressing himself, his wants, his desires, his need to use sign language - he was using about 60 signs in order to communicate with people, including myself - has almost diminished. We still use it because I think sign is a good thing to know.. But his need to use it is not there anymore. His father actually understands him now.”

Ryan’s success at The Montessori School has created a consensus among the preschool team. “During the evaluation that we just had about a couple of months ago,” Terri stated, “they all agreed that Montessori was a good place for him.” Keene School District picks up the cost for the preschool plus provides tutors to the program to support Ryan and three other students with disabilities who attend along with approximately 30 typically developing students. Ryan also receives speech therapy twice a week at the school, usually in the morning before school starts, Terri explained.

“A lot of the children come early and go into the daycare room,” Anne Wilber, Ryan’s speech therapist explained. “There’s a lot of free play in there. That’s where the kitchen set is and the trucks. So, (with) some of the children I do play therapy in there before they start circle time at the school.”

Bus transportation was offered to Ryan, but Terri is uncomfortable having a three-year old who cannot talk well ride a bus. “So his grammy picks him up after school, and his daddy drops him off in the morning.”

Terri’s comfort with and confidence in the preschool team has grown through this transition process. “They’re a good team,” Terri says without hesitation. “They actually let you know that, that it’s not ‘them and us.’ It’s ‘we’re a team.’ And they stress that during the whole thing.”

Terri has also felt the support of Judi Ryner, the director of The Montessori School as well as being a teacher there. “Judi’s always willing to try to share information with me,” Terri stated. “And she’s like, here’s my home number, call me at home if you have questions. Touch base with me on Friday night. Understanding again that I’m a single mom and I don’t see him at pickup time so I can’t touch base with her (then). So she goes the extra mile to try to make sure that I know what’s going on.”

Terri’s apprehension about working with the preschool team has subsided gradually. “It was an accumulation (of experiences),” she reflected. “It was a lot of the knowing initially that they did not want Ryan to attend Montessori, but they took my belief in my son, in his needs, and what I know him to be and they put aside their beliefs and said, okay, she’s the mom and she knows best.”



Dashel and Judi Ryner listen to a classmate’s story during preschool at The Montessori School in Keene. Judi is the director of the school and a teacher there, too.

Photo: E.G. Stone

Alex and Brian (Dover)

Alex and Brian are identical twins. But most times people don’t realize that. “What happens a lot of times,” David Arkel, their father, explained, “is when people see me carrying Alex and when they see Brian run around, they’re not sure. What do you mean they’re identical? Because they’re expecting two to be running around. They assume Alex is like a year or two younger than Brian.”

What accounts for the difference is an intra-uterine condition called twin to twin transfusion. Before they were born, they were sharing blood flow. The problem is that Brian got too much blood and Alex too little. The repercussions of that were greater for Alex..



Brian throws a ball while his father David watches in their classroom at Woodman Park School. Physical therapist Sue Vaillancourt works with Alex on the floor while Oliver looks on. **Photo: E.G. Stone**

County, the area agency in Region IX. When the twins turned three, the early intervention specialist who had been working with Alex and Brian recommended the preschool program offered by the Dover School District.

"We heard good things about the program," David remembered. "My wife had talked to a few people and they seemed to think that was a good program. The gal from developmental services had glowing remarks for Nancy Brown (the preschool teacher) and that program, so that's what we decided to do."

David said that other options were presented to them, but "pretty much they felt that it would be best for him at Woodman Park." Based on that and the recommendations they had received from their early intervention specialist and a few others, along with the fact that they liked Nancy Brown and felt that the therapists were "on the ball," the Arkels chose the Dover preschool program. "We decided that rather than bring him (Alex) somewhere else and have everyone come to him, then if he's there then they're all right there. They just come to him."

Brown and an aide who had been hired to work with Alex visited the twins at home a couple times before they started preschool, according to David. David opted not to have the twins use bus transportation. Getting the twins ready to go in the morning is complicated and takes a lot of time, David explained. As a stay-at-home dad, he has the responsibility of getting the twins and his seven year old son ready for school and he just didn't think he could have them ready by 8:10 for the bus. Instead, he drives them to the preschool, which is not far from his home, and even then he is usually 10 or 15 minutes late, he admitted.

Alex has a full time aide in the classroom with him, "a former nurse," David pointed out. She "helps with his changing diapers and keeping him clean and that kind of stuff. And she also helps with the toys, tries to keep doing the things that the OT and the PT are doing. In other words, she tries to do exercises and the music and that kind of thing.

"She does all of that stuff, but in addition she's involved with the class. If the teacher's reading a book or something, she's explaining it to Alex so she does a lot more than just personal care stuff," he added.

Alex gets speech therapy and occupational therapy each week, one session of each separately and one session with both together. In addition, NH ATEC was recently asked to come in and set up a communication system for Alex using buttons and switches, "so that he can sort of tell us....or make choices between things, like this toy or this toy, or do you want a bottle or food," David explained.

"He says about, I would say, 20 or so words," David added. "He doesn't really tell you right now that he's hungry, other than the fact that he would get upset or scream. And if it's around the time of mealtime, then obviously.... as soon as he hears 'bottle' he's opening his mouth. So he knows bottle and food. The problem with him is that he understands a lot of what we say but his body is not allowing him to respond."

Brian's needs are not so challenging, but David sees benefit to his being in the district's preschool. If Brian continues to progress the way he has been, David sees as a real possibility that Brian could go on to regular kindergarten, with sup-

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He developed spastic quadriplegia, a form of cerebral palsy and periventricular leukomalacia (PVL). Essentially, that means Alex has white spots in the grey matter of his brain indicating places where his brain has not matured. He also had retinopathy of prematurity which required surgery on his eye when he was a couple months old.

When Alex was two days old, he had a temporary ileostomy because of a perforation of his intestines. By the time he was three months old, his intestines had healed enough to be reattached.

All of these medical problems have created challenges for Alex. He uses a wheelchair and has little ability to communicate without aids. He is extremely nearsighted and needs more assistance with personal care than a typical three year old.

Brian, on the other hand, has been minimally affected. His neurologist does not see any indication of neurological problems that would hold him back, according to his father. He has some fine motor problems, but his dexterity is improving with the occupational therapy he is receiving in his preschool program.

Both Alex and Brian received early intervention services from Behavioral Health and Developmental Services of Strafford



David Arkel joins his son Brian in a moment of fun as Brian climbs his father's legs. In the background is Alex's wheelchair.

Photo: E.G. Stone

ports. Alex, on the other hand, would most likely stay in special education classes for a longer period of time, David believes.

The Arkels are very pleased with what is happening for their children. The transition was “smooth,” reported David and they like the preschool teacher and all the support and related services personnel in the program.

Next year, Dover is planning on expanding their district preschool program to include a small number of children from Head Start and other children in the community who need but cannot afford a preschool experience, such as children whose parents are taking English as a second language (ESOL) course, or children whose parents are working toward their GED. David welcomes the addition of the other children into the program. “I think that would be great for Brian,” he said. “Brian plays with all the kids around here. He’s very social.”

Tomi (Keene)

Tomi is a four year old little girl who was born with Down syndrome. She received early intervention services from Rise and attended the daycare there as well. When Tomi turned three, she lived with her mother, Aerie Ingalls, in a town outside of Keene, where she entered preschool. One day, Tomi “freaked out,” according to Aerie, because of the way a situation was handled with another preschooler, so she took her out of the preschool. “I actually moved to Keene to live with my mother and work nights so she could go to the Jonathan Daniels program,” Aerie stated.

Her first visit to Jonathan Daniels was positive. “I went and I spent the day,” Aerie remembered, “and Tomi absolutely adored it. She didn’t do real well the day I was there, but the next day she was there with her tutor and she did wonderful. And then she had a testy day and then after that, she did nothing but progress the whole time she was there.

“She loves all of her therapists. They’re wonderful with her. And they send her home a whole bag of activities to do so she doesn’t regress in any of the areas that she’s having problems with, like oral things and what not, and sensory things.

“She absolutely loved Jonathan Daniels,” Aerie stated. “She had the most wonderful tutor while she was there who stayed with her the whole time she was there. And her teacher was Joe LaBrecque. I think he’s the home visitor for the whole preschool team. He is wonderful.

“He is how I got her to get up every morning and how I got her to go to school every morning,” Aerie added. All she would have to say was, “you’re gonna see Joe” and Tomi would get right up, her mother said. “And soon as we got to the street that Jonathan Daniels was on, she’d start yelling ‘Joe.’ She really loved it cause they really, really know how to deal with the kids there.”

But, as a single mother, Aerie needed to go back to work full time, and she wanted Tomi to go to The Montessori School, which offers pre- and after-care for the children who attend there. Asked how difficult it was to initiate that change of placement, Aerie replied: “To begin with, it was difficult, because there are a lot of other places out there and I actually had to get something saying that it would be beneficial to Tomi to go (to The Montessori School).”

So Aerie approached several people to write in support of the placement - Tomi’s doctor and John Moran, a behavioral specialist who was working with her and Tomi through the area agency, Monadnock Developmental Services (MDS), the area agency in Region V. “I’m not exactly sure who said it might be a good idea (to do that),” Aerie admitted. But it could have been Donna Rinaldi, her caseworker at MDS.”

Aerie credits Rinaldi with providing her needed guidance. “When I don’t know exactly where to go and what to do, she’ll guide me and tell me, this is a good idea to do.”

But Aerie also counts as an ally Joanne Mulligan, the preschool team coordinator in Keene. “Joanne Mulligan was the one who pulled the strings... who got Tomi enrolled there (The Montessori School). And made it so that it wasn’t much of a hassle to get into.”

In reality, Aerie had wanted to enroll Tomi at The Montessori School even before she moved to Keene, but it was too expensive for her to afford as a single mom. But once the preschool team agreed on Tomi’s placement there, they picked up the cost for the preschool portion of her day. She receives assistance for the daycare portion from the Department of Health and Human Service through childcare assistance. “There is some remainder,” Aerie explained. “I believe it’s like \$24 a week that I pay for.”

The services the preschool team offers to Tomi and Aerie are not limited to the preschool program. They also get home visits to reinforce and augment the skills Tomi is learning in school - skills like concentration, matching objects from memory, playing by the rules. LaBrecque, who was Tomi’s teacher at the Jonathan Daniels preschool, comes to their home twice a month at 6:30 in the evening, a time convenient for Aerie because of her work. LaBrecque has a “tight schedule,” Aerie stated, because the list of children he visits at home is long. If she has to cancel a visit for some reason, she pretty much has to wait the two weeks until the next scheduled visit.

