The New Hampshire Challenge

disability issues from a family perspective

published quarterly by: The New Hampshire Challenge, Inc. P.O. Box 579, Dover, NH 03821-0579
Volume 16, Issue 4
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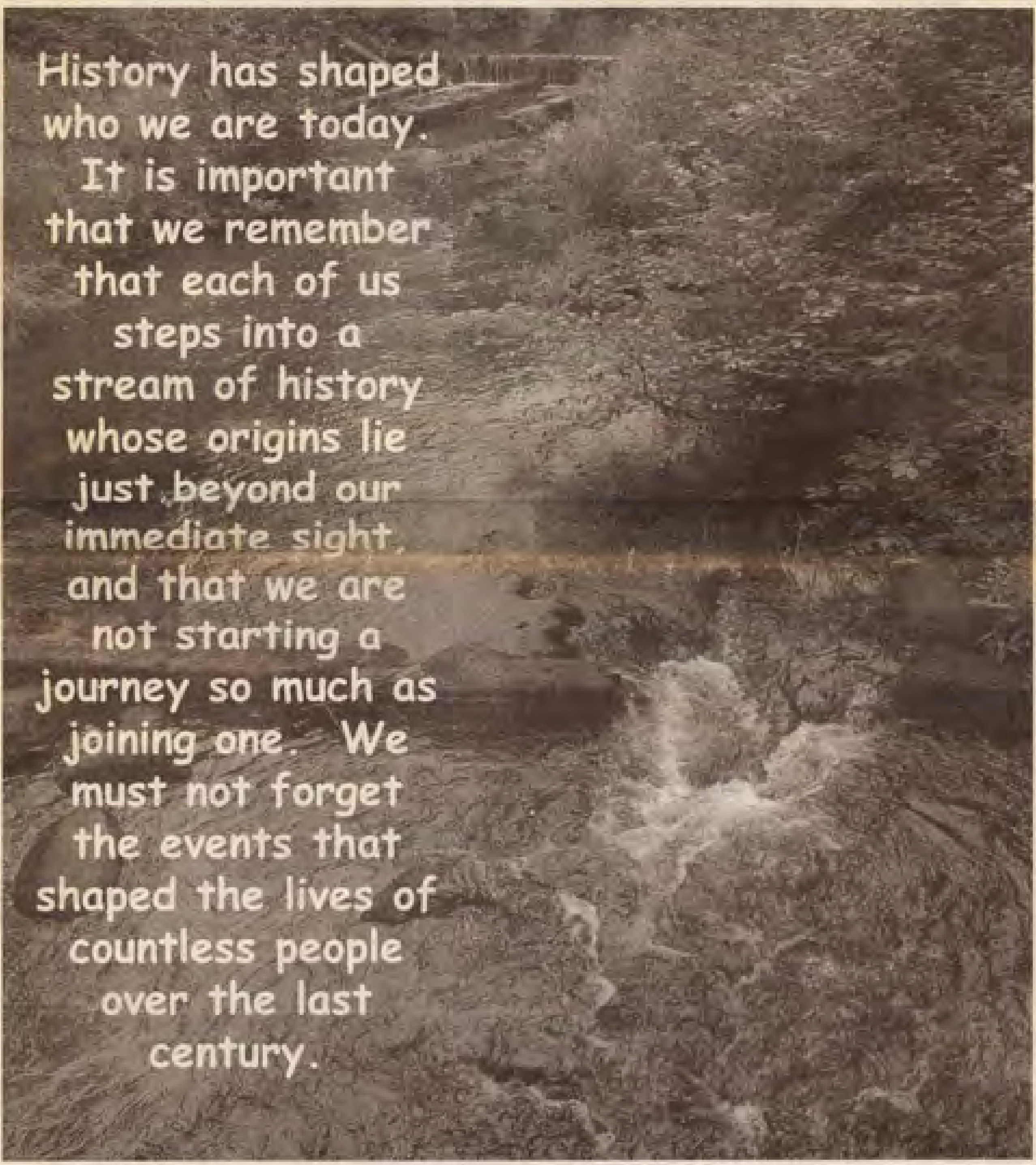
Summer, 2004



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."

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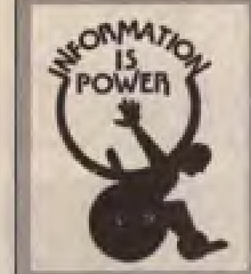

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Printed by: Seacoast Newspapers

The New Hampshire Challenge
P.O. Box 579
Dover, NH 03821-0579

Website: www.nhchallenge.org
Wewbsite Host: PortCity Web

THE NEW HAMPSHIRE SCHOOL FOR FEEBLE-MINDED

LACONIA, NEW HAMPSHIRE

1921

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.XCI, 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 256, 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 is it 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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The History of Laconia State School

by: Janet M. Kramm

Special thanks to Gordon Dubois and Heather Crocker who collected, preserved and studied the huge amount of records from Laconia State School when it closed its doors. This article, originally published in the Fall, 1994 issue of The New Hampshire Challenge, is the result of their research. Some additional material comes from the book Making Minds Feeble, by J. David Smith, an Aspen Publication.

Archival Photo

The first administration building on the grounds of The New Hampshire School for Feeble-minded, 1903. This building was the living quarters of the Superintendent, and also served as the dining hall for the first residents. Meals were cooked and served by the Superintendent's wife.

In 1901 legislation was passed that created the New Hampshire School for Feeble-Minded 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 teenaged 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 included 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 segregation of the insane, or toward the suppression of the social evil, we shall contribute little 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."

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> I know no safe depository of the ultimate powers of the society but the people themselves;
>
> and if we think them not enlightened enough to exercise their control with a wholesome discretion,
>
> the remedy is not to take it from them, but to inform their discretion by education.
>
> Thomas Jefferson
>
> In a letter to William Charles Jarvis
> September 28, 1820

A classroom for the first residents. **Archival Photo**

Continued from page 3

I.Q. tests, marriage laws, and sterilization

In the second decade of 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. Now professionals had a means to scientifically identify feebleminded people.

In 1915, New Hampshire passed legislation which regulated the marriage of people considered "mental defectives". The law stated: "No woman under the age of forty-five years, or man of any age, -- except he marry a woman over the age of forty-five years, -- 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 by preventing people 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 put the decision-making authority in the hands of the Board of Trustees and three 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 thoughts 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 inherited.

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 Charities 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 Charities and Corrections. Not considered appropriate for foster care, feebleminded children needed another option. What to do about them?

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

There was great pressure to build a school like the Fernald School in Massachusetts. The effort to do so was led the by Federation of Women's Clubs, under the influence of Lilian Streeter, a member and a nationally recognized advocate for children.

Mrs. Streeter was one of the co-signers of the petition to the Legislature quoted above, which advocated for the creation of the New Hampshire School for Feebleminded Children.

(Mrs. Streeter was named the Chairman of the Committee on Dependent Children for the New Hampshire State Conference of Charities and Corrections. Their 1915 report to the Legislature recommended institutional care for all 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 without families who lived in the almshouses.

By 1910, the School had a new superintendent, Dr. Benjamin Ward Baker, a nationally known and well-respected leader. The number of buildings had increased to include a farm building, a boiler house, a laundry, dining hall (which also housed a dormitory for employees), an additional dormitory (which allowed girls to be housed separately from the boys), and a hospital, in addition to the already existing school and administration building. There were 96 admissions in that year, with the average age being eleven years.

With the emphasis on segregation, the goal of the Home was to be self-sufficient. Dr. Baker, in his report to the Legislature in 1910, recommended that the state purchase as much land as possible around the buildings, to prevent trespassing and to enable the School to raise all the food it needed for the inmates, as well as to feed the horses and cows.

Because of the change in laws regarding eligibility mentioned above, children were kept beyond the age of 21, especially women of childbearing age. The population quickly changed from all children to children and adults. By 1916, there were 293 residents and overcrowding became a problem.

To address the overcrowding, a parole program was instituted, allowing the most capable inmates to be placed in family homes. There they received room and board in exchange for their work as either domestics or farm laborers. However, it was not until 1925 that a parole agent, Herma Rowe, was hired to supervise home placements.

Genetics "research"

In 1912, the results of a study begun in 1906 of the hereditary nature of feeblemindedness were released. This study, called the Kallikak study, 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 descendent was living at the Training School for Feeble-minded 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 reports: "...one of the improvements within which I want to call your attention, and which I hope is only the beginning of further research along

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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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that line, is the one of making careful hereditary studies of our children, with the view that the public may be shown the results of having in the general community this class of defectives. This work, **which has largely been performed by the office assistant,** (emphasis added)...consists of taking some of the most interesting families from which there are, say four in our institution, and then visiting the town from which they came and carefully making a record of as many generations of that family as possible, the whole later being charted and thus showing the number of feeble-minded, epileptic, insane and criminals. The results are very interesting and will be an object lesson to the public."

Note that the above "research" is being done by an office assistant, without any stipulation about his or her research credentials.

