



State of Connecticut
Department of Developmental Services



Dannel P. Malloy
Governor

Terrence W. Macy, Ph.D.
Commissioner

Joseph W. Drexler, Esq.
Deputy Commissioner

DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE PUBLIC HEALTH COMMITTEE

S.B. No. 874 - An Act Concerning Various Revisions to the Department of Developmental Services' Statutes

H.B. No. 6388 - An Act Concerning Intermediate Care Facilities for Individuals with Intellectual Disabilities

February 27, 2013

Senator Gerratana, Representative Johnson, and members of the Public Health Committee. I am Terrence W. Macy, Ph.D., Commissioner of the Department of Developmental Services (DDS). Thank you for the opportunity to testify in support of our agency bills **Senate Bill 874 - An Act Concerning Various Revisions to the Department of Developmental Services' Statutes** and **House Bill 6388 - An Act Concerning Intermediate Care Facilities for Individuals with Intellectual Disabilities**.

Senate Bill 874 updates the statutes of various councils that the department has under its auspices.

Sections one and two of Senate Bill 874 creates an Autism Spectrum Disorder Advisory Council in succession to the Autism Advisory Council and the Autism Feasibility Study Workgroup, to work with DDS and our Autism Division on matters related to autism in the state.

An Autism Advisory Council was originally established in connection with the autism spectrum disorder (ASD) pilot program (PA 06-188); however, there was no specific membership list or formal appointment process. CGS17a-215b required a report recommending the establishment an independent council. The report in January 2009 noted that a 40 member steering committee had been replaced with the Independent Advisory Council and that they had adopted bylaws. The current membership of this group includes state agencies, a legislator, advocates, individuals with ASD, providers and parents of individuals with ASD.

Section 27 of Public Act 11-6 required a study of issues related to the needs of persons with ASD, including the feasibility of a Center for Autism and Developmental Disabilities. This study commenced in May 2011 led by the Department of Social Services (DSS) and included the Departments of Developmental Services (DDS), Mental Health and Addiction Services (DMHAS), Education (SDE), Children and Families (DCF) and the Office of Policy and Management (OPM). ValueOptions, the administrative services organization (ASO) for the

Phone: 860 418-6000 ♦ TDD 860 418-6079 ♦ Fax: 860 418-6001

460 Capitol Avenue ♦ Hartford, Connecticut 06106

www.ct.gov/dds ♦ e-mail: ddsct.co@ct.gov

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Connecticut Behavioral Health Partnership (CT BHP), provided assistance with literature reviews, data analysis and summary documentation of the activities and findings of the ASD Workgroup. The Governor's proposed budget includes \$1 million in FY14 and \$1.25 million in FY15 to begin to implement the recommendations of the Autism Feasibility Study. The report cites a multi-year coordinated plan to expand and improve the ASD service system through improved training for providers, professionals and families; the creation of a centralized catalogue of ASD resources; a review of current reimbursement and insurance coverage for ASD services; and increased capacity for in-home supports and social and recreational opportunities for individuals with ASD, as just some of the recommendations. The report is under final review and is expected to be released in the coming weeks.

The new Autism Spectrum Disorder Advisory Council's membership will include various commissioners of state agencies that have a stake in the provision of services to individuals with autism spectrum disorder (ASD). Also, included in the membership are individuals with autism spectrum disorder, parents of both adults and children with ASD, advocates and licensed professionals in the field, service providers and education professionals. All of these stakeholders will be able to share their knowledge and experience regarding the need for services and supports of individuals living with autism spectrum disorder.

The new Autism Spectrum Disorder Advisory Council will play an integral role in implementing the recommendations of the Autism Feasibility Study and in providing recommendations for the coordinated provision of service delivery for individuals with ASD in Connecticut.

Section 3 of the bill corrects the designation of one appointment to the Camp Harkness Advisory Committee by clarifying that it be a member of the family support council who represents persons who use the camp.

Section 4 of the bill is technical and updates certain federal citations in the Birth-to-Three program statutes.

Section 5 revises and updates certain appointments to the State Interagency Birth-to-Three Coordinating Council. Currently, appointees may serve indefinitely. This bill introduces a limit of two consecutive three-year terms for appointees. However, members may serve until a successor is appointed.

Section 6 makes a conforming language change to federal regulation regarding the how quickly primary referral sources such as health care providers refer children to the Birth to Three system. The original IDEA Part C regulations required primary referral sources to refer a child to the Part C program "within two working days of the child's identification". That is why this was included in the state statute. The newest Part C regulations (2011) changed and now say that a state's policy must "Provide for referring a child as soon as possible, but in no case more than seven days after the child has been identified." Since state statute is the highest form of state policy, it is important that our statute conform to the new regulations.

House Bill 6388 originated when the final rule from the Centers for Medicare and Medicaid Services (CMS) was published changing the term "Intermediate Care Facility for the Mentally Retarded (ICF/MR)" to the more respectful and more "person first" term "Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)". This change in federal terminology allowed DDS to move forward with its efforts to remove all references to the term "mental retardation" in Connecticut statutes. This bill changes all references from ICF/MR to ICF/IID to conform with CMS terminology.

Previous legislation (Public Act 11-4) eliminated almost all references to "mental retardation" in state statutes. However, it has come to our attention that various state agency statutes (DMV,

DVA, DSS, DCF, etc.) still contain stray references to “the mentally retarded” or “mental retardation”. We have contacted all agencies with these references in their statutes and have now received their approval to make the change to “intellectual disability” and “person first” language. As you may imagine, getting approval from 10 state agencies to change their statutes was time consuming. DDS did finally get all agencies to sign off but not before our bill was submitted to the Public Health Committee. We ask that you consider adding the attached proposed joint favorable substitute language when you vote H.B. No. 6388 out of the committee.

Finally, I would like to express my thanks to the members of the Public Health Committee who, over the years, have supported our department’s efforts to change the way persons with intellectual disability are referred to both in statute and in everyday life. Although it seems to have been done in a piecemeal fashion over several sessions and in several bills, it only has been since 2007 when the department changed its name that the Department of Developmental Services and we set a goal to end the use of all terms that were demeaning and disrespectful to the individuals we support. In just three short years from its first use in 2010 in Governor Rell’s Executive Order No. 42, “persons with intellectual disability” has become the respectful and appropriate term throughout Connecticut statute in no small part because of the Public Health Committee’s efforts.

In addition to our agency bills, I would like to offer thoughts and comments on several other bills before your committee today. Separate testimony for each of these bills has been submitted.

Thank you again for your continued support of DDS, persons with intellectual disability and individuals with autism spectrum disorder in Connecticut. My staff and I would be happy to answer any questions that you have on Senate Bill 874 and House Bill 6388 or any other bills that we have testified on today.