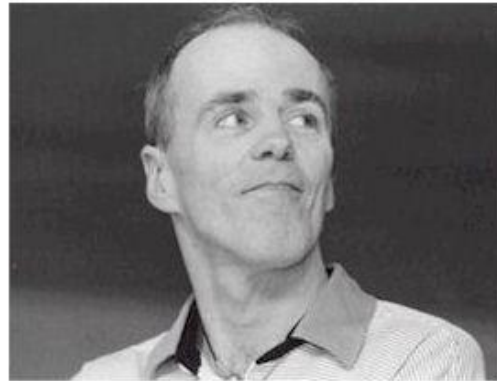


RENEWING THE VISION



New Hampshire's Plan to Provide Essential Community Supports for Individuals with Developmental Disabilities

November 2001

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New Hampshire's Plan to
Provide Essential Community Supports
for Individuals with Developmental Disabilities

Submitted to:

**Governor Jeanne Shaheen
Senate President Arthur Klemm
House Speaker Gene Chandler
Developmental Disability Waitlist Fund Allocation Oversight Committee**

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I. Introduction

In response to a 1978 lawsuit brought by parents of residents at Laconia State School and Training Center, New Hampshire established a statewide community system of services for individuals with developmental disabilities (referred to as individuals throughout the rest of this report) and their families. The creation of Area Agencies paved the way for the 1991 closure of the Laconia State School - New Hampshire's only institution for individuals with mental retardation and other developmental disabilities. Thus, with significant support from the State Legislature, New Hampshire transitioned from institutional services to a more humane community-based system.

New Hampshire has made great strides in providing services to all former residents of Laconia State School. For the last ten years, however, the capacity of the developmental services system to meet the needs of individuals who never resided at Laconia State School has been limited. To track and document unmet needs, a statewide waiting list was initiated. Currently, there are over 200 people whose names are on the list and this number is growing daily.

The waiting list includes three distinct groups of individuals; young adults aging out of public education programs, middle-aged and older adults living with elder parents, and those individuals with complex medical and/or behavioral needs.

While fellow classmates have moved on to college, jobs, or the armed services, too many former



special education students sit at home waiting for openings in the adult service system. Parents are frustrated that, after investing twenty-one years in their child's education, the future remains uncertain. Families are concerned that these young adults not only are losing the skills they worked so hard to attain, they also are losing their self-confidence and sense of purpose. One mother talked with sadness about her daughter's slide into a severe depression once the structure of the school day and the companionship of other students were no longer part of her life.

In addition to its effect on individuals, the lack of vocational and other day activities has significant ramifications for the entire family. In some instances, a parent - typically the mother - is forced to quit work in order to care for or provide needed support and supervision to the family member with a developmental disability. Giving up a career is not only emotionally difficult for a parent staying home; it also results in a substantial loss of necessary family income. Other children in the family must postpone or forego educational opportunities, health insurance can be cancelled, and paying bills is a constant struggle.

The waiting list also includes middle aged and older adults who are living with elder parents.



Many of these individuals, born before the federal government declared that *all* children have a right to a public education, have been isolated from the outside world. As parents age and the needs of their children with disabilities increase, the ability of these families to continue providing care is at risk. Older caregivers may experience failing health, physical frailty, impaired mental capacity, and often increasingly impoverished circumstances. Added to these difficulties is the parents' overriding anxiety about what will happen to their children when they are no longer able to care for them. Contrary to the normal course of life's events, many of these parents express the heartrending hope that they will outlive their children. These families need support to continue providing care and their family members with developmental disabilities need to be introduced to services in the

community while their parents are still living. Getting used to being away from home with other caregivers will help lessen the trauma of moving into a new home when parents become incapacitated or die.

Another major group awaiting services is families who have adult family members with complex medical needs or extremely challenging behaviors. These are individuals who require total care and supervision; many are dependent on sophisticated medical equipment that must be



monitored; others cannot be left alone for fear of harming themselves. Parents report that sleeping through the night is frequently a problem. Families living in these circumstances are under extreme stress and risk physical and emotional exhaustion. As one mother explained, even the most loving of families cannot indefinitely sustain 24 hours a day, seven days a week of caregiving. Without adequate support, family stability will deteriorate forcing parents to seek out-of-home services for their family member. Providing trained respite care, regular in-home supports, appropriate day activities, and other supportive services will enable families to continue to keep their family member at home as long as possible. When living at home is no longer an option, these individuals will require intensive community-based

residential services. Currently, New Hampshire's developmental services system lacks the capacity to provide adequately for the needs of its most challenging citizens.

