Human Services Committee
JOINT FAVORABLE REPORT

Bill No.:	HB-7108
Title:	AN ACT CONCERNING AUTISM AND INTELLECTUAL DISABILITY SERVICES AND ABUSE AND NEGLECT INVESTIGATIONS.
Vote Date:	3/19/2025
Vote Action:	Joint Favorable Substitute
PH Date:	3/6/2025
File No.:	470

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Human Services Committee

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REASONS FOR BILL:

Increases in prevalence of autism and other disorders has drawn attention to the evolving needs for services in the home, school, and the community for those individuals with high level of need (LON). It has become clear that changes are needed in eligibility criteria that currently includes intelligence quotient (IQ) and other measures using current assessment processes within several state agencies. An urgent reminder of the need for reassessment of the availability and the eligibility of HCBS and other services is the number of individuals that become "stuck" in EDs, sometimes for weeks or even months, when it is inappropriate to return to their home and no appropriate placement in the community is available. In 2023 PA 23-137 directed further study and OPM commissioned a report: "Evaluation of Statutory Definitions and Regulations: Intellectual Disability and Related Programs" resulting in five recommendations. This bill is an effort to respond to Recommendation 1: Conduct Additional Research and Analysis on Impact of Changes and Recommendation 2: Revisit Statutory Definition of Intellectual Disability.

SUBSTITUTE LANGUAGE:

The title was changed; in Section 1(d)(5), "with high" was changed to "who have significant" for clarity; in Section 2(c), subdivisions (1)(B) and (2) were redrafted and "need" was inserted before "not be limited" for clarity; the second reference to "Sec. 4" was changed to "Sec. 5" for accuracy; in newly designated Section 5(c)(2) and Section 6(f)(2), "investigated by a contracted provider and the department" was inserted before "in each category" for clarity; in Section 5(c)(7) and Section 6(f)(7), "department" was inserted before "response times" for clarity; and in Sections (5)(a)(7)(B) and 6(f)(7)(B), "sixty days" was changed to "not more than sixty days" for internal consistency.

RESPONSE FROM ADMINISTRATION/AGENCY:

Connecticut Department of Social Services (DSS), Commissioner, Andrea Barton Reeves: expressed neither support nor opposition, yet cautions the bill will require extensive planning and reporting regarding strategies for altering the eligibility criteria and the delivery of autism services in Connecticut. DSS has reviewed the final report of the study commissioned by Public Act 23-137, Section 4, titled the “Evaluation of Statutory Definitions and Regulations: Intellectual Disability and Related Programs,” and participated in the working group during its research period. The Department appreciates the recommendation to further study these important issues, however, this analysis will have a significant financial impact on the state, as well as an unknown impact on the availability of services for the *individuals that would either fall into or out of eligibility*. Cost, member access, and sustained commitment to existing participants and those currently waiting for services must be taken into careful consideration. Such changes would require a thorough evaluation to allow DSS to identify the various areas of impact, including the section 1915(c) home and community-based services waivers, section 1915(k) Community First Choice state plan option, state plan services for individuals with autism, services provided by our sister agency, DDS and other programs and supports.

Connecticut Department of Developmental Services (DDS), Commissioner, Jordan A. Scheff: expressed neither support nor opposition, but includes unique observations from the vantage point of DDS. The bill calls for a robust study process under the auspices of OPM to implement the recommendations of the recent report regarding eligibility for services available for individuals with intellectual disability or autism. These recommendations call for exploration, research, and analysis of potential changes to statutory definitions, eligibility criteria, and needs assessment tools, and DDS agrees that any such recommendations would demand substantial staff resources and fiscal support that are not reflected in the budget. Section 2 requires OPM staff to serve as a liaison to hospitals caring for certain individuals and to report regarding alternatives to hospitalizations. DDS already does much of this work and is in regular communication with hospitals on individual cases and has an established escalation process to address any urgent or emergency matters, meeting regularly with CT Hospital Association. Given these ongoing relationships and protocols, the Department has concerns about the responsibility for this work being transitioned to a sister agency (see OPM testimony summary below re: this role). Sections 3, 4 and 5 require DDS to report annually regarding the reports of abuse and neglect received regarding individuals with ID, individuals receiving services through the autism spectrum disorder program at DSS, and through the protection and advocacy agency. It is stated DDS has a robust process in place for receiving and processing such reports and has no concerns with providing summaries of this information annually. Regarding the reporting requirements in Section 6, DDS already provides this information through our quarterly Management Information Reports, posted on the DDS website upon publication, and the Comprehensive Financial Status Reports, submitted to OPM and OFA a monthly basis.

