

# **THE 2003 REPORT:**

**REGIONAL AND NATIONAL PERSPECTIVES ON  
DEVELOPMENTAL DISABILITIES SERVICES IN  
NEW HAMPSHIRE**

**PRESENTED TO THE NEW HAMPSHIRE LEGISLATURE  
CONCORD, NEW HAMPSHIRE**

**by**

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# Contents

Listing of Figures and Tables .....	ii
1. INTRODUCTION.....	1
2. AN HISTORICAL PERSPECTIVE.....	1
Opening the New State School .....	2
The 1915 Survey of Feeble-Mindedness .....	5
Laconia Grows .....	7
A Parole Study .....	7
A Federal Review of Laconia .....	8
Concern about Consumers .....	10
3. SETTING THE STAGE FOR REFORM .....	11
National Forces .....	12
Challenges to Laconia.....	14
4. OVERVIEW OF CURRENT SERVICES IN NEW HAMPSHIRE.....	15
Financing Community Services in 2002.....	18
Area Agencies and Family Support.....	19
5. COMPARATIVE ANALYSIS: NEW ENGLAND .....	20
Vermont.....	21
Massachusetts .....	22
Connecticut .....	22
Maine.....	23
Rhode Island .....	24
United States.....	25
6. CENTRALITY OF MEDICAID HCBS FUNDING .....	27
Waiver Utilization in New Hampshire .....	27
Fiscal Effort for Developmental Disabilities Services in New England .....	29
7. FORCES IMPACTING ON SERVICES IN NEW HAMPSHIRE.....	31
Growing Waiting Lists.....	32
Aging Family Caregivers .....	33
Increased Longevity of Persons with MR/DD.....	34
Impoverishment of Direct Support Staff .....	34
Waiting List and Other Lawsuits in the States.....	34
Impact of Economic Decline in the States.....	36
8. CONCLUSION: ACHIEVEMENTS AND CHALLENGES .....	37
Achievements.....	37
Challenges .....	38
Cash Subsidy for Families.....	38
Expansion of Supported Living and Home Ownership.....	39
A Cross-Disability Challenge.....	41
REFERENCES.....	43

## Tables and Figures

<u>Table 1</u> : Laconia, New Hampshire, State School Compared with Institutions for Mental Defectives and Epileptics in Other States, 1940 .....	8
<u>Table 2</u> : Institutional Per Diem Rates, New England States and the United States .....	13
<u>Table 3</u> : Family Support Spending Per Capita: New England States and the U.S. ....	20
<u>Table 4</u> : States Ranked by Federal HCBS Waiver Expenditures, 2000 .....	29
<u>Table 5</u> : Ranking of MR/DD Fiscal Effort in the New England States and Change in Rank, 1996-2000.....	30
<u>Figure 1</u> : Institutional Placements Per 100,000 Population: New Hampshire and the U.S.	12
<u>Figure 2</u> : Institutional Per Diem Rates: New Hampshire and the U.S.....	13
<u>Figure 3</u> : United States: Institutional Closures by Decade.....	14
<u>Figure 4</u> : New Hampshire: Trends in MR/DD Spending, FYs 1977-2002.....	16
<u>Figure 5</u> : New Hampshire: Residential Services: 2002.....	17
<u>Figure 6</u> : New Hampshire: Community Services Revenue in 2002 .....	18
<u>Figure 7</u> : Vermont: Trends in MR/DD Spending, FYs 1977-2002.....	21
<u>Figure 8</u> : Massachusetts: Trends in MR/DD Spending, FYs 1977-2002 .....	22
<u>Figure 9</u> : Connecticut: Trends in MR/DD Spending, FYs 1977-2000 .....	23
<u>Figure 10</u> : Maine: Trends in MR/DD Spending, FYs 1977-2000.....	23
<u>Figure 11</u> : Rhode Island: Trends in MR/DD Spending, FYs 1977-2000 .....	24
<u>Figure 12</u> : United States: Trends in MR/DD Spending, FYs 1977-2000.....	26
<u>Figure 13</u> : United States: Federal ICF/MR and Waiver Spending, 1977-2001 .....	28
<u>Figure 14</u> : New Hampshire: Federal ICF/MR and Waiver Spending, 1977-2002.....	28
<u>Figure 15</u> : Fiscal Effort in the New England States.....	30
<u>Figure 16</u> : Out-of-Home Residential Placements of Persons with DD per 100,00 Population.....	31
<u>Figure 17</u> : New Hampshire: Individuals on Priority One Waiting List.....	32
<u>Figure 18</u> : New Hampshire: Distribution of Individuals with a Developmental Disability Living with Family Caregivers, 2000. ....	33
<u>Figure 19</u> : New Hampshire Direct Support Wage .....	35
<u>Figure 20</u> : New Hampshire: Long Term Care Spending for Disability in 2001 .....	42
<u>Figure 21</u> : New Hampshire: Long Term Care Spending, 2001 .....	42

# The 2003 Report: Regional and National Perspectives on Developmental Disabilities Services in New Hampshire

## 1. INTRODUCTION

This paper is a revision and update of our 1995 study of New Hampshire developmental disabilities services in the comparative contexts of the New England region and the United States (Braddock & Hemp, 1995).

Services for individuals with developmental disabilities in the United States have undergone profound changes. State-operated developmental disabilities institutions once dominated long-term care and served 195 thousand persons in 1967. These institutions now serve fewer than 48 thousand individuals. In 1977, only 25% of developmental disabilities financial resources in the U.S. supported community services in settings of fifteen beds or less. By 2000, 75% of all such resources were supporting smaller community residences and related community services (Braddock, 2002). States are continuing to close institutions, and redirecting institutional resources to a range of community options. Federal programs, exemplified by the \$10 billion Medicaid Home and Community Based Services (HCBS) Waiver, are now offering states a viable alternative to the institutional financing which dominated the 1970's and 1980's.

New Hampshire literally transformed its developmental disabilities service system beginning in the 1980s. The history of the evolution of developmental disabilities services in the state has generally paralleled national trends in deinstitutionalization and community development. However, New Hampshire's extensive utilization of the HCBS Waiver, and reliance on a system of area agencies is noteworthy. New Hampshire has, over the past 15 years, exemplified systemic change and the use of innovative practices in program development and funding (e.g., Braddock, 1985; Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990; Bradley, Conroy, Covert, & Feinstein, 1986; Miano & Brail, 1994; Racino, 1994). There are new challenges on the horizon, however.

## 2. AN HISTORICAL PERSPECTIVE

The history of publicly financed services for people with developmental disabilities in New Hampshire, for the first three-quarters of this century, is a history of the Laconia State School.

The state shall establish and maintain a school for the care and education of the idiotic and feeble-minded, between three and twenty-one years of age, which shall be known as the New

Hampshire School for the Feeble Minded Children...(Section 1, Laws of 1901, Chapter 102).

The establishment of the school was in part due to pressure from the General Federation of Women's Clubs, interested in the development of institutional care, and state welfare leaders' desire to end out-of-state placements in, for example, Massachusetts and New Jersey (DuBois & Crocker, 1993; Crocker, 1993, p. 32). In the late nineteenth century, New Hampshire's "feeble-minded" children and adults were housed in the state insane asylum, orphanages, and almshouses or county farms. Safety and adequacy of care in many of these settings was a central issue. For example, a concurrent resolution in 1893 of both houses of the New Hampshire legislature provided for an inquiry into the Strafford county almshouse fire which killed forty-one of the forty-four "insane persons therein confined" (Streeter, 1893, p. 8).

Two of the six New England states, Massachusetts and Connecticut, had already opened the first institutions in the United States including Samuel Gridley Howe's initial residential school experiment in South Boston (1848). Maine established Pineland Center, and Rhode Island opened Ladd Center, in 1907. Vermont established its state school for feebleminded children, which became Brandon Training School, in 1915 (Braddock, 1988; Vermont Agency of Human Services, 1993).

Mrs. Lilian C. Streeter (1893), at the first meeting of the New England Conference of Charities and Correction, reported that unlike most states, New Hampshire had no board of charities and correction. However, in 1889 the New Hampshire State Board of Health was vested with the authority to visit all "insane asylums" in the state each four months, and report annually to the governor. In 1892, the State Insane Asylum served 368 persons at a cost of \$97,505.89 of which some \$22 thousand was appropriated by the state. The balance was provided by private patients and invested funds. Ten county farms (almshouses) served 1,270 persons of whom 401 were insane including "idiots and epileptics." This was more than the 368 served in the state institution. "Yet, of the indigent insane sent to the state asylum for remedial treatment in 1892, 18.75 per cent were discharged as "recovered," and 17.71 per cent as "much improved." These facts are eloquent and need no comment" (Streeter, 1893, p. 5).

New Hampshire's five "orphan asylums" served 148 children in 1892. "In addition to these asylums, the state itself assumes the expense of the support and education of its deaf and dumb, blind, and feeble-minded children, appropriating \$10,000 annually for that purpose. Thirty-two children are now thus supported in institutions outside the state" (p. 7). State appropriations in 1893 for charities and correction totaled \$23,200, allocated to: deaf and dumb (\$5,000); blind (\$4,000); idiotic and feeble-minded (\$1,000); indigent insane (\$6,000); Commission of Lunacy expenses (\$1,200); and state industrial school (\$6,000).

### OPENING THE NEW STATE SCHOOL

The original law (Laws of 1901, Chapter 102) established the school (Section 1). Section 2 provided for the governor to appoint five trustees. One trustee was to be a woman, and they were to visit the school monthly and furnish a report annually

“containing a history of the school for the year and a complete statement of the accounts.” The Trustees’ first report described the site selected for the proposed school.

After thorough investigation, covering nearly a year, the trustees decided to locate the home in Laconia, and purchased for the purposes of the school farms containing 247 acres of land. These farms are beautifully situated on a rise of land about half way between Laconia and Lakeport, on the westerly side of Lake Opechee, and extend westerly to Lake Winnesquam. The land is in a good state of cultivation, well wooded, and has good buildings thereon, many of which can be used to good advantage for the purposes of the school (Trustees, 1902, p. 5).

The site included three farmhouses, one of which was occupied by a farmer. Another house was remodeled to be the superintendent’s residence, and a brick dormitory was constructed. Dr. C. S. Little of Webster, New Hampshire, a specialist in brain diseases with experience in institutional work, was selected as the first superintendent. His wife, also a physician, served as matron (Board of Charities and Correction, 1902).



The School opened February 1, 1903, and quickly filled to capacity. By 1904, there were 34 boys and 33 girls in residence and a waiting list of 80 (Board of Charities and Corrections, 1904, p. 56). Superintendent Little and his wife “have been untiring in their efforts in behalf of the school and if they are allowed to carry out their intelligent policy in developing its best interests, New Hampshire will have one of the best institutions in the country for this class of children” (p. 91). The Board recommended custodial care for women and also a separate building for epileptics (p. 8). All “feeble-minded” children in almshouses were admitted to the new state school when it opened (p. 63).

On November 15, 1904, a fire destroyed the recently constructed dormitory but there was no loss of life. Sixty-six children had to be temporarily accommodated, and boys lived in the basement of the school building while girls were housed in the assembly hall.

The new dormitory, of slow burning construction, and pronounced by one of the Insurance Inspectors as nearly fireproof as possible with the funds appropriated, was completed and furnished within the appropriation. It was occupied Feb. 1st, 1906, and accommodates 84, twenty more than the one destroyed by fire (Trustees, 1906, p. 9).

By 1906 there were 84 residents of the school and 117 applications on file, "many of which represent most urgent cases whose friends are crying for their admission. What shall be done with this waiting list?" (Trustees, 1906, p. 10). The school's officers in 1905-1906 included the superintendent, Dr. Little, a matron, two teachers, an instructor in manual training, and a farmer. Dr. Little resigned on July 1, 1910, and left for Thiells in Rockland County, New York, to develop a new institution which would become Letchworth Village.

After careful deliberation the Trustees elected Dr. Benjamin Baker of Manchester to fill the vacancy (Trustees, 1910). The school's population had reached 175. The 96 admissions in 1910 were from county farms (27), Children's Home, Dover (6), Franklin Orphans' Home (8), St. Paul's Orphanage (1), Mercy Home (2), other (3), and private homes (49) (p. 13). The boys' regimen at the school required that "everybody over six years of age should be kept employed for such portion of the day as he is not in school, with the exception of save half a day a week for play" (p. 61). There had been no deaths in the school, and with the exception of a "very mild epidemic of mumps, the general state of health has been excellent" (p. 58). Professor Johnstone from the New Jersey Training School at Vineland consulted in testing of the children with the Binet system.

This thorough examination is now given to all new admissions and is proving not only of scientific interest, but of real value in ascertaining early the child's proper place in the school. Many of the children of twelve or fourteen years of age, whose appearance to a stranger or untrained observer would suggest nothing abnormal, have been found by the Binet test to be, mentally, only five or seven years old (p. 62).

By 1914, the school was serving 183 children. Dr. Baker's report cited the pressing need for "more land, both field and pasture" (Superintendent, 1914, p. 5), and discussed the growing national reputation of the facility and other developments in his state.

There are frequent inquiries for literature and printed reports from states establishing schools for their feeble minded. Educators are interested and eager for information on this subject.

The feeble minded are being recognized in our public schools, singled out in our courts, acknowledged in our county farms, orphanages and insane hospitals. I feel that a classification of defectives is being slowly brought about. As the many town farms have been merged into the county farms and as the insane have been taken from the county farms to the State Hospital, so must all the needy feeble minded persons eventually be cared for apart from other classes (p. 5).

### THE 1915 SURVEY OF FEEBLE-MINDEDNESS

The New Hampshire Children's Commission report (Children's Commission, 1915) contained Mrs. Lilian Streeter's special section on a state-wide census of feeble-mindedness in New Hampshire (Streeter, 1915). The Commission was concerned that, despite the establishment of the facility at Laconia, the almshouses still contained feebleminded children and normal children of jailed parents (p. 28). The *Carnegie Station for Experimental Evolution*, and the experiences of the states of Virginia and North Carolina, called for segregation of the feeble-minded and examination and deportation of all immigrants with "mental defects" settling in the state. These methods, the authors maintained, could diminish attendance at State institutions for the feeble-minded (p. 34).

The Children's Commission report presented the prevailing view on procreation by feeble-minded women. Although laws including the Laws of 1905, Chapter 23, had provided for detaining feeble-minded girls after the age of twenty-one,

...no matter how many such feeble-minded girls or women may be committed now by the judge of probate, they can not be received at the State school for Feeble-minded because there is absolutely no room for them. Only seventy-eight such girls are now being cared for at the institution, after its twelve years' existence, while 550 are still at large in the state...[and] the State Hospital is caring for forty-five and the county farms seventy-one. The most pressing demand at the School for Feeble-minded at present is for the admission of the feeble-minded girl of child-bearing age, not only for her own protection, but for the protection of the community from so dangerous a menace to its welfare (pp. 33, 34).

New Hampshire ranked second in the nation in 1910 in the institutionalization of children in almshouses and orphanages (261/100,000 population compared to New York's 332/100,000) (p. 28). This fact was noted by Mrs. Streeter in her section describing the survey of feeble-mindedness in institutions "and at large throughout the state" (Streeter, 1915, p. 71). "As New Hampshire stands second in the Union in the number of children in institutions in proportion to her total population, these tests cover a sufficiently large number of children to make them extremely valuable and significant" (p. 74). The census employed the Binet-Simon Measuring Scale of Intelligence in the state's 18 orphanages and the State Industrial School. The Binet had already been administered at Laconia and the State Hospital in Concord. The mental status of the mostly adult inmates of the ten county almshouses (county farms) was

reviewed with the superintendent and matron of each setting (p. 74). In addition, questionnaires were sent to all school superintendents and the chairmen of school boards, physicians, overseers of the poor, county commissioners, probation and truant officers, district nurses, and charity workers throughout the state.