II. A Legislative Mandate

In the spring of 2001, the New Hampshire Legislature passed and Governor Shaheen signed Chapter 270, laws of 2001 - an Act requiring the Department of Health and Human Services to develop a plan to include the following:

1. A method to reduce the waitlist over a period of 5 years and to reduce the waiting period to 90 days;
2. A description of minimum supports and services available to all eligible individuals and their families;
3. A method for determining eligibility criteria for different levels of services;
4. A method for adjusting support and service levels on the basis of the needs of the eligible individual combined with family or other circumstances affecting the support of the individual;
5. A method for determining the circumstances when out-of-home, 24 hour supports may be necessary;
6. A description of how the plan would be implemented on a statewide basis; and
7. The statutory changes that would be required to implement the plan.

The plan presented here includes:

1. Family, individual, and community input regarding satisfaction with developmental services and recommendations for improving services;
2. A data and fiscal analysis of current and future waiting list needs; and
3. Specific actions that need to be taken to reduce the waiting list.

III. Input from Stakeholders

The legislative mandate to develop a plan for reducing the waiting list provided an opportunity for the Division of Developmental Services (Division) to take a closer look at the State's developmental services system. The Division sought input from individuals, families, and providers about where developmental services has been most successful and where things need to change. Ideas were solicited for improving supports to people with developmental disabilities and continuing to assure the provision of supports and services that are efficient, cost effective and of high quality.

The methodology for developing the plan included a series of six regional forums (Newington, Plymouth, Manchester, Nashua, Claremont, and North Conway) held in the spring of 2001, solicitation of written comments from those unable to participate in the forums, and meetings with consumers both individually and in self-advocacy groups. On July 25, 2001, key stakeholders came together at a planning retreat to help focus and refine the ideas and recommendations that came out of the regional forums and meetings with self-advocates. In all, over 350 individuals were involved in the planning process. Participants included individuals, family members, community providers, direct support professionals, Area Agency staff, enhanced family care providers, Division personnel, disability advocates, legislators, and interested community members.

The following sections summarize the most important topic areas identified at the six regional forums and the subsequent planning retreat. A full list of comments and input received through the forums and planning retreat is available upon request.

A. The Importance of Values

Participants at the July planning retreat were asked what values should guide the State as it moves forward. They made the following recommendations:

- ❖ Individuals should be fully included in the life of their community.
- ❖ Supports and services should be individualized and community-based.
- ❖ The service system should be consumer driven. Individuals and their families should be given the opportunity to make informed choices about the services and supports they receive.
- ❖ Individuals and their families should have the same opportunities as other members of their community.

B. Preserving What Works Well

In planning for the future, it is important for the State to recognize and hold onto those aspects of the service system that have been successful. Participants in the regional forums and self-advocacy meetings discussed the services and supports that have most benefited individuals and their families. People expressed the greatest degree of satisfaction with:

- ❖ Supports that were individually tailored to meet the needs of the individuals and/or their family;

- ❖ Flexibility and willingness on the part of Area Agencies and providers to include the individual and family in decisions concerning services;
- ❖ Family support (especially respite care);
- ❖ Early intervention for families with children birth to age three;
- ❖ Assistance in obtaining and keeping meaningful employment;
- ❖ Service coordination that included advocacy on behalf of the individual; and
- ❖ The opportunity to participate in self-advocacy groups.

C. Maintaining an Adequate Direct Support Workforce

In every forum individuals and their families talked about the problems created by high staff turnover and the lack of capable direct support professionals. The quality of life for individuals is directly related to the quality of care provided by their direct support professionals. A significant impediment facing New Hampshire's developmental services system is the ability of the Area Agencies and community providers to attract and keep qualified direct support professionals. In the best of circumstances, the low wages and limited benefits for direct support professionals make it difficult to attract people to this vocation. While it is not addressed in this plan specifically, the Department of Health and Human Services has organized a workforce development committee to manage this issue comprehensively.

