STATE OF CONNECTICUT
DEPARTMENT OF MENTAL RETARDATION

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TESTIMONY OF
DEPARTMENT OF MENTAL RETARDATION
COMMISSIONER PETER H. O'MEARA
TO THE
PUBLIC HEALTH COMMITTEE
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Good Morning. Senator Handley, Representative Sayers and members of the Public Health Committee. I am Commissioner Peter O'Meara, and on behalf of the Department of Mental Retardation (DMR) I am here to testify on several bills before your committee today. HB 7007 and HB 7008 were both submitted by DMR this session.

H.B. 7007, AN ACT RENAMING THE DEPARTMENT OF MENTAL RETARDATION. This bill is a result of the DMR Name Change study required by Public Act 06-92 that passed during the 2006 legislative session. The act required DMR to solicit input regarding a name change for the Department from clients and families receiving services provided by the department, advocates of person with mental retardation and other interested parties. The required report was submitted to the Governor, the Office of Policy and Management and the Public Health Committee on December 29, 2006. DMR would like to thank everyone who took the time to share their thoughts and opinions on this issue. The proposed new name for the department is **"Department of Developmental Services."**

There has been a national movement among self-advocates and others to use more respectful language when referring to individuals with disabilities. The challenge throughout this debate has been to contemplate how a suggested new name will withstand time in regards to evolving perspectives and perceptions that are constantly changing.

There has been increasing interest from advocates, families, and consumers nationally and specifically in Connecticut, in response to the term "mental retardation" because it is sometimes thought to be stigmatizing and offensive to people. However, the primary concern that has been raised in changing the name of the Department is that it might create an expectation of services for persons that DMR does not currently have the statutory authority or funding to serve.

As an agency whose mission is to promote respect and dignity for people with mental retardation, it is imperative that those who are supported by us feel respected, starting with the name of the agency that provides support to them.

Gathering input from many interested individuals has been an important step in this process of pursuing a statutory name change for the department. DMR took many steps to ensure that

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outreach on this issue was widespread throughout the state. These many steps are outlined in the Name Change report issued in December.

The Department contacted facilities staff in each of our three regional offices to solicit information on potential cost implications involved in a name change. The questionnaire also included a question regarding any potential implications of a change. Based on the results, we would put an estimate of ***approximately $50,000*** on a name change. Some of this cost could be spread out over a period of time or potentially avoided depending on the timeframe for implementation.

Many states serving individuals with mental retardation have removed the diagnosis from human service department names. Some use terms that refer to the service being provided rather than the population being served. Thus, a number have adopted the term "developmental services" to refer to the office, division or department responsible for serving individuals with developmental disabilities (e.g., NH, CA and NV). Still other states have consolidated responsibility for serving individuals with developmental AND physical disabilities within the same executive branch unit and assigned the agency a title that includes the word "disability" or "disabilities." An important note in this discussion is that the majority of changes in agency titles that have occurred came about as the result of an administrative, rather than legislative, action and frequently for reasons other than dissatisfaction with the agency's existing title. This is unlike in Connecticut, where the driving force for a name change has been a growing discontent with the term "mental retardation" among consumers and advocates.

DMR strongly recommends that legislation be as clear as possible, especially in reference to associated eligibility. Also, it is essential to the success of a name change that educating the public is addressed so that misconceptions are minimal and it is apparent as to who is eligible for support from the Department of Developmental Services. The name "Department of Developmental Services" is respectful of individuals who are currently served by DMR yet is also inclusive of individuals in the Birth to Three program and the Autism Pilot who do not have a diagnosis of mental retardation. In addition, it is consistent with other human service agencies in Connecticut that use a service related name rather than a disability related name.

References to the old name of the Department should be replaced with the new name however; it is not the intention to replace the words "mental retardation" throughout the statutes. The Diagnostic and Statistical Manual of Mental Disorders "DSM-IV" (published by the American Psychiatric Association), still includes a diagnosis of "mental retardation." The DSM-IV is the standard for medical diagnosis in the United States. In addition, the DSM-IV diagnosis of mental retardation is the same as used in the International Classification of Diseases (ICD-9). As the terminology still continues to have a purpose in terms of a clinical diagnosis and in reference to eligibility, it will continue to be used in some places. As the Director of the Office of Protection and Advocacy has pointed out, eliminating all references to "mental retardation" could inadvertently affect the current legal standards for protective services. A majority of states, even the ones who have taken "mental retardation" out of their agency title, still use the term and define it. In addition, the terminology "mental retardation" is still applicable in regards to bigotry and bias statutes, the Commission on Human Rights and Opportunities' discrimination statutes, federal waiver classifications, certification for Intermediate Care Facilities and the Americans with Disabilities Act.

