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May 1, 2006

Representative Charles E. McMahon
State House
Concord, NH 03301

Re: Addressing the DD Waitlist

Dear Representative McMahon:

After the last DD Waitlist Committee, I indicated that I would prepare a brief paper as to why the waitlist problem has not been fully addressed in the five years since Renewing the Vision. As you know I chaired the Governor's Commission on Area Agencies, and most of the points below are based on what the Commission found. I think what is commonly meant by "fully address the waitlist," is that the wait time for services from the time of application should be no more than 90 days. Services then provided should be fully in accord with each person's needs, not reduced as a way to take more people of the Waitlist.. Finding the most efficient and cost effective ways to provide services should be ongoing, but not at the expense of meeting a person's needs.

In that regard, it has been well recognized that NH has historically not only provided good services, but has done it highly cost effectively.

As to the waitlist, the failure to address it has been frustrating to all, including lawmakers, state officials, Area Agencies, providers, and most importantly individuals and families who have to wait months and sometimes years for badly needed services.

The BDS waitlist graphs show an up and down pattern since Renewing the Vision (2001) with regard to the number of days on the waitlist and number of people on it, but never to the point where we can say the problem has been resolved. A slide I showed at the Governor's Commission presentation on January 31, shows that we actually had more individuals on the waitlist, waiting a longer period of time than when Renewing the Vision was crafted. I have attached a copy of the slide for your convenience.

Here are the reasons why in my view we have not fully addressed the waitlist issue, some of which Mathew Ertas and Commissioner Stephen spoke to at the January 27 Waitlist Committee hearing. As noted some of the points were discussed in the Governor's Commission report as well.

- **The budgetary and residential placement projections of Renewing the Vision were predicated on only one third (1/3) of adults coming off the waitlist receiving residential services outside of the family home, and two thirds (2/3)**

remaining at home and receiving principally day services. That assumption was not borne out in practice. It was also a faulty projection from the start. The findings in Renewing explicitly indicated that virtually all families understandably saw their adult children moving out into residential supports, some sooner, and some later. As stated in Renewing:

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 there were grown**. Section IIIG of Renewing. (Emphasis added.)

In short, the recommendations in Renewing and the subsequent budgetary planning was almost directly the opposite of what the expressed needs and findings were. Where the rate of placement out of the home has likely been at a higher than 1/3 rate, the total number that was projected to be served has been less. This is because the cost of out-of-home residential services on average is over twice as much as in-home. My opinion is that this will continue to be a problem as the strain on families will continue and likely grow and the demand on out-of home residential services will increase. Projections must be more realistic and mindful of real needs in the next biennium and beyond.

- **The lack of any significant rate increase, for operating expenses, particularly when compared with the rising costs in key areas, has forced Area Agencies to spread waitlist funds to cover current operations as well as new clients**. This further dilutes the impact of new waitlist funding. Area Agencies justifiably feel a legal and moral obligation to support current clients. From a risk management/liability viewpoint, they have an obligation to existing clientele so it is natural for them to try to shore up existing services and meet current obligations when the funding is scarce. The problem is that in trying to do both—meet needs of existing clientele and serve new clients when the funding is insufficient, the AAs are not able to fully accomplish either, as the Governor's Commissions found.

- **Insufficient periodic, bi-annual planning as to future needs.** There are occasional individuals who seek services from service system that are unanticipated. Mat Ertas actually mentioned a group during his testimony on January 27. However, the HHS/SS system can generally project most individuals and their needs in advance. The Area Agency statute, RSA 171-A:18(V) and regulations, He-M 505.03 (s)-(u) in fact require that comprehensive, classic needs assessment planning and projection be done on a biennial basis so that HHS and the legislature have complete and accurate data upon which to plan and act. Biannual plans are developed and approved by the DHHS, but they are more in the nature of strategic plans, than "service needs" assessments upon which service projections can be made. While there are many excellent and strategic components to these plans, and they should continue to be developed and

implemented, the planning should and must include a breakdown of (a) the needs of current clients and especially their changing needs and services and supports, (b) projection as to prospective clients and their needs, and (c) the budgetary implications and projections for both variables. Without good and comprehensive data, it is impossible to make good and informed budgetary and policy decisions.