Tomi presents some challenges to her mother. She can be “defiant,” Aerie admitted. She has difficulty with transitions and language.

But Aerie can see progress. “She plays with other kids better. She is speaking better. Her potty-training is excellent. She’s a little *too* helpful with the younger kids,” Aerie added. And she’s handling the transitions - from the preschool activities to daycare, and the bus ride home - well.

For her extended year program, Aerie would have liked her to continue at The Montessori School, but they only offered a five week, three day a week program. Aerie needed a five day a week program for a good part of the summer. So the preschool team helped her to secure a spot for Tomi at Camp Holiday, a camp for children with disabilities of all ages.

Mulligan explained that the team doesn’t usually tuition to Camp Holiday because it’s recreation-based, but “due to Aerie’s circumstances - a single, working mom - we agreed to pay for half a day, five days a week for seven weeks.” The team is not providing a tutor, “but the camp is geared to special education students, so they have the expertise,” Mulligan added.



Tomi fixes herself a snack of strawberries as her tutor Linda watches. Tomi attends The Montessori School in Keene. **Photo: E.G. Stone**

Aerie is pleased with the support she receives from the preschool team. "I'm very happy," Aerie commented. "I thought it was going to be much harder. Everyone told me that (with) the school system, it was going to be a fight to get what I needed.

"But it has not been. Joanne Mulligan is wonderful to make sure that any question that I have is answered whenever I need it answered. And she calls me back whenever I need her. I just have had nothing but a good experience so far."

Oliver (Dover)

Oliver, a three year old boy born with Down syndrome, is the child of Judi and Robert Livingston. A first time mother, Judi approached parenting with single-minded energy. She joined a post-partum support group organized by the local hospital where Oliver was born.. "We met a lot of other moms there," Judi explained. "not special needs at all, just moms and infants that we just kind of meshed with. It was about 8 moms.

"And we just stayed together as a play group. We celebrate all the kids' birthdays together and we have Christmas parties and Valentine's parties and in the good weather, we get together more often."

This support group has been the springboard for many opportunities. "Oliver's best friend Mary is the same age as him and she's a typical child and all his friends from there are typical kids. Of course, they're all doing a lot more than he is. They're climbing, they're talking in full sentences, they're running and jumping. They don't seem to notice and he doesn't seem to notice though.

"I think it's really good for him to have that influence. He doesn't really even try to keep up with them anymore because he's not even walking and here they're practically doing cartwheels around him. But he loves to be with them. He knows all their names and he gets so excited to see them.

"They're in tune to him, too. I don't think they really think he's different but they just know that he's not doing exactly what they're doing and they'll spend a little time with him and then they'll run off. They still interact with him fine.

"So that's been good and it's been good for me, too. Because I feel like I can be a part of everything that other three year olds are doing even though he's not necessarily doing all of those things. But he's a very social little guy."

Social doesn't begin to describe it. As the moms in the group got their children involved in other activities, Judi got Oliver involved, too. "When I met all those people, they told me about the HUB (a parent resource center in Dover). They all got into the swim class, so we went along. They all got into Kindermusic, so we went along. We just sort of went along with what everybody was doing and we learned all these things. Now we just continue them on our own."

So Oliver belongs to a playgroup at the HUB; has taken swim lessons at The Works, a local athletic club; participated in Kindermusic sessions four or five times; participated in Gymboree once; went to the library weekly for story time; and accompanies his mom to the Down syndrome support group every other month. And received early intervention services from the area agency. "The calendar up there is all him," his mother admitted.

As he was approaching three, however, the Livingstons were faced with a dilemma. "We had an interesting situation," Judi explained, "because right from before he was born, we had in mind that we wanted him to go to Westwood Preschool. And then when he was born with Down syndrome, we assumed that would be out of the question."

Both of Oliver's cousins had gone to Westwood, an established preschool in the area. "As it got closer and talking with (the teacher at Westwood), she was saying that she didn't mind if he went there. It would be no problem.

"So then we were faced with the big, well, where is he going to go? Is he going to go in the public program or is he going to go to a private one? We had to wrestle with that a lot," remembered Judi.

So Judi talked with the early intervention people about their dilemma. She visited both Westwood Preschool and the Dover School District preschool program at Woodman Park Elementary School. "And so talking with the early intervention people before he transitioned, getting advice from them, visiting both programs and having a meeting with the school, we were really leaning towards Westwood," Judi said.

But there were less than four months left in the school year and there were no openings at Westwood. If Oliver were to go there, he would have to wait until September. So Judi decided to put Oliver into the district preschool until the end of the school year, until there was an opening at Westwood.

"I was anticipating not really liking the public program very much," Judi admitted. "because I'm the one that doesn't like to think that my child needs any extra help. I like to think that he can do it and I sort of had a little bit of an attitude about the special ed program."

She wonders how she was viewed by the school as the transition process started. "They were probably dreading me coming.," she admitted. "I have an overprotective attitude and I did kind of have my back up.

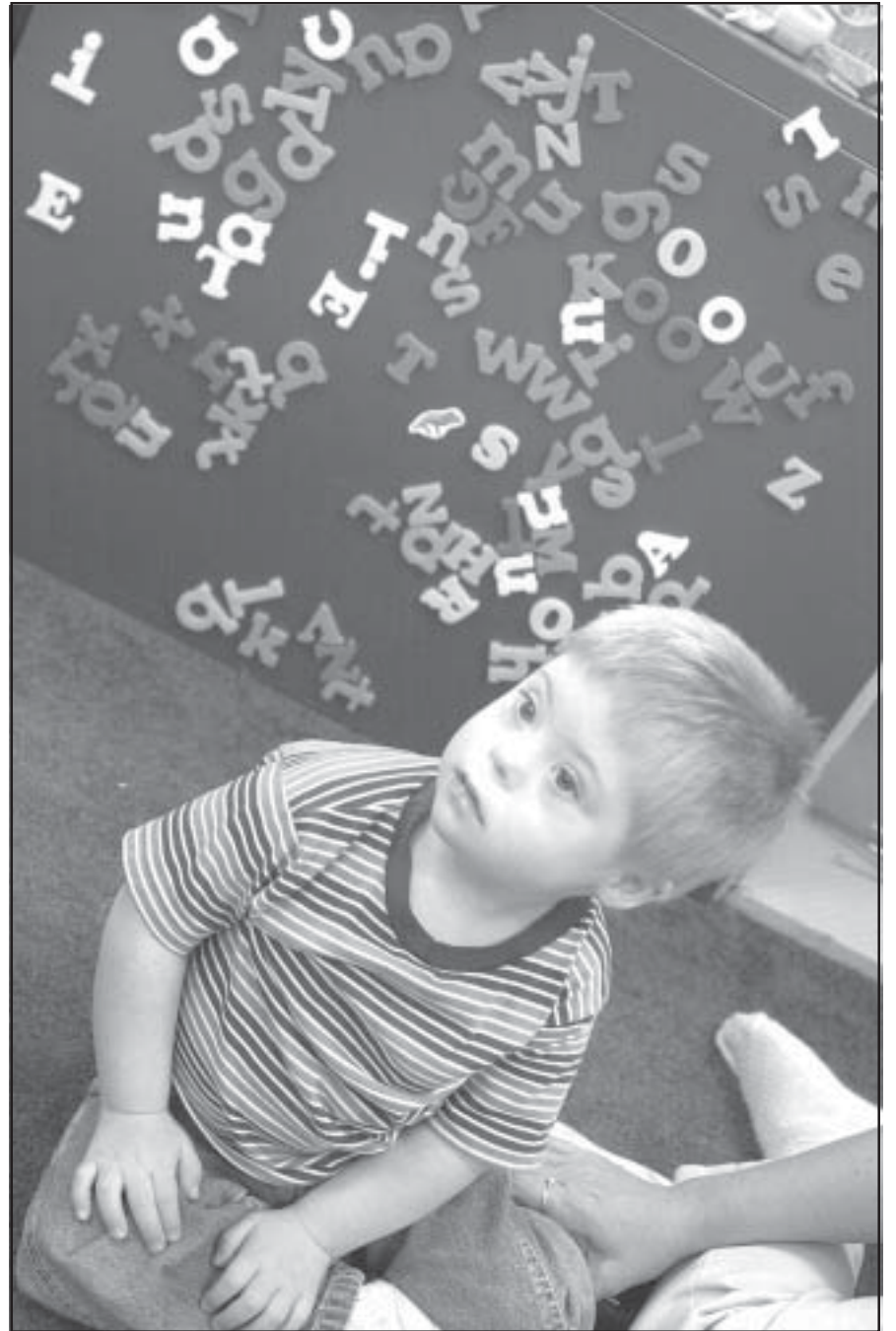
"I went in with letters from the librarian, his kindermusic teacher and from different people who know him about how well he does in a typical environment and how he doesn't need special education and how he should be able to go to Westwood. They were probably like, oh, brother, not this one.

"But like I said, that really was a fear thing. I just didn't know what it was going to be like and I didn't want to be trapped into that program just because my kid has Down syndrome.

"So I was kind of digging my heels in that he would just go there as long as he needs to and then he'll go to Westwood. So we had a meeting and that's the plan that we made."

What Judi was not prepared for was how much she and Oliver would like the program. She was concerned about just dropping him off with complete strangers, but "he did great," she stated. "He had a great time. He had so much fun. He loves to go. Every morning, when he wakes up, (he says) 'school, school.' He knows all the teachers. He knows all the kids and I can see the things that he's doing there."

She sees the progress Oliver is making and is delighted with it."I can see the carry-over at home," she commented. "He's asking for help, which he wasn't



Oliver sits in front of a collection of letters in his preschool classroom at Woodman Park Elementary School. **Photo: E.G. Stone**

doing. He's pulling to stand a lot more than he was. He's doing a couple of signs. And he's only been in this program for four weeks."

As a result, "I'm having a complete change of heart," Judi said. "I really like that program. I feel that it was better than I expected because I wasn't expecting too much. I don't know why I didn't think I was going to like it, but I really do."

At the time of the interview, Judi was getting ready for another IEP meeting to discuss next year's placement. "We've pretty much decided he's going to stay with two days there and then in September go two days at the private program," Judi said. "So he'll have two days of each."

