

Human Services Committee

JOINT FAVORABLE REPORT

Bill No.: HB-5001

AN ACT CONCERNING RESOURCES AND SUPPORT SERVICES FOR

Title: PERSONS WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY.

Vote Date: 3/22/2023

Vote Action: Joint Favorable Substitute Change of Reference to Appropriations

PH Date: 3/9/2023

File No.:

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SPONSORS OF BILL:

Human Services Committee

REASONS FOR BILL:

For years, the waiting list for individuals with an intellectual or developmental disability (I/DD) through the Department of Developmental Services (DDS) under the Medicaid waiver programs has not been reduced. Additionally, the waiting list for individuals with an autism spectrum disorder (ASD) through the Department of Social Services (DSS) has not been reduced. A lack of access to services, resources, and support has placed individuals and their families unsure of where to go to receive assistance. Due to the lack of funding, there has been a workforce crisis among providers that can provide quality care to the I/DD and ASD communities. Reducing the waiting lists will require the efforts of qualified and trained staff that are dedicated to providing the highest level of care.

The purpose of this bill is to appropriate funds to serve individuals with I/DD who are waiting for services through DDS and individuals with autism who are waiting for services through DSS and the Autism Waiver program; to require better data collection, management, and mandated reporting to the legislature regarding the I/DD population demographics and needs; to increase and promote better interagency communication and coordination; to mandate studies by key agencies and stakeholders to look at employment, transportation, special education, and eligibility concerns impacting the I/DD population; and to enhance and increase access to programs and services that positively impact the lives of individuals with I/DD or Autism.

SUBSTITUTE LANGUAGE:

The substitute language establishes within available appropriations "Transition Academy" to help persons with intellectual or developmental disabilities to transition from elementary

school system or living with parents to independent living. Creates bonding to help group homes finance 5,000-gallon water tank requirements for group homes. Additionally, it establishes new positions within the Office of Health Strategy and Office of Healthcare Advocate to coordinate services for persons with disabilities and/or autism spectrum disorder. Lastly, May 23rd is recognized as the state commemoration day for persons with intellectual and developmental disabilities.

RESPONSE FROM ADMINISTRATION/AGENCY:

Connecticut Council on Developmental Disabilities, Executive Director, Walter Glomb; supports this bill stating developing a new statutory definition for intellectual and developmental disabilities will result in changes and updates to programs to be by the revised definitions. It is stated the Council recently completed a review and analysis of existing services and supports for individuals living with developmental disabilities in the state and offers [various suggestions](#) that would improve the proposed provisions.

Connecticut Department of Education (CSDE), Commissioner, Charlene Russell-Tucker; takes no position on this bill stating there are concerns with Section 4 and the creation of new state statutory definitions for intellectual disabilities and developmental disabilities as it may conflict with federal special education law.

Department of Aging and Disability Services (ADS), Commissioner, Amy Porter; supports this bill stating the intention of this bill aligns with its mission. It is suggested that the workforce assistance program efforts be addressed through the Governor's Workforce Council since ADS is an existing partner. It is also suggested that the proposed deadlines be spaced out as there are overlapping deadlines for some agencies mentioned in the bill.

Department of Developmental Services (DDS), Commissioner, Jordan Scheff; supports this bill stating the proposals within this bill will improve access to services and safety measures for individuals with intellectual and developmental disabilities. It is suggested that the deadlines should be spaced out as there are overlapping deadlines for some agencies mentioned in the bill.

Department of Labor (DOL), Commissioner, Danté Bartolomeo; supports the intent of the bill stating it will expand services for the I/DD population. It is suggested that in Section 11, CT DOL be changed from a lead agency to a consulting role as the agency currently does not have a direct service delivery model nor funding to implement this program.

Department of Mental Health and Addiction Services (DMHAS), Commissioner, Nancy Navarretta; neither supports nor opposes stating that there are current funding efforts throughout the state that provides a variety of employment and education services that are specific to an individual. It is stated that the healthcare worker shortage in the behavioral health system is currently being addressed through various programs and suggested that current initiatives are assessed to avoid duplication of services. It is suggested that DMHAS have input when redefining the I/DD population as it may have budgetary costs.