Connecticut Office of Policy and Management (OPM), Lead Planning Analyst, Tara Viens: opposes the bill as the necessary funding needed to successfully implement the requirements are not in the Governor's budget. The changes to be explored include the removal of the IQ as a criterion for eligibility for state services for individuals with intellectual disability, as well as a broader definition of developmental disorder that includes intellectual disability, autism, and other conditions that result in impairment of general intellectual functioning or adaptive behavior. If a new definition of developmental disorder is adopted for determining eligibility, it would also impact the Autism waiver administered by the Department of Social Services (DSS). A previous study that did not necessitate extensive data analysis, predictive modelling, or interagency strategic planning required an investment of $200,000. Based on industry estimates, OPM projects funding of approximately $800,000 would be needed to undertake this work. Given the uncertainty surrounding changes at the federal level with proposed funding reductions to programs (e.g., Medicaid & SpEd), there is a substantial risk to the continuity of services for individuals with disabilities who currently qualify in Connecticut. Exploring eligibility expansion at this time, without a clear understanding of future funding availability, would be imprudent, as these changes may further destabilize services for those who are already receiving support, and ultimately not achieve the intended goal of broader service availability. Section 2 directs the OPM statewide autism services coordinator to liaise with hospitals in Connecticut regarding the provision of care for patients with autism and intellectual and developmental disabilities (IDD). OPM believes the functions outlined in Section 2 would be better suited to operational executive branch agencies, who already employ case managers, care coordinators, ombudspersons, and other staff to assist hospitals, depending on a patient’s service needs (see DDS testimony summary above re: this role). The research, analysis, and reporting requirements required under H.B. 7108 are costly, time-consuming and will not ultimately improve access to services and supports for Connecticut residents with autism or IDD who have a higher IQ. Engaging in additional analysis without the proper assurance that more individuals will ultimately be able to access services risks creates expectations that the state is not currently positioned to meet.

NATURE AND SOURCES OF SUPPORT:

Center for Children's Advocacy (CCA), Executive Director, Sarah Healy Eagan, JD: supports the bill as it will move CT closer to expanding eligibility to individuals with developmental disabilities, as most other states no longer use IQ as a measure of eligibility. CCA supports the intent of Section 2 that requires OPM to designate a liaison to hospitals as data continues to show children with autism and intellectually disability (ID) get "stuck" in hospital EDs due to lack of community-based services, with one study showing an average length of stay of 11 days in hospital EDs. Regarding Sections 3, 4, and 5, CCA strongly supports greater transparency and accountability for instances of abuse and neglect of persons with ID, and agrees that DDS needs additional funding, and notes that concerns persist regarding critical incidents of abuse and neglect, especially related to the timing of corrective action. Specifically, CT did not ensure that group homes reported all incidents involving potential abuse and neglect to DDS, and DDS did not implement new analytical procedures to detect incidents involving potential abuse & neglect during the audit period (US-HHS OIG). CCA recommends that the Human Services Committee require, 1) an annual report and review of DDS and their compliance with federal requirements pertaining to safety and quality of care with HCBC Medicaid waiver funds, 2) DDS report how many abuse/neglect petitions are conducted and how many are self-investigated by the provider, 3) DDS report how many programmatic findings of abuse/neglect it makes and whether they lead to a requirement for corrective action by the provider, 4) that DDS be required to report regarding steps it is taking to ensure corrective actions are actually implemented by the provider, 5) that DDS be required to report how often, and how timely it re-visits providers are substantiations of abuse & neglect and issuance of corrective actions.