"Because there's so much value in each. In the private program he gets to be with the typical kids, doing the more complicated activities and the outside experiences of the field trips and all that. But the public program he's doing so well because he's gets a lot of one-on-one attention. The teacher-student ratio is really high."

Next year, Dover is expanding its preschool program to include children from Head Start and other children in the community who need a preschool experience but cannot afford it; for example, children whose parents are learning English as a second language (ESOL) and children whose parents are studying for their GED. Buese explained that the district plans to have two preschool classes for a total of 60 children, 40 of whom would be identified as having disabilities, 10 of whom would be Head Start students and 10 of whom would be referred to the district by HUB, the parent resource center in Dover.

Commenting on Dover's plans to integrate their preschool program next year, Judi said: "True integration is integrating the child with a disability into the program geared towards the higher functioning children. This is going to be the opposite. It's going to be integrating the typical children into a special ed program."

"So the whole program is going to be scaled down to children with special needs as opposed to helping the children with special needs be able to function in the typical environment. It's sort of the opposite. Which is why I'm going to have him go to both. Because I want him to have both of those experiences. I think he needs to have that - more of a challenge from the typical setting."

Since the initial interview, however, things have changed. Judi reported that she had visited the Westwood preschool again and decided that the program was not appropriate for Oliver. She didn't think Oliver would be able to participate in the activities at Westwood in ways that would be beneficial for him, and that his specific needs would not be addressed like they are at Woodman. So she has decided to have Oliver go to the Woodman program three days a week.

An important factor in this decision, however, was the pronouncement by Mary Buese, the preschool coordinator, to Judi that Dover would not support Oliver's placement in the Westwood program. "We'll have to pay for it," Judi explained. "And if he needs any kind of aide or anything, it'll have to be volunteer, people in our family. Because they said that now that they've got this integrated program then they won't be placing children anywhere else. If you choose to go somewhere else, you're financially responsible."

"Which to me is not necessarily fair the first year," Judi argued, "because it's not a program you have the opportunity to observe, visit, know what it is, so it's not really a choice."

Judi admits that, if Dover were to provide supports to Oliver at Westwood, her decision to keep him at Woodman might be different. She said if Oliver could have an aide with him and have some help from the district in adapting the curriculum at Westwood to meet Oliver's needs, she would definitely send him to Westwood. She can not afford to pay Westwood's tuition and pay for an aide for Oliver, which is what Mary Buese told her she would have to do if she opted for Westwood.

Also, even if she opted to do that, Buese has told her that any related services provided by Dover would have to be done at Woodman Park School, not at the preschool site. She would have to make appointments for Oliver at times he was not at Westwood for him to come and receive his therapies. Judi reported that Buese told her Dover will not be sending therapists out into the community next year.

Judi is happy with the positive experience Oliver has had at the district preschool. "I really like Nancy Brown (his teacher)," she stated. "She's very good with him." She is hoping that Oliver has her for his teacher next year.

She also has praise for Mary Buese. "She's very involved," Judi said. "I mean, you see her a lot. She's easy to talk with and get a hold of and she responds like that (snapping her fingers) to an issue."

"Like when I said just last week, I mentioned about meeting again and changing the plan so that he could continue there. That was in the morning and by the afternoon it was written in his notebook that we'd have a meeting."

Keene

SAU 29 includes the city of Keene, located in the southwestern corner of the state, population about 22,500, and six neighboring towns: Harrisville, Marlborough, Marlow, Munsonville, Westmoreland and Chesterfield, with a combined total population of a little under 10,000.

The city of Keene has five elementary schools, one middle school and one high school. Each town has its own elementary school. Some of the towns provide education to their students grades 6 through 8, but all of the towns send their high school students to Keene High School.

There is a public preschool program in the towns, and one in the city of Keene, located at the Jonathan Daniels Elementary School. Each program has separate staff and coordinators. This article will examine the preschool program in the city of Keene.

Keene's preschool pro-

gram used to serve only children with disabilities. That changed about nine years ago, when the preschool teachers and related services personnel came to an enlightening realization. Kathy Blair, OT, who has worked in the Keene preschool program for about 20 years remembers the moment well.

"We had a particularly bad circle time. It just hadn't gone well. I remember having a meeting where the teacher and I and speech pathologist sat there and said, they have no good models. How would they know how to act well in circle?"

"I said, why don't we get some typically developing kids? That's what we need. We need good models. So let's do it."

"And we wrote a proposal to take to the SPED director and then to the School Board through whatever channels, and said, this isn't working. It was about 1992. That's where it started. It was really a

grassroots thing. It was the teaching staff who was working there who just said, this isn't working, isn't how it should be going."

The School Board considered the proposal and gave its approval to open the preschool to the larger community. "We opened it up to children in the community," Blair said. "There was already a Head Start. There was a Chapter 1 program and we did not take children from those programs to bring them into our preschool. We mostly had children from the Keene area, but there were some children from towns who came in those early years, as typically developing students."

While the school district funds the preschool, parents of the typically developing students who enrolled are charged a nominal tuition. "It's always been a very reasonable tuition," Blair explained, "so that the opportunity was available to people of all different

income levels to be able to send their children here, their typically developing children, so it wasn't exclusive to a certain income." Every year, she added, there's a long waiting list.

Today, the preschool offers three sessions a week, serving approximately 21 children with special needs and 27 typically developing children. Overall, however, they serve between 80 to 100 students in the Keene district. Because there isn't enough room in the public preschool program at Jonathan Daniels, the preschool team reaches out to the community preschool and daycare programs and supports children in these programs.

Several years ago, the SPED coordinator heard about a grant being offered by the Institute on Disability - Community Options in Early Care and Education. The preschool team applied for the grant "hoping to expand our model," explained

Blair, "and be able to better consult and provide more comprehensive services in the community specifically."

"The vision was to take the expertise that we had at the Jonathan Daniels preschool and spread that expertise out around the community a little bit more so that we had a wider variety of sites that could feel comfortable serving children with more significant developmental needs. We had lots of children out in the community who had speech and language issues, but we were talking about hoping to have community sites that could also deal with children with more significant developmental learning issues, behavioral issues, and those sorts of things."

"And that was the point of having the grant, to develop relationships with people in the community sites, develop a consultation model, develop a new model for providing related ser-



Keene's preschool team: (from bottom left) Joe LaBrecque, sped teacher/home visitor; Joanne Mulligan, preschool coordinator; Susan Brennan-Sawyer, school psychologist; Katherine Hildreth, speech and language therapist; Cindy Gustafson, sped teacher; (Back row, from left) Joan Binder, K-5 sped coordinator; Deb Bock Helin, physical therapist; Jane Taragowski, classroom assistant; Kathy Blair, occupational therapist; Anne Wilber, speech and language therapist; Bruce Thielen, sped director. Not pictured: Janet Finesilver, occupational therapist; Diane Abbatie, speech and language therapist. **Photo: E.G. Stone**

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vices in a more comprehensive way.

"It really came from the preschool team saying there must be a better way to meet the needs of all the preschool children who've been identified," Blair stated.

This preschool team takes pride in its team work. "It's a very cohesive team," emphasized Joan Binder, the SPED coordinator for preschool through grades 5, "a lot of years of experience. The team has an incredible amount of experience and expertise that they bring to it and utilize within both the school setting and within the community for both direct and consult services."

The team consists of a part time coordinator, 2 SPED educators, 3 speech and language people (not all full-time), an occupational therapist, a physical therapist, a school psychologist, an instructional assistant, tutors for students (as indicated on IEPs). "And we have clerical help," added Mulligan, the preschool coordinator, "very important. Especially when there's paperwork."

In addition to the pre-

school program at Jonathan Daniels, "we also work in about 13 community preschools throughout Keene, Head Start, various daycares and we provide all related services., OT, PT, speech as needed," Mulligan explained. "We also have four area sites that we do monthly consults with, that we meet with their staff on a monthly basis and discuss the children that we have enrolled there but also try to offer assistance in whatever area they need, whether it be classroom management or some issues within the classroom that we can help with. Not necessarily being related to the students that we have there, but generally just for the programs itself."

Judi Ryner is director of The Montessori School, one of the community preschools that the team supports. "I cannot say enough positive about them," she stated. "This year in particular....it seems like every year it grows a little bit.... this year they have been extraordinarily supportive."

"We have monthly meetings. We meet on all of the children that come from the dis-

trict. We have, of course, your semi-annual reviews and your IEP renewals. Whenever there's a new child that they think might benefit from our program, they start early and they say, take a look at this child. And when I run into a problem, they're right there. Maybe the tutor isn't quite a good match for this child. What do you have for ideas? Alright, let's try this and this and see how it works. But they have been wonderful."

Ryner has been accepting students with disabilities into her program for a number of years. "In the beginning, we were approached when we first started the school twelve years ago," she explained. "When Maria Montessori began her studies, she began her experimentation and observation in places where there were a lot of children with disabilities. It just seemed like the natural course to follow. And so we did."

While children with disabilities are eligible for services the day they turn three, preschools don't typically take in children during the year. Ryner, however, has made exceptions after being approached

by the team. "Well, you know I always resist," she admitted, "and I always say, oh, no, we can't do it. Just three years old in March? Are you crazy? That poor child."

"And nine times out of ten, I'm totally wrong. So, they just sort of listen to me and go, uh huh. We took three this year since January and it has been just wonderful. I never would have thought it would have worked as well as it did."

Her ability to do that is limited by the number of vacancies that occur during the year because she has a limit to the number of children she can serve. "Unfortunately, we're not as elastic as I'd like to be," she admitted.

When asked if the school district keeps up with her vacancy list, Ryner said: "Yes. Or else they cry a lot. And they know. My reputation is she can't say no; she just makes a lot of noise."

In addition to their school based program and the many sites with which they consult, the team provides home visits for families as well. "Our home visiting program actually

started with a grant a long time ago," Blair remembered. "It was twenty years ago that we actually received a grant to begin the home visiting part of the program - when we were not an inclusive preschool program. The home visit component is for students who are eligible and are on an IEP." Joe LaBrecque, one of the special educators, is responsible for the home visits and teaches part time at Jonathan Daniels.

These home visits are separate from and in addition to the home visits "for purposes of intake, gathering information and follow-through by some members of the team for at-risk children or children in the process of being evaluated," added Blair.