Also note that this person, without any acknowledged medical or educational background, is being asked to make diagnoses of people, alive and dead, as to whether they were feeble-minded, epileptic, insane or criminals. In the cases of deceased individuals in particular, these diagnoses were made on the basis of remembrances of others who knew them, some only slightly.

The results of such "research" had powerful influences: the creation of legislation which prohibited marriage and, in 35 states across the country (NH included), permitted sterilization. Ultimately, the conclusions of the "research," coupled with the use of the Binet I.Q. test, led to federal laws which created immigration quotas.

These quotas were based on research which involved giving I.Q. tests to immigrants arriving on Ellis Island. Not surprisingly, there was a high percentage of people who scored in the "feeble-minded" range. The quotas were instituted to prevent an influx of feebleminded people from abroad, with a heavy emphasis on people from eastern and southern Europe. At a time when Jews were trying to leave Europe to escape the Nazis, the United States was preventing their entry to our shores.

Conditions at the School deteriorate

In 1924, the name of the New Hampshire School for Feebleminded Children was changed to Laconia State School. The years during World War I, the depression and World War II were difficult years for the institution. Because there were less resources at home, more and more families applied for their family members to be admitted to the school. However, the state was not willing to increase the funding for the school. In the superintendents' reports in those years, there are requests for new construction and repairs that are repeated for years without being addressed by the legislature.

There is a dearth of records on individuals for this period, which is consistent across the country.

By 1942, there were 614 people living at Laconia State School. There developed a class society within the School, with the more capable individuals working (without pay) and the less capable doing nothing. At this time, the farm at the School yielded huge crops, providing capable workers with plenty to do. Women helped care for other less capable inmates, which augmented a meager staff. Staff were working 51 hours a week on two shifts, with one staff person typically responsible for 30 to 50 people.

Inmates did leave Laconia State School. During the war years, those able to enlist in the armed services were encouraged to do so. However, in order to return to the community, inmates had to agree to submit to sterilization. The law provided that inmates could be sterilized without the consent of a parent or guardian. The Board of Trustees of the Laconia State School were invested with the authority to decide such matters.

By 1950, conditions at the School were grim. The dormitories were overcrowded. Some residents worked around the institution, but many did nothing for the entire day. Rooms were drafty, beds were pushed together with no room in between. There was no room for personal possessions.

The walls and floors of the buildings were made of brick and tile. Drains were built into the middle of the floor to facilitate cleaning, which consisted of hosing down walls and floors. Furniture was selected for its facility in cleaning, so there were no stuffed chairs or couches. Benches lined the walls.

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.

Inmates did not have personal clothing items. People wore what was available, whether it fit or not, creating a bizarre look. There were no shoes available, only cloth slippers, and not enough for everyone. It was common for the inmates to be barefoot. Some didn't even wear clothes.

Drugs were used to control the inmates because the

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Laconia State School Archival Photo

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staffing shortage was so severe. In 1952, a television was donated to the School and that became the preferred "program" for the inmates. Televisions soon filled the common rooms, encased in boxes covered with wire, and controlled by the staff.

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."

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 groups. They appealed to community groups across the state to donate needed items to the School to supplement the minimal supplies allotted by the state. They created a St. Nicholas Club to provide gifts for the residents at Christmas. They worked with Hungerford to build an all-faiths chapel on the grounds.

It wasn't long before they realized they needed funds, and in 1955, they participated in the national fundraising campaign of the National Association of Retarded Children (NARC), an annual campaign which grew more successful each succeeding year.

Chemung Cemetery

Photo: E.G. Stone

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.

A major achievement in the early years of the parent movement was the creation of the Summer Workshops for teachers at the Laconia State School. Targeting public school teachers throughout the state, the purpose was to train teachers how to teach children with mental retardation. Teachers could receive either undergraduate or graduate credit for completing the workshop.

Additionally, the parents' group lobbied to pass legislation amending the Public School law to include "educable child with retarded intellectual development" under the definition of handicapped, which before had meant only physically handicapped children. They fought for mandatory education for children with mental retardation, but the legislation that ultimately passed merely allowed education.

> ***"In order to be effective partners...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

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 homelike. There were curtains on the windows, room for private possessions, bedrooms for 2 or 3 people instead of large groups. He instituted co-educational activities for the residents, and succeeded in having a geriatrics 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."

The parents circulated petitions in support of Hungerford, collecting 1,600 signatures on one petition alone in a matter of hours. But to no avail. Hungerford resigned in 1960.

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

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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 dismantled by 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 1968, 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 instituted 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 990 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 developmentally 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 rehabilitative services as this 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 into Laconia to make recommendations on how to improve the program. His observations reflect the bleak atmosphere of the School. Despite the gains secured by the lobbying efforts of the parent movement, living conditions at the school remained desolate.

Buildings were old, lacked privacy, needed renovations. Resources were few, clothing spare, shoes almost non-existent. Understaffing was rampant, turnover frequent, burnout the norm. Education programs were limited, arbitrarily offered, poorly organized. The entire School had only 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 state of 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 on more pressure to improve conditions. Parents invited the community in to see the institution. Jack Melton, 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 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 clients 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, parent groups resorted to the power of the court to force change.

The Garrity v. Gallen suit resulted in a court order to reduce the size of the institution and ordered 235 community placements, stopping short of ordering the institution to close it doors altogether. A backlash in the communities resulted. Hostility emerged to having group homes in the local communities. Newspapers were filled with articles about community reactions as well as letters to the editor protesting this move.

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 philosophies.

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 viable to keep it open any longer.

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

An excerpt from Freda 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. These fears are still very real.

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 that they hear and understand 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 purse 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 see that these 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 alternatives to caring, cost-effective community programs live in the haunted halls of this institution.

Each of us have 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 bodies were held captive here.

We must never forget that there once was a place called Laconia State School and Training Center. For those who know of our past let us take turns reminding us of what it was like to live in Murphy, Powell, Felker, Blood, Baker and Floyd. For those who don't know, 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 live in. I ask each of you to join me - to look ahead, to work hard in the present, but

NEVER TO FORGET THE PAST."

A Glimpse of What Used to Be

by: Janet M. Krumm

Photo: E.G. Stone

Originally published in the Summer, 1995 edition of The New Hampshire Challenge

"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 parent" 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 as an inpatient 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 lifeline 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 in to visit. She credits 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 benefitted 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 propellor 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 would be 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 with them, and

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With all the talk about block grants, cutting services and eliminating benefits, The Challenge thought it would be important to give our readers a taste of what life was like for families before all those services, benefits and laws we take for granted were around. The following are the stories of three New Hampshire women who, out of love for their children, worked to change the status quo. Their advocacy affected the lives of thousands of families in the Granite State.

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soon were joined by others. This group became the Great Bay Association for Retarded Children.

Since their children were not allowed into the schools, these parents decided to create educational opportunities for their children themselves. They started a fund drive and raised a little over $900, which they used to hire a part-time teacher. They were given space in the basement of St. Thomas Church in Dover for a classroom. This was the beginning of the Great Bay School and Training Center, which is presently located in Newington.

Vera and George worked hard to get this project going, but Sally never attended the classes. "Sally never could go," remembered Vera. "She never fit in." But Vera holds no bitterness about that. "We did it because there were others who could go."

Then the Hills heard about a school at Cape Cod that was founded by the Kennedys and they set off to see it. When they arrived, they were told that 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: "They'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 all around. It was new; it hadn't been open very long. They took Sally and showed her around."

The Hills were told by the Mother Superior that Sally was the type of child eligible for the school, but that the decision was made by the Board. Excited and hopeful, the Hills had to wait three weeks before they received word that Sally was accepted. They were ecstatic.

Sally was six years old then, still not talking or even feeding herself. She had never been away from home before. Her attendance at the Kennedy 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 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 herself 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 creation or 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 no recourse. "I cried a lot about it when they let her go," Vera admitted.

Sally, who was now eight, came back home to live once again. There were no resources for the Hills, no school, no programs in the community to help their daughter. There was only one place that offered any help at all - Laconia State School. It was there, that after a year, the Hills took Sally.

Getting Sally into Laconia was not an easy task. An admission form had to be signed by two or three doctors, it then had to go through the courts, and finally, Sally could be committed to the school. "There were "committal" papers," Vera recalled. "Such a hateful word!"

Sally's admission to Laconia coincided with two other major events in the Hills' lives: the death of George's mother and Michael's entrance into elementary school. The days were empty with Sally, Michael and Eva not around. "It was terrible," admitted Vera. "It was a hard thing to do. The only reason people did it was because you didn't know what would happen to your children if something happened to you."

Acknowledging that conditions at Laconia State School were less than ideal, Vera emphasizes that Sally was always treated well. "They were good to her."

Sally was admitted to Laconia State School at the time Richard Hungerford was Superintendent. It was a time of reform. Hungerford was on the cutting edge of best practices at the time, encouraging parents to come to the institution and get involved. He emphasized education for those considered able to benefit, and worked hard to improve conditions at the institution.