D. Providing Better Support to Caregiving Families

Participants at the forums pointed out that the majority of adults with disabilities live with family members, most with their parents. Unfortunately, with limited resources for services, many of these families receive support only when their situation becomes grave. When support finally comes, it is often too late; no longer able to continue as primary caregivers, the families request residential services for their family member.

Parents talked about their frustration with this all or nothing approach to services. Some whose situations had so deteriorated received a full array of services while others continue to wait with rarely more than occasional respite. Providing lower cost essential supports to families early on can avert costly residential services.

Furthermore, parents attending the forums testified that the most significant support extended to a family is the assurance that their family member experiences a meaningful day outside the family's home. A meaningful day includes opportunities for the individual to develop new skills, work in a job he or she enjoys, and participate in a variety of leisure activities. When the individual has these opportunities, caregiving family members are able to continue working and have time for themselves. Additional support requested by families included adequate respite, help with transportation, resources for home modifications or specialized equipment, in-home personal assistance or nursing services and opportunities for their family member to connect with people who share similar interests.

E. Improving the Transition Process for Students with Disabilities

In every forum and in many of the written comments submitted to the Division, families expressed frustration with the lack of transition planning and support for students with developmental disabilities. Since these students will likely require support at age 21, transition

planning will help prepare them for adulthood, better skilled to live and work as independently as possible. Parents asked that:

- ❖ The Department of Education and Division of Developmental Services develop a better-defined transition process with specific guidelines to ensure that there is a more collaborative approach at the local level;
- ❖ Area Agencies and local school districts do a better job of collaborating to meet the needs of students who are eligible to receive developmental services;
- ❖ The transition from school to adulthood begin earlier - when students who have already been found eligible for developmental services are 14 to 16 years old, rather than waiting until their last year or two of school;
- ❖ The planning process include the student and family, the school, and the Area Agency;
- ❖ Relevant state and community agencies be involved as the student approaches graduation;
- ❖ Services for older students (18-21) take place within the context of their community, not in the school; and
- ❖ Better information about the transition process and the adult service system is shared with parents and schools.

Finally, parents expressed their exasperation and anxiety over having their adult children leave school only to be put on the waiting list for developmental services. Families emphasized the necessity of providing continued opportunities and support for their children as they move from school to adulthood.

F. Accessing More Meaningful Employment Options

Many participants in the regional forums expressed concern about lack of employment opportunities for persons with developmental disabilities. People want the Area Agency and service providers to develop stronger partnerships in their communities. The developmental services system should continue working with local businesses to open up employment opportunities and connect with community organizations improving individuals' access to education and training programs, volunteer opportunities, and recreational activities.

G. Developing Residential Options

Nearly every family attending the forums worried about whether the State would have adequate resources to provide residential services. A small number of parents anticipated their adult children would live with them until they were no longer able to provide support. The majority of parents, however, expect their children to remain in their home community, but move out of the family's house once they were grown.

Families agreed that no one model of residential services would work for everyone. They urged that all individuals have the opportunity to live where and with whom they choose. They asked that there be an increased effort to develop a variety of residential options, including supervised apartments, group homes, family care, and individual homes. They also talked about the importance of including individuals and their families as active partners with the Area Agency in planning services. In particular, families of children with specialized needs were concerned about the availability of accessible housing or residential services for those who have intensive medical problems or behavioral issues. A major barrier to providing residential services is the lack of affordable and accessible housing in many New Hampshire communities. Area Agencies

and residential providers should be working with local housing authorities, land trusts, banks, realtors, and advocates for low-income people to address this issue.

H. Building Stronger Partnerships with Families

Discussions at the forums pointed out the need for increased effort to strengthen the involvement of each individual family in decisions concerning their family members' supports and services. Those families who are interested should be offered increased control over support dollars, and parents should be allowed to be service brokers for their sons and daughters. In general, families could be creative, frugal, and most likely have better community connections. Giving increased control to families may help State resources go farther. Another strategy to maximize developmental services dollars is for Area Agencies to work with families to determine what resources and supports families can reasonably contribute to their own family member's care and services.

The New Hampshire developmental service system is committed to continued partnership with families. Family representation on the Area Agencies' Boards of Directors and Family Support Councils ensures that families formally participate in decisions concerning the services in their community. Parents act as legislative liaisons, helping to familiarize elected representatives about the needs of individuals. They volunteer their time to provide information and support to other families through Parent-to-Parent programs. Parents also serve on New Hampshire's Family Support Council, are represented on the State's waiting list advisory committee, and are included in a variety of initiatives sponsored by the Division of Developmental Services.

