History has shaped who we are today. It is important that we remember that each of us steps into a stream of history whose origins lie just beyond our immediate sight, and that we are not starting a journey so much as joining one. We must not forget the events that shaped the lives of countless people over the last century.

This issue is devoted to the history of the disability community in NH. We can better understand the events of today when we look at them in the context of the past. As Jean-Paul Sartre said: "Those who ignore the past are condemned to repeat it."
The New Hampshire Challenge is a quarterly publication which disseminates in-depth information on disability issues from a family perspective. Printed items do not necessarily reflect the views of The Challenge or its publisher, The New Hampshire Challenge, Inc. The Challenge reserves the right to exercise editorial judgment in the selection and publication of materials.

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The New Hampshire Challenge is printed four times a year, and welcomes the submission of articles. Copy must be typed and may be mailed, faxed or e-mailed. Pictures are welcome. Questions should be directed to the editor.

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The following document was submitted to the House of Representatives by representatives of the Federation of Women’s Clubs on February 14, 1901. Introduced by Chuttes Littleton, it was referred to the Committee on Education for action:

The laws of New Hampshire require that every parent or guardian of any child of schoolage “shall cause such child to attend school twelve weeks each year, six of which shall be consecutive, unless such child shall be excused from attendance by the school committee of the town or the board of education of such district, upon its being shown that the physical or mental condition of such child was such as to prevent his attendance at school for the period required....” Chap.XCL, Sec.14

Provision is made for the proper education of the normal child, but for the deficient child against whom the doors of the public schools are necessarily closed, no opportunity is offered whereby the dwarfed and latent mental faculties, its unhappy birthright, may be awakened and trained, as scientific investigation has conclusively demonstrated may be done. The State indeed recognizes that it has an obligation to this deficient class, of whom there are in the state of New Hampshire to-day according to the best statistics obtainable, about 250, for annually one-thousand dollars has been appropriated since 1879 to care for three of these children at the Massachusetts School and Home for the Feeble-Minded.

As a simple act of justice, is it right for the State, the guardian and protector of all its citizens--its children--to discriminate wholly in favor of those who are well endowed, and cast off those, who through no fault of theirs, are lacking in mental equipment? Furthermore, as an act of self-protection, is it not the part of wisdom to guard society from the crimes, the vice, and the immorality of this degenerate class, who with their weak will power and deficient judgment are easily influenced by evil? “As a matter of mere economy,” so states a modern authority, “it is believed that it is better and cheaper for the community to assume permanent care of this class before they have carried out a long and expensive career of crime.” In view of these facts, We, the undersigned, members of the New Hampshire Federations of Women’s Clubs, do most earnestly call the attention of the New Hampshire Legislature now assembled to the great need in our state of a School and Home for the Feeble-Minded and do urgently request that your honorable body give the matter your careful consideration and make such appropriation as shall be necessary for such a school.

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In 1901 legislation was passed that created the New Hampshire School for Feebleminded Children. The original law affected only those children considered feebleminded between the ages of 3 and 21. Subsequent amendments to the law broadened the eligibility, first to include girls over the age of 21, then to include any feebleminded people of any age.

An examination of the forces that led to the creation of Laconia State School demonstrates that how problems are defined in our community (and society at large) often shapes the solutions.

**Background**

As the document on page 2 indicates, there were two prevailing schools of thought regarding what was then termed "feebleminded" people. Several well-respected professionals had demonstrated that feebleminded people could be taught, and benefit from an education. In his book, *Wild Boy in Avignon*, Jean Itard of France described educational methods for children who were feebleminded. Eduard Seguin, also of France, used sensory activities to teach feebleminded children, and advocated that they live at home and have educational expertise available.

Samuel Gridley Howe founded the first public program in the U.S. for children with mental retardation. Located in a friend’s house in Massachusetts, the program taught 8 teenage boys functional skills. They were required to live in a special home for one year while receiving the education.

With the success of the program came the demand to help more children and the size of the house was expanded to serve 100 children, changing the nature of the endeavor from a project rooted in a community’s response to a state’s bureaucratic intervention.

In 1860, Howe abandoned his work in frustration. Commenting on his experience, Howe said: "Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other, and equally important, half.”

**The Eugenics movement shapes the debate**

At the end of the 19th century, the eugenics movement came into prominence. Inspired by the work of Charles Darwin, eugenics advocated improving the inborn qualities of the human race. That meant eliminating the bad qualities.

"Feeblemindedness", for the eugenicists, was a condition that was hereditary, and involved not only impaired cognitive functioning, but also impaired moral functioning as well. Feeblemindedness was seen as the root cause of all social problems: adult crime, sexual immorality, juvenile vice and delinquency, and the spread of venereal disease. (The 1910 report of the Trustees of the New Hampshire School for the Feebleminded incited this observation: "...in 1900 the legislature awoke to the fact that there were in this State between two and three hundred such children who were growing up ignorant and vicious, a constant menace to the community...".)

The solution for these problems, then, was the segregation of feebleminded people and the creation of measures which would prevent such people from having children. In a 1915 report of the Children's Commission to the Governor and Legislature, the authors quoted a report from the Virginia State Board of Charities to support its recommendation to segregate feebleminded women:

"In view of these facts it is apparent that our great problems of crime, insanity, and the social evil are inseparably intertwined with the problem of feeble-mindedness. Whatever progress we may make in the treatment of criminals there can be no great reduction of crime so long as we ignore the fact of criminal inheritance, and whatever we may do toward the actual solution of these problems, so long as we make no attempt to stem the appalling tide of feeble offspring that is increasingly pouring forth from our large and evergrowing class of mental defectives. So far as modern investigation enables us to see, the most pressing social need of our time is the segregation of the feeble-minded."
inmates to be placed in almshouses. Prior to the creation of the Superintendent's house (which also served as the dining room for the children), a brick dormitory building for boys and girls, and a school building. The first Superintendent was Dr. Charles Sherman Little, a nationally prominent physician.

By 1906, there were 82 "inmates" (no longer referred to as "children"), and there was a waiting list of 117 children. Of the 82 people at the School, 57 came from the almshouses, and 25 came from homes. Prior to the opening of the New Hampshire School for Feebleminded Children, most children with mental retardation lived at home. It was only the poor children who were considered a disease that was hereditary.

In the 20th century, the I.Q. test was developed. It was the first instrument to measure a person's intelligence. The first use of the Binet I.Q. test in the United States was in a state institution for feebleminded people in New Jersey. The test was heralded for its accuracy and its validity, and became a widely accepted tool for determining who was feebleminded. New professionals had a means to scientifically identify feebleminded people.

In 1915, New Hampshire passed legislation which regulated the marriage of people considered "mentally deficient." The law stated: "No woman under the age of forty-five years, or man of any age, except he be married a woman over the age of forty-five years, or either of whom is an epileptic, imbecile, feeble-minded, idiotic or insane person, shall hereafter intermarry or marry any other person within this state."

The law also stipulated that no clergyman or other officer authorized by the state to solemnize marriages be allowed to perform a marriage ceremony for such people, nor could a city clerk issue a marriage license. Anyone violating this law was punishable either by fine or imprisonment, or both.

This effort to prevent feeblemindedness from reproducing was expanded to include sterilization. In 1917, a law was enacted which permitted sterilization of people who were diagnosed as feebleminded or having mental disease. Initially, a person could not be sterilized without his or her consent, and the consent of the nearest relative or guardian. Later, this was amended to permit the decision-making authority in the hands of the Board of Trustees and the physicians, and the consent of the individual was no longer needed.

It is interesting to note that the marriage and sterilization laws passed in the United States were the models upon which Hitler fashioned the German laws of race purification.

So there were two schools of thought about feebleminded people: they could be taught, and they should be segregated and prevented from reproducing in order to protect society. This was the climate in which the New Hampshire Home for the Feebleminded was created.

New Hampshire events leading to the legislation

Prior to the creation of the School, many feebleminded children lived in "almshouses," or county farms (predecessors to today's county nursing homes). Also living in the almshouses were paupers, yesterday's homeless people. Pauperism, at that time, was considered a disease that was hereditary.

In 1893, there was a devastating fire at the Strafford County Farm, killing 41 or 44 "insane" people. A huge controversy arose about the conditions in the almshouses, particularly for children.

In 1895, legislation was passed to provide for the education and maintenance of dependent children. As a part of that legislation, a state Board of Trustees and Corrections was created to oversee the care of dependent people in the state who were housed in county farms. The Board recommended that radical changes were needed in the methods of caring for the poor and the mentally ill.

In 1896, a survey was done and it was reported that 420 children lived in almshouses. Within two years, all but 60 of those children were moved into foster care. Those 60 were feebleminded children. "Children 3 to 15 shall not be supported in the almshouse unless mentally incapacitated for education," read the legislation which created the Board of Trustees and Corrections. Not considered appropriate for foster care, feebleminded children, as well as special classes in school wherever feasible for all backward children.

After the legislation was passed in 1901, communities around the state lobbied to have the institution located in their communities. It was considered very prestigious. Laconia was chosen for the site and the doors of the institution opened in 1903.

The Institution opens its doors

The site consisted of 250 acres of land, and three buildings: the Superintendent's house (which also served as the dining room for the children), a brick dormitory building for boys and girls, and a school building. The first Superintendent was Dr. Charles Sherman Little, a nationally prominent physician.

By 1906, there were 82 "inmates" (no longer referred to as "children"), and there was a waiting list of 117 children. Of the 82 people at the School, 57 came from the almshouses, and 25 came from homes. Prior to the opening of the New Hampshire School for Feebleminded Children, most children with mental retardation lived at home. It was only the poor children who were considered a disease that was hereditary.

The marriage and sterilization laws passed in the United States were the models upon which Hitler fashioned the German laws of race purification.

Genetics "research"

In 1912, the results of a study begun in 1906 of the hereditary nature of feeblemindedness were released. This study, conducted by the German physician, was considered a definitive proof that feeblemindedness was an hereditary trait.

Done in New Jersey, the study traced two branches of a family whose female descendant was living at the Training School for Feebleminded Girls and Boys in Vineland. Despite later professional criticism of the research methods and conclusions drawn, the study captured popular attention and a social myth was created that had ramifications in public policy.

This type of research was not unique to New Jersey. New Hampshire was conducting similar research of its own. In the 1910 Superintendent's report to the Board of Trustees, Dr. Baker reported: "..one of the improvements within which I want to call your attention, and which I hope is only the beginning of further research along..."
There was very little privacy. There were no stalls in the bathroom and often not even seats on the toilets. In one building which housed 80 people, there was only one toilet with a pull chain, and a pipe jutting out of the wall for use as a shower. Inmates were hosed down in communal showers and personal hygiene was poor. The outstanding characteristic of the institution was the overwhelming stench.

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Parents organize

Parents of residents at the School, under the tutelage and with the support of Hungerford, organized and created the New Hampshire Council for Retarded Children in September, 1953. In addition to this State Council were born loosely organized regional groups: the Keene Association, the Great Bay Association, the Nashua Regional Unit, the Manchester Unit, and the Exeter Unit. These groups were the predecessors of the New Hampshire Association for Retarded Citizens (later known as The ARC) and its regional chapters.

The parents’ group became a powerful force advocating for improvements at Laconia State School and in the communities. Through the use of the film mentioned above, the parents brought to the attention of the public the terrible conditions at the school. They hosted conferences which focused on how to organize existing resources into a statewide program for the mentally retarded. They developed out-of-state associations with other

Hungerford and the parent movement - agents of change

In 1953, change arrived in the person of Richard Hungerford, the new Superintendent. For the first time, the superintendent was not a medical doctor, but a teacher. He brought a change of philosophy and began a reform movement. His tenure lasted only seven years, but the movement he inspired and facilitated planted the seeds for the lawsuit that would occur twenty years later.

Instead of discouraging parents from visiting the School, Hungerford invited them in. He was one of the first persons in the nation (the first in New Hampshire) to recognize the potential political power of parents as reform agents, and helped them to organize.

He even invited parents to film the institution, and a newly created parent organization, the Great Bay Association, did just that. In 1956, they made and paid for a film of the Laconia State School as it was in the early fifties, and showed it to community groups throughout the state.

This disclosure of conditions at Laconia State School happened at the same time that the world was discovering the true extent of the Nazi atrocities in Germany, and the two events became linked in the public mind. When pictures of conditions at the Laconia State School were published by the Portsmouth Herald, public reaction was that it looked like Nazi Germany, and there was a demand to “do something.”

“...you must have the facts. Maintaining a parents’ organization is your responsibility; giving you the facts is mine.”

Richard Hungerford, Superintendent, Laconia State School 1953-1960

Chemung Cemetery

Since 1941, this has been the final resting place for those who spent their lives at Laconia State School. The headstones are all flat in the ground so there is no visible sign from the road hinting at the purpose of this hallowed ground, save a statue which has been relocated from the front of the grounds of what used to be Laconia State School.

