



TESTIMONY

Public Health Committee Public Hearing

March 19, 2014

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Dungarvin CT, LLC

HB-5534: An Act Concerning The Provision Of Services To Individuals With Intellectual Disabilities

Good morning co-chair Senator Gerratana and House Representative Johnson, and members of the Public Health Committee. My name is Hannah Jurewicz and I am Senior Director with Dungarvin CT.

Like many of the other community agencies in CT, Dungarvin provides residential and day services for individuals with intellectual and related disabilities throughout the state. We support them as they perform meaningful work in these communities; we assist them when they contribute to the commerce of their towns by shopping, dining, and enjoying various recreational interests.

I am testifying today in favor of this bill.

As evidenced by the Family Day hearing, CT's families caring for individuals with disabilities are incensed and alarmed at what they see as being "completely on their own" in caring for their loved ones. These families deserve to have their concerns addressed, starting with a plan for how to provide services to our state's citizens with disabilities.

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The state currently lacks a plan for how to get services to all of CT's individuals with disabilities. DDS maintains lists categorized by levels of priority including emergency. These lists are not well maintained, and as a provider, I have often reviewed the list to see who I may be able to serve, only to find out the individuals' circumstances have been changed; they are either no longer in need of services, the level of need has changed and the information about their needs has not been updated to truly reflect what they need or how they are doing, or the case manager assignment has changed and I have to start calling around DDS to find out which case manager has been assigned to this individual. While DDS no longer keeps an official waiting list, FOIA requests show the true waiting list to be more than 3,000 Connecticut citizens with disabilities. Most of the individuals on these lists have little or no funding so they remain on the non-waiting list lists.

Residential supports outside of family homes are reserved for emergencies only, such as when a parent dies, or they demonstrate significant health and safety risks. For these extreme circumstances there is never sufficient time or funding to permit truly person-centered planning. DDS does not appear to have developed adequate planning nor funding for these individuals before it reaches these critical states. Further, DDS mechanisms for additional funding when needed beyond whatever funding is available, do not guarantee payment, even if approved in writing, do not cover all of the operational and fixed costs of developing and overseeing the high level of services delivered, and require significant labor and time intensive efforts in order to ensure payments are paid, and paid in full.

HB 5534 will be an important step toward ensuring that all of CT's citizens with disabilities receive the services that they deserve.

The creation of a service plan for all of CT's individuals with disabilities is crucial, and must include provisions for comprehensive services for each of these individuals, according to each of their specific needs.

We currently have a network of private community providers fully prepared to provide high quality services for all of CT's individuals with disabilities. The question is whether the state is willing to purchase those services. We must also consider the continuing and astronomical cost of state institutions

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that are still operating. The annual cost of care for an individual at Southbury, for example, is approaching a half million dollars.

However, there is no way to afford serving everyone with state services remaining in place; there must be a significant shift to the private sector in order to create a long-term, sustainable system.

We would ask the Committee to consider a date for completion that is more in keeping with the system change that must take place. We would very much like these changes to be in effect by 2016, but also understand that it may take longer. But bottom line, changes must be made now and they must continue consistently until all people with disabilities have a menu of services that meets their needs.

Thank you for your time and attention.

Hannah Jurewicz

Senior Director