There needs to be limitations and constraints in any legislation regarding the timeframe for implementation and eligibility not changing so that the scope of the Department is clearly defined. We feel that our proposed language addresses these issues.

H.B. 7008, AN ACT CONCERNING THE DEPARTMENT OF MENTAL RETARDATION. This bill is composed of several agency proposals. I will outline each proposal separately:

The proposed deletions in Sections 1 and 2 of this bill refer to an evaluation of each DMR region's adherence to approved protocol used in determining which clients shall receive services and in selecting service providers. DMR produces an annual report (commonly referred to as the "Committee of Cognizance Report") to address the requirements in CGS 17a-212 and 17a-213. In addition, regional comparisons of Waiting List information and client populations are available quarterly and annually through the Department's Management Information Report (MIR). The MIR is distributed to a list of internal DMR staff. OPM & OFA also receive copies. It should be noted that the way DMR does business has changed recently and significantly as it has transitioned to having only three regions. Also, with the introduction of the new Medicaid Waivers and their rules, there are new systems of resource allocation based on fixed rates and Waiver Requirements.

Section 3 of this bill deletes the requirement of a report from 1996 that has been met (lines 43-46) and deletes an annual report describing the status of the reduction of the waiting list and the establishment of a Recreation and Respite Care Services Division (lines 53-61). DMR produces a quarterly Waiting list Report for the Appropriations and Public Health Committees that tracks residential placements and costs for the department as well as the reuse of existing resources. In addition, as mentioned above, DMR produces the MIR, which provides information on a quarterly basis including all placement activity by funding category as well as information about the planning list and projected needs. Due to budget constraints over past years, DMR does not have an established Recreation and Respite Care Service Division. However, any information regarding these services is included in the previously mentioned "Committee of Cognizance Report." Although there used to be a separate Recreation and Respite Report, it has not been done in several years. The report covered many of the same things that are in the Committee of Cognizance Report and also reported on the recreation staff and how many people they served. The layoffs and early retirement a few years ago impacted recreation staff and programs. The report stopped being produced as a stand-alone report around the same time that publicly provided recreation was significantly reduced.

Section 4 of this bill allows DCF and DMHAS to have access to DMR's abuse/neglect registry as requested by those agencies.

Section 5 of the bill deletes a requirement for the Southbury Training School (STS) Board of Trustees to review and co-prepare an annual report with the Director of STS for transmission to the Council on Mental Retardation for inclusion in a report to the Governor (lines 130-134). The Director of STS currently reports to the Commissioner any information regarding the status, operation and administration of STS for inclusion in the Commissioner's Annual Report to the

Governor. There is no statutory requirement for the Council on Mental Retardation to report to the Governor.

Section 6 of the bill expands a current prohibition of DMR employees to private provider staff and Community Training Home (CTH) licensees and their relatives or household members (lines 186-203). Currently, DMR employees may not be appointed as a plenary guardian or limited guardian of a person with mental retardation residing in a state-operated residential facility for persons with mental retardation located in the DMR region in which such person is employed (unless no other suitable person to serve can be found). A potential conflict of interest exists when people who are working for a private provider may become a guardian for someone directly supported by that agency or a CTH licensee may become a guardian for someone served in that CTH. The current statute only prohibits DMR staff from serving as a guardian for someone in their region. Our proposal is that private provider staff and CTH licensees should have similar restrictions.

Section 7 repeals several sections of statute as outlined below:

Section 17a-211a, the "Annual Spending and Placement Plan." This information is provided in other reports that DMR compiles and distributes including the quarterly Waiting List Report, (as required by the 97-98 budget act), which tracks residential placements and costs for the department as well as the reuse of existing resources. Last year this was expanded to include EFS (enhanced family support) dollars, age outs and high school grad funding. DMR also produces this as an end of year report summarizing the year's expenditures as well as the annualized costs. In addition, the CFSR (Comprehensive Financial Status Report) is a monthly financial report, produced by the DMR business office, which lists the department's activity to date by account, allocation, commitment, and expenditures. The CFSR, which is distributed to OPM and OFA, lists year-to-date spending by SID (Special Identification Codes) and projected monthly spending by SID. It also includes some supplemental/detailed reports for our PS account and the Other Expense account. This report includes information submitted by each region.

Section 17a-211d, the "Workers' Compensation and Private Providers" report. From DMR's perspective, this is a service that appears to be no longer considered necessary based on the lack of requests from private providers to DMR for technical assistance in the area of managing Workers Compensation claims. In talking with DMHAS and DCF, both agencies agree that this requirement is not necessary for their respective agencies.

Section 17a-215a, "Advisory Commission on Services and Supports for Persons with Developmental Disabilities." The Commission completed its duties under this statute when it issued a final report during July 2002, thus the statute is now obsolete. DMR has received inquires from the State Auditor encouraging the repeal of this section.

