A History of Family Centered Early Support and Services
Historical Developments And Forces That Have Shaped The Service System

Where did it all start? It started with the question:

“What do we do with the paupers?”
Elizabethan Poor Laws were established in 1601:

- Outdoor Relief ("welfare")
  - Food, fuel, clothing, etc.
  - Application made to "Overseer of the Poor"

- Indoor Relief
  - Room, board, clothing in exchange for work (e.g., stone breaking)
  - Required to enter a congregated workhouse/poorhouse
  - Men, women and children were segregated
  - Parents forfeited their rights and responsibilities for their children
  - Conditions were hard to deter people from relying on Indoor Relief
Poorhouses - Almshouses in the 1700s

✓ First Almshouses in US were built in Philadelphia
  • In 1713 by William Penn (for Quakers)
  • In 1728 open to general public
✓ By 1850 the majority of people living in the almshouses were the aged, infirm, poor children (people unable to work)
✓ States began requiring the establishment of County Poorhouses/County Farms
  • By 1866 NH had established that requirement
February 9, 1893

From the local newspaper *The Republican*:

“The most terrible calamity that has ever fallen upon Strafford county occurred [sic] last night.”

“The Insane Asylum at the Strafford County farm was totally destroyed by fire and 40 out of 44 inmates perished in the flames.”

“Large crowds of people have visited the place today, many of whom well remember the fire which destroyed the main building in January, 1881, by which thirteen people lost their lives.”
A monument was erected in Strafford County in memory of the victims of the poor farm asylum fire. The inscription reads:

“In memory of those who lost their lives by the burning of the Strafford County Asylum Feb. 9, 1893.”
After the fire a controversy arose in NH about the conditions in the almshouses, particularly for children.

1895 - state Board of Charities and Corrections was created by the legislature

- To oversee the care of adults who were housed in county farms and children in orphanages.

The Board of Charities and Corrections recommended that radical changes were needed in the methods of caring for the poor and mentally ill.

At this point in history, most people who were identified as “feebleminded” were cared for at home – (without supports!)

- There was only a small percentage of people, labeled “feebleminded,” that lived in the poorhouses (almshouses).

But the significance of the almshouse is that it had become an acceptable form of care for devalued persons.
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Segregation and Congregation is accepted as a way to care for people.
50 - 60 years earlier the belief that the poorhouse was **not** a good place for children had emerged...even if their parents were there.

“This Indenture, made the tenth day of November, in the year of our Lord one thousand eight hundred and thirty five, Between ....the Superintendents of the Poor-house of the County of Washington, in the State of New-York....and Robert Foster, of the town of Jackson in the county of Washington, in the state aforesaid...witnesseth, that the said Superintendents... by these presents, do **put, place and bind** Simeon Bingham, aged *seven* years old...who is now a pauper...to be apprenticed with said Robert Foster...until said Simeon Bingham shall come to the age of twenty one years.”
Waltham, MA  1842

Samuel Gridley-Howe established the first “public program” to educate young people with intellectual disabilities
✓ The price of success….

- Howe began with 8 young people who would reside for one year.
- His program over the years grew to over 100 young people
- Additional living space was added
- After 18 years, Howe gave up in frustration. He is quoted as saying….

“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.”

- Samuel Gridley Howe, 1860

How we support people is crucial!
New Hampshire

✓ 1896 – A survey reported that 420 children lived in almshouses, (many were raised there.)
  • Within two years, all but 60 of those children were moved into foster care. Those 60 were “feebleminded” children, who were not considered appropriate for foster care.

✓ “Children 3 – 15 shall not be supported in the almshouse…unless mentally incapacitated for education.”