Change...and reaction

Meanwhile, under Hungerford’s direction, physical changes at the school were taking place consistent with his philosophy. Two cottages were built, which were more home-like. There were censures on the windows, room for private possessions, bedrooms for 2 or 3 people instead of large groups. He instigated co-educational activities for the residents, and succeeded in having a gymnastics building built.

Hungerford inspired admiration and support from the parents, but, as time went on, the legislature did not look kindly upon what were considered his “radical ideas.”

In the History of the Early Years of the New Hampshire Council for Retarded Children, 1953-1960, Edna St. John wrote: “When (Richard Hungerford) came to New Hampshire in 1953 he was hailed with hosannas. Then, as his total professional and moral commitment to the retarded came to be understood, he was looked upon with wariness, and finally and tragically with hostility. In the main, New Hampshire’s bureaucracy felt no moral commitment whatsoever to the retarded and from now on it was going to keep a close rein on its financial commitment. The accolades had turned to venomous criticism.”

Reform was here to stay

But 1960 was the year John F. Kennedy was elected President. President Kennedy drew national attention to the plight of people with mental retardation because of his family’s personal experience with his sister Rosemary.

The President’s Commission on Mental Retardation was created, and federal funding became available for research projects designed to improve conditions at institutions and develop community services for people with mental retardation. There was increased national attention and energy focused on the problem.

At this time, Laconia State School had a new superintendent, Arthur Toll, an educator from the Berlin School District. Under Toll’s administration, the emphasis on education continued, but was somewhat tempered because of the fallout from Hungerford. Despite these efforts, the medical
History

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mindset was firmly entrenched. Therapies were the prevalent program for residents, and medication was frequently used to control and make people fit into a norm.

In 1961, the Board of Trustees was more interested in making changes in the legislature and more power was concentrated in the hands of the superintendent and the Department of Health and Welfare. As the institution grew, familiar components disappeared. In 1962, the farm program was shut down, and in 1970, the dairy herd was sold. The more capable people went into community placements, leaving behind those with more severe disabilities. A Work incentive program was established that was based on a developmental theory of learning and a small portion of people worked in sheltered workshops.

The number of residents continued to grow. In 1962, there were 790 residents; in 1974, there were 1,000 residents, with a waiting list of 400.

On the federal level, increased funding became available from numerous sources. The Hospital Improvement Grant was a federal effort to develop model programs in institutions. Title I funding became available to provide educational services. The Developmental Disabilities Act was passed and with it came funding to the states.

Protective laws passed

In 1975, the New Hampshire legislature passed a law (RSA 171-A) which mandated "the Division of Mental Health to establish, maintain, implement and coordinate a comprehensive service delivery system for developmentaly disabled persons."

It was this law which created area agencies, defined eligibility, and guaranteed certain services to eligible clients. The service delivery system mandated by the law included Laconia State School as well as community agencies, and mandated that each client in the system have an individual service plan.

It also guaranteed that:  "Each developmentally disabled client has the right to adequate and humane habilitation and treatment including such psychological, medical, vocational, social, educational or recreational services, as his condition requires to bring about an improvement within the limits of modern knowledge."

At the same time that the bill was being debated in the legislature, Michael Dillon, a Superintendent of the Central Connecticut Regional Center, was invited to Laconia to make recommendations on how to improve the program. His observations reflect the bleak atmosphere of the School. Despite the gains occurring by the lobbying efforts of the parent movement, living conditions at the school remained desolate. Buildings were old, time lacked privacy, needed renovations. Resources were few, clothing sparse, shoes almost non-existent. Understaffing was rampant, turnover frequent, burnout the norm. Education programs were limited, arbitrarily offered, poorly organized. The entire School had one Speech Therapist and one Audiologist. Recreational services were few and did not serve all residents.

Dillon ended his report with the following remarks: "In the end, however, while federal funds may lighten the cost, the New Hampshire must consider: what it will provide to its handicapped citizens. Will it tolerate its citizens to live in a barren, sterile environment, devoid of stimulation? Will it seek to find a better, more humane way of providing for them?"

"The issue then is apparent. What needs to be done is known. That it is costly is true. Who will take the initiative?"

Parents resort to a lawsuit

The same year the report was submitted, parents put more pressure to improve conditions. Parents invited the community in to see the institution. Jack Mellon, the new Superintendent, was appointed to clean things up and get things back on track.

He implemented the Intermediate Care Facility for people with Mental Retardation (ICF-MR) funding system, purchased adaptive equipment and increased the number of occupational, physical, and speech and language therapists.

He invited the Foster Grandparent program into the School, which augmented the efforts of the staff. Holidays became times of great celebrations for the residents. More volunteer programs arose.

Residents were getting services, especially education. There was more community placement (but not much follow-up). Despite the fact that from 1974 to 1979, New Hampshire moved from 44th in the nation in its daily spending for children to 5th in the nation, conditions were still not optimal.

On April 12, 1978, parents took a major step and filed a class-action lawsuit against the State of New Hampshire. (At this point there were 1,100 residents with 500 staff working three shifts.) The grounds of the lawsuit were that New Hampshire had violated its own law (recently passed RSA 171-A) for the provision of a minimum amount of services. Additionally, and perhaps more importantly, the suit charged that New Hampshire was in violation of the U.S. Constitution. "The complaint alleges widespread deprivations of (the residents') rights to freedom from harm, and to habilitative treatment in the least restrictive setting under the eighth and fourteenth amendments."

New Hampshire was not the first state to file such a lawsuit. As conditions at similar institutions around the country were being revealed, parents groups around the state and in New Hampshire sought solutions. Will it tolerate its citizens to live in a barren, sterile environment, devoid of stimulation? Will it seek to find a better, more humane way of providing for them?"

"The issue then is apparent. What needs to be done is known. That it is costly is true. Who will take the initiative?"

Concurrently with the lawsuit, the state developed a plan called Action for Independence which called for an expansion of community services and created the area agency system as we know it. Standards regulating that system, however, were not established until 1984.

Because of the lawsuit and the resulting court order, improvements were made to the physical plant at Laconia, and the numbers of staff were increased. Staff training was implemented, using Social Role Valorization and normalization as the guiding principles.

Alongside the efforts to improve the conditions at Laconia were efforts to build an effective community based system. Community Care Waivers allowed Medicaid funding to be used for placements in the community, when previously, all Medicaid funds were used exclusively to provide care in institutional settings.

In 1986, Rich Crocker became the last Superintendent at Laconia State School, It was during his administration that the institution was slowly and carefully downsized to the extent that the Governor announced it was not economically feasible to keep it open any longer.

On January 31, 1991, the doors of the institution closed for the last time.

An excerpt from Fred Smith's remarks at the official ceremony commemorating the Closing of Laconia State School, June 20, 1991.

"...it took a lot of courage on the part of parents of residents at LSS to support the closing of this institution. Many feared the possibility of state and federal funds drying up, day programs and residential services ending. Times were and are still very uneasy.

These parents are the pioneers who blazed the trail and made it so much easier for the parents of today's developmentally disabled children. These parents will never know the pain of having to place a child in an institution. I hope they know the joy and understanding how far we have come and what we all went through.

If our efforts had touched only one child, it would have been enough. The extraordinary thing about our accomplishments, parents together with legislators, state workers, and advocates, is that we did not touch one child. We changed an entire state. And by example we have changed other states as well.

To those here today who hold the parse strings for the State of New Hampshire, a gentle reminder to you that the closing of this institution has brought about substantial savings - that you have a moral obligation to ensure that additional dollars follow the individuals, with the argument based on humanity and better habilitation that is offered in the community. If anyone is thinking of cutting money out of the budget for services to the developmentally disabled, I respectfully suggest that you don't try it. The alternative is having cost-effective community programs live in the humiliated halls of this institution.

Each of us can come here for a different reason. I'm here because I'm glad to see an end to this chapter of our history. Never shall I forget the grim reality of what happened just 13 or 14 or even 5 years ago. Never shall I forget the little faces of the children whose faces were just captured here.

We must not forget that there once was a place called Laconia State School and Training Center. For those who know who of us here to take time reminding us of what it was like to live in Murphy, Powell, Fisher, Bland, Baker and Floyd. For those who don't, I assure, we need to keep this alive to remind everyone that institutions must never be a way of life for anyone ever again.

Our work is not over. I ask each and every one of you to recommit yourselves to making a better place for our children to grow in. I ask each of you to join me - to look ahead - to work hard in the present, but NEVER FORGET THE PAST.
"You live in the times where you are and you do the things that are necessary for that particular time of life," Vera Hill explained as she recounted the story of her daughter Sally. "We did what was necessary."

What was necessary back in the 1940's seems almost unimaginable today, with the legal protections accorded to people with disabilities under the Americans with Disabilities Act, the Rehabilitation Act, and the Individuals with Disabilities Education Act. None of that existed when Sally was born in 1943.

It was wartime. Sally's father, George Hill, was in the navy when Vera, who was pregnant with her second child, began the search for reasons why Sally's development was suspiciously slow.

There weren't many doctors, Vera recalled, because of the war and the doctors who were available were so overworked that they didn't spend much time with their patients. Even so, Vera was not prepared for the reaction of her doctor when she raised concerns about Sally's development. "He laughed at me," Vera remembered. He called her a "worrisome patient" and attributed Vera's concern to the overanxiousness of a new mother. Vera never returned to him.

She found another, more sympathetic doctor, Dr. Albert Barcomb, and when Sally started having seizures, this doctor succeeded in getting Sally admitted to an impatient at The Children's Hospital in Boston for an evaluation. This was no easy accomplishment. Coupled with the scarcity of doctors was the polio epidemic, which was at its height, and the hospitals were filled with polio patients.

So Vera, who had no car, whose husband was somewhere in the South Pacific, who had returned to New Hampshire from Harrisburg, Pennsylvania when her husband was sent overseas, and who was in her third trimester of pregnancy, went to Boston. By this time, Sally's seizures were so frequent that Vera padded her playpen to prevent her from being injured.

Vera called the Red Cross to contact her husband about the situation, but was told he could not be located. Meanwhile, after exhaustive tests, Sally was diagnosed with brain damage and epilepsy. She had been a "blue baby" at birth. "If she had been given oxygen, she would have been okay," Vera remembered being told.

Her lifetime was her husband's mother and father, Harry and Eva Hill, who provided the emotional and practical support her absent husband could not. Hospital rules were very strict then. The only visitors allowed were birth parents. The Hills willingly drove Vera to Boston and waited patiently while she visited with Sally. Vera, however, successfully talked the nurses into allowing her in-laws to visit. She credited her advanced state of pregnancy as the determining factor in that change of heart.

The focus of the medical community in those war years was on the soldiers who were coming home with injuries. Because of the increasing numbers of men with head injuries and resulting brain damage and epilepsy, there was more demand for new and effective treatments for epilepsy. Dr. William Lennox, of The Children's Hospital at Boston, was testing a new medication for epilepsy, and Sally benefited from this research by becoming one of his first patients. Sally was discharged with a prescription for this new medication.

At first, there seemed to be no improvement, and not long after, she had a reaction to the medication. But the doctor advised Vera to continue, believing the setback represented an adjustment to the medication. Eventually, the medication started to work, and Sally started to improve. "But she never did things like she was supposed to," remembered Vera.

In the midst of dealing with this, Vera was scheduled for a Cesarean operation. She was apprehensive and worried that her second baby would be born needing immediate attention, as did Sally. Her doctor assured her that whatever attention the baby might need, he would make sure it was given. And, indeed, there were medical personnel waiting, particularly in case the baby needed oxygen. Fortunately, Michael was born healthy, with no complications. But Vera will always remember the sensitivity of this doctor to her concerns.

About two weeks after Michael's birth, George came home. He had received no news since being informed about Sally's seizures. He didn't know whether Sally had died or come home from the hospital, Vera recounted. He didn't even know that his son had been born.

Now the family was reunited, and George and Vera began their search for whatever could help their daughter. The resources in the area were few. Vera remembers having to take Sally to Boston for blood tests once a month to measure the levels of the new medication in her system.

There were clinics in the area, Vera remembered, and a rehab center in Portsmouth, but these were outpatient departments that did mostly evaluation and some therapy. "I took Sally to every clinic and every doctor there was to have her tested and find out what we could do with her," Vera recalled. "I don't know how many places we had her for evaluation."

Their search eventually took them beyond the borders of New Hampshire to the Naval Hospital in Philadelphia, a doctor in Baltimore (whom they continued to see for about three years), and even to a program in Kansas.

They tried every program that offered any hint of help for their daughter. The doctor in Baltimore, who specialized in working with people with cerebral palsy and mental retardation, focused on setting the dominance in the brain. "We had to test her over so many weeks," explained Vera, "and keep records of which hand she used picking up objects." The doctor decided that the right side of her brain was dominant. "I made little sleeves (in her clothes) to slip over her right hand so that she would have to use her left hand," Vera recalled. The day Sally pulled herself up in her playpen seemed like a day of victory.