The preschool team offers an extended year program for both students with disabilities and typically developing children. "That's a four week program that we run.," explained Mulligan. "We do two sessions per day, two hour sessions three days a week for four weeks during the summer, mostly the month of July. We take typically developing students who pay minimum tuition, \$15 a week. And we also then are able to serve our special needs students."

"Also, students that are in community programs that remain open during the summer, if they need extended school year services we support them in the setting that they're in rather than have them move out of that setting to the Jonathan Daniels program. If they're already in a community preschool program, such as the Montessori, then we put the supports in place for them to remain there through the summer."

Some parents have needs which pose some challenges for the team. Single parents may need daycare in addition to the preschool program because of their work schedule. While the school district will not pay for the daycare piece, it will help parents figure out solutions to these challenges.

"I would say that the team really advocates if the family needs extra support," Binder offered, "to go the extra mile to try to help gain those resources, to talk with area agencies or to talk with the preschool setting. We try to come up with some kind of middle ground."

"Usually the school district goes beyond what sometimes is really our obligation in

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order to maintain a student within their setting," she added. "And other times we've been very creative in terms of collaborating with cojoined sites. Like sometimes a student will come here if they need a more intensive program and then go to another area provider for the rest of the day.

"So there's a lot of creativity involved in terms of trying to work through some of those daycare issues for parents."

Binder is proud of all the work accomplished by the preschool team, particularly how the program evolved with the Community Options grant. "It was a state model that people did come and observe," she stated. "People would come

and try to sort of look at how they could replicate the model because it was very effective in many ways.

"It's a very challenging model," she added, "because it really utilizes all your resources and people. Its taps people's creativity and strengths to the max, that's for sure. Because you have to travel, you have to deal with a lot of different sites, you have to deal with a lot of coordination."

Anne Wilber, one of the speech and language therapists on the team, talked about the challenges of coordination. "Every site's different," she explained. However many children they have, I have to adjust my schedule.

"That's one of the

tricky parts, to go to 8 or 9 different places where all the preschools meet pretty much from 9 until 11:30, to try and be in all those places. But usually, I'll have a few kids who are in daycare situations, maybe a couple of kids I can see at home in the afternoon.

We prefer to do therapy at school, but I have had some kids in the past who were working on articulation and (who had) stay-at-home moms, so I'd go there in the afternoon. And that works out nice, too, because the mom knows what we're working on, and it's not something that needs to be integrated according to the program.

"I think flexibility is the key," she added. "I change my schedule probably every two

weeks because we get new kids all year or new needs. You try to work with the child at the time that's ideal for them, which is hard to do, but.... That ideal time might change as the year goes on, so you try to change everybody around, if you can."

Wilber admitted that, while not preschools are as welcoming as The Montessori School, the preschool team is unswerving in its aim of working with every program which is willing to cooperate. "But that's our goal, going out into the community," she emphasized, "to bring in more and more preschools and have them be ready to take on anybody."

Wilber discussed the challenges posed by the differing philosophies governing each

program. She finds she has to adapt activities accordingly. "But a big part of the job is figuring out a way for what we feel is important for a child to get funneled into their program," she stated.

"That's the challenge of going out into the community. It's much easier, I think, to just have your own programs and do it your way than to go out and try to adapt what's already there, but I really feel like that's what typical preschoolers are doing. They're going to a variety of places. Parents are choosing where they're comfortable so special needs kids should be able to do that. That's the idea behind the whole thing."

Dover

SAU 11 is the city of Dover, located on the eastern border of New Hampshire above the Seacoast, population just under 27,000. Dover has three elementary schools, one middle school and one high school. The towns of Barrington and Nottingham send some of their high school students to Dover High School.

Dover has a preschool program serving exclusively children with disabilities located at Woodman Park Elementary School.

"There's only been one class for (approximately) 20 years that the program has been in, from the time when we were mandated by law to have preschool, Dover opened this class," stated Jackie Adams, SPED director.

The preschool team in the district includes a full time coordinator, 2 full time preschool sped teachers, one full time each speech and language therapist, physical therapist (PT) and occupational therapist (OT), a part time school psychologist, a preschool evaluator (a sped teacher) who does educational evaluations, an aide for each classroom and individual aides as needed.

In the school year that recently ended, the district preschool served 25 children, according to Mary Buese, preschool coordinator. The total number of preschool children

served was approximately 50. The program also received 115 referrals last year.

Some preschool children served by Dover were supported in community preschools. "If a child is in the community, we would consult with the program," Buese stated. "The district would support a child in a community placement if that's what the team decides and it's child appropriate."

Some children have a combination program - time at

stated. "Some parents declined" to have the school district pay for the community placement, she said.

Buese said there is a trend away from community placements. "I have worked for the district for 11 years. I started the community placement program," she said. Now, instead of community placements, parents are opting to have their children in the district preschool. "Parents like the structure, the routine, the trans-

"Parents whose child has significant challenges want good and firm support structure early on with lots of repetition, structure and skill development to give their child a good basis for education," Buese stated. "It's hard to get that when the child is out in the community. We can consult, but follow-up isn't always there."

Decisions about placement are made by the team, emphasized Buese. Who makes up a team? "It depends on the

her program. "We started a long time ago," Arkwell remembered. "I really can't even remember exactly when we did start. I have to say that we stopped for a few years. We were just not feeling that the children were getting what they needed."

That concern was not based on the limitations of her program, she added. "There wasn't enough communication (with the district) and it seemed to be just not working, but I think it tended to be more the people. When Mary Buese got involved in Dover, we went back on to the program and ever since it has been wonderful. They have provided wonderful speech language services. We have a couple of kids that are getting the OT and we have seen wonderful, wonderful success rates in the children that we have here."

When children with disabilities were enrolled in Happy Helpers, the district picked up the tuition costs, Arkwell stated, and provided aides for children who needed them. "Just the past school year, one of our little girls had quite a few aides," she said. "She was here three days a week in the morning and I think she had one that was here full time with her but then she also had her occupational therapist and she had a

Now, instead of community placements, parents are opting to have their children in the district preschool. "Parents like the structure, the routine, the trans-disciplinary approach that we provide."

Mary Buese, Preschool Coordinator, Dover

the district preschool and time at a community preschool, according to Buese. The related services provided by the district for children in community preschools are "child specific," and would include speech and language therapy, OT, PT and may include aides.

Where the children went and whether the district paid for the services was "dependent on the child," Buese

disciplinatory approach that we provide."

In some instances, parents who had children in a community placement "came back" and wanted their child in the district preschool. When asked to speculate why, Buese suggested the reasons might be: high turnover of staff, and situations where implementing the curriculum even with modifications was a challenge.

child," she answered. "If the child has speech and language problems, the team will include a speech and language therapist, for example. There would be an educator, and a parent or two. There would be a minimum of three people on the team."

Karen Arkwell, director of Happy Helpers, a preschool that has been in the community for nearly 30 years has accepted children with disabilities into

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(Top) Alex laughs with pleasure as his physical therapist Sue Vaillancourt works with him.

(Bottom) Brian enjoys some time at the computer in his preschool class.

Photos: E.G. Stone

couple of other people who would come in throughout the week.

"They (the district) were paying what it would have cost to send her to preschool. It happened to be in our daycare preschool and we bill hourly and some days she was here more than the two and a half or three hours that the city paid for so the parents picked up the extra," Arkwell stated.

This child is kindergarten age but the parents were undecided about whether she was ready for kindergarten or whether they wanted her to spend one more year in preschool, Arkwell said. When asked if the child could return to Happy Helpers next year if the parents felt she wasn't ready for kindergarten, Arkwell replied: "I think they know that's not a possibility."

Arkwell was told by Dover that it would be more cost-effective for them to serve children in their district preschool rather than going out into community placements. "I felt that most of what they gave me was that it would be much more cost effective and easier to do if they were all in one place," she recalled. "It would mean there were a lot of people that were not traveling. The traveling time could be spent with the children rather than traveling from one school to another. And that part of it make sense.

But there's another aspect of community placement that Arkwell believes will be lost. "The interaction with the kids here, I think, is very beneficial. I have a little boy that I remember started with us about two years ago at age three. You could not understand a thing he said. This past year, he has just grown. You hardly ever hear him stutter or have a problem anymore. He is just doing wonderfully. And he doesn't get anything from the other kids. He doesn't get harrassed. He doesn't get made fun of. He's just one of the kids, which is great. I think it's wonderful."

Happy Helpers serves "approximately 220 children," Arkwell said, "not



all at one time, though. We're broken down into six classes. And I would have to say that the majority of the time, there were probably eight children (with disabilities) in the building. They were all in different classes. They weren't even in the same classes".

Arkwell had no complaints about the support she and her staff received from Dover and felt that they tried to integrate therapies in with her curriculum. "Especially with children who had more than one need," she said. "Like our little girl who had lots of needs this year and had lots of aides in here, they were wonderful about saying, how about we try and do this or how about we try and do that, how about we change this or change that to make it more accessible or to make us more aware or whatever."

She also felt supported in other ways. "They were definitely available to talk with, to give us advice: well, gee, it sounds like maybe that person could benefit from being evaluated, or let's get him in and let's talk about it and see what happens. They were very good about that. If I had a child and I was pulling my hair out, thinking there's gotta be a reason, and I would talk to them, no problem."

Even though Dover has made it clear that they will not be placing children in her preschool anymore, Arkwell is hopeful that they will continue to be available for advice and help. "I know that when I have called Mary Buese before in the past and asked her to do a workshop on behavior or disabilities or something, she's been wonderful and come and done it for my staff," Arkwell said, "even when we haven't known if we were going to have any kids that year. She's been excellent with that.

"I'm hoping that will continue, that she or any somebody will be available to us for needs and for help, and just to call."

The district is planning changes in its preschool program beginning next year. Adams explained to the school board that she intends to expand its one preschool classroom to two next year and bring in children without disabilities. Her goal, she stated, is to bring all the children into the program from community placements so that the staff would not have to spend most of its time travel-

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ing. The plan is to create an "integrated" program by bringing in "students from Head Start and we will be accepting referrals from the HUB." (The HUB is a parent resource center located in Dover and serving the surrounding communities.)

"There will be ten children from the Head Start program because their preschool is pretty well, or their childcare program is pretty well crowded. So there will be ten children from the Head Start preschool coming to our preschool and we will be taking ten students referred by the HUB. That one we haven't worked out exactly what the criteria is, but many of them would be eligible under Title 1. We also have a large community of ESOL (English as a Second Language) students and we may be able to, through the HUB, open that opportunity to newly arrived ESOL students."

