



School of Education

29 Everett Street  
Cambridge, MA 02138-2790  
Tel 617 349 8394  
Fax 617 349 8607  
www.lesley.edu

#### Testimony

Good afternoon, my name is Dr. Anne Larkin, and I am here to testify in support of S. 223 An Act to Improve Alternative and Augmentative Communication Opportunities for Children with Disabilities. I have been asked to give a brief description of my background. First and foremost, I am the parent of a 44 year old son with autism. My son has been my teacher in trying to understand this syndrome. I am also a Professor Emerita at Lesley University in Cambridge, and have been a member of the Lesley faculty for over 40 years in the Special Education Department in the School of Education, specializing in Autism.

Over the last 40 years, I have worked with hundreds of children and adults on the autism spectrum as well as children with many other disabilities. I have also supported many families struggling with all the barriers their children face in schools. In my role at Lesley, I have prepared teachers, both in general education and special education to not only educate, but to understand children with mild, moderate and severe disabilities. I have also supervised these students in their practicum settings.

I have served on several Boards including Mass. Autism Chapter, PALS, Inc, Cambridge Families and Children Services, the Mass. State board of Education and the National State Board of Education.

The inclusion of children with disabilities in public schools and in regular education settings has been a wonderful movement in this country, and Massachusetts has been in the forefront in embracing the concept of Inclusion. It has been a vehicle that has improved the normalization of children with disabilities and given them a promise for a brighter future, if, of course, it is done well.

However, for children who are nonverbal, it can be a very difficult transition. If these children are unable to communicate their thoughts, feelings, abilities and their pain, both physical and emotional, they experience great frustration, which may escalate all kinds of behavioral issues. In special education, we tell all who will listen that: "All behavior is communication!"

The use of augmentative and alternative methods would help these children break through a world of "silence" and enable them to actively participate in an inclusion setting. What I have seen over the years, in many of the schools that I have visited, is that the schools may have purchased some of the necessary equipment and devices, but the staff, all too often, have not had the training in the use of them. So, it is not only a missed opportunity for the school personnel, but especially for these children who are nonverbal and do not have access to these important devices which would make such a difference in their lives.

This Act would mandate that all teacher preparation programs include the training of AAC in their coursework and ensure that all general education and special education teachers receive not only the instruction, but the practical experience so they can understand and utilize all the necessary methods to enable non-verbal students to interact with their teachers and their peers. These children deserve to have the tools that will enable them to actively participate in classes and to have a Voice.

Thank you.

A handwritten signature in cursive script that reads "Anne Larkin".

Anne Larkin, Ph.D  
Lesley University  
Professor, Emerita  
School of Education

# Testimony of a Parent Of a Child with Autism

My name is Cynthia Reed. I am here to testify in support of Senate Bill 2692. You just heard from my son, Jantsen.

Our search for tools to assist him started when he was diagnosed as non-verbal. As a pre-schooler, he relied on family members to anticipate his needs. We introduced the use of industry standardized picture icons. (You have examples). We labeled everything that he used at home and in school to get him to understand his world. He used these symbols to let us know what he wanted.

In elementary school, we tried an early augmentative device. It had 128 icons at his command, effectively giving Jantsen a voice for the first time. It was also our first experience of helping teachers learn to use and to encourage Jantsen's use of an augmentative device. Any changes to his device, to help with schoolwork, for example, were done at home. Every new classroom has required us to introduce his device to the teachers. Technology advances are improving the capability of these devices at an

astonishing rate. Jantsen's current device has over 2000 icons.

For the past four years, Jantsen predominantly uses the keyboard to communicate. He will ask for help when he doesn't know how to spell something. Most of you remember your child's first words. Our moment was at the dining room table with extended family. Jantsen looked around the table, then, used his device to announce "family". He was 11 years old.

His switch over to full use of the keyboard has been remarkable AND made possible, by hours of word acquisition programs at his current school. It is something that we would not have expected even a few years ago. It enables him to express himself and most importantly to talk, nightly, with his brothers via Skype, while they are away at college.

The key to understanding Jantsen and to facilitate his ability to learn, even to give him a voice, is to recognize his dependency on AAC, and then to have teachers with the skills necessary to work with him in the classroom. Please support this bill so others will have the chance to learn.

Thank you.

My name is Leslie Lockhart, and I am here to testify in support of S. 223. My daughter, Julia, will be 25 years old in December. Julia has cerebral palsy and has never used speech to communicate. She wanted to come today to testify herself, but her communication device – a computer which speaks – broke about two weeks ago. Julia uses a wheelchair and cannot speak because her facial, mouth and throat muscles don't work well enough. Her disability and her communication device are similar to Stephen Hawking's. She uses actions, gestures, some signs, a paper communication board and her computer. Although Julia is very good at communicating, a lot of people ignore her because they don't know how to interact with someone who speaks with a voice output device or their hands.

When Julia started school, I thought her using a wheelchair and having the use of only one hand would be the biggest obstacles to success and inclusion at school. I was wrong – lack of a voice was the biggest impediment. Although Julia did get several communication devices, the teachers' lack of understanding and training sometimes effectively disabled the equipment because it wasn't used effectively at school and did not enable Julia to participate in class. Without communication, Julia was as left out of school as if there was no ramp and she couldn't enter the building.