It was with his encouragement that parents became more organized and eventually lobbied the Legislature for money to improve conditions and the passage of a law to include children with mental retardation in public education. The legislation was watered down to "allow" school districts, rather than mandate them, to provide an education to children with cognitive disabilities.

The Hills turned their attention and energy to the Laconia State School Association of Retarded Children, becoming very involved. George also became President of the NH Council of Retarded Children, while Vera served as Secretary.

George and Vera both got jobs at the school, George as Supervisor of Food Services, and Vera as Secretary to Richard Hungerford. "He was soft-spoken, very quiet and gentle, and very intelligent," recalled Vera. "He had a lot of empathy for people. He was wonderful to work for."

At first, Hungerford enjoyed the support of the elected officials. The governor at the time was Wesley Powell, and according to Vera, he "was very good to Laconia. He used to come quite a lot to the school and we got a lot of improvements.

"John MacIntyre was Senator at the time," Vera added. "They both got involved and knew the school."

The attitude among most officials, however, was different. "You were supposed to put your child in Laconia and forget him or her," recalled Vera. "It was the end of life, really, or so they thought."

Vera remembered an incident at a legislative hearing that she has never forgotten. The parents were lobbying for money to put in new toilets in the buildings at Laconia to replace those that were cracked and leaking. During the hearing, one of the legislators said plainly: "What's the point in getting all these new bathrooms? They won't know how to operate them anyhow."

Hungerford soon lost his popularity with the Legislature. "All the parents were behind him," remembered Vera. "All he did was for your children." Despite the support of the parents, however, Hungerford was forced to resign in 1960.

Sally continued to live at Laconia until its closing. George died in 1974. Vera sold the secretarial business she founded and went back to school when she was in her sixties to get a Bachelor's degree in Social Work. "I always wanted to do that," she answered when asked why.

At the present, Sally lives in Barrington with Cindy, John, Jake and Dawnelle, a family who is "wonderful" according to Vera. She visits Vera at her home every other week, and is happy. She never did learn how to talk, but communicates her needs effectively with gestures and expressions.

Vera admits to being less involved as she gets older. As long as Sally is happy and well taken care of, Vera is content. Her only worry, albeit a major one, is for Sally's future. Despite the conditions, Laconia State School represented security for Vera. She had placed Sally there, believing that there would always be a place for Sally and people to take care of her. Now, that certainty is gone. "It's lost. I have no security now," Vera laments.

Vera does not see herself as a leader, nor as someone who did anything extraordinary. "We all did what we had to do," she stated simply. "You had your children. You wanted more for them, you worked for it. There was nobody to tell you how to do it."

She pointed, out the lack of information for families when Sally was young. Richard Hungerford had come to New Hampshire from New York. "We didn't know what was going on in New York," Vera explained. "There was no media, no communication." It was difficult to get information of any kind. She scoured magazines for ads or any hint of programs that might help Sally.

She sees no point in painting her efforts as remarkable, and demands no debt of gratitude from parents of today. "I don't think you owe us any great debt," she stated, "because most parents would have done the same thing."

But she does acknowledge that times today are different. "Society has changed. The whole picture has changed," Vera continued. "The approach is different: people's attitudes are different. If nothing else has been gained, there is more of an acceptance of the handicapped."

She does not, however, believe that all is rosy. "There's still so far to go," Vera admitted. "You hesitate to say there's more acceptance.

"That is what is so frustrating."

Vera Hill died on August 25, 1998 at the Wentworth Home in Dover, NH.

Once there was a place called Laconia...

By: Freda Smith

Freda Smith, the parent of Janet Brooke Smith, is a strong advocate for people with developmental disabilities. She was instrumental in the filing of the Garrity vs. Galen lawsuit that first improved conditions at the state institution and eventually led to its closure. Freda has received many awards and recognitions for her work as an advocate and was profiled by the Concord Monitor as one of the 100 People Who Shaped the NH Century. This is a talk Freda delivered to a workshop at the Family Support Conference in Bartlett, NH in Mar. 2004.

Photo: E.G Stone

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 ½ 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

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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 housemate 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.)

"Developmental disability"

means 'developmental disability' as defined in RSA 171-A:2,V, namely "a disability:

1. (1) Which is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other condition of an individual found to be closely related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or requires services and supports similar to that required for mentally retarded individuals; and

(2) Which originates before such individual attains age 22, has continued or can be expected to continue indefinitely, and constitutes a severe handicap to such individual's ability to function normally in society."

"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 prison, always a prison," 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 to be speaking to you today as 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 treatment, 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 house dresses in mental hospitals, staring at the walls. I swore 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 ans seemed interested in hearing from consumers about their needs. Legislators 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 lose 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.

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.

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 by "toxic" or "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.

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 experiential 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 center 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 undeserved 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.

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Update on the Alliance for the Mentally Ill of New Hampshire

by: Janet M. Krumm

From the humble beginnings of Peggy Straw's efforts around her kitchen table over 20 years ago, the Alliance for the Mentally Ill of New Hampshire (NAMI-NH) has grown to 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 to 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 receiving services from multiple systems (e.g., 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 hooking them 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 their situation, and they 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 at how 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 to 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 the information and referral line," he said, "and we have a resource library." The Frameworks 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 in our mission. It's important for us to ensure that families have access to quality services."

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go through the stages of grief that they needed to after the loss of their loved one as they had known him or her, they began to feel empowered as I had after that first meeting in Chicago.

They began to feel in control after having been only reactive in the past to a terrible situation. This empowerment was not only therapeutic for them but it was what was needed to bring about the third Truth - the Change only comes about when enough people care enough to make that change.

Change doesn't come about overnight, unfortunately. But as I look back over the last fourteen years, I can see huge changes in the way families and people with mental illness live in New Hampshire.

The most dramatic change is the closing of the huge, old expensive outdated state hospital and the building of a new, small, state-of-the-art acute psychiatric facility with only 125 beds. We lobbied very hard for a long time to make this happen.

There was no research into mental illness or training in the state for mental health professionals that dealt with people with mental illness. We now have an Institute for Mental Health at UNH, and Dartmouth Medical School provides psychiatrists to the state hospital and conducts valuable research there and throughout the state.

Community Mental Health Centers dealt mainly with people with emotional problems and had few services for those with severe mental illnesses. Today, every one of the 10 CMHC has 24 hour mobile emergency services 7 days a week.

There was no outpatient day program once a patient left the state hospital and there are now programs in every region and liaisons from hospital to community.

There were no individual treatment plans in the hospital, at discharge or in the community. Now, each client has an ITP and a C-3 conference with staff, families and significant others at least once a year.

There was no one to help the client through the maze of entitlements and services available to him or her. Today, there are case managers for every state client, although the case loads are still too high.

There was no supported housing. Today, every region has an array of housing alternatives, although there is still not enough permanent housing. Who among us would not be stressed out by not having a permanent place to live?

The importance of having a job was not recognize and there were no supported work programs beyond what time-limited Vocational Rehabilitation Services offered. Today, every region has supported work programs through the CMHCs.

Families were ignored at best or shunned and left in the dark about their loved one's illness. Today, there is a law in place that provides information to the family if they are primary caregivers. Also, each region provides a family education series to educate the family about mental illness and services.

From a small office in my home, our Alliance now has a 26 member Governing Board, a central office in Concord, an executive director, three staff members and a large volunteer force. There is at least one self-help advocacy group in every region. There is a family 800 Helpline that provides information and referral to families and consumers and a large array of brochures available for information in crisis packages. We are hoping soon to see a bill through the Legislature that mandates equal insurance coverage for mental illnesses with other catastrophic physical illnesses.

I have been credited with having good leadership qualities. I really do not think this is so. In a new book reviewed in Time magazine called Certain Trumpets, the question of what makes leaders successful is addressed. The writer, Gary Wills, asks,

"Where are the great issues and programs that unite leader and led in action? A leader without committed followers is an unheard voice in the wilderness. Followers without a leader who understands their needs are a mere mob. And without a timely, common cause, neither leader nor followers will affect history, for good or ill."

We just had a very necessary cause - one that was right, humane, timely - and we addressed a terrible injustice both to families and their loved ones. I just happened to be the person that got things started because I had an overwhelmingly powerful motive.

In recruiting leaders for self-help groups throughout the country as I did for the National Alliance for years, I would pick out one person from the group who I sensed had that kind of motive and I would encourage him or her just to try leading the group for a while, even though he or she would protest that he or she had no leadership qualities.

The feeling of power that doing something about a bad situation gave them instead of just reacting to it was therapeutic for them and later for their loved ones who learned the power of taking control of their lives and managing their illnesses. Many of them turned out to be much better leaders than I ever was.

They told me at one convention that you "couldn't get there from here" when we were talking about systems change. There were too many jobs that depended on doing things the old way and too many people trained in the old disciplines. Well, in the state of New Hampshire, we have gotten there and the rest of the country is beginning to catch up, albeit slowly.

We still have a long way to go, and we still have to be watchful that things do not slide backwards, but we are all leaders in the Alliance in our own ways, and it can be done.