✓ What to do about “feebleminded” children?
“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...it is believed that it is better and cheaper for the community to assume permanent care of this class before they have carried out a long and expensive career of crime.”
1903 - **NH School for the Feebleminded** at Laconia opened.
Sewing classes for the girls

Woodworking classes for the boys
The Institution as a Self-Sufficient Farm
The National Scene

✓ 1910 - Visiting nurse agencies existed in most urban areas and initiated prevention programs for school children, infants, and mothers.
✓ 1913 - New York City teachers visited homes, becoming familiar with the neighborhood, attitudes of the people toward education, available school programs and services available.
  • Funds were allocated for teachers to go out to homes to work on “deficit scholarship, truancy, incorrigibility, adverse home conditions and neglect.”
  • These were the forerunners to social workers
Just as some positive things were happening… The Eugenics Era surfaces:

- “Improvement” of hereditary qualities of a race

“Sterilization of the feeble-minded is logically the solution for the problem of prevention of the propagation of the mentally unfit where feeble-mindedness is due to heredity”

Cornell University, 1915
• A prominent member of the American Psychiatric Association, Dr. Foster Kennedy, proposed a program of euthanasia for the “hopelessly unfit”

--A major stumbling block in making this an official stance of the A.P.A. was the, “Sense of the obligation on the part of parents toward the defective creature they have caused to be born.”
Two schools of thought:

✓ “They” could be taught.
✓ “They” should be segregated and prevented from reproducing in order to protect society.

Within this developing social climate, “NHSF” began to grow.

• 1924 name changed to Laconia State School
• WW I, the Depression and WW II: more and more families sought placement for their children.
• Following WW II parents begin to form advocacy groups for their children with mental retardation and associated disabilities.
• 1950 The first National Parent Conference was held in Minnesota and the National Association of Retarded Children is formed.
1950 – LSS conditions “grim.”

• Overcrowding, some worked but most did nothing all day, no room for personal possessions, beds pushed together in rows, furniture selected for cleaning-ease, not comfort, no bathroom privacy.

• “Meds” in vogue to control “inmates” due to staffing shortages
“When you’re short of staff and short of money, it’s really depressing.”
—Peter Guzman
1952 an important appointment:
new Superintendent Richard Hungerford.

- He was a teacher – [Not a medical director]
- Invited parents to visit
- Recognized their political power for reform
1953 The first NH Parents’ Association was formed in Dover and called “The Great Bay Association;”
  • Parents started a school and workshop for their children. (Still operating today)

1956 Film of the conditions at Laconia State School made by the Laconia Parents Association. The State continued to put most of its resources into the institution.

The state committed limited resources to locally based Parents Associations for programs and services.
1962 President John F. Kennedy created the President’s Panel on Mental Retardation to create a national plan for addressing issues surrounding the mentally retarded.

- This continues to exist today but is currently called The President’s Committee For People With Intellectual Disabilities.

1965 Project Head Start was created to:

- Provide supports and services to low income preschool children to assist them in attaining positive outcomes when they entered school.
1966  Burton Blatt published *Christmas in Purgatory*, providing a pictorial account of life in state institutions for people with mental retardation in four eastern states.
Later part of 1960s: This is the time when people began to leave institutions nationwide. The institutions were terribly overcrowded and parents began to work to make room for them in the community.

Parent groups in NH, supported with funds from the Division of Developmental Services, established local programs to provide supports to people with developmental disabilities.

1967 Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program under Medicaid was developed to ensure early and periodic screening and developmental testing of children who qualified.

1971 The Pennhurst class action suit was filed in Pennsylvania based on the right of all children, including those living in institutions, to receive an education.
In 1972:
- The Wyatt vs Stickney law suit in Alabama focused on applying the prohibition of involuntary servitude to include institutionalized individuals.
- Willowbrook class action suit was filed in New York based on the 8th Amendment barring cruel and unusual punishment.
- Children with disabilities were included in Head Start. Home-based programs were added to the array services. (Head Start began in 1965.)

1972  In NH sheltered workshops and Early Intervention programs are funded with Title XX (Social Services Block Grants) and NH DHHS/BDS dollars.

