

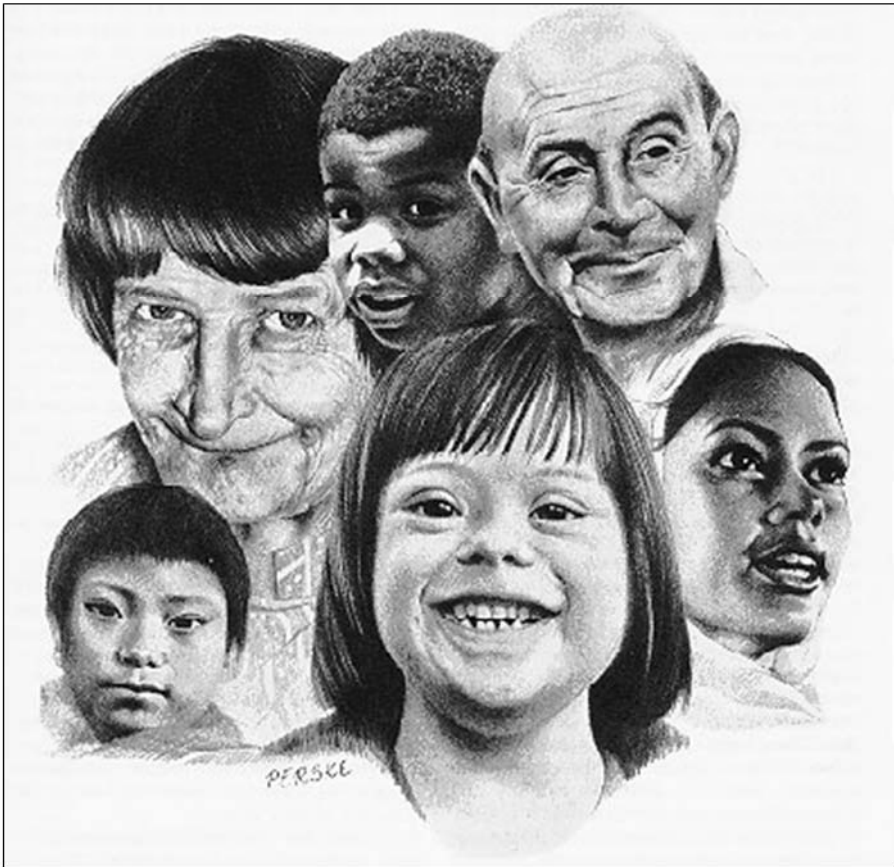


# ***Governor's Commission Report***

*Pursuant to Executive Order 2005-03  
of Governor John H. Lynch*

*November 18, 2005*

**Governor's Commission to Study Area  
Agencies and their Role in Providing  
Services to New Hampshire**



## ACKNOWLEDGEMENTS

The members of this Commission displayed extraordinary commitment, caring and capacity in their charge to study the Area Agency system. While the work was hard, and there were spirited debates, because of shared values and vision, we were able to achieve unanimous agreement on this report amongst all active participants. Commission members were a diverse group. Several members were from the business community or represented the public and had no previous connection to this area. Two were parents of adults with developmental disabilities. Others have worked inside the DD/AA service delivery system at the State, AA and Provider level in senior and field positions, including as Bureau or Area Agency Directors or have worked outside the system as advocates, many for over 25-30 years.

This Commission was charged with determining ways to improve the efficiency and cost effectiveness of the AA system, without compromising services. The purpose of the DHHS/DD/AA system is to provide supports and services to individuals with developmental disabilities, not only so that they may feel safe and secure, but to enable them to be truly part of the community, leading quality and rewarding lives. The Commission's work was strengthened by its understanding and commitment to the system's purpose as well as by its commitment to its charge.

I am not only grateful for the hard work and contribution of each member of the Commission, but I want to recognize and thank Beth Kelley, my assistant, for her tireless work on this project, as well as Julia Freeman-Woolpert for her work on the tables, figures and graphics. Thank you also to Amber Parshley, a self-advocate, who was voted on as an ex-officio member, who kept us grounded and enriched our work.

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The Commission and each Commission member stands ready to work collaboratively on the recommendations in this report with all persons, both in the public and private sector, on the state or community level, who have a stake in the system and in the lives of citizens with developmental disabilities in New Hampshire.

November 18, 2008

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Richard A. Cohen,  
Chairperson

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## **Executive Summary and Highest Priority Recommendations**

### **The Commission's Purpose**

This 13-member Commission<sup>1</sup> was established by Governor John Lynch to examine possible ways in which the Area Agencies (AAs) could operate more efficiently and cost effectively, without compromising services to individuals with disabilities and their families. While prompted by the proposal to merge four of the twelve AA regions into two, the Governor's Executive Order called for a comprehensive examination of the AAs. To fulfill this mandate, the Commission reviewed the larger service delivery system of which the AAs are a major part. This includes the contractual service providers and vendors and the Department of Health and Human Services (HHS), which has system-wide supervisory, funding and oversight responsibility.

### **The Evolution Of New Hampshire's System For Serving Individuals With Developmental Disabilities**

New Hampshire has received national and international recognition for its accomplishments in transforming its Developmental Disabilities (DD) service system. In closing Laconia State School (LSS) in 1991, and through the unprecedented collaborative efforts of legislators, state oversight agencies, service providers, advocates and families, New Hampshire became the first state to establish a comprehensive community-based system of services to individuals with developmental disabilities without a state-sponsored institution. The foundation for this innovative change was set in 1975 by the Legislature, which enacted RSA 171-A, the state's Services for the Developmentally Disabled law, providing for a *comprehensive community-based system* to provide individuals with developmental disabilities access to services "*within the limits of modern knowledge*", "*in the least restrictive environment.*"<sup>2</sup> The mandate and vision of RSA 171-A was fulfilled by various actions, as chronicled in more detail in the Commission's Report. These actions include in the late 1970s and early 1980s the insertion of Area Agencies into the delivery system, the decision in Garrity v. Gallen, a suit filed by residents of LSS through parents and the state parent association, and the development of the "Action for Independence" plan by HHS and its Division of Mental Health and Developmental Services. "Action" became the guidepost for the Legislature, HHS, AAs and other key stakeholders, in the development of the "comprehensive community based system" which ultimately allowed the state to close LSS in 1991.

New Hampshire's DD system has proven to be an innovative and adaptive network anchored by non-profit corporations which have been given designation by the State as local Area Agencies. This statewide network has adopted or developed its own best practices in community based housing, employment, day services, and community inclusion. Based on experience and emerging best practices, the DD system replaced or modified operations and models to: (a) improve efficiency and cost effectiveness, (b) improve and promote quality and outcomes, and (c) reflect changing philosophies resulting from the family support and self-advocacy movements and desire for choices. Many of the innovations met all three objectives. Examples include:

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<sup>1</sup> List of members in Appendix B.

<sup>2</sup> RSA 171-A: 6(III), 13.

1. Making maximum use of federal funding over the past 25 years by obtaining a number of Medicaid waivers from the federal government which also allowed the system to provide services more flexibly and less expensively, and at the same time draw down a 50% federal match for virtually all developmental services provided.
2. For residential services, replacing more expensive staffed or ICF-MR<sup>3</sup> group homes with (a) in-home supports and (b) enhanced family care (a type of adult foster care) for individuals moving out of the family home. As of 2005, 83% of residential services were provided through these models and only 17% through staffed models.<sup>4</sup> This is in contrast with the national average where 73% live in generally more expensive staffed models.
3. Reducing the allowable General Management Cap for AAs from 15% to 12%, with AAs reducing administrative costs still further down to a statewide average of only 8.64%.<sup>5</sup>
4. The AAs formation of an association in 1997 known as Community Support Network Incorporated (CSNI) and on its own studying or finding additional ways to save costs and improve efficiency through group purchasing of employee benefits; computer hardware and software; etc. In addition, CSNI provides centralized services such as eligibility determinations for member agencies.

### **The Commission's Findings Regarding The Current DD System**

While the system has continued to adopt or refine innovative and cost saving models and measures, it has faced significant and continuing budgetary constraints particularly since the mid 1990s. Increases in funding have not kept pace with increases in enrollment and inflation particularly in housing, health insurance, utilities, and transportation.

- From 1994 to 2004, the amount of spending per individual with DD under the waiver has declined from **\$58,000 to \$41,000** when adjusted for inflation, and will likely continue to decline through the biennium.
- From 1996 to 2004, NH dropped from **10th** in the country in “fiscal effort”<sup>6</sup> to **35th** in funding services to individuals with developmental services.

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<sup>3</sup> Intermediate Care Facility for Mental Retardation. This is part of the Federal Medicaid program and it funds on a matching basis with the states community group homes (generally 4 persons or more) as well as institutions. Cedarcrest, a 16 bed children’s facility, highlighted in the figure above is the only remaining ICF-MR in NH.

<sup>4</sup> The average annual per client cost of DD waiver services in NH is \$41,000, and \$70,000 when residential services are added. This is in contrast, for example, to a \$200,000 cost for individuals residing in community or institutional ICF-MRs in the other New England states.

<sup>5</sup> Bureau of Developmental Services (BDS) Director Handout, p. 52

<sup>6</sup> Braddock 2005, p. 57. *Fiscal effort is the “ratio utilized to rank states according to the proportion of their total statewide personal income devoted the financing of [dd]services.” It “is spending for MR/DD services per \$1,000 of aggregate statewide person income.” Braddock 2005 p. 53, 54.*

The funding constraints have increasingly threatened or already impacted not only the level and quality of services available, but the efficiency of current operations and development of further cost saving or efficiency measures. As the Commission's Report details, impacts include:

- Lack of capacity to provide adequate wages to direct support and other staff, including case managers. 2002-2003 surveys indicated that the **average** wage for DD system direct care staff in New Hampshire was **\$8.67** per hour. This amount was **below the poverty level** for a family of four and the **starting** wage of **\$10.22** for direct care staff at New Hampshire Hospital. Turnover rates are at least 50% annually in the system, with an alarming 36.2% vacancy rate.
- Decreased ability to attract qualified case managers and maintain and attract mid-level management and professional staff so critical to the infrastructure and support of direct support staff and individuals with disabilities alike.
- Decreased progress, at best, in promoting more meaningful and/or higher paid job opportunities for individuals with developmental disabilities with more hours and benefits as well as more meaningful and substantial day, avocational activities and pursuits.
- Inability to end the waitlist for services or even keep the number of individuals and the time waiting below the goals set in *Renewing the Vision*, the plan developed in 2001 to end the wait list in 5 years.
- Ever decreasing capacity to offer out-of-home placement when it is desired or needed for young or older adults unless the home situation has significantly deteriorated.
- Inability to expand choices and services for some children with developmental disabilities when more intensive in-home services or out of home placement is needed due to general budgetary issues, the caps on programs, and interagency issues.
- Reduced (or inability to increase) expertise to address individuals with more significant behaviors, forensic and complex needs in the community often resulting in crisis responses or resort to more expensive, overly restrictive or inappropriate service models such as New Hampshire Hospital.

Lack of resources (including start-up or infrastructure funds) also has been a significant factor in the ability of the system at all levels to initiate, follow through or sustain improved efficiency and cost effective measures in management information systems, information technology, reporting, and quality assurance.

While the resource limitations have been the overriding threat to both efficiency and quality, of equal concern especially in recent years is the breakdown in collaboration on multiple levels. This has not only affected relationships but creativity, efficiency and thus basic operations. While HHS and AAs have the authority and responsibility to ensure quality services and

protection of rights, the hallmark of the DD system has been its collaborative efforts by multiple stakeholders in the private and public sectors.

The need for collaboration in developing measures to save money and improve services was characterized as essential by Thomas McLaughlin, an expert in non-profit management and mergers, who presented to the Commission. It is a theme that underlies all the steps for not only a successful merger but other types of alliances designed to improve efficiency and quality. Valerie Bradley stressed input and involvement as well in regard to developing and refining quality assurance systems. Indeed the experience of the system shows that collaboration, input and partnership have been among the key reasons why the system has been so successful generally both in terms of savings and cost effectiveness as well as quality.