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 and 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 would be 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. He, along with Pelletier, 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 it 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 demands and yet are 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. Innovation is possible because the Area Agencies are built to be responsive to the people in their particular communities.

Citizen involvement and local control are the cornerstones on which local communities and the state of New Hampshire are founded. 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 concerns 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

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A Brief History of Special Education

by: Jamie Stephenson

In June 2004, throughout New Hampshire students with disabilities walked and rolled across stages, football fields, wooden gymnasium floors, linoleum cafeteria floors, and grassy lawns to receive high school diplomas along with their typical peers.

No one needed to remark on these events. No reporters wrote headlines heralding these diplomas because this is not news now; it is expected.

But in 1975, when the first Federal special education law was passed by Congress, the notion that so many students with disabilities would graduate from their local high schools almost thirty years later would have stunned some of the politicians who voted for the Public Law 99-142.

New Hampshire's commitment to educating students with disabilities officially began in 1965 with the enactment of RSA 186-C which gave children with disabilities a vague entitlement to minimal education. There were no guidelines in the beginning and the wording of the statute was problematic.

The law provided for access to education for children capable of benefiting which some school districts regarded as a release of their obligation to enroll some (or any students) with disabilities. Families and advocates for children with disabilities saw the flaws in the law as a challenge to improve the entitlement. Along the way they were encouraged by national events.

In the 1954 Brown v Board of Education ruling the Supreme Court agreed that segregated schools were detrimental to students. In 1965, the Civil Rights Act outlawed discrimination in housing, employment, and access to public services.

Families of students with disabilities around the nation, inspired by the achievements of the civil rights movement, formed groups and began the uphill climb toward full entitlement to education. Like other citizens, individuals with disabilities should be entitled to a non-segregated education and a non-discriminatory life. Their efforts paid off with numerous state statutes and one landmark federal law.

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.

According to Judith Raskin, former director of the Parent Information Center, it is one of the best written laws ever passed. Now called the Individuals with Disabilities Act (IDEA), it has been amended in large and small ways over the years but the basic requirements of entitlement, least restrictive environment, and due process stand today.

The decades following PL 94-142 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 H that offered states funding to plan for early intervention service systems for infants and toddlers
* 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

Events in New Hampshire also changed special education during those years. The establishment of the Parent Information Center in 1977 swelled the ranks of parent advocates as a catalyst for change.

The establishment of the Institute on Disability in 1987 further invigorated families to seek better, more inclusive programs for their children with disabilities.

The closing of Laconia State School in 1991 spotlighted New Hampshire as a leader in community based services for individuals with disabilities.

Teacher preparation is an important part of special education. Training well-qualified, enthusiastic teachers has been a goal in New Hampshire. In addition to the Institute on Disability, the Institute on Emotional Disabilities at Keene State College established in 1994 and the Center for Professional Educational Partnerships at Plymouth State College offer training and staff development for special education professionals.

Many New Hampshire parents have exercised their due process rights to mediation and hearings over the years. Two cases stand out in their influence on special education around the country as well as in New Hampshire.

The 1989 Timothy W. 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.

In the James O. case in 1991 the U.S. District Court ordered that children with disabilities in state custody are entitled to educational services.

Other Federal laws and programs have affected special education in New Hampshire over the years:

* Rehabilitation Act of 1973 extended civil rights to individuals with disabilities in federally assisted programs and opened the door to employment for many qualified individuals with disabilities.
* Katie Beckett Waiver (Home Care for Children with Severe Disabilities, HC-CSD) allowed children with disabilities to be cared for at home with Medicaid support.
* The Medicaid to Schools initiative enabled schools to use Medicaid funds to provide nursing and therapies to students with severe disabilities.
* Assistive Technology Act gave students access to computers, communication devices and other technology so they can benefit from education.
* Americans with Disabilities Act of 1990 provides for access to public transportation and communication systems.
* Carl Perkins Act of 1998 provides students with disabilities access to vocational education.
* The School to Work initiative paired local businesses with schools to create internships for students planning to enter the workforce after graduation.

There is still more work to be done and families must continue to be involved in state policy decisions as well as their own child's education.

Special education is transforming the lives of a second generation of citizens with disabilities and continues to create brighter futures for everyone. This year's graduates will lead the way to meaningful employment, fulfilled lives, home ownership, and make it all possible for those who follow them.

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.

Prison

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programs exist, but are run by area agencies or subcontracted out with vendor agencies. The Laconia facility is the most restrictive program, however. Graduates from the Laconia program move to Columbia House in Region I and then on to community settings, all of which have restrictions, but they are not as extensive.

"This is a very challenging aspect of our system," Ertas explained. "In our regular services, our primary objective is to assist the person receiving services. With our forensic services, our primary objective is to keep the community safe. In the treatment goals, the individual's needs and preferences are secondary to community safety."

The treatment does not result in a cure, Ertas admits. "Treatment stabilizes the risk," he said, "but you're never cured."

Because of the intensive treatment and staffing needs, the cost for forensic services is much higher than for other services. "It's one of the most costly aspects of our system," Ertas added. "A good part of new money that we get goes to these folks." This causes understandable anger on the part of families whose sons or daughters are on waiting lists, Ertas admitted.

Ironically, most of the individuals admitted to the Laconia DRF have not gone through the 171:B process; they are voluntary admissions.

Regarding the arson case that created the support for the legislation in 1994, individuals who are suspected of arson or who have fire-setting tendencies are in more individualized settings, Ertas stated. "Professionals recommend that these populations not be mixed," he explained.

These individuals are placed in closely-monitored arrangements in the community with strict security and a lot of supervision. The building in which they live is made of fire-retardant material. There is constant vigilance to assure community safety, he added.


LACONIA
STATE
SCHOOL

The Evolution of Family Support in NH

(Originally published in the January, 1991 issue)

by: Kathy Mandeville

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 so that fewer families would place their children in residential care.

Laconia had been closed to new residents and was in the process of relocating its clients back into communities and family homes. The costs at that time for the annual care of a person with severe disabilities were estimated at somewhere around $74,000.

The Division of Mental Health had, through the regional Area Agencies a few years before, made funds available for respite care for families. "Respite" is occasional relief. This program provided skilled people and some funding to make it possible for families to get a "breather" every so often, so that they wouldn't fall apart. It was really the first direct help to "families" and not just help for the person WITH the disability that the formal disability system had ever provided.

The national trend was to close institutions like Laconia, and to encourage families to keep their children at home from birth on. The Federal government made it an entitlement that all children with disabilities be educated in the least restrictive environment. Therefore, it made all the sense in the world for the NH Legislature to determine how it could best help its families. So the bill establishing the Task Force was passed.

The Task Force, composed of nine appointed members and several dedicated parents, family advocates and service providers, met over a sixteen month period. The motto of the Task Force was: "When all is said and done, let there be more done than said." The recommendations reflected the needs, frustrations, pleas, ideas, and solutions from over 350 families interviewed, and input from service providers and disability advocacy groups throughout the state.

The recommendations 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 capacities through the love and support of their families and communities, instead of being cared for in isolated facilities at an emotional, ethical and monetary cost to themselves and their families far exceeding description.

The overwhelming need voiced by family members was the problem of getting information - for 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 Mom 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 recommendation 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.

The New Hampshire Legislature heard, and unanimously passed the bill. The bill appropriated $500,000 to be available over each of two years under the administration of the Division of Mental Health and Developmental Services. The money would be divided up proportionately among the Division's 12 regional service areas, and managed in collaboration with the Area Agencies in each region.

The plan for how that money would be used would be determined by local councils made up of family members representative of each region. The families would determine WHAT the needs of families were in their area and decide HOW the money should be spent. The Councils, made up of from 6-15 family members (a total of 120 people throughout the state) convened last Fall.

Families living in New Hampshire and caring for a person with a developmental disability, are not alone. Information and support is a phone call away. In all twelve regions of this state, families have someone whom they can call that can help them, and in the 14 months since the program began, there have been approximately 940 requests from New Hampshire families across the whole state. Table 1 shows the most frequently requested services provided.

How has the $500,000 appropriated for each of the two years of this bill been used? During testimony, some legislators had voiced concern that this bill might create another personnel bureaucracy. Family council members didn't want that anymore than legislators did. Personnel represents only 17% of the appropriation; the majority has gone directly to families. Table 2 shows what kinds of financial requests families made of the program.

Most Frequently Provided Services

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

What about financial resources outside of the State appropriation? Throughout the state, service clubs, town and city governments, and local resources are being tapped before 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, in Keene a 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 1988, 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

Average Cost of Services Provided

	Per family served
Day Care/Child Care	$966
Medical/Adaptive Supplies	$588
Recreation	$549
Temporary/Emergency Placements	$546
Counseling	$400
Respite	$363
Transportation	$348
In-Home Supports	$277
Community Education	$200
Parent Training	$104
Direct Support	$ 83
Information and Referral	?
Home Visits	?
Community Links	?