I. Continuous Quality Improvement in the Developmental Services System

As many of the participants at the planning retreat pointed out, while New Hampshire's developmental service system is ahead of many states, it can still be made more efficient, cost-effective, and responsive to the needs of individuals and their families. For too long, New Hampshire's developmental service system has been crisis driven; it needs to become proactive. Parents are asking for more information and training provided at each stage of their family member's development. They want information specific to their family member's disability as well as information about how to access community resources, developmental services, Medicaid, and other benefits. Also requested was a greater emphasis on the use of family, friends, and other generic community resources.

Having locally governed, community-based services is a strength of New Hampshire's system; however, because services are decentralized, communication and collaboration across regions requires more effort. Area Agencies and service providers need to do a better job of sharing creative solutions and success stories with one another. Moreover, a coordinated effort is needed to improve the efficiency and responsiveness of the service system.

In 1995, the Community Support Network, Inc. (CSNI) was founded to identify and undertake joint activities or services to realize programmatic and financial efficiencies for the developmental services system. This alliance of Area Agencies has achieved efficiencies through joint purchasing of health, dental and workers compensation insurance products. Other joint purchasing opportunities include disposable medical products, telecommunications, and technology. CSNI has also been able to help standardize operating processes across all Area Agencies in staff development, billing, contracting, and quality outcomes.

Many New Hampshire organizations are working with or on behalf of individuals and their families: the Division of Developmental Services; the Community Support Network, Incorporated; the Private Provider Network; the Institute on Disability at the University of New Hampshire; the New Hampshire Developmental Disabilities Council; and the Disability Rights Center. Continued collaboration among all these organizations will lead to creative and cost effective ways to address the issues confronting the developmental services system.

IV. The Future of Developmental Services

The fabric of New Hampshire's community developmental services system is evolving. The system was originally designed to reintroduce its citizens with disabilities back from the institution to community life. Its mission was to develop community-based residential and day services for persons who had few connections to their families and communities. The Area Agency was often the only support available to the individual and therefore was required to provide for all of the person's needs, 24 hours a day.

Today most of the individuals seeking support from the developmental services system live with their families, attend school, work in their community and have established community and family connections. They do not need or want to rely on the developmental services system for their full network of supports. Yet, Area Agencies and providers have become accustomed to providing for the total needs of individuals. Working with an individual and his or her family to design a flexible package of supports that meets his or her unique needs requires a different set of skills. Reorientation and ongoing training is needed to help Area Agencies and provider agencies become facilitators of service arrangements where full participation of individuals and families is an important and customary aspect of the service system.

Parents and family members, without exception, expressed the extreme stress of uncertainty concerning services for those who are nearing the end of their involvement with their school system. The lack of a commitment to ongoing support following 21 years of early intervention and special education services cannot be condoned. While New Hampshire needs to commit to funding a minimum level of essential service for all persons who are eligible, families and individuals need to accept that comprehensive, 24-hour supports will be available only for those with the most urgent and critical needs. While specific criteria to determine the need for 24-hour out-of home care will be developed, it is anticipated that those with the most urgent need would include students aging out of Division of Children Youth & Families services or residential school placements who cannot return home, individuals with significant medical and/or behavioral needs which cannot be managed in their family home, and individuals living with aging caregivers who can no longer provide adequate support.

The vision of the developmental services system, beginning in the late 1970's, was to support persons with developmental disabilities to receive services within their home community. While New Hampshire has achieved this vision, communities have not been supported to fully embrace all individuals. It is time to renew the vision to build communities that support *all* members to live full and productive lives. Implementing the recommendations outlined in this plan will result in significant systems change that will shift emphasis from a community-based service system to a system of support which focuses on individual, family and community capacities.