The Hills held no expectations that Sally would be allowed to enter school in Dover, where they lived. "There was no school available for children with disabilities." Vera stated simply. But they wanted to help Sally learn how to talk. Through an ad in a magazine, they learned about a place called the Institute of Logopedics in Kansas, and made an appointment for their daughter.

It was the middle of winter when Vera boarded a propeller plane with Sally to fly to Kansas. During the flight, they hit a snow storm and were forced to land in Chicago. Since flying was out of the question, Vera and Sally boarded a train for the rest of the journey.

Vera and her three year old daughter finally arrived in Kansas for their appointment. After the evaluation, Vera learned that the program Sally had been accepted into was a part-time program. Vera and Sally would have to live in a hotel and Vera would have to take her in for treatment every day. Michael, then one year old, was back in New Hampshire with his father and grandparents. "I couldn't do it," Vera stated flatly.

This experience forced Vera and George to look at what they were doing and what exactly they were accomplishing. "You get to a point," Vera reflected, "where you realize you're not really accomplishing anything."

Back at home in New Hampshire, the Hills began to hear about a couple in Durham, the Stalworthys, who had a son with Down syndrome, who were starting a parent group. They joined them, and

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Sally a chance to adjust. Sally attended the Kennedy school for two years, at a cost to the Hills of $25 a week. What was so exciting for Vera and George about this school was that Sally actually attended classes. She was learning. "She didn't feed her self when she went in at the end of summer," recalled Vera. "But when we had her home for Thanksgiving, she was feeding herself."

Vera and George visited Sally every other week and each time they visited, a Sister would say: "Sally, show your mom what's on your desk." Vera remembers that Sally would go directly to her desk and eagerly point out her latest accomplishment. "They (the Sisters) taught Sally many things," Vera reminisced.

It came as a surprise, then, and a great disappointment when the Sisters informed the Hills that Sally would have to leave after two years. "They said she had reached her fullest potential," Vera recalled sadly. Though Vera did not agree with their assessment, she had to accept the fact that Sally would have to attend a different school.

Sally was too young for this school, but were referred to a school in Brighton that accepted children Sally's age. So, on the way home, they decided to take a detour to Brighton.

Vera remembers sitting in the car with George across the street from the building and both of them thinking: "We'll never take Sally. It was Catholic...we're not Catholic."

Vera recalls George suggesting that they go have a look anyway, and they climbed out of the car and went up to the front door.

"It was wonderful!" remembered Vera. "They showed us around. It was new, it hadn't been open very long. They took Sally and showed her around."

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Sally was six years old then, still not talking or even feeding herself. She had never been away from home before. Her mother, Eva, was elected School Secretary and Memorial School required her to live away from home. "It was terrible to leave her," remembered Vera. "She couldn't talk...it was very bad." They were told to wait a couple of weeks before visiting to give

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Once there was a place called Laconia...

By: Freda Smith

Once there was a place called Laconia State School and Training Center. The very name was deceiving - there was no schooling; there was no training. People just existed in that sterile environment. In reality, it was a warehouse for human beings - and such an insult to humanity.

The LSSTC was founded in 1901 as the NH School for the Feebleminded. My youngest child Janet was born on August 30, 1961. She was 2 1/2 months old when she displayed signs of having serious problems. Once when I was bathing her, Janet suddenly began trembling, making odd little sounds and her eyes were darting very rapidly.

I drove Janet to the hospital immediately. After a brief examination, I was told that I had to take her to Children’s Hospital in Boston. So I did. There she remained for two weeks.

The day before she was to be discharged, I was called down to the doctor’s office and given her diagnosis. I was told that Janet had severe damage to the right side of her brain, and because of that, she had epilepsy. Her trembling resulted from brain seizures. Her right eye was 1/3 smaller in circumference and had no optic nerve, so she had no vision in that eye.

I was told that she would be nothing but a vegetable. The doctor recommended that we institutionalize her and forget about her.

In a state of shock, I couldn’t believe that a doctor could be so insensitive. I cried all the way home.

We brought Janet home, determined to do all we could to make her life as comfortable and meaningful as possible. The whole family - her father, sister, brother and I - worked with her everyday trying to teach her how to walk, how to drink from a glass and how to feed herself. Janet did learn how to walk a little, but she never mastered the art of drinking from a cup or feeding herself.

She was a hyper-active child. She didn’t sleep much - just catnapped. I knew nothing about mental retardation or disabilities. There were no services, no support system, no programs available in the community for individuals with developmental disabilities. There was no one for me to talk with.

The continuous care Janet needed eventually took its toll on me both mentally and physically, and I was hospitalized.

Janet was placed at LSSTC at that time. She was 5 years, 2 months and 19 days old.

Conditions at the institution were deplorable. In 1962, there were 900 residents at Laconia. By 1974, there were 1,000 with a waiting list of 400. Staffing was inadequate, with a ratio of 15-20 residents for every staff person trying to provide care. Turn-over was high.

I joined the Board of Directors of NH ARC in Concord. Other parents of residents at LSSTC also served on the Board. I met the parents of a young man who resided in the same building as Janet. Every time I saw the mom, she would say, “Mrs. Smith, we have to do something about this place.”

I avoided her like the plague, knowing fully well what would happen if I got involved. And it did.

Our many concerns regarding the care of our children - lack of care was more like it - were brought up to the full Board. On August 14, 1974 members of the Board met with the Acting Superintendent of LSSTC, followed by a tour of the buildings on campus. A fact list was compiled listing the deficiencies with hopes that this would bring about some necessary changes. The rest is history.

Letters to the editor written by some parents began to appear in newspapers all over the state. I was at the State House so often that people thought I was a legislator long before I got elected. We spoke to civic and church groups and conducted tours of the institution in an attempt to educate the public about what life in an institution was like.

I wrote a letter to the Justice Department asking for an investigation of Laconia. Another parent and a grandparent signed the letter with me. The Justice Department agreed to conduct an investigation.

NH Legal Assistance, after much prodding, agreed to file a class action lawsuit on behalf of the residents at LSSTC. Janet was one of the six named plaintiffs.

The Mental Health Law Project of Washington, D.C. contacted me and asked if I could arrange a tour of the institution for them. They were interested in pursuing the possibility that abusive amounts of psychotropic drugs were being administered to the residents. Amazingly, staff at the institution opened the meds books to the attorneys, proving their suspicions correct. This was exactly the proof for which they had been looking - for a long time.

The Mental Health Law Project did join the lawsuit, but not for long. The parent organization gave them a $3,000 retainer fee. Then NH Commissioner of Mental Health and Developmental Disabilities - Gary Miller - who had been an expert witness for them on several occasions, convinced them to drop out of the lawsuit. We never got our retainer back.

The lawsuit was filed on April 12, 1978 and the trial opened two years later in Federal Court in Concord. We brought Janet home before the trial started because we feared for her safety. She had many unexplained bruises and cigarette burns on her hand, and she had regressed and was no longer walking.

The trial lasted 10 long weeks. I testified, as did other parents and staff. I sat in that courtroom every day of the trial. There were many days when John Distaso, a reporter from the Manchester Union Leader, and I were the only people in the courtroom besides the attorneys, the witnesses, the judge and his staff.

Not everyone agreed with the lawsuit. Some parents were concerned that if their son or daughter was released from Laconia and sent back to their home community, future federal and state funds could dry up. Group homes would have to close, forcing them to take their family member back home. Many were elderly, sickly and unable to care for themselves, let alone take on more responsibility. Returning from a vacation, I found out that a group...
of parents had circulated a petition demanding improvements at Laconia at the same time stating their opposition to its closure.

Judge Shane Devine handed down his decision on August 17, 1981, a year and a half after the trial ended. He did not order the closing of the institution, but he did order the State to educate every resident of LSSTC in the least restrictive setting possible. He also embraced a plan to develop alternatives to institutional care which became the cornerstone on which the current service system was built. Twelve Area Agencies were formed and the exodus from the institution began.

Janet's health has always been delicate. She did return to Laconia for a short while. The medication for her seizures had been changed and she had become very lethargic. We were very concerned, and when visiting her one Sunday, we decided to take her directly to Children's Hospital in Boston. She was treated there for dehydration and released. We brought her home - never to return to Laconia again. She was formally discharged one year later.

The Salem ARC got a grant from HUD to build an 8 bedroom home that would house individuals who would be returning from LSSTC to their community of origin. Janet moved into Teloca, the name given to the house. The name Teloca came from Tender Loving Care.

I'm not going to tell you that everything was perfect from that time on. It wasn't. Once again, Janet got her bruises.

A decision was made to open another home on Brady Avenue in Salem and Janet and three other individuals moved in. And once again, Janet got bruised up by another client.

The house was eventually downsized from four to two individuals. Janet and her house-mate were both medically fragile and nurses came in daily to oversee their medications. Janet and her house-mate attended a day program and both were taking part in community activities.

Janet's health remained a concern and she was hospitalized both in Boston and locally many times. She had major surgery of the esophagus, which failed. She had a history of anemia and received many transfusions. In February, Janet had her blood tested. I got a call from the nurse shortly after midnight telling me to take Janet to the hospital to receive two units of blood because her count was down.

Janet was at the hospital early that morning to receive the two units of blood. I was getting her ready for the trip back home when she had a large bowel movement. It was very black. The doctor had it tested and I was told she was actively bleeding and needed to be admitted. She received another unit of blood.

The next morning I took her down for a colonoscopy. After a conversation with the doctor, he elected to do an endoscopy first. Half an hour later, he came to me with devastating news. Janet had esophageal cancer. The tumor covered 2/3 of her esophagus and was very aggressive. He said she had two months to live.

Janet passed away four weeks later on March 20, 2004. I'm still in shock - in denial. God knew that she was tired and her work was done, so He called her home. She was my life. I loved her so much and I miss her terribly.

"It takes courage to be crocus-minded."

Lord, I'd rather wait until June, like wise roses, when the hazards of winter are safely behind, and I'm expected, and everything's ready for roses.

But crocuses? Highly irregular. Knifing up through hard-frozen ground and snow, sticking their necks out, because they believe in spring and have something personal and emphatic to say about it.

Lord I am by nature rose-minded, even when I have studied the situation here and know there are wrongs that need righting, affirmations that need stating, and know also that my speaking out may offend -- for it rocks the boat -- well, I'd rather wait until June. Maybe later things will work themselves out, and we won't have to make an issue of it.

Lord, forgive, wrongs don't work themselves out. Injustices and inequities and hurt don't just dissolve.

Somebody has to stick his neck out, somebody who cares enough to think through and work through hard ground, because he believes and has something personal and emphatic to say about it.

Me, Lord? Crocus-minded?

Could it be that there are things that need to be said, and you want me to say them?

I pray for courage.

Amen.

(This was sent to Freda Smith by a friend in 1975 when she and other parents were working hard to educate the public about the conditions at Laconia State School.)

"Judge Shane Devine (who presided over the Garrity vs. Galen lawsuit) was a man of courage, a man of wisdom," asserted Freda Smith. "He showed the country, the whole world, that an injustice had been done to the DD population, and really to humanity itself because of the treatment, and sometimes the lack of treatment that the residents of these institutions received." Because of Judge Shane Devine, Smith no longer was forced to live the nightmare of her daughter's "imprisonment" at Laconia State School. ("Once a prisoner, always a prisoner," Smith commented about the current status of the old State School as a state prison.)
How Do You Get There From Here?

(This was a keynote speech given at a fund raising conference "Making the Pieces Fit" organized and sponsored by The New Hampshire Challenge, the New Hampshire State Council on the Arts, and the New Hampshire Charitable Foundation in May, 1994.

By: Peggy Straw

First of all, I would like to identify myself as no expert on anything, a real dilettante in many fields of interest, a pain in the neck to many professionals with degrees, a zealot without credentials, a missionary without a church... I could go on and on about what I am lacking in being a keynote speaker. What I do have that makes me different from some of you - I hope, for your sakes - is an overwhelming desire to do something about something that seems unsolvable but has devastated my life and that of those I love the most.

Mental illness - so little knowledge, so many myths, so much stigma. No wonder most of us who had to deal with it were still in the closet.

What could I do? Where did I go from that first realization that my daughter had a mental illness and I was being blamed for causing it, those 22 years ago, after the death of her father? I was alone and no one really understood what our whole family was going through. I had to go through all the stages of grief the Dr. Kubler-Ross identified: denial, anger, depression and acceptance - although the depression was never finite since sometimes we almost got her back. I was on a roller coaster of emotions for years until I finally recognized the three truths the could help us through our crisis.

The three truths are:
1. Knowledge is power.
2. Power is in numbers.
3. Change only comes about when enough people care enough to make that change.