The Commission views collaboration as a principle, a process and an action, and because of its paramount importance, it is an element of or underlies most of the recommendations in the report. We also strongly urge that the spirit of collaboration and partnership be restored in the system, and as a number of the specific recommendations suggest, taken to new heights. This includes:

- a. Collaboration and meaningful consideration of input both vertically up and down the HHS/Area Agency system and across the system, bureaus and AAs
- b. Collaboration across government agencies, e.g. HHS and DOE and their “subauthorities” on the local level, e.g. AAs, school districts, mental health centers, etc.
- c. Collaboration between state and local government.
- d. Collaboration between AAs and providers.
- e. Stronger partnerships and engagement with (on the state and/or community level) business, community organizations, and less formal community networks, e.g. volunteers, neighborhoods, etc.
- f. And in all these collaborations, real involvement and input of individuals and families and where needed advocates.

Our recommendations also recognize the need for specific actions or refinements in areas of quality assurance, accountability and transparency, as well as in areas such as employment and residential options, which go to the core of the systems mission. We feel all our recommendations are important and interdependent, but so that the system is not overstressed as it regains its infrastructure, a planned phase-in of the recommendations is suggested to be coordinated by HHS and the Governor’s office. However, the recommendations below (and which are more fully described in the report) are of the highest priority, and for the reasons just described **we believe the first three are particularly critical to fully accomplishing most of the other recommendations.** Without adequate and experienced staff and infrastructure at all levels, appropriate technology, and collaboration, it is not possible to sustain current levels, let alone advance.

- 1. Improved collaboration and community partnership at all levels as described above.**
- 2. Prompt legislative action in the 2006 session on the direct support staff wage issue by bringing the starting minimum wage at parity with levels for direct care staff at NHH and**



**support for the HHS Commissioner's efforts to increase the enhanced family care stipends which have been stagnant for years.**

**3. Development and implementation of a human resources enhancement plan to provide for adequate numbers of qualified administrative, professional/programmatic, supervisory, direct support personnel in the system taking into account: (a) rural and transportation issues and challenges; (b) the needs of more complex populations; (c) types and levels of skills necessary to enhance and afford more employment opportunities for individuals with disabilities; and (d) that some specialty areas only need to be available on a regionalized or centralized basis.**

**4. Other high priority recommendations:**

- Assessment by designated work group(s) building upon current systems (1) of the need to further standardize and automate programmatic, business, reporting and quality assurance functions, (2) of the need to refine the type and accuracy of performance data and methods of dissemination and use of performance and outcome data, and (3) whether any regulatory requirements in the system are unnecessary and burdensome and may be removed without compromising services.
- With regard to the pending mergers of Regions 1, 2, 11, and 12--
  - HHS should (a) provide funding to engage an outside consultant to assist with the process; (b) allow flexibility in timelines; and (c) provide adequate funding for the transition costs.
  - External monitoring and evaluation of the merger process should be established to assure that the availability and quality of services are not compromised.
- Provision of expanded and/or diverse options in in-home and residential services for children and adults and reducing waitlist time for services to no more than approximately 90 days not only through increased resources but by leveraging existing resources through improved interagency coordination.
- To leverage lower prices, further collaboration is recommended between AA and Provider organizations to (1) determine ways to access state purchasing, (2) develop joint purchasing arrangements, and (3) standardize Request for Proposals.
- Legislation requiring employers to check a central registry of persons found to have abused or neglected individuals before hiring a person who will have direct client contact.

## **I. Governor's Executive Order and the Charge**

This Commission was established by Governor John Lynch by Executive Order 2005-3 issued on July 6, 2005 “to Study Area Agencies and their Role in Providing Services to New Hampshire.” A copy is attached as Appendix A.

The Executive Order asks the Commission to (1) identify essential operations of the Area Agencies (AA), (2) identify ways in which AAs may operate more efficiently and cost-effectively without compromising service, and (3) make findings and recommendations for proposed legislation and rules changes. The Order also recognizes that “any restructuring of the developmental disabilities service system<sup>7</sup> must be addressed in a comprehensive and methodical manner” and through a “thorough examination.”<sup>8</sup>

The Executive Order was modeled after a 2005 legislative bill (SB 216) which called for a nearly identical Commission study. While the bill ultimately died in conference committee, the need and desire for this Commission received majority support from both the House and Senate.<sup>9</sup> The work of the Commission is thus responsive to the Governor's order as well as the language in the bill.

## **II. Commission Membership and Approach**

As provided for in the Executive Order, the 13-person commission represents a wide cross section of citizens, including the Commissioner of the Department of Health and Human Services, or his designee, two representatives from the area agencies, two members of the public, two members from the business community, two representatives selected by the State Family Support Council, a representative from the New Hampshire Developmental Disabilities Council, and a representative from the Disabilities Rights Center, who was chairperson.<sup>10</sup>

The Executive Order also called for two legislative members to be appointed. Although none were appointed, several legislators attended some of the sessions on their own. We are hopeful that after reading this report, the House and Senate Leadership, as well as the full chambers, will take up the actions called for in this report where legislative action is called for.

The Commission also solicited input from the public through public hearings and written comments, and by specific invitation. 42 comments in all were received from individuals with disabilities, family members, providers and area agency personnel. We also requested and

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<sup>7</sup> The developmental disabilities system hereinafter is sometimes referred to as the DD or DD/AA system.

<sup>8</sup> Because the AAs are a component of a larger state supervised service delivery system, the system as a whole was also examined in regard to efficiency, effectiveness, etc. Additionally, where the Order called for an examination of the 12 AAs, and 4 are being consolidated into 2, the consolidation was examined from the viewpoints of efficiency, cost effectiveness, and service quality.

<sup>9</sup> The bill died because a member of the conference committee felt that language in the bill might restrict HHS from going forward with rule changes consolidating 4 of the 12 AA regions, not because of the need and desirability for the Commission generally.

<sup>10</sup> One of the public members slot was filled by a DD service provider. The Commission also voted a self-advocate to be an ex officio member. A complete list of all Commission members is contained in Appendix B.

received presentations from Mathew Ertas, the current Director of the Bureau of Developmental Services<sup>11</sup> (BDS), as well as the benefit of input from three national experts, Valerie Bradley, Jan Nisbet, and Thomas McLaughlin.<sup>12</sup>

Commission members and individual subcommittees reviewed numerous documents. See Appendix C for a list of primary documents. In addition to public hearings, the Commission held 10 meetings between August 5, 2005 through November 18, 2005, with a number of subcommittee meetings in between.

Because we had a short time to conduct the study, issues were prioritized. We believe the recommendations that emerged are all important. It is our sincere hope that those with the authority and responsibility to implement the recommendations will consider and craft the actions necessary to carry out the recommendations. Members of the Commission and the Commission as a whole stand ready to collaborate in that effort.

### **III. Background**

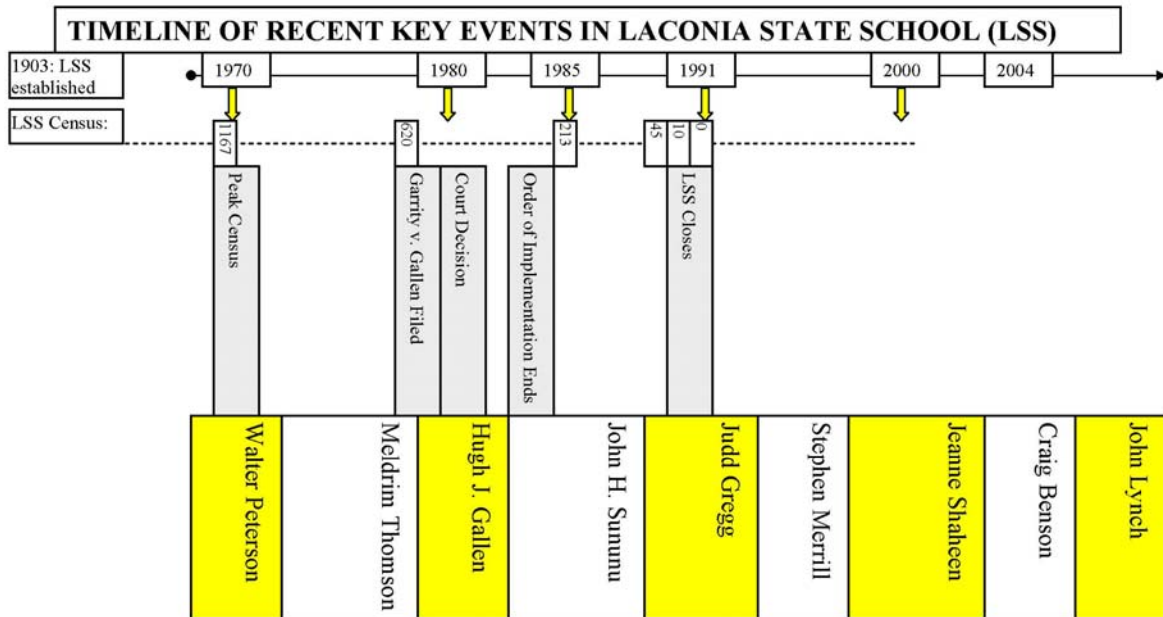
The evolution of the developmental disabilities (DD) system in this state, particularly in the latter part of the twentieth century, has been well chronicled, in large measure because New Hampshire became the first state in the Nation to close its state-operated DD institution and operate an essentially totally community-based system. The timeline below depicts this evolution. However for most of the 1900s, conditions were difficult at best and intolerable at worst for many of New Hampshire's citizens with developmental disabilities. For many years, individuals and families received little or no support in the community, and had to resign themselves to cope on their own or pursue the only alternative—institutionalization at Laconia State School. Opened in 1903, Laconia reached a peak census of 1167 in 1970.

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<sup>11</sup> At the Commission's request, Bureau Director Ertas presented a system overview at the August 16, 2005 Commission meeting, and provided a 78 page handout. His testimony is hereinafter sometimes referred to as "BDS Director presentation or handout."

<sup>12</sup> Ms. Bradley is the current president of the American Association of Mental Retardation (AAMR), former Chairperson of the President's Committee on Mental Retardation, and long term President of Human Services Research Institute (HSRI), a nationally known consulting firm in developmental disabilities and human services, and is currently the principal technical assistance contractor for the Center for Medicare and Medicaid Services (CMS) to the states for DD "waivered services." Bradley and HSRI have had consultant roles in developmental disabilities in NH dating back to the deinstitutionalization of Laconia State School in the 1980s. Dr. Nisbet, has been the Executive Director of the Institute on Disability at UNH since it was founded in 1987, and is former president of The Association of Persons with Severe Handicap Persons, TASH, an internationally based organization. Mr. McLaughlin, a native of Claremont, NH is the Senior Manager from Grant Thornton LLP, an internationally recognized expert and author of several books on nonprofits, including Nonprofit Mergers and Alliances.

**Figure 1**



**Passage of State DD Law, Garity v. Gallen, and Closure of Laconia State School**

The New Hampshire Legislature in 1975 began to set the stage for a radical change by enacting the state’s Services For The Developmentally Disabled law, RSA 171-A, providing for a comprehensive community-based system to provide individuals with developmental disabilities access to services “within the limits of modern knowledge”, “in the least restrictive environment.”<sup>13</sup> With insufficient funds to fund the new law, a law suit, best known as Garity v. Gallen, was filed against the state in 1978, resulting in a court decision in 1981.

In 1980, the State developed a plan known as “Action for Independence,” to implement the vision and mandate of the 1975 state law, RSA 171-A. The Area Agencies, inserted into the RSA 171-A in 1979, became the vehicle for this change. In 1991, Laconia State School closed. New Hampshire received national and international praise not only because it became the first state to operate essentially institution-free, but because of the ground-breaking community-based models that were developed to replace its segregated institution.

**Present Day**

New Hampshire has been cited as a national model both for its efficiency and the quality of its community-based services as well as its efforts to leverage community resources and promote true community inclusion. In 2003, the Centers for Medicare and Medicaid Services (CMS)<sup>14</sup> cited New Hampshire as one of nine states with exemplary practices in long-term care for

<sup>13</sup> RSA 171-A:6(III), 13.