Among the 1,248 children cared for in 18 New Hampshire orphanages, 376 were determined to be "backward" and 262 "feeble-minded." Streeter noted that these 638 children exceeded the 185 being accommodated at the State School at Laconia (p. 84). Of the 147 boys and girls at the State Industrial School in Manchester, 120 were tested feeble-minded and 24 backward (p. 86). In the 10 county farms where interviews were conducted, 29% of the 946 residents, or 275, were determined to be feeble-minded. Of these, 137 were "high grade" and 138 were "low grade" (p. 87). At the State School for Feeble-Minded, 85 (46%) were tested high grade and 100 (54%) were tested low grade. "It is interesting to note that the girls and boys are so evenly divided at the State School for the Feeble-minded, and that there is so little difference in the numbers of high and low-grade cases" (p. 88). The State Hospital for Insane served 10 high grade and 95 low grade children and adults. "The fact that 105 feeble-minded are included among the inmates of the State Insane Hospital, shows great injustice both to the feeble-minded so cared for, and the hospital" (p. 89).

The Streeter (1915) census recorded 1,158 feeble-minded children and adults "at large" in the state, determining that 60% were high grade, 30% were low grade, and the remaining children were "ungraded." Streeter (1915) presented a prevalence estimate based on the 4:1 ratio of the number of canvass returns to the number of questionnaires returned in the 52 towns studied intensively. Applying this ratio to the 792 individuals reported in the questionnaires yielded an estimate of 3,168 individuals. Adding to this the 947 persons in almshouses, county farms, the State Training School, the State Hospital for the Insane, and the State School for the Feeble Minded Children produced an estimated 4,115 "feeble-minded" individuals in New Hampshire in 1914. This constituted .95% of the state population of 430,572 (p. 93).

In developing recommendations about care for the feeble-minded in New Hampshire, the Commission and Mrs. Streeter sought advice from Dr. Walter E. Fernald, Dr. H. H. Goddard, Professor Johnstone and Mr. Alexander, and visited institutions in New Jersey and Massachusetts. There were four recommendations (Streeter, 1915, pp. 100, 101): 1) custodial care for feeble-minded girls and women of child-bearing age at the State School or in a colony under its supervision; 2) until establishment of a colony, preference in State School admissions for girls and women of child-bearing age; 3) provision for care of all the feeble-minded children in the state; and 4) provision in the state's large public schools for Binet testing and special classes for "backward" children. "The Commission does not advocate sterilization as a preventive measure, because the experience of the eight states (California, Connecticut, Indiana, Iowa, Nevada, New Jersey, New York, and Washington) which have adopted such laws does not show it to be advisable" (p. 101).

## LACONIA GROWS

By 1920, the average number served at Laconia had reached 349. Dr. Arthur E. Perley was appointed assistant to Dr. Baker and the Trustees proposed that he help to supervise "pupils out on parole" (Trustees, 1920, p. 4). The school acquired 238 more acres of land, bringing the total acreage to 485. The Trustees discussed the bequeathing of land, "tactful" negotiations with other heirs, and the pressing need for tillable land adjacent to the school.

Such land is absolutely essential for agricultural purposes, if healthful labor is to be provided for the boys of the School, and if the School is to be in any sense self-sustaining and able to provide the varied diet necessary for the well-being of the entire school population, without excessive cost to the State in these days of the high cost of living (Trustees, 1920, p. 5).

Jacob Sanborn's estate was willed to the school and a separate "boys' colony" was established. The average population had grown to 399 in 1924, and Dr. Baker recommended changing the name from New Hampshire School for the Feeble Minded Children to "Laconia State School" (Trustees, 1924, p. 10). By 1928, when the population had reached 430, there was a need for an infirmary and an improved water supply (Trustees, 1928).

### A PAROLE STUDY

A handwritten report indicated that the Trustees in their annual meeting of October 18, 1911, had discussed the potential of placing three children with families who would provide care and guardianship. "It was moved and so noted that the Superintendent, Dr. Baker, be instructed to place these children if any family could be found that was satisfactory to him." In May, 1932, the school's assistant physician and the social worker (Little & Johnson, 1932) reported on "discharged parolees" from the Laconia State School. They observed that Dr. Walter E. Fernald's (1919) earlier parolee study "and the influences of newly acquired knowledge persuaded Dr. Fernald to almost reverse his attitude toward returning institutional inmates to the community" (Little & Johnson, 1932, p. 2).

To address the questions "What is a successful adjustment?" and "What is failure?" Little & Johnson (1932) relied on previous studies by Foley (1929) and Storrs (1929). Ninety-one males and 83 females left Laconia during the five years between July, 1925 and July, 1930. Of these 174, there were 31 deaths. Transfers to the Industrial School (6), the State Hospital for the Insane (5), County Farms (2), the Army or Navy (2), and out-of-state institutions (7) totaled 22. Finally, one was discharged because she was a non-resident. Little and Johnson (1932) considered these 120 parolees (not counting deaths and transfers), and determined that 94 were successful, 19 were unsuccessful, 4 had left the state, and 3 could not be traced. Omitting these 7, Little and Johnson (1932) discussed their "successful" rates of 84% for boys and 83% for girls, compared to Storrs' (1929) report that boys were 73% successful and girls, 75%.

Perhaps we have graded less rigidly, perhaps our cases have been out a shorter time, perhaps the average type of case we deal with

may be different. But in evaluating human nature one can never even approximate the exactness which one expects in reckoning interest on a bank account. The remarkable thing is that the figures are only 10% apart (p. 10).

Little and Johnson (1932) included a section in their paper on “sterilized cases.” They cited another study of 605 parolees (Popenoe, 1927) and included Popenoe’s conclusions that sterilization favored stabilization in marriage, did not favor the spread of venereal disease, and was a “valuable adjunct to a system of parole for the mentally defective” (Little & Johnson, 1932, p. 14).

### A FEDERAL REVIEW OF LACONIA

The U.S. Public Health Service surveyed Laconia State School in 1941 and provided comparative data from Delaware, Maine, Massachusetts, New York, and the United States. The survey compared Laconia’s professional staffing ratios and management and physical plant structures to the 1940 *Practical State Program for the Care of the Mentally Deficient* standards of the American Association on Mental Deficiency. Laconia in 1940 appeared to compare well to institutions in other states and across the nation with its relatively low admission rate, its relatively high discharge rate, and the lower death rate per 1,000 residents (*Table 1*).

**Table 1**  
**Laconia, New Hampshire, State School**  
**Compared with Institutions for Mental Defectives and Epileptics**  
**in Other States, 1940<sup>1</sup>**

	Patients Under Treatment <sup>2</sup>	Admission Rate Per 1,000 Under Treatment	Discharge Rate Per 1,000 Under Treatment	Death Rate Per 1,000 Under Treatment
Laconia State School <sup>3</sup>	761	68.3	78.8	7.9
Delaware <sup>4</sup>	562	128.1	74.7	7.1
Maine <sup>4</sup>	1,145	48.0	8.7	28.8
Massachusetts <sup>4</sup>	7,151	54.3	33.7	13.0
New York <sup>4</sup>	23,782	108.4	53.6	13.6
<b>United States<sup>4</sup></b>	<b>118,449</b>	<b>93.5</b>	<b>39.0</b>	<b>20.6</b>

<sup>1</sup> Table III, reproduced from U.S. Public Health Service (1941, p. 17)  
<sup>2</sup> Includes patients on books at end of year plus separations  
<sup>3</sup> Source: Data collected by the Division of Mental Hygiene, U.S. Public Health Service, 1941  
<sup>4</sup> Source: Patients in Mental Institutions, Bureau of the Census, U.S. Department of Commerce, 1938

The public health survey also addressed sterilization, describing the schools procedures of parental consent, certificate by two outside physicians, and the hearing held by the Board of the institution or the county commissioners. In 1940, 8 boys and 23 girls were sterilized (p. 42).

In a survey section on "Visits, Parole, Discharge, Aftercare," the U.S. Public Health Service noted the relatively large numbers of visitors, and that seventy-five to eighty residents were usually on parole. The various community parole responsibilities of the social worker were also described: visiting wage earners monthly, making approximately 35 pre-parole investigations a year, investigating relatives who were delinquent in paying board charges, writing histories of prospects for sterilization, and administering approximately 20 Binet tests annually to school children likely to be dropped from school.

Family care has not been attempted. It could probably be instituted at a slight saving, when a second social worker is available. In those states where family care is an active program, the placement of young defective children in homes has shown a beneficial response of children to this type of care, giving them as it does the benefit of normal community life. It has also interested the community in developing resources for other children who are similarly handicapped. Thus institutionalization in many cases may be averted (p. 45).

The U.S. Public Health Service's concluding recommendations addressed additional personnel including a second social worker to institute family care. The U.S. Public Health Service recommended "citizens shall not be encouraged to think that the sterilization of a few uninhibited defectives can take the place of a strong program of training and supervision" (p. 50). Several recommended capital projects included those already underway at the school. "The size of the institution should be such as to preclude the existence of any considerable waiting list" (p. 50). One of the 23 recommendations addressed serving children under the age of five because "a seriously defective child in early years may be not only a burden to his family but also a detriment to the normal children" (p. 51).

Superintendent Baker disagreed with the U.S. Public Health Service's recommendation about serving younger children. According to Dr. Baker, Laconia had "wisely considered" that the very young and older individuals could be cared for in the community and that "those who are both sex problems and school problems should be given prior consideration by the institution" (Trustees, 1942, p. 8).

The *Twenty-fifth Biennial Report* (Trustees, 1950) anticipated modern problems with staffing at the School. The Trustees found it necessary to build a facility for delinquent boys who had "committed unlawful acts" upon residences near the institution (p. 14). With an "intramural" population of 735 and 79 on parole or home visit, there needed to be new ward space to increase the capacity from 720. The facility should serve "deteriorating defectives," for whom ramped buildings were recommended (p. 16), and should collect more reimbursement from parents.

At the present time it costs approximately \$10.50 a week to maintain a child at the School. Where possible, parents and relatives of children are requested to pay something toward this maintenance cost each month...It is highly probable that with the

proposed increase in employees' salaries that this present per capita cost for maintenance will increase considerably in the next biennial period (p. 18).

### CONCERN ABOUT CONSUMERS

Dr. Baker finished his long tenure as Superintendent, retiring in 1945 after thirty-five years. There were two superintendents in fairly quick succession, R.J. Depner, MD, and then Harold Connelly, MD, appointed in 1948. In 1953, Richard H. Hungerford was appointed Superintendent. He had worked as Director of New York City's special education program, and before that was special education director in Detroit.

Hungerford was a renowned educator and had some very strong ideas about the role of education and professional methodology in the institution....He put a good deal of effort into increasing the numbers of direct care staff and professional staff. He was responsible for hiring the first clinical director, recreation director, more social workers, teachers, and psychologists. Hungerford developed a program in which Keene State College students worked in intern-training programs at the institution with clients (DuBois & Crocker, 1993, p. 7).

Superintendent Hungerford was visionary in many of his efforts and ideas. In 1952, he had authored fifteen "minimums of protection" for persons with mental retardation. Included were recommendations that each state have a separate mental retardation department, that there be continued research in the field on prevention, training and public education, and that there be training for parents and staff.

There must be workshops for parents, places where they can learn that there is no stigma to mental retardation...except that society in its ignorance makes the burden upon family and child almost overpowering.....The Boards of all...institutions, public or private, must include not less than two parents of retarded children; and there must be no corners hidden from them (Hungerford, 1952, p. 1).

Hungerford (1953) invited parents to be partners in administration of the school. "In order to be effective partners...you must have the facts. Maintaining a parents' organization is your responsibility; giving you the facts is mine" (p. 1). Hungerford believed in segregation of institutions and units for those needing custody and for those who could benefit from training. He implemented coeducational activities and (behind the backs of the Trustees) ordered curtains for cottages (DuBois & Crocker, 1993). Apparently Hungerford moved too quickly for his superiors (DuBois, 1995). In 1958, the American Psychiatric Association (APA, 1958) was asked to conduct an extensive review of Laconia State School. The review found staff to be poorly organized and not well trained. Some were found to be "incompetent, cruel and irresponsible" (APA, 1958, p. 143, cited in Crocker, 1993, p. 34). The review added criticism of the exploitation of residents who worked without pay for 10-14 hours per day. Furthermore, the facility

had not received sanitation, fire and safety licensure because of overcrowding for several years. Overcrowding in some buildings had reached 200% (Crocker, 1993, p. 35).

The Laconia Trustees asked for Superintendent Hungerford's resignation on May 3, 1958, and recommended that he fill a new position as director of special education at the institution (Anderson, 1958). Hungerford was replaced by Arthur Toll, an educator and public school administrator, who worked to change the school from custodial care to a therapeutic program. Attendants were required to take courses in medicine, psychology, counseling, interpersonal relations and nursing care (DuBois & Crocker, 1993 p. 9). In 1961 the Board of Trustees was dismantled by the New Hampshire Legislature. Resident population at Laconia in 1962 was 990 (Crocker, 1993).

As the 1960's ended, the dairy herd was sold off and the farm was closed. More capable farm hands had been placed in the community and, "from a business point of view...food products could be purchased at the same price or below what LSS's cost was." In 1969 the facility was named the "Laconia State School and Training Center" (DuBois & Crocker, 1993, p. 10).

### **3. SETTING THE STAGE FOR REFORM**

For six decades, New Hampshire's service system for individuals with mental retardation was defined by Laconia. The School had closely reflected institutional trends nationally: Laconia assessed and classified residents with the Binet-Simon system; it employed the self-supporting institutional farm economy model; it grew steadily over the years in size; and it sterilized male and female residents. In the 1970's, the institution would come under increasingly close public scrutiny, and this scrutiny would set the stage for comprehensive reforms.

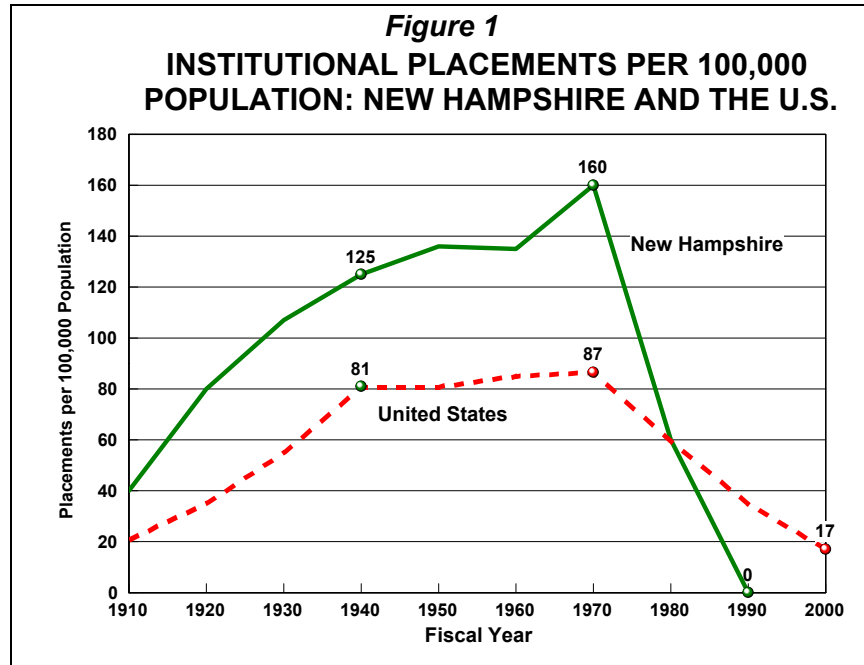
*Figure 1* presents institutional placements per 100,000 of the general population in New Hampshire over 81 years of the 89-year history of the institution. Encompassing 1910 to 2000, the figure illustrates how New Hampshire's institutional placement rate exceeded the average for the United States for each year until 1980. New Hampshire's transformation from an institution-dominated system began in 1970 when Laconia's population peaked at 1,169. (The U.S. population peaked at 194,650 in 1967). Laconia closed in 1991.

### **NATIONAL FORCES**

The Laconia State School and Training Center's experience during the period of 1960 through the facility's closure in 1991 can also be understood in the context of national trends. New Hampshire's response to key national events helps illustrate directions the state took in developing particular types of services and in utilizing certain funding strategies.

