September 3, 2019

Re: H.403 (Representative Barber)/S.318 (Senator O’Connor)
An Act to Improve Augmentative and Alternative Communication Opportunities for Children with Disabilities

Members of the Massachusetts Joint Committee on Education:

I submit testimony today on behalf of Autism Speaks in strong support of H.403/S.318, An Act to Improve Augmentative and Alternative Communication Opportunities for Children with Disabilities.

Autism Speaks is a leading, global autism research and advocacy non-profit. We are dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

In 2018 the CDC determined that approximately 1 in 59 children is diagnosed with an autism spectrum disorder (ASD). An estimated one-third of people with autism are nonverbal.

Assistive technology is used to support and enhance communication for people with autism, regardless of speech ability. Augmentative and alternative communication (AAC) is a specific type of assistive technology that can benefit people with autism of all ages by promoting independence, expanding communication, and increasing social interactions.

Professional evaluation and training are important to maximize the effectiveness of AAC. It is worth noting that the cost of caring for Americans with autism reached $268 billion in 2015 and will rise to $461 billion by 2025 in the absence of more-effective interventions and support across the life span.

One compelling solution is to ensure that students with autism who require the use of AAC in order to communicate are instructed by educators who have been appropriately trained in this critical intervention. H.403/S.318 achieves this by requiring that teachers who apply for an initial Massachusetts educator license (beginning in 2021) receive training and preparation in the use of AAC for students who are nonverbal (include the one-third of children on the autism spectrum who are nonverbal) or who have limited speech, as a requirement for licensure. This
will help reduce costs for school districts by facilitating inclusion and supporting placements in the least restrictive environment.

On a personal note, I have experienced the positive impact of AAC with my own son, Jack, who was diagnosed with autism spectrum disorder at the age of two. As he grew older and remained nonverbal, he became increasingly frustrated with the inability to communicate his most basic needs.

When evaluated by his neuropsychologist at the age of eight, this frustration was clearly reflected:

_The presence of Jack’s behaviors is highly concerning as it continues to interfere with his ability to participate successfully in other aspects of his life. Additionally, his aggressive acts towards family members have become very worrisome and a significant safety concern. Therefore, strong efforts should continue to be made to decrease their presence. In the absence of direct interventions, these maladaptive behaviors are likely to predominate over time, resulting in further alienation as they clearly have the largest impact in defining his presentation as atypical for others. It is strongly felt that if Jack’s behavioral presentation does not improve, he will require placement in a residential setting._

As communication is one of the most pronounced areas of deficit in his neurodevelopmental profile, impacting his progression across every domain of functioning, a combination of augmentative communication/assistive technology expertise must take a prominent role in his educational programing.

Subsequently, a program was implemented in Jack’s IEP implementing an evidence-based AAC program. This occurred after appropriate evaluation by a speech language pathologist who specialized in autism spectrum disorder was completed. Additionally, Jack’s educational team was trained in how to communicate effectively with him using AAC.

Jack is now sixteen and continues to live at home with us. His aggressions have diminished to a point of almost non-existence. With the use of AAC via his iPad, he is able to communicate the most basic, teenage comments. For example, he loves to tell us to “go away” quite frequently.

His communication isn’t restricted to that of teen angst. Recently, when his beloved older sister was preparing to leave for her freshman year of college, he sat down beside her on the couch one of the final evenings that she was home and spontaneously typed “brother, sister.” These were words he had never used before. Their simplicity and power spoke volumes in that moment.

One of the more gut-wrenching instances reflecting the power of AAC was when Jack was able to repeatedly request the dentist through the use of his iPad. We honored that request and quickly discovered he was suffering from an abscessed tooth.
Imagine if he had not been able to communicate his pain.

The opportunity to express the mundane to the deeply emotional to the most incredibly painful should not be an opportunity that is exceptional in nature. Students diagnosed with autism spectrum disorder in the Commonwealth need access to the most basic form of communication. For the one-third of those with autism who are non-verbal, that includes the consistent usage of AAC at school working with educators who are appropriately trained.

Thank you for your consideration of this legislation. Should you need additional information, please do not hesitate to contact me at judith.ursitti@autismspeaks.org.

Sincerely,

Judith Ursitti
Director, State Government Affairs