I had always been considered a "good little banker's wife," a follower, a worker bee, a let-the-other-guy-do-it-but-I'll-follow-when-given-directions. The trouble was that no one was giving me any directions. I was simply reacting again and again to a horrible situation and becoming less and less powerful and in control of my life.

The worst thing was that, in spite of thousands of dollars on treatments, my daughter was getting no better and it looked as if she would be joining the legions of the mentally ill who sat on benches in home clothes in mental hospitals, starting at the walls. I knew that I would do everything in my power to keep this from happening to my beautiful young daughter.

It was time to confront the first Truth - that Knowledge is power. So, I subscribed to Hospital and Community Psychiatry, the Psychosocial Journal, and read everything I could get my hands on about mental illness. I got on the Board of the Mental Health Association, the Board of our Community Mental Health Center, and became a Board representative on the Council of Community Mental Health Centers so that I could become aware of what services were available in our state and who the major players were.

The Director of the Division of Mental Health and Commissioners became acquaintances and seemed interested in hearing from consumers. Legally, my daughter and I began to listen to some of the things I was telling them and I was included on many planning committees as representing families of the mentally ill.

I was beginning to be spread too thin and consequently low effectiveness, so it was time to consider the second Truth - that Power is in numbers. Self-help had been very effective in dealing with the problems that families faced and I had gone to the first incorporated meeting of the National Alliance for the Mentally Ill in Chicago in 1980 as representing our state "group," which at the time consisted of a few people I knew who had a family member with mental illness.

Meeting with 350 people from all over the country with my same problem and realizing that I was not alone was the impetus for coming home to New Hampshire and organizing self-help groups all over the state. It was not easy because of confidentiality laws, the reluctance of professionals to view families as other than the enemy camp, the shame families felt in admitting that their loved ones had a mental illness, the stigma that accompanied that admission and the denial that was so counterproductive in dealing with mental illness.

There were four major things that provided the ammunition to do this:
1. First, there was the knowledge that, contrary to much outdated material I had read, families were NOT to BLAME. Twin and adoptive studies had proved that, and the brain was increasingly being looked at as a biological, chemical entity that could get a disease just like any other part of the body.
2. Twenty-two years ago, however, most psychiatrists and mental health professionals that I dealt with either did not or would not subscribe to this concept. They were still wedded to the Freudian theories — and they were just that, theories — that upbringing "left us non-functional". Families was the cause of mental illness, and by gaining insight into what dark secrets lurked in disturbed minds, a cure could be found.
3. I remember asking my social worker during my daughter's first hospitalization if her illness had anything to do with the fact that my father, sister and aunt had a mental illness and my husband's grandmother had schizophrenia. She replied that it had no bearing.

At that time, I was assigned someone who could delve into my background, find out what horrible things my husband or I had done to this 15 year old girl and give me the therapy I needed. I was interviewed by seven "experts" in white coats who looked at me as if I were some sort of criminal - and this was one of the most prestigious hospitals in Boston! Despite this scrutiny, I knew that we had loved her very much, given her a great deal of positive reinforcement in her growing up years and I would not accept the blame. I knew that the "experts" were on the wrong track and I could hardly blame them for sticking to their theories that had cost them thousands of dollars to learn. That realization, however, was not getting my daughter anywhere and I knew there had to be a change.

Secondly, what had been done in the past - hospitalization and psychotherapy - had not worked.

Long-term hospitalization for people with mental illness was a) expensive, b) non-therapeutic, and c) inhumane. In fact, it was dehumanizing and taught people only how to become docile and dependent on the hospital. Psychotherapy or insight therapy was worthless as a treatment for schizophrenia as many families found out thousands of dollars later. How could you have insight into thought when that thought was so disordered? The way people with mental illness were treated had to be changed to something better.

Thirdly, medications and a community support system could work and families were in a unique position to state this with their exponential knowledge. People with mental illness deserved to live in the community like everyone else. They could become contributing citizens with supports in place.

I began to see this as my daughter began to be treated in our local mental health centers and learn coping skills. After almost 18 hospitalizations, she was beginning to learn what she had to do to live in the community. For the sake of all those who were still incarcerated in hospitals, there had to be a change in the system.

Lastly, there was hope and empowerment for us all through self-help and self-management for those with mental illness. Once families began to meet, deal with their undiagnosed shame, share coping skills and

Margaret (Peggy) Small is the Founder and first President of the Alliance for the Mentally Ill of New Hampshire. She has served on numerous state and national boards, among them the National Alliance for the Mentally Ill. The awards she has received include an Honorary Doctorate of Humane Letters from Franklin Pierce College, the NAMI Outstanding NAMI member award, and the New Hampshire Social Welfare Council Award.

Continued on page 73
Update on the Alliance for the Mentally Ill of New Hampshire

by: Judith M. Krause

From the humble beginnings of Peggy Stein’s efforts around her kitchen table over 20 years ago, the Alliance for the Mentally Ill of New Hampshire (NAMI-NH) has grown into an organization with 500 members today. Their mission is to help ensure that families have access to quality services, according to Mike Cohen, Executive Director.

NAMI-NH offers direct support services to families and individuals with mental illnesses, and public education to dispel myths and fight the stigma of mental illness.

The Family Partners program links parents who have children with severe emotional disturbances to services from multiple systems (Behavioral Health, DCYF, and Special Education) with other parents who have been trained to help them navigate those systems. “Our job is to help these families by looking up with families who have been through it,” Cohen explained.

“These are not kids with ‘behavior problems’, Cohen emphasized. “These are kids who have severe illnesses.”

The Visions for Tomorrow program helps parents learn about their child’s illness and teaches them strategies for working with their child. Information helps them cope with the situation, and receive help navigating the mental health system.

In addition, NAMI-NH has completed five years of a six-year federal grant called CARE-NH. The purpose of this grant is to set up a system of care for children with severe emotional disturbances. “It looks as though you wrap services around the child so that the whole family gets the services they need,” explained Cohen.

The Family-to-Family program is a community education program. Family members go into schools and various community groups to educate people about mental illness. “It’s effective in fighting the stigma of mental illness,” Cohen said, “but it also provides early intervention and prevention. Someone with a mental illness who gets into the system early will receive the benefit of earlier treatment.”

In Our Own Voice is a program for the adult consumer. Individuals with mental illness tell their recovery stories in classrooms, to church groups, to community mental health agencies, to boards of directors for non-profit agencies, to other civic groups. “It’s a very effective anti-stigma program,” Cohen stated.

Frameworks is a community-based suicide prevention program offered by NAMI-NH, and there is a program for the Latino community in Nashua that helps individuals who speak Spanish access mental health services in their community.

In addition to the programs, NAMI-NH maintains an 800 information and referral line and a resource library that is open to the public. Most of the direct support and education programs offered by NAMI-NH are funded by the NH Department of Health and Human Services. NAMI-NH has recently learned that DHHS has chosen not to renew their funding for next year, offering instead a 90 day extension of last year’s contract to give them time to prepare for the loss (pending approval by Governor and Council). According to Cohen, the Department plans to move the direct support services to the community mental health centers.

Cohen is quick to reassure families that NAMI-NH will not be shut down. “We will continue to maintain information and referral lines,” he said, “and we have a resource library.” The Visions for Tomorrow program and the program for the Latino community have other sources of funding and will continue.

“We will continue our advocacy efforts,” Cohen said. “It’s our mission. It’s important for us to ensure that families have access to quality services.”

Continued on page 12...
Area Agencies - the cornerstones of the service system

(Updated from an article in the July, 1989 issue)

by Janet M. Krumm

Area agencies are the cornerstones of the community-based service system in New Hampshire for people with developmental disabilities, acquired brain injuries and chronic health conditions. They were created to provide an alternative to institutional living - a way for people to stay in their communities and live full, productive lives.

In the late seventies, a model program was created which consisted of placing one case manager in each of four regions who would develop community options for persons with developmental disabilities. The concept of case management came out of concerns voiced by parents that they didn’t understand how to access services.

Sandy Pelletier, currently Executive Director of Area Agency of Greater Nashua, Inc., was one of the original four case managers. She said the early effort “was very client-centered when it started out.” She said her colleagues spent lots of time talking with persons with disabilities, looking at generic services as solutions, and creating service systems only when there were no appropriate generic systems in existence.

In 1978, the lawsuit against the state over the conditions at Laconia State School and Training Center was filed by NH Legal Assistance. Not the first state to experience such legal action, New Hampshire had the opportunity to learn from the experience of other states.

In other states, court orders to deinstitutionalize created largely bureaucratized responses, of which people in the community were distrustful. State officials in New Hampshire had two paramount concerns: a general fear on the part of ordinary citizens who had minimal or no contact with persons with disabilities; and the strong desire of local communities to exercise control in decision-making.

“The state wanted to minimize opposition,” Pelletier remembered. So the concept of Area Agencies was born and nurtured.

Originally, Area Agencies were conceived of as entities which would provide no services themselves, but would instead subcontract out with existing service providers. That plan was altered when it was realized that some existing groups applying for Area Agency designation were already providing services and were unable to subcontract due to the lack of other existing service providers in their region.

When all applications were received and reviewed, there emerged 12 Area Agencies as opposed to the 10 Mental Health regions. These twelve still exist today.

Boards of Directors were recruited from the local communities. As Pelletier said, “We looked for people who aspired to integration.” It was believed that the best way to overcome a general fear in the community of people who had effectively been locked away for most of their lives was to have local community members speak to their neighbors and friends from their own convictions.

Stipulations from the Division of Mental Health and Developmental Services (DMHDS) called for at least 1/3 of the Board to be consumers of services to ensure that persons with disabilities or their family members would have a voice in determining how their needs were met.

The services provided by an area agency include: respite, family support, early supports and services, case management, day programs, supported employment and residential supports. The extent to which Area Agencies or their subcontractors are able to actually provide these services depends on the number of people requesting them and the amount of money they are allocated by the Legislature.

Bruce Pacht, Executive Director of United Developmental Services (Region XII) has been involved with this area agency as Director since 1975, when it was the Upper Valley Training Center. Working with Pelletier, he has seen the enormous changes over the years.

One of the major problems he believes, is balancing the issue of freedom and dignity with the reality of cost. “How do you get people dignity without costing more money than the average person is willing to spend?”

In addition, there are administrative concerns. Attracting and keeping people in a field where they face great anxiety and yet not rewarded adequately enough to provide themselves with a minimum quality of life is a real problem, he added.

Because of the way the original concept for local control has been translated into how an Area Agency operates, the way services are provided vary widely from region to region. Each Area Agency looks at the needs in its community and decides how best to meet those needs.

Citizen involvement and local control are the cornerstones on which local communities and the state of New Hampshire are formed. Citizens in New Hampshire have more opportunity than in most states to directly affect the system serving them.

Today what used to be the Laconia State School is now a state prison.

by Janet M. Krumm

Photo: E.G. Stone

Fences with barbed wire surround the property and the buildings are being used to segregate another population.

In the 1994 legislative session, a law was passed, RSA 171-B, which mandated involuntary commitment of people with developmental disabilities suspected of having committed a Class A felony. At the time this bill was introduced, there was media coverage of a suspected arsonist who had allegedly started several fires in Manchester. The suspected arsonist had a developmental disability, and was eventually declared incompetent to stand trial. The frustration of the criminal justice system over the lack of resources (legal and otherwise) available to them to deal with this situation and, at the same time, protect the community, led to their support for this legislation. The community's concern about the incidents of arson fueled support for this bill.

In the ten years since RSA 171-B was enacted, it is estimated that 15 people have been through the legal process established by the legislation, according to Matthew Ertas, acting Director of the Division of Developmental Services. A couple of cases have been dismissed; others have been committed.

The designated receiving facility (DRF) for individuals who present a danger to the community is situated on the grounds of the old Laconia State School & Training Center. In fact, it is the old Superintendent's house and the structure next door to it that comprise the DRF. A fence has been constructed around the two buildings and the facility is heavily staffed.

This facility is the only treatment program run by the state for individuals with developmental disabilities with sex offending behaviors. Other
A Brief History of Special Education

by Jamie Stephenson

Throughout New Hampshire, students with disabilities have worked hard to receive diplomas along with their typical peers. In 1975, when the first Federal special education law was passed by Congress, no one could have imagined how much it would change education. The decades following PL94-142 were a heady time for individuals with disabilities and their families. Each five-year reauthorization of the law brought changes and adjustments. Some of the major changes to IDEA include:

* 1986 Part B that mandated services to preschool children with disabilities
* 1990 mandate for transition planning for 16 year olds
* 1997 mandate for transition planning beginning at age 14

The 1975 passage of the Education of the Handicapped Act (PL 94-142) was the climax of a long, careful process including parents in national education policy-making for the first time. The 1989 Timothy W. Brown ruling by the First Circuit Court stated that the school district must provide educational services to all children and can’t exclude anyone based upon the severity of a disability. The message was: all students can benefit from education.

