NEIL ABERCROMBIE GOVERNOR OF HAWAII



STATE OF HAWAII DEPARTMENT OF HEALTH P.O. Box 3378 HONOLULU, HAWAII 96801-3378 DIRECTOR OF HEALTH

In reply, please refer to: File:

House Committee on Health

H.B. 2228, Relating to the Hearing Disabled

Testimony of David Sakamoto, MD, MBA Deputy Director, Health Resources Administration February 12, 2014

Department's Position: The Department of Health (DOH) appreciates the intent of H.B. 2228 to have 1 2 the DOH conduct a pilot program on Hawai'i island for children with cochlear implants. DOH questions the needs for a pilot program as it currently provides services outlined in this measure for 3 4 children with cochlear implants. 5 Fiscal Implications: There is a general fund appropriation for this bill. Funding for this pilot program 6 should not replace or adversely impact priorities indicated in our Executive Budget. Purpose and Justification: H.B. 2228 requires the DOH to conduct a three-year pilot program to assist 7 preschool-aged children with cochlear implants to acquire spoken language skills. The program 8 9 includes coordination with existing services and program; provision of space, staff, training, equipment, and materials; developing appropriate learning opportunities; provision of information about existing 10 services, options, and supports for families; and use of appropriate assessment and service delivery 11 12 models. A child who receives a cochlear implant needs therapy services in order to benefit from the 13 implant. As such, it would be highly unlikely that a child with an implant would not be eligible for 14

15 DOH or Department of Education services, unless the child has had successful therapy and no longer *Promoting Lifelong Health & Wellness*

- 1 needs services. DOH provides services for children zero through three with cochlear implants and offer
- 2 the services in the proposed bill.
- 3 Thank you for this opportunity to testify.

Subject: HB2228 RELATING TO THE HEARING DISABLED

I am sharing this testimony in support of HB2228. I am an orally-trained Deaf and Hard of Hearing educator who has been donating my services to a family in Kailua Kona, Hawaii since January of 2013. While working with this family, I learned that there as many as 12 children currently in the Hawaii Department of Health system between the ages of 0 and 3, on the Big Island of Hawaii, who wear hearing aids, who have not been offered information regarding ALL the communication methods available to children with hearing loss. The family that I am working with was only told about sign language by their audiologist and their son's IFSP Deaf and Hard of Hearing Teacher

The evidence-based research shows that over 90% of children with hearing loss have parents who can hear and speak. These parents want their children to hear and speak as well. Due to advancements in technology and programs like Universal Newborn Hearing Screening, hearing and speaking are attainable, even to children with profound hearing loss. Research also shows that children who receive early diagnosis, early amplification and early intervention services are able to catch up to their hearing peers in grade school and go into mainstream classes. These children grow up to be contributing members of society, working in careers they are passionate about. They are not limited because they can only communicate with other individuals who sign. They can communicate with anyone who speaks and listens.

If the state of Hawaii is doing their due diligence, then professionals like audiologists and Deaf and Hard of Hearing teachers will disclose to parents that there are 3 options regarding communication and a child with hearing loss. There is American Sign Language (currently the only method being shared with Hawaiian families), Total Communication, and Oral Deaf or Auditory Oral Communication. This also means that Hawaii must have the appropriate professionals available to provide intervention, beginning at birth and made available until age 22.

Hawaii must provide orally trained deaf educators. The family that I worked with was offered Deaf education services from a DHH teacher who pushed sign language and tried to convince the family their child would never speak. Not all DHH teachers are the same. A teacher trained to specialize in American Sign Language has a different skill set than a teacher trained to specialize in Auditory Verbal Communication.

Hawaii must provide pediatric audiologists, trained to work with infants and children, who understand all the current technology. The child I work with in Hawaii was fit with an adult hearing aid by an audiologist who did not know how to work with a child. His family has also struggled to find a pediatric audiologist who understands cochlear implants and knows how to map a child's cochlear implant. Currently, the family visits Oahu to get services from the only pediatric audiologist who specializes in this area in all of Hawaii. Hawaii must hire oral deaf ducators who are committed to working with the A.G. Bell Association and earning their Listening and Spoken Language Specialist certification (LSLS), also knows as Auditory Verbal Therapists (AVT) or Auditory Verbal Educators (AVeD). The family that I work with is currently paying a Canadian AVT out of pocket for twice-weekly therapy sessions.

Hawaii must hire or train Speech Language Pathologists who are committed to and trained in auditory verbal methods so that they may work successfully with children with hearing loss who are properly amplified.