In a statement to the School Board, Adams stated: "If parents want to place their children in a community based preschool, we will continue to provide consultation and services. We are not taking this option away from anyone. The difference is we will no longer continue to pay tuition."

That unilateral decision, though, is not in compliance with IDEA, according to Mallory. "We all know that if a child has an identified disability, then there needs to be an IEP and a team, including the parents and the service providers that develop that IEP and decide whether or not an aide is appropriate and if so, then the school district pays for those services so the child can receive a free, appropriate public education. Those kinds of contingencies that might be presented to a family are really illegal and unethical."

Adams claimed that the district was receiving assistance from UNH in its planning, specifically from Stephen Calculator, professor in the Communications Department. When contacted, Calculator denied that he was providing technical assistance. "I was never asked to consult with Dover," Calculator stated. "I would not do so anyway because my wife works in the building. (She is a speech and language therapist.) It would be a conflict of interest."

His contact with Dover,

he explained, came about when he approached the sped department about placing one of his college students in the program as an intern. He wanted to observe the class before the placement and spent a couple hours doing so. After his observation, Adams asked him to write a report on what he observed, according to Calculator.

"I told her that it would not be a comprehensive report - just an observation after a two hour visit," he reported. "She said that was okay."

Calculator's report contained these observations:

- Dover should be doing more in terms of transdisciplinary service; for example, putting different centers around the classroom targeting specific goals for children;

- Classroom teachers and aides can implement the program but need more input and consulta-

ted programs but their main focus is supporting parents. There are playgroups and parenting classes that are open to everyone in the community. There is an Even Start program that helps parents who have not graduated from high school to work toward their G.E.D., and teaches English to parents who've come to the community from another country and don't speak the language.

Sheffield said that no criteria has yet been set for the families the HUB will refer to the Dover preschool program. "They have to live in Dover, of course," she said, "and they have to have transportation." The Dover school district will not provide transportation for these families.

They must not have other options for preschool in the community, she added. Families who have access to a

integrated preschool and wanted to collaborate.

Head Start serves about 239 children throughout Strafford County., explained Meatty. In Dover, they run five preschool classes, serving about 60 to 65 preschoolers. One of the classes is a traditional Head Start class - half day (5 hour) program. The other four classes offer extended day services - child care before and after the preschool class. "Families needed the extra child care because of the Welfare to Work rules," Meatty explained.

Head Start will accept children into the program throughout the year up until March. "Strafford County tends to be pretty transient," Meatty explained. Still, "we have waiting lists," she admitted.

Head Start offers comprehensive programs, according to Meatty. There are two models in which they operate: the

other children twice a month, either through field trips in the community or with the children in the preschool classes.

A unique feature of Head Start is the family involvement that characterizes the program. Each regional office is governed by a policy council made up of parents whose children are receiving Head Start services. Each local program has a parent group, from whom is elected the representatives to the policy council.

The policy council has specific responsibilities. They develop policy for the local programs, interview applicants for staff positions, approve any terminations, assist in developing the budget and sign off on the finished budget. No regional program can send its budget to Washington without the signature of the policy council, according to Meatty.

"It's very parent-empowering," Meatty emphasized. "Parents become empowered by being involved."

Meatty took the idea of collaborating with the Dover school district to the policy council, who gave its approval. "Nobody balked at the proposal," she stated.

There will be only ten openings for Head Start students in the plan. None of the children referred to the Dover preschool program will have disabilities, Meatty stated. Head Start has a federal mandate that at least 10% of the students it serves must be children with disabilities, though Meatty says that 15% is more typical in their program.

Participation of Head Start eligible students will be voluntary, Meatty emphasized. "We'll be talking with families of new children coming in," she said.

The collaboration with Dover will offer a combination of the two models to the families who choose to participate. Parents who opt for the three day a week preschool class will get 2 home visits a month. Those who opt for the four day a week program will get one visit a month.

It was unlikely, she thought, that parents whose children were already going to the five day a week Head Start program would want to decrease that time to go into the Dover program.

"I do have concerns whenever we do anything that tends to perpetuate existing definitions that tend to further segregate children over time, especially when they're very young. I mean, that's a time when they should have experiences with peers who are different from them. Maybe that places greater demands on teachers, and greater demands on administrative systems to figure out how to do that, but that's not a reason not to."

**Bruce Mallory,
vice provost and dean of the UNH Graduate School, and
professor of Early Childhood and Special Education**

tion from outside specialists (speech and language pathologist, OT, PT); and

- It's a self-contained program. The children need more role models from typical peers.

"It's a program with a lot of needs," Calculator concluded.

The two programs Dover intends to collaborate with are HUB and Head Start.

HUB

Mary Ellen Sheffield, executive director of the HUB describes her program as "open to all families. We bring in families across the board socially and economically," Sheffield explained. "Over 300 families come in here in a week."

They offer many tar-

preschool and the ability to pay for it will not be considered.

For that reason, Sheffield said, she and Mary Buese, the preschool coordinator for Dover, have been discussing the possibility of making available the 10 openings targeted for the HUB to families in the Even Start program. "There are so few openings," Sheffield said.

Head Start

Head Start is a federally mandated program which has regional offices. Pat Meatty, project operations manager for Head Start of Strafford County, acknowledged the proposed collaboration with the Dover preschool program. "We were approached by Dover," said Meatty, and they indicated that they were interested in doing an

classroom model and the home based model.

The classroom model offers children the opportunity to attend classes five days a week and receive one home visit a month. Each family is assigned a family advocate - a resource and referral person - who offers them pragmatic help. They connect families with resources in the community, according to Meatty and help them identify their strengths and set goals.

The home-based model partners a family advocate with a family. The family advocate visits the family once a week and helps them access social services, information, and community resources. They teach parents about child development through play activities, concentrating on the particular needs of the child in that family. The children socialize with

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Lessons in Life

“To a man laboring under calamity, the heat of his own fire hath sadness in it. Then, there is a kind of contempt of the landscape felt by him who has just lost by death a dear friend. The sky is less grand as it shuts down over less worth in the population.”

- Ralph Waldo Emerson, *Nature*.



by: Sean Raymond

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

All too often people take things for granted. I know I have. About eight years ago someone special came into my life and slowly changed every aspect of my personality. The biggest regret in my life, thus far, is never getting to show that special someone just how much she meant to me.

After nearly eight years of a day-in-day-out friendship, cancer took away my dearest friend without a moments notice. One day she was here and the next day she was gone. I have promised her that I would pay tribute to all she has done and I always keep my promises.

I was a shy kid and kept to myself for about the first ten years of my life, but all this changed when Dara came into my life. She was so beautiful. She had long, flowing golden hair that just lit up the room when she came in. She had the most beautiful walk I had ever seen and she never looked sad when she was out with me. At her full height she was about twenty-five inches tall, measuring from the floor to the top of her head. Her name was Dara and she was my dog.

Most people have heard

of seeing-eye dogs, well Dara played a similar role to a seeing-eye dog as my Canine Companion. She assisted me in doing things that I physically could not do on my own.

For example, she would pick a pencil up for me that I dropped, or get objects off counters for me, and not only could she open the refrigerator, but she could retrieve drinks and food from it too. The list goes on to a count of over one hundred total commands, but Dara brought more to me than any command ever could.

The first lesson I learned was responsibility. As a ten year-old kid I was handed complete control over Dara, who would be with me twenty-four hours a day everyday. We went through two weeks of intensive training in New York, where I first met the two year-old Dara.

After the two weeks of training, we came back home to New Hampshire and I was the only face Dara knew. She was one hundred percent dependent on me, and in a kind of ironic way, I put a lot of my dependency on her. No longer did I just have to worry about myself, but I had to watch out for Dara too. She went everywhere with me: school, band, camp, and even Disney World. Her well-being was put into my hands and the responsibility I learned from my time with Dara is unparalleled to anything I have ever done.

I learned many important lessons because of Dara and the one I am most proud to practice is compassion for others. Everyone knows how frustrating dogs and people can be at times, but the best way to handle those situations is through compassion. I've seen what anger can do and I would much rather choose compassion.

The basic rule of compassion that I learned is to always think of what I can do to help someone else. This takes all the selfishness away and puts all the aim on serving others. There is no better way to make yourself feel good than through helping someone else.

The twinkle in Dara's eye when I took time out of my busy life to play catch, or go for a walk was more rewarding than anything I could ever dream of buying. Dara's entire life was devoted to helping me just as I

Dara was the smartest dog I have ever known. She was always learning new tricks, but her favorite thing to do was learn people's daily routines. She watched everyone and everything they did, and once Dara learned that a particular person had a pattern she would start helping them without a word being said. It came to the point where I would get ready to go to school each day and Dara would be going through the daily motions before anyone else.

At 6:00 a.m. she would hop off my bed and go lye down in the doorway to my bedroom and wait for my grandfather's alarm to go off. Then she would follow him down the hallway and wait by her dog dish for food. If he forgot about her she would almost sound out in doggy language, "Feed me!" It wasn't crystal clear, but we all knew what that sound was.

her home, but she still went through the daily routine and gave me a hug before I went off to school.

One day Dara just didn't care about the routine. She slept through everything and didn't even eat. I had to go back in my bedroom and tell her I was leaving before she even got up to see me, and even that looked painful.

That day at school was awful because all I could think about was how sick Dara was. When I got home my grandparents said Dara had been sick all day and had absolutely no energy. I remember looking at her and it almost appeared as if she had lost some color just over the length of a day!

The next day we brought her to the vet for them to check her out, and they requested to keep her overnight. I couldn't sleep and all my thoughts were around Dara and

"I met more interesting people because of Dara than I have ever met in my entire life, and I loved it!"

was there to help her when she needed it, and there has never been a bond as strong as ours.

How can anyone not be intrigued when they see a dog walking through the mall? I met more interesting people because of Dara than I have ever met in my entire life, and I loved it! People would come right up to me and start firing questions about Dara and what she could do.

Some of the people were just one-time acquaintances, but every now and again lasting friendships were built all because a person saw a dog in a public building for the first time and was absolutely fascinated. If Dara didn't do anything else for me, the way she just attracted people, which broke me of my shyness, is priceless. No longer was I just a spectator in life, but I was an active and leading participant.