According to Boggs (1994), key developments with national impact during the 1960's included the broad dissemination of a pictorial essay of inhumane institutional conditions presented in *Christmas in Purgatory* (Blatt & Kaplan, 1967), publication by the President's Panel on Mental Retardation of the first edition of *Changing Patterns of Residential Care for the Mentally Retarded* (Kugel & Wolfensberger, 1969), and the

introduction in the United States of the Scandinavian concept of "normalization" (Wolfensberger, 1972). The President's Panel on Mental Retardation (1962) had also urged the development of a wider range of small, community-based residential arrangements. According to Baker, Seltzer, & Seltzer (1974) 239 new community residences were established between 1970 and 1973 in the United States (cited in Braddock, 1977, p. 28).



Braddock (1987) identified four key events in developmental disabilities services which occurred during the early 1970's: a) right to education litigation on behalf of students with mental retardation (*Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania*, 1972); b) the first class action litigation on institutional conditions (*Wyatt v. Stickney*, 1972); c) federal special education legislation culminating in P.L. 94-142; and d) Congressional amendments to Title XIX of the Social Security Act permitting state institutions to receive federal reimbursements as Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). The ICF/MR program rapidly became the largest federally financed mental retardation services program.

Beginning in 1970, the U.S. institutional per diem rate escalated dramatically. The acceleration of New Hampshire's daily cost of care also began in the early 1970's. *Figure 2* compares per diem rates in New Hampshire and the United States during 1950 to 2000. The data are adjusted for inflation (constant 2000 dollar values).

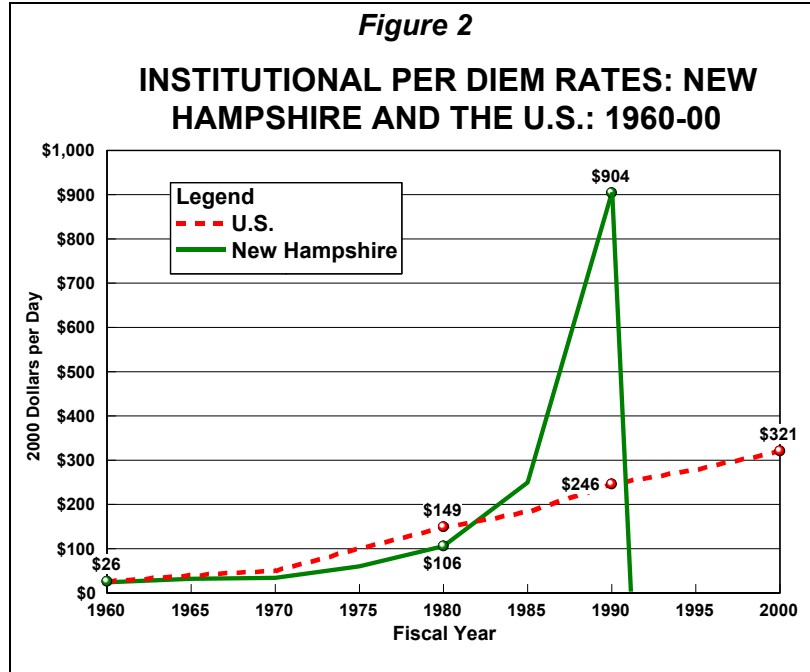
New Hampshire's per diems trailed U.S. costs until 1983 and the implementation of reform efforts associated with the Laconia lawsuit (*Garrity v. Gallen*). Costs rapidly escalated after 1983, reaching a peak of \$904 (constant 2000 dollars) in FY 1990, the year prior to closure. Average costs in the U.S. reached \$321 per resident per day in 2000.

New Hampshire's major acceleration in daily cost of care began with Laconia's federal Medicaid certification in the late 1970's.

**Table 2** compares per diem rates at six points during the past two decades for the New England states and the U.S. With the exception of Rhode Island, the New England region states' per diem rates in 1977 were at or below the national average.

By 1982, only New Hampshire lagged substantially behind the national average. By 1988, daily costs of care in all states in the region exceeded the nation's average as facilities built decades earlier for larger populations were downsized. Maine's per diem rates in 1992 and 1995 reflected rapid downsizing of Pineland Center as part of closure activities. In addition, during the 1970's and 1980's class action litigation in every

New England state had targeted the improvement of institutional conditions. The major cases focused on Connecticut's Mansfield Training School in 1978 (*Arc v. Thorne*); Maine's Pineland Center in 1975 (*Wuori v. Zitnay*); Massachusetts' Belchertown Center in 1972 (*Ricci v. Greenblatt*) and the Wrentham Center and Paul Dever School in 1975 (*Arc v. Dukakis*); New Hampshire's Laconia State School and Training Center in 1978 (*Garrity v. Gallen*); Rhode Island's Ladd Center in 1977 (*Iasimone v. Garrahy*) and Vermont's Brandon Training School in 1978 (*in re Brace*). In 1991, New Hampshire closed Laconia and became the first institution-free state. Following New Hampshire, Vermont and Rhode Island closed Brandon (1993) and Ladd Center (1994), respectively.



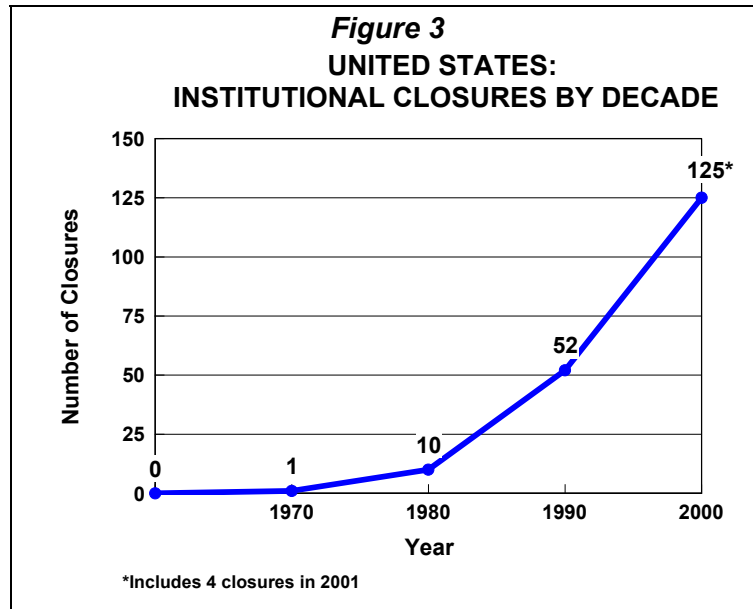
**Table 2**  
**INSTITUTIONAL PER DIEM RATES, NEW ENGLAND STATES AND THE UNITED STATES**

	1977	1982	1988	1992	1995	2000
Connecticut	\$40	\$96	\$185	\$309	\$414	\$552
Maine	\$45	\$122	\$175	\$505	\$452	\$258
Massachusetts	\$39	\$139	\$275	\$437	\$423	\$439
New Hampshire	\$27	\$78	\$278	\$0	\$0	\$0
Rhode Island	\$51	\$118	\$245	\$439	\$0	\$0
Vermont	\$38	\$91	\$164	\$268	\$0	\$0
<b>UNITED STATES</b>	<b>\$45</b>	<b>\$92</b>	<b>\$154</b>	<b>\$212</b>	<b>\$260</b>	<b>\$321</b>

*Figure 3* summarizes all institutional closure activity in the United States from 1970 to the present. In addition to the closures in New Hampshire, Rhode Island, and Vermont, Connecticut closed Mansfield in 1993 and New Haven in 1994; Massachusetts closed Belchertown in 1992, the John T. Berry Center in 1995, and Paul A. Dever Center in 2002; and Maine closed Pineland in 1996.

### CHALLENGES TO LACONIA

The volunteer office at Laconia kept a scrapbook of newspaper accounts of issues at the institution. While there was a record of approximately 100 articles during 1950-59, this increased to 141 in the 1960's and to 306 in the 1970's (Crocker, 1993, p. 53). The institution which for decades had been the principal component of New Hampshire's developmental disabilities service system was, by the mid-1970's, the focus of great public concern. Laconia's Association for Retarded Citizens decided in 1977 to file a class action suit, and was joined by the state Association for Retarded Citizens (Crocker, 1993, p. 92).



The lawsuit was filed in 1978 and *Garrity v. Gallen* (1981) became the longest civil suit in New Hampshire's history (Covert, MacIntosh, & Shumway, 1994). The case included compelling testimony by national leaders in the field of developmental disabilities including Lou Brown, Marc Gold and Gunnar Dybwad. The suit changed how the press, politicians, and the public perceived Laconia's residents. Residents came to be seen as "victims of a political and educational system that saw them as valueless" (Covert et al., 1994, p. 200).

State legislation enacted in 1975, RSA 171-A, had mandated individual service plans and the concept of area agencies, although no funding was available initially for their administration (Crocker, 1993, p. 53; Covert et al., 1994, p. 202). The authorization of these twelve quasi-public area agencies, substantially independent from state control, set the stage for a systematic expansion of New Hampshire's community services options. The Division of Developmental Services collaborated with advocates and parents to construct a proposal ultimately accepted by the court. The Division's *Action for Independence* responded to the class action suit with unit-by-unit plans for Laconia, and with a multi-year plan for community service development.

In the original *Action for Independence* plan (State of New Hampshire, 1980, p. 241) new funding for community spending (non-adjusted) was to grow from \$5.1 million in 1981 to \$30.4 million in 1987, while Laconia's annual budget was to decline from \$11.6 million to \$5.5 million. The institutional cost was based on a projected \$70 per day for 215 residents. In fact, Laconia's average daily population in 1987 was 213, and the per diem had reached \$212 making total spending \$17 million -- triple the original projection for that year (Braddock et al., 1990). New Hampshire's 1987 community spending slightly exceeded the original target and totaled \$38.8 million. The Division's plan to combine institutional reform and community placements left open the possibility of phasing out Laconia, but did not guarantee its closure.

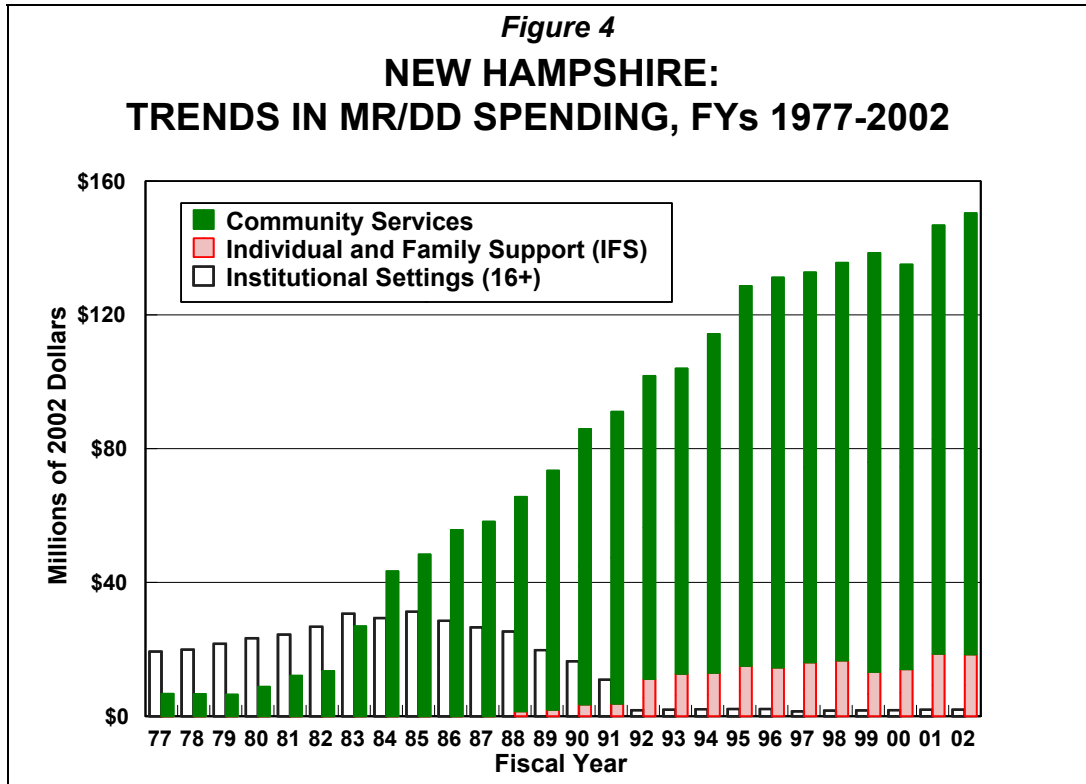
The recommended implementation plan by the Division of Developmental Services relied heavily on community resources, but over an extended period of time....The concept of gradual movement to a community-based system over a period of 5 or more years meant that the court would continue to be involved should the state's commitment waiver. This was a *key factor* in the ultimate closure of Laconia....These dynamics provided the necessary tension to move decisively toward a community-based system (Covert et al., 1994, p. 201).

Laconia closed on January 31, 1991, by which time the state's array of community services and family supports had been dramatically expanded. The following overview traces this expansion of services and resources in the community.

#### **4. OVERVIEW OF CURRENT SERVICES IN NEW HAMPSHIRE**

The first community programs in New Hampshire were operated by non-profit organizations established in the 1960's and 1970's, notably the Great Bay School and Training Center (Newington), the Moore Center (Manchester), and the New Hope Workshop (Keene). Besides the voluntary efforts of parents, friends and advocates, these early community developments were assisted by the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (P.L. 88-164) (Crocker, 1993, p. 64). Public Law 88-64, however, only provided limited federal assistance for community facilities.

*Figure 4* illustrates New Hampshire's allocation of financial resources for Laconia compared to an expanding range of community residential services. The figure encompasses 1977-2002. The solid bars denote spending for fifteen person or fewer community residences and non-residential community services including sheltered employment, case management, and other community services and supports. The cross-hatched subcomponent of the solid bars represent "individual and family support" spending (family support, supported living and personal assistance, and supported employment). The light gray bars, through 1980, represent spending for Laconia State School and Training Center. Beginning in 1981, the institutional expenditures also include federal/state spending for Cedar Crest, a 35 person private ICF/MR for



children. Cedar Crest's funding expanded from \$.1 million in 1981 to \$2.0 million in 2002. All data are adjusted for inflation, and are represented in constant 2002 dollar terms.

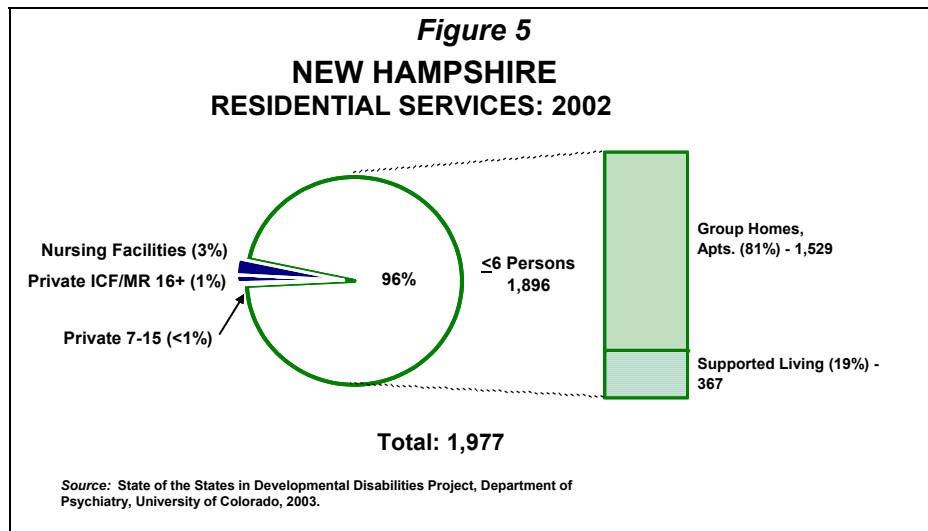
Consistent with the compromise established between the Court, the Division, and advocates, New Hampshire simultaneously pursued reform of the institution, and community development. Prior to the court's involvement in the late 1970's, Jack Melton, Ph.D., (who succeeded Toll as superintendent in 1975), was committed to reorganizing and upgrading Laconia. This included attaining ICF/MR certification to produce Medicaid reimbursements (DuBois & Crocker, 1993). Federal ICF/MR reimbursements to the institution were initiated in 1975 and grew from \$567 thousand in 1977 to over \$10 million in 1985. Federal ICF/MR funds then declined annually to \$1.7 million in 1991, the year of Laconia's closure. Each year saw more of New Hampshire's federal and state resources allocated to community services, and declines in spending for institutional care, leaving only the \$2.0 million for Cedar Crest by 2002.

