

Testimony of Michelle Rivelli, M.D., F.A.A.P. on Raised H.B. No 5534-AN ACT CONCERNING THE PROVISION OF SERVICES TO INDIVIDUALS WITH INTELLECTUAL DISABILITIES and H.B. No 5558-AN ACT CONCERNING SERVICES FOR PERSONS WITH AUTISM SPECTRUM DISORDERS March 19, 2014

Senator Gerratana, Representative Johnson and Members of the Public Health Committee,

My name is Michelle Rivelli and I am the parent of a 19 year old daughter with autism and intellectual disability and a pediatrician to many individuals with disabilities. When my daughter was 9 years old, the state of CT Department of Developmental Disabilities eliminated individual case managers due to decreased state funding. My husband and I “flew” the plane ourselves, alternating our work schedules, and caring for Jessie and her twin sister. After Jessie turned 18, when I was told she would be assigned a case manager, this did not happen until I complained to the ombudsman and had my own personal breakdown. A case manager is critical once your child turns 18, to access the Medicaid waivers that allow our children access to day programs and to apply for in home supports. As I have quickly learned however, the provision and availability of these essential services for my daughter are not easily understood nor obtained.

I am speaking to support Raised H.B. No 5534 and No 5558. After attending committee meetings for DDS, a meeting with Commissioner Macy, meetings here at the legislature, personally questioning Governor Malloy and speaking with many other parents, I am concerned that there is not a clear understanding of the enormous disconnect between DDS’ mission and what DDS is able to provide. Looking at individuals with similar needs, there is too great a disparity in the services that are provided to them—we shouldn’t perpetuate a system of “haves” and “have-nots”. Despite the DDS’ mantra that “one size does not fit all”, there is not a mechanism within DDS to tackle the practical task of figuring out what each individual’s “size” is. There is a lack of adequate assessment of the needs of current DDS clients. At this point in time unless a family admits to being in crisis, DDS does not have the staff or funds to address their client’s needs. This leads to greater personal, emotional and financial cost in the long run.

I strongly agree with **Bill 5534** that DDS should have a timeline to assess the services needed for the individuals they are charged with serving. DDS should have a clear understanding of how these services will be implemented and their cost. There should be a deadline as to when these services should be implemented.

From experiences I have had with friends and patients, I understand the tremendous need for appropriate services for those with significant behavioral challenges. There needs to be a coordinated program that includes staff with appropriate training and credentials, including training in applied behavioral analysis as **BILL 5558 states**.

I had the naïve understanding when my daughter was younger that DDS was already aware of these issues and addressing them. I trusted that DDS as an agency would advocate for and assist my family with obtaining appropriate supports and services for my daughter in adulthood. I was recently told by Commissioner Macy that the families have to advocate for their children to the legislature as he is unable to do so. I have realized that I was misguided in my trust that DDS would provide the assistance we require. I am here to advocate for my daughter and my patients and hope that by legislation such as **Bills 5534 and 5558**, my daughter and others like her will have a safe and meaningful life and future.

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