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disabled family members, and they are having some success with these grants.

What about funds already appropriated through the Area Agency system in the state? There has been an enormous in-kind commitment to helping families by the Area Agencies. Over $300,000 in in-kind expenses representing personnel and personnel cost-sharing, office space, utilities, travel, xeroxing, office equipment, phone expenses and numerous other contributions have been made.

Very costly requests for emergency respite and placement can and have been reduced by provision of regular creative respite options, supported employment, more responsive educational programing and community-based recreation - all at a lower cost, utilizing typical community resources instead of creating specialized programs.

Waiting lists have been reduced, in part due to the appropriation made by the Legislature in 1989 with the "Waiting List Bill." But in areas such as respite and residential placement, family support programs have helped families feel less pressured and more able to find creative options.

The creation of the statewide family support programs has required cooperation between families and their respective Area Agencies. This has not always been easy. Testimony heard in 1989 voiced some of the frustration that family members have had with some Area Agencies.

For some Councils, a lot of energy was put into establishing a trusting relationship with the Area Agency. Who would hire the person to work with families? Who supervises that person? Who determines how much time or money can be spent on any one family request? Who knows better - the families or the Area Agency? Collaboration is a working marriage, and it is happening.

In Manchester, families felt a great deal of dissatisfaction at how families were helped and what helps were available. There was a great deal of hesitation in having the family support program sit in the Area Agency, fearing that it, too, would become crisis-oriented, uncreative and center-based.

Through many hours of dialogue, the Council and Area Agency agreed that the program would sit within the Area Agency - and that the Family Support Staff would be under the direction of the Council and the supervision of the Agency. The Agency would in addition place the Respite Coordinator under the direction of the Council and add an additional staff position so that there would be more likelihood of success in bringing about the changes mandated by the Council.

Seven months later, both the Council and the Area Agency are looking back at a program that is working exceptionally well. The family support program benefits from the easy access to services for families already centered at the Agency, as well as several thousand dollars in in-kind contributions. The Area Agency has become more creative and community-based in hearing and responding to the needs of people with disabilities.

Collaboration is happening and a partnership has emerged. The people with disabilities in the Manchester area and their families are benefiting. Over 110 families have been served since February.

Calls to the program in the first few months were primarily from families who were "on the edge." They had been waiting for services, in some cases, for years. If the agency could provide the service to the family member, they had. If it was not a service that was typically provided, or was unfunded, requests had been recorded but nothing happened. Gradually, the staff have been working with families around less crisis-oriented activities (e.g., accompanying family members to I.E.P. meetings and application processes for things already available - i.e., Medicaid, - Katy Beckett benefits, doctor's appointments, etc.)

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 sessions on guardianship, trusts and benefits; coordinated meetings among local agencies to help them address

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Supporting Families Is Her Job

(Originally published in the first edition of The New Hampshire Challenge, October, 1988)

by Janet M. Krumm

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 to fill a secretarial job. Her volunteer work in high school at a state school, and her subsequent education in the field of special education made her a desirable candidate.

Two weeks after being hired, Tonkin was asked to run the respite program and four weeks after that, she was asked to add "assistant case manager" to her job description.

She ran the respite program for a year, working in case management for four years, and became an educational advocate by completing the 13 week Educational Advocate course offered by the Parent Information Center.

Her experiences in Region IV ranged from working with the families in early intervention to coordinating special education services for eight children in a residential placement in Pittsfield. Because of all these experiences, she has made many contacts throughout the area and the state that she finds are helpful in her present position.

When Lysbeth Noyes, the Executive Director of Region IV, appealed to the Division of Mental Health and Developmental Services for permission to create the unique position, Tonkin was the obvious choice to staff it. "We were very fortunate to have her be the one to start the program," Noyes declared. It is obvious that Tonkin enjoys her complete respect and trust.

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 needs turned out to be: 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 continue her position. 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 the mother went out to buy food. She helped people purchase such diverse items as a plastic cover for a bed, and eyeglasses. She helped parents secure respite or childcare.

Because of the diversity of people's needs, Tonkin began working closely with other people in her region who were providing direct services. She now meets regularly with Robin Montgomery, the respite coordinator; Susan Schneider, the Family Services Coordinator in the Early Intervention program; and Lee Holly from the integrated daycare program. She feels that this networking goes a long way to coordinating the supports that people receive.

In reviewing the evolution of her job since 1980, 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 to do and I do it."

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

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 rediscovering 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 had 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 relationship 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.

The major concern voiced by the many council members was the challenge of remaining independent.

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 workability and accountability, at the same time cautioning against the councils' becoming another bureaucracy. There was strong emphasis on the flexibility 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

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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 was a good one. 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 cost 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 1-866-634-9412 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 '05. 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 councils 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 Katy Beckett Bill *(October, 1988 issue)*

Family members, legislators, advocates and state officials , including (third from right) Health and Human Service Commissioner Mary Mongan, joined Governor Sununu last spring when he signed into law a bill that makes some Medicaid funding available for severely disabled children who are being cared for at home. Increasing the flexibility of such funds is just one of several recommendations of the Task Force on Family Support. Such changes can assist New Hampshire families who provide care to a disabled relative or child.

The History of Early Supports and Services in NH

"They took the time to understand what he needs. That means a lot to me as a parent."
Cathlin Daley-Meinhardt, Brookline, mother of Brandon

"I have learned so much from those who helped us care for John."
Elizabeth MacDonald, Hinsdale, mother of John.

"It was so comforting that they wanted to help."
Patti Penick, Manchester mother of Matthew.

"My advice to parents is it can't hurt to have the evaluation because the sooner they get help the better."
Patti Penick

"The child is not just a piece of paper that you can stuff in a file."
Cathlin Daley-Meinhardt.

"The early intervention was child centered and led."
Elizabeth MacDonald

by: Jamie Stephenson

New Hampshire's adoption of regulations for Family Centered Supports and Services in 1993 hallmarked the end of a process that began almost 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 infants 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 funded 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 I.Q., 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.

There was also the problem of waiting periods for evaluation and services. Early childhood is a unique time of learning and development that can't be revisited years or even months later. The immediacy of the need for intervention becomes obvious when viewed in this light. Parents and professionals involved with early intervention soon realized the need for an entitlement with short timelines for service after referral.

The 1973 federal special education law did not mandate services to infants and toddlers but, rather, offered funds for pilot programs in early intervention for children with disabilities. The Model Infant and Toddler Project in Hanover from 1974-1977 was one of these.

The Federal mandate for special education services for children under five (P.L. 99-457) was added to the 1986 reauthorization of the Education of All Handicapped Children Act - now called Individuals with Disabilities Education Act (I.D.E.A.). Part H of P.L. 99-457 created funding incentives for states to plan a system of services for children birth through two.

Congress charged the U.S. Department of Education Office of Special Education Programs (OSEP) with responsibility for guiding each state through the process of creating an early intervention service system within the framework provided by the law.

Unlike their school age peers, infants with disabilities require a service plan that meets the needs of the family in the home and provides support to the family caregivers as well as services to the infant. Studies have shown that direct therapy provided to the infant at home will be continued by the caregivers, thus compounding the benefit to the child. Instead of an Individualized Education Program (IEP) infants and toddlers require an Individualized Family Service Plan (IFSP).

The IFSP needed to include the child's level of development, the family's concerns about the child, the family's re-

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sources, the goals for the child and family, the services to be provided, the setting for the services, and a plan for transition into preschool services. To accomplish this, early intervention systems had to be interagency and multidisciplinary as well as comprehensive. This requires cooperation and collaboration between professionals from the human service field and education.

New Hampshire's participation in P.L. 99-457 Part H began in 1989 with Governor John Sununu's executive order creating the Interagency Coordinating Council (ICC) and naming the Department of Education (DoE) lead agency (in 1992 the lead agency changed to DHHS). The Council membership included representatives from DoE; Department of Health and Human Services (DHHS); the Legislature; The Governor's office; Department of Insurance; Division of Children, Youth, and Families (DCYF); early intervention providers; and parents.

Parents constitute one quarter of the ICC membership; the current ICC chairperson is Mollie White, a parent.

Charged with designing a system of referral, information, service provision, public awareness, personnel preparation and data collection in a family-friendly atmosphere, the Council began the five-year planning period.

During the planning period, the ICC set the framework for the statewide program to serve infants and toddlers with assistance from National Early Childhood Technical Assistance System (NEC*TAS), U.S. Department of Education.

Several projects were funded by ICC grants including the Family Resource Connection, a central directory funded collaboratively by the NH Department of Education and DHHS housed in the New Hampshire State Library that continues to provide information and resources to families in the state. (See *Statewide Resources*.)

In September 1990, the Lake Region Community Health Agency was awarded a grant, entitled Family First, to study risk factors for newborns in New Hampshire and develop a system for family focused infant screening and assessment. The project was expected to collect data that would be used 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.