V. Goals And Objectives

This plan proposes to address the waiting list by making available essential services to all eligible individuals aged 21 or over. Essential services may include day and/or vocational activities, as well as family support and service coordination; however, families and individuals can design supports as they choose to meet their particular individual needs. In order to achieve this outcome, the Division will:

1. Identify a level of essential supports to be provided to all eligible persons aged 21 or over.
 - a. Review and clarify the definition for developmental disability in RSA 171-A.
 - b. Provide training on eligibility determination.
 - c. Establish criteria to determine the level of essential supports needed.
 - d. Establish criteria to determine the need for 24-hour, out-of-home supports.
2. Reallocate system resources to promote alternative service provision.
 - a. Provide funding for pilot projects in community development, fiscal intermediary services, consumer directed services, futures planning, family and community capacity building, and self-advocacy.
 - b. Provide training to families, individuals and staff regarding the opportunities and responsibilities around choice, control, individual budgeting, and consumer directed services.
3. Improve the transition from high school to adult life for those individuals who have been found eligible for developmental services.
 - a. Revise He-M 503 (rules of the Division of Developmental Services) to require Area Agencies to:
 - i. Participate with local school districts in transition planning beginning at age 16 to provide a better transition to adult life; and
 - ii. Collaborate with families and school districts to stress the importance of providing a foundation of useful functional skills (home, community, vocational) by age 16.
 - b. Provide training about transition from high school to adult life.
4. Provide resources, training and technical assistance to implement:
 - a. Meaningful opportunities for people to work and recreate within their communities;
 - b. Self-advocacy and peer support efforts statewide;
 - c. Opportunities for individuals to live, work and recreate with whom they choose; and,
 - d. Recruitment of home providers and direct care staff who are connected to and involved in community life.

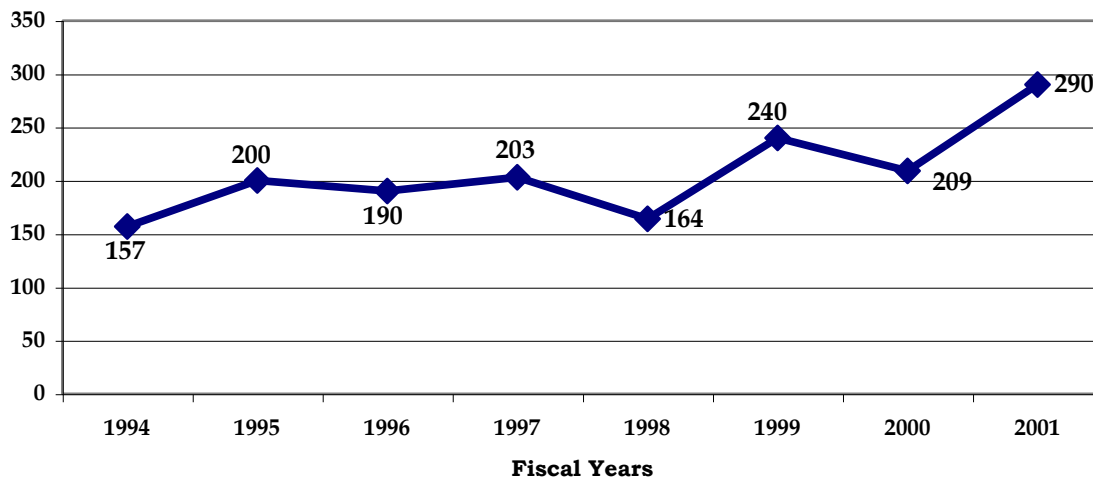
5. Provide orientation to families, individuals, and Area Agency and provider staff regarding:
 - a. the nature and extent of assistance available under this plan;
 - b. partnership building, facilitation, negotiation skills; and
 - c. the use of individual, family, and generic community resources.
6. Improve system resources to achieve the goals of this plan.
 - a. Review all Division regulations and Area Agency policies to reduce paperwork and redundancies.
 - b. Increase technology available to relieve staff from paperwork to allocate more time to direct service to individuals.
 - c. Assign a management level staff person within the Division to direct this plan.

VI. Financial Impact

In the early 1980's, New Hampshire worked to improve services at the Laconia State School and to establish a community-based service system for individuals with developmental disabilities. Recognizing the fiscal challenges involved in such an undertaking, the State sought to enhance its financial capacity by accessing federal funds through the Medicaid program. Specifically, the Division of Developmental Services began to use Medicaid's Intermediate Care Facility for Mentally Retarded (ICF/MR) and Home and Community-Based Care for individuals with developmental disabilities (HCBC-DD) Waiver programs to fund long-term care services. In the mid-1990's, when the State further recognized the cost effectiveness of the HCBC-DD Waiver over the ICF/MR funding, it converted all of its ICF/MR programs to Medicaid HCBC-DD Waiver funding. As a result, the Medicaid HCBC-DD Waiver, which is recognized nationally to be the most cost effective funding stream, has become the primary funding source for New Hampshire's community-based service system. By bringing in federal dollars, the State has been able to avoid more serious waiting list problems and by taking proactive financial measures, it has averted paying high ICF/MR rates. (New Hampshire's average per person cost of \$42,000 under its HCBC-DD Waiver compares very favorably with the nationwide average ICF/MR rate of about \$114,000.)

