



September 12, 2017

Dear Committee Members,

Thank you for the opportunity to come before you.

My name is Maura Sullivan, I am the Director of Government Affairs for The Arc of Massachusetts and I am also the Director of our Operation House Call Program, which is a medical student training program to enhance care provided to people with autism and other intellectual and developmental disabilities. In addition, I am representing Advocates for Autism of Massachusetts. I am grateful to be here today to support S1169. The Arc is committed to this legislation because it aligns with our #1 health policy priority – which is to improve access and reduce disparities in all areas of health care for individuals with autism and other types of I/DD. And the disparities are grave. For our community, access to dentists is a huge challenge. Quality of care can be atrocious. The Arc has worked with the dental coalition and state house leadership to add language to this legislation that will require the Dental Therapist to have training in the oral health care needs of people with disabilities. Through our work with Operation House Call we know that training makes an impact.

I would like to take a minute to speak to you from my more important role – that of a mom. I have 3 children, and my two boys are significantly affected by autism. I'll briefly share a story.

Our home is full of love and chaos. My two boys are 16 and 13 years old and both have autism and mitochondrial disease.

Life with Gillian, Neil and Tyler is sometimes all laughter, a lot of hard work and often we are in crisis. From the time the boys were diagnosed with autism – oral hygiene meant tackling them with a tooth brush twice a day, without great success. I struggled to find a dentist that would take them. I ended up finding a dentist that was three towns away and his practice didn't take Mass health but I took them there anyway and paid out of pocket, to add to their other uncovered medical expenses.

Neil and Tyler had GI reflux which had been affecting their back molars. The dentist never mentioned any problems with their teeth and did very brief exams with nothing but positive remarks. Then on our 4th or 5th visit, he told me to call the hospital and book operating room time. He said, he hadn't been able to treat the boys in his office and was just waiting until their oral decay was bad enough to put them under anesthesia. Last thing I remember him saying was, "book it soon because they could be in pain or get an infection".

My heart dropped. They desperately needed improved access to dental care and prevention. They deserve better care, more effort and I needed more communication and oral hygiene support strategies. In the OR, they both needed many pulpotomies and extractions. Neil was already developing a self-injurious behavior of punching himself in the jaw, which I realized was not an “autistic behavior” but in an attempt to stop his pain.

Please pass S 1169 favorably. Although this bill will make an enormous impact on an even greater scale, you have the opportunity to make monumental changes for the disability community.

Thank you for your consideration and time.

Maura K. Sullivan, MPA

A handwritten signature in cursive script that reads "Maura Sullivan".

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