Connecticut Hospital Association, Anonymous: supports Section 2 that would create a statewide coordinator to serve as a liaison with hospitals that care for patients with autism spectrum disorder or with ID or IDD. CHA and Connecticut's hospitals have been working for several years with various CT agencies, including DDS, and the legislature to better address the needs of complex patients, including those with IDD and BH issues. There is an urgent need to increase the availability of community-based beds and resources for these patients who otherwise often get "stuck" in the hospital when their needs would be better served in a different care setting. A January survey of our members identified the number of "stuck" or "difficult to place patients" present in each hospital. More than 200 patients, who are clients of or accessing services from the state, were stuck in hospitals. (DCF: 26, DDS: 42, DSS: 109, DMHAS: 49, and those with multiple agencies: 48). An additional 100 patients were stuck in hospitals due to complex medical needs, including the need for ventilator care, dialysis, behavioral health services, or other complex care needs. The lack of appropriate care settings, too few community or specialty facility beds, and frequent delays due to limited agency resources or probate court proceedings, converge to create a domino effect that significantly reduces timely throughput at hospitals. Having an agency liaison is a welcome step that hopefully will have an immediate positive impact in assisting hospitals to place patients in the right setting of care as soon as possible.

Connecticut Council on Developmental Disabilities, Executive Director, Walter Glomb: supports the bill that would start the process to remove IQ scores as a component of eligibility and expand to a broader definition of developmental disability that includes intellectual disability, autism, and any other condition that results in impairment of general intellectual functioning or adaptive behavior (meaning the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group as measured by assessments that are individualized, standardized and clinically and culturally appropriate to the individual). Detailed analysis, including statistical evidence and an extensive bibliography, is provided in the full testimony.

Connecticut Children's Pediatric Health System, Develomental-Behavioral Pediatrician, Dr. Robert D. Keder, MD: strongly supports the provision that removes IQ as a determining factor for eligibility for Autism services. This change will allow OPM to serve a broader population of children with ASD who currently do not qualify for necessary support. Further, children with IDDs, especially very social young children who do not have autism and are too young to have appropriate administration of IQ assessments are excluded from access to evidence-based supports and interventions. Expanding the eligibility for children with IDDs under 18 years old would address behavioral problems more successfully at younger ages, reduce risk of abuse/neglect, and reduce risk of future inappropriate placement or need for inpatient levels of care. Children with IDDs should have access to well-known evidence-based practices including BPT, PCIT, and RUBI and/or BCBA consultation supports. The bill suggests efforts to enhance collaboration with hospitals to find alternative care options for children with ASD, DD, and IDD who do not require inpatient hospital care. This initiative is crucial in ensuring that children receive appropriate care in the least restrictive and most supportive environments. An extensive glossary of terms is appended to the testimony.

The Arc Connecticut, Inc., Director of Advocacy, Carol Scully: supports the bill seeking to implement the first two recommendations of the recent report regarding definitions and regulations regarding intellectual disability commissioned by OPM. Nationwide, eligibility criteria and assessments are being revisited to improve access for persons with IDD to services and supports. CT is one of many states evaluating IQ as an eligibility assessment tool, including Arkansas, Massachusetts, Minnesota, Vermont, and Washington State. The Arc Connecticut also supports the greater transparency of abuse and neglect cases in the provision of this bill directing the Commissioner of DDS to file a report by January 15, 2026, and annually thereafter identifying the number of abuse and neglect complaints against former (state) employees received in the preceding calendar year.

Nuvance Health, Danbury and New Milford Hospitals, Vice Chair of Emergency Medicine, Dr. Douglas Smith, MD: supports Section 2 seeking to create a statewide coordinator/liaison to consult with agencies that serve people with ASD and IDD and help hospitals navigate the difficult course of being sure patients are discharged to the right setting of care as soon as practicable. There is an urgent need to increase the availability of community-based beds and resources for these patients who otherwise get “stuck” in the hospital, when their needs would be better served in a different care setting. The lack of appropriate care settings, too few community or specialty-facility beds, and often delays in some Probate Court’s proceedings, create a domino effect that significantly reduces timely throughput in the Emergency Department and across the continuum of care. Recently, one 17-year-old spent two months in the ED and another minor was in the ED for several weeks, and clinical nursing staff were asked to help the person with their homework. It was stated, having an agency liaison will be a welcome step that will have an immediate positive impact in assisting hospitals to place patients in the right setting of care as soon as possible.

Connecticut Community Nonprofit Alliance (The Alliance), Senior Public Policy & Division Advisor, Julia Wilcox: supports the raised bill which would improve services and support for individuals with autism and intellectual disabilities in Connecticut, by introducing new definitions and assessment criteria that prioritize culturally appropriate evaluations. Furthermore, the bill establishes new staff positions to coordinate autism services and creates an interagency coalition aimed at improving service delivery for individuals with intellectual and developmental disabilities, along with required annual updates on abuse and neglect complaints, with additional accountability, and transparency.

