Executive Summary and Highest Priority Recommendations

The Commission's Purpose

This 13-member Commission[1] 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.*"[2] 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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[1] List of members in Appendix B.
[2] 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[3] 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.[4] 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%.[5]

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"[6] **to 35th** in funding services to individuals with developmental services.

[3] 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.
[4] 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.
[5] Bureau of Developmental Services (BDS) Director Handout, p. 52
[6] 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.