Section 17a-242, "Annual Evaluation Report" for USD #3. This repeals the requirement for USD #3 to do an annual evaluation report as the "school district" is just one of 33 providers of the Birth to Three system. A profile of all programs (including USD #3) is posted on the Birth to Three website and their information is also included in all Birth to Three reports and quality assurance reports and activities. In addition, the State Department of Education receives any

information it requests of the USD #3. For example, the Director reports annually on all certified staff by name, salary and certification as well as non-certified staff full time equivalents.

Section 20 of PA 91-11 of the June Special Session, "Executive Director salary cap". PA 91-11 set a cap of $75,000 in state funds for the salary of directors of private provider agencies. This was established in 1991 and has never been adjusted. This has posed a problem for a number of agencies contracting with DMR. Larger agencies can use other, non-state revenue to pay amounts above the cap. Smaller agencies, however, do not have that flexibility. It has been reported, that staff in some of the agencies impacted now make more than their Executive Director. The original provision did not contain any provision for indexing, thus the cap has remained the same for 16 years.

In addition to our agency proposal, we would like to comment on the following bills:

S.B. 1220, AN ACT CONCERNING THE BIRTH-TO-THREE PROGRAM.
In addition to recommending $989,000 for annualization of the rate increases implemented in FY07, the Governor's Recommended Budget for FY 08 and 09 proposes a significant expansion of Birth to Three by providing eligibility for very low birth weight babies, babies born at fewer than twenty-eight (28) weeks, children with significant delays in speech or biological risk factors and children with mild or unilateral hearing loss. This expansion is projected to cost $900,000 in FY08 and $1.2 million in FY09.

Our concern with Section 1 of this bill is that it expands the program even further to include "environmental risk factors." This would have a significant fiscal impact on our program that is not included in the Governor's proposed budget. If the state decided to include environmental risk factors it would also have to broaden eligibility to include children with mild developmental delays. We project that approximately 2,300 additional children would be eligible each year at an approximate additional cost of $8.9 million in the first year and $17.2 million in the second year. As a note of caution, any significant expansion of Birth to Three enrollment must take into consideration the time and resources necessary to ensure sufficient provider capacity. This would include RFPs for new programs, training of new personnel, data system expansion and other start-up requirements.

The proposed changes in Section 2 of this bill refer to a credentialing process for Birth to Three providers. DMR and Birth to Three have agreed to allow our credentialing process to remain voluntary and we are not seeking this change of statute.

S.B. 683, AN ACT CONCERNING EARLY CHILDHOOD LEAD POISONING.

There are multiple proposed bills this session regarding the issue of childhood lead poisoning including SB 1340, which was before this committee on March 5th, and HB 6723 that has been sent to Public Health from the Children's Committee. Through the Results Based Accountability initiative in the Appropriations Committee, DMR was asked to provide cost projections for automatically making any child with a blood lead level of 20 micrograms per deciliter or more eligible for Birth to Three. At this level, the Department of Public Health estimates (based on screening numbers of about 50% of one and two year olds) that approximately 300 children

would be eligible. Others think that because 90% of the children most at-risk for lead poisoning have been screened that the 300 figure is too high and that the figure is closer to 150. The cost for serving an additional 150 children would be roughly $700,000 in the first year of phase-in and $1.2m annualized in the second year. The cost of serving an additional 300 children would be double.

The department does not support the new language in lines 35 through 43 of SB 683. First of all, it is not clear whether the proposal intends for all children with blood lead levels of 10 or more to be automatically eligible for Birth to Three services. If so, the estimate from the Department of Public Health is that there are 500-1000 such children under the age of three. The cost of providing services to all of these children would be $4m - $8m per year. The funding to support such an expansion is not included in the Governor's recommended budget.

If, on the other hand, the intent of the bill is not to affect eligibility for our Birth to Three program, then we are very unclear about what the intent actually is. It states that we would identify children who are eligible for Birth to Three for other reasons, but who also have a blood level of 10 or greater. If we modified our existing data system to accommodate such data, we would still need a release from each family to obtain the information from the child's physician. And since the child could be screened at any time during his or her enrollment in Birth to Three, it is not likely that the program would know when to ask for that consent. Aside from that issue, the language stating that the "commissioner shall review and analyze the data collected to assess individual growth as well as the effectiveness of early intervention services" is confusing. It is not clear what the purpose of the analysis would be and on what basis the legislature wishes to determine the effectiveness of early intervention services.

Again, for the reasons mentioned above, DMR cautions against any additional expansion of Birth to Three eligibility other that that currently funded in the Governor's recommended budget for FY 08 & 09.

Thank you for allowing me the opportunity to speak before you today and I would be happy to address any questions that you have on our agency proposals or my testimony today.