Hawaii's Department of Education must not only offer all three communication methods to parents whose children have hearing loss, but they must provide the specially trained educators, therapists AND appropriate classroom environments necessary for true Least Restrictive Environment compliance as mandated in IDEA laws. In order for a child to benefit in a classroom when they have hearing loss, the classroom must have certain modifications. The classroom should have soundabsorbing tiles, carpets to absorb sound, and, depending on the age and reporting skills of the students in the classrooms, either soundfield systems or personal FM systems in the classrooms and educators who know how to use and troubleshoot the low-incidence equipment.

All of these things that I have mentioned are being offered across the United States. In many school districts, parents are educating themselves and then suing school districts when oral deaf education services are not offered. I know that the family I have been working with in Hawaii is hoping to not have to pursue that course of action, but they will if they must.

There is a great demand for oral deaf educators. I believe that even if Hawaii must begin by bringing in professionals from the mainland, that in short order, Hawaii's own educators and speech therapists will begin to see the need and seek to get the proper training to help the children of Hawaii. There are graduate programs on the mainland that offer classes primarily online. These programs offer federal assistance to participants that cover roughly 75% of their tuition. I am certain you have some strong teachers in Hawaii that would jump at an opportunity to earn a master's degree and then work with Hawaiian children with hearing loss.

This bill will open the door to long-overdue change in Hawaii that will bring the islands of Hawaii into compliance with IDEA laws. It will bring job opportunities to Hawaii. I see it as a win-win and I hope to see this bill go the distance. I visit the Big Island frequently. I hope to be able to visit one day soon and visit your 3-year pilot program. Or maybe I will even be fortunate enough to help create it. The children and families of Hawaii truly deserve this.

Subject:

HB2228/ Feb. 12th,2014

My testimony is in support of HB 2228

Thank you so much for the opportunity to testify in support of HB 2228, a bill that will bring much needed services to the children of Hawaii.

I know that if this bill is passed many children who have hearing loss, but who can communicate through spoken language with proper professional services and early intervention, will benefit.

Evidence-based research shows that Deaf and Hard of Hearing Children who receive an early diagnosis, proper amplification and professional intervention services from trained experts can be mainstreamed into our school system early. They can be great scholars and grow up to be doctors, lawyers or any other kind of professional that they choose to be. Hawaii must follow the example of other states and provide the proper information to parents and the proper services to children with hearing loss. Our children deserve the best.

We are from Kona and my son Julian is now 3 years old. At age two, he was diagnosed with a hearing loss. I will never forget that day. I asked the doctor, "Well, will he speak?" She said, "Don't worry, he can learn American Sign Language (ASL). Many children I see are happy with that." She didn't mention that over 90% of children with hearing loss have hearing parents and that speech could be his mode of communication.

Time went on and many months after his diagnosis, he was he amplified with hearing aids. After eleven repairs and a lot of waiting around for care, we decided to go to Los Angeles for a second opinion. There, we found out he had been fit with an adult hearing aid and that it was programmed incorrectly. We also learned that his hearing had dropped and he was now a cochlear implant candidate.

In Hawaii, all I was told by his audiologist at diagnosis what the he would need sign to communicate. At that time we didn't know one person who signed fluently. Being a parent, I felt compelled to research the alternatives. I found out that children today with a hearing loss can have beautiful speech. As parents who communicate using spoken language, this was wonderful news. However, I had no idea what battles that I would have to go through to get Julian what he needed.

What has been lacking for Julian within the Department of Education:

Inclusion Class: At Julian's first Individualized Education Program (IEP), I had to request and fight for an appropriate classroom setting for Julian. He was ultimately bumped up on the waiting list to get into an inclusion classroom, which is what he is in right not. The true Least Restrictive Environment for Julian would be a classroom with an auditory/oral trained Deaf and Hard of Hearing teacher who knows exactly how to work with his disability, with other children with hearing loss. These teachers are also trained and can troubleshoot the equipment that Julian has (cochlear implants, FM system). Right now

he has a special education teacher with no training or understanding of how to work with a child with hearing loss.

Acoustic Classroom: It is critical that Julian has a classroom where he can best learn auditorily. I fought for a sound field system, carpeting and sound absorbing ceiling tiles. So far, the only thing in the classroom is the soundfield system, but his teacher does not really know how to use it to best benefit Julian. Currently the classroom only uses this system at circle time. Ceiling tiles have been promised, but not delivered by the DOE. My request for sound absorbing carpet was flatly denied.