THE FOLLOWING INDIVIDUALS PROVIDED TESTIMONY IN SUPPORT OF THE LEGISLATION:

Allyn, Christian: sibling with Spina Bifida.
Baughman, Michelle: person with ASD & high IQ not qualified for services.
Brazalovich, Joanne: parent of young adult with ASD; waited 10 years for waiver services.
Breunig, Lisa: adoptive parent of 13 yo w/ASD & Type 1 DM on Autism waiver waitlist; believes earlier services would have had significant impact.
Brodeur, Jeannette: parent of two adult sons w/ASD with very different access to services because of different IQ levels (higher IQ + higher LON - fewer services = poor outcomes).
Freitas, Joe: foster parent of several ASD children with borderline IQ that did not qualify for adequate supports; often results in ongoing challenges as adults, e.g., drug abuse, homelessness, and incarceration, etc.
Freitas, Mary Lou: parent of a child living in a group home; reports of abuse but inadequate information and response; recommends investigation by 3rd party, not the agency of care.
Hardy, Mary: parent of adult child with significant disabilities, BH issues, and poor adaptive skills, but their IQ exceeds the threshold; would benefit from additional services but does not qualify.
Lambert, Beth: BCBA and parent of an adult son with profound ASD; worries about his care after her death and welcomes provisions of increased reporting and transparency re: abuse & neglect in HCBC.
Thomas, Delia: parent of two young adults with multiple disabilities and expresses appreciation for DDS services. Her child with a low IQ has had more supports/services and has higher function than her other child with a somewhat higher IQ but a much higher LON yet lacks eligibility for care. "It is time to readjust our thinking so that we can give those who need the support a chance at a productive and better life."
Traceski, Francis: Using IQ as a qualifier excludes many individuals who live with IDD and other disabilities in need of services within the HCBS waiver and other services. Clarifying the eligibility for individuals with profound DD with a high LON who do not meet the current criteria for support is a critical reason for continuing this work.
Willis, Crystal: calls for proper investigation and accountability in cases of abuse & neglect.

NATURE AND SOURCES OF OPPOSITION:

Rare Disease Advisory Council (RDAC), Co-Chair, Lesley Bennett: opposes the bill as the RDAC is not named as one of the participants in the group that will be working with OPM to implement recommendations 1 & 2 of the November 2024 OPM-Altarum Report concerning ID. This creates an equity issue for those living with rare disorders known to cause ID or IDD. All groups or state advisory councils representing those who have a diagnosis of ID or a condition known to cause ID should be included in these decisions (see testimony for a list of several conditions). Members of the RDAC agree that it time to modernize the state’s statutory definition of ID/IDD and the level-of need tools used by DDS and DSS for waiver eligibility assessments. The Committee is urged to amend Section 1(b) of HB7108 to include the RDAC as a participant in the group addressing ID/IDD decisions and DDS waivers eligibility.

Rare Disease Advisory Council (RDAC), Member, Brunetti, Colleen: opposes the proposed language of the bill as it makes no mention of those living with rare disease, particularly those with a diagnosis that carries with it a high chance of co-morbid ID. Further, the title and the language of the bill skews heavily towards autism, creating an equity issue for other conditions. The specific naming and inclusion of one set of diagnoses and the leaving out of others, or more precisely grouping them into simply “other than autism” is a serious oversight. It is said, the RDAC stands ready and willing to advocate for their community, but they must have a seat at the table. We strongly urge you to amend this bill to include representation of rare diseases which may result in an ID diagnosis as well, resulting in a more inclusionary and equitable result.

Rare Disease Advisory Council (RDAC), Member, Caruso, Mary: opposes the bill as it ignores the significance of the thousands of rare diseases that present with intellectual and developmental disabilities (IDD), autism, or both. It is stated, the RDAC is not asking for special treatment—only that those with rare diseases known to cause ID or IDD have equal access to DDS waivers. No single group should be favored in revising the ID/IDD definition or modernizing the level-of-need tools used by DDS or DSS. The RDAC’s expertise is essential to ensuring these critical policy decisions reflect the full spectrum of affected individuals. The Committee is respectfully urged to amend this bill to include the RDAC in Section 1(b). Their input is vital to crafting inclusive, equitable, and well-informed policies.

Reported by: Rebecca McClanahan **Date: April 9, 2025**