New Hampshire's community services expansion, beginning in 1984, was largely underwritten by the Home and Community Based Services (HCBS) Waiver. The Waiver was authorized by Section 1915(c) of the Social Security Act, which was enacted by Congress as Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (OBRA, PL 97-35). States can provide a wide range of services under the Waiver. New Hampshire's Waiver services include assistive technology, specialty services, crisis response, consolidated development services, case management, personal care, community support and habilitation, supported employment, respite care, and environmental modifications such as home adaptations (Centers for Medicare and Medicaid Services,

2003). The options now available through the Waiver helped to promote the goals envisioned by the Division of Developmental Services and the area agencies to create individualized housing and regular work opportunities for those living in the community.

The community housing options included supervised apartments, group homes, enhanced family care (an expanded foster care arrangement), and a handful of eight-bed ICFs/MR...Supported employment became the day program of choice for adults with developmental disabilities. Many former state school residents, along with individuals with disabilities who had never lived in an institution, began to join the state’s work force. (Covert et al., 1994, pp. 203-204).

Figure 5 illustrates the New Hampshire’s residential service options for individuals with developmental disabilities in 2002. In 1977, Laconia State School dominated developmental disabilities services in New Hampshire. By 2002, the only individuals in institutional settings were the 25 residents of the Cedar Crest private ICF/MR, and 49 individuals residing in nursing facilities. The six person or fewer community options consisted primarily of one, two or at most three individuals living in apartments or houses. The vast majority of these individuals are supported by the HCBS Waiver.

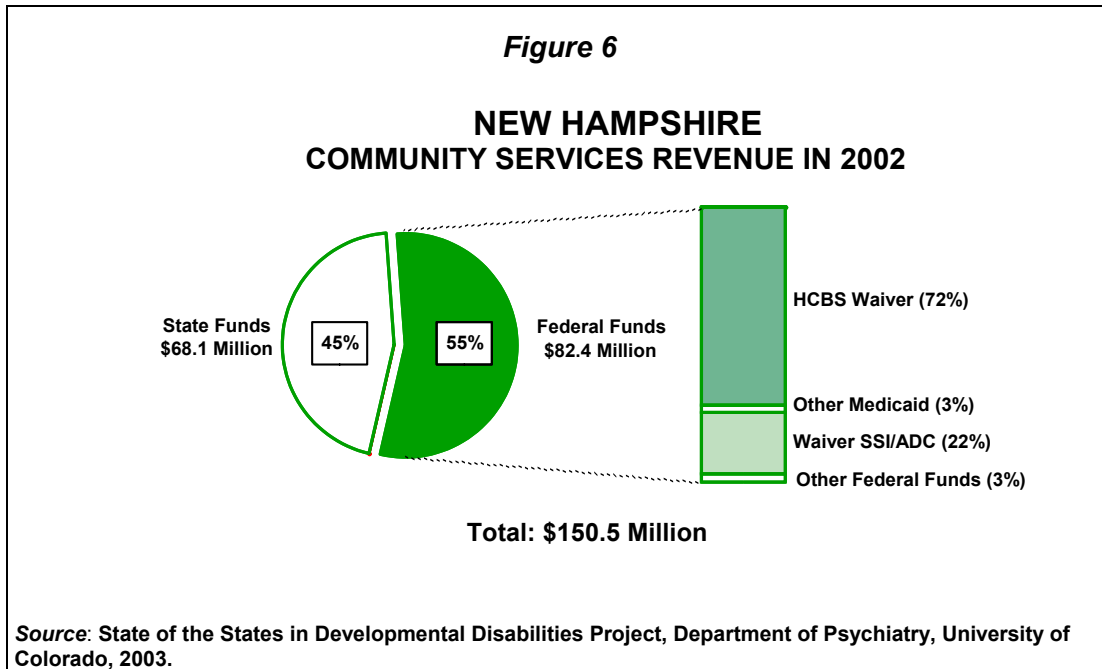


Between 1986 and 1991, as the Laconia population decreased to zero, the proportion of individuals served in settings of three persons or less expanded from 10% to 67% of all persons served. In 2000, state-by-state comparative data indicated that New Hampshire ranked 3rd nationally, with 95% of individuals in out-of-home care residing in 6 person or fewer settings. The national average of placements in settings for 6 or fewer individuals in 2000 was 61% (Braddock, 2002).

It is also noteworthy that the number of individuals served in out-of-home residential services in New Hampshire expanded substantially since 1992, the year following Laconia’s closure. While the New Hampshire general population increased by 15% (1.11 million in 1992 to 1.28 million in 2002), the numbers of individuals served expanded by 55%, from 1,274 to 1,977.

**FINANCING COMMUNITY SERVICES IN 2002**

Figure 6 illustrates the financial structure of New Hampshire’s community developmental disabilities services in 2002. Total developmental disabilities spending in New Hampshire in 2002 was \$152.5 million. Community spending of \$150.5 million accounted for 99% of the total. The private institutional option, Cedar Crest, received \$1 million in federal ICF/MR reimbursements and \$1 million in state matching funds in 2002.



More than half (55%) of all community resources consisted of federal payments and reimbursement. This included federal HCBS Waiver reimbursement (\$59.4 million), and associated federal Supplemental Security Income -- SSI and Adult Disabled Child social security payments for Waiver participants (\$18.4 million). Other federal Medicaid reimbursement consisted of \$1.2 million for targeted case management, and \$1.0 million in Medicaid funding under the “rehabilitation option” for early intervention services. The remaining federal reimbursement for New Hampshire’s community services was Title I, PL 89-313 federal education funds (\$2.5 million).

Federal funding for New Hampshire’s community services totaled \$82.4 million. Eighty-four percent of this -- the \$59.4 million in Waiver reimbursement (including the same amount in state match funds) and \$18.4 million in Waiver participants’ federal

income maintenance benefits -- supported over 2,800 individuals. The vast majority of New Hampshire's out-of-home placements, nearly 1,900 of the total 1,977, were supported by the Waiver. The remaining Waiver participants, approximately 900, received case management, respite, home adaptation, and other supports while living in the family home.

Employment opportunities in New Hampshire, like housing options, were personalized and integrated. A large-scale effort in the 1980s converted sheltered work and day training programs to supported employment options for individuals (DiLeo & Hagner, 1990). In 2000, New Hampshire ranked 25th nationally in the percentage of workers with mental retardation in supported/competitive employment (Braddock, 2002). New Hampshire was one of the first states to direct HCBS Waiver funding to supported employment, when this was authorized in 1986 by Congress (Section 1915(c)(5) of the Social Security Act) (Smith & Gettings, 1994). In 2002, federal-state Waiver funding in New Hampshire constituted 65% of family support spending, 70% of supported employment spending, and 100% of supported living spending.

### AREA AGENCIES AND FAMILY SUPPORT

Area agencies in New Hampshire played a key role in managing Waiver funding, developing community housing and work options, and providing case management for families. New Hampshire's 12 area agencies functioned effectively in part because they were compatible with the state's home rule tradition, and its highly representative state legislature with 400 members serving a little over a million citizens (Miano & Brail, 1994). The legislature passed the important developmental disabilities legislation in 1975 (RSA 171-A) that established the area agencies and promoted individualized approaches and supports for families. The President of the Senate, Speaker of the House and other legislators participated in state task force investigations of services system issues (e.g., Task Force to Study Support Services for Families of Developmentally Disabled Children, 1988).

As of 2002, New Hampshire did not provide family cash subsidies. In 2000, 19 states funded direct cash subsidy programs for families, totaling \$69 million nationally. Across the 19 states, cash subsidy payments averaged \$2,674 per family per year. Illinois, Michigan, and Texas had the nation's largest direct cash subsidy programs for families, spending \$16.5, \$13.7, and \$12.7 million, respectively. Michigan's cash subsidies benefited 5,264 families, at about \$2,607 per family per year, slightly below the 19-state average. For example, Michigan expended \$29.6 million, or \$2.06 per capita, for total family support activities in 2000. The United States expended \$1.049 billion in 2000 for total family support services (cash subsidies, respite care and other family support activities). This was a spending level of \$3.83 per U.S. citizen that year. For the 19 states that funded cash subsidies, the national per capita spending level was \$.25 (*Table 3*).

In New England, Vermont, Rhode Island, Massachusetts, and New Hampshire had strong family support programs. Vermont's family support spending was \$20.29 per capita, Rhode Island's was \$9.36, and Massachusetts spent \$6.40 per capita in 2000. The per capita figure for

New Hampshire in 2000 was \$6.00; it advanced to \$8.87 in 2002. New Hampshire's funding for respite care and other family supports in 2002, \$11.3 million, was three times the state's \$2.7 million family support expenditure in 1992. The number of families supported in 2002 was more than double the number supported in 1992.

Connecticut's total family support spending per capita in 2000 was \$2.19 and Maine's was \$0.42. Among the six New England states, only Rhode Island and Connecticut (consequent to 1994 state legislation, PA 94-222) offered cash subsidies directly to families (*Table 3*).

Family support spending per family varied across the states. Some states provided primarily episodic respite care, while others provided more intensive in-home supports and direct cash subsidies. The range of spending per family in New England was approximately \$1,000 per family in Maine and Vermont, \$1,500 in New Hampshire, \$1,800 in Connecticut and \$2,600 in Massachusetts. Rhode Island, including their cash subsidy program, had the largest per family spending level: \$9,642. The U.S. average per family spending level in 2000 was \$2,700.

## 5. COMPARATIVE ANALYSIS: NEW ENGLAND

All of the New England states now spend substantially more for community services than for institutional care. State variations in deinstitutionalization and community expansion are apparent in four areas: a) the year in which the state reached "parity" between community and institutional spending; b) the extent to which the community transformation was complete by 2000; c) the magnitude and types of programs supporting community services; and d) the types of residential programs utilized in community services development.

Resource allocation profiles for each of the other five states in the New England region and the U.S. are presented below. Accompanying each graph is a brief description of the financial and programmatic structure of the state's service system.

**Table 3**  
**FAMILY SUPPORT SPENDING PER CAPITA:**  
**NEW ENGLAND STATES AND THE U.S.**

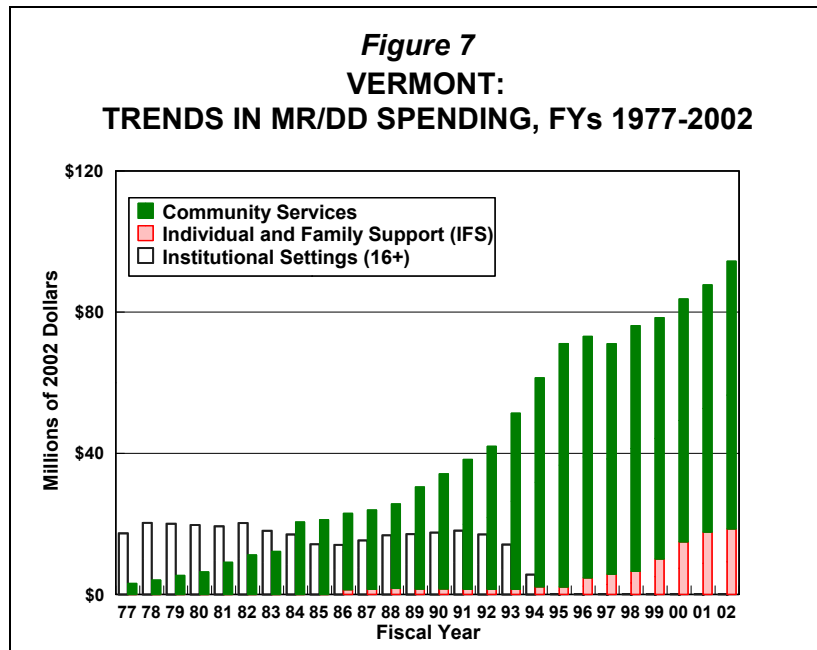
	<b>2000 Family Support \$s per Capita</b>	<b>National Rank</b>	<b>Number of Families Supported</b>	<b>Number of Families, Cash Subsidy</b>
Vermont	\$20.29	1	2,164	
Rhode Island	\$9.36	7	965	54
Massachusetts	\$6.40	12	15,010	
New Hampshire	\$6.00	14	4,917	
Connecticut	\$2.19	28	4,019	911
Maine	\$0.42	43	500	
<b>United States</b>	<b>\$3.83</b>		<b>385,414</b>	<b>25,802</b>

The descriptions focus on the similarities and contrasts between the states' deinstitutionalization and community development efforts, and New Hampshire's. When this paper was prepared (March 2003), the State of the States in Developmental Disabilities Project had received updated 2002 data from three New England states, New Hampshire, Massachusetts, and Vermont. Their spending graphics through 2002 are presented first, followed by graphics through 2000 for Connecticut, Maine and Rhode Island.

**VERMONT**

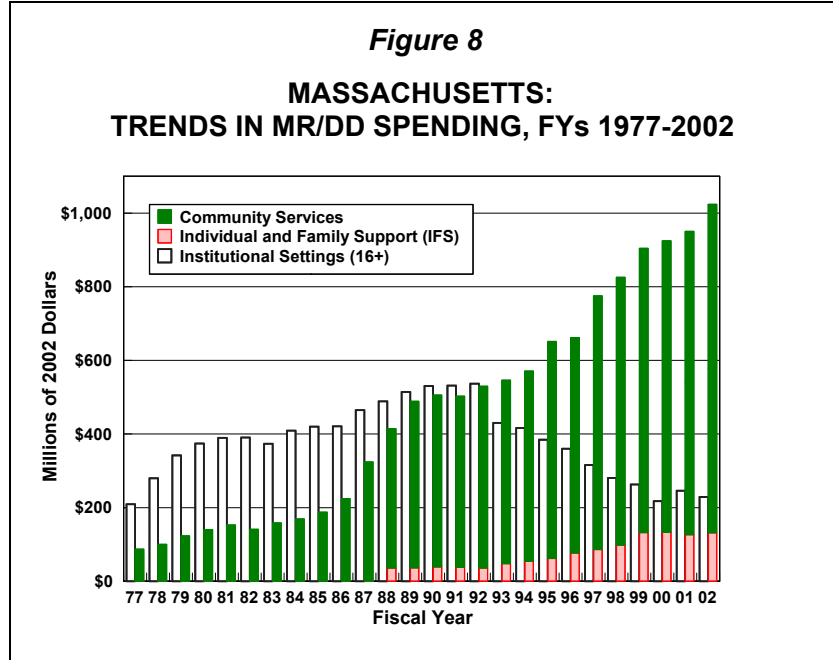
*Figure 7* illustrates resource allocation for institutional (16 plus bed) and community services in Vermont. Vermont reached parity for community spending in 1984, and by 1995 had terminated funding for all large congregate services. Brandon Training School closed November 17, 1993 (FY 1994). Vermont did not fund community residences larger than 7 beds and by 2002, 97% of all the state's out-of-home residential placements were in settings of 6 beds or less. In 2002, 12 individuals resided in 6-person private ICFs/MR. The remaining 6 person or fewer settings consisted of developmental homes averaging slightly more than one person per home; group homes serving approximately 4 individuals per home, and supervised and staffed apartments with an average of just over one person per apartment. The HCBS Waiver supported nearly all of the individuals who resided in these settings.

Thirty-eight individuals with mental retardation resided in nursing facilities in Vermont. In 2000, 77% of Vermont's federal funding for developmental disabilities services derived from the HCBS Waiver. Federal and state Waiver funding in Vermont accounted for 80% of the state's total developmental disabilities resources. This was the highest Waiver spending proportion in the nation, and in 2002 the Waiver percentage remained 80%. Vermont's community services were managed by fourteen geographically organized community mental retardation provider agencies.