- **Related to or an illustration of the previous points, is the failure to adequately take into account the higher cost needs of individuals with more complex needs**. This was the case in the budgetary projection section of Renewing and in biannual budgetary planning generally. The average cost of serving an adult who remains with their own family has been about $41,000, although the cost has slipped to about $35,000 in recent years (despite increase costs.) The average out of home residential costs is about $70,000. As these are averages, they assume that there may be some individuals who services will cost more. However, it is believed that prior budgetary requests and more specifically the legislative authorizations do not fully take into account the numbers of individuals whose service costs will significantly exceed the average. While the focus in this area always seem to be on individuals whose behaviors are considered a danger to the community, there are other subgroups as well, e.g. individuals with complex medical needs, multiple disabilities, self-injuious behaviors, and those that are aging. **When the need of these groups are not taken into account, the funding is again diluted, impacting on the ability to meet wait list projections.**

  With regard to the first group, sometimes characterized as individuals with forensic needs, the problem is often oversimplified. First, since the one-dollar funded RSA 171-B law went into effect, only 11-12 individuals have been committed under it. The effect of the number of people committed under that law has therefore been small on the budget or the waitlist. To be sure, there others whom some feel display forensic behaviors, but are not committable under RSA 171-B. Whether their behaviors are forensic in nature or something less, they must be served by the AA system. As with any individual or group of individuals who have more needs or issues, their service costs will necessarily exceed the average. As discussed below with a more solid infrastructure and up front investment in high quality services, the costs over time may decrease. That issue aside, certain people will cost more to serve. (The costs of surgery in a 5-day inpatient stay at a hospital will be far higher than the cost of a brief emergency room visit, or physician outpatient visit.) Unless planned for, the higher costs will impact the ability to serve new individuals. However, the fault is not with the current clients, with or without more complex needs, but with the planning or allocations for not taking into account all needs. When we had an institutional model of services, all of these subgroups resided at Laconia, ranging from individuals with less complex needs, to individuals with complex medical, behavioral or multiple disabilities. As in the community we spoke of average costs—

per diems—but the actual cost to serve individuals even in the institution varied widely. That fact has not changed in the community, and planning and budgeting on a macro and individual level must continue to take the diversity of needs into account.

- **Improvements are needed in how well schools in the state prepare children with disabilities for adult living, including employment.** While the type of improvement needed to have a significant impact on the waitlist will take some time, it should definitely be part of the long range solution. While there are pockets of very good practices it the state, overall the education system needs to do a far better job in preparing children with disabilities for adult life and employment, and particularly during the legally mandated transition years beginning at 16 or earlier.

  This is similar to the point the Commissioner and several members of the Committee made at the January 27 meeting in speaking about the rational and importance of early intervention for children 0-3, with delays. It is well documented that early intervention services are important in preventing some of the effects of developmental disabilities. However the education that follows during the 3-21 age range, is obviously equally, if not more important in preparing individuals for more independent adult living and employment. Grounded with a good education and transition services, many individuals with developmental disabilities may require much less service from the Area Agency system, some may actually need little or none. As with all improvements we need to have our actions match our words. While all stressed or concurred with the importance of early intervention services at the January 27 Committee meeting, two years ago HHS tightened eligibly guidelines on early intervention services thereby restricting the number of children eligible for the program.

  While a comprehensive discussion of the effectiveness of NH educating system in preparing children with developmental disabilities is beyond the scope of this paper, several points are worth highlighting.

  (1) While the 0-3 early intervention program operated by the Area Agencies has received praise, **the state educational system, and many school districts, have been cited for failing to pick these children up upon reaching their third birthday. Delays can be for months, negating some of the benefits of the prior interventions.**

  (2) **A number of indicators, and an abundance of anecdotal evidence, point to the fact that most schools are not providing a nearly adequate education to children with developmental disabilities to prepare them for employment, independent living, etc**. Of particular concern is the pervasive lack of good transition and interagency collaboration during critical transition years beginning at 16 or earlier. Schools often graduate children before they are ready, exacerbating the lack of preparation and

good transition, and often placing children between 18-21 at high risk and/or rendering them more needy when the Area Agencies do finally pick them up.

(3) As discussed in the Governor's Commission report (pp. 20, 28-29) interagency coordination on the state and local level between educational and HHS agencies remains very suboptimal. This occurs not only during the transition points discussed above, but during all school years. Interagency coordination is critical for children and families with significant needs. It avoids duplication, unnecessary costs and promotes better service quality. **And again because it improves outcomes, it will often reduce the need for services from the Area Agency system.**

Properly funded, the Medicaid community waiver program in New Hampshire is a highly cost effective way to serve all individuals eligible for AA services. Addressing the above points also makes sense economically and programmatically. From an economic viewpoint the Medicaid waiver makes more sense than community ICF-MRs, a point many have made before. Many families may begin choosing this alternative. While ICF-MRs are generally more expensive and less flexible, it is an alternative to which there is an entitlement.

People were heartened by the statements at the last Waitlist committee meeting to end the waitlist once and for all during the next biennium. However to do so, and do it in the most cost effective way possible, I would urge that the Waitlist Committee incorporate the above points in their recommendations as well as for Executive Branch and the Legislature to do the same in their budgetary planning and authorizations.

I would welcome the opportunity to answer any questions of the Committee at its May 1 meeting or otherwise summarize these points.

Sincerely yours,

Richard A. Cohen
Executive Director

cc: Members of the DD Waitlist Oversight Committee
John Stephen, Commissioner
Matthew Ertas, Bureau Director