Public Health Committee
JOINT FAVORABLE REPORT

Bill No.: SB-372
Title: AN ACT CONCERNING THE PROVISION OF RESOURCES TO GUARDIANS OF ADULT CHILDREN WITH INTELLECTUAL DISABILITY.
Vote Date: 3/29/2019
Vote Action: Joint Favorable Substitute
PH Date: 2/25/2019
File No.:

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SPONSORS OF BILL:
Public Health Committee

REASONS FOR BILL:

To allow family members or guardians caring for adults with intellectual disabilities to receive a stipend for providing care. HB 372 requires the commissioner of the Department of Social Services (DSS), in collaboration with the commissioner of the Department of Developmental Services (DDS), to apply for any applicable federal Medicaid state plan amendments, waivers, or waiver amendments that allow for such stipends. Starting July, 2020 or 15 days after DSS receives federal application approval, they must provide the stipend to the family members or guardians providing care.

Receiving a stipend for providing personal care to an individual with intellectual disabilities is conditional. The individual must be at least 21 years old, have complex medical or behavioral needs as determined by DDS and be at risk for institutionalization, and have an income at or below the federal poverty level. If the conditions are met, DSS must provide the stipend in accordance with the same fee schedule that is used for the Connecticut Home Care Program for Elders (CHCPE).

RESPONSE FROM ADMINISTRATION/AGENCY:

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

DDS expresses many concerns with the bill and is currently unable to support such legislation. CHCPE is a Medicaid waiver program that is administered through DSS and
assists the elderly who are at risk of nursing home placement to instead continue living in the community. Critically important to note is the fact that these waivers do not provide for reimbursements of spouses or other legally liable family members or guardians of the elderly. Family members who provide personal care and are not legally liable may be reimbursed for adult family living services.

While DSS administers CHCPE, DDS administers other Medicaid Waivers including the Individual and Family Support Waiver, the Comprehensive Supports Waiver and the Employment and Day Supports Waiver. Similar to CHCPE, these waivers do not provide reimbursements to the caretakers who are legally liable for such individuals. The proposed waivers in SB 372 would also be similar to CHCPE because those legally liable for individuals with intellectual disabilities would not be eligible for reimbursements. As a result, stipends provided to legally liable caretakers would need to be funded by the state.

Although this legislation requires state appropriations, DDS cannot approximate these costs because there is no existing mechanism that identifies the number of family members or guardians who may be interested in providing paid services. The Department is not able to identify state appropriations for funding without the ability to project costs for this proposal.

Leonard Fasano, District 34 Senator, Senate Republican Leader, Connecticut General Assembly:

Sen. Fasano fully supports the bill. This legislation was developed after many conversations with caretakers who have experienced the adversity of caring for individuals with intellectual disabilities. The bill would allow caretakers to receive a stipend in a similar manner to those receiving stipends under CHCPE. Providing care is a full time job and therefore it prevents parents or guardians from maintaining regular employment. Receiving a stipend would assist individuals with intellectual disabilities and their families in providing care while simultaneously fulfilling Connecticut’s responsibility to care for those most in need.

NATURE AND SOURCES OF SUPPORT:

Walter Glomb, Director, Connecticut Council on Developmental Disabilities:

Mr. Glomb supports the intent of the bill but not the limits it places on identifying stipend recipients. SB 372 rewards guardianships but does not reward individuals with disabilities who only require assistance with decision making and have chosen to retain personal freedom. Alternatively, the Council suggests that adults with intellectual disabilities who receive assistance through Supported Decision Making should also be included in stipend eligibility. This will allow them to preserve personal freedom without being penalized.

Additional suggestions provide for the expansion of disabilities as eligible stipend recipients, such as autism. Mr. Glomb’s last concern lies with the impact this legislation would have on Medicaid and Social Security benefits and urges the committee to address his concern.
Zofia Wozniak:

Ms. Wozniak supports the bill and shares a personal experience about her son Adam who became disabled after being struck by a car, and the journey endeavored by the family since that unfortunate event. Ms. Wozniak is currently 65 years old and Adam is 25, but his disability occurred before he turned one. While Adam was growing up and required ongoing complex care, Ms. Wozniak had to address Adam’s needs as well as worry whether the basic needs of the rest of the family would be met. She struggled to find a part time job that offered benefits. The alternate consideration of utilizing a babysitter in order to obtain a full time job proved to cost more than the jobs paid. Unable to work since 2001, a stipend would greatly assist the family’s limited financial income. It would allow them to continue offering Adam a happy home without the worry of meeting basic needs for the rest of the family.

Dawn Johnson Oduor:

Ms. Oduor supports the bill and recounts the failures of four different group homes regarding her son Amasai. Amasai has multiple developmental disabilities including cerebral palsy, spina bifida oculta, and many other internal organ issues in addition to being a quadriplegic. Ms. Oduor has needed to place her son in a nursing group home four different times as a result of her own declining health. This included two private and two public providers. His care at each home was neglected to such a degree that Amasai suffered a broken femur, e-coli infection due to improper administration of antibiotics, delayed catheterization by 44 hours causing urine to travel to his kidneys, among other unfortunate events.

While Ms. Oduor is provided staff through DDS to assist her with Amasai’s care, in addition to the small amount of Social Security Insurance Amasai receives, it is not sufficient to meet his needs. Her total household income is $1,600 a month because she has had to resign from her job to address the neglectful treatment of Amasai by the group homes. Ms. Oduor draws a parallel between CHCPE and SB 372 and asks that caretakers of individuals with intellectual disabilities should be recognized and qualify for financial assistance for their challenging work.

Additional sources of support include:

Bela Barros
Dawn DeMatteo
Lynn Arezzini

NATURE AND SOURCES OF OPPOSITION:

Win Evarts, Executive Director, The Arc of Connecticut:

Mr. Evarts does not support the proposed legislation because it could result in abuse and financial exploitation of individuals with intellectual disabilities. Although Mr. Evarts is the parent and guardian of a son with intellectual disabilities whom this legislation would benefit, he expresses concerns with the bill’s unintended consequences. These consequences may result in a conflict of interest for the parent or legal guardian receiving stipends for providing
A legally liable individual may continue to provide care even if the care becomes inadequate and is no longer in the best interest of the individual they are assisting, so as to continue receiving stipends.

Reported by: Valentina Mehmeti  
Date: 4/4/19