**MASSACHUSETTS**

The resource allocation profile for Massachusetts (*Figure 8*) illustrates the effects of class action litigation focused primarily on reforming institutional conditions. Massachusetts' institutional per diem rate in 2002 for the 1,199 residents still residing in six institutions averaged nearly \$523 per day. In fact, resources allocated for institutional services increased steadily



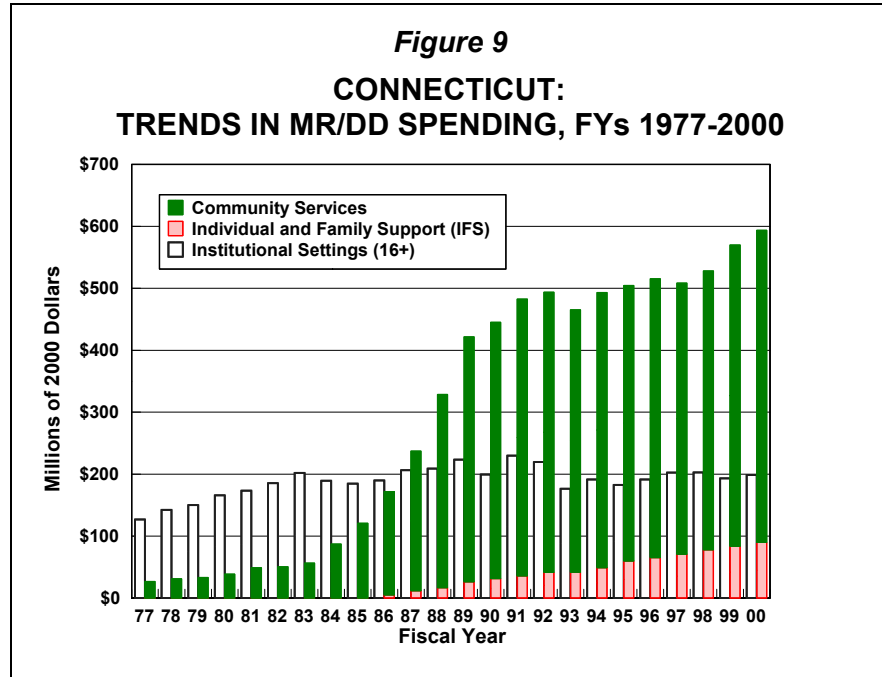
from 1977-92 and began a rapid decline with the state's first closure (Belchertown State School). Community spending grew at a modest rate from 1977-85 and more rapidly from 1986 to the present. Until 1993 Massachusetts exemplified the financial characteristics of a state government funding a "dual system," continuing funding of institutions while expanding community services resources as well. The Commonwealth began to rapidly expand community services during 1993-2002.

In 1962, Massachusetts had 9,000 residents in institutions, served by 3,000 staff. Twenty-five years later, in 1988, over 10,000 staff worked to provide support to 3,000 residents. The extensive resource demands of meeting higher building standards in the older institutional settings and the staffing costs contributed to Massachusetts' not achieving parity in community spending until 1993. In the last ten years, however, the Commonwealth has substantially expanded the funding base and the availability of small community residential options. The small public and small private ICFs/MR, serving 232 and 320 individuals, respectively, were closed in 1993. All individuals previously served in these small ICFs/MR are now served under the Waiver or in other small residences. Federal Waiver reimbursement reached \$247.9 million in 2002 -- nearly four times the Waiver reimbursement amount in 1993. In 2002, 71% of Massachusetts' out-of-home residential placements were in settings of 6 beds or less.

**CONNECTICUT**

In Connecticut (*Figure 9*), there have been two major trends. First, community spending increased steadily from 1984 to 1992, dropped or was essentially flat through 1997, and then climbed steadily during 1998-2000. Second, institutional spending climbed rapidly from 1977 to 1983 and then leveled off through 2000.

Connecticut achieved community spending parity in 1987, and by 2000 was spending 75% of total resources for community services. While Connecticut relied on small (15 bed or less) public ICFs/MR and small private ICFs/MR, the HCBS Waiver also played a key role in community development. Federal Waiver spending in 2000



was \$175 million, substantially more than the \$111 million in federal ICF/MR spending in the state that year. In 2000, Connecticut served 71% of persons with developmental disabilities in settings for six or fewer persons. These settings included small public ICFs/MR, small private ICFs/MR, private community living alternatives (CLAs), public CLAs, and Department of Mental Retardation licensed community training homes.

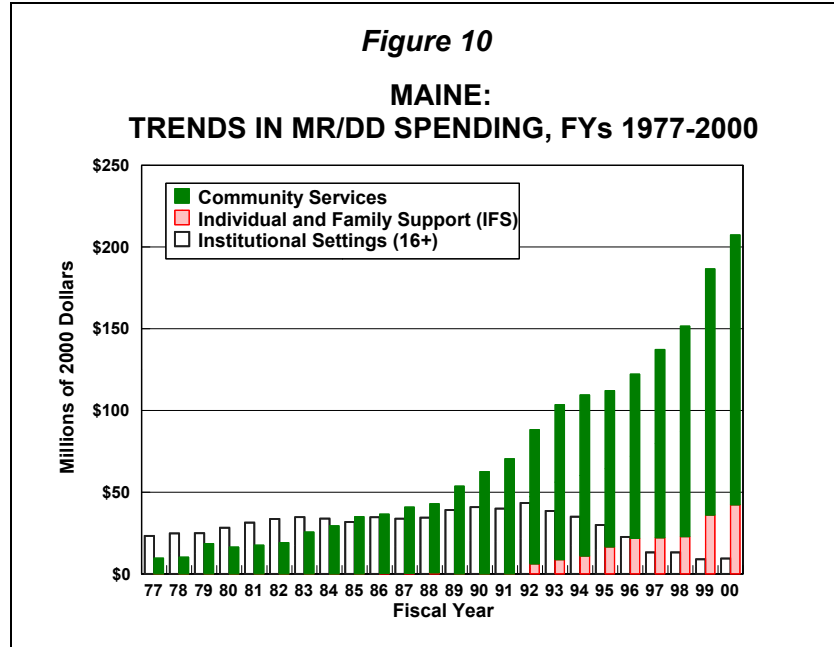
By 2000, seven state institutions in Connecticut served 970 persons. The largest facility was Mansfield Training School, serving 698 individuals; the 6 other facilities served seventy-five or fewer individuals each. The Seaside Center and the John Dempsey Center closed in 1996 and 1998, respectively.

**MAINE**

*Figure 10* illustrates Maine’s developmental disabilities resource allocation profile. Community spending in Maine has been increasing steadily from 1980 through 2000. Spending growth to finance institutional reform occurred steadily between 1977-83 and 1989-00. Since 1992, institutional spending began to decline dramatically as the Pineland Center phased down.

Maine achieved community spending parity in 1985. By 1995, Pineland served an average daily population of only 85 persons, and closed in 1996. Remaining institutional services in 2000 consisted of 11 residents in the Aroostook Center in Presque Isle, and 36 residents in large private ICFs/MR (down from 109 in 1992). Nursing facilities in Maine housed 145 persons with mental retardation and related conditions.

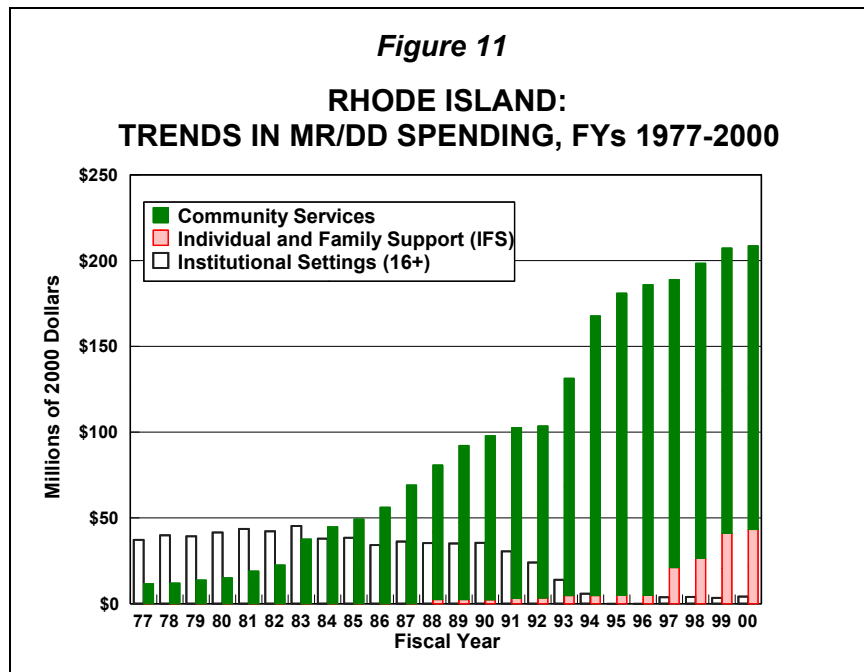
Maine has been working to convert ICFs/MR to the Waiver funding mechanism. In 2000, 120 persons were served in ICFs/MR for 7 to 15 persons, and 11 people were served in two smaller public ICFs/MR. Private ICFs/MR for six or fewer persons served 107 individuals in 2000. Other community options consisted of Waiver residential homes and semi-independent living options. In 2000, Maine served 2,795 individuals in settings for 6 or fewer individuals, 87% of all persons served in out-of-home settings.



**RHODE ISLAND**

Rhode Island’s developmental disabilities service system (*Figure 11*), like those of New Hampshire and Vermont, achieved parity for community spending in 1984. Rhode Island began reducing institutional sector spending in 1984, and by March 25, 1994, closed the state’s public institution, the Ladd Center.

Community spending increased virtually every year from 1977-2000. Small private ICFs/MR were a major part of Rhode Island’s community financing pattern, providing more than twice the level of federal reimbursement that the state received from the



HCBS Waiver in 1992. However, the Rhode Island HCBS Waiver expanded greatly beginning in 1994, and by 2000, Waiver federal reimbursement of \$78 million constituted 80% of all Medicaid long term care reimbursement in the State. Rhode Island terminated use of small public ICFs/MR in 1990 (Braddock et al., 1995).

In 1992, Congress added Section 1930 to the Social Security Act to provide a more flexible Medicaid funding source. Rhode Island became one of the nation's first eight states to be awarded federal Medicaid funding under this "Community Supported Living Arrangement (CSLA)" amendment to Medicaid (OBRA, 1990, PL 101-508). The other seven states were California, Colorado, Florida, Illinois, Maryland, Michigan, and Wisconsin. CSLA stressed individualized supports in place of the traditional ICF/MR packages of services.

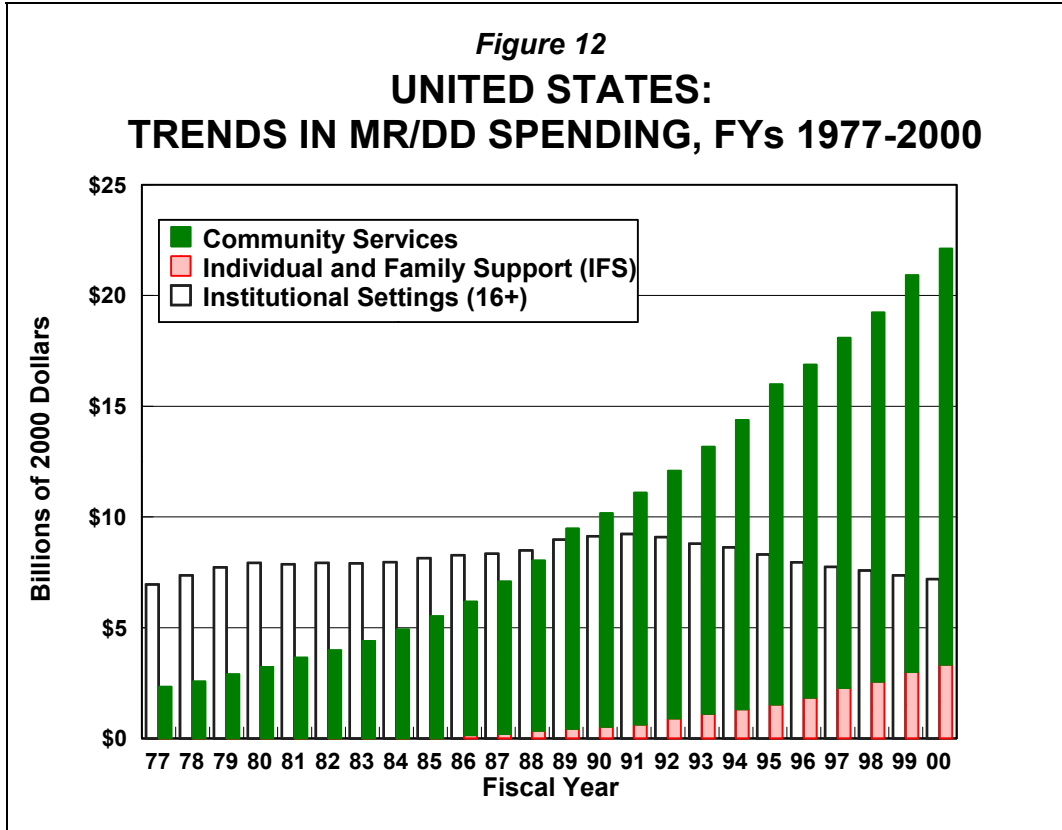
In 1966, Rhode Island adopted a policy of no new admissions to the Ladd Center (Miano & Brail, 1994, p. 100). Furthermore, the 1982 consent agreement in *Iasimone v. Garrahy*, similar to New Hampshire's lawsuit, required institutional reform and community development. State officials initially used community ICFs/MR to place individuals with the most complicated needs. Ladd Center's unionized staff did not actively oppose deinstitutionalization, largely due to two factors. First, the facility's chief administrator, the father of a person with mental retardation, helped staff to understand the value of community alternatives. Second, the state developed an agreement with the principal union and used various strategies including state-run community residential programs to provide for staff transition to the community (Miano & Brail, 1994). In 2000, 81% of Rhode Island's out-of-home placements were in settings for six or fewer persons.

**Analytical Summary.** Three of the six New England states, New Hampshire, Rhode Island, and Vermont, were among the first states in the nation to achieve parity in community spending compared to spending for large congregate care. By 2000, all the New England states were spending more for community services than for institutional services. In 2000, the New England region in the aggregate was spending 83% of all resources for community services. Maine, New Hampshire, Rhode Island and Vermont combined spent 98% of total resources on community services by 2000.

## UNITED STATES

*Figure 12* illustrates resource allocation patterns in the United States. Note that spending parity was achieved in 1989. Spending in the United States for institutional services, adjusted for inflation, declined steadily at 3% per year from the peak in 1991 through 2000. Adjusted community services spending grew an average 10% per year from 1977 to 2000.

By 2000, all states but Mississippi spent more for community services than for congregate residential care. In 2000, 75% of the nation's resources were devoted to community services. By the early 1980's, however, only seven states were spending more for community services than for large congregate care and three of these states were in New England -- New Hampshire, Rhode Island and Vermont (each achieving



community spending parity in 1984). Alaska had achieved parity in 1981, followed by Colorado and Michigan in 1982, and Montana in 1983.

Comparative institutional and community spending data for the United States further illustrate that, since 1984, New Hampshire has been a national leader in deinstitutionalization and community development. The smaller New England states in particular have led the nation in the conversion of resources from large congregate care to community services. On a national basis, a number of states have followed the examples of the New England states and Michigan and demonstrated major transformation and conversion of resources from institutional care to the support of individuals with developmental disabilities in the community. These states include Alaska, Arizona, Colorado, DC, Hawaii, Kansas, Minnesota, New Mexico, Oregon, and West Virginia.

As noted above, all New England states have terminated or substantially reduced the use of community ICFs/MR serving less than 16 persons. Maine and Massachusetts terminated the use of small ICFs/MR during 1993-95, and New Hampshire did so in 1996. In 2002, 12 persons resided in two ICFs/MR for six or fewer persons in Vermont, and in Rhode Island, 18 persons resided in three remaining publicly operated ICFs/MR for six or fewer persons.

Clearly, the region has also substantially reduced ICF/MR funding for state institutions during this period. Throughout New England in 2000, ICF/MR

reimbursement for public and private ICFs/MR of all sizes constituted 24% of all Medicaid long-term care spending. The ICF/MR proportion of total Medicaid spending was only 8% for the four less populous states of Maine, New Hampshire, Rhode Island and Vermont.

New Hampshire now has 12 years of experience operating a completely non-institutional service delivery system -- the most experience of any state. Moreover, as empirically demonstrated in the following section, New Hampshire's transformation was achieved with an economy of resources when compared to other New England states and to the nation as a whole.