Photo: E.G Stone

> *"We are looking forward to his mainstreaming into the regular class."*
> Elizabeth MacDonald

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 not 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 referral 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 on Infant Mental Health was convened and in 1995 an Infant Mental Health Advisory Committee was formed.

In 1996 the issues of managed care, insurance, and welfare reform predominated along with the pending reauthorization of IDEA where the name Part H was changed to Part C.

In 1997 autism became an issue of interest for the ICC and in 1998 an Autism Coalition was formed.

Ongoing ICC projects focus on funding issues, training of EI professionals, data collection, changes in EI, and transition to preschool services.

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 mainstream society need to understand hunger should be treated 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-to-$50.00 for weekly groceries and it does not buy much these days as we see food prices rising 32%-to-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, his or her case manager will say "no, you cannot have anymore more 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 governments 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 treadmill for those with disabilities who are forced to remain stuck in poverty.

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 realities 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 wage 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 reverence for "cost benefit." 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 view.

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 you 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.

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 athletes with disabilities and able-bodied 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 Skiing
Date: August 14, 2004
Time: 7:30 (breakfast for all racers); Race begins at 9 AM
Cost: Team of 1: $60; 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 Guay, Race Coordinator at 1 (800) 639-7770 or tguay@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 Deparment 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.ndsccenter.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 Linda Hughes at (603) 547-3311, x 598, or e-mail:
linda.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 JanetWilliamson at (603) 228-2084 or (800) 238-2048 or e-mail: jgw@cisunix.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 Dennehy 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/

Area Agencies for Developmental Services

REGION I North Country

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

Area Offices:
Upper Connecticut Valley Mental Health and Developmental Services(MH)
Charlie Cotton, area director
34 Colby Street, Colebrook, New Hampshire 03576
Phone: 237-4955

White Mountain Mental Health and Developmental Services (MH) outpatient
29 Maple Street, P. O. Box 599, Littleton, New Hampshire 03561
Jane MacKay, area director
Phone: 444-5358

Family Centered Early Supports and Services
29 Maple Street, P.O. Box 599 Littleton, New Hampshire 03561
Director: Kelly Desilets, OTR/L
Developmental Specialists:
Berlin/Groveton: 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: 444-5358

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

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

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

Littleton -
Family support /Respite coordinator:
Diana Flick 444-5358 x 3460 dflick@nnhmhds.org
Benefits technician: Suzanne Beauchesne 444-5358 sbeauchesne@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@dsscofnh.org
Case Management: 542-8706
Adult Services: 542-8706
Family support coordinator/Respite coordinator/Legislative liaison:
Jean Warner 542-8706 jwarner@dsscofnh.org
Early supports and services: Kathie Sarles, 542-8706 x135 ksarles@dsscofnh.org
Benefits technician: Rhonda Desmarais 542-8706 x114 rdesmarais@dsscofnh.org
Family support council chair: 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@lrcsc.org
Website: www.lrcsc.org
Assistant exec director and family support director:
Christine Santaniello 524-7755 chriss@lrcsc.org
Respite coordinator: Lynn Carlson 524-7755 lynnc@lrcsc.org
Benefits technician: Lisa Richardson 524-8811 richardson@lrcsc.org
Legislative liaison: Chris Collier 536-1884 chriscollier@adelphia.net
Family support council chair:
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
E-mail: rgerstenburger@communitybridgesnh.org
Website: www.communitybridgesnh.org
Director of family support: Jo Edwards 225-4153
(800)499-4153, ext.224 jedwards@communitybridgesnh.org
Respite coordinator: Renee Carlisle
225-4153(800)499-4153,ext.215 rcarlisle@communitybridgesnh.org
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 akowalczyk@comcast.net

REGION V Monadnock

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

REGION VI Nashua

The Area Agency of Greater Nashua, Inc.
144 Canal Street, Nashua, New Hampshire 03064
Sandra Pelletier, exec. dir. **Direct Phone line:** 459-2701
E-mail: spelletier@region6.com
Beth Raymond, assoc. dir. **Direct Phone line:** 459-2704
E-mail: braymond@region6.com
Phone: 882-6333 **Fax:** 889-5460
Website: www.region6.com

Family support coordinator:
Nicolah Obinolo 459-2749 nobinolo@region6.com

REGION VI Nashua (continued)

Partners in Health family support coordinator:
Nancy Lucci 459-2744 **Fax:** 889-5460 nlucci@region6.com
Respite coordinator: Christie Arnold 459-2705 carnold@region6.com
Benefits technician: Diane Luszey 882-6333 dluszey@region6.com
Intake coordinator: Sue Rockwell 459-2730 srockwell@region6.com
Ramona Burgess 459-2712 rburgess@region6.com
Director of QI - service coordinator supervisor:
Jennifer Boyer 459-2715 jboyer@region6.com
Legislative liaison: Bob Mackintosh 459-2746 bmackintosh@region6.com
Family support council chair: Kelly Walker 465-4131 kewswalk@charter.net

Affiliate Agencies:
The PLUS Company, Inc.
240 Main Dunstable Road, Nashua, NH 03062
Kim Shottes, exec. dir. Phone: 889-0652 **Fax:** 880-8938
E-mail: kshottes@region6.com **Website:** www.thepluscompany.net

Adult day service program
200 Derry Road, Hudson, NH 03051-3398
Deb Wall, director Phone: 883-0994 **Fax:** 886-1238
E-mail: dwall@alvirnehs.org

Early Intervention and Pediatric Therapy
144 Canal Street, Nashua, NH 03064
Nancy Dowey, Prog. Coord. Phone: 882-3434 **Fax:** 889-5460
E-mail: ndowey@region6.com

REGION VII Manchester

Moore Center Services, Inc.
132 Titus Avenue, Manchester, New Hampshire 03103
Paul Boynton, CEO
Phone: 668-5423 **Fax:** 206-2706 **E-mail:** paul.boynton@moorecenter.org
Website: www.moorecenter.org

Family support: 645-9474 **Info Hotline:** 206-2846 **Fax:** 206-2709
Family services resource manager: Joe Rojek 206-2855
joe.rojek@moorecenter.org
Community Liaison/Respite coordinator:
David Johnson 206-2743 david.johnson@moorecenter.org
Early supports and services and children to age 6: Celeste D'Innocenzo
206-2791 celeste.d'innocenzo@moorecenter.org
Transition coordinators:
Susan DiPalma 206-2792 susan.dipalma@moorecenter.org
Marge Louney 206-2745 marge.louney@moorecenter.org
Parent To Parent: Marge Louney (as above)
Benefits technicians:
Linda Lawrence 206-2768 linda.lawrence@moorecenter.org
Audrey Mason 206-2770 audrey.mason@moorecenter.org
Legislative liaison: Jan Larsen 206-2744 jan.larsen@moorecenter.org
Family support council chair: Keith Foster 624-9471 kfoster@earthlink.com

REGION VIII Seacoast

Community Developmental Services Region VIII
Parade Office Mall, 195 Hanover Street, Suite 40, Portsmouth, NH 03801
Bob James, exec director 436-6111 x 303 bob@cdsregion8.org
Cathy King, associate exec director: 436-6111 x 306 cathy@cdsregion8.org
Phone: 436-6111 **Fax:** 436-4622 **E-mail:** cds@cdsregion8.org
Director of family support:
Lenore Sciuto 436-6111 x 307 lenore@cdsregion8.org
Children's support coordinator:
Mary Dawn Corey 436-6111 x 334 MaryDawn@cdsregion8.org
Adult support coordinator:
Pam Raley 436-6111 x 342 pam@cdsregion8.org
Transition age (16 years) support coordinator:
Karen Tellier 436-6111 x 308 karen@cdsregion8.org
Resource coordinator:
Mandy Thibodeau 436-6111, x 329 mandy@cdsregion8.org
Respite coordinator: Geoff Simons 436-6111x 327 geoff@cdsregion8.org
Benefits technician: Denise Larsen 436-6111x 326 denise@cdsregion8.org
Legislative liaison: Sally Weiss 463-7104 sallyaweiss@hotmail.com
Family support council chair:
Kathy Ennis 964-9740 Kennis@northeastrehab.org

REGION IX Strafford County

Community Partners
Forum Court, 113 Crosby Road, Suite #1, Dover, New Hampshire 03820-4375
Brian Collins, exec. director E-mail: bcollins@bhdssc.org
Phone: 749-4015 **Fax:** 743-3244 **Website:** www.dssc9.org
Family support coordinator: Deirdre Watson 749-4015 dwatson@bhdssc.org
Respite coordinator: Karen Juckett 749-4015 kjuckett@bhdssc.org
Early supports and services: Suzanne Iverson 749-4015 siverson@bhdssc.org
Benefits specialist: Julie Picard 749-4015 jbatchelder@bhdssc.org
Legislative liaison: Hugh Philbrick 749-4015 hphilbrick@bhdssc.org
Partners in Health coordinator: Sarah Small 749-4015 ssmall@bhdssc.org
Complaint investigator: Lee White 749-4015 lwhite@bhdssc.org
Family support council chair:
Chuck Raymond 743-3909 chuck.raymond@comcast.net
Family support council vice-chair:
Karen Salter 692-2088 ksalter643@aol.com