Prison

Continued from page 14...
The Evolution of Family Support in NH

(Originally published in the January, 1991 issue)

by: Kathy Manderline

In 1987, the members of the New Hampshire legislature were asked to consider passing a bill that would create a Task Force. The mission of that Task Force would be to study the needs of families caring for people with developmental disabilities in their homes, and to make recommendations back to the legislature on how the needs of those families could be better met.

The Task Force was composed of nine appointed members and several dedicated parents, family advocates and service providers, met over a six-month period. The mission of the Task Force was "when all is said and done, let there be more done than said." The recommendations of the Task Force were to be practical, achievable, and reasonable. The goal was that with the implementation of these recommendations people living in New Hampshire who have developmental disabilities would be better able to develop to their fullest capacity through the love and support of their families and communities, instead of being cared for at isolated facilities at an emotional, ethical, and monetary cost to themselves and their families for exceedingly.

The overwhelming need voiced by family members was the problem of getting information and services, for equipment, for help, understanding how they could help themselves and their loved one - and the problem of getting INTO those services and making those services more responsive to their needs as family members.

Families voiced frustration at often being unaware of services already available to them, of not knowing how to enter into services if they moved in from out of state or even across county lines; of information too confusing to understand; or of simply needing to talk with another parent who has a similar kid.

The Recommendations were released in January of 1989 at an event at the State House, called "Celebration." A few weeks later, a bill was drafted and introduced that embodied the recommendations of creating a statewide family support network. It became known as the Family Support Bill.

Legislators heard from families whose parents had separated because of the stress, mothers who were exhausted, and fathers working two jobs just to keep minimal health benefits. They also heard families saying that they didn't want a handout, but a hand-up, and an opportunity to participate in the typical community activities that most New Hampshire families can take advantage of.

During testimony, some legislators had voiced concern that the bill might create another personnel bureaucracy. Family council members didn't want that anymore than legislators did. Personnel represents only 1% of the appropriation, the majority of the money has gone directly to families.

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Table 2 shows what kinds of financial requests families made of the program.

### Average Cost of Services Provided

<table>
<thead>
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<th>Service</th>
<th>Per Family</th>
<th>% of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day Care/Child Care</td>
<td>$966</td>
<td>28%</td>
</tr>
<tr>
<td>Medical/Adaptive Supplies</td>
<td>$588</td>
<td>16%</td>
</tr>
<tr>
<td>Recreation</td>
<td>$549</td>
<td>16%</td>
</tr>
<tr>
<td>Temporary/Em try Placements</td>
<td>$546</td>
<td>16%</td>
</tr>
<tr>
<td>Counseling</td>
<td>$400</td>
<td>16%</td>
</tr>
<tr>
<td>Respite</td>
<td>$363</td>
<td>16%</td>
</tr>
<tr>
<td>Transportation</td>
<td>$348</td>
<td>16%</td>
</tr>
<tr>
<td>In-Home Supports</td>
<td>$277</td>
<td>16%</td>
</tr>
<tr>
<td>Community Education</td>
<td>$200</td>
<td>16%</td>
</tr>
<tr>
<td>Parent Training</td>
<td>$104</td>
<td>16%</td>
</tr>
<tr>
<td>Direct Support</td>
<td>$83</td>
<td>16%</td>
</tr>
<tr>
<td>Information and Referral</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Home Visits</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Community Links</td>
<td>?</td>
<td>?</td>
</tr>
</tbody>
</table>

### Most Frequently Provided Services

<table>
<thead>
<tr>
<th>Service</th>
<th>Provided</th>
<th>% of families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information &amp; Referral</td>
<td>279</td>
<td>30%</td>
</tr>
<tr>
<td>Direct Support</td>
<td>259</td>
<td>28%</td>
</tr>
<tr>
<td>Parent Training</td>
<td>244</td>
<td>26%</td>
</tr>
<tr>
<td>Community Education</td>
<td>238</td>
<td>25%</td>
</tr>
<tr>
<td>Recreation</td>
<td>152</td>
<td>16%</td>
</tr>
<tr>
<td>Home Visits</td>
<td>148</td>
<td>16%</td>
</tr>
<tr>
<td>Community Links</td>
<td>144</td>
<td>15%</td>
</tr>
<tr>
<td>Medical/Adaptive Supplies</td>
<td>136</td>
<td>15%</td>
</tr>
<tr>
<td>In-Home Supports</td>
<td>61</td>
<td>7%</td>
</tr>
<tr>
<td>Respite</td>
<td>58</td>
<td>6%</td>
</tr>
<tr>
<td>Day Care/Child Care</td>
<td>54</td>
<td>6%</td>
</tr>
<tr>
<td>Transportation</td>
<td>43</td>
<td>5%</td>
</tr>
<tr>
<td>Emergency Placements</td>
<td>40</td>
<td>4%</td>
</tr>
<tr>
<td>Counseling</td>
<td>12</td>
<td>1%</td>
</tr>
</tbody>
</table>

What about financial resources outside of the State appropriation? Throughout the state, service clubs, town and city governments, and local resources are being tapped too. Most monies are drawn from the budget. This has amounted to an approximate $7,000, from $25 donations and up.

Additionally, non-cash donations have been sought. For instance, Keene family needed a ramp to get their child's wheelchair in and out of the house. An estimated cost would have been around $900. Two calls from the Family Support Coordinator in that region explaining the purpose of the request resulted in the donation of materials and labor.

Thanks to a pilot project passed by the Legislature in 1986, Nashua is in its 3rd year of a family support program. They are at a point now of building on local contributions by approaching major corporations for grants. They can show that helping families costs a lot less than institutionalizing.

Continued on page 19
Supporting Families Is Her Job
(Originally published in the first edition of The New Hampshire Challenge, October, 1988)

by Janet M. Kreidieh

Little did Lynn Tonkin dream when she began work as a secretary at Region IV Area Agency in 1980 that she would be the first person in the state of New Hampshire to hold the position of Family Support person in an area agency.

The agency was looking for someone who had some experience with people with disabilities in the field of special education and could provide services for eight children in a residential placement in Pittsfield.

Tonkin had no specific job description. She said they needed money. The big need was for money.

Since she had no specific job description, Tonkin did some homework. She spent a year researching what other states were doing in the area of family support and then looked at her region. Her primary concern was that families communicate their needs to her.

Tonkin made a list of the different kinds of supports that she discovered in her research and defined them. She then took the list to a number of agencies which provided services to families and asked for feedback. This strengthened her list of information.

Next, she asked families to pull the information together and evaluate whether the list reflected what they considered actual supports. She also solicited suggestions for possible supports that were not listed.

She distributed the list she was compiling to all the families she could identify in her region. Many of these families had never received services. Tonkin wanted each family to identify what their needs were. She told them, "Use this as a menu, create your own meal. Here are the ingredients you could use."

What was surprising to Tonkin was that very few families said they needed money. The big need seemed to be for a central point of referral (ideally a person or agency who would always know their child), someone to make home visits, respite and child care.

The next fiscal year brought a small discretionary fund along with the authorization from the Division to do the job. Tonkin divided her time between home visits and office work.

She found herself doing a wide variety of activities. Sometimes she sat and talked with families. Sometimes she went to someone's house to help with filling out paperwork, only to find herself babysitting while her mother went out to buy food. She helped people put such diverse items as a plastic cover for a bed and eye glasses. She helped parents secure respite or child care.

By the end of the first year, Tonkin had made a list of what other states had considered a regional, creative and community-based approach to helping families with disabilities. She had received a regional discretionary fund.

Tonkin says, "What I thought family support was when I first started and what I do now is very different." Basically, she said, "Families tell me what they need and I do it."

Tonkin explains that family support services will be more widely available, but caution that they should not be program specific. Instead, family support should address the real needs of families as families define them.

They began helping set up opportunities for children to go to NORMAL day care programs and TYPICAL summer recreational and after-school programs. They helped search out sources of equipment and diapers, and networking parents with other parents whose kids have a similar challenge.

They organized information sheets on guardianship, trusts and benefits; coordinated meetings among local agencies to help them address
Councils Gather to Discuss Family Support

(Originally published in the December, 1992 issue)

by: Jamie Stephenson

What is the condition of family support in New Hampshire? Pretty good, said most Family Support council members at a recent "Gathering of Councils" held on October 17, 1992 in Boscawen. Hosted by the Division of Mental Health and Developmental Services, the meeting was primarily for council members, with only four invited guests attending.

But while the consensus was favorable, there were a few councils that admitted experiencing major problems. Possible solutions emerged as other more successful councils recounted ways problems had been addressed in their regions. However, even those councils where working conditions were good cautioned the group that there are risky roads ahead and that councils must navigate them carefully.

The theme of the day was redicovering the roots of family support and planning for the future. What led to the drafting of the legislation? Kathy Mandeville, who chaired the Family Support Task Force out of which the legislation was born, gave the participants an overview of the history of family support in the state. Janet Krumm then presented an overview of the Division of Mental Health and Developmental Services.

After this brief introduction, representatives from each council reported on their respective council's accomplishments and challenges.

Some councils reported a great deal of success in negotiating strong working relationships between the councils and the area agencies. The Manchester council is one which admitted to starting their relationship with their area agency with distrust. However, through careful negotiations and a clear vision of what they wanted to be, they have been successful in defining themselves and their responsibilities.

Others are still struggling to define that relationship. Several councils reported problems defining their autonomy from agencies who have been too willing to assume the responsibilities of family support. In those councils, members are feeling frustrated and unable to accomplish their task.

Those who have been successful have a common thread; they set up rules governing participation at council meetings. In order to safeguard the autonomy of the councils, area agency directors and family support coordinators attended meetings at the invitation of the council. Some councils also used executive sessions to resolve problems which might involve coordinators or their relations with the area agency.

The major concern voiced by the many council members was the challenge of remaining independent. The inter-relationships of the area agencies and councils appear to be complicated by the relationships between the two and the family support coordinators. To whom are the family support coordinators responsible? This question evoked strong discussion. The overwhelming answer was: to the councils. However, there are councils who have no say in the selection of their coordinator, and some who feel tension with the area agency over the issue of their authority.

In addition, the issue of council membership was raised in relation to the autonomy concern. Some coordinators, as well as area agency personnel, are actively soliciting new members for the councils. The councils felt strongly that solicitation for new membership was their domain, and brainstormed effective ways to attract new members.

The issue of a formal structure for councils was raised and discussed. Members believed that there indeed ought to be some formal structure to ensure accountability and accountability, at the same time cautioning the councils' becoming another bureaucracy. There was strong emphasis on flexible use of the family support system to respond to individual family needs and be "voice activated," rather than create an even more paperwork-oriented system for families. The Manchester council boasted of its own phone number and answering machine which is monitored 24 hours a day, revealing their commitment to immediate and personal contact with families.

While the need for more funds was acknowledged, there was also pride expressed in the way councils have used generic services as much as possible. All of the councils were united in defining their primary purpose as serving the needs of families, at the same time revealing their diversity by the many and varied ways in which they chose to carry out their mission.

A suggestion was made that councils should avoid unnecessary duplication of effort. The role of the State Family Advisory Council was discussed and suggestions were made on how to revise that role to make it more effective and complementary to the regional family support councils. Discussion also touched on ways in which the Division of Mental Health and Developmental Services could be of assistance in helping the councils fulfill their primary mission.

A small group of council members agreed to compile the information gathered that day into recommendations which would be distributed to all the councils across the state.

Evolution

Continued from page 19 -- gaps and duplications that exist. They let physicians and libraries and real estate agencies and service providers and town governments know that there is a central knowledgeable source of information and support for families.

The recommendation to create a statewide family support network seemed to have been met.

The programs are well off the ground and helping families cope. The need for the program will increase even more as the economic picture continues with parents losing jobs, health benefits, employment opportunities for those with disabilities - and costs of medical supplies, food and housing continue to rise.

There are increasing concerns about more children being born at risk of life-long disabilities because prenatal care and food and basic child health is becoming more and more difficult to afford. The Family Support Bill represented only 1 of 25 recommendations made by the Task Force. Most are still in need of implementation, and the majority need no appropriation - just leadership armed with the values so basic to the dignity of a compassionate and free society. When all is said and done, let there be more done than said.

ServiceLink

One phone call connects you to resources and support services

ServiceLink is a statewide network offering adults with disabilities, older adults and family caregivers access to information regarding supports and resources. There is no call for this service, regardless of income.

ServiceLink provides information regarding community, state and national resources. Knowledgeable staff will work with individuals to identify supports and resources that best meet their unique needs. ServiceLink can make home visits, schedule appointments at local offices and offer services after hours by appointment.

Because ServiceLink is a statewide information and referral service, there are no "wrong doors." One call is all it takes to begin exploring the services and resources available within the community.

Questions regarding home care services, caregiver support, employment issues, financial retirement planning, wellness education, prescription drug options, healthcare benefits, disease management, housing and other topics can be answered with a toll free phone call.

