

Massachusetts General Hospital  
125 Nashua Street | Suite 821  
Boston, Massachusetts 02114  
Tel: 617-643-3196 | Fax: 617-726-4148  
bskotko@mgh.harvard.edu  
www.massgeneral.org/downsyndrome

Brian G. Skotko, MD, MPP  
*Emma Campbell Endowed Chair on Down Syndrome*  
*Director, Down Syndrome Program*

Medical Geneticist, Massachusetts General Hospital  
Associate Professor, Harvard Medical School

## Testimony presented to Joint Committee on Financial Services

### Re: House 1084/Senate 617, “An Act Relative to Applied Behavioral Analysis Therapy”

October 30, 2023

My name is Dr. Brian Skotko. I am the Director of the Mass General Hospital (MGH) Down Syndrome Program.

I am here today to testify for the passage of House 1084/Senate 617, “An Act Relative to Applied Behavioral Analysis Therapy.” Simply put, the bill is urgently needed for our citizens with Down syndrome. The bill would incur no costs to the state budget, and the costs to Medicaid and third-party insurers are absolutely negligible, based on this Committee’s commissioned financial analysis.

In my capacity as Director, I oversee a multidisciplinary clinical team that provides medical evaluations, behavioral consultations, family support, advocacy, care coordination, and assistance with identifying resources. I am also a practicing physician in our Program. Together, our team follows more than 700 patients with Down syndrome each year. As such, I feel that I have a unique understanding of the complexity of systems and the barriers around access to services for individuals with Down syndrome.

Most notable is the barrier in accessing Applied Behavior Analysis (ABA) services, which research shows improves outcomes for individuals with Down syndrome. Currently, ABA is the “gold standard” of treatment for individuals with a diagnosis of autism. Yet, research paper after research paper have also shown that ABA improves the acquisition of skills in children with Down syndrome while decreasing behaviors that can interfere with learning and developmental progress.

I am here today to advocate for individuals with a single diagnosis of Down syndrome to have access to ABA therapies that can substantially improve their quality of life. In 2010, Massachusetts passed ARICA (Act Relative to Insurance Coverage for Autism), requiring private health insurers in MA to provide coverage treatment of autism. Today, we simply advocate for insurance to cover ABA therapy based on the singular diagnosis of Down syndrome.

Importantly, not all children with Down syndrome require or need ABA services. In my professional opinion, there would be at most 80 children with Down syndrome in any single year in Massachusetts who medically require ABA services. These are the children with Down syndrome who have substantial behavioral needs that do not show improvement with typical parenting approaches.

The Massachusetts Down Syndrome Congress (MDSC) has filed legislation – **House 1084/Senate 617** – which would mandate Medicaid and third-party insurances to cover ABA therapy for a singular diagnosis of Down syndrome. Last year, this legislation was referred by this committee to the Massachusetts Center for Health Information and Analysis (CHIA) for a Mandated Benefit Review.

The review conducted over several months by Berry Dunn McNeil & Parker, LLC, and citing a plethora of peer-reviewed studies regarding the effectiveness of ABA therapy on children with a single diagnosis of Down syndrome, agreed with my professional assessment that (and I quote), “ABA therapy has been shown to be an effective treatment for Down syndrome, helping to improve social interactions, communication abilities and cognitive skills. ABA therapy can lead to improvement in skills such as speech, cognition, and functioning, while also helping to decrease problem behaviors associated with Down syndrome. Therefore, if the bill were to pass, individuals with a singular diagnosis of Down syndrome would have access to ABA service, increasing the likelihood of their success in inclusive educational and community environments.”

Simply put, I think that this legislation proposal is a no brainer. The very small number of children with Down syndrome who need ABA therapies would be distributed among Medicaid and the other third-party insurers. The costs, as cited in the Mandated Benefit Review, on any one insurer for such few children would be insubstantial—to be precise about 1 cent per member per month in increased premiums. Research has shown over and over again that this is also the right thing to do to ensure that our citizens with Down syndrome reach their full potential.

On behalf of the patients that I serve and their families, I’d like to again thank committee members for this opportunity to present to you today.



Brian Skotko, MD, MPP  
Emma Campbell Endowed Chair on Down Syndrome  
Director, Down Syndrome Program, Massachusetts General  
Hospital Associate Professor, Harvard Medical School  
[bskotko@mgh.harvard.edu](mailto:bskotko@mgh.harvard.edu)  
617-643-3196