REGION X Atkinson/Salem

Region 10 Community Support Services, Inc.
8 Commerce Drive, Atkinson, New Hampshire 03811
Jane Dichard, exec. director E-mail: jdichard@region10nh.com
Phone: 893-1299 **Fax:** 893-5401 **Website:** www.region10nh.com
Family support coordinator:
Kathy Waterson 893-1299 x 329waterson@region10nh.com
Respite coordinator:
Kathy Garafalo 893-1299 x 333kgarafalo@region10nh.com
Early supports and services:
Tammy Dudal 893-1299 x 326 tdudal@region10nh.com
Benefits technician:
Deanna Johnson 893-1299 x 323 djohnson@region10nh.com
Legislative liaison:
Terri Cadorette 893-1299 x 321 tcadorette@region10nh.com
Family support council chair:
Carol Ingram 893-1129 carol-ingram@rcn.com
Family support council co-chair:
Lynn Aboujaoude 437-3885 aboujaoude@adelphia.net

REGION XI Carroll County

Center of Hope, Inc.
626 Eastman Road, Center Conway, New Hampshire 03813-4219
Margie Matthews, exec director
E-mail: mmathews@centerofhope.org
Phone: 356-6921 x 16 or (800) 290-0905 **Fax:** 356-6310
Director of adult and family services: Christine MacDonald
356-6921 x 52 or (800) 290-0905 cmacdonald@centerofhope.org
Respite coordinator: Lindelle Gorham
356- 6921 x26 lgorham@centerofhope.org
Benefits technician: Same
Legislative liaison: Marti Shedd 447-4723 mshedd@centerofhope.org
Family support council chair: Linda Ingemi 447-6511 lisa35969@yahoo.com
Family support council co-chair: Ruth Clough 539-3509 rclough@ttlc.net

REGION XII Grafton County (serving Grafton, Canaan, Enfield, Lebanon, Hanover, Lyme and Orford)

United Developmental Services
85 Mechanic Street, Suite 300, Lebanon, New Hampshire 03766
Bruce Pacht, exec director E-mail: bruce@uds.org
Phone: 448-2077 **Fax:** 448-1841 **Website:** www.uds.org
Family centered early supports and services:
Kathy Marshall 443-4132 kathy@uds.org
Family support coordinator: Tara Mullen 443-4109 tara@uds.org
Respite coordinator: Kristin Walker 443-4114 kristin@uds.org
Benefits technician: vacant
Legislative monitor: Philip Eller 1-800-698-5465 p2pnh@VALLEY.NET
Family support council chair:
Roberta Gross 643-4267 bobbigross@earthlink.net
Upper Valley Support Group (UVSG) (provides emotional support & info)
Phone: 448-6311 **E-mail:** p2pnh@valley.net **website:** www.uvsg.org
UVSG respite program coordinator:
Nicole Demers 448-1268 respitecare@valley.net
Partners in Health coordinator: Katie Ouelette 603-448-7108 pih@uvsg.org
Human Rights complaints: Andrew Forbes 443-4124 andy@uds.org

Where to Find Help

Statewide Resources

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

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

ASSETT - Assistive Services to Schools for Education, Technology and Training -
117 Pleasant Street
Dolloff Building
Concord, NH 03301
603-226-2900
Donna Furlong, Admin. Assist
E-mail:
dfurlong@nhaat.mv.com
Consultations & Technical assistance; Loans of specialized equipment and materials; Training for educators, parents & children; Library for families & educators

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

TEC Exploration Center
117 Pleasant Street
Dolloff Bldg.
Concord, NH 03301
603-226-2900
Leo Benoit, Technician COTA/L
E-mail:
lbenoit@nhaat.mv.com
Hands-on technology exploration; loans of assistive technology; training, technical support

Autism Society of NH
P.O. Box 68
Concord, NH 03302
603-679-2424
E-mail:
nhautism@yahoo.com
website:
www.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
www.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- 271-7095
E-mail:
slambert@ed.state.nh.us
www.ed.state.nh.us
Provides individualized guidance, counseling and placement services to eligible consumers; also provides family services around needs of individual

Child Development Center
Dartmouth-Hitchcock Medical Center
603-653-6060
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@dhhs.state.nh.us
Website: www.ccachc.org
Information and advocacy

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

Disabilities Rights Center, Inc.
18 Low Ave. P.O. Box 3660
Concord, NH 03302-3660
603-228-0432, or 1-800-834-1721 (V/TTY)
Fax: 603-225-2077
E-mail:
advocacy@drcnh.org
website: www.drcnh.org
Provides legal services and other advocacy assistance to persons with disabilities; information/referral

Early Education and Intervention Network of N.H.
10 Ferry St. #416
Concord, NH 03301
603-228-2040
E-mail: info@eein.org
website: www.eein.org
Information & support to promote best practices in early intervention and early childhood/special education

Family Resource Connection
603-271-7931 or
1-800-298-4321
Alice Nye, Coordinator
E-mail:
anye@library.state.nh.us
Website:
www.state.nh.us/nhsl/frc/
Free, statewide program of NH State Library providing materials on all aspects of raising, caring for and educating children, especially children with special needs; free lending library of books and videos mailed to your home with postage paid envelopes for return; free research and reference service.

Family Support contact person, DDS (Michelle Rosado)
271-55034
1-800-852-3345 x 5034
mrosado@dhhs.state.nh.us
Can direct you to services available through the Division of Developmental Services (DDS), the 12 Regional Area Agencies and Regional Family Support Programs

Governor's Commission on Disability
57 Regional Drive
Concord, NH 03301
271-2773 (Voice),
271-2774 (TTY)
1-800-852-3405 (Voice)
Fax: 271-2837
www.state.nh.us/disability
Information and referral. Provides information about the many services, laws, and regulations that affect citizens with disabilities. Implements and operates the federally funded Client Assistant Program designed to work out problems that may arise between persons with disabilities and the Division of Vocational Rehabilitation

Granite State Guardianship Services
34 Jefferson Road
Whitefield, NH 03598-1221
Phone: 603-837-9561
Fax: 603-837-2613
18 Low Avenue
Concord, NH 03301-4902
Phone: 603-224-0805
Fax: 603-229-1758
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)
21 Chenell Drive
Concord, NH 03302-9680
603-228-9680, (V, TTY)
1-800-826-3700(V/TTY
Fax: 603-225-3304
E-mail:
erica.marden@gsil.org
website: www.gsil.org
Information and referral, peer support and counseling, skills training, advocacy, interpreter and personal care attendant services, transportation, social and recreational programs, accessibility services, and deaf and hard of hearing services.

Institute on Disability/UCED
(Concord office)
Phone: 603-228-2084 or
1-800- 238-2048
Fax: 603-228-3270
(Durham office)
Phone: 603-862-4320
Fax: 603-862-0555
www.iod.unh.edu
Training, technical assistance and resources with the goal of improving the quality of life and level of participation of people with disabilities in schools, the community and the workplace

Medical Genetics
Dartmouth-Hitchcock Medical Center
603-653-6044
Genetic testing and counseling, information and referral

M.I.C.E. (Multi-sensory Intervention through Consultation and Education)
603-228-1028(V)
603-228-5755 (TTY)
Statewide program for educational and developmental services for children with visual or hearing impairments and their families.

NAMI-NH - Alliance for the Mentally Ill of NH
15 Green Street
Concord, NH 03301
603-225-5359,
or 1-800- 242-NAMI
E-mail: info@naminh.org
www.naminh.org
Statewide organization and affiliates offer information and support to people with serious mental illnesses and their parents, children, spouses, siblings and friends.

NH Association for the Blind
603-224-4039 or
1-800- 464-3075
E-mail:
services@sightcenter.com
www.sightcenter.com
Provides information and gives direct services to people of all ages who are blind and visually imparied to enable them to maintain their independence

N.H. Developmental Disabilities Council
10 Ferry Street
Concord, NH 03301
603-271-3236
1-800-852-3345, x 3236
E-mail: nhddcncl@aol.com
www.nhddc.com
Monitors services; promotes policy, advocacy

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

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Where to Find Help *Statewide Resources*

Continued from page 28

vices by providing information and emotional support, identifying resources available within the community, and making available a lending library of books, videos and audio tapes; distributes free newsletter, *Pass It On*

Northeast Passage
UNH/Recreation
Hewitt Hall
4 Library Way
Durham, NH 03824
603-862-0070
TTY-NH 1-800-735-2964
TTY-ME 1-207-955-3323
E-mail:
northeastpassage@unh.edu
website: www.nepassage.org
Provides (for a fee) equipment and expertise to individuals, schools and companies to ensure access to educational outings and recreational activities.

Office of Public Guardian
10 White Street
Concord, NH 03301
603-224-8041
E-mail: info@opgnh.org
website: www.opgnh.org
Provides legal guardianship services for people with developmental disabilities and mental illnesses.

