

# Public Health Committee JOINT FAVORABLE REPORT

**Bill No.:** SB-393

AN ACT CONCERNING THE DEPARTMENT OF DEVELOPMENTAL  
**Title:** SERVICES' LEVEL OF NEED ASSESSMENT.

**Vote Date:** 3/29/2019

**Vote Action:** Joint Favorable Substitute

**PH Date:** 2/25/2019

**File No.:**

***Disclaimer:** The following JOINT FAVORABLE Report is prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and does not represent the intent of the General Assembly or either chamber thereof for any purpose.*

## **SPONSORS OF BILL:**

The Public Health Committee

## **REASONS FOR BILL:**

This legislation requires the Department of Developmental Services (DDS) to:

1. Examine the data and policies regarding medical assessments and update the level of need (LON) system
2. Collaborate with the families, providers, and advocates of individuals with intellectual disabilities in implementing these changes, within available appropriations

These tasks must be completed by January 1, 2020. This bill was proposed in response to submitted testimony that outlined the challenges and issues with the current LON assessment.

## **RESPONSE FROM ADMINISTRATION/AGENCY:**

### **Peter Mason, Deputy Commissioner, Department of Developmental Services (DDS):**

This proposed legislation would require DDS to update the level of need (LON) assessment system to reflect the most recent medical data and terminology regarding behavioral health. When an individual is approved for DDS services, the Department case managers determine their level of financial and service need utilizing a standardized system. This LON system was designed by DDS and the University of Connecticut, and launched in 2008. The assessment evaluates several critical areas, including safety, support, medical, transportation, and behavior, among others. Based on the responses, a score is given ranging from zero to eight, with eight being the highest level of need. The score, in conjunction with the data, contributes to the creation of an Individual Plan that outlines potential risks and areas requiring focus or assistance. The establishment of these highly individualized plans requires participation from a number of parties, including the individual,

their family, and healthcare providers. While the LON system is the primary method for determining aid, there are additional opportunities for securing aid that are unrelated to this assessment. While DDS has utilized this system to maintain consistency in determining aid, the Department is more than willing to discuss any potential changes to improve the system. However, given the fiscal environment, DDS would be unable to support any changes that would bear an expense.

**Senator Len Fasano, 34<sup>th</sup> District, Connecticut General Assembly:** Senator Fasano supports this legislation because it will initiate an important discussion regarding the concerns of families of individuals with intellectual and developmental disabilities (I/DD). This bill requires the Department of Developmental Services (DDS) to update their level of need (LON) assessment to include updated medical data and terminology regarding behavioral health. The LON system is utilized to determine qualifications for aid for I/DD families. Testimony reflects problems with the current system, including a lack of guidance for families as well as difficulty determining which concerns to include on forms. This bill would protect the I/DD community.

#### **NATURE AND SOURCES OF SUPPORT:**

**Lynn Arezzini, Cos Cob:** Ms. Arezzini has worked with the level of need (LON) assessment firsthand, as her 28 year old son has autism. For the 22 years that her son has received DDS services, the LON system has remained unchanged. It is 16 pages long, redundant, and an “antiquated” way of collecting data compared to data collection in other sectors of healthcare. The LON does not account for many behaviors associated with autism, which supports the point that there is no “one size fits all” assessment tool. Since this one tool determines funding for all clients, it should reflect the complex nature of intellectual and developmental disabilities.

**Richard Rothstein, Treasurer and co-Founder, CT DDS Families First:** DDS currently serves approximately 14,000 clients and allocates over \$1 billion in resources. After speaking to families around the state and through personal experience, Mr. Rothstein proposes the following changes:

1. Steps should be provided for families filling out the assessment. Case managers can be inconsistent with directions, which makes it difficult to determine how to answer certain questions or how to understand a change in assessment score.
2. Although the LON was launched as a web-based form, it is not completed electronically. Answers are provided to case managers on paper, who then enter the responses online. Often, the families do not get to review the answers before they are processed. Changes should be considered that would require answers to be submitted at the meeting where it was prepared.
3. The current LON is recorded with a date of 07/08. This was the last and only revision of the document. While the assessment should not be changed often to ensure consistency, Mr. Rothstein suggested an update approximately every five years.
4. The LON is supposed to be updated annually, though that is not always the case. Updating the assessment requires the involvement of all interested parties (families, friends, and case managers) and in some cases, families are left out of the discussion and are unaware of an assessment change.
5. Certain medical and behavioral conditions and treatments are not reflected on the LON assessment. While there is a space designated for comments, these do not affect

the scoring. A panel of DDS staff, medical professionals, healthcare providers, and families should meet to review and revise the tool.