<sup>14</sup> “Promising Practices in Long Term Care Systems Reform: New Hampshire’s Community-Based System For Persons with Developmental Disabilities”. Prepared for DHHS, CMS by Medstat Research and Policy Division, December 5, 2003

persons with developmental disabilities. In 2004, New Hampshire was identified as a state with innovations in employment supports by the Institute for Community Inclusion at UMASS Boston.<sup>15</sup> In addition, a 2003 Braddock Report ranks NH third in the nation relative to the percentage of individuals who live in small (1-6 person) residential settings.<sup>16</sup>

While the DD/AA system has continued to support innovative models, it has also endured significant and continuing budgetary constraints, resulting in an increased wait list for services and a diminished ability to offer the same level of services. Against this backdrop, the Legislature required HHS in 2001, to develop a plan to address the increasing wait list for services, determine supports necessary to enable families to keep their family members with developmental disabilities at home, and specify the circumstances under which out-of-home placement is necessary.<sup>17</sup> HHS launched a statewide planning effort, obtaining input from over 350 individuals, culminating in the November 2001 plan, “Renewing the Vision” (hereinafter referred to as “Renewing”).<sup>18</sup> As noted in Renewing:

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.<sup>19</sup>

As found in this report, there has not been significant progress since Renewing, and in some respects the system is even more challenged due to the continuing pressures from inflationary costs, increased numbers of eligible persons, and other factors.

### **Recent Legislative Response**

The Legislature both before and since Renewing has not ignored these issues. The very act of calling for a study in 2001 demonstrated a clear concern. In 1998, the Legislature established a Wait list Oversight Committee,<sup>20</sup> which meets quarterly. The issue of services to individuals with developmental disabilities is also reviewed by the Joint Legislative Oversight Committee on Health and Human Services. The Legislature has provided additional wait list funds as well. However, the findings and recommendations in Renewing have not been fully addressed, leaving the DD/AA system in a position to address the needs of individuals with developmental disabilities and their families under difficult economic constraints.

### **Area Agency System’s Efforts**

To the credit of the Area Agency system, the system has been innovative and creative in saving costs and implementing service quality measures. However, the wait list continues to exist for

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<sup>15</sup> “Innovations in Employment Supports: New Hampshire’s State Division of Developmental Services.” Research to Practice bulletin, Institute for Community Inclusion (UMass Boston), May 2004.

<sup>16</sup> “The 2003 Report: Regional and National Perspectives on Developmental Disabilities Services in New Hampshire”. Presented to the New Hampshire Legislature by David Braddock, PhD, and Richard Hemp. March 25, 2003 (p.17)

<sup>17</sup> Chapter 270, laws of 2001.

<sup>18</sup> A copy of Renewing is attached as Appendix D.

<sup>19</sup> Id. at Section I.

<sup>20</sup> RSA 171-A:1-c.

many persons, and as discussed further in this report, fluctuates above and below the number of persons on the wait list when Renewing was developed. There are also continual stresses even on services for current clients, placing the system on the brink of further deterioration. Resource issues not only affect access and quality, but have a major impact on efficiency. The growing workforce problems, caused by poverty-level wages, and resultant rising turnover, vacancies, costs of retraining, and lack of continuity for persons served, are by far the largest source of the system's inefficiencies as well as the biggest threats to the system's capacity and quality.

Of equal concern especially in recent years is the breakdown in collaboration and partnership within and outside the system. This has not only affected relationships but creativity, efficiency and the ability to fulfill the basic mission of the system. While HHS and AAs have the authority and responsibility to ensure quality services and protection of rights, the hallmark of the DD system has been its collaborative efforts by multiple stakeholders in the private and public sectors.

Fortunately, the commitment, the penchant for efficiency as well as the desire for continued innovation, collaboration and community partnership remains strong. The recommendations of this report are designed to reinforce and capitalize on those attributes.

#### **IV. System and Area Agency Purposes, Functions, Operations and Responsibilities**

Paragraph 2 of the Executive Order requires an identification of the "essential operations and delivery systems of the 12 AAs." As the AAs are part of a larger system, the operations/functions of those parts of the delivery systems, as well as their purposes, are also identified.

##### **A. Underlying Purposes and Functions**

- **RSA 171-A:1 Purpose and Policy.** The purpose of this [law] is to enable the department of health and human services to establish, maintain, implement and coordinate a comprehensive service delivery system for developmentally disabled persons.

*Service delivery system* "means a comprehensive array of ...including but not limited to, service coordination, community living arrangements, employment and day services and supports to families of individuals with developmental disabilities." RSA 171-A:2 (XVI)

- **171-A:13 Service Guarantees.** – Every developmentally disabled client has a right to adequate and humane habilitation and treatment including such psychological, medical, vocational, social, educational or rehabilitative services as his condition requires bringing about an improvement in condition **within the limits of modern knowledge.** (Emphasis added.)
- Services shall be provided in the "**least restrictive environment,**" that is "the program or service which least inhibits a client's freedom of movement, informed decisions and participation in the community, while achieving the purposes of habilitation and treatment." RSA 171-A:6(III); 171-A:2(XII). See also He-M 503.08(d).

- HHS is responsible for monitoring the services provided and functions performed by the AAs to assure compliance with HHS rules, contract provisions, and each AA plan for its region.

**B. Area Agency Specific Program Operations, Responsibilities and Functions** (Primarily taken from the BDS Director’s presentation and statutes and rules.)

The Area Agency:

- Is the primary recipient of HHS funds in establishing, operating and administering DD programs and services including diagnosis and evaluation, service coordination, community living arrangements, employment and day services, and programs designed to enhance personal and social competence
- Is responsible and accountable for all services to eligible individuals whether administered directly or under contract with individuals or organizations
- Is required to provide oversight over the services delivered within the regions.

Specifically, the Area Agency is responsible for:

- Coordinating entry into the service delivery system (including intake, evaluation, and eligibility)
- Providing service coordination
- Developing and monitoring service agreements
- Providing services as per the service agreement
- Periodically reviewing quality of services
- Ensuring that individuals are free from abuse and neglect and exploitation
- Monitoring and safeguarding other rights<sup>21</sup>
- Meeting individual needs in personal care, employment, social and leisure skills
- Promoting the individual’s personal development and quality of life
- Increasing the individual’s experience of community in a variety of integrated activities and settings
- Enhancing the individual’s ability to perform personally meaningful and/or functional activities
- Providing services in a way that the individual is seen as a valued, contributing member of his or her community

**C. Administrative and Business Operations**

The Area Agency business operations are typical of most organizations. They include:

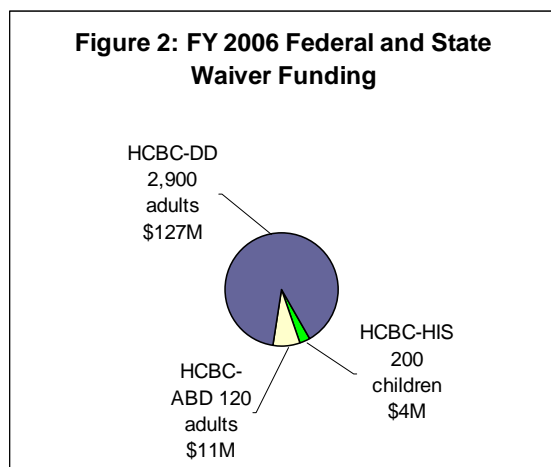
- Human resources and staff development
- Accounting, billing, purchasing, insurance procurement

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<sup>21</sup> Appendix E contains excerpts of rights of individuals who are clients of the AA system.

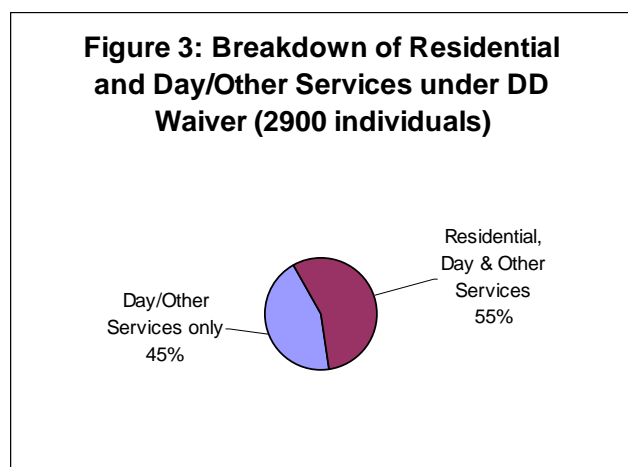
- Contracting, contract monitoring, quality assurance, performance and compliance, and reporting to the state
- Investigations, complaint resolution

## V. Budget Breakdown



The fiscal year (FY) 2006 budget for BDS and AA system is \$174M.<sup>22</sup> \$150M (of the \$174M) comes from Medicaid which is comprised of a 50-50 match of federal and state dollars.<sup>23</sup> Three of the main programs/populations funded by this system are: (1) services to individuals with developmental disabilities, (2) services to persons with acquired brain injury, and (3) IDEIA Part C, 0-3 Early Intervention program.<sup>24</sup>

Three programs known as Federal Medicaid waiver programs fund most of the services to these three groups of persons. As shown in Figure 2, one program is the HCBC-DD waiver (the DD waiver);<sup>25</sup> a second is the HCBC-ABD waiver; and a third is the IHC waiver.<sup>26</sup>



The AA/DD system serves in total about 10,000 individuals with developmental disabilities.<sup>27</sup> The majority, approximately 6,700, receive respite care, in-home supports to families, etc. on a limited basis, mostly out of state funds. 2,900 individuals, almost all adults, receive more comprehensive services under the DD waiver. 200 children receive services under the IHC waiver.

<sup>22</sup> See Appendix F for a complete breakdown on the revenue and expense side of the \$174M budget. This was provided by the BDS Director as part of his presentation.

<sup>23</sup> BDS Director Handout, pp. 30-31.

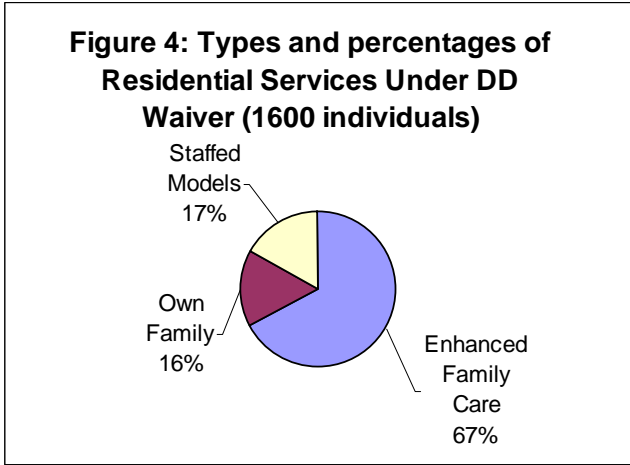
<sup>24</sup> IDEIA (Individuals with Disabilities Education Improvement Act) Part C, the Early Intervention Program for Infants and Toddlers with Disabilities, age 0-3, is authorized by Congress, provides federal funding to the states, and in New Hampshire is administered by the Area Agencies. The prime focus of this report is on individuals with developmental disabilities, which is by far the largest population served by the AA system, however many of the recommendations will benefit this overlapping 0-3 population as well as individuals with brain injury served by the system.

<sup>25</sup> Home and Community Based Care Waiver for individuals with developmental disabilities. (DD waiver)

<sup>26</sup> The ABD waiver is for individuals with acquired brain disorders and the IHC is an in home support waiver for children with developmental disabilities up to age 21. The IHC program is a different program and in addition to the above referenced 0-3 early childhood program.

<sup>27</sup> BDS Director Handout, p. 52





As indicated in Figure 3, of the 2,900 individuals under the DD waiver, a little over one half--1,600--receive funds for residential services.<sup>28</sup> The others receive some form of day or other support services.<sup>29</sup> Figure 4 gives the breakdown of residential models. Of the 1600 receiving residential services, 67% reside in enhanced family care, 16% reside with their own families; and 17% reside in staff supported living arrangements mostly of three or fewer individuals.

**VI. Findings With Regard to Efficiency, Cost Effectiveness and Service Compromise**

**A. Area Agency Efficiencies and Cost-effectiveness**

The AA system has operated efficiently, economically and highly cost effectively. While the Legislature has increased the BDS/AA budget in previous years,<sup>30</sup> those increases, particularly since 1995, have not kept pace with increased costs of housing, health insurance, food, utilities, and transportation. The increases have also not fully reflected and provided for the increased number of eligible individuals with developmental disabilities. To its credit, the AA system has endured through this difficult budgetary time and maintained quality services and its reputation as an innovator. This has been accomplished through some remarkable adaptation, use of cost effective initiatives, and cost cutting measures.