Department of Social Services (DSS), Commissioner, Andrea Barton Reeves; supports the intent of this bill and offers suggested changes. It is stated that DDS is the lead agency responsible for providing services to the I/DD population, and therefore, should be the

appropriate agency to work on reducing waiting lists. It is stated that since the Governor's proposed budget does not include appropriations for ASD waiver expansions or increasing the asset and income limit for HUSKY C, the agency opposes these proposals. It is suggested the bill language be amended to be more specific when identifying the types of coverage intended to avoid any conflicts with other statutory provisions.

Office of the Child Advocate, Child Advocate, Sarah Eagan; supports this bill stating the importance of improving access to services for people with intellectual and developmental disabilities. It is suggested that recommendations about workforce development be included that would have reimbursement rates for services reflect the actual costs, funding for hiring and retaining qualified workforce, and create a behavioral health workforce development center.

Office of Workforce Strategy, Chief Workforce Officer, Kelli-Marie Vallieres; took no position on this bill stating OWS is aware of the need to provide and expand opportunities for Persons with Intellectual and Developmental Disabilities and build and retain a workforce that serves this population. It is stated there are existing programs that address many of the workforce-related aspects included in the proposal.

NATURE AND SOURCES OF SUPPORT:

The Arc of Connecticut, Inc., Executive Director, Win Everts; supports this bill stating the workforce crisis is the largest obstacle to reducing waiting lists for services. It is stated a workforce is needed to onboard new individuals to services along with the development of appropriate services for currently under-served populations.

The Arc Eastern Connecticut, CEO, Kathleen Stauffer; supports this bill stating safety nets have been broken leaving staff without the proper means to provide care and services. It is suggested that the state shutdowns its institutions and provide a 9 percent budget increase for the state's human services safety net. It is stated that there should be an index for future increases in annual inflation growth.

Autism Speaks, State Government Affairs Director, Emily Frankel; supports this bill stating home and community-based services are vital to improving the quality of life for individuals with intellectual and developmental disabilities. It is stated that expanding the Medicaid waiver is a step in the right direction in addressing the long wait times.

Connecticut Association for Behavior Analysis, Licensed Behavior Analyst, Justine Randall; supports this bill stating the creation of the Behavioral Health and Human Services Career Pipeline program will allow that there are enough providers to service the I/DD population. It is suggested that there should be an increase in access to behavior analyst services including insurance coverage and Medicaid policies.

Connecticut Community Nonprofit Alliance, Director of Government Relations, Ben Shaiken; supports this bill stating it is critical to expanding the employment options for the I/DD population in Connecticut. It is stated that thousands of individuals with I/DD are on the waiting list for residential services and there are not enough allocated resources to support those eligible for care. It is suggested that funding be increased for nonprofit providers to

cover the true cost of inflation, eliminate the dual service system, eliminate contract requirements, and establish legislative oversight.

Connecticut Council on Developmental Disabilities, Chair, Doris Maldonado Mendez; supports this bill and [shares her experience](#) as a mother with children who have developmental disabilities.

The Connecticut Hospital Association; supports this bill stating Section 11 makes important improvements and investments in the state programs created to support individuals with disabilities and those with intellectual and developmental disabilities. It is stated these provisions invest in the training, education, hiring, and retaining of behavioral health and health and human services providers.

Connecticut Legal Rights Project, Executive Director, Kathy Flaherty; supports this bill stating some of their clients have intellectual and developmental disabilities. It is suggested that the definition of developmental disability be revised to reflect the federal definition. It is also suggested that the income and asset limits be increased for HUSKY C eligibility.

Connecticut Rate Action Network, State Ambassador, Lesley Bennett; supports this bill stating the provisions will help the I/DD population. It is suggested that Sections 4 and 5 be amended as it does not seem to be inclusive of other disorders and only focus on one group. It is stated not including other groups that are the primary cause of I/DD, such as Down Syndrome Fragile X, birth defects, or rare genetic disorders, may violate the state's policies on health equity.

Connecticut Voices for Children, Intern, Jeremy Otridge; supports this bill stating Connecticut has been lacking in providing services to the I/DD population and the proposed provisions will address these shortcomings. It is stated Connecticut has the most restrictive definition of intellectual disability in the country. It is also stated there is a need to provide supportive services to the I/DD population so they can be active community members.

Disability Rights CT, Litigation Attorney, Sheldon Toubman; supports this bill stating that Sections 6 and 7 will help to address the discrimination against people with disabilities in our Medicaid program. It is stated that HUSKY C has much lower income and asset limits than the other HUSKY programs while most of the programs have no asset limits at all. It is suggested that HUSKY C income and asset limits be increased.