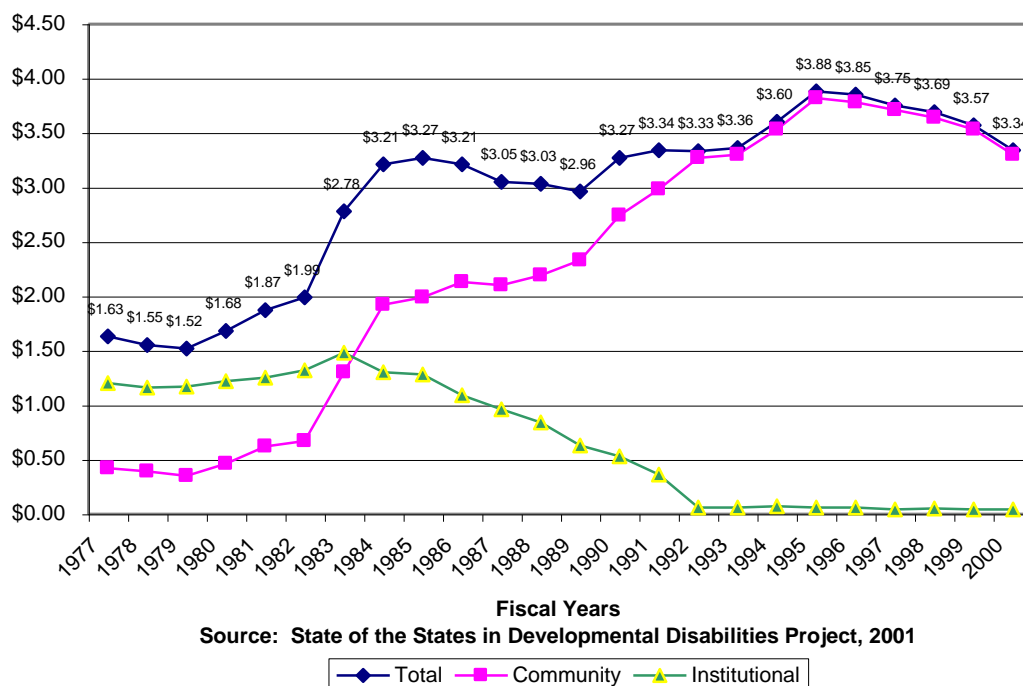
Even with the maximization of federal funds through Medicaid and the deployment of a cost-effective funding stream, New Hampshire's developmental service system has not had the necessary resources to provide supports to all individuals who need them. Figure 1 depicts the number of people waiting for developmental services at the end of each fiscal year.

Figure 1
Developmental Services Waiting List
Year End Totals
FY 1994 - 2001



Particularly since 1998, New Hampshire's waiting list problem has deepened. As illustrated in Figure 2, New Hampshire's fiscal effort support of developmental services has declined since 1995. (A state's fiscal effort is defined in terms of the annual volume of system wide expenditures for services per \$1,000 in statewide personal income. This metric reflects the proportion of a state's aggregate wealth committed to the financing of community developmental services.) New Hampshire was one of only four states whose fiscal effort in developmental services had declined over the past several years.

Figure 2
New Hampshire's Fiscal Effort
(Spending per \$1,000 of personal income)



Although the most recent biennial appropriation has helped with the waiting list problem, as of this writing there are still approximately 200 people on the highest priority waiting list. The average length of stay on the waiting list as of June 30, 2001 was 271 days. The funding methodology proposed in this plan will reduce the time an individual waits for funding for home and community-based services to a maximum of 90 days. However, the goals and objectives specifically aimed at reducing the time waiting for requested services cannot be achieved without the additional funds requested in this plan.