**One** cost saving measure has been HHS’ ability over the past years to maximize the use of federal funds by taking advantage of the Medicaid waiver programs and thus obtain a 50% match for funding for developmental disabilities services. 97 % of the state DD budget, is made up of 50% of federal funding. Only 3% is pure state or local dollars, down from a peak of 19% in 1984. Braddock 2005, p. 31, 197

**A second** cost-saving strategy has been an increased focus on in-home supports for both children and adults to prevent more expensive out-of-home placements.

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<sup>28</sup> Id.  
<sup>29</sup> The service categories under the waiver in addition to residential/personal are: service coordination/case management, day habilitation, supported employment, community support/independent, respite/medical and behavioral respite, environmental modification, crisis response, assistive technology, specialty services, consolidated developmental services. Id. at 41.  
<sup>30</sup> From FY1995 to 2006 the budget increased from \$120 to \$174M. See Appendix G.

A third has been increased reliance on the enhanced family care<sup>31</sup> model (also known as adult foster care) for adults moving out of the family home, coupled with continued reduction of the use of more expensive staffed models or community ICF-MRs (Intermediate Care Facilities-Mental Retardation).<sup>32</sup> As can be seen from Figure 4 above, 83% of 1,600 individuals who receive residential services receive it in-home or in enhanced family care, and only 17% in a staffed model. This is in contrast with the national average where 73% live in the generally more expensive staffed models.<sup>33</sup>

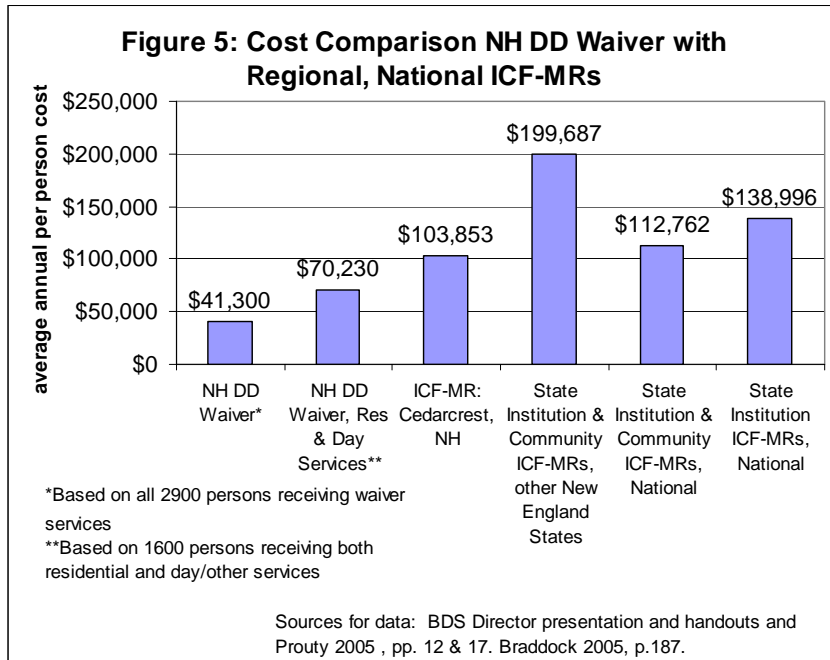
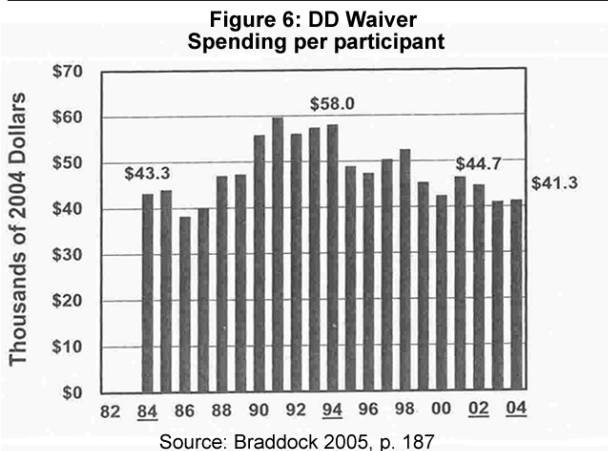


Figure 5 shows just how economical this approach is. The per person annual cost is \$70,230 for combined day and residential services in New Hampshire under the waiver, \$103,853 for the only ICF-MR in the state, Cedarcrest, and \$112,762 for ICF-MRs nationally, and \$199,687 on average for neighboring New England states that still have them.

By relying more on in-home supports and enhanced family care, the average cost for all 2,900 persons on the waiver has been reduced



significantly, when adjusted for inflation. As shown in Figure 6, the average annual cost per person of persons on the waiver has declined from nearly \$60,000 in 1991 (\$58,000 in 1994) to \$41,300 in FY 2004 when adjusted for inflation. Since 1999, the amount of new wait list funding from the legislature has averaged \$31,463 per person.<sup>34</sup> This is over \$10,000 less than the overall average of \$41,300, and this is in real dollar terms.

<sup>31</sup> In enhanced family care the individual with the developmental disability moves in with another family or provider who receives an allotment for caring for the individual. The situation need not be a typical family arrangement, that is the provider may be a single individual in an apartment who is the provider/caretaker. The provider is generally a contractor with the Area Agency or a vendor. All providers must be certified.

<sup>32</sup> The staffed model is generally where paid staff, employed by the vendor or Area Agency, staff the apartment or home where the individual resides. Because it is not the staff's home, there are often staff shifts, e.g. every 8 hours. Frequently, in staff models more than one person with developmental disabilities will be residing in the home. For ICF-MR Intermediate Care Facility for Mental Retardation, there are generally at least 4 individuals with developmental disabilities residing in the residence. It can be larger including up to the size of more institutional settings.

<sup>33</sup> Appendix K.1, p.1, "Residential Services."

<sup>34</sup> BDS Director Handout, p. 69.

**A fourth** resulted from the AAs' formation of Community Support Network Incorporated (CSNI) in 1997. CSNI has studied and found ways to save costs and improve efficiency through group purchasing of employee benefits; computer hardware and software; etc. In addition, CSNI provides centralized services such as eligibility determinations for member agencies.

**Fifth**, although harder to quantify, the efforts to form partnerships and leverage community resources, and natural supports have had a cost saving effect. The flexible and person centered nature of this system, has enabled it to capitalize on and leverage the community, private sector, employment opportunities, volunteers and natural supports. Like many of the other measures or trends, this not only saves the state money in the long run, but fulfills the basic mission of the system to help include individuals in the community and to use natural supports, instead of paid supports where possible. To be sure, there is much more to be done in this area, however the strategies necessary to accomplish these goals will require planning, skilled staff and collaboration, an additional but clearly worthwhile investment.

**Sixth**, there also has been a reduction over time in allowable General Management Cap for AAs from 15% to 13% and now to 12%, although AAs have reduced actual administrative costs below the CAP. Statewide administrative cost are averaging only 8.64% for FY 2006.<sup>35</sup> This compares, for example, with Connecticut where 18% is considered to be low.<sup>36</sup> The Area Agencies have not been the only part of the system that has had to reduce administrative staff. BDS itself, the monitoring and oversight agency, despite increased demands from among other things, increased numbers of eligible individuals with developmental disabilities or with brain injury, has experienced a staff reduction from at least 31 (employees and contracted staff) in 2000 to about 20 today.<sup>37</sup>

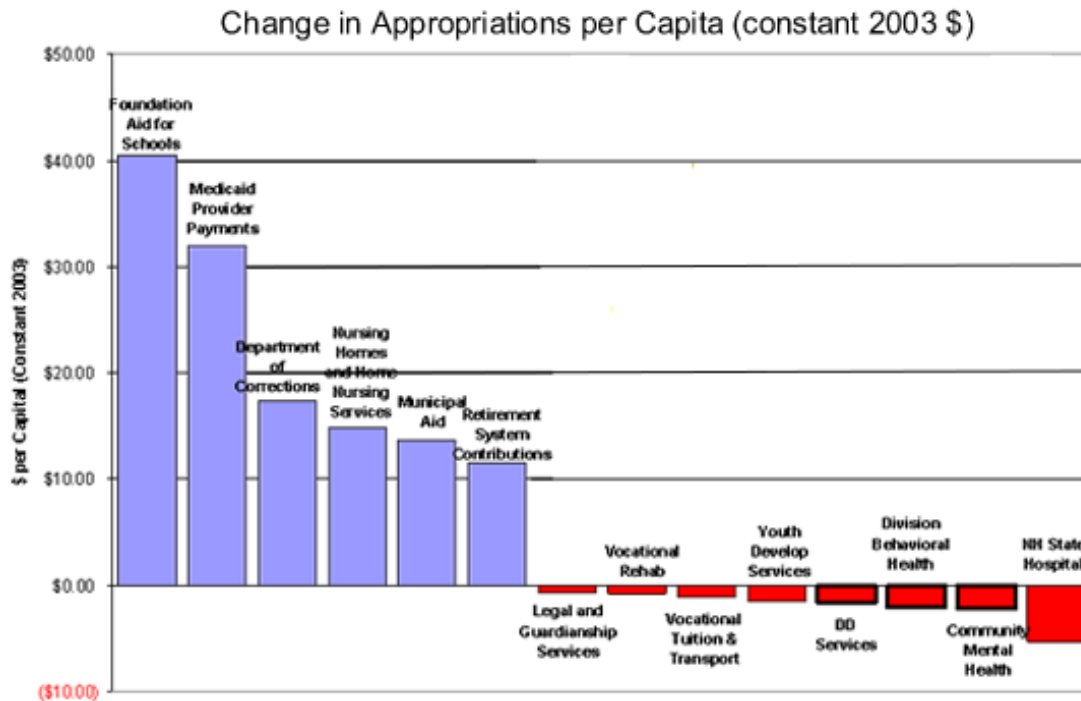
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<sup>35</sup> BDS Director Handout, p. 52

<sup>36</sup> OLR Research Report. 3/23/05. [www.cga.ct.gov/2005/rpt/2005-5-0310htm](http://www.cga.ct.gov/2005/rpt/2005-5-0310htm)

<sup>37</sup> See also footnote 40.

Figure 7: Comparison of Developmental Service Funding with other Parts of State Budget from 1993 to 2003



Source: Adapted from Monadnock Developmental Services Power Point Presentation, "Seeking Solutions to the Funding Gap for Developmental, Mental Health, and Other HHS Services in New Hampshire" (2004), which relied on data compiled for a study by the NH Center for Public Policy Studies, Hall, D., "Budget History and Drivers: Budget of the State on NH" (1/03), <http://www.unh.edu/nhcpps/jan142003.pdf>.

While the BDS Director presented a graph during his testimony showing that the Legislature has increased the developmental services budget every year since 1989,<sup>38</sup> as the Director pointed out, it has not kept pace with inflation, increased eligible persons, or other factors, a point also made in *Renewing* in 1991.<sup>39</sup>

Appropriations for DD Services from 1993 to 2003 (adjusted for inflation) are depicted in Figure 7, based on data compiled in a report by the NH Center for Public Policy Studies. Based on 2003 dollars, six areas of the budget accounted for 96% of the increase on a per capita basis over the ten year period. Based on 2003 dollars funding for DD services was actually less than it was for 1993. The “decline” in DD was the second greatest, next to mental health services.

Another indicator of the widening gap between need and resources can be seen in the declining level of the state’s fiscal effort. In 1996, New Hampshire was ranked **10th** in the country in fiscal effort, by 2002, New Hampshire had dropped to **33rd**, and by 2004, it was **35th**. Table 1 shows how New Hampshire compared with its neighboring states on this indicator in 2002 and 2004.

<sup>38</sup> Attached as Appendix G

<sup>39</sup> See Appendix D, Section VI.

**Table 1 Fiscal Effort Rankings of New England States in 2002 and 2004**

State	2002 National Fiscal Effort Ranking	2004 National Fiscal Effort Ranking
<b>New Hampshire</b>	<b>33</b>	<b>35</b>
Connecticut	7	6
Maine	1	3
Massachusetts	19	18
Rhode Island	2	1
Vermont	14	17

*Source: Braddock 2005, p. 57. Fiscal effort is the “ratio utilized to rank states according to the proportion of their total statewide personal income devoted the financing of [dd]services.” It “is spending for MR/DD services per \$1,000 of aggregate statewide person income.” Braddock 2005 p. 53, 54.*

The AAs have had to be creative, both in finding ways to save money and in attempting to maintain quality services. While they have risen to the challenge, more than 10 years of budget austerity has strained the system literally beyond its capacity, with increasing signs of stress even for those currently being served. Most of the stresses and impacts we see today were identified in Renewing in 2001, and only appear to have worsened.