FOCUS Center for Autism, Transitional Case Manager, Nicolas Iannacito; supports this bill stating that he feels individuals with more complex developmental disorders or disabilities should not be punished for their intellectual ability as a result of long delays.

FOCUS Center for Autism, Executive Director, Donna Swanson; supports this bill stating that without funding and support, it is difficult to provide services to those on the spectrum.

HARC, Inc., Vice Chair of Public Policy and Advocacy, Michelle Joyce; supports this bill stating years of stagnant funding have been difficult on private providers that receive DDS support. It is suggested that moving services for individuals living in facilities to the nonprofit sector will be cost-effective and can be reinvested into service delivery. It is also stated

changes to the service system will help the I/DD population as providers will be paid more and the wait list will decrease.

Horizons, Founder & CEO, Chris McNaboe; supports this bill stating they have had to end services over the past 2 years for 32 people with I/DD due to staff shortages. It is stated that staff is leaving as they are finding higher wages elsewhere due to not receiving a raise in years and without experienced staff, they have been unable to train newly hired staff.

Journey Found, Inc., CEO, Tracey Walker; supports this bill stating it is difficult to create new services due to staff shortages and a lack in revenue due to not having a full workforce. It is stated having the funding to cover the true cost of delivering these services can help the I/DD population.

Keep the Promise Coalition, Co-Chair, Marcia DuFore; supports this bill stating that limiting the eligibility for individuals with developmental disabilities will prevent them from crucial services. It is stated those with developmental disabilities need these services to live their lives.

Keep the Promise Coalition (KTP), Coordinator & Community Organizer, Jordan Fairchild; supports this bill stating that the current statutory definition of intellectual disabilities restricts many since there is a maximum IQ requirement. It is stated removing this and including intellectual and developmental disabilities will allow further access to services and will not exclude individuals and their family members.

MARC, Inc. of Manchester, Executive Director, Nathan Briggs; supports this bill stating there has been an increased level of need amongst the I/DD population, but the funding levels have been stagnant. It is stated not being able to provide a livable wage hurts the workforce and retention of employees. It is suggested that when contracting with the state, there are many costly and unnecessary administrative burdens on providers, and these should be removed.

MARC, Inc. of Manchester, Residential Director, Peter Engelbrecht; supports this bill stating the I/DD population should have an opportunity to contribute to their community and the work of service providers can ensure this can become a reality.

MARC, Inc. of Manchester, President & CEO, Kevin Zingler; supports this bill stating the changes proposed will improve the service system for the I/DD population and paying providers the true cost of services will reduce the waiting list and grow the overall system.

Marrakech, President & CEO, Heather LaTorra; supports this bill stating they are currently unable to deliver a full array of services to individuals who are no longer on the wait list due to a lack of funding to cover the actual cost. It is stated there is currently a 20 percent vacancy rate and enough funding is needed to continue the delivery of services to individuals and families.

National Multiple Sclerosis Society, Senior Manager of Advocacy, Laura Hoch; supports this bill stating improvements to Connecticut's accessible transportation infrastructure will reduce barriers for individuals living with a disability and this is a good first step in providing accessible transportation for all.

TransitionCT, Managing Partner, Ann Ramos; supports this bill stating by managing a DDS agency, they have had to turn away individuals due to their IQ level being a few points above the threshold as they do not qualify for services. It is stated that with the right changes these individuals and their families can get the services needed to have a fulfilling life.

WeCAHR, Executive Director, Christina Calabro; supports this bill stating the provisions will address the many concerns the I/DD community has faced for years.

Windsor Public Schools, Special Educator, Sara Anderson-Potts; supports this bill stating she has seen firsthand the inequities young adults with developmental disabilities are faced. It is stated other states have created inclusionary definitions of developmental disability and Connecticut can do the same.

Connecticut Resident, Aida Abril; supports this bill stating that removing the wait list will allow military families to retire in Connecticut knowing their children will have access to therapies and services.

Connecticut Resident, Christian Allyn; supports this bill stating he is an adult with high-functioning autism. It is stated that he was able to earn a bachelor's degree and currently has a part-time job. It is stated if he has access to individualized support and services such as job training, he would be able to find a full-time job. It is stated disabled individuals deserve to succeed in life and contribute to society.

