

Testimony of Shanon McCormick on Raised H.B. 5534 -- An Act Considering the Provision of Services to Individuals with Intellectual Disabilities

To the Members of the Committee – My name is Shanon McCormick. I live in Pawcatuck and sit on the Board of Directors of the Connecticut Down Syndrome Congress. I also have a sixteen-year-old son, Sean, who lives with Down syndrome.

I am in favor of the concept of open communication and transparency presented in H.B. 5534, but have serious reservations about its restriction to those individuals who qualify for services under the current criteria.

Currently, the Department of Developmental Services relies on IQ test results with a strict cutoff at a score of 69 or below to qualify for adult services. Reliance on a strict cutoff is outdated and not in line with the American Association on Intellectual Disabilities (AAIDD)-recommended practices. **It unfairly disqualifies people who need support.**

I am currently working with an elderly parent of a 36-year-old son with a Down syndrome diagnosis. His IQ score before he turned 18 was 69, which would have qualified him for services in Connecticut; however, she placed him in a setting out-of-state, so never applied for services from DDS. For health reasons, she has moved him back to Connecticut to be closer to her. When she applied for services here, she had his IQ re-tested, resulting in a score of 70, and was rejected for assistance from DDS. **Her son's functional needs did not change between 69 and 70.** Many, many families with loved ones on the autism spectrum also face this issue.

The outlook for people living with Down syndrome has changed dramatically in recent decades. Even in the sixteen years since my son was born, our understanding of Down syndrome has changed significantly and resulted in highly effective educational, therapeutic and medical interventions. There are drugs currently in clinical trials that may result in enough increased cognitive function that day-to-day quality of life would be improved. With our strict eligibility criteria, however, Connecticut parents are put in the untenable position of having to choose between enhancing their children's quality of life, and retaining eligibility for necessary supports. What if their adult children were able to take medication that enhanced their verbal memory, so they were better able to communicate their needs, but it pushed their IQ to 70, disqualifying them from needed employment supports? Most parents would be forced to forgo medication and limit their children whom they have worked so hard to provide opportunities, because of Connecticut's outdated practice.

I hope you will include language requiring the Department of Developmental Services to address its outdated eligibility criteria as part of this bill.

Thank you for your consideration.