## **B. Stresses and Impact on the System**

In order to successfully operate any large human service enterprise, certain administrative, management, and programmatic components must be in place. It is clear that many of the essential elements of the system or infrastructure have been threatened or already weakened by the economic constraints. The above described economic constraints have been the largest threat to efficiencies, as well as quality and safety, as evidenced by the increasing challenges and problems in several key areas.

### **1. Staff Wages, Recruitment, Retention, Vacancy and Turnover Rates**

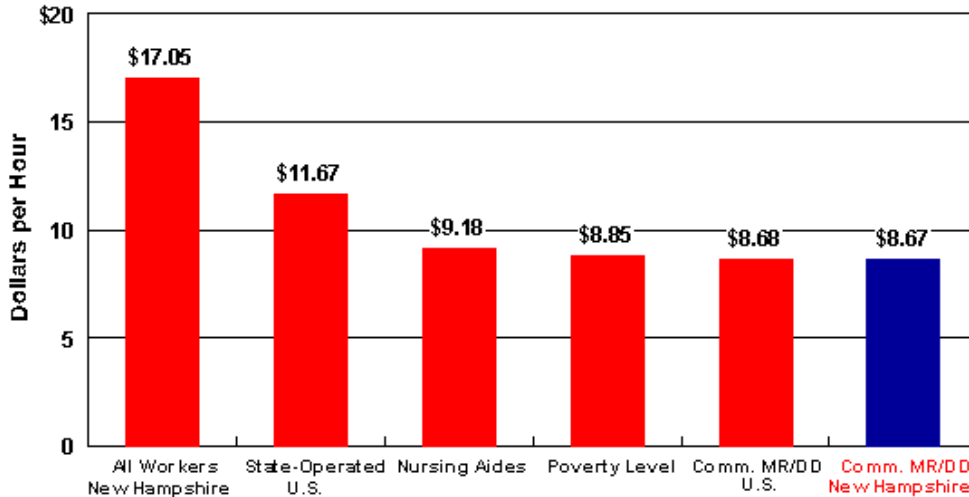
Limited budget increases have caused staff wages at all levels to stagnate (and to decline) when adjusted for inflation. Employee benefits have also been significantly reduced. This has led to increased rates of turnover, making it necessary to provide constant retraining which is highly inefficient. Also it is increasingly difficult (and sometimes impossible) to attract candidates with the skills and qualities necessary to facilitate successful employment of individuals with developmental disabilities and their inclusion into their communities as well as to meet other basic needs.

Figure 8 shows that the average hourly wage in New Hampshire for an AA/provider direct care staff was \$8.67 per hour in 2002/2003. This wage was below the NH poverty level for a family of four of \$8.85 as well as the average wage of \$11.67 for direct care staff in state operated facilities.<sup>40</sup> By way of further comparison, the starting wage for direct care staff at New

<sup>40</sup> According to Prouty 2005 p.52, in 2002, the average direct care staff wage in institutional settings nationally was \$12.33 per hour, with MA and CT, the only two NE states reporting averaging \$13.58 and \$22.42, respectively.

Hampshire Hospital is \$10.22 per hour, with a significantly better benefits package than that offered to community direct support or other staff. Starting wages for direct care staff, including job coaches, a position of some skill level, can be as low as \$7.00 per hour currently, below what is often paid babysitters today.

**Figure 8: NH Direct Support Community Staff Wages Relative To Poverty Level and Other Measures**



Sources Braddock ADD State Monitoring Visits State Summaries, NH 5/05 citing: :Bureau of Labor Statistics (2003, average wage all workers in New Hampshire in 2001); Lakin et al. (2003, average wage for U.S. state-operated and for U.S. and New Hampshire community MR/DD in 2002); BDO Seidman (2002, nursing aides' wage in the U.S. in 2002); and ASPE (2003, poverty level wage in the U.S. for a family of four in 2003).

Largely as a result of the low wages and poor benefits (especially in contrast to the job expectations and responsibilities), turnover and vacancy rates are disturbingly high in New Hampshire, and again higher than national rates. As reported by NH Quality Outcomes Partnership Report<sup>41</sup> FY 2003, the turnover rates in New Hampshire of direct support staff was 50% annually. The vacancy rate was at an alarming 36.2% rate.<sup>42</sup>

Given the low wages, limited benefits and the lack of support from dwindling numbers of skilled supervisors, it is not surprising that the turnover and vacancy rates are critically high. This puts enormous strain on a system that is so personnel-intensive. The BDS Director described staff and provider recruitment and retention and high staff and provider turnover as one of the major challenges of the system,<sup>43</sup> and as noted in *Renewing the Vision* (Section III(C):

In every forum individuals and families talked about the problems created by high staff turnover and the lack of capable direct support professionals. The

<sup>41</sup>The New Hampshire Quality Outcomes Partnership FY 2003 Report, is compiled and prepared by BDS and Community Support Network, the Area Agency Association. (Hereinafter referred to as NHQOP FY Report.)

<sup>42</sup> See Appendix H for comparative national and state data on turnover and vacancy rates.

<sup>43</sup> BDS Director Handout, p. 78.

quality of life for individuals is directly related to the quality of care provided by direct care professionals.<sup>44</sup>

With a vacancy rate of 36.2% in New Hampshire, on top of a high turnover rate, the problem demands urgent attention and solution.

Similarly, the stipends paid to enhanced family care providers, by far the largest source of residential services, has stagnated over the past 10 years, making it increasingly difficult to attract qualified providers.

Other critical components of the system's infrastructure which have suffered were reviewed. While time restricted a thorough examination, based on the experience of the Commission members from the AA/DD system and, testimony from several witnesses, and basic management principles, the following overlapping or interrelated concerns warrant further analysis and strategic action planning:

- The ability to attract and retain qualified staff to fill **case manager positions**, a job which requires a considerable amount of skill, judgment, and knowledge and when performed effectively can be of great benefit to the individual and the system qualitatively and economically.
- A shortage of **highly skilled professionals** available to address the varied and individualized (and sometimes complex and challenging) needs and aspirations of individuals with developmental disabilities both directly and through support, supervision, training and mentoring of direct support staff.<sup>45</sup>

In a state this size, not all areas require a cadre of experts. Comprehensive human resource planning enables professionals to be dispersed and avoids duplication.

- Growing lack of experienced mid **and more senior level supervisory, oversight, management, and professional staff at the BDS/HHS** as well as at the AA level.<sup>46</sup>

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<sup>44</sup> Section III(C). The consequences of staff turnover has also been reported in studies. As Braddock (p. 23) summarized, citing several studies: "If there is excessive staff turnover, persons with disabilities can experience a steady withdrawal of the support staff upon whom they depend for nurturing, consistency, understanding, and appropriate habilitation programs." "Employee turnover affects all organizations, but the problem is often magnified in human service organizations."

<sup>45</sup> As J. Nisbet put it:

"Professionals with skills in augmentative communication, behavior, assistive technology, and adult learning must be more readily available. People with disabilities can continue to learn and grow throughout the lifespan with appropriate supports."

<sup>46</sup> For example, there has been a staff reduction at BDS from approximately 31 to about 20 in the last five years, despite having a complex set of fiscal, oversight, monitoring, technical assistance, and support responsibilities and increased demands. Included in the staff eliminated were an IT person, a behavior specialist, a training coordinator, the forensic psychologist, fiscal person, and the medical director. Licensing/Certification surveying staff with HHS dedicated to the DD system was cut about 40% over the past two years. With regard to the professional or administrative capacity within Area Agencies, an AA director stated most incisively that he no longer has the mid level personnel necessary to support and manage the components necessary to provide significant staff supported housing or provide for a wider array of rewarding employment options.

- The need for enhanced utilization of professionals on quality review and innovation teams to periodically review the supports and services at the provider and AA level to better promote the most efficient and effective best practices and ensure health and safety needs are met.

## 2. Employment and Meaningful Avocational or Day Activities

The recognized progress the DD/AA system has made in providing employment opportunities has begun to stall, due in large measure to the wage, workforce, and infrastructure<sup>47</sup> problems just described. The problem of unemployment of people with disabilities is estimated nationwide to be over 62.5%<sup>48</sup>. Unemployment and underemployment of individuals with developmental disabilities is a huge and challenging problem. Despite the existence of good supported employment practices and technological advances, many dating back to the 1970s and the enactment of the ADA in 1990, few if any states have been fully successful in meeting this challenge.

- A total of approximately 1,149 individuals served by the AAs were employed in competitive jobs in New Hampshire between July-December 2004.<sup>49</sup> As noted above, there were 2,900 individuals on adult DD waiver alone.<sup>50</sup> While clearly not all can or wish to have paid work, data from the NHQOP FY 2003 indicated that “almost 50% of ...persons surveyed who expressed a desire to work [were] unemployed.”<sup>51</sup> p. 4.
- The average number of hours worked was 13 per week for what appears to be all forms of employment, supported, integrated and sheltered between July-December 2004, with a great deal of variability between regions ranging from 5 to 18 hours. Only 17 and 13 individuals respectively received medical and dental benefits. 1235 received no benefits whatsoever including no vacation or sick time.<sup>52</sup>
- Data on meaningful day or avocational activity both for adults generally and older adults is not compiled. As with employment, there are many wonderful examples of avocational pursuits, volunteer activities, and the like that would have been rare 20 to 30 years ago. However there is also an abundance of anecdotal information that too many

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<sup>47</sup> The need for strong infrastructure was illustrated by the testimony of an individual consumer, a former resident of Laconia State School. Shortly after she left Laconia State School, she was placed in a program which supported and offered employment opportunities. That program, which was based out of Henniker and operated in association with New England College, enabled her to work full time for two years. That program ended. She has never been able to acquire full time work again and at best is employed sporadically or seasonally part time despite the fact that she remains ready, willing and able to resume steadier and more full time work and needs the income.

<sup>48</sup> A Cornell University study indicated that the employment rate of persons with disabilities for 2004 was 37.5%, which is a .4% decline from the previous year. <http://www.news.cornell.edu/stories/Oct05/Disab.work.rpt.html>.

<sup>49</sup>“Employment Summary[s] By the Area Agency” obtained from BDS. The summary indicated that a grand total of 1351 were employed, but 142 were specified in “sheltered” or and 60 in “other” work, leaving 1,149.

<sup>50</sup> Employment data looking at how New Hampshire has done historically and in comparison with other states is contained in Appendix I.

<sup>51</sup> Braddock 2005 reported research showing that nationally two-thirds of unemployed persons with disabilities desired to work. p. 39.

<sup>52</sup> Same data sources as that referenced in footnote 44.



individuals being served remain isolated and not nearly as active and engaged as they could or should be.

In order to begin making significant progress, effective strategies and well-trained job developers and job coaches, among other things, are needed. External factors such as attitudes of employers, cyclical nature of the economy, transportation issues (etc), also must be addressed. The AA/DD systems and individuals with disabilities cannot do this by themselves. This has to be done in partnership with the business community and other parts of state and local government (e.g. DVR, DOE, post secondary vocational training institutions, Community Development Finance Authority).<sup>53</sup>

Two other factors affect this area as well. One, is how well students with developmental disabilities are prepared for employment and transitioned from schools to adult life so as to maximize chances of success and possibly require less service, training or support from the AA system. The lack of adequate preparation for work as well as poor or uneven interagency coordination has plagued the system(s) for years, as it has in most states, in spite of the enactment of laws and policies designed to address it. Several comments were received on this point from family members and professionals in the field.<sup>54</sup> A second is the perceived or actual effect receipt of public benefits have on employment, including limiting earnings and hours people work, also commented on at the public hearings. Accordingly recommendations in this report are aimed at the critically important AA/provider workforce and infrastructure<sup>55</sup> issues as well as these external factors.

Experience and research show that investment in employment and other meaningful activities is well worth the return in human and economic returns. Several longitudinal studies of persons moving from sheltered to supported employment show the benefits both to the consumer and the taxpayer. Braddock 2005, p. 39.