6. Technology has advanced considerably and some individuals have personal computing and communication systems that play a role in daily life. These systems should be monitored and further improved on the assessment tool.
7. It is possible that grants are available to address the potential cost associated with the updates to the LON.

Mr. Rothstein noted that legislation is the appropriate action to ensure that updating the LON assessment becomes a priority for DDS. CT DDS Families First is willing to work with the committee and DDS to offer support and information regarding this matter.

**Dawn DeMatteo, East Haven:** Ms. DeMatteo is the mother of a 26 year old son with disabilities. The level of need (LON) assessment determines an individual's degree of need based on responses to questions relating to health and medical, personal care, and safety. Since the system is the initial "snapshot" and the force behind allocation, the system should be revised to address changes in behavioral health and data. Without an updated assessment, the results will be inaccurate, which could negatively impact other issues. It is critical that the LON is updated to benefit individuals and their families.

**Dawn Johnson Odour, East Haven:** Ms. Odour is the mother of a 26 year old son with disabilities. According to the level of need (LON) assessment, her son has been a level seven his whole life; however, he has required greater medical services since 2007, creating some confusion since his score has not changed. For 9 years, Ms. Odour raised her concerns to her son's case managers and in 2018, she also submitted items to the DDS Director of Health and Clinical Services. As of yet, neither have addressed the issues. All involved parties must act as a team and furthermore, scores cannot be viewed as one size fits all. For instance, Ms. Odour was told that her son was not a level seven because "all sevens are in hospitals and cannot be living at home." Case managers often do not understand what scores mean and altering an individual's score can have a significant impact. Amending this tool must be a group effort.

## **NATURE AND SOURCES OF OPPOSITION:**

**The Arc Connecticut:** The Department of Developmental Services (DDS) utilizes the level of need (LON) assessment to determine the degree of assistance required by an individual eligible to receive DDS services. The system is completed by DDS caseworkers, in conjunction with people who know the individual well such as family and friends. The assessment examines a number of areas, ranging from health and medical to social life. Essentially, the system is utilized to determine how much funding an eligible individual could potentially receive. If the funds are insufficient to meet an individual's needs, a request can be submitted to the Regional Planning and Resource Allocation Team (PRAT). If PRAT rejects the proposal, there is a two-step appeal process that goes through the DDS Regional Director, followed by the Commissioner. The organization feels that the language in the proposal is vague and it is difficult to determine why and how the changes will be implemented. It is assumed that this legislation is in response to the inadequate funding provided by DDS to meet certain levels of need; however, the Arc argues that this is not an assessment issue, but one of funding. In addition, this bill would require the LON system to be revised, which would take individuals away from other DDS tasks. Given their numerous other functions, staff and funding should not be diverted away from other tasks. DDS and

Commissioner Scheff have worked to improve internal systems so the Arc suggests that the committee work with the Commissioner before any legislation is passed.

**Walter Glomb, Director, Connecticut Council on Developmental Disabilities:** This legislation implies that the level of need (LON) assessment does not contain updated medical information and terminology regarding behavioral health. Mr. Glomb notes that there has not been any expert testimony that suggests that this tool is “inaccurate or archaic.” The LON assessment is utilized in a number of states and is often met with disapproval. This can be attributed to the fact that the funds provided according to an individual’s estimated degree of need do not fulfill all financial obligations. The Department of Developmental Services (DDS) in Connecticut has been regulating this assessment to ensure that it is meeting national standards. This bill does not explicitly outline any specifics of change, notably what would be considered an “adequate update.” If there are specific changes to be made, individuals should bring it directly to the professionals at DDS who update this assessment. An additional statute is not necessary regarding a task that DDS is already completing.

**Reported by: Meagan Schantz**

**Date: 4/11/19**