



Massachusetts Down Syndrome Congress

TO: Members of the Joint Committee on Financial Services
FROM: Sarah Cullen, MDSC Family Support Director
RE: HB3715 - An Act relative to applied behavioral analysis therapy
DATE: November 18, 2019

The Massachusetts Down Syndrome Congress (MDSC) is a non-profit organization established in 1983 representing more than 5,000 people with Down syndrome in the Commonwealth.

Today, with access to innovative health care, early intervention, and best practices in education, individuals with Down syndrome can contribute to their communities in meaningful and fulfilling ways.

As the Family Support Director at the MDSC, it is my responsibility and privilege to advocate for and support our member families who have a loved one with Down syndrome. Our primary mission is to ensure that all people with Down syndrome have access to services they need to lead meaningful fulfilling lives. And, since individuals with Down syndrome now live to an average age of 60 and beyond, up from 30 years of age just a few decades ago, our organization is in constant search of new programs and protocols that will allow our loved ones to be active and engaged members of their communities throughout the course of their life.

Last year, it came to our attention through Dr. Brian Skotko, the Chair of MDSC's Medical and Scientific Advisory Council, that many patients he was seeing as Director of the Massachusetts General Hospital Down Syndrome Program, were benefitting from a therapy known as Applied Behavior Analysis (ABA.) He found that this intensive behavioral therapy is having a transformative effect on his patients with Down syndrome, allowing them to fully develop appropriate responses to situations and unexpected stimuli, reactions that most people inherently possess. People with Down syndrome can and do benefit from ABA services during the school day, as funded by the Department of Education. However, their behavioral issues do not stop when the school day ends. Instead, they often need the benefits of ABA services at home and in other social settings. The problem, really the barrier, is that insurance does not typically cover the costs of this therapy at-home for individuals with a single diagnosis of Down syndrome.

You will hear today from Leah Campbell of Peabody, the mother of beautiful five year-old, Mia. It was only through Leah's unflappable persistence, her deep knowledge of the healthcare system and insurance industry, and a few fortuitous introductions, that she was able to eventually secure insurance coverage for Mia's ABA therapy. You will also hear from Clo Cottrell, a licensed social worker, from the Massachusetts General Hospital Down Syndrome Program. Ms. Cottrell works side-



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by-side with Dr. Skotko and, together, they see hundreds of patients with Down syndrome. She has first-hand knowledge of how difficult it is to secure at-home ABA therapy and how exasperated families are becoming without this crucial behavioral support.

Most parents of a child with Down syndrome have neither the time, institutional knowledge, nor the fortitude to tackle such a difficult endeavor.

Through legislation passed by the Massachusetts legislature in 2010, individuals with autism are now eligible to receive insurance coverage for at-home ABA services, and if a person with Down syndrome is also diagnosed with autism or is on the spectrum, they too, are eligible for insurance coverage. However, a person with a diagnosis of Down syndrome *alone* is not typically eligible to receive insurance coverage for at-home ABA services, unless a parent or caretaker knows how to successfully untangle a massively complex healthcare system and an unpredictable insurance industry. In other words, this critically important and effective therapy is currently available only to those individuals with Down syndrome who have parents that can afford to pay privately.

We ask that you please consider the thousands of individuals with Down syndrome in this State who go to our public schools and who deserve to have every opportunity to lead meaningful lives as engaged participants in their community. Please help make their lives even better by requiring that, in addition to the diagnosis of autism, insurers across Massachusetts cover the cost of this critically important ABA therapy for people with a single diagnosis of Down syndrome.

On behalf of our entire organization and the families we serve, we thank you for taking the appropriate steps to support HB3715 and move this bill out of Committee.

THANK YOU.

Note: For further comment, you can reach me or our Executive Director, Maureen Gallagher at 781-221-0024 or scullen@mdsc.org mgallagher@mdsc.org.