### 3. Residential Service Options Choices and Wait List for Services

#### **Adults**

**a.** The lack of resources has also meant that many people eligible and in need of services are placed on wait lists. BDS data showed that as of June 2005, 281 individuals were on Priority 1 wait list which means that each person is currently in need of a full array of waiver services, day and/or residential. The average wait for services is 361 days, with many waiting much longer. On average 150 persons are added each year. Renewing, which was developed in larger part to

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<sup>53</sup> This lack of employment opportunities (and the reasons) was expressed as a concern by many participants at the Renewing the Vision forums, in which they called for “the Area Agency and service providers to develop stronger partnerships in their communities” in regard to employment as well as “education and training programs, volunteer opportunities, and recreational activities.” Section III (F)

<sup>54</sup> See Appendix J and Appendix D, Section III(E)

<sup>55</sup> It was learned during the Commission proceedings that NH may be in danger of losing \$1.5M in federal funds per year for up to five years after 2006 under the Medicaid Infrastructure Grant. The grant is for improving employment outcomes for individuals with disabilities. To be eligible for these funds, the state must have a certain number of persons with physical disabilities receiving agency directed personal assistance services in the workplace. Currently they do not and need to implement measures to do so. It is anticipated that if NH becomes eligible and receives the total of \$7.5M, the funds will be used to address employment needs of all disabilities groups, including individuals with developmental disabilities.

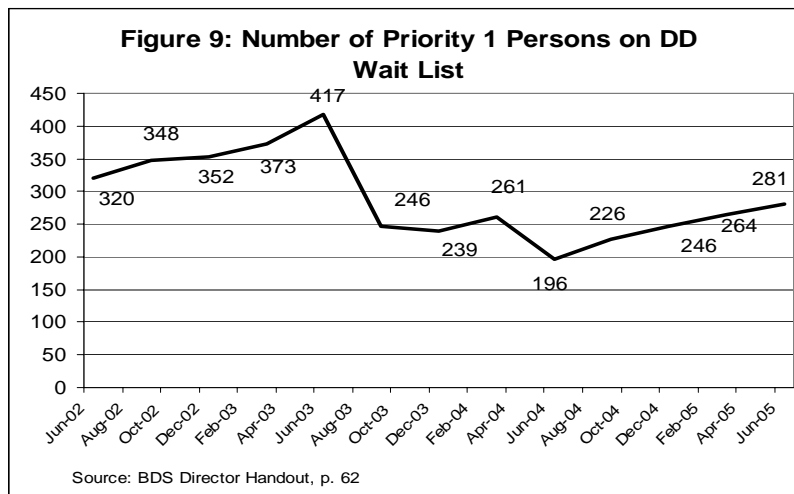
address the growing wait list problem, described the plight of the three groups of individuals and families waiting for services this way (Section I):

- Young adults, whose classmates have gone onto college or military, sitting at home, losing skills and self-confidence, with uncertain futures after years invested in education.<sup>56</sup>
- Middle aged and older adults living with elder parents often isolated from the outside world, where care-giving becomes increasingly difficult placing both caregiver and the individual “at risk” and creating increasing anxiety about the future
- “Adult family members with complex medical needs or extremely challenging behaviors,” in which the “total care” requirements are physically and emotionally exhausting for the family.

While in theory wait lists may save money in the short run, there is evidence to indicate that it is a real case of “penny wise and pound foolish.” As noted, young people lose academic and functional skills acquired in schools and may regress in other ways. As was also stated in *Renewing*:

Participants at the forums pointed out that the majority of adults with disabilities live with a family member, most with their parents. Unfortunately, with limited resources for services, many of these families received 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.

While additional funds have been allocated for the wait list since the development of *Renewing*, it was below the requested amounts, and coupled with increasing costs and persons served, the progress on the wait list continues to fluctuate. The goal of *Renewing* to end the wait list in five years will not be realized. At the time *Renewing* was being drafted in 2001, the number of



persons on the wait list was 200 persons with an average wait of 271 days.<sup>57</sup> As seen in Figure 9, the wait list has gone up and down since, almost always above the 200 mark. As of June 2005, it was 281, and the average number of wait time was 361 days,<sup>58</sup> 90 more days than at the time *Renewing* was being developed.

BDS, in a November 4, 2005 presentation to the Legislative

<sup>56</sup> One of several other consequences to this situation is the “parent—typically the mother—is forced to quit work...” ROV, Section I.

<sup>57</sup> *Renewing*, p.13.

<sup>58</sup> See Appendix K..

Wait list Oversight Committee, indicated that the wait list, as of November 2005, has been reduced to 170, due to increased funding, but the average wait had increased to 425 days. Renewing had in fact indicated that unless all components of the plan and identified needs were addressed the plan as a whole would not work.<sup>59</sup>

**b.** Even those receiving services, especially those coming off the wait list in recent years are not necessarily receiving out of home residential services or all the services they need or desire. As noted above, while 2,900 adults are eligible for institutional level of care and therefore are on the DD waiver, only 1600 receive residential services, and of that, about 1328, receive services out of the family home. As less funding is available, the number of adults coming off the wait list and living at home is increasing, and the state is actually requiring through contracts that AAs meet or exceed the state average of 17% in-home “residential services.”<sup>60</sup>

This is the opposite of the need expressed in Renewing (Section III (G):

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.<sup>61</sup>

**c.** Even for those individuals who are able to move out, the choices continue to narrow. Virtually the only model available is enhanced family care. While many regions use this model creatively so that the caretaker is more of a peer than perhaps a parent, for many adults it means moving in with another family. This may not be the choice for everyone. In Renewing it was found that: “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,” including in supervised apartments, family care, and individual homes.” Section III (G). (Emphasis added.)

This sentiment was also expressed in 2003 by individuals with developmental disabilities, themselves, as reported in the NHQOP FY 2003 Report: “In spite of this overall satisfaction rate, the results also indicate that one third of the individuals are not getting the opportunity to exercise choice in deciding where to live, with whom to live, in the selection of providers and staff...”<sup>62</sup>

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<sup>59</sup> As was stated in Renewing (Section VI): “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 [DD] 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. The plan will only work if responsible efforts are made to address these issues in addition to the waiting list.”

<sup>60</sup> See Appendix K.1, p. 1, “Residential Services.”

<sup>61</sup> Further evidence of the stagnating nature of the residential system can be seen by a comparison of the census at Laconia State School, the principal out of home placement, at its peak in 1970 vs. the out of home residential placements today—1,167 vs. 1,328. Given that the state’s overall population has almost doubled since 1970,<sup>61</sup> and likely so has the developmental disability population, the rate at which adults with developmental disabilities have been able to live outside their family has gone down substantially. While this may be appropriate and welcomed for children, it is contrary to normal societal expectations, and direction and philosophy of the self-advocacy, disabilities rights movement, philosophy, and choice.

<sup>62</sup> J. Nisbet addressed this as well, stating: NH must make available to people with disabilities a range of residential opportunities. Living with one’s parents or other families should not be the only options. Supported living must be

Budgetary constraints continue to limit choices. As with in-home care, HHS has required each area agency to meet or exceed a statewide percentage. The statewide percentage for enhanced family care is 67%.<sup>63</sup>

**d.** For adults who remain home, they may be receiving increasingly fewer services. In one region, an AA director testified that 15-16 individuals who have come off the wait list are now only getting day services and not needed residential services.

Resource constraints clearly account for the diminishing options and services. As noted above, the average annual cost per person of persons on the waiver has been reduced over time from nearly \$60,000 in 1991 to \$41,300 in FY 2004 when adjusted for inflation. See figure 6. That includes all individuals on the waiver. Moreover, as was also pointed out, the amount of new funding from the legislature since 1999 allows funding of persons coming off wait lists at the rate of \$31,463 per person, over \$10,000 less than the overall average of \$41,300 and about \$39,000 less than those receiving combined residential and day services, and this is in real dollar terms.. BDS data presented to the Legislative Wait list Oversight Committee on November 4, 2005, showed that for the first quarter of FY 2005, the average per person cost of persons coming off the wait list (not needing forensic services) was now down to \$26,000 per person.

### **Children**

Limitations on three children's programs operated by the AAs--

- One is family support, which consists principally of state funds. According to Braddock 2005, New Hampshire ranks 38<sup>th</sup> in the country in funding for family support.<sup>64</sup>
- A second is the In-Home Support Medicaid Waiver, begun in 2003, in response to the need for more in home services for families with children with developmental disabilities. Many of the families who became eligible for this program were effectively switched from services provided under the regular Medicaid state plan to this waiver. The total number was capped at 200 children, and there is a waiting list now for this waiver.
- Third, is the Early Childhood Program for children with disabilities 0-3 under Part C of the federal special education law, IDIEA. Approximately two years ago, HHS restricted eligibility to the program to those children who were experiencing a 33% delay in development. Previously it had been 25%. Little or no budgetary savings may have actually occurred, and to the extent children with delays have been denied eligibility

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put back on the table. People with disabilities should have the opportunity to live in their own home with people they care about and choose to live with.

<sup>63</sup> See Appendix K.1, p. 1, "Residential Services."

<sup>64</sup>Braddock 2005. p. 46

under the new criteria, the measure may prove cost ineffective in the long run given the research in support of early intervention of children with all levels of disability.<sup>65</sup>

Limitations on how existing resources are used and coordination issues between state and local agencies have contributed to three other somewhat overlapping problems concerning services to children.

- The lack of an adequate comprehensive interagency agreement between HHS and DOE and ancillary and local Memoranda of Understandings (MOUs) or agreements, which give clear direction on which system is responsible for services, funding and oversight, and when. Most children with developmental disabilities, as well as other significant disabilities, are eligible for services from AAs, school districts, community mental health centers, DCYF and providers within each system. While an interagency agreement exists between DOE and HHS as mandated by RSA 186-C:7:a,<sup>66</sup> it does not adequately spell out a process and criteria for determining responsibilities and a prompt and adequate process for resolving disputes between agencies. There have been good examples of local collaboration and shared funding and some interagency pilots in the past. However there is not clear top-down direction and guidance, there is much inefficiency and duplication (e.g. in the form of multiple meetings, evaluations); lack of adequate programmatic coordination; and delays or denials of services. The lack of an adequate interagency dispute mechanism may cause agencies or families to resort to more costly or adversarial dispute resolutions such as due process hearings or child protection or involuntary commitment proceedings.
- For children with serious behavior or medical needs, where the parents cannot care for their child at home, and where a residential education placement cannot be obtained, some parents are forced to use (or be subjected) to the DCYF child protection process. This results in their unjustifiably incurring a determination of parental neglect. The BDS/AA system does not generally provide for out of home options for children with developmental disabilities, even when it is needed.<sup>67</sup>
- For children with developmental disabilities between 18-21, who cannot live at home and who have aged out of the DCYF system and are not being picked up by the schools, they can “fall totally through the cracks,” potentially causing harm to themselves or the community. Testimony on SB 101 (2005 session), a bill designed to address this problem, revealed some heart wrenching problems. While the bill passed

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<sup>65</sup> It was also reported by two individuals during the public hearing that the HHS Commissioner was exploring moving the Early Childhood program from the Area Agencies to Public Health, and thus to the HHS District offices on the local level. The Commissioner did not present the idea to the Commission to study. It is recommended that if the idea continues to be explored that collaboration and input be sought and considered from all stakeholders, particularly families.

<sup>66</sup> A copy of the statute and the current interagency agreement is attached as Appendix L and M, respectively.

<sup>67</sup> The State DD law, RSA 171-A draws no distinction in determining eligibility or providing services between children and adults, except to indicate the AA should take into account services provided by school districts. RSA 171-A:6(II). Thus children under 21 not having their service needs met by a school should be eligible for services to the same extent as an adult. Of course with better interagency coordination and cost sharing, many of these problems and their consequences may be avoided.

the Senate, it was voted inexpedient to legislate by the Health and Human Services Committee, but with both a majority and minority report urging further recommendations or actions. The minority report which urged passage called for a comprehensive solution, referencing the interagency problems alluded to above.<sup>68</sup>

#### 4. Services for Persons with More Intense or Complex Needs

The consequences from funding constraints are heightened for individuals with more complex needs, i.e. children or adults with developmental disabilities:

- with very challenging behaviors
- who may pose a danger to others and the community and have so-called forensic issues
- with complex medical needs, including aging adults with significant medical needs
- with multiple other disabilities, e.g. communication, deafness, motor, (coupled especially with significant cognitive impairments) and particularly in more rural parts of the state where services are more difficult to obtain

In a highly constraining budget situation, several concerns emerge. One is that individuals in these groups will receive services, and high cost services, at the expense of others. This is because they have greater service needs and/or public safety issues are of concern, in the case of the “forensic group.” A second, is that their needs will not be met well or they will be placed in an inappropriate or overly, and generally more costly, restrictive environment. All of these phenomena have occurred.