While Dara was eating and going outside to do her business, I would be getting up. When I made way to the kitchen that meant it was time for Dara to run inside, and she did exactly that everyday. She ran full force into the house to see me! Then, while I combed my hair, my grandfather, or grandmother, would brush Dara and get her looking all beautiful for the day.

When all that was done Dara would go grab her leash, we would put her jacket on and she would lead the way to the bus for our daily ride to school. Dara even had a favorite seat on the bus; it was the first seat on the right. Dara new that routine like the back of her hand and followed it flawlessly to the very end.

Eventually, Dara got too old and arthritic to go to school with me and walk around all day, so I would have to leave

how she was.

The next day I got up, without Dara being there, and went to school. About halfway through the day I saw my grandmother at school and I knew something was wrong. She told me Dara was really sick and that she had cancer. I couldn't believe it and I just started crying.

I left the school and went to visit Dara. The vet talked to me and said that I should come back later because they were going to perform something similar to a sonogram on her stomach to see where the cancer had spread. I was invited to watch, so I went home and tried to relax myself.

This leads me to the single most unforgettable and painful moment in my life. Dara had been in the vet for a few days of testing, but it all came

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down to this last test as to whether or not she was going to be able to live. I came back for the viewing, and as I watched the vet hook up the equipment I helped to soothe Dara as she just stared at me the entire time with a little grin of happiness knowing that I was there.

When the black and white monitor started displaying what was inside I can remember the vet taking one look and just shaking her head. They printed out the screen shot and explained that the cancer was everywhere from her liver to her heart and even her lungs. Every time she took a breath her lungs would slowly fill with blood due to all the tumors in her body, so the vet had to pump out the blood so that she could breathe.

I couldn't bear the thought of putting her to sleep when I looked into her big brown eyes. But, I couldn't let her go on in incredible pain gasping for air every four hours! That is no way to live!

That's when I had to make the most responsible, compassionate decision of my life. All the lessons I had learned prior to that moment were put to test and I gave the word to put Dara to sleep. I was told exactly what was to happen and that it was painless. All the pain she was feeling would soon be gone, but the pain I was feeling would just begin.

I signed the necessary paperwork and stayed right with Dara while the vet went to prepare the injection. I talked to Dara and told her I loved her and that I would never forget her. I tried to say more but I was crying so hard that I couldn't. The vet asked if I was ready and I nodded my head. She started the injection and slowly Dara's eyes became lifeless and she was gone. I didn't want to leave without my dog, but I knew that was it, that it was all over.

I won't lie and say that I came to the decision easily. When I knew that was the only option I cried for what seemed like life times. I couldn't stop thinking about that moment for a few months. I would cry every time I thought about it, and I occasionally still do cry when I think about her big brown eyes slowly closing as she passed away to a better place.

I chose not to think about Dara from then on because not thinking about Dara was the only

way not to be sad. It took me a long time to realize that by repressing all of my memories of the happiest times of my life was foolish. Dara's name was a taboo around me. I regret those actions and now know the best way to heal the pain is to confront the memories and pay respect to all she did. I held much sadness in my heart by ignoring my memories of Dara, until one day I just confronted all the memories, all the regrets, and all the questions and wrote my ode to Dara.

I thoroughly enjoy writing poetry and it is my favorite way of expressing my emotions. I cried tears of joy and sadness while I wrote the poem for Dara, but at the end all of the sadness and anger was lifted. Nearly nine months of me being in purgatory I finally came to understand Dara's death. I put my heart and soul into the poem, and the final product was more than I could have possibly imagined. Dara was more than a dog to me; she was an extension of me. She was part of my independence and what gave my life fulfillment. Canine Companions, like Dara, change the lives of disabled people in ways that are hard to imagine. She was more than a best friend and as close to me as any person I know. I only hope that other disabled people can one day experience the benefits of such a relationship.

Sean welcomes your response to his articles. You can email Sean at sumdeus@attbi.com



This picture of Dara and Sean was taken in 1998.

Photo: E.G. Stone

Now that you're gone I find myself alone.
 A shadow, a memory, but in my heart you still grow.
 Since the first day we met we found ourselves in a special unity,
 But I will always regret never getting to tell you just how much you meant to me.
 We went everywhere, did everything and broke all the rules!
 I loved you and you loved me even though we were crazy fools!
 Never have I known someone as loving and open-minded as you;
 You gave me the strength to see the world in a full, panoramic view.
 In your last few minutes I saw into your big brown eyes,
 And in just a few moments I said my last goodbyes.
 Watching your life slowly fade away
 Caused me numerous days of heart-felt pain,
 But being there for you at the very end
 Is the least I could do for my very best friend.
 As I sit here and write this tears roll down my face,
 I realize now I will never feel your warm embrace or see the sun shine off your golden face.
 I pray and pray that one day we will reunite,
 In a place where we can play on sun beams in endless dreams and everything is right.

Dover

Continued from page 19

Opening the preschool program to Head Start and children eligible for Title 1 services does not necessarily open the program to typically developing children, according to Bruce Mallory, vice provost and dean of the Graduate School at UNH, and professor of Early Childhood and Special Education.

"If we take children from Head Start and Title 1, and children identified as eligible for special education services," Mallory stated, "we're beginning with three different groups that have been defined legally and segregated in kind of a legal and programmatic fashion in the past.

"Head Start children have to meet certain eligibility guidelines. Title 1 children re-

flect a neighborhood that has particular income characteristics, socio-economic characteristics. So essentially, we're taking three segregated groups and putting them together in a single program. It kind of creates an enclave of segregation, even though there's perhaps more diversity in that enclave. It's still remains separate from the mainstream of the community.

"I would much rather pursue opportunities, classroom opportunities, again that have a full range of diversity in terms of ability and family background and characteristics, language and ethnic differences and so on," Mallory commented. "I think that's always what we should be striving for.

"I do have concerns whenever we do anything that

tends to perpetuate existing definitions that tend to further segregate children over time, especially when they're very young. I mean, that's a time when they should have experiences with peers who are different from them. Maybe that places greater demands on teachers, and greater demands on administrative systems to figure out how to do that, but that's not a reason not to."

Debra Nelson, whose five year grant program through UNH's Institute on Disability/UAP, *Community Options in Early Care and Education* provided assistance to school districts to reach out to community placements for preschool children, agrees. "It's absolutely doable," she stated. "People just need to figure it out."

Editorial

The Preschool Paradox

If you had a choice, where would you want your preschool child educated? In Keene or Dover? Upon examination, the answer seems obvious. Keene's educational services are child- and family-driven; Dover's are staff-driven. Keene supports the parents' needs and desires for their child; Dover says: we are the smart guys, we know what's best for you - take it or leave it. Keene believes itself to be an integral part of the larger community; Dover seems to be circling the wagons.

If preschool is a child's first experience of being integrated into the community, Keene is sending the right message, Dover is sending quite another.

How is it that Keene can successfully support children in many different preschools with differing philosophies and differing curriculums while Dover believes it must offer a one-size-fits-all program?

How is it that Keene takes seriously the federal mandate that a district should not remove a child from a regular education program (community preschool) solely because of needed modifications while Dover actively discourages the opportunity for inclusion in the community?

How is it that Keene can look to the community preschools as a solution for meeting a growing need while Dover looks at their community preschools and sees only problems?

How is it that Keene can believe that all the hard work and complicated logistics involved in creating a network of supports in the community are well worth the effort while Dover pulls its resources back into a self-contained program because going out into the community is too wearing on the staff?

How is it that both districts can say that their programs are "individualized"? Does the meaning of the word change when you travel across the state?

Both districts are serving preschool children. Both face similar challenges and obstacles. Yet one reaches out with imagination while the other pulls back for the convenience of the staff, and other imagined difficulties. One shares its power to influence and teach while the other uses its power to limit choices and box kids into separate services. One helps create an inclusive community where everyone belongs and the other thinks the stand-alone preschool community it creates in district is sufficient.

Where would you rather have your preschool child educated?

Shumway Leads the Way Once Again

Donald Shumway is a complicated and dedicated individual. He hates accolades, avoids the spotlight, and rarely shows the full hand of cards he holds. He is so unassuming that there have been times when people in power who didn't initially know him dismissed him as unimportant and not worth their attention.

But you ignore Don Shumway at your peril. Under his watch, Laconia State School closed - the first institution for people with developmental disabilities in the country to do so. Under his watch, a community-based service system was conceived..... and financed! (No small feat in New Hampshire.) Under his watch, a movement to empower individuals with developmental disabilities gained momentum across the country. Under his watch, a state agency which had been demoralized grew in confidence and mutual trust.

The most important thing about Don Shumway, however, is not his accomplishments.

Yes, he is a talented and shrewd man who is comfortable with power. But that is not what is remarkable about him. The world is full of talented and shrewd people who are comfortable with power. What is remarkable about Don Shumway is his heart. He truly cares about people. He believes in the inherent dignity of each individual, especially those most tend to ignore. He really listens to them, he hears what they say, and he acts on their requests. He uses his power for their gain, not his own. That is what is remarkable about Don Shumway.

That's why his decision to take over the leadership of Crotched Mountain must not be dismissed, ignored, downplayed or derided. For those of us who care about people with developmental disabilities, his decision is a harbinger of new possibilities. Don Shumway loves a challenge, and he will find one as he sheds the mantle of leadership at the NH Department of Health and Human Services and assumes a similar mantle at Crotched Mountain.

In seeking his challenge, however, he challenges all who have looked at Crotched Mountain as the red haired stepchild of the New Hampshire disability community. Indeed, just by his acceptance, he has shifted the perception of the organization from one mired down by outdated beliefs and service deliveries to one poised on the cusp of positive change. (How about that for an accomplishment, and he hasn't even started yet!)

We at The Challenge bid Don well as he begins a new chapter in his life. Because we know that in that new chapter, he and we who love our family members with developmental disabilities are all on the same page. Those who would attempt to ignore or dismiss this new chapter of Don's do so at the expense of those we love.

Letters to the Editor

Conditions need to improve

To the editor:

There are 33.1% of people with disabilities that are still unemployed in this State. People are still making low wages in entry level jobs. We need to do more to move people with disabilities out of low wage entry jobs into higher paying jobs promoting opportunities for people to get an education, post-secondary education, and attending college for lifelong learning and other universities in this country.