The financial projections in this plan focus specifically on addressing the cost of serving persons on the waiting list. The figures do not address the extensive needs of persons who are mentally retarded, have been accused of a serious felony, and have been committed to the developmental services system under RSA 171-B. In addition, rate adjustments to address provider increases in direct support professional wages, insurances and other operational expenses are not reflected. This plan will only work if responsible efforts are made to address these issues in addition to the waiting list.

In projecting the developmental services system's needs over five years, Figure 3 uses the current number of people on the waiting list and takes into account the significant number of individuals who will be leaving the educational system and needing supports from the developmental services system. Based on projections of future service demands, population growth and system vacancies, it is believed that the figures represented in this plan accurately reflect the needs of persons living with aging caregivers and persons with significant behavioral and/or medical needs who can no longer remain in their family home as well as those of students turning 21.

Figure 3

Number of Individuals Age 21 and Over Needing Services
FY 03 - 07

Fiscal Year 2001 (4th quarter waiting list)	290 (1)
Less: Number served with FY 02-03 waiting list appropriation	<u>(99)</u> (2)
Individuals remaining who require services (on waiting list)	191
Add: Individuals turning 21 - FY 03 -07 and no longer eligible for LEA funded services	<u>582</u> (3)
Total number of individuals needing services over next 5 years	773
Needed to be served per fiscal year (773/5)	155
Less: Projected Annual Vacancy Occurrence	(26) (4)
Add: Projected Population Growth	<u>23</u> (5)
Number to be served per fiscal year to address all waiting list needs	152

Data Sources

- (1). Waiting list data
- (2). Financial system data
- (3). Information from area agencies/SPEDIS
- (4). Historical data
- (5). Study conducted by the National Association of State Directors of Developmental Disabilities Services

*The study conducted by the National Association of State Directors of Developmental Disabilities Services was commissioned by the Division to carry out an analysis of the waiting list problem in N.H. and to provide projections for future solutions. The study utilized five years of data regarding the numbers of people served, numbers of people on the waiting list and population projections. The study concluded that an estimated 159 people would need to be served each year in order to serve everyone on the waiting list and continue to meet caseload increases, assuming the demand for services remains constant. To validate the study's number, Division staff collected data from Area Agencies and the Special Education Information System (SPEDIS) to determine the number of students known to the Area Agency system and to the educational system who are likely to be eligible for adult services when they turn 21 during the next five fiscal years. Division staff also analyzed waiting list data and program data to determine the numbers of older adults who seek services each year. Since the numbers from the study (159) and the Area Agencies (152) were comparable, the data from the area agencies based on actual consumer information were used in projecting future needs.

Figure 4

Proposed Funding Methodology

Projections:

Estimated Annual Caseload	150
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Utilization Assumptions:

100 people (2/3) will receive essential services
 50 people (1/3) will receive 24 hour supports

Expense Detail:

Proposed Average Level of Service: (determined based on an individual's need)

Day Supports (30 hours/week x \$17.53/hour x 52 wks/year)	\$	27,347
Family Support (Respite) = (30 hours/month x \$8.25/hour x 12 months/year)		2,970
Case Management		1,514

Total Average Cost/Essential Services	\$	31,831
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Estimated number of people receiving essential services	100	\$	3,183,080
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Estimated number of people receiving 24 hour supports	50		<u>3,116,920</u>
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Total individuals served and dollars needed annually	150	\$	<u>6,300,000</u>
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Summary:

Estimated Annual Cost/Person	\$	42,000	*
Estimated Annual Cost - Total	\$	6,300,000	
Less: Area Agency Contribution - Reallocation of existing resources	\$	<u>(1,000,000)</u>	
Total Required Annual Additional Medicaid Funds (50% state, 50% federal)			\$ <u>5,300,000</u>

	Annual Year 1-5	Cumulative Year 1-5
Required Additional General Fund Appropriation In Year 1	\$ 2,650,000	\$ 2,650,000
Required Additional General Fund Appropriation In Year 2	\$ 2,650,000	\$ 5,300,000
Required Additional General Fund Appropriation In Year 3	\$ 2,650,000	\$ 7,950,000
Required Additional General Fund Appropriation In Year 4	\$ 2,650,000	\$ 10,600,000
Required Additional General Fund Appropriation In Year 5	\$ 2,650,000	\$ 13,250,000

*HCBC-DD Waiver average