



TO: Members of the Joint Committee on Financial Services
FROM: Maureen Gallagher, MDSC Executive Director
RE: H1084/S617 - An Act regarding Applied Behavioral Analysis for Down syndrome
DATE: October 30, 2023

Thank you to Members of the Joint Committee on Financial Services for giving me the opportunity to testify on behalf of H1084/S617 - An Act regarding Applied Behavioral Analysis for Down Syndrome.

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 Executive Director of 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.

Through the past few years, it has come to our attention through Dr. Brian Skotko, the Chair of MDSC's Medical and Scientific Advisory Council, and Director of the Massachusetts General Hospital Down Syndrome Program, and Dr. Nicole Baumer of our Medical and Scientific Advisory Council and the Director of the Boston Children's Hospital Down Syndrome Program, that many of their patients were benefitting from a therapy known as Applied Behavior Analysis (ABA.) They found that this intensive behavioral therapy is having a transformative effect on their 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.

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.

As you know, the Massachusetts Center for Health Information and Analysis (CHIA) recently completed its Mandated Benefit Review of H1084/S617. We were very pleased, but not surprised that the conclusion of this report matched those of our experienced medical experts, including Dr. Brian Skotko and Dr. Nicole Baumer. For years they have personally witnessed the success of ABA therapy for their patients with a single diagnosis of Down syndrome, yet they were frustrated that most families were financially unable to access those services for their loved ones with Down syndrome.

The Mandated Benefit Review concluded that “requiring coverage for this benefit by fully insured health plans would result in an average increase, over five years, to the typical member’s health insurance premium, of between \$0.006 to \$0.015 per member per month or between 0.0010% to .0025% of premium.”

We ask that you please consider the relatively small number of individuals with Down syndrome in this state - Dr. Skotko estimates that to be less than 80 patients per year - who can benefit from this transformative therapy so that they 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 the Massachusetts Down Syndrome Congress and the families we serve, we thank you and ask that you vote affirmatively for H1804/S617.

THANK YOU.

Note: For further comment, you can reach me at 781-221-0024 or mgallagher@mdsc.org .