We need to promote planning strategies that will improve skills. People with disabilities should not have to live their life in low wage entry level jobs and sheltered workshops in this country. Vocational Rehab mandates that if a persons IQ is below 70 then they are denied opportunities. The IQ testing should be abolished in this country. IQ testing is discriminatory against persons with disabilities. It holds them back. That is not where we should be in the 21st. Century!

There are more citizens with disabilities that own their own home today since the "Home of Your Own" Project started in 1992. The Division of Vocational Rehabilitation has not changed with the times. It still labels persons with disabilities today. We need to practice self-determination, giving people with disabilities more choices in their life, having more control of their own services.

The Services system needs to be changed in this Country. The State needs to focus on Sheltered Workshops, Day Programs Closer in this country. If the Federal Government wants people with disabilities, welfare recipients, to be more self-sufficient, then they need to be given more chances for employment opportunities.

How can we become totally self-sufficient when all we can get are jobs like retail, supermarkets, and cleaning. This is the reality we face. We must make changes happen in the 21st Century Workplace.

There is a lack of public transportation in many communities such as Salem. It has no public transportation sources and that is a major barrier that needs to break down.

I serve on the Institute on Disabilities Consumers Advisory Committee and I have been a board member for the past 5 years on the Institute on Disabilities Consumers Advisory. I served on the Greater Derry, Greater Salem, Southern New Hampshire Mass Transit Council.

We have to break the cycle of poverty so people with disabilities can live decent lives in their own communities like everyone else without disabilities

Sincerely,

Jocelyn Gallant
Salem, NH

Parents as direct care providers are not treated with respect

To the editor:

I read with great interest your article "Who Cares for the Direct Care Providers?" however from a much different point of view.

I consider my husband and myself to be direct care providers since we have chosen to keep my 36 year old mentally challenged son in our home. We provide him with personal care, grocery shopping, laundry, managing his money, job support, transportation, recreation and many other activities considered essential to his quality of life.

Do we get any respect? No. Do we receive any help? No. Did we need any training? No. We learned as we went. Whenever I ask for help, which is rarely, I am told my son is very low priority because he lives with his parents.

My son has a full time job, at the same place going on four years. He has always had full time employment since gradu-

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Letters to the Editor

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ating from a special education program at our local high school. He has continued interaction with family members, including his 89-year-old grandmother, his sister, his 5-year-old nephew and 7-year-old niece. He is a six-year member of our bowling league, where he interacts very well and is very well liked. He participates in a recreation program that meets every Thursday evening. They go to the movies, out to dinner, archery lessons, shopping, etc. We take him on vacations. We do many other things for him too numerous to list.

The point that I am trying to make is this. If I sent my son to live with you, you would receive about \$30,000 a year tax-free. You would receive paid transportation for him to and from work. You would have two evenings a weeks (2.5 hours each) of respite plus respite on the weekends. And you would have the luxury of staying home. While we in turn get nothing. Well almost nothing. We get \$200 a quarter from Community Bridges for respite but they never have anyone to do respite. And if they do give us a respite provider he/she never stays in their employ very long.

What makes Direct Care Workers so different from us? We are providing the same thing they are plus much, much more and lots of love. Many of my friends who have handicap adults have them living at home. Some of those friends are on Social Security and barely making ends meet. And some are working full time jobs AND taking care of the needs of their disabled adults. I know they could use some compensation. The way I look at it we are saving agencies and government money by opting to keep our loved ones with us for as long as we can. Why not give us something?

In your article you state Michelle Mayo is a home care provider for her cousin. And she receives compensation for doing so. When we asked if my husband (my son's step dad) could receive compensation for taking care of him we were told NO. Because I was he mother and I lived in the same house he could receive nothing. My husband is the one who cooks all of my son's meals, and makes sure his daily living needs are taken care of. Mayo also states, "Not being valued causes a great deal of frustration among direct care workers and home care providers". She should have walked in my shoes for the last 36 years. She would know what frustration really is.

I don't know what it would take to get agencies to:

Treat us with respect.

Give us fair and equitable compensation.
to us.

Expand benefits

All we want is to continue to enrich our disabled adults lives as much as they enrich our lives.

Sincerely,
Sandra S. Sigel

Action is needed to solve direct care problems

To the editor:

Thank you for the enlightening article "Who Cares for the Direct Care Provider?" in the winter issue of the NH CHALLENGE. The truth of the situation was well expressed, particularly the point that without direct care providers there is no system. The network of NH CARES works to educate legislators to that very truth. [NH Citizens Advocating for Responsible and Essential Services].

NH CARES is a network of consumers, providers, agencies, legislators and everyday citizens who advocate for a state budget that supports the economic and social fabric of life in New Hampshire. As your article points out, money is not the only issue, but, when the problems continue to accrue, there is a correlation. If the people who provide professional services are compensated in keeping with the valuable work they do, the entire system benefits. Stability of employment benefits both the caregiver and the recipient, not to mention the agency. Respect and trust are more likely to be attained when the salary is equally respectful and trustworthy.

When the NH House and Senate consistently vote for an inadequate budget, they reveal their lack of knowledge about the system of care giving that is so vital to families and their loved ones. Just before going home to their re-election campaigns, legislators had to confront a Medicaid payment shortfall. Their solution? The first choice was to just make providers wait 6-8 weeks for their payments. Ultimately the Health Care Fund was used to make the payments in a timely fashion. The incident reveals a lack of respect for providers. It comes as no surprise to discover that there have been no rate increases for providers since 1993, and when this recent budget crisis loomed, there was even talk of rate decreases!

There is a famous saying that recognizing a problem is the first step. It seems the problem is well recognized by all but those who actually vote for the budget. The next step is speak up to elected officials. It is never too soon to start.

Call your Senator or Representative to talk about the issues of decent pay, training, and respect for direct care providers. Since this is an election year, chances are you will be able to get a dialogue going. The best way to get results is to establish a relationship with that person who travels to Concord to represent you. Tell the stories - how much the pay actually is, and how many people a direct care provider is asked to cover. The time to build interest and support is now, because a good foundation needs to be set before the budget wrangling unfolds in 2003.

Another key player in budget decisions, is of course, the governor. The various candidates are covering the gamut of possibilities for education funding solutions but there has been little talk of budget issues. Try to visit a candidates' forum and bring your one question to the candidates: How do you intend to address the direct care system and what will you do for providers who have received no rate increase for almost 10 years? Imagine, if those candidates heard the same question over and over as they traverse the state, they and the press will take notice.

The work of direct care providers is one element in the health and human services aspect of the state budget. NHCARES works to educate and advocate for health and human service justice for all. If you would like more information, or care to join the network by endorsing the NHCARES principles, please email nhcared@nhnonprofits.org or call 225-1947.

Sincerely,
Sheila Evans, coordinator NHCARES

Pay attention to the upcoming elections

To the editor:

As you know the election season is upon us again.

The next governor most likely will be a Republican and not "friendly" to the needs of the poor, elderly and disabled. If that is not enough we are losing "friends" such as Senator Katie Wheeler, HHS Commissioner Don Shumway and several others.

In addition to members of the state senate and house we also have federal elections to deal with. We will be electing a US Senator and two Congressmen.

I wish to remind people that we (as in all of us) need to educate ourselves on the candidates who are seeking these high offices. We should attend "town meetings" and any other events where one could get a chance to ask the candidates questions about your concerns. If you have access to the Internet you can go to <http://capwiz.com/familiesusa/election/> and read a short biography of the candidates. Enter your zip + 4 code to find out who is running for office. If you are not sure of the "+4" look at a piece of your "junk mail" and it will be there.

It is very important that you make up your own mind who you want to vote for. Don't be swayed by endorsements from newspaper editorials or out of state "feather merchants". Talk to the candidates; listen to what they have to say. Ask questions; take notes and if you don't like the answer or they respond with a song 'n dance hold their feet to the fire until they give you an acceptable answer. They are working for you, not a special interest group. Just because a candidate raised a ton of money from the drug manufacturing groups or Hollywood hot shots does not mean they will support your issues.

It's up to you folks. When they are in office we will be stuck with them so choose wisely. And remember, if you don't vote don't complain about who gets elected. You are ENTITLED to one vote-use it and use it well.

The New Hampshire Challenge usually publishes interviews with candidates for major office. Read them and study the answers.

Pete Eldredge, Chair
Granite State Concerned Parents and Advocates, Inc. (GSCPAs)

Foster parents needed

To the editor:

The future is not certain for children living in troubled families. Many need foster placement while their families try to find balance again. You could make a difference in the life of a child by becoming a foster parent. Call your local Department of Health and Human Services' Division for Children, Youth and 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.nh fostercare.org email: jfeuer@dhhs.state.nh.us

Area Agencies

for Developmental Services

REGION I

North Country

Northern New Hampshire Mental Health and Developmental Services, Inc.

87 Washington Street, Conway, New Hampshire 03818
Dennis MacKay, Exec Dir., Eric Johnson, Assoc. Director
Phone: 447-3347 **Fax:** 447-8893

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

Area Offices:

Upper Connecticut Valley Mental Health and Developmental Services(MH)

Charlie Cotton, Area Director
34 Colby Street, Colebrook, New Hampshire 03576
Phone: 237-4955

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

29 Maple Street, P. O. Box 599, Littleton, New Hampshire 03561
Jane MacKay, Area Director
Phone: 444-5358

Family Centered Early Supports and Services

31 Brooklyn Street, Groveton, New Hampshire 03582
Director: Pat Arneson **Phone:** 636-6193 or 1 (800) 862-8634 parneson@nnhmhds.org

Developmental Specialists:

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

Littleton: Peggy Bromley **Phone:** 444-1742 x 4 pbromley@nnhmhds.org

Developmental Services:

Community Services Center

69 Willard Street, Berlin, New Hampshire 03570
Art Froburg, Area Director
Phone: 752-1005

Common Ground

headquarters for day service & case management
29 Maple Street, Box 599, Littleton, NH 03561
Phone: 444-6894

Vershire Center

39 Colby Street, Colebrook, NH
Phone: 237-5721

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

123 Main Street, Gorham, NH 03581
Phone: 466-9011, or 1 (800) 771-8531

Region I:

Berlin area -

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

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

Colebrook/Groveton -

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

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

Littleton -

Family support and Respite coordinator: Diana Flick 444-1742 x 6
dpelletier@nnhmhds.org

Benefits Technician: Terri Paige 444-5358

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

REGION II

Sullivan County

Developmental Services of Sullivan County, Inc.