For more information, call ServiceLink toll free at 1-800-634-8412 or visit their website at: www.servicelink.org.
Family Support - an Update

by: Janet M. Krumm

Family support was a relatively new concept on 1989 when the Legislature passed a bill to create a family support network. That network focused exclusively on families who had sons and daughters with developmental disabilities. Now, family support has become ingrained throughout the service system and has been extended to include families who have members with acquired brain disorders and chronic health conditions.

From an initial appropriation of $500,000 per year, funds for family support have increased to nearly $7 million for fiscal year '95. In 1990, there were 940 requests for some type of family support. This year, 3,879 families are being served.

Originally, family support money came exclusively from state funds, allowing a great deal of flexibility. The amount of no-strings-attached state funds has increased to approximately $1.2 million per year, 17% of the total amount spent. Medicaid now funds a portion of family support services: respite and environmental modifications. The rest is personnel costs for the family support coordinators in each agency.

"Most of what family support is," stated Allita Paine, Director of Child and Family Support Services at the Division of Developmental Services, "is one person helping another. The purpose of family support is to provide the help the family needs, whether that be information, respite, day care, help with I.E.P. meetings, etc. Families themselves determine what they need."

Family support coordinators provide information, make community connections, provide monetary assistance when needed, and help families access services. To augment the money allocated by the state, family support coordinators continue to access natural supports in the community and to develop in-kind contributions, just as they did in the early days.

Family support counselors continue to function in their advisory roles at each agency. But they no longer submit plans to the Division outlining how the family support money in their region will be allocated. "Family support is part of a larger system," Paine explained. "The plans for family support are rolled into the area agencies biennial plans."

Paine emphasized that the most important function of the family support councils is to bring their family values to the area agency. She sees that influence permeating the entire service delivery system.

In the 13 years since Laconia State School closed its doors, the community-based service system has steadily moved away from supporting individuals who came out of Laconia and moved toward supporting individuals who have families, Paine commented. "More and more, our area agencies are serving families, not just individuals," she said.

As is true for everything else in the area agency system, family support varies from region to region. There is no universal job description for family support coordinators, although the bottom line for all of them is to help families get the supports they need to function well.

Kathy Mandeville wrote in 1991 that "families didn't want a hand-out, but a hand-up." Instead of placing their children in residential facilities, families are raising their children at home, in their communities, saving the state millions of dollars. In 1991, it was estimated that institutional costs for a child with severe disabilities averaged $74,000 a year. In 2004, New Hampshire is spending approximately $1,800 per family in family support services. (These figures are not adjusted for inflation.)

From 1987 to 1988, the Family Support Task Force spent 16 months interviewing families, conducting surveys, sponsoring regional forums, reviewing data and materials from national studies and studies from other states, listening to an array of state and private providers, educators, pediatricians and administrators. They articulated a set of values that guided their work. Those values guide family support today:

Every family is unique and its needs change over time. All individuals belong in families or family-like settings. Families are, or can become, competent caregivers. Services should support the everyday needs of the family. Each family needs services tailored to build on its natural supports, unique skills and existing community resources.

Alan Bergman, former Deputy Director of United Cerebral Palsy Associations, said: "Family Support is common sense. Family Support is sound financial policy. Family Support is reinforcing the family as the foundation of our society. Family Support, in the best of systems, is the empowerment of families to choices and control over their destiny."
The History of Early Supports and Services in NH

by: Jamie Stephenson

New Hampshire’s adoption of regulations for Family Centered Supports and Services in 1993 marked the end of a process that began more than 20 years earlier and the beginning of a brighter future for infants with disabilities in our state.

Family Centered Early Supports and Services (FCESS), also known as early intervention (EI) or early supports and services (ESS), is the name for the statewide program that looks after our tiniest citizens with disabilities.

Staffed by dedicated, skilled professionals, each early intervention center provides direct educational and therapeutic services to eligible families in community settings (e.g., home, day care center) and support to families learning how to raise a child with a disability.

The system is designed to be smooth and stress free for the family and cost effective for the state. Investing in early intervention for infants with disabilities has been proven to reduce some children’s need for future services.

The success of New Hampshire’s early intervention program can be attributed, in part, to the collaboration between the Department of Health and Human Services and the Department of Education. Those two important, independent state agencies came together to create a service system that utilizes the expertise of educators and human service providers to implement a unique part of the federal special education law.

The federal government began to address infant health and development in early twentieth century with the establishment of The Children’s Bureau in 1912. That agency focused on children with disabilities and serious illness. The Social Security Act of 1935 included Maternal and Child Health Services and the 1965 amendments added the Early and Periodic Screening Diagnosis and Treatment (EPSDT) program as part of the newly established Medicaid services for children living in poverty.

The value of early childhood education was already well documented in 1872 when the first public kindergarten opened in the United States. In the early twentieth century, nursery schools were established to offset the effects of the deprived environments of urban children living in poverty.

The preschool movement gained more momentum through government initiatives during the Great Depression of the 1930s and World War II in the 1940s. Many women were drawn into the labor force during those decades and nursery schools and kindergartens supported the working mothers.

Two decades later, in 1965, as part of his “War on Poverty” President Johnson established Head Start, the largest early childhood program funded by the federal government. Head Start began serving low income 4 and 5 year olds but the outcomes were so positive that it was later expanded to include infants and toddlers.

A recent longitudinal RAND study demonstrated gains in IQ, higher achievement in elementary school, lower incarceration rates and fewer referrals to special education in children who have attended Head Start programs.

New Hampshire showed its commitment to serve infants and toddlers beginning in 1968 by supporting the creation of parent led cooperatives and service centers for children with disabilities. In 1975, RSA 171-A established a comprehensive statewide service system for citizens with disabilities that included early intervention services for infants and toddlers. The Area Agency system grew out of this statute and remains the contact point for early intervention services throughout the state.

But the initial programs for infants and toddlers were not reaching all the eligible children and there was a question of entitlement. Each Area Agency created its own program for clients under three with a model sometimes based on the adult service system that is not particularly family oriented.

Continued on page 23
Continued from page 22

...to create eligibility standards for infants and toddlers under Part H. Also, it would serve as a model for community based early screening programs for infants at risk for developmental delay.

In collaboration with Lakes Region General Hospital, Laconia School District, Lakes Region Child Development Program, and Lakes Region Community Services Council, the project began screening all newborns in Region 3 between May 1991 and April 1992. The Family First project assessed each infant’s risk factors (e.g. low birth weight, low Apgar score,) and family demographic information as stated on the birth certificate.

Parents who chose to participate answered a questionnaire that assessed the family’s risk factors, including parental disability, access to medical providers, chronic illness, social isolation, and concern about their newborn. Families deemed at risk were offered a home visit and all infants were offered an additional screening at 6 months and 12 months.

At each level of screening, eligible infants were referred to early intervention. Of the 487 births, 229 families participated and 4 infants were referred to early intervention. Although this number is surprising, the project leaders believed that eligible infants received services sooner and that all participating families benefited from the information about infant development and community resources.

Like the Family Resource Connection, Family First provided information and referrals to all families whether at risk or not. In 1992, the ICC sponsored a Pediatric Leadership Conference designed to educate medical providers about early intervention and receive their support to improve EI services. Families nominated physicians to attend the two-day conference at the Minary Center on Squam Lake.

The ICC recognized that, after the family, the infant’s doctor is most knowledgeable about the developmental risk factors facing each family and most likely to know when an EI referral is appropriate. Therefore, the 36 physicians attending the conference were encouraged to form connections with the early intervention system and to encourage their colleagues to do the same.

The impact of this ICC project has continued to this day with increasing physician referrals in all regions, according to the 2003 ICC Annual Report.

Another major pilot program, the Family Resource Project, was sponsored in 1993. Prompted by the existence of waiting lists for services for eligible infants, the ICC chose to fund programs in 5 Regions (Concord, Manchester, Merrimack, Dover and Atkinson) that offered families waiting for services the option of receiving cash assistance to buy supports and services to meet their child’s and family’s needs.

This proposal was not without controversy. Some opponents argued that families were not equipped to make wise choices; that the children in need of service would not benefit; and it would lead families into dependence on public assistance.

The results of this project proved those concerns to be unfounded. The families made careful, child focused choices when expending funds. 73% of all funds expended went toward therapies and developmental services for the children. In fact, when left to make their own decisions, families chose services that closely replicated those in the existing EI system proving that parents’ and professionals’ viewpoints were not too far apart.

One thing that families in the Project unanimously requested was more information about their child’s disability and about community resources in order to make informed decisions when spending their allotted funds. Families were also very conservative spending project funds - one family offered to share a portion of their funds with other families with unmet needs.

In 1994 a Conference...
Opinion
Letters to the Editor

Hunger, poverty and lack of work opportunities plague people with disabilities

To the Editor:

The Food Stamp Program should be remain a solution to end hunger in America until every individual who wants to work is able to find meaningful employment. Congress and mainsteam society need to understand hunger should be tackled like any other health problem including mental or physical illness. In fact hunger creates or can be responsible for many kinds of illnesses.

Individuals with disabilities are forced to rely on between $35.00 - $50.00 for weekly groceries and it does not buy much these days as we see food prices rising 32% - 50% for all people, and that’s even higher if you don’t have the ability to shop around or buy in bulk. When individuals with disabilities ask for more money to buy enough food to eat, has or her case manager will say “no, you cannot have anymore money for food.”

My sister Roberta and I, as well as many like us receive $10.00 a month in food stamps. $10.00 does not buy anything!

The system that does not offer opportunities for people with disabilities does not offer job training services for people with disabilities under the Vocational Rehabilitation Act, 1973, and offers no way out of poverty. Meanwhile food prices will keep going up. The State and Federal governmenls do not see the real problem in this underbelly of society because they never live it! People with disabilities should not be penalized.

Donations are down, people cannot afford to contribute to soup kitchens or food pantries, and not every community has soup kitchens. Salem, where I live, does not offer soup kitchens.

The Food Pantry and Soup Kitchen are short term solutions. They do little to end hunger in America. Until employment becomes more the norm food stamps are the best solution. People with disabilities still face an unfair lack of employment opportunities with unemployment rate at an all time high of 77%. Compare that to the national unemployment average of 4% to 5%.

Congress has not changed the federal income guideline rules since the 1930’s when Congress designed the Federal income guideline limits for benefits such as SSI, SSA, and SSDI. Cash Assistance Services is the Federal income guideline limits for benefits such as SSI, SSA, and SSDI. Cash Assistance Services is the Federal income guideline limits for benefits such as SSI, SSA, and SSDI. Cash Assistance Services is the Federal income guideline limits for benefits such as SSI, SSA, and SSDI. Cash Assistance Services is the Federal income guideline limits for benefits such as SSI, SSA, and SSDI. The Eligibility Rules need to be restructured in this country, especially when it comes to people with disabilities who often have no other option. There is no financial safety-net for people with disabilities.

Employment opportunities for people with disabilities is the answer but that is extremely difficult when you take everything into consideration in this country.

Jocelyn C. Gallant
Salem, New Hampshire

Power in History

"Those who ignore the past are condemned to repeat it."

Confronted with the realization of disability in New Hampshire in the year 2004, it became clear to our staff that the best service we could provide the Granite State is an accurate history of what brought us here.

Our history provides the answers to those who question the fierce defense parents and families waged so as not to lose the hard won rights of and supports for people with disabilities. History reveals that without parents such as Vera Hill, Freda Smith and Peggy Straw, State Legislatures and Governors past would have kept our disabled family members hidden away from a world they walk in freely today. We must not take that for granted.

Our history is witness to the bravery of families who stood up for their family members in the face of resistance for “cost benefits.” Parents before us were forced to initiate a lawsuit to end the results of budgets based on the cost benefit of providing working toilets for example, for people with mental retardation. Such cost benefit analysis allowed abuse to be easily hidden from public-review.

And, remember, the Laconia State School only closed in 1991; a scant thirteen years ago.

Last year, The Challenge covered a story about a movement to restore a pastoral segregated setting for people with disabilities.

Read carefully the history of our people in this issue. Listen carefully to the upcoming arguments involving various attempts at reform. Listen for the cost benefit analysis that could have major impacts on people’s lives. Remember always that cost benefit and good intent created Laconia, and could once again create an environment devoid of supports exactly the situation that forced families to commit their children to an institution in the first place.

Families must become fully informed, fully aware of the alternatives, and fully aware of the motivations behind the various “improvements and modernizations” that are being currently espoused. Without family scrutiny, and family recourse to their elected officials, another Laconia will rise.

None of us want that. Families, pay attention to the gathering clouds that signal a coming storm.

Read, educate yourself, advocate, contact your legislator, and vote your best interests in the upcoming elections.

Only by your personal vigilance will your family members’ liberties and well-being be assured.

Please give generously to The Challenge. Help us to help you.