Connecticut Resident, Lisa Allyn; supports this bill stating she is a mother of two adult sons with developmental disabilities. It is stated that due to their IQ, they cannot receive services from DDS, and it is not fair that he does not have access to services due to his IQ. It is stated removing the IQ eligibility criteria will allow her son the support and services to have an increased quality of life.

Connecticut Resident, Carol Barans; supports this bill stating the Medicaid home and community-based waiver for autism has been effective in helping individuals with ASD find employment and to live independently.

Connecticut Resident, New Britain, Adrienne Benjamin; supports this bill stating staffing shortage and waiting list are closely linked. It is stated more staff must be provided to offer care and resources. It is also stated the rates must be increased for nonprofits and the wages for direct support professionals.

Connecticut Resident, West Hartford, Darlene Borre; supports this bill stating that young adults with severe autism with a high level of need (LON) are entering the adult day program system at age 22 to find day program agencies are having a hiring crisis, agencies are rejecting young adults with severe autism because they require individualized support, and prior programs designed for high LONs are being closed across CT without replacement programs.

Connecticut Resident, East Granby, Joanne Brazalovich; supports the bill stating the disabled community needs support and services to be successful in life.

Connecticut Resident, Cathy Catey; supports this bill stating individuals who suffer from developmental disabilities but are not intellectually disabled have major life challenges. It is suggested the eligibility for individuals with developmental disabilities be included rather than just intellectual disabilities.

Connecticut Resident, Lisa Clark; supports this bill stating that the removal of the IQ threshold will address the discrimination individuals with developmental disabilities have faced and will increase inclusivity. It is stated this bill will allow her son to achieve his dreams and aspirations.

Connecticut Resident, Wallingford, Dawn DeMatteo; supports this bill stating her son was on the waitlist for over 15 years and since getting services he is living in a group home. It is stated the services provided to the I/DD population have a great impact on their livelihoods. It is also stated that nonprofits need to be funded to support these efforts and to continue serving this population.

Connecticut Resident, Tom Fiorentino; supports this bill stating that private providers and state agencies are providing efficient services. It is stated now is the time to expand these existing services rather than create new pilot programs.

Connecticut Resident, Special Education Teacher, Susan Kittredge; supports this bill stating that the maximum qualifying IQ is not the practice used in the human services and education field. It is stated that limiting access to services to only individuals with intellectual disabilities is exclusionary and discriminatory.

Connecticut Resident, South Windsor, Diane Olmsted; supports this bill stating increased funding will provide necessary services and support for individuals with disabilities. She [shared a personal story](#) regarding her son and his experience while residing in a private group home. It is stated her son now resides at a DDS public group home and there has been a noticeable difference in his care as they have been able to meet his level of need.

Connecticut Resident, Toni Pederson; supports this bill stating expanding employment opportunities and transportation access will allow those with neurological disabilities the ability to display their talents in the job market.

Connecticut Resident, Unionville, Edward Preneta; supports this bill stating that it seeks to do much of the same as the CGA Advisory Committee, the Council on DD, and the now-named Department of Developmental Services (DDS) did in the early 2000s.

Connecticut Resident, Debra Yurschak Rich; supports this bill stating the staffing crisis will be rectified so that programs can accept individuals requiring 1:1 support.

Connecticut Resident, Waterford, Annemarie Ryan; supports this bill stating that reducing and eliminating the waitlist for the autism waiver program's services and supports is crucial to many, including her brother.

Connecticut Resident, Elaine Santiago; supports this bill stating removing the IQ criteria will help individuals with autism who do not meet the threshold to be considered intellectually

disabled, and therefore, cannot receive services from DDS. It is stated without DDS support, these services are costly to afford out of pocket for most families.

Connecticut Resident, Patrick Strout; supports this bill stating he has autism spectrum disorder. It is stated including those with autism and removing the IQ factor will allow services to be provided regardless of the number.

Connecticut Resident, Delia Thomas; supports this bill stating that providing DDS services will be beneficial for all and supporting individuals with developmental disabilities will allow them to become integral members of the community.

The following individuals have submitted written testimony in support of this bill. It is stated the proposed components will address the many concerns the I/DD community has faced for years and promote overall safety and well-being.