Parent Information Center
603-224-7005 V/TTY
1-800-947-7005 (in NH only)
E-mail: picinfo@ parentinformationcenter.org
website: www. parentinformationcenter.org
Information, support and training around educational issues nd advocacy

Parent to Parent of NH
12 Flynn Street
Lebanon, NH 03766
1-800-698-5465
www.p2pnh.org
E-mail: contact@p2pnh.org
Specializes in networking parents of children with special needs; support and information

People First of NH
4 Park Street, Suite 201
Concord, NH 03301
603-568-2128,
or 1 -800- 566-2128
E-mail: janet.peoplefirstofnh @verizon.net
website:
www.peoplefirstofnh.org
Self-advocacy group of people "working together to help each other take charge of our lives"; help team available for new or existing groups; 24-hour answering service

Seacoast Child Development Clinic at UNH IOD/UCED
312 Morrill Hall
Durham, NH 03824
603-862-0561 (Voice/TDD)
603-862-0034 (fax)
E-mail:
Seacoast.Clinic@unh.edu
www.seacoastclinic.unh.edu
An interdisciplinary clinical consultation service, assisting families of children with developmental disabilities by using a team approach. Evaluation may include home and/or school visit, depending on needs of child and family. The program is affiliated with Dartmouth Center for Genetics and Child Develpment and the Insitute on Disability, UNH.

ServiceLink
(Toll free) 1-866-634-9412
website: www.servicelink.org
A statewide network of locally-administered, community-based resources for seniors, adults with disabilities and their families. Free information on home care services, caregiver support, employment issues, financial/retirement planning, wellness education, prescription drug options, healthcare benefits, disease management, housing and more.

Special Medical Services Bureau
603-271-4488, or
1-800-852-3345 ext. 4488
Division of Public Health: broad range of health programs for diagnosis and treatment of children (0-21) who have physical disabilities, chronic illnesses or developmental delays

Special Olympics NH
650 Elm Street
Manchester, NH 03101
603-624-1250
or 1-800-639-2608
Fax: 603-624-4911
website: www.sonh.org
Provides sports opportunities for athletes with developmental disabilities.

"Talking Books"
NH State Library Services to Persons with Disabilities
117 Pleasant Street
Concord, NH 03301
603-271-3429,
or 1-800-491-4200
website:
www.state.nh.us/nhsl/talkbks
FREE service for people with visual, physical, and reading disabilities. Supplies (by mail) cassette books and records and equipment needed to use them. Fiction, non-fiction and popular magazines available

VSA arts of New Hampshire
44 South Main Street
Concord, NH 03301
603-228-4330 (V/TTY)
Fax: 603-225-7240
E-mail: info@vsaartsnh.org
website: www.vsaartsnh.org
Provides opportunities in the arts for people with disabilities and technical assistance for programmatic and cultural access

Partners in Health

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

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

Partners In Health Locations

REGION 1: Berlin, NH
Family Resources Center
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 Hartunian
780 N. Main St.
Laconia, NH 03246
603-524-8444

REGION 4:
Community Bridges
Janice Boudreau
525 Clinton St.
Bow, NH 03304
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 Katsikas &
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
603-422-8208

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

REGION 10: Derry, NH
Child and Family Services
Maura Pennisi
48 W. Broadway
Derry, NH 03038
603-432-8362 or
1-800-640-6486, x 424

REGION 11
Center of Hope, Inc.
Leslie Stanicki
626 Eastman Road
Center Conway, NH 03813
603-356-6921

REGION 12:
Upper Valley Support Group
Katie Ouelette
12 Flynn St.
Lebanon, NH 03766
603-448-7108

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

Administering Agency:
The Hood Center for Children and Families
One Medical Center Drive
Lebanon, NH 03756 Phone: 603-653-1481
Contact: Tina Wilcox tina.wilcox@dartmouth.edu

To have a resource listed in
The Challenge,
contact us at:
(603) 742-0500, or
1 (800) 758-6430,
or e-mail us at:
nhchallenge@comcast.net

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.nnhmhds.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)
111 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

Region VI
Community Council of Nashua, Inc.
Zlatko M. Kuftinec, MD, executive director, medical officer
Carol Farmer, deputy director
7 Prospect Street
Nashua, NH 03060
Phone: 603-889-6147
Fax: 603-883-1568
website: www.ccofnashua.org

Region VII
The Mental Health Center of Greater Manchester
Peter Janelle, executive director
William Rider, chief operating officer
401 Cypress Street
Manchester, NH 03103
Phone: 603-668-4111
Fax: 603-669-1131
website: www.mhcgm.org

Region VIII
Seacoast Mental Health Center, Inc.
Jay Couture, executive director
1145 Sagamore Avenue
Portsmouth, NH 03801
Phone: 603-431-6703
Fax: 603-430-3753
website: www.seacoastmentalhealth.org

Region IX
Community Partners
Brian Collins, executive director
113 Crosby Road, Suite 1
Dover, NH 03820
Phone: 603-335-6470
Fax: 603-743-3244
website: www.dssc9.org

Region X
CLM Behavioral Health Systems
Victor Topo, executive director
CMHSA Contact: Linda Brown
Salem Professional Park
44 Stiles Road
Salem, NH 03079
Phone: 603-893-3548
Fax: 603-898-4779
website:
www.centerforlifemanagement.org

NH Department of Health and Human Services District Offices

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

Claremont
17 Water Street
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

Conway
73 Hobbs Street
Conway, NH 03818-6188
(603) 447-3841, or
1 (800) 552-4628

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

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

Littleton
Lisbon Road
80 North Littleton Road
Littleton, NH 03561-3814
(603) 444-6786, or
1 (800) 552-8959

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

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

Portsmouth
30 Maplewood Avenue, Suite 200
Portsmouth, NH 03801-3737
(603) 433-8300, or
1 (800) 821-0326

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

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

TDD 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:

www.aapd.com
American Association of People with Disabilities

www.abledata.com/
Federally funded project providing information on assistive technology and rehabilitation equipment from domestic and international sources

www.access-able.com/
Access-Able Travel Resource

www.adanet.org
American Disability Association

www.albinism.org
The National Organization for Albinism and Hypopigmentation

www.ani.autistics.org
Autism Network International -a self-help and advocacy organization for people with autism by people with autism

http://aspe.os.dhhs.gov
U.S. Department of Health and Human Services site lists hundreds of publications on disability-related subjects available on-line.

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.

www.assistivetech.net/
AT Tech Solutions - resource for assistive technology & a link to a wide variety of AT & disability-related information.

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

www.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.

www.closingthegap.com
Provides practical up-to-date information on Assistive Technology products, and best practices.

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

www.csni.org
Community Support Network, Inc., 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 .

www.dhhs.state.nh.us
NH Department of Health and Human Services - infomaton on benefits programs

www.dot.gov/accessibility
The US Department of Transportation's site for information about air travel for people with disabilities

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

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

www.eseals.org
Easter Seals NH

www.firstgov.gov/Topics/Grandparents.shtml
U.S. Government site for grandparents raising grandchildren. Lists benefits and assistance, health and safety resources, reports and publications, and state resources.

www.fctd.info
The Family Center on Technology and Disability offers a range of information and services on the subject of assistive technology (AT).

www.hhs.gov/newfreedom/
US Department of Health and Human Services' New Freedom Initiative

www.inclusionresearch.org
Inclusion Research Institute - a nonprofit organization whose activities include education, research and dissemination of information promoting inclusion

www.nhhelpline.org
New Hampshire Help Line - provides information, referral, assistance and crisis intervention services.

www.nhspinal.org
NH Chapter of the National Spinal Cord Injury Association

www.nichcy.org
National Dissemination Center for Children and Youth with Disabilities

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.

www.peoplefirstofnh.org/ Advocacy%20and%20Politics.htm
Provides information for people who have an interest in what is happening in the government.

www.sath.org
Society for Accessible Travel & Hospitality

www.section508.gov
Offers resources for understanding and implementing Section 508 which requires federal agencies' electronic and information technology be accessible to people with disabilities.

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

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

www.yourtickettowork.com
Information on the Social Security Ticket-to-Work program

Publications of Interest

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

Exceptional Parent Magazine
Paid subscription $39.95 a year
1 (877) 372-7368
website: www.EParent.com
Feature articles; extensive listing of national organizations for specific disabilities/conditions

New Developments
Benefit of membership
(301) 652-2263
E-mail: devdelay@mindspring.com
website: www.devdelay.org
(cost of membership - $48 for families; $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 preventions 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: nhfv@yahoo.com
website: www.nhfv.org
Resources and information for families with special health care needs; quarterly

Ragged Edge
Paid subscription $35 a year
Fax: (502) 899-9562
e-mail: circulation@raggededgemagazine.com
website: www.raggededgemagazine.com
Magazine written by and for people with disabilities with information on issues pertinent to the disability movement; bi-monthly

To Do What Has To Be Done

Vera Hill *Photo: E.G. Stone*

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.

INFORMATION IS POWER

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.*

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