

Public Health Committee JOINT FAVORABLE REPORT

Bill No.: SB-463

AN ACT ESTABLISHING A TASK FORCE TO STUDY THE NEEDS OF

Title: PERSONS WITH INTELLECTUAL DISABILITY.

Vote Date: 3/23/2018

Vote Action: Joint Favorable Substitute

PH Date: 3/16/2018

File No.: 300

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SPONSORS OF BILL:

Public Health Committee

REASONS FOR BILL:

The bill would commission a task force to study the short- and long-term needs of individuals with intellectual disabilities. The study would examine alternative and underutilized resources, such as nursing homes and rehabilitation centers, and consider repurposing these facilities to better serve this population.

The task force would be charged with the development of a state-wide facilities and resource plan and are required to report their findings to the Public Health Committee.

Appointed members of the task force will include professionals with expertise in the treatment of individuals with intellectual disabilities, professionals who have provided program support services to this population, and guardians or relatives of individual with intellectual disabilities, including those who have high-level needs. Members will also include the Commissioner of Developmental Services, the Secretary of the Office of Policy and Management, or their designees.

RESPONSE FROM ADMINISTRATION/AGENCY:

Jordan, A. Scheff, Commissioner, Department of Developmental Services (DDS):

The DDS appreciates the creativity of stakeholders who are trying to develop additional residential options for individuals with intellectual disability (ID), but has concerns with the charge of the proposed task force from a policy, fiscal and legal perspective. Across the nation and certainly within Connecticut, the policy direction has been against the use of congregate facilities for the purposes of serving individuals with intellectual disability. A move

in the other direction or even an investigation into its potential benefits could be seen as violations of the Americans with Disabilities Act, the Olmstead Act, and the Centers for Medicare and Medicaid Services' (CMS) final settings rule.

Nationally, there has been a shift from institutional settings to settings that promote fuller community integration. CMS issued a Final Settings Rule that reflects its intention to ensure that individuals receiving funding and services through Medicaid's home and community-based services (HCBS) programs have access to community living and are able to receive services in the most integrated setting possible. The development of a model that separates individuals with ID from the general population would potentially invite the oversight of both CMS and the Department of Justice (DOJ).

In the guidance on new residential construction, CMS states, "It was CMS' expectation that after the publication of the final regulation, stakeholders would not invest in the construction of settings that are presumed to have institutional qualities, but would instead create options that promote full community integration, per the HCBS Settings regulatory requirements found in 42 CFR 441.301(c)(4)(i), 441.710(a)(1)(i), and 441.530(a)(1)(ii), respectively."

While nursing home costs are covered under Medicaid and not federal HCBS waivers, the national perspective is similar regarding what the federal government is willing to consider as appropriate services.

Other states have considered or implemented similar ideas, and for example, in Massachusetts such action triggered an investigation and oversight from the US Department of Justice. The intent of this legislation would violate the mission and vision of the department recognizing the inherent worth of individuals with intellectual disability and their right to live in the most integrated setting possible, such as the nationally recognized Money Follows the Person (MFP) program in Connecticut. According to the Department of Social Service, 4,950 individuals have transitioned from nursing homes to the community under MFP and, of those, 255 are individuals with intellectual disability who receive Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care.

The DDS cannot support any model that will segregate individuals with ID in any way from the general population. Our progress can be seen in recent decisions to close two of five congregate care settings, and the 1986 decision to close admissions to Southbury Training School (STS).

DDS is currently exploring several opportunities to expand available residential options for individuals with intellectual disability through the ID Partnership and with new funding proposed by Governor Malloy as part of the FY19 mid-term budget adjustments. The department cannot support investing our limited staff resources in a task force with goals which we are opposed to and for the many reasons previously stated.

It is important to note that there are multiple entities including the ID Partnership and the Medical Assistance Program Oversight Council's Developmental Disabilities Work Group, that are already charged with examining our current system and making recommendations on innovation to our continuum of supports.

NATURE AND SOURCES OF SUPPORT:

Mathew Barret, President and CEO, Connecticut Association of Healthcare Facilities:

The 3,000 open beds in Connecticut nursing homes could be used to provide residential services for individuals with intellectual disabilities as part of a larger spectrum of options. These spaces could serve both those with highly complex medical needs and those with less-intensive medical needs. The bill is cost-effective and consistent with Connecticut's current long-term services rebalancing and nursing home restricting initiatives.

Arlene Reith: Over 50% of individuals with Down Syndrome will develop Alzheimer's Disease, which will require many of them to spend time in nursing homes that are unprepared to care for this population. The task force should create facilities that can serve individuals with complex needs.

NATURE AND SOURCES OF OPPOSITION:

Melissa Marshall, Connecticut Cross Disability Lifespan Alliance (CCDLA): The CCDLA stands with a coalition of more than 200 members of the disability rights movement in opposition to this bill. The task force's focus on nursing homes and rehabilitative centers will lead to isolation and segregation of people with intellectual disabilities. Individuals on the waiting list for services could benefit from the closure of Southbury Training School and the Regional Centers. The CCDLA organizations are concerned with the establishment of another task force given the existing literature and testimony suggesting improvements to Connecticut's mental health system.

Collette L. Bement, Ph.D: Non-profit community providers are already providing support to individuals with I/DD across their lifespan and individuals with high levels of need. The legislature should focus on person-centered planning and community-based residential supports.

Lauralyn Lewis: I am in support of the original intent of the bill, to care for individuals with intellectual disabilities with mental health issues and aging individuals with complex issues, but I don't think the current language reflects that intent. Instead, the bill should create a task force of stakeholders similar to the Medicaid Assistance Program Committee's involvement with their Developmental Disabilities Working Group. My recommendation is that future efforts include input from the ID Partnership to foster transparency.

Lisa and Dan Hennessey: Having examined the budget analysis of Southbury Training School, we do not believe nursing homes are an appropriate place to put public funding for this population.

Christina Calabro, Executive Director, Western Connecticut Association of Human

Rights: The proposed bill represents a reversal of recent efforts to move seniors and individuals with intellectual disabilities back to the community with appropriate support.

Jamie Lazaroff: Connecticut has moved nearly 5,000 seniors and individuals with intellectual disabilities out of nursing homes since 2005 and I believe this bill would work to reverse our progress. The task force described in the bill lacks representation from self-advocates.

Benjamin Davies, Advocacy Manager, MARC: MARC fears this bill would reverse the state's recent progress in moving seniors and individuals with intellectual disabilities back to the community. MARC does not believe nursing homes would be a cost-effective solution. Instead, the state should invest in nonprofit community-based providers who have experience serving this population.

Tom Florentino, Arc of Connecticut: Arc of Connecticut believes institutional care is both an inefficient use of the state's resources and harmful to the health of individuals with intellectual disabilities. Moving seniors from institutional settings to the community saves Connecticut \$2,500 per person, per month in Medicaid costs.

Susan Desrosiers, Executive Director, The Arc – Quinebaug Valley: The cost of care is too high in institutional settings. Legislatures should invest in nonprofit community-based providers with expertise in supporting individuals with intellectual disabilities.

Imelda Reno: This testimony opposes the use of nursing homes and rehabilitation centers to house individuals with intellectual disabilities. Nonprofit community-based providers are both less costly and more qualified to serve this population.

Shelagh McClure, Connecticut Council on Developmental Disabilities: The Council opposes this bill and urges legislators to support programs that allow individuals to remain in their homes, such as Money Follows the Person and the Independent Living Centers. The Council recognizes that the waiting list for residential services is too long in Connecticut but would like DDS to be less reliant on these organizations.

Reported by: Jacqueline Goldbach

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