## 6. CENTRALITY OF MEDICAID HCBS FUNDING

A state's success with federal reimbursement can be evaluated along two dimensions: 1) the absolute level of federal support received; and 2) the types of federal programs that most promote consumer values. Although federal programs for citizens with developmental disabilities that can readily be used to promote community integration have historically had relatively little money attached to them, this has changed with the rapid expansion of HCBS Waiver spending in virtually every state.

By contrast, federal ICF/MR funding from 1972 until recently had dominated services and reimbursements for individuals with developmental disabilities. Through 1982, the ICF/MR program was the only major federal services program that could support community services in the states. In 1977, 99% of all federal ICF/MR funding went to state institutions or private congregate settings of 16 beds or more. This large institutional care dominance declined somewhat as a growing number of states redirected federal reimbursement to fifteen person or fewer community facilities.

As noted, the HCBS Waiver first became a community financing option for states in 1982. Advocates, state officials and legislators had sought, successfully, to curb the growth of the institutionally biased ICF/MR program in order to re-direct federal support to more individualized community services. Gettings (1994) noted that the escalation of ICF/MR costs was one of the factors limiting states' capacity to address increasing demand for community-based services. Oregon and Montana were the first two states to implement HCBS Waiver services, in 1982, followed, in the New England region, by Vermont in 1983, by Maine, New Hampshire, and Rhode Island in 1984, and by Massachusetts in 1985. Connecticut's Waiver was implemented in 1988.

### WAIVER UTILIZATION IN NEW HAMPSHIRE

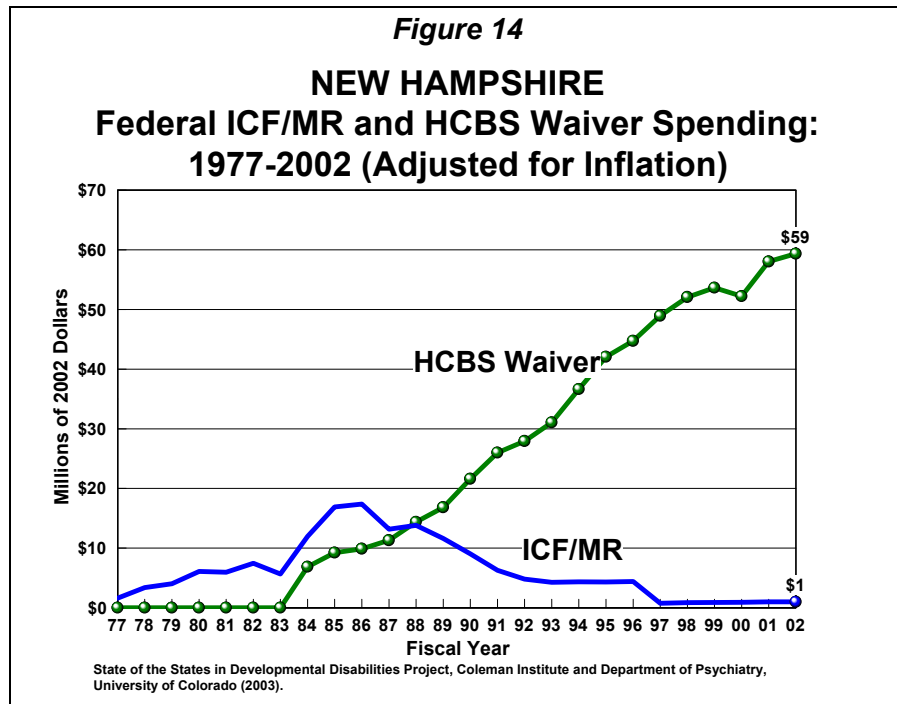
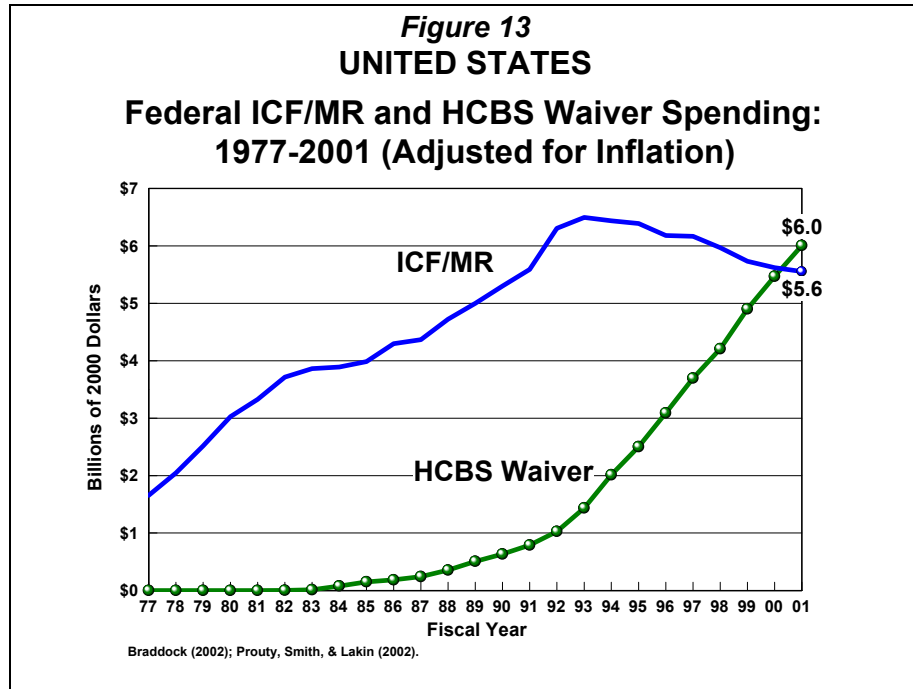
*Figure 13* illustrates this national trend in the dominance of federal ICF/MR reimbursement, and the ascendance of the HCBS Waiver as the principal funding source for developmental disabilities long-term care. In 2001, reimbursement for the HCBS Waiver first surpassed ICF/MR reimbursement (Prouty, Smith, & Lakin, 2002). The graphic does not include federal reimbursement for other Medicaid options exercised in certain states. These include targeted case management, day habilitation or other Medicaid "rehabilitation option" or "clinic option" services, and Medicaid personal

assistance services specifically for individuals with developmental disabilities. In 2000, Medicaid reimbursement for these other optional services totaled \$1.3 billion in the United States.

New Hampshire's utilization of federal Medicaid reimbursement is in marked contrast to the national trend.

Under Superintendent Melton, New Hampshire had initiated federal ICF/MR certification for Laconia. Pursuing this federal revenue was consistent with the negotiated court order calling for institutional reform as well as community program development. In 1990, a federal Health Care Financing Administration "look behind survey" found Laconia to be in 100% compliance with federal standards (Crocker, 1993, p. 68). With Laconia's downsizing and closure in 1991, the state's reliance on institutional ICF/MR reimbursement ended. New Hampshire then became a national leader in the use of the HCBS Waiver, which had much greater programmatic flexibility than the ICF/MR funds.

Figure 14 presents New Hampshire's profile of federal Medicaid reimbursement across 1977-2002 for the HCBS Waiver and for the ICF/MR program. As



noted earlier, the only remaining ICF/MR reimbursement in 2002 was \$1.0 million for 25 persons at the private children’s facility, Cedar Crest. (Federal Medicaid reimbursement of \$1.2 million for targeted case management and \$1.0 million for rehabilitative services is not included in the figure).

New Hampshire began receiving HCBS Waiver funds in 1984, and in 1988 converted adult day programs to the Waiver reimbursement mechanism. Federal Medicaid reimbursement for targeted case management was initiated in New Hampshire in 1988.

Together with the state match, New Hampshire’s HCBS Waiver and other community Medicaid program reimbursements totaled \$80.3 million, or three-quarters of all developmental disabilities spending in the state. As illustrated in *Table 4*, New Hampshire in 2000 ranked 11<sup>th</sup> nationally in the amount of federal Waiver reimbursement allocated on a per capita basis in terms of the state general population,

below all the New England states of comparable size, and also below the comparably sized states of Wyoming, North Dakota, and South Dakota.

New Hampshire’s two decades utilizing Medicaid funding has been opportunistic and creative, both in terms of the level of reimbursement received from Washington, and

in the types of services that were supported by the federal government. Institutional reimbursement for Laconia was used to attain court-mandated institutional reform objectives, and then terminated. The Waiver, the nation’s most creative and individualized Medicaid program for supporting individuals in the community, now dominates the New Hampshire service delivery system.

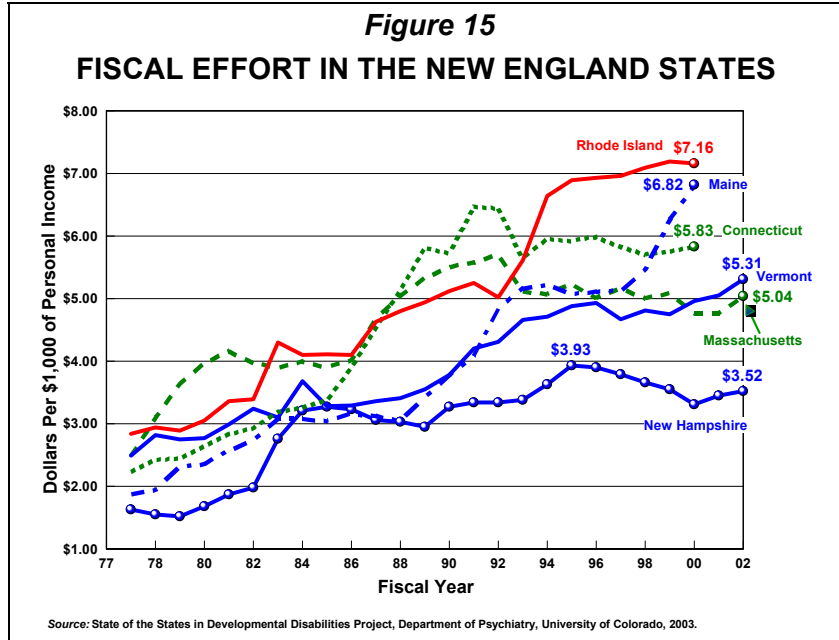
**Table 4  
STATES RANKED BY FEDERAL  
HCBS WAIVER EXPENDITURES PER CAPITA, 2000**

Rank	State	Partici- pants	Years in Effect	Federal Expenditures (\$\$ in millions)	Federal Medicaid \$\$ Per Capita	Federal-State Waiver % of Total MR/DD Spending
1	Rhode Island	2,471	17	\$78.4	\$79	68%
2	Maine	1,840	17	\$84.8	\$67	59%
3	Vermont	1,719	18	\$39.6	\$65	80%
4	Wyoming	1,226	10	\$28.3	\$56	60%
5	Connecticut	4,783	13	\$174.6	\$53	44%
6	New York	38,696	9	\$848.6	\$47	40%
7	Minnesota	13,600	16	\$223.8	\$47	53%
8	South Dakota	1,988	18	\$34.4	\$46	57%
9	New Mexico	2,160	16	\$80.8	\$45	70%
10	North Dakota	1,856	17	\$27.8	\$43	36%
11	New Hampshire	2,638	17	\$49.9	\$41	76%
	<b>UNITED STATES</b>	<b>293,713</b>	<b>19</b>	<b>\$5,471.3</b>	<b>\$20</b>	<b>33%</b>

**FISCAL EFFORT FOR DEVELOPMENTAL DISABILITIES SERVICES IN NEW ENGLAND**

“Fiscal effort” is a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to financing developmental

disabilities services (Braddock and Fujiura, 1987). *Figure 15* illustrates total fiscal effort, institutional and community fiscal effort combined, during 1977-2002 for New Hampshire and the five other New England states (data available through 2000 for Connecticut, Maine, and Rhode Island). Fiscal effort in New Hampshire substantially lagged behind each of the other New England



states, with the exception of a brief period, 1984-88, when the New Hampshire effort level was near that of Maine and Vermont. In 2000, fiscal effort levels in Connecticut, Maine, and Rhode Island exceeded New Hampshire’s levels by \$2.31 or more. Massachusetts and Vermont’s effort levels in 2002 were also substantially above New Hampshire’s (by at least \$1.52).

*Table 5* illustrates New Hampshire’s national fiscal effort rankings in 1996 and 2000, and the change in ranking for New Hampshire and the other New England states from 1996 to 2000. The table also presents New Hampshire’s 2002 fiscal effort level, and the projected 2002 fiscal effort level for the United States.

**Table 5**  
**RANKING OF MR/DD FISCAL EFFORT IN THE NEW ENGLAND STATES AND CHANGE IN RANK, 1996-2000**

	1996	2000	Change in Rank 1996-00	2002*
Connecticut	5	5	0	
Maine	10	4	+ 6	
Massachusetts	11	12	- 1	
New Hampshire	23	33	- 10	
Rhode Island	1	2	- 1	
Vermont	12	9	+ 3	
<b>United States</b>	<b>\$3.61</b>	<b>\$3.65</b>		<b>\$3.67</b>
<b>New Hampshire</b>	<b>\$3.85</b>	<b>\$3.34</b>		<b>\$3.52</b>

\*Note: 2002 U.S. data projected based on 1996-00 trend.

During 1988 to 1992, New Hampshire underwent the transformation from an institutional to a community based system. However, even throughout this period of “dual system” funding, New Hampshire’s total fiscal effort ranking (institutional and

community combined) declined from 19th in 1988 to 32nd in 1992. This decline in fiscal effort occurred despite the state a) incurring considerable transition and development costs associated with institutional closure, and b) expanding the total number of individuals served during 1988-92 by 10%, from 1,166 persons to 1,274 persons. Except for the five-year period from 1983 to 1988 when NH was immersed in Laconia’s costly court-ordered reform efforts, New Hampshire’s over-all fiscal effort for developmental disabilities services has been at or below the national average.

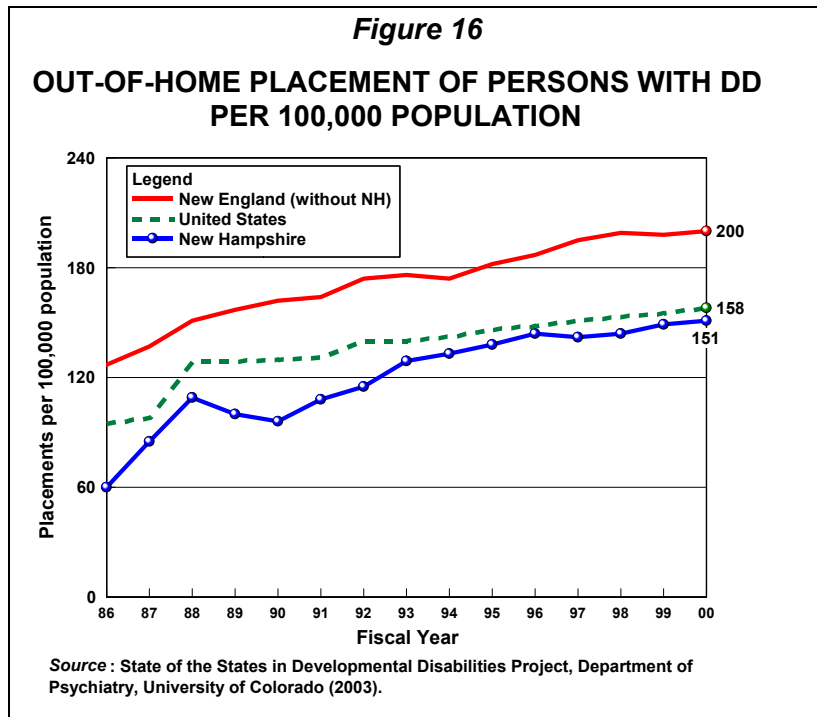
As illustrated in *Table 5*, New Hampshire’s fiscal effort commitment is relatively weak in comparison with each of the other New England states, all of which ranked from 4<sup>th</sup> to 12<sup>th</sup> in fiscal effort compared to New Hampshire’s ranking of 33<sup>rd</sup>. New Hampshire’s fiscal effort level in 2002 is still well below the projected national average.