Connecticut Resident, Rocky Hill, Wayne Camarro

Connecticut Resident, Branford, Marina Derman

Connecticut Resident, Berlin, Julie Erickson

Connecticut Resident, Berlin, Stephen Nims

Connecticut Resident, Burlington, Annette LeBlanc

Connecticut Resident, Canton, KayO Christopher

Connecticut Resident, Colchester, Stan Soby

Connecticut Resident, Coventry, Michelle Heimall

Connecticut Resident, Cromwell, John Whitney

Connecticut Resident, Derby, Mary Ellen Corey DuBail

Connecticut Resident, Farmington, Matthew Donelan

Connecticut Resident, Griswold, Jo-Ann Flynn

Connecticut Resident, Guilford, Terry O'Hara

Connecticut Resident, Hamden, Venezia Michalsen

Connecticut Resident, Hamden, Halle Lisette Pierce

Connecticut Resident, Hamden, Ricardo D Rogayan

Connecticut Resident, Harwinton, Cheryl Dunbar

Connecticut Resident, Milford, Marlene Procino

Connecticut Resident, New Canaan, Alyssa MacKenzie

Connecticut Resident, New Canaan, Elaine MacKenzie

Connecticut Resident, New Canaan, Chris MacKenzie

Connecticut Resident, New Haven, Myra Stanley

Connecticut Resident, Westport, Mickey Herbst

Connecticut Resident, Tolland, Susan Lucek-Hughes

Connecticut Resident, Old Lyme, Pam Ingersoll

Connecticut Resident, Preston, Sue Guiher

Connecticut Resident, Quaker Hill, Eleanor Mariani

Connecticut Resident, Quaker Hill, Ron Murallo

Connecticut Resident, Ridgefield, Sheryl Knapp

Connecticut Resident, Fairfield, Marian Leal

Connecticut Resident, Stafford Springs, David Bachiochi

Connecticut Resident, Simsbury, James Lewis

Connecticut Resident, Simsbury, Lynn Lewis

Connecticut Resident, Stratford, Ann Melody Lehrman

Connecticut Resident, Tolland, Kim Little
Connecticut Resident, Trumbull, Lee Ann Schlatter
Connecticut Resident, Tolland, Connecticut
Connecticut Resident, Tolland, Annette Scully
Connecticut Resident, Trumbull, Todd Schlatter
Connecticut Resident, Seymour, Elaine Sojka
Connecticut Resident, Simsbury, Barbara Wehrly
Connecticut Resident, West Hartford, Mary-Ann Langton
Connecticut Resident, Westport, Diane Yormark
Connecticut Resident, Maggie Goodwin
Connecticut Resident, Carol Hulbert
Connecticut Resident, Robert Johnston
Connecticut, Suffield, John Kearney
Connecticut Resident, Eilene Kleva
Connecticut Resident, Shannon Leary Knall
Connecticut Resident, Mary Hardy
Connecticut Resident, Melissa Martins
Connecticut Resident, Enid Corash Mikulski
Connecticut Resident, Fairfield, Noreen Noll
Connecticut Resident, Richard Rothstein
Connecticut Resident, Henry Sikorski
Connecticut Resident, Lisa Silva
Connecticut Resident, Victoria Smith
Connecticut Resident, Michael Alan Snyder
Connecticut Resident, Britt Spiegel
Connecticut Resident, Raquel Stabinski-Leib
Connecticut Resident, Kathryn Strout
Connecticut Resident, Trumbull, Diane Vergara
Connecticut Resident, Special Education Teacher, Vickianne Palma
MARC Inc. of Manchester, Direct Support Professional, Laura Kelley

Four people submitted testimony anonymously in support of this bill.

NATURE AND SOURCES OF OPPOSITION:

None stated.

NATURE AND SOURCES OF GENERAL COMMENTS:

ABC Family Farms, Owner, Raul Infante; took no position on this bill stating black and brown people need to be on a higher level of importance.

Connecticut Resident, John Board; took no position on this bill and stated the Higher Education and Employment Advancement Committee suggested he reaches out to the Human Services Committee to incorporate establishing a postsecondary services advisory committee (PSAC) to improve outcomes for students with disabilities. It is stated Connecticut does not have statewide data that analyzes postsecondary outcomes for students with disabilities and having a PSAC would provide recommendations to higher education institutions.

Connecticut Resident, Trumbull, Pat Tyler; took no position on this bill and [provided suggested recommendations](#) regarding the Bill of Rights for persons with I/DD.

Reported by: Isaac Agyemang-Duah

Date: April 6, 2023