Julia attended public school in Newton from age 3 to 22; 19 years of her education were in mainstream classes with an aide. Julia had many speech therapists and several Augmentative and Alternative Communication (AAC) specialists, who helped develop communication boards and program her computer to communicate. Julia's first speech therapist told me that Julia would be functionally illiterate if she had no way to communicate. Without communication, she could not express what she knew or thought and she couldn't ask questions. People would treat her as someone who was illiterate because they couldn't understand what she knew. I soon learned that communication is two-sided and required the person receiving the communication to understand and respond as well as Julia reaching out with her communication.

Although Julia had classroom aides to help implement the communication system, throughout her years in the classroom, in elementary school, middle school, or high school, the classroom teachers often were at a loss with how to communicate with Julia. And as Julia's mother, I had to wonder how a teacher could actually *teach* my daughter, if they could not communicate with her.

I realize this was no fault of the teachers, for they usually had no training or experience in Augmentative and Alternative communication. The teacher must have the skills necessary to implement methods and programs developed by the AAC expert, speech therapist, and in Julia's case, the aides. The classroom teacher is the most important person in the class, teaching and guiding the students. The teacher is a model for the students – if she is interacting with the assistive technology user appropriately, the students will follow her example. Even with a speaking computer, an individual will

remain mute if no one listens to their voice because it takes longer or sounds different, curtailing their ability to learn and succeed in school.

I urge you to support S. 223, so that teachers in the future will have the course work and practical experience to teach all the Commonwealth's students with disabilities.

Leslie Lockhart  
46 Clyde Street Newton, MA 02460

# MASSACHUSETTS ADVOCATES *for* CHILDREN



My name is Ann Guay. I am Policy Analyst with the Autism Special Education Legal Support Center at Massachusetts Advocates for Children (MAC). I also Chair the Government Affairs subcommittee of Advocates for Autism of Massachusetts and am the parent of a fifteen year old son with autism.

I come here today seeking your support for S. 223, legislation which will require the Board of Education to revise regulations for teacher licensing to make sure that teachers receive training in how to use devices that children who are non-verbal or unable to speak use to communicate.

Thousands of children (including children with Autism Spectrum Disorder, cerebral palsy, and acquired brain injury), are non verbal or unable to speak. It is estimated that half of all children with ASD are non verbal or have limited speech. Many rely on augmentative and alternative communication methods to communicate. There are a range of communication aides available to improve communication including simple picture boards that children point to in order to make a request to more high tech electronic communication devices that can fit in your hand and emit language.

Some nonverbal children acquire these devices at a young age and use them to communicate at home. When children who are nonverbal come to school to

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learn, they need to be able to communicate effectively with their teachers and classmates. Unfortunately, many teachers do not have any familiarity with these communication methods and were never trained in their use. As a result, teachers are unable to communicate effectively with their nonverbal students or help them access the curriculum.

As you listen to testimony today, try and imagine how incredibly frustrating it must be for a child not to be able to communicate with his teachers, friends and other students. Effective communication leads to success in the classroom and a decrease in challenging behaviors.

The impetus for this legislation stemmed from our work in the Autism Center, representing students on the autism spectrum who are nonverbal or who have limited speech. This afternoon, Cynthia Reed and her son, Jantzen will show us all what is possible for a non-verbal student when given access to a communication device.

Difficulty with communication is not limited to students with autism spectrum disorder. The need for this bill also came from MAC's work in the Disability Justice Project where we represent the interests of children with a range of

disabilities who rely on AAC. This afternoon, Julia Lockhart will share her own experiences as the mother of a young adult daughter who uses AAC to communicate.

Years ago, when my own son was four, he was totally non-verbal. Much of my day was spent guessing what he needed. He was a very frustrated little boy and I was at a loss as to how to understand his needs. One day he came home from school with this black book full of communication symbols. Not only did it allow Brian to tell us what he wanted, it enabled our entire family to talk with him. His cousins still remember using this book. His communication book was a bridge to his language development. Today, Brian is verbal and no longer needs the book. Yesterday, I took the book out of a box where I store it and showed it to him. He looked at it, opened it and said "No thank you, I do not need it anymore."

Frankly, we filed this bill in the hopes that in the future we will improve outcomes for students with significant disabilities, and significantly diminish the need for advocacy and litigation. As you listen to today's panelists, keep in mind that many students do not even receive devices necessary to communicate because so many teachers have not received sufficient training regarding Augmentative and Alternative Communication.

Consider what happens to children who do not have parents with economic resources, educational background, and English skills like Cynthia or me? What happens to children who don't have parents who can go out on their own, arrange for communication specialists to develop AAC methods for their children and then train the teachers themselves?

Think about the unlocked, wasted potential of those children.

Even when attorneys and advocates get involved and advocate successfully for a child's need for AAC equipment, too frequently the AAC device remains in the classroom unused, gathering dust, or not fully utilized because special and regular education teachers, due to no fault of their own, have not received adequate training about Augmentative and Alternative Communication methods. Our vision and hope is that with enactment and implementation of this bill, we won't have to expend advocacy resources trying to enforce the rights of a child who is nonverbal or has limited speech—because all educators will have the experience and training necessary to recognize the student's potential.

By giving nonverbal students the means to communicate, teachers enable them to participate in school and be an active participant in the classroom. This in

turns increases the likelihood for success in school. Effective means of communication for nonverbal students may reduce the need for MORE RESTRICTIVE placements and make it possible for students to remain in their neighborhood school. This is not only cost effective for schools; it is the right thing to do.

Thank you.