- With regard to individuals with so-called **forensic needs**, the issue and costs associated with this group have been well and publicly chronicled. There have been only 11-12 individuals committed under RSA 171-B, the Involuntary Admission For Persons Found Not Competent To Stand Trial law passed in 1995, with only a one dollar appropriation. There are significantly more than 11-12 individuals who are reported to have forensic type issues being served by the AAs who have never been committed under RSA 171-B and/or may not be committable. There is concern amongst family members of persons on the wait list or receiving services that persons with forensic needs are taking away resources from their family members. There are overgeneralizations here to be sure. There has not been clear agreement on the nature, scope or solution to the issue. The need for more expertise in treating this population has been recognized. A recommendation is proposed below (Section VI(C)(5)(e)) which is cost effective and addresses the critical treatment and safety needs.
- As to “adult family members with complex medical needs or extremely challenging behavior,” who require total care and supervision” or “cannot be left alone for fear of harming themselves,” as found in Renewing, families are under great “stress and at risk of physical and emotional exhaustion,”<sup>69</sup> while the individuals are on the wait list. These persons are of high priority to be taken off the wait list. Generally services are in-home, which does relieve the stress. However, an overriding concern remains “when living at

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<sup>68</sup> See Appendix N for both the majority and minority reports on SB 101.

<sup>69</sup> Renewing, Introduction.

home is no longer an option [and] these individuals will require intensive community-base residential services.” Id. at Section I. As was stated in Renewing in addressing this population:

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

- Individuals with a **primary** diagnosis of developmental disabilities are increasingly finding themselves at the state psychiatric facility, where the cost of care is between 10-15 times the cost of DD community services. This despite the fact that positive, humane and effective approaches to address serious behavior problems have been in existence and enjoyed fairly widespread use for 20-25 years. However, from 1998 to 2004, there was a 450% increase in the number of individuals with a primary diagnosis of a developmental disability when discharged from NHH, from 7 individuals to 32.<sup>70</sup>

## C. Recommendations

### Recommendations--Infrastructure and Workforce

1. The Commission recommends prompt action (a) on the direct support staff wage issue by recommending **legislative action** in the 2006 session guaranteeing a starting minimum wage for direct support staff in the DD system at parity with starting levels for direct care staff at NHH (and to fund it accordingly), and (b) to increase enhanced family care stipends to appropriate levels consistent with the demands of and qualifications for the job. Efforts by the HHS Commissioner on this front should be supported.

2. A human resources enhancement action plan should be developed, utilizing consultant services as needed, with input from key stakeholders to determine:

a. Adequate numbers of qualified administrative, professional/programmatic, supervisory, paraprofessional/direct support personnel at all levels of the Service Delivery System (including HHS/BDS, AA, generic or specialty provider) to carry out the responsibilities of the service delivery system (including but not limited to job development and coaching and community participation/inclusion functions), taking into account:

- rural and transportation issues and challenges
- the needs of more complex populations, such as individuals with serious behavioral challenges, forensic issues, or complex medical or multi-disability needs (e.g. medical, nursing, forensic, persons skilled in positive behavior supports, speech or communication specialists, etc.)

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<sup>70</sup> See Appendix O. See also Appendix P, in which two illustrations are presented of persons with more complex medical needs, ending up in a nursing home because of lack of a community alternative, including one who had to give up her “home of your own.” Additionally, a review of BDS investigations trend data from 1995 to 2004, indicates that individuals with behavior issues are more likely to be at risk for abuse and neglect, and that staff quality, training, turnover, vacancies, and supervision are one of the contributory factors to abuse and neglect. As noted above, these staffing issues are a direct by-product of the budgetary problem, and put both clients and programs at risk.

- that some specialty areas only need to be available on a regionalized and/or centralized basis.
- the availability of qualified personnel from other service systems, a relevant factor given the number of instances of multi-agency involvement.

b. Other measures to attract and retain qualified staff, including the establishment of a loan forgiveness program for new graduates in specified certificate or degree programs when they work in the DD system, such as:

- (1) Free college tuition program in the state university system.
- (2) Resources to create a state-wide recruitment campaign including public service announcements.

c. A review of current pre-service and in-service training within the DD system to determine what improvements are necessary, including, but not limited to, areas related to job development and coaching, community participation/inclusion, and addressing the needs of individuals with more complex needs.

### **Recommendations--Employment/Meaningful Day**

3. The Governor, and where legislative initiatives are involved, the Legislature, should prioritize the following initiatives based on input from stakeholders, and initiate, lead and/or oversee their development and implementation:

a. Improvements to the interagency processes at the state and local level between HHS and Division of Vocational Rehabilitation aimed at improving coordination and employment-related services and outcomes for individuals with developmental disabilities.

b. Creation of an Employer Council, made up largely of representatives of New Hampshire's business community with other key stakeholders to develop and promote key initiatives to increase employment opportunities, giving consideration to the recommendations below.

c. A statewide public education campaign to both the business and non-profit sectors to promote employment of individuals with disabilities, including those with developmental disabilities, including breaking down attitudinal barriers. Collaborative efforts to reach employers should be made with such organizations as the New Hampshire Businesses for Social Responsibility and the New Hampshire Community Loan Fund, which may add the employment of individuals with disabilities to their criteria of socially responsible business practices.

d. Promotion of self-employment for individuals with disabilities by integrating employment for individuals with disabilities formally into the efforts of the Community Development Finance Authority (CDFA). In addition, allow local businesses to obtain tax credits by partnering for employment/self-employment with the local area agency for a



specific project that would only require nominal CDFA approval, but include technical assistance from CDFA.

e. **Legislation** offering state tax incentives to employers, such as a business enterprise or business profits tax credit for hiring individuals with disabilities, which along with current federal tax incentives, should help to increase employment.

f. **Legislation** requiring local, state, and county government entities to contract with developmental service providers for services in defined situations, a model that has been used in the State of Washington.

g. **Legislation** to, at a minimum, reinstate post secondary employment in RSA 193-E(I) as a school reporting requirement and consider placing it in RSA 193-H(2)<sup>71</sup> as a performance outcome indicator, and in either case include a requirement to disaggregate in order to measure employment outcomes for children with disabilities.

h. Development of measures or guidelines to promote through the IEP<sup>72</sup>/Transitions and DD System Service Agreement processes and on a more system level basis increased access of individuals with disabilities to vocational training in high school and in the Community College/NHTI system.

4. It is further recommended that:

a. The Governor/HHS actively pursue full eligibility under the Medicaid Infrastructure Grant in order to obtain federal funding to support the HHS' focus on employment.

b. Individuals, families, service coordinators and other relevant persons have readily available, clearly understandable information clarifying misinformation and misperceptions about limits on or disincentives to working resulting from public benefits or Social Security. Where there are actual limitations or disincentives to working, they should be identified and consideration given to addressing particularly to those on the state level.

### **Recommendations--Individuals with Serious Behavioral, Forensic, Medical, Multiple Disability, and Aging Needs**

4. In conjunction with the human resource enhancement plan in Section VI(C)(2) above, for both efficiency and effectiveness reasons, in developing strategies to meet the needs of persons in these more complex or challenging groups, HHS should consider one or more sets of teams, specialists, technical assistance personnel or programs in the state to assist AAs, providers, families and individuals in addressing challenging behaviors, forensic issues, complex medical needs or needs arising from multiple and significant disabilities.

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<sup>71</sup> Both statutory provisions are attached in Appendix Q.

<sup>72</sup> Individual Education Plan

5. It is also recommended that:

a. Under the oversight of the Governor and/or HHS, the establishment of a task force of leaders/experts in the health, home health, aging, mental health, developmental disabilities, with input from key stakeholders, to develop initiatives promoting at the state and/or local level better coordination, integration and best practices in physical and mental health, acute and chronic health prevention and treatment for individuals with developmental disabilities with challenging or complex needs, e.g. through symposiums, cross training, MOUs, changes in regulations, policies, and funding streams.

This would promote better integration of resources between mental health, acute health, and developmental service providers---outcomes could be less inappropriate use of health care, better health for consumers (mental and physical), less inappropriate use of NHH.

b. To provide services to children with significant behavioral or medical needs, the in-home support waiver capacity be expanded as well as out of home placement capacity, when needed, as further described in VI(C)(6) &(7).

c. HHS, DOE, and NH Atech, with input from key stakeholders,<sup>73</sup> implement steps to increase the availability of and aggressive use of NH Atech (Assistive Technology) services and more information, outreach and education on the role assistive technology can play in significantly improving quality of life and opportunities generally.

d. HHS should ensure that AAs (and specifically the individuals they serve) have access to the Medicaid State Plan for nursing oversight and coordination within the system and programs, and in relation to acute and other generic health care entities around the health care needs of individuals with disabilities. This is in addition to nursing capacity for medication utilization administration paid for under the waiver.

e. **Re-introduction of legislation** similar to SB 161, as it was originally developed by HHS in 2001,<sup>74</sup> which proposed five intensive-treatment group homes, each housing four to six people, regionally located around the state on state property for individuals committed under RSA 171-B and others with developmental disabilities envisioned by SB 161.

## **Recommendations--Residential Choices and Options and Wait list Issues**

6. As the In-Home Supports Waiver<sup>75</sup> has proven itself to be of great value to children being served under age 21 and their families and is a cost-effective way of reducing the need for more expensive out of home placement, it is recommended that the number of slots be increased (and re-assessed periodically), to support more than the maximum of 200 families.

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<sup>73</sup> The phrase “key stakeholders” from this point forward, unless stated otherwise, means one or more participants from HHS/BDS, AA, Providers, individuals with disabilities, Families, DRC, DD Council, IOD, and anyone else specified.

<sup>74</sup> See <http://www.gencourt.state.nh.us/legislation/2001/sb0161.html>.

<sup>75</sup> In Home Supports is designed for families needing long term in home/ community supports for their family member (birth to 21 years) with developmental disabilities.

7. For those children under 21 whose needs cannot be met at home even with supports, more out of home options be developed in cases where an education residential placement may not be available.

Solutions here do not necessarily or always require increases in funding, but can be funded with existing funds with better coordination, braiding or pooling of funds involving DCYF, school districts, CMHCs, and/or AAs. This is discussed further in Section VIII (4) below.

8. For those aging out of the school system at 21 or who have already been found eligible but are not being fully served: Continue to make available a full array of in-home supports (including those who were on the children's In-Home Support Waiver, who should continue to receive supports without interruption), enhanced family care, and other options, based on the needs and choices of individuals/families as reflected in *Renewing the Vision*, Section III (G).

9. Ensure that wait lists for Medicaid waiver services are no more than 90 days.

10. Family and Individual Control Options. With the goal of promoting the increased use of family and consumer control models<sup>76</sup>, a key stakeholder work group, with the assistance of an outside expert legal consultant, should be established to study and address issues or barriers to the use of these models such as insurance liability issues, workers' compensation, Department of Labor requirements, and other legal/technical issues.

## **VII. Area Agency Sole Provider Issue<sup>77</sup>**

1. An external evaluation be conducted as to whether AAs should perform essentially all service delivery functions in their region, .e.g. sole provider, sole source of service coordination, investigations, non HHS level quality assurance and monitoring.<sup>78</sup>

## **VIII. Other Efficiency and Related Recommendations**

### **Introduction**

The recommendations below are principally aimed at improving efficiency. While many of the previous recommendations do as well, most of the ones in this section are especially aimed at more business oriented operations. Many of the recommendations in this section are based on the particular expertise and knowledge of persons working in the system (e.g. recommendation for AA and Provider organizations to develop further joint purchasing arrangements, in order to leverage lower prices). Some of the recommended initiatives are ongoing or revive previous

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<sup>76</sup> The fiscal intermediary model (which can take several forms, e.g. a Support ISO or Individual Supports Options and an Agency with Choice Model) and cash & counseling models, are described in Appendix R.