Tidal wave

The New Hampshire Challenge, Summer, 2004
Upcoming Events

August

Secondary Transition Planning Institute
Sponsored by: NH Department of Education State Improvement Grant, College for Lifelong Learning, Keene State College, Plymouth State University and Rivier College
Date: August 6, 2004
Time: 8 AM to 3 PM
Where: Plymouth State University's Prospect Dining Hall, Plymouth, NH
Cost: Unknown
For more information, contact Barbara Raymond, Bureau of Special Education, NH Department of Education at 271-3791 or e-mail her at braymond@ed.state.nh.us

Summer Sports Challenge (formerly the Casco Bay Challenge)
A 5 event 35 mile relay race for both able-bodied and disabled athletes. The course consists of swimming (1 mile), biking/hand cycling (20 miles), canoeing (4 miles), running/wheelchair racing (5 miles) and kayaking (5 miles). The Summer Sports Challenge, unique to Maine, is the only competitive sports event in Maine that encourages people with physical disabilities to participate alongside able-bodied athletes.
Sponsored by: Maine Handicapped Sports Council
Date: August 14, 2004
Time: 7:30 breakfast for all racers; Race begins at 9 AM
Cost: Team of 1: $50; Team of 2: $95; Team of 3: $130; Team of 4: $165; Team of 5: $200; and Team of 6: $235
For more information, contact Terrie-Anne Gury, Race Coordinator at 1 (800) 639-7770 or tgage@skimhs.org or visit the website at www.skimhs.org.

Educating Students with Autism Spectrum Disorders in General Education Classrooms
Sponsored by: UNH Institute on Disability/UCED and NH Department of Education
Date: August 16 - 19, 2004
Time: 8:30am - 4pm daily
Where: UNH Memorial Union Building, Holloway Commons
For more information: call (603) 228-2084

Boundless Horizons
32nd Annual Convention of the National Down Syndrome Congress
Date: August 20 – 22, 2004
Where: Hyatt Regency, Minneapolis, Minnesota
Cost: $85 individual, $150 family (member NDSC); $115 individual; $150 family (non-members), Additional cost for pre-conference sessions, banquet, Youth/Adult conference and Brothers/Sisters conference.
For more information: call 1 (800) 232-NDSC or visit website: www.ndsc.org

September

Solving the Relationship Puzzle: Opening Doors to Friendship for People on the Autistic Spectrum
Sponsored by: Crotched Mountain
Featured speaker: Dr. Steven E. Gutstein
Date: September 17 & 18, 2004
Where: The Wayfarer Inn, Bedford, NH
Cost: Unknown
For more information: contact Lindy Hughes at (603) 547-3311, x 598, or e-mail: lindy.hughes@crotchedmountain.org

Real Choice, Systems Change
2nd Annual Real Choices for Older Adults and Individuals with Disabilities Living in Your Community
Date: September 28 & 29, 2004
Where: Grand Summit, Bartlett, NH
Cost: Unknown
For more information: contact Janet Williamson at (603) 228-2084 or (800) 238-2048 or e-mail: lgw@caunhs.unh.edu

Approaches that Work: Multi-Stressed Families and their Young Children
Sponsored by: New Hampshire Association for Infant Mental Health
Date: September 30 and October 1, 2004
Where: The Red Jacket Mountain View Resort, North Conway, NH
Cost: $125 registration fee; Room rate: $109 per night
For more information: contact Linda Thomas at (603) 225-5359 regarding registration; Red Jacket Mountain View at 1 (800) RJACKET for reservations

October

Third Annual Buddy Walk
To promote acceptance and inclusion of all individuals with Down syndrome
Sponsored by: 2004 Buddy Walk Committee
Date: October 2, 2004
Where: State House Plaza, Concord, NH
For more information, contact Sara Denney at 715-2450

Lakes Region Self-Advocacy Group Celebrates 20 Years!
The Lakes Region Self-Advocacy Group is the longest running self-advocacy group in the state.
Date: October 23, 2004
Time: All day into the evening with a pizza dinner and dance
Where: Unitarian Universalist Church of Concord
Cost: about $10
For more information, contact

November

Blazing the Trail 2004 TASH International Conference
The TASH Conference, one of the largest conferences in the world to focus on model, innovative, and effective strategies for achieving full inclusion of all people with disabilities, features over 250 sessions, exhibits, roundtable discussions, and poster sessions jam-packed with info. It provides a forum for individuals with disabilities, families, researchers, administrators, policymakers, educators, scholars, and others to create a dialogue and action for reform.
Date: November 17-20, 2004
Where: The Hilton, Reno, Nevada
Cost: Varies
For more information, call 410-828-8274 or visit the website: http://tash.org/2004reno/

Ride-Away Corporation Helps You Get Back On The Road Again!
Ride-Away Corporation is New England's largest provider of modified vehicles and adaptive equipment for people with disabilities. The company sells new and previously owned vehicles as well as offering a full range of vehicle modifications including hand controls, wheelchair and scooter lifts, ramps, raised doors, lowered floor and specialized gas, brake and steering controls. Flat-taxed warranties and financing are also available. Rental vehicles are available on a daily, weekly or monthly basis with 24 hour emergency roadside assistance.

Contact an office near you at 1-866-Ride-Away.
Area Agencies for Developmental Services

REGION I - North Country
Northern New Hampshire Mental Health and Developmental Services, Inc.
87 Washington Street, Conway, New Hampshire 03818
Dennis Mackay, exec dir.
Eric Johnson, operations manager
Phone: 447-3347 Fax: 447-8893 1 (800) 439-3347
e-mail: dmackay@nnhmhds.org  website: nnhmhds.org

Area Offices:
Upper Connecticut Valley Mental Health and Developmental Services (MH)
Charlie Cotton, area director
34 Colby Street, Colebrook, New Hampshire 03576
Phone: 237-4955
White Mountain Mental Health and Developmental Services (MH) outpatient
29 Maple Street, P. O. Box 599, Littleton, New Hampshire 03561
Jane MacKay, area director
Phone: 444-3535

Family Centered Early Supports and Services
29 Maple Street, P.O. Box 599 Littleton, New Hampshire 03561
Director: Kelly Deslerts. OTR/L
Developmental Specialties:
Berlin/Groveton - Ann Griffin  Phone: (800) 862-8634 x 4551 agriffin@nnhmhds.org
Littleton - Peg Roy 444-1742 mroy@nnhmhds.org

Developmental Services:
Community Services Center
69 Willard Street, Berlin, New Hampshire 03570
Art Froburg, area director
Phone: 752-1005
Common Ground (headquarters for day service & case management)
29 Maple Street, Box 599, Littleton, NH 03561
Phone: 444-3535

Vershire Center:
39 Colby Street, Colebrook, NH 03576
Phone: 237-5721

Berlin area -
Family support/Respite coordinator: Lena Parent 752-1005 x 3343 lparent@nnhmhds.org
Benefits technician: Sharon Kolinsky 752-1005 x 3307 skolinsky@nnhmhds.org

Colebrook/Groveton -
Family support /Respite and resiliency coordinator/Legislative liaison/Parent to
Parent coordinator: Stacey Bilodeau 636-6193 x 3558, or
(800) 862-8634 x 3558 sbilodeau@nnhmhds.org
Benefits technician: Lynda Biron 237-5721 lbiron@nnhmhds.org

Littleton -
Family support /Respite coordinator: Lena Parent 752-1005 x 3343 lparent@nnhmhds.org
Benefits technician: Sharon Kolinsky 752-1005 x 3307 skolinsky@nnhmhds.org
Family support council chair: Nancy Norman 638-2650 nnorman@adelphia.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@dscofnh.org
Case Management: 542-8706
Adult Services: 542-8706

Family support coordinator/Respite coordinator/Legislative liaison:
Jean Warner 542-8706 jw WARNER@dscofnh.org
Early supports and services: Raymonda Semara 542-8706 x114 rsemarais@dscofnh.org
Benefits technician: Rhonda Desmarais 542-8706 x114 rdesmarais@dscofnh.org
Family support council chair: William Hodge 542-3124
Q/A complaints: Mark Mills (as above)

REGION III - Lakes Region
Lakes Region Community Services Council
(Serves all of Belknap & 12 towns in southern Grafton Co.)
P. O. Box 509, Laconia, New Hampshire 03247
(Residential, vocational, quality assurance, business, case management, family support, & enhanced family care)
Rich Crocker, exec. director
Phone: 524-8811 Fax: 524-0702 E-mail: richc@lnsc.org
Website: www.lrcsc.org
Assistant exec director and family support director:
Susan Gunther 293-7371 smgunther51@juno.com
Complaint investigator: Peter Bacon 524-8811

REGION IV - Capitol District
Community Bridges
525 Clinton Street, Bow, New Hampshire 03304-4609
Roy Gerstenberger, exec. dir.
Phone: 225-4153 or 800-499-4153
Website: www.communitybridgesnh.org
Director of family support: Jo Edwards 225-4153
(800)499-4153, ext.224 jedwards@communitybridgesnh.org
Respite coordinator: Renee Carlisle
225-4153 ext.215 rcarlisle@communitybridgesnh.org
Parent-to-Parent liaison: Becky Thompson 225-4153 or
(800) 499-4153, ext. 241bthompson@communitybridgesnh.org
Benefits technician: Rebecca Spinney
225-4153 ext. 222 rspinney@communitybridgesnh.org
Family support council chair:
Annette Kowalczyk 224-1524 skowalczyk@comcast.net

REGION V - Monadnock
Monadnock Developmental Services, Inc.
121 Railroad Street, Keene, New Hampshire 03431
Alan Greene, exec. director
Phone: 352-1304 Fax: 352-1637
E-mail: alan@mds-nh.org  Website: www.mds-nh.org
Director of service coordination: Sheila Mahon 352-1304
juJie@mds-nh.org
Director of children’s service coordination: Julie Cashin 352-1304 julie@mds-nh.org
Director of adult service coordination: Lance Forster 352-1304
LanceF@mds-nh.org
Respite coordinator: Carol Byrnes 352-1304 carolb@mds-nh.org
Benefits technician: Sue Raymond 352-1304 suer@mds-nh.org
Early supports and services: Anna Lake 352-1304
Azana@mds-nh.org
Legislative liaison/Family support council chair:
Larry Butcher 357-8383 lb butcher@aol.com
Family support council vice-chair: Danteirirr 355-0152 ddowning@co.cheshire.nh.us

REGION VI - Nashua
The Area Agency of Greater Nashua, Inc.
144 Canal Street, Nashua, New Hampshire 03064
Sandra Pelletier, exec. dir.  Direct Phone line: 459-2701
E-mail: spelletier@region6.com
Beth Raymond, assoc. dir.  Direct Phone line: 459-2704
E-mail: braymond@region6.com
Website: www.region6.com
Family support coordinator
Monadnock - 459-2700
Monadnock - 459-2700

Family support coordinator:
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Monadnock - 459-2700
Monadnock - 459-2700

Family support coordinator:
Where to Find Help

Statewide Resources

Hands-on technology exploration; loans of assistive technology; training; technical support

AETECH Services
603-228-3900 V/VVI, or 1-800-932-5837
Website: www.nhassistivetechnology.org,
AETECH is an umbrella organization under which the following organizations function:

NH-AETEC
67 Communications Drive
Laconia, NH 03246
1-800-932-5837
Lorraine Halton, Clinical Director
E-mail: lorraine@nhetservices.org
Provides highly specialized evaluations and consultations in the area of assistive technology: Seating and wheeled mobility Augmentative & alternative communication
Computer access
Home & worksite modifications

ASSETT - Assistive Services to Schools for Education, Technology and Training - 17 Pleasant Street
Dulilloff Building
Concord, NH 03301
603-228-2900
Donna Furlong, Admin. Assistant
E-mail: dfurlong@nhaat.mv.com
Consultations & Technical assistance; Loans of specialized equipment and materials; Training for educators, parents & children; Library for families & educators

REM (Refurbished Equipment Marketplace)
84 A Iron Works Rd.
Concord, NH 03301
603-224-7630 or 1-800-427-3338
Paul Laff, Coordinator
E-mail: plaff@nhaat.mv.com
website: www.nhatassistivetechnology.org
Sale of quality refurbished equipment; Rentals, service & repair; Information & referral services; Inventory on website

TEC Exploration Center
117 Pleasant Street
Dulilloff Bldg.
Concord, NH 03301
603-224-2900
Leo Benoit, Technician COT/A
E-mail: lbenoit@nhaat.mv.com

Autism Society of NH
P.O. Box 68
Concord, NH 03302
603-236-2424
E-mail: nhautism@yahoo.com
website: www.autism-society-nh.org
Statewide organization provides information, advocacy and support to individuals with Autism and Pervasive Developmental Disorders (PDD), and their families.

