H.B. 111 Testimony

Good Morning Representatives,

My name is Andrea Samuel. I am an Anchorage resident and mother of two school-age children. My second child uses cochlear implants to listen and talk. She was born with a recessive genetic deafness and thanks to the Universal Newborn Hearing Screen her hearing status was detected in her first few weeks of life.

As irony would have it, I had been a practicing as a speech-language pathologist for ten years at the time of my daughter's birth in 2011. My job was to help individual with communication disorders develop (or regain) their ability to access language. But despite all the tools I had learned to help the various populations I worked with, habilitating, and educating a deaf or hard of hearing child was not one of them. The few people I had met in my life who were deaf either used sign language or were oral but relied heavily on lip reading.

My first reaction to my daughter's diagnosis was shock and denial. No one in my or my husband's family was deaf or hard of hearing and I remember the day that both my husband and I looked at each other and realized that life was going to be different raising child number 2. Language access was not a given for her. We needed to decide if we wanted to provide her access to sound in a rich spoken language environment, or if we wanted to raise her to learn a visual Language in a rich visual language environment - but the latter was a language we did not know. Conflicted by national and local experts' espousing a visual language approach as best practice, I delved into the latest research and came up with guarded optimism that we could raise our daughter in our native spoken language.

The hearing technology in 2011 had become highly sophisticated at delivering high fidelity sound to the young developing brain. With early access through digital hearing aids and a lot of attention paid to her daily listening experiences, she ended up babbling at 8 months and uttering her first words at 14 months and talking in full sentences by age 3. She was off to preschool at age three, and participated in the Auditory Oral Program in the Anchorage School District so she could strengthen her listening skills to learn in a mainstream neighborhood classroom. In first grade, her hearing levels dropped further, and we pursued a cochlear implant on her left side and then two years later her right side. We pursued Auditory-Verbal Therapy at various points in her early years: this is a specialized therapy designed to stimulate and enrich a child's auditory brain development which in turn allows the child to develop spoken language and listening skills.

My daughter is now 12 and thriving as deaf individual who is no longer on an IEP, who uses listening and spoken language to access her English language- based education. She is highly literate, a great self-advocate and has lots of friends.

Greater than 90% of children who are born deaf or hard of hearing **are born to hearing parents like us** -with no familial history of hearing loss, with no proficiency in Sign Language. When given outcomes data, many will choose an auditory-oral approach like we did so that their child can learn to listen and talk. They will choose this option, either alone or in combination with a visual language like American Sign Language, or a by supplementing listening with a visual modality to increase access to spoken language.

According to the Centers for Disease Control and the NIH, 1-3 in 1,000 babies are born with hearing loss, but by the time a child reaches kindergarten that number can double due to later-onset hearing loss, for which, sadly, there is not yet a universal means of screening.

This means that many children coming into the school districts may have passed their newborn hearing screen but developed deafness later. These parents may be faced with communication decisions that look very different from the family whose child's deafness was detected at birth or in the first few months of life. These families, like all families, need unbiased counseling and ultimately need to make the final call as to what they want for their child.

There are two reasons I support this House Bill 111. First,
First, this is a pro- parent choice bill and one that prioritizes literacy outcomes regardless of communication option. It respects parent choice and full inclusion. It appreciates a student's need to communicate with peers who use the same language. Secondly, it acknowledges there being two recognized languages of the American public school system: English - spoken and written, and American Sign Language, with American Sign Language being supported by the AK School for the Deaf. It also recognizes that Spoken English must be made available as an option to students who are deaf or hard of hearing and it recognizes the myriad communication methods available so that spoken and written English can be accessible in every school district.

This bill, if interpreted in the spirit it was written will increase the likelihood that whether a child uses ASL or a spoken language, he or she will become literate in English and will be able to go on and fulfill his or her potential independently.