### 7. FORCES IMPACTING ON DEVELOPMENTAL DISABILITIES SERVICES IN NEW HAMPSHIRE

The numbers of individuals served by states’ developmental disabilities systems of out-of-home residential care can be compared on the basis of placements per 100,000 of the general population. As discussed earlier, from 1910 through 1980, New Hampshire’s rate of institutional placements greatly exceeded the average institutional placement rate for the United States. *Figure 16* illustrates *total* out-of-home residential placements per 100,000 of the general population for New Hampshire, for the New England region (exclusive of New Hampshire), and for the United States.

During 1988-91, New Hampshire concentrated on providing community alternatives for Laconia residents transitioning to the community, resulting in a decline in the over-all placement rate.

However, from 1991 to 2000, the rate began to increase steadily. New Hampshire’s community system began to meet the needs of larger numbers of its citizens with developmental disabilities during this time. The development of a more complete community system is now meeting the needs of a larger proportion of New Hampshire’s citizens with developmental disabilities. This



growing capacity of the system became possible due to reallocated funds once used to operate the Laconia State School. Though the New Hampshire placement rate has increased steadily over the past decade, it still lags behind the U.S. by 4%, and is 25% below the aggregate placement rate of the other five states in the New England region.

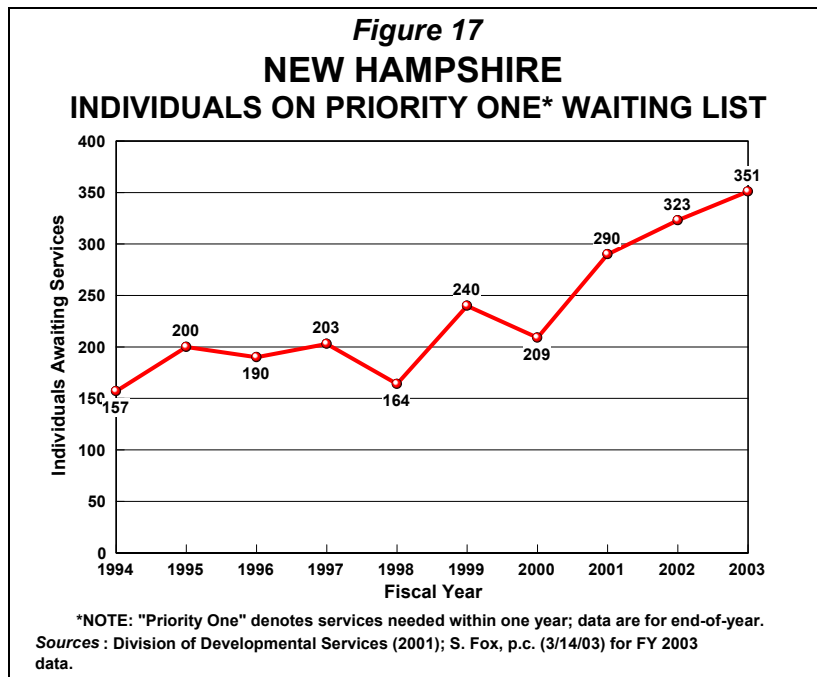
There are notable pressures on state developmental disabilities systems to expand community services and supports. These forces stem from the nation’s changing demography coupled with increased longevity of persons with developmental disabilities, downturns in most states’ economies, and the impact of pending lawsuits in the states addressing waiting lists, Medicaid access, and *Olmstead* implementation.

**GROWING WAITING LISTS**

The numbers of individuals with developmental disabilities awaiting services in New Hampshire has increased steadily over the past eight years (*Figure 17*). Recent waiting list data from the former New Hampshire Division of Developmental Services Director (p.c., telephone, Sue Fox, 3/13/03) indicate that 351 individuals are now at the “priority one” level of service need (i.e., service is needed within one year).

These waiting list data can be expressed as 29 persons per 100,000 of New Hampshire’s general population compared to a national average of 29 per 100,000 in the 30 states that reported waiting list data (Prouty, Smith, and Lakin, 2002). New Hampshire ranked 17<sup>th</sup> highest among the 30 reporting states in the number of individuals with developmental disabilities per 100,000 population awaiting community services.

Rates ranged from 157/100,000 in Alaska to 2/100,000 in Arizona and Missouri. In the New England region (not including New Hampshire) the number of individuals awaiting community services was 3,908, or 36 per 100,000 of the combined general population of those five states. Connecticut, Maine, and Massachusetts contributed virtually all of the waiting list numbers for New England; Rhode Island and Vermont reported that in their states no individuals were awaiting services (Prouty et al., 2002).



Smith (2001), in a report prepared for the Division of Developmental Services, looked at the growth necessary in New Hampshire's residential service system in order to meet future service needs, as well as address the 209 persons who were awaiting services at the end of 2000. He considered 1995-2000 trends in a) the end-of-year number of persons served; b) the end-of-year number of persons awaiting services; and c) the past and likely future rate of growth in New Hampshire's general population aged 21 years and older. Smith (2001) concluded that if New Hampshire increased system capacity by 125 persons per year, this would likely meet anticipated annual need and would also reduce the waiting list in two years to 100 (approximately one-half the 2000 level), or, in a "best-case" scenario, the list could be reduced to zero. However, as displayed in *Figure 17* above, the 2001 and 2002 waiting list data are from 50% to 80% higher than the average of the previous seven years (195) considered in Smith's (2001) estimations.

The Division of Developmental Services has been able to substantially reduce the time that persons spend on the waiting list, from 302 days in 1997 to 160 days in 2000 (Home and Community Based Services Resource Network, 2003). The waiting list has grown rapidly even given the reduction in time spent on the list. This is indicative of the increasingly rapid growth of persons awaiting services in New Hampshire.

There are other factors that must be considered in projecting New Hampshire's future community service demand. These include whether or not there will continue to be the same rate of "projected annual vacancy occurrence" resulting from families moving, individuals moving home or to more independent settings, deaths, or other factors that historically have produced 26 vacancies per year that could be utilized by waiting list individuals (Shumway and Fox, 2001). Other factors to consider are aging family caregivers, the degree to which demand will rise due to increased longevity of persons with developmental disabilities, general population growth, and the impact of litigation.

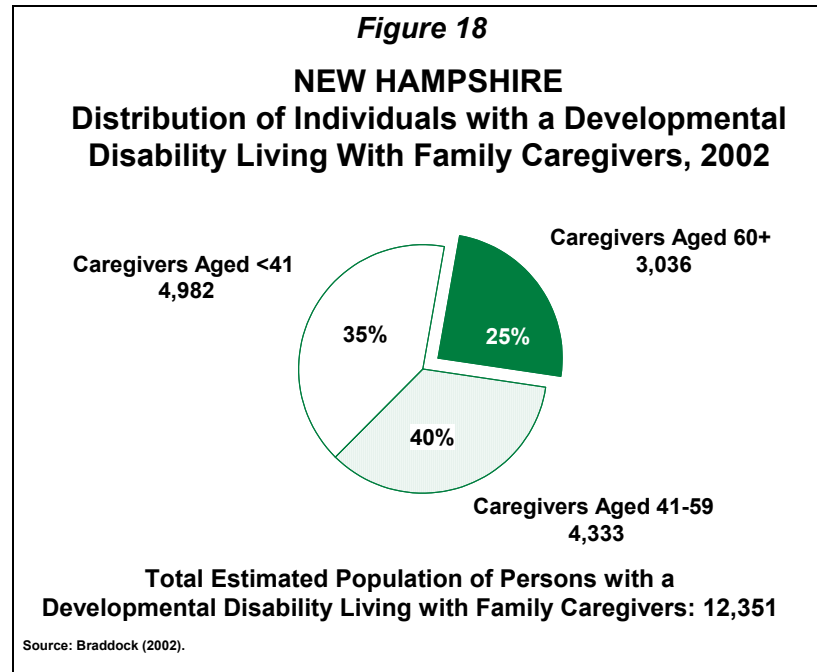
### AGING FAMILY CAREGIVERS

Persons with developmental disabilities residing with aging caregivers represent one of the most critically important components of states' residential and community services waiting lists. As caregivers age beyond their care-giving capacity, supervised residential care must be established.

In the year 2000, an estimated 61% of the nation's 4.32 million children and adults with mental retardation/developmental disabilities in the U.S. resided with family caregivers, and 26% of these caregivers were aged 60 years or more (an estimated total of 673,000 aged caregivers). In New Hampshire in 2002, there were an estimated 20,150 persons with MR/DD, of whom 12,351 (61%) were living with family caregivers, and 3,036 were residing with caregivers aged 60 years or more (*Figure 18*). The estimated 3,036 persons living with aging caregivers in New Hampshire exceeds the total of 1,987 persons with MR/DD currently served in all types of supervised residential settings in the State.

The number of aging caregivers in New Hampshire is substantial today, and will grow significantly in the years ahead. The baby boom generation was born during 1946 to 1964. The first members of this cohort will reach age 60 in 2006 and the youngest boomers will attain that age in 2024. Largely because of the aging of the baby boom generation, the U.S. Census Bureau (2002) projects that

the number of Americans aged 65+ years will double from 35 million in the year 2000 to 70 million in the year 2030. Certainly the pressure imposed on New Hampshire MR/DD residential services by aging caregivers will continue, if not increase, in coming years.



### INCREASED LONGEVITY OF PERSONS WITH MR/DD

Another factor that impacts on the growing demand for MR/DD services is the growing lifespan of persons with mental retardation and developmental disabilities. The mean age at death for persons with mental retardation was 66.2 years in 1993, substantially increased from 59.1 years in the 1970s. This compares to a mean age at death of the general population of 70.4 years (Janicki, 1996; Janicki, Dalton, Henderson, & Davidson, 1999). With continued improvement in their health status, individuals with mental retardation, particularly those without severe impairments, can be expected to have a life span equal to that of the general population. As the lifespan of persons with MR/DD increases, they require residential care services for longer periods of time. This directly impacts on the finite capacities of service delivery systems in New Hampshire and in other states.

### IMPOVERISHMENT OF DIRECT SUPPORT STAFF

Direct support staff provide critically necessary support for persons with developmental disabilities living in community settings in New Hampshire. New Hampshire's community wage was estimated to be \$8.67 in fiscal year 2001 (Senate Bill 36 FH-A, 2000 Session, Senate and House of Representatives in General Court convened, approved February 16, 2000, effective date July 1, 2000). This wage was 20% below the poverty level for a family of four (*Figure 19*). When adjusted for states' varying costs-of-living, the New Hampshire adjusted wage of \$8.19 was 25% below the poverty level.

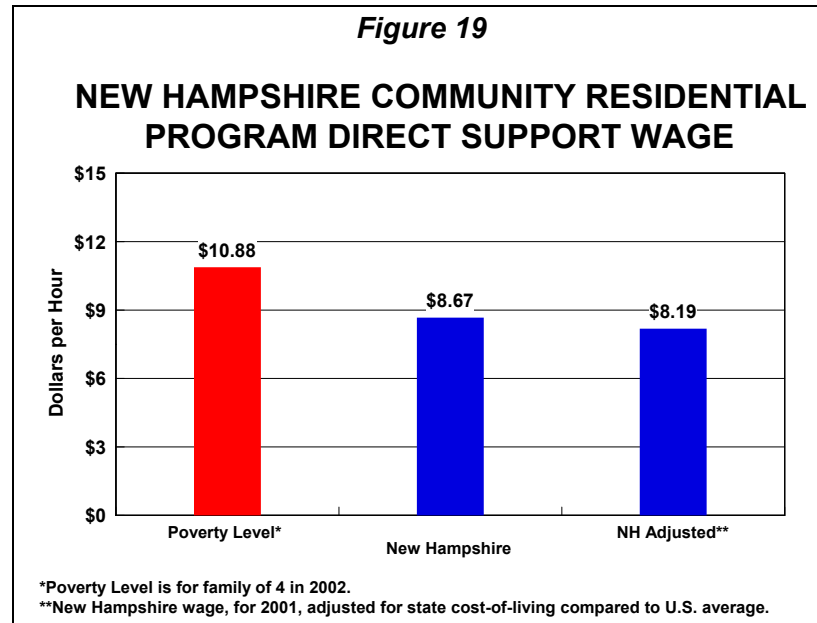
Although there have not been recent studies on turnover rates for direct care staff in New Hampshire, Braddock & Mitchell's (1992) study of institutional and community turnover rates in each state recorded a turnover rate of 83% in New Hampshire community residential

facilities. Turnover of direct support staff is detrimental to the quality care (King, Raynes, & Tizard, 1971; Lakin, 1988) and is directly correlated with both starting and average wages in community residential developmental disabilities programs (Braddock & Mitchell, 1992; Lakin & Bruininks, 1981; Larson, Lakin, & Bruininks, 1998; Minnesota Department of Employee Relations, 1989; and Pivrotto & Bothamley, 1986).

Recently, the accounting and consulting firm BDO Seidman (2002) completed a national study of recruitment and retention of direct support workers in privately operated developmental disabilities day and residential programs. They noted three general economic constraints to recruitment and retention of developmental disabilities direct care staff: 1) rapidly increasing health insurance costs, 2) a growing job demand in competing service industries, and 3) the advantage that private sector "supply and demand" employers have over publicly funded human service systems with their constraints of fixed appropriations compounded by growing state budget deficits. These economic constraints, they noted, were compounded by growing numbers of aging caregivers and the consequent need for more direct support workers (Braddock, 1999).

The Bureau of Labor Statistics (2001) projects a 63% increase in demand for developmental disabilities direct support staff through 2010, more than double the projected job demand for nursing aides, fast food workers, or across all occupations. The BDO Seidman study noted that developmental disabilities support worker hourly wages and benefits lag substantially behind nursing home aides, state and local government entry level workers, and the civilian workforce overall. Developmental disabilities direct support hourly wages increased only \$.82 during 1992-00, contrasted with a \$3.16 increase for public (i.e., state-operated) direct support workers, and a \$2.11 increase for fast food workers.

The economic and demographic constraints that BDO Seidman (2002) used to



describe the growing staffing crisis are significant problems in the New Hampshire developmental disabilities system as well. New Hampshire's cost-of-living adjusted wage of \$8.19 in 2001 for community direct care workers was only slightly higher than the nationwide developmental disabilities direct support wage of \$7.62 reported in the BDO Seidman report for 2000.

The New Hampshire legislature in 2000 established a study committee to consider the allocation of \$4.5 million for direct care provider salary increases (HCBS Resource Network, 2003), resulting in the increase to \$8.67 in 2001. Nevertheless, high direct support staff turnover and recruitment problems continue to be a major issue affecting quality of services in the state (Shumway and Fox, 2001).

### WAITING LIST AND OTHER LAWSUITS IN THE STATES

Earlier in this paper we discussed the impact of class action litigation to address institutional reform and the early stages of community development in each of the New England states. Today, class-action litigation has emerged once again in the United States and in New England as a force shaping the funding and development of service delivery systems for persons with developmental disabilities. In the 1990s, three types of class-action litigation emerged: lawsuits filed to force states to expand services to people on waiting lists; lawsuits filed to force states to meet the requirements of the community integration mandate in the *Olmstead* Supreme Court decision; and lawsuits filed on behalf of individuals eligible for, but not receiving, Medicaid services. By February 2003, waiting list lawsuits had been filed in 23 states, *Olmstead* lawsuits in 13 states, and Medicaid access lawsuits in 13 states. One or more lawsuits have been filed in the New England states of Connecticut, Maine, Massachusetts, and New Hampshire (Smith, 2003).

Waiting list lawsuits included cases in Connecticut, Maine, Massachusetts, and New Hampshire. *Arc/Connecticut et al. v. O'Meara and Wilson-Coker* was filed October, 2001, in U.S. District Court for the District of Connecticut. The Court denied the state's motion to dismiss in September 2002. *Rancourt et al. v. Maine Department of Human Services et al.* was filed August, 2001, in the U.S. District Court for the District of Maine. The Court denied the state's petition in July 2002 and a trial is scheduled to begin in May 2003. *Boulet et al. v. Cellucci et al.* was filed in March, 1999, by private attorneys on behalf of plaintiffs and their families. In July, 2000, the District Court of Massachusetts issued a summary judgment in the plaintiffs' favor, ruling that the State was required to furnish Medicaid residential services with reasonable promptness. In December, 2000, the parties developed a settlement agreement, and the State committed to spend \$355.8 million over 2002-06 to expand services. Despite the Commonwealth's economic downturn, the legislature approved \$36.5 million in new funding in 2002-03.