1974  The Model Infant and Toddler Project was started in Hanover, New Hampshire.

1975  Federal law PL 94-142 came into effect mandating all states to provide free and appropriate education to all school aged children including those with disabilities.
1975  With the passage of NH law RSA 171-A, a comprehensive statewide service delivery system including early intervention was established.

1977  More than half of the people nationwide who had mental retardation were living in the community (mostly without supports).

1978  NH parents filed class action law suit in Federal District Court regarding poor living conditions at Laconia State School.
Freda’s tireless efforts led to the closing of the State School and sparked the creation of the community-based service system.
✓ **1981** Area Agency system was formed as part of the settlement, Garity vs Gallen law suit.

  - The Federal Court ordered improvements at the institution and creation of a community system of services and discharge of 235 residents of the institution.

✓ **1981** The federal government established the Medicaid Home and Community Based Care Waivers

  - Over the years this has become the primary source of funding for services for people with ID (MR)/DD

✓ **1984** NH state standards for Early Intervention (He-M 510) were adopted.

✓ **1986** PL 99-457 Individuals with Disabilities Education Act (IDEA) included Part H

  - Gave states the option to participate in developing a statewide system of coordinated, comprehensive, multidisciplinary, interagency programs to provide appropriate early intervention services to all infants and toddlers with disabilities and their families.
1988 New Hampshire established an Interagency Coordinating Council (ICC) to explore the possibility of adopting Part H of IDEA.

- Concerns about whether the State could support an entitlement program (there was a waiting list of 2 ½ to 3 months for services) and there was fear that many more children would be identified as eligible.

Federal government established the Katie Beckett eligibility category under Medicaid

- The parents’ income is not considered for Medicaid eligibility
Julie Beckett and her daughter Katie Beckett. Julie is the one who single handedly convinced the Reagan administration to establish a new eligibility category under Medicaid so that children with severe disabilities can live at home and receive services.
✓ **1989** NH Family Support legislation was enacted into law, creating locally based Family Support Advisory Councils.

✓ **January 31, 1991** Laconia State School closed

✓ Until the passage of the 2010 state budget the former Laconia State School campus housed

  ✓ A minimum security state prison
  ✓ A treatment program for multiple offenders in impaired driving
  ✓ An area agency
  ✓ The prison is closed

✓ The area agency is looking to relocate
Historical Themes

Segregation
Congregation
When community-based housing/service options were proposed in the 1980s...
It is clear that many communities are not yet ready to accept the presence of retarded people living in their midst.

Not in My Neighborhood

group homes for the retarded trigger an emotional debate

“I don’t think it will work; and I don’t think people are going to stand to have this shoved down their throats.”

—Harold Achber

“All they want to do is take these people from a large institution and put them in a smaller institution.”

—A Laconia resident
We have come a long way…

Different types of stories are appearing in the papers…
Billy Hickey
From the 2/27/09 issue of Concord Monitor
Billy has done soccer, basketball, cross country running and swimming. According to his mom, being engaged in sports keeps Billy from "the black hole of autism"
Billy’s mom Martha: "We weren't going to let autism dictate how far Billy could go or what he could do…We knew we wanted our boys to have a full life"
Billy’s mom Martha: "The kids we're bringing up in the world today are just so naturally inclusive... most of the time these kids are just doing the right thing on their own"
Other students say "He's taught us a lot…He brought the cross-country team together and the swim team, too," [Billy is not only in the community but is helping to build community]
Samuel Habib

[Including Samuel Project   www.includingsamuel.com]
Samuel
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Samuel
What is one of the most important lessons learned from the families of Billy and Samuel?

Both families have developed expectations and a vision about their children participating fully in community life and having a meaningful and productive life.
Think of the crucial role that ESS staff and providers can play in helping families create important and positive expectations about their children’s future.

ESS staff and providers give some of the “earliest signals” to parents about the condition of their children and what future may hold for them.
The history of Family Centered Early Supports and Services in New Hampshire continues to be written…

…And, each ESS staff/provider has a critical role to play in shaping the outcomes for children with disabilities and their families