Brain Injury Association of New Hampshire
109 N. State Street, Suite 2
Concord, NH 03301
603-225-8400, or 1-800-773-8400
E-mail: mail@bianh.org
Statewide organization provides resource information to survivors of brain injury and their families.

Bureau of Vocational Rehabilitation
78 Regional Drive, Bldg. 2
Concord, NH 03301
*New address as of 8/23/04*
21 S. Fruit Street, Suite 20
Concord, NH 03301
(phone numbers will remain the same)
603-271-3471 (V/TTY)
or 1-800-299-1647
Fax: 603-271-7931
E-mail: slambert@ed.state.nh.us
website: www.ed.state.nh.us
Provides individualized guidance, counseling and placement services to eligible consumers; New program provides family services around needs of individual

Child Development Center
Dartmouth-Hitchcock Medical Center
603-655-6060
Assessment, diagnosis, follow-up, information and education

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

Department of Education Bureau of Special Education
101 Pleasant Street
Concord, NH 03301
603-271-3741
Fax: 603-271-1099
E-mail: nhvity@ed.state.nh.us
website: www.ed.state.nh.us
Responsible for ensuring that school districts provide a free and appropriate education to all educationally handicapped students

Disabilities Rights Center, Inc.
18 Lov Ave.
P.O. Box 3660
Concord, NH 03302-3660
603-228-0432, or 1-800-834-6721 (V/TTY)
603-225-2077
E-mail: advocacy@drccn.org
website: www.drccn.org
Provides legal services and advocacy assistance to persons with disabilities; information/referral

Early Education and Intervention Network of N.H.
10 Ferry St., 6141
Concord, NH 03301
603-228-2840
E-mail: info@eein.org
website: www.eein.org
Information & support to promote best practices in early intervention and early childhood/special education

Family Resource Connection
603-228-2311 or 1-800-228-4321
Alice Nye, Coordinator
E-mail: aynye@library.state.nh.us
Website: www.library.state.nh.us

Granite State Independent Living (GSIL)
21 Chenell Drive
Concord, NH 03302-9680
603-228-9680, (V/TTY)
1-800-826-3700 (V/TTY)
Fax: 603-225-3394
E-mail: info@gsgs.org
website: www.gsgs.org
Provides guardianship, protective, fiduciary services and 24 hour emergency coverage to incapacitated residents of NH

Granite State Independent Living (GSIL)
Concord, NH 03302-9680
603-228-9680, (V/TTY)
1-800-826-3700 (V/TTY)
Fax: 603-225-3394
E-mail: info@gsgs.org
website: www.gsgs.org
Provides guardianship, protective, fiduciary services and 24 hour emergency coverage to incapacitated residents of NH

NH Association for the Blind
603-224-6039 or 1-800-464-3075
E-mail: services@sightcenter.com
website: www.sightcenter.com
Provides information and gives direct services to people of all ages who are blind and visually impaired to enable them to maintain their independence

N.H. Developmental Disabilities Council
10 Ferry Street
Concord, NH 03301
603-231-3236
1-800-852-3345, x 3236
E-mail: nhdncel@aol.com
website: www.nhddc.org
Monitors services; promotes policy; advocacy

NH Family Voices, a Family to Family Health Information and Resource Project
603-271-4525, or 1-800-852-3345 x 4525
E-mail: nhfv@yaho0.com
website: www.nhfv.org
Assists families in finding their way through the maze of services
Where to Find Help

Statewide Resources

Partners in Health

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

PIH offers families the services of a Family Support Coordinator, respite funds, a resource library and the opportunity to participate in community health care planning. Families can also receive help accessing resources, and solving problems with insurance, finances, and education. As of FY ending June 20, 2001, PIH served 500 families, made 2,900 child contacts, 1,400 of which were contacts with children on Medicaid.

Partners In Health Locations

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

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

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

REGION 4: Community Bridges
Janice Boushrea
525 Clinton St.
Bos, NH 03040
603-226-3212

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

REGION 6: Area Agency of Greater Nashua, Inc.
Nancy Lucci
144 Canal Street
Nashua, NH 03064
603-429-2744

REGION 7: VNA of Manchester and Southern New Hampshire
Sandra Kazaks &
Carmen Polo
1850 Elm St.
Manchester, NH 03104
603-622-3781

REGION 8: Families First of the Greater Seacoast
Georgie Clark
100 Campus Drive, Suite 12
Portsmouth, NH 03801
603-423-8208

REGION 9: Community Partners
Sarah Small
Forum Court,
113 Crosby Road, Suite 1
Dover, NH 03820
603-749-4015

www.state.nh.us/nhsl/talkbks

FREE service for people with visual, physical, and reading disabilities. Supplies (by mail) cassette books and records and equipment needed to use them. Fiction, non-fiction and popular magazines available.

VSA arts of New Hampshire
44 South Main Street
Concord, NH 03301
603-228-4330 (V/TTY)
Fax: 603-225-7240
E-mail: info@vsartsnh.org
website: www.vsaartsnh.org

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

To have a resource listed in The Challenge, contact us at:
(603) 742-0500, or 1 (800) 798-6430, or e-mail us at:
nhchallenge@comcast.net
Additional Resources

NH Community Mental Health Centers

Region I
Northern NH Mental Health and Developmental Services
Dennis McKay, executive director
87 Washington Street
Conway, NH 03818
Phone: 603-447-3347
Fax: 603-447-8893
website: www.nhmdhs.org

Region II
West Central Behavioral Health/Dartmouth-Hitchcock
Jesse Turner, executive director
2 Whipple Pl., Suite 202
Lebanon, NH 03766
Phone: 603-448-0126 or 1-800-540-0126
Fax: 603-448-0129
website: www.wcbh.org

Region III
GENESIS Behavioral Health
Michael Coughlin, executive director
771 N. Main Street (Children’s services)
III Church Street (Adult services)
Laconia, NH 03246
Phone: 603-524-1100
Fax: 603-524-6000
website: www.genesisbh.org

Region IV
Riverbend Community Mental Health Center
Alan Moses, interim executive director
Bret Longgood, chief operating officer
70 Pembroke Road
Concord, NH 03301
Phone: 603-228-1600
Fax: 603-226-7526
website: www.riverbendcmhc.org

Region V
Monadnock Family Services, Inc.
Kenneth Jue, executive director
64 Main Street, Suite 301
Keene, NH 03431
Phone: 603-357-4400
Fax: 603-357-6859
website: www.mfs.org

NH Department of Health and Human Services
District Offices

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

Claremont
17 Water Street
Suite 301
Claremont, NH 03743-2280
(603) 542-9544, or 1 (800) 982-1001

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

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

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

Littleton
Lisbon Road
80 North Littleton Road
Littleton, NH 03561-3814
(603) 444-6786, or 1 (800) 352-8959

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

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

Portsmouth
30 Maplewood Avenue, Suite 200
Portsmouth, NH 03801-3737

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

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

TOO Acess; Relay NH
1 (800) 735-2964

People First of NH has a great way to raise funds for their organization while you shop online at your favorite stores. If you haven’t visited their website recently, please do. There, you will see a few different links to take you to shop at Amazon, Current, and Heartof (which is like a huge online mall of various stores such as Target, Orvis, Eddie Bauer, Office Max and more). Once you make a purchase by first going to their site, People First of NH will receive a percentage of the sales.

Remember to shop through People First of NH, first, so that they receive credit on your purchase.

www.peoplefirstofnh.org or http://www.peoplefirstofnh.org/online_fundraising_for_people_fi.htm
Additional Resources

Helpful Websites:

1. **www.aapd.com** - American Association of People with Disabilities
2. **www.abledata.com** - Federally funded project providing information on assistive technology and rehabilitation equipment from domestic and international sources
3. **www.access-able.com** - Access-Able Travel Resource
4. **www.adanet.org** - American Disability Association
5. **www.albinism.org** - The National Organization for Albinism and Hypopigmentation
8. **www.ataccess.org** - The Alliance for Technology Access, a network of community-based Resource Centers, Developers, Vendors, and Associates, provides information and support services to children and adults with disabilities to increase their use of standard, assistive and information technologies.
10. **www.benefitscheck-up.org** - A nonprofit initiative led by the National Council on Aging which features a database of roughly 1,000 federal and state programs for the elderly and people with disabilities.
11. **www.cast.org** - Center for Applied Special Technology is a not-for-profit organization whose mission is to expand educational opportunities for individuals with disabilities through the development and innovative uses of technology.
14. **www.cssn.org** - Community Support Network, Inc., a not-for-profit organization that works in support of the 12 Area Agencies. It serves as the communication and contact center on developmental disability issues and services.
15. **www.dhhs.state.nh.us** - NH Department of Health and Human Services - information on benefits programs
16. **www.dot.gov/accessibility** - The US Department of Transportation's site for information about air travel for people with disabilities
21. **www.fctd.info** - The Family Center on Technology and Disability offers a range of information and services on the subject of assistive technology (AT).
22. **www.hhs.gov/newfreedom/US Department of Health and Human Services' New Freedom Initiative**
23. **www.inclusionresearch.org** - Inclusion Research Institute - a nonprofit organization whose activities include education, research, and dissemination of information promoting inclusion.
25. **www.nhs spinal.org** - NH Chapter of the National Spinal Cord Injury Association
27. **www.nod.org** - National Organization on Disability - works to expand the participation and contribution of American men, women, and children with disabilities in all aspects of life.
28. **www.peoplefirstofnh.org/Advocacy%20and%20Politics.htm** - Provides information for people who have an interest in what is happening in the government.
29. **www.sath.org** - Society for Accessible Travel & Hospitality
30. **www.section508.gov** - Offers resources for understanding and implementing Section 508 which requires federal agencies' electronic and information technology to be accessible to people with disabilities
32. **www.socialsecurity.gov** - Information on Supplemental Security Income (SSI), disability and related benefits

Publications of Interest

**Disability Solutions**
FREE
A resource for families and others interested in Down syndrome and related disabilities
Published six times a year
For information on subscriptions, call (503) 244-7662
www.disabilitysolutions.org
subscription@disabilitysolutions.org

**Exceptional Parent Magazine**
Paid subscription $39.95 a year
(877) 372-7368
website: www.EParent.com
Features articles, extensive listing of national organizations for specific disabilities/conditions

**New Developments**
Benefit of membership
(800) 652-2263
E-mail: devdelay@mindspring.com
website: www.devdelay.org
(cost of membership $50 for families; $60 for educators; $90 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 prevention for developmental delays by seeking healthy options for the whole child

**Family Voices**
FREE
(603) 271-4525 or 800-852-3345 x 4525
E-mail: tafve@yahoo.com
website: www.nod.org
Resources and information for families with special health care needs; quarterly

**Rugged Edge**
Paid subscription $35 a year
Fax: (301) 652-2263
E-mail: calculation@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
To Do What Has To Be Done

Even though our journeys may seem lonely at times, we must never forget that people of singular courage walked before us. Vera Hill was a gentle person. Her strength was hidden beneath humility, but it was there. Listening to her reminisce about a time when people with disabilities were hidden out of shame was like visiting another era. How did she change the world into which her daughter was born over 50 years ago? What did Vera do to give her child what every parent wants... a promising future?

Vera’s answer was simple and clear: “I did what I had to do.”

This phrase, arising from deep within the soul of an eighty-one year old woman, captures the essence of every parent in this Granite State - past and present. For Vera, that meant joining the staff at Laconia State School, and with a group of other equally devoted parents, playing a part in laying the groundwork for human dignity to enter that place. From that foundation would develop a groundswell of families with dogged courage to challenge Laconia’s very existence. Vera joined in with still other families to help create opportunities for people with disabilities in their communities when there were none at all, and their efforts were the small beginnings of what would ultimately become a system of community-based services and an educational system that was inclusive.

“I did what I had to do.” The power of that single-minded devotion has echoed throughout the corridors of state government, stymying the efforts of more than a few otherwise brilliant public servants who failed to understand the bottomless well of motivation and courage that families possess.

Vera returned to her maker in 1998, after a singular life of service and dedication to her daughter and countless others. She left New Hampshire a better place for those who came after her. We are continually amazed at how many “Veras” we have met over the last 16 years - parents who do what they have to do, who are fearless in the face of political pressure and who, in the process, discover talents they never knew they had. All because of the deep love they have for their sons and daughters.

If we have learned one lesson over the last 16 years, it is this: In New Hampshire, progress for people with disabilities occurs only in partnership with families. The power of their love breaks down walls, even those made of granite. And the combined power of their determination erects walls as strong as granite against those who choose to ignore them.

In our state, it’s about families. It’s about every parent who, like Vera, has said: “I did what I had to do.”

We at The Challenge pledge to follow Vera’s example. We will do what has to be done to bring accurate information to you. With information, you will find the power to do what you have to do.

Spread the Word! Do you know someone who could use The Challenge?

Name ____________________
Street address ____________________
City __________________ State ______ Zip ______
Phone __________________
E-mail address ____________________

* There is no cost for this publication.