In New Hampshire, *Cumming et al. v. Shaheen et al.* was filed in January, 2002, by the state Protection and Advocacy Agency in the Hillsborough County Superior Court. The suit alleges that more than 500 individuals are awaiting services and, furthermore, those who are receiving support are receiving inadequate or inappropriate services. The Judge denied the plaintiffs' petition for injunctive and declaratory relief in April 2002; however, the trial is likely to start in the Fall of 2003.

*Olmstead* cases have been filed in Massachusetts and New Hampshire. *Rolland et al. v. Romney et al.* was filed October, 1998, on behalf of seven Massachusetts residents with MR/DD in nursing facilities. In May, 2002, the Court granted the plaintiffs injunctive relief and mandated that all class members receive services meeting the "active treatment" standards. On January 28, 2003, the Appellate Court rejected the state's appeal, holding that active treatment must be furnished to all individuals in need, and that the nursing home reform provisions did indeed confer a private right to action.

In New Hampshire, *Bryson et al. v. Shumway and Fox* was filed in December, 1999, by two persons with neurological disabilities residing in nursing facilities, but on the waiting list for services through New Hampshire's Acquired Brain Disorder (ABD) "model" HCBS Waiver. The plaintiffs alleged that the state capped and inadequately funded the Waiver. On October 23, 2001, the U.S. District Court Judge dismissed two of the plaintiffs' seven counts, ruled in their favor on a third, and decided that a fourth was moot. The three remaining issues that were deferred were: a) whether waiting lists violate the principle of "reasonable promptness" in Medicaid law, b) if there were ADA violations by defendants, and, c) if there were Rehabilitation Act Section 504 violations. The District Court judge ruled on December 10, 2001, that Waiver services must be furnished with reasonable promptness to eligible recipients up to the "model" Waiver limit of 200. On the state's appeal, the 1<sup>st</sup> Circuit Court of Appeals in October, 2002, vacated the District Court Order, and ruled that a state could limit model waivers to less than 200 participants. Nevertheless, the Appellate Court made it clear that the State was obligated to furnish waiver services to individuals with reasonable promptness up to the limit it had established.

Access to Medicaid benefits cases were filed in Connecticut and Maine. *Pragano et al. v. Wilson-Coker* was filed November, 2002, by three Medicaid beneficiaries with disabilities, alleging that the state of Connecticut was refusing to pay for durable medical equipment that they needed to improve their health and to live independently. The plaintiffs are represented by the New Haven Legal Assistance Association and Connecticut Legal Services, and are seeking a preliminary injunction and class certification. In Maine, *Risinger et al. v. Concannon et al.* was filed in June, 2000, alleging the state's violation of federal Medicaid law by failing to provide medically necessary Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to children with disabilities. The District Court granted the plaintiffs' motion for class action certification in July, 2001, and the parties settled in May 2002: children will be evaluated more quickly and no child should wait more than six months to receive approved treatment and services.

### IMPACT OF ECONOMIC DECLINE IN THE STATES

Raymond Scheppach, executive director of the National Governors Association, has called the states' current economic condition "the worst budget crisis states have faced since World War II" (Brownstein, 2002). States are facing budget deficits in the range of \$70-\$85 billion for fiscal year 2004, representing from 14.5% to 18% of states' expenditures. The 2004 deficits are on top of a \$50 billion 2003 deficit and are also in addition to \$17.5 billion in 2003 deficits that have impacted states since those 2003 state

budgets were enacted (Lav and Johnson, 2003; National Conference of State Legislatures, 2002).

Projected fiscal year 2004 fiscal shortfalls are in excess of 20% of state budgets in Alaska, California, New York, and Oregon, and constitute over 10% of state budgets in 19 other states. All states but Wyoming are projecting deficits at 3% or more of their budgets (data were not available for DC, LA, MS, NM, ND and UT). In New England, fiscal year 2004 deficits, as a percentage of states' budgets, were: Connecticut (12.9%), Maine (est. 14.5% - 18.4%), Massachusetts (est. 6.1% - 8.8%), New Hampshire (8.6%), Rhode Island (est. 6.6% - 9.4%), and Vermont (3.2%).

Across the states, the 2003 and 2004 budget shortfalls are impacting Medicaid enrollment, eligibility standards, and payment levels for a range of optional health care services. The major impact to date has been reduced coverage for adults in low-income families, and it remains to be seen whether there will be substantial Medicaid cuts that directly affect recipients with disabilities, although such cuts seem likely to occur in some states.

The 12 area agencies in New Hampshire are not immune from the state's economic problems. According to the Area Agency association, the Community Support Network, Inc. (Haines, 2002), "the fiscal well being of the collective Area Agency system could be presently described as marginally adequate" (p. 4). Among the most significant factors driving agency costs are: a) health insurance premium increases; b) workers' compensation insurance costs; c) property, casualty and liability insurance premium increases due to insurance companies' stock market losses and the impact of September 11<sup>th</sup>; and, d) the Health Insurance Portability and Accountability Act (HIPAA) and other agency reporting requirements that translate into a need to finance the construction of an integrated electronic infrastructure (Community Support Network, 2002).

## **8. CONCLUSION: ACHIEVEMENTS AND CHALLENGES**

The following summative observations can be made about the contemporary structure of the New Hampshire developmental disabilities service system and its many achievements.

### **ACHIEVEMENTS**

As the data presented in this paper indicate, New Hampshire:

1. Is one of only four states that commit 99% or more of total developmental disabilities resources to financing community services. The other states are Alaska, Vermont, and New Mexico.
2. Has 12 years of experience with an institution-free service delivery system, the most experience of any American state.
3. Is among the three leading states in the proportion of individuals served in small, family scale settings for six or fewer individuals (95%).

4. Has established a system of 12 area agencies that are compatible with New Hampshire's home rule tradition, and that are playing a key role in managing Waiver funding, developing community housing and work options, and providing case management for individuals with developmental disabilities and their families.
5. Has been a leader in the provision of self-directed and person-centered planning and support. New Hampshire was recently awarded a "Real Choice Systems Change Grants," was the first state to receive an "Independence Plus Waiver," and, for a number of years, New Hampshire's Home of Your Own initiatives have served as models for other states.
6. New Hampshire has achieved the above with a substantially smaller level of expenditure of its collective state wealth than all other New England states.

## CHALLENGES

Despite the positive achievements in New Hampshire noted above, many challenges remain for state leadership, service providers, families, and consumers.

### **1. Fiscal effort for MR/DD services in New Hampshire is declining:**

- The state declined 10 positions between 1992 and 2000, to 33<sup>rd</sup> nationally;
- New Hampshire's fiscal effort in 2002 was 38% below all five other New England states in the aggregate, and 50% below the aggregate effort level of Maine, Rhode Island, and Vermont;
- In federal Waiver reimbursement per capita, New Hampshire ranked behind each of the comparably populated New England states;
- To match the federal Waiver reimbursement per capita level in Rhode Island, New Hampshire would need to receive an additional \$46.5 million in Waiver reimbursement, nearly double the current reimbursement of \$49.9 million.

### **2. The waiting list is growing and this growth is likely to continue.**

- The growth is due to factors such as increased longevity of persons with developmental disabilities, growth in the number of students exiting special education, aging caregivers, general population growth in the state, and the possible consequences of class action lawsuits.
- New Hampshire's residential services placement rate per 100,000 population was 25% behind the rate of the other five New England states combined and 4% below the national average.

### **3. Individual and family support services require significant strengthening in New Hampshire.**

- Unlike Connecticut and Rhode Island, New Hampshire has yet to implement a cash subsidy program for families;

- New Hampshire ranked 43<sup>rd</sup> nationally in supported living spending per capita, and next to last in the New England region.

#### **4. Area Agency financial solvency is a serious problem.**

- The fiscal well-being of the State's Area Agencies is deteriorating at precisely the time these entities are being asked to carry out additional responsibilities to provide critical services to consumers and families.

### **CASH SUBSIDY FOR FAMILIES**

Now that the New Hampshire community system is substantially in place, and the state institution no longer demands costly resources, the State can systematically continue to meet the needs of more youth emerging from special education and of adult children living at home with aging caregivers. Like New England states Connecticut and Rhode Island, New Hampshire should now seriously consider direct cash subsidies for families.

Families use subsidies for a wide variety of items and services important to keeping the child with a disability as a part of the family. According to Herman (1991), the most frequent uses of the subsidy in Michigan were: clothing; educational aids and toys; general household expenses; sitters for the child with a disability; transportation; and medical expenses and health-related needs (p. 255). Family support is a key element in New Hampshire's community system, and expanded resources including a cash subsidy program can help assure that New Hampshire's vision in *For the love of our families* (Task Force, 1988) can be more fully realized.

### **EXPANSION OF SUPPORTED LIVING AND HOME OWNERSHIP**

Another area in which New Hampshire can take more of a leadership position on a statewide basis is supported living. Supported living is defined as providing opportunities for individuals to choose where and with whom they live, to enjoy housing options owned or rented by themselves or their families, and to be supported by staff who are sensitive to individuals' changing needs over time. In 2000, supported living constituted a statewide initiative in 45 states. New Hampshire spent \$1 million for 341 individuals but, as noted, ranked only 43<sup>rd</sup> in terms of supported living spending per capita, and next to last in New England.

A 1995 evaluation by one of New Hampshire's area agencies captured the essence of supported living:

This housing model was embraced by consumers, families, guardians, vendor agencies and the Area Agency...The opportunity to live in individualized housing was offered to people regardless of their need for care or level of disability. Individual housing is less expensive....People may move more [in supported living] but they have to learn to live with significantly fewer people. The consistency of roommates/staff offsets the

instability of moving more (Area Agency for Developmental Services, Region VI, 1995, p. 3).

The University of New Hampshire has also been a leader in promoting federally funded “home of your own” demonstration and technical assistance initiatives to the benefit of many states.

New Hampshire’s substantial Waiver foundation and its commitment to individualized housing and support place the State in an excellent position to expand supported living and family support programs such as cash subsidies. Such increased capacity for community support will add to New Hampshire’s growing tradition of innovation in developmental disabilities services.

### A CROSS-DISABILITY CHALLENGE

In closing, we wish to note that the state of New Hampshire is a wealthy state, ranking 6<sup>th</sup> nationally in per capita personal income and first among the smaller New England states. The State also has virtually the nation’s lowest “need index” -- the smallest proportions of school-age children and welfare recipients placing demands on state resources. New Hampshire has an educated population, and the nation’s lowest taxation as a percentage of personal income (Hovey and Hovey, 2003). In this context, we suggest that New Hampshire has a special responsibility and a unique capacity to become perhaps the nation’s leading state -- a “model state” if you will -- in the provision of services and supports to people with developmental and other disabilities.

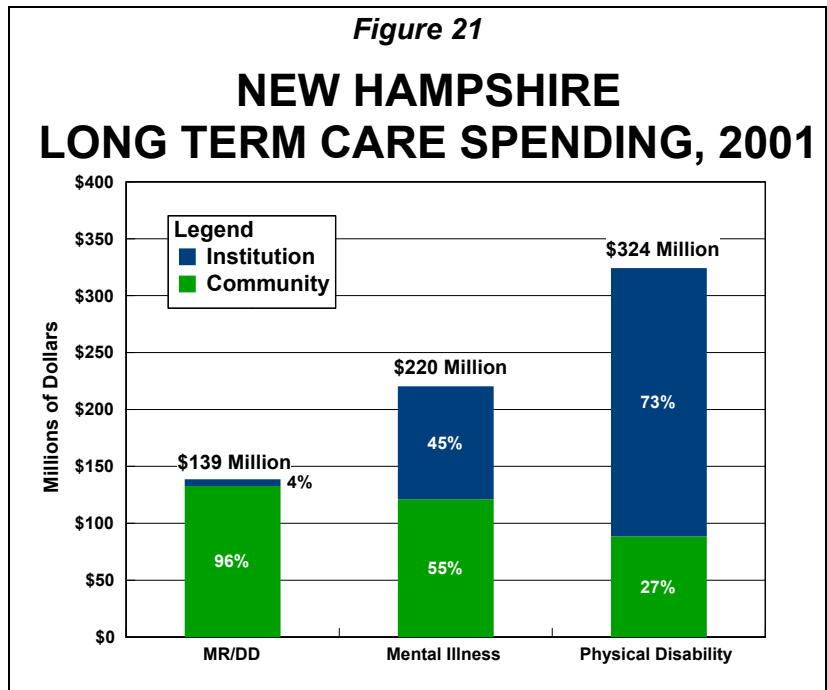
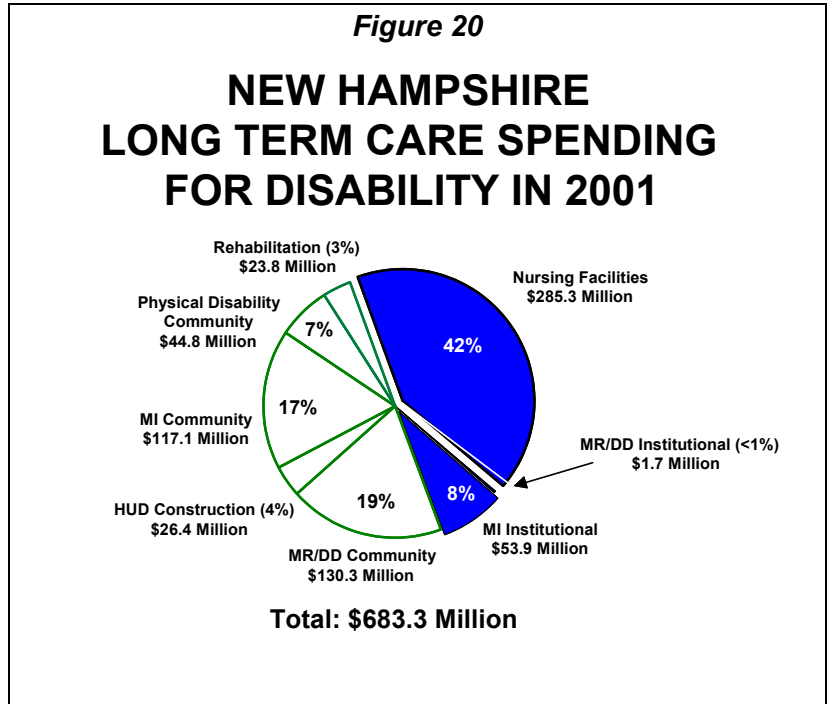
In this regard, it is particularly important for the State and consumers to stress cross-disability approaches to the development and implementation of community services for all people with disabilities. The experience in the mental disability field in facilitating the implementation of community-based living would seem to provide some helpful guidance and inspiration in the construction of similar programs and opportunities for people with physical disabilities. Further analysis of this topic is presented in a related publication (Braddock, 2002a) that is being distributed to legislators at the March 25, 2003, conference in Concord.

*Figures 20 and 21* illustrate the proportion of New Hampshire’s financial resources being allocated to support disabled citizens living in supervised long-term care settings. It is notable that one-half of these resources (50%) support placements of persons with disabilities in institutions, nursing facilities, and other settings for 16+ persons. Developmental disabilities is the least “institutionalized” sector of the long-term care disability services system, followed by mental illness (45% of resources allocated for institutional/nursing facility purposes) and physical disability (73% of resources committed to nursing facilities).

For purposes of this analysis, the “physical disability” component of the long-term care system includes all persons with disabilities other than mental retardation/developmental disabilities and mental illness. Thus the “physical disability” construct employed in this analysis includes myriad disabilities such as acquired brain injury, Alzheimer’s disease, and stroke and other cardiovascular disorders that lead to

significant limitations in functioning. For a discussion of the methodology used to produce *Figures 20* and *21*, see Braddock (2002a).

The data presented in the figures illustrate the substantial and disproportionate component of resources being allocated to institutions and nursing facilities for mental illness and physical disability in New Hampshire. A great challenge to be addressed by the next generation of leaders and advocates in New Hampshire would clearly seem to be in building on successful examples in community living and family support in developmental disabilities. We hope that this paper helps stimulate critical discussion and meaningful planning in the state about building successful partnerships in long-term care advocacy and services development for all persons with disabilities and their families.



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