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

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

Case Management: 542-8706

Adult Services: 542-8706

Family support coordinator: vacant

Respite coordinator: Kristina Allen 542-8706

Kallen@dsscofnh.org

Early Supports and Services: Kathy Sarles 543-0391

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

Family Support Council Chair: John Milliken 826-4361

rollingthunder@mapscape.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@lrsc.org **website:** www.lrsc.org

Family support coordinator:

Christine Santaniello 524-7755 chriss@lrsc.org

Respite coordinator

Denise Sleeper 524-7755 denises@lrsc.org

Benefits technician: Lisa Richardson 524-7755

Family support council chair: Tracy Mansfield 528-1713

Tiam91@aol.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: roy@comm_bridges.mv.com

Family support: Jo Edwards 225-4153 (800) 499-4153, x 224

jo@comm-bridges.mv.com

Respite coordinator:

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

Benefits Technician: Rebecca Spinney 225-4153 ext. 222

Family support council chair: Annette Kowalczyk 224-1524

REGION V

Monadnock

Monadnock Developmental Services, Inc.

121 Railroad Street, Keene, New Hampshire 03431

Alan Greene, Exec. Director

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

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

Family support coordinator:

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

Respite coordinator:

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

Early Supports and Services: Anna Lake 352-1304 A

nna@mds-nh.org

Benefits technician: Sue Raymond 352-1304

sue@mds-nh.org

Family support council co-chair: Cameron Tease 827-3538

ctease@marken.com

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

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

144 Canal Street, Nashua, New Hampshire 03060

Sandra Pelletier, Exec. Dir.

Beth Raymond, Assoc. Dir.

Phone: 882-6333**Fax:** 889-5460**e-mail:** sandyp@region6.com **website:** www.region6.com**Affiliate Agencies:****Located at 144 Canal Street, Nashua, NH 03064:****Early Intervention and Pediatric Therapy**Nancy Dowey, Prog. Coord. **e-mail:** nancyd@region6.com**Phone:** 882-3434**Fax:** 889-5460**Partners in Health**Karin Harvey-Olson, Family Support Coordinator **Phone:** 882-6333 x 373**Fax:** 889-5460 **email:** karinh@region6.com**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**No Fax****e-mail:** dwall@alvirnehs.org**Family support coordinator:** Nzenalu Obinelo 882-6333, ext. 372

nzenaluo@region6.com

Respite coordinator: Carole Smith 882-6333 x 325

caroles@region6.com

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

pmarcoux@verizon.net

REGION IX**Strafford County****Behaviorial 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 technician: Julie Batchelder 749-4015 jbatchelder@dssc9.org**Family support council chair:** Chuck Raymond 743-3909 chuckray@ttlc.net**Family support council vice-chair:** Karen Salter 692-2088 ksalter@aol.com**REGION X****Atkinson/Salem****Region 10 Community Support Services, Inc.**

8 Commerce Drive, Atkinson, New Hampshire 03811

Dennis Powers, Exec Director

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

kwaterson@region10nh.com

Respite coordinator: Anna Gonzalez (Child and Family Services) 889-7189**Early Supports and Services:** Aleece Pappas 893-1299

apappas@region10nh.com

Benefits technician: Maureen Monahan 893-1299 monahan@region10nh.com**Family support council chair:** Carol Ingram 893-1129

cingramcarol@netscape.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

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

Family support council chair: Donna Nicholaides 624-1592

donna.nicholkildes@yahoo.com

REGION XI**Carroll County****Center of Hope, Inc.**

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

Peter Blue, Exec Director

e-mail: pblue@centerofhope.org

Margie Matthews, Assoc. Exec. Dir.

e-mail: mmathews@centerofhope.org**Phone:** 356-6921 or (800) 290-0905**Fax:** 356-6310**Family support coordinator:** Christine MacDonald 356-6921 x52

(800) 290-0905 cmacdonald@centerofhope.org

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

lgorham@centerofhope.org

Family support council chair: Frances Hyslop 539-3599

thanks@nhadelphia.net

Family support council vice-chair: Dennis Parcels 539-6674

dparcels@earthlink.net

REGION VIII**Seacoast****Region VIII Community Developmental Services Agency, Inc.**

Parade Office Mall, Suite 40, 195 Hanover Street

Portsmouth, New Hampshire 03801

Bob James, Exec Director

Cathy King, Associate Executive Director

Phone: 436-6111 **Fax:** 436-4622 **e-mail:** bob@cdsregion8.org**All of the following can be reached at 436-6111:****Family support & Early Supports and Services:**

Lenore Sciuto lenore@cdsregion8.org

Respite coordinator: Geoff Simons geoff@cdsregion8.org**Resource coordinator:** Judy Saddler judy@cdsregion8.org**School to Adult Transition Coord.:** Raymond Pillsbury:

raymond@cdsregion8.org

Benefits technician: Denise Larsen 436-6111 denise@cdsregion8.org**Family support council chair:** Kathy Ennis 964-9740**REGION XII****Grafton County** (serving Grafton, Canaan, Enfield, Lebanon, Hanover, Lyme and Orford)**United Developmental Services**

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

Bruce Pacht, Exec Director

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

104 Lyme Road, Hanover, New Hampshire 03755

Kathy Marshall, Coordinator

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

elizabeth.s.larsen@hitchcock.org

Upper Valley Support Group (UVSG) (provides emotional support & info)**Phone:** 448-6311 **UVSG Respite 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

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

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

Brain Injury Association of New Hampshire
225-8400, or (800) 773-8400
www.bianh.org

Statewide organization provides resource information to survivors of brain injury and their families.

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

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

Council for Children and Adolescents with Chronic Health Conditions and their Families
271-4991 or 1-800-852-3345
Fax: 271-5166
email: pclarke@dhhs.state.nh.us
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
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 www.eein.org
email: info@eein.org
Information/referral; early intervention and pre-school pro-

grams for children with developmental disabilities or at risk for developmental delay.

Family Resource Connection
1-800-298-4321
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 5057
kbregler@dhhs.state.nh.us

Can direct you to services available through the Division of Developmental Services (DDS), the 12 Regional Area Agencies and Regional Family Support Programs

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

VSA arts of New Hampshire
228-4330
email: info@vsarts.org
website: www.vsarts.org
Provides opportunities in the arts for people with disabilities



Where to Find Help

Helpful Websites:

www.aapd.com

American Association of People with Disabilities

www.access-able.com/

Access-Able Travel Resource

www.adanet.org

American Disability Association

www.albinism.org

The National Organization for Albinism and Hypopigmentation

www.allsupinc.com

Healthcare and Disability Reimbursement Services

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

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

www.assistguide.com

Assist Guide - National resource for disability and long term care

www.csni.org

Community Support Network, Inc.

www.disabilityresource.com

The Disability Resource

www.eseals.org

Easter Seals NH

www.essential schools.org

Coalition of Essential Schools

www.hcfa.gov/

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

www.hhs.gov/newfreedom/

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

www.newhorizons.org

New Horizons for Learning

www.nhhelpline.org

New Hampshire Help Line

www.nod.org

National Organization on Disability

www.ppcd.org

People to People Committee on Disability

www.sath.org

Society for the Accessible Travel & Hospitality

www.ssa.gov.SSA_Home.html

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

Publications of Interest

Common Sense

Paid subscription (\$15.00 for individuals, \$30.00 for organizations)

Published by the National Program Office on Self-Determination; three times a year

Send in check to: Common Sense, 3700 Riverside Drive, P.O. Box 21322, Columbus, OH 43221-0322

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

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.

Pass It On

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

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

BarrierFree Travel

A Nuts & Bolts Guide for Wheelers and Slow Walkers

by Cindy Harrington, editor of Emerging Horizons,

is a useful resource which contains detailed information about the logistics of planning accessible travel by plane, train, bus and ship.

A great resource for wheelchair or scooter-users, slow walkers, travel agents, CILs and libraries, it is filled with worldwide resources, travel tips, and updated information about accessible travel options.

Topics include: the ACAA and air travel, protecting your wheelchair, traveling with oxygen, how to advocate for yourself, cruising, finding a travel agent - do you even need one?, accessible ground transportation tips, accessible recreation options, budget travel, finding an accessible room, and much more.

To order your copy, call (888) 795-4274 or (215) 923-4686. Or visit EmergingHorizons.com/book

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Upcoming Events

Educational Surrogate Parent Training

Parent Information Center (PIC)

Where: Concord

When: July 27 8:30 am - 5:00 pm
August 19, 20 & 22 6:00 - 9 pm

No cost

For more information, call 1 (800) 232-0986

Autism: Differential Diagnosis and Comprehensive Treatment Approaches

presented by: Neurodevelopmental Institute of New Hampshire

Where: The Puritan Back Room Restaurant, Manchester, NH

When: Wednesday, July 24

Cost: \$120.00

For more information, call (603) 669-1417

Set Your Sights a Mile High

National Down Syndrome Congress conference

Where: Denver, CO

When: August 23 - 25, 2002

Cost varies depending on number of days/events

attending

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

Access Expo of Northern New England

A complete showcase of adaptive products from common everyday items to the extraordinary for people of all ages

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

When: Thursday, September 5, 10:00 am - 5:00 pm

No pre-registration

Everybody welcome!

For more information, call 1-800-826-3700 V/TTY or go to this website: www.gsil.org

AAMR / Direct Support Professionals Conference

Where: Holiday Inn in Manchester, NH

When: October 24 & 25 for AAMR conference

October 25 & 26 for Direct Support Professionals Conference

For more information, call 225-5870

SouthEast Augmentative Communication Conference

Sponsored by United Cerebral Palsy of Greater Birmingham, Inc.

Where: Birmingham, Alabama

When: October 3 - 5, 2002

Cost: \$275.00 (before September 13)

\$350.00 (after September 13)

For more information, call 1-205-251-0165, ext. 234

Change and Exchange of Information

The Landscape of Rehabilitation

sponsored by: New Hampshire Rehabilitation Association

Where: Holiday Inn - Center of NH, Manchester, NH

When: November 7 & 8, 2002

For more information, call (603) 669-8733 or visit the website: www.nj-ra.org



Do you know someone who could use The Challenge?

Send us their name and address so they, too, can receive this important source of information.

Name _____

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City _____

State _____

Zip _____

I would like to make a tax-deductible donation of _____ to support The Challenge.

Name _____

Address _____

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