<sup>77</sup> See comments related to this section in Appendix R.

<sup>78</sup> It is suggested that HSRI, or an organization with equivalent background and expertise, be retained for this purpose. See note 7 for more information on HSRI.

work. Most of the recommendations in this section are therefore not preceded by findings. Where some comment or explanation is provided, it is referenced and provided in Appendix R.

## **1. Information Technology (IT), Quality Assurance, and Standardization of Certain Functions<sup>79</sup>**

a. Through an existing work group of BDS/AA representatives, augmented by an outside IT consultant and provider representation (and with input from other key stakeholders) continue IT development and further standardization of program and business functions. The work group shall inventory current automated functions, equipment, platforms, software and applications, and, with due regard to confidentiality requirements, consider the need to:

(1) Further standardize and automate functions such as service agreements<sup>80</sup> and other forms and functions, e.g. attendance, billing, contract requirements, formats and financial reporting between AAs and Providers.

(2) Provide for standard or widespread use of notebook computers or personal digital assistants (PDAs) in the field as well as common platforms and the internet to:

(a) perform data collection, reporting, analysis, dissemination, and feedback in regard to QA/QE, including the functions described in subsection 1 b below.

(b) transact other basic operations, business services, and programmatic functions.

(3) Make funding recommendations, giving consideration to state capital budget, grants, and private sector donations.

b. The Quality Outcomes Partnership Group under BDS/DHHS' leadership, with renewed involvement from key stakeholders, and with the assistance of an outside consultant,<sup>81</sup> review:<sup>82</sup>

(1) And make refinements, where necessary, based on best practices, in type, validity, and accuracy of performance measures, standards or norms of performance, and methods of dissemination and use.

(2) Whether and how Licensing, Certification, Redesignation, other QA/QE and monitoring functions could be streamlined or consolidated, and more professional

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<sup>79</sup> See comments related to this section in Appendix R.

<sup>80</sup> With regard to service agreements, the standardization that the Commission is referring to relates to format and common data elements for ease of reporting/monitoring, not the content/narrative related to the individual.

<sup>81</sup> One possible consultant to consider is, HSRI of which Val Bradley who presented to the Commission is president. HSRI helped develop the Quality Outcomes initiative in New Hampshire and has other extensive involvement in the DD system in this state. Her organization currently contracts with CMS to provide technical assistance to states under the DD waiver program. Through a request to CMS, NH therefore should be able to receive 15 days technical assistance at **no cost to the NH** by making an appropriate request to CMS. Given the complexity and the importance of the task, and the need for several HSRI staff, it is recommended that the state purchase additional time if needed.

<sup>82</sup> See comments related to this section in Appendix R.

review/oversight added; and whether such measures will result in efficiencies or require more resources, and whether service quality could be improved.

(3) Whether any requirements of HHS regulations, including but not limited to He-M 507, He-M 517, and He-M 518,<sup>83</sup> are unnecessary and burdensome<sup>84</sup> and may be removed without compromising the rights or services to individuals.

## **2. Establishment of Central Registry of Abusers**

It is recommended that **legislation** be enacted establishing a central registry of names and social security numbers of individuals who have a substantiated findings of abuse or neglect against them of persons with a developmental or other disability whereby before such persons are hired in the AA/DD, Behavioral Health/CMHC/NHH, elderly/chronically, or child protection or juvenile systems, a waiver must be obtained or such persons will have had the finding expunged by a court.

## **3. Comprehensive Electronic Resource Director and Navigator<sup>85</sup>**

a. The Governor or Legislature **through legislation**, or BDS/AA administratively, (with input from key stakeholders) should consider development of (or enhancement of pre-existing) an electronic resource directory to display in user-friendly, accessible, and informative manner information on benefits and services in and outside of HHS as a tool to assist case managers, individuals, families, and others in navigating the system and accessing appropriate and needed services.

Note: This directory could be built for use for other or all populations served by HHS.

## **4. Interagency Relationship On Local And State Level Between Schools, Areas Agencies, Mental Health Centers, DCYF, etc.**

a. A task force should be established to improve the efficiency, effectiveness and coordination of services provided by multiple agencies to children with developmental disabilities. The task force should be headed by the Governor's designee or a Governor's designee with the chairs of House and Senate Education, or their designees, with representatives from DHHS and DOE, their local subdivisions or sub-authorities and other stakeholders, and it should determine whether and what:

(1) Changes or improvements are needed in the HHS-DOE interagency agreement required by RSA 186-C:7-a (included in Appendix L) and other inter or intra agency agreements or MOUs.

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<sup>83</sup> He-M 507 are the day service regulations; He-M 517 regulations are the DD Medicaid Waiver regulations; and the 518 are the employment regulations.

<sup>84</sup>Neither the cited nor any other regulations were reviewed by the whole commission for this purpose, and the commission does not have an opinion as to whether any requirements are unnecessary and burdensome.

<sup>85</sup> See comments related to this section in Appendix R.

(2) Reforms should be made to funding streams, including measures or **legislation** to enable pooling, cost sharing or “braiding” of multiple funding sources.

(3) Other measures are needed, including but not limited to:

(a) Improvements in the efficiency and effectiveness of transition services to children 16 (or younger) to 21 with developmental disabilities

(b) The need for services of children between 18 and 21 who are not (or no longer) served by the education system or DCYF.

**5. To leverage lower prices, further collaboration between AA and Provider organizations to (1) determine ways to access state purchasing, (2) develop joint purchasing arrangements, and (3) standardize Request for Proposals.**

**6. Explore ways to promote more AA partnering with regional planning commissions around housing, transportation, etc.**

## **IX. Review of Consolidations of Regions 1 and 11 and 2 and 12.**

### **A. Findings**

In addition to direct Commission consideration of this issue, a subcommittee was formed and met for a total of 10 hours over 6 weeks. The entire Commission also heard considerable testimony on this subject as well as presentation by Thomas McLaughlin, Senior Manager from Grant Thornton LLP and author of Nonprofit Mergers and Alliances. As with the other parts of this report, the findings and recommendations below are those of the commission as a whole. Further description of this subcommittee’s process is in Appendix S.

The charge to this subcommittee was to review the issue of mergers within the area agency system. Rather than focus *exclusively* on the mergers currently underway in the northern and western parts of the state, the group decided to explore the key elements of a successful non-profit merger. By doing this, we hope to make recommendations for a process to make these and any future consolidations successful.

In his presentation, Mr. McLaughlin listed seven steps to a successful merger. They are:

1. Mutual Learning, especially as it relates to the different cultures of the organizations;
2. Planning Structure, where each organization designates 3-4 people to serve as the steering group for the process;
3. Decide on the Leadership of the Merged Organizations;
4. Structure the Entity;
5. Communicate throughout the Process;
6. Formalize the agreement; and
7. Implement.

Throughout his presentation, Mr. McLaughlin emphasized that mergers rarely save money in either the short or long term. In fact, in the first year mergers can actually cost more due to increased transaction costs. In the long term, it is more likely that quality will increase rather than costs decrease. He indicated that mergers are most often proposed for strategic reasons rather than cost savings and that it often takes three years or more before the new entity is functioning smoothly.

The literature which we reviewed was corroborated by Mr. McLaughlin's presentation in that mergers are usually seen as the last resort for agency collaboration, with several other alternatives available for cost savings. Mr. McLaughlin presented a hierarchy of potential corporate alliances with increasing integration of services. These ranged from simple purchase of service agreements to consolidation of "back room" functions such as HR, IT, and billing, to actual integration of programs and services. All of these alliances can be accomplished short of merging the corporate entities and often result in significant cost savings.

In the case of the current area agency mergers, it does not appear that other alternatives were seriously explored nor were the basic steps for a successful merger followed. In fact, the proposed consolidations appear to have more elements of what is commonly referred to in corporate culture as a "hostile takeover" than a true merger.

Another area of concern is that the catalyst for these mergers appears to be primarily economic in that the DHHS Desk Audit proposes that these mergers will save the state approximately \$800,000. As mentioned previously, mergers do not usually achieve significant cost savings and can, in fact, lead to higher costs in the first year. This is validated in "Preparing for Change" submitted by Developmental Services of Sullivan County where they estimate that transaction costs could range between \$225,000 and \$350,00 in order to make this transition successful.

## **B. Recommendations**

1. With regard to the current mergers, HHS should (a) provide the four regions involved (1, 2, 11, and 12) with funding to engage an outside management consultant to assist with the corporate mergers in progress; (b) allow flexibility in established timelines to assure that all necessary tasks are completed; and (c) provide adequate funding for the transition costs associated with these consolidations in order for them to be successful.

The Commission feels it is essential that there be an expert in non-profit mergers involved in the process. The consultant's ongoing role (from the current process, and for up to 3 years after the mergers are completed) would be to provide assistance to HHS as well as the Area Agencies so that the merger process will proceed smoothly and the mergers will ultimately be successful. The decision as to which consultant should be engaged, should be mutually agreed upon by the current executive directors of the involved regions, the Commissioner, and the BDS Director so that the consultant's advice will be respected by all parties.

2. Because of the potential impact on services to people with disabilities and their families, there should be ongoing monitoring and evaluation of the current merger process to assure that the availability and quality of services is not compromised. It is further

recommended that this function be performed by an independent body separate from HHS or the involved area agencies.

3. Any consolidations contemplated by HHS in the future should fully involve the Boards of Directors of the involved agencies from the earliest planning stages with decisions made at the local level and with the involvement of an outside consultant skilled in non profit mergers. It should also include the involvement and input of staff, providers, families and individuals with disabilities at the earliest possible stages. This process should also include exploring other options short of merger.

## **X. Collaboration and Community Partnership**

As previously noted, collaboration and community partnership are among the main reasons why the DD/AA system has been so successful both from a cost savings and quality viewpoint. The Commission is concerned that as both underlying principles and operating elements these concepts have been increasingly strained in recent years, threatening and impacting continued progress.

The need for collaboration in developing measures to save money and improve services was characterized as essential by Thomas McLaughlin, an expert in non-profit management and mergers, who presented to the Commission. It is a theme that underlies all the steps for not only a successful merger but other types of alliances designed to improve efficiency and quality. Valerie Bradley stressed input and involvement as well in regard to developing and refining quality assurance systems. Indeed the experience of the system shows that collaboration, input and partnership have been among the key reasons why the system has been so successful generally both in terms of savings and cost effectiveness and quality.

The Commission views collaboration as a principle, a process and an action, and because of its paramount importance, it is an element of or underlies most of the recommendations in the report. We also strongly urge that the spirit of collaboration and partnership be restored in the system, and as a number of the specific recommendations suggest, taken to expanded levels. This includes:

- a. Collaboration and meaningful consideration of input both vertically up and down the HHS/Area Agency system and across the system, bureaus and area agencies.
- b. Across government agencies, e.g. HHS and DOE and their “subauthorities” on the local level, e.g. AAs, school districts, mental health centers, etc.
- c. Between state and local government.
- d. Between AAs and providers
- e. Stronger partnerships and engagement with (on the state and/or community level) with business, community organizations, and less formal community networks, e.g. volunteers, neighborhoods, etc.



- f. And in all these collaborations, real involvement and input of individuals and families and where needed advocates.

## **XI. Extension of Commission Studying Area Agencies**

To help promote consideration and implementation of the recommendations in this report, it is recommended that the Commission or a similar commission or task force be extended for 1 to 2 years (or whatever time is needed), with additions/changes to its charge to reflect this new role. It is also recommended that in addition to the current membership list, slots should be added for a provider representative, a self-advocate with supports, a representative from the Institute on Disability/University Center for Excellence and a representative from the Institute on Health, Law and Ethics of Franklin Pierce Law Center. The Commission/task force would meet at least quarterly.

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This report and the findings and recommendations contained in this report as well as the executive summary are based on the unanimous agreement of the active and voting participants<sup>86</sup> in the commission.

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<sup>86</sup> The HHS Commissioner did send a representative to a number of the meetings, but she did not actively participate. There was no HHS representation at the public hearings. The Commissioner attended parts of two meetings, and although indicated that he had concerns with the original draft of the report did not provide comments to that draft or subsequent ones. As to the specific deliberations and votes on the recommendations and body of the report, when the Commissioner's representative attended, she abstained from voting. Nevertheless, it remains the sincere hope of the Commission that the Commissioner will put the full weight of his office and department behind the recommendations.