Oral Professional. With Julian and many other newly implanted children, there is a need for their auditory abilities to catch up with their cognitive development. Using audition first is one of the primary techniques for an Oral Speech Therapist or an Auditory Verbal Therapist. Currently Julian does not see an Oral Speech Therapist. We have spent our personal money to hire an Auditory Verbal Therapist who works with Julian via teleconferencing at home. To our knowledge, there is not a single Auditory Verbal Therapist in Hawaii. I have also requested an Oral DHH teacher for Julian and, after filing a formal complaint, I have been told a position will be established. I was encouraged to drop that compliant, but as of today there still isn't an official position listed with the DOE. An Oral Deaf and Hard of Hearing Teacher would be qualified to work with children with hearing loss who have Cochlear implants or hearing aids to access sound and communicate with spoken language so they can catch up to their hearing peers.

Let me give you an example of what is happening in Julian's class. The very first day Julian got back from his activation, after only hearing for two weeks, his Special Education teacher wanted him to be able to respond to his own name. This would be like expecting newborn baby to respond to their name. It was not an appropriate goal to have for Julian at that time. An Oral Deaf and Hard of Hearing Teacher is trained to know what a 2-week-old listener who is 3 years old should be expected to do and can set appropriate goals. I showed his current IEP to several orally trained deaf education professionals on the mainland for review and their response was that Julian's goals weren't appropriate and that he needed proper intervention immediately.

The Urgency of this matter: My first IEP was May 9th 2013. Julian still doesn't have a trained Oral Speech Language Therapist, an Oral Deaf and Hard of Hearing Teacher or a Least Restrictive classroom. No other family in Hawaii should have to go through what my family is going through. No other child should have to go through what Julian is going through. Many experts have told us that time is of the essence for Julian to catch up. The auditory function of the brain can only play catch up for so long. After a while the brain will never absorb information in the same way and Julian will have gaps in his language and cognitive understanding of language. With Julian's late diagnosis, late PROPER amplification, and the lack of appropriate intervention services, he will be impaired even more if Hawaii doesn't make some needed changes now. Sadly, Julian is one of many children in Hawaii that will be impacted if change does not occur. I reiterate. The time for change is now.

Bottom-line: My dream is that one day soon when a parent in Hawaii gets the news that their child is deaf, they will be given all the current information about hearing loss and their options so that they can

make an educated communication choice. Once they make that choice, whether it be using American Sign Language or Oral Communication or Both, Hawaii should have all the resources and professionals to support their choice.

HB2228 will bring Hawaii the necessary professionals to these children. Let the results of the pilot program be the example and like many other States. Hawaii can then say they have a successful Oral DHH program that enriches many.

HB2228 Submitted on: 2/11/2014 Testimony for HLT on Feb 12, 2014 10:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Linda Elento	Individual	Support	No

Comments: If the current systems in place provided for the spoken and sign language needs of our children who have some hearing loss (or who have Down syndrome and can hear) then bills like this one would not be created. About 10 years ago when I looked for a signing and speaking classroom for my son, I found a Dept of Ed special ed preschool class held at a private preschool, filled with children with cochlear implants and the teacher knew sign, but knew this class needed to be taught spoken language. While this class learned to speak, my child needed to learn sign too, so this wasn't the class for him. Help the families on the Big Island as their children also need what this bill addresses.

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

HB2228 Submitted on: 2/12/2014 Testimony for HLT on Feb 12, 2014 10:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
mune morichika	Individual	Support	No

Comments: My daughter is CI user and she is in Japan to have education because of luck of support from DOE such as oral speech lesson. I hope DOE and DOH can afford to have auditory speech and language specialists and pathologist for impaired cochlear and amplification children. Thanks.

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HB2228 Submitted on: 2/11/2014 Testimony for HLT on Feb 12, 2014 10:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Teresa Cruzan	Individual	Support	No

Comments:

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Date: 2/12/2014

Bill: HB 2228

I am in support of HB 2228. I am taking the position of **support** of this bill to give deaf and hard of hearing (DHH) children with cochlear implants (CI) in our community a chance to be a part of a more successful future by supporting development an appropriate spoken language program in a school in Kona. We must be the voices of those who cannot yet speak.

Currently, in Kona, we are behind in the suggested standard of education for the CI population that have chosen speech as a vehicle for communication. While our schools in Kona are attempting to accommodate as best they can, it is not meeting needs of the children. Current teachers are not educated, nor have they practiced, in the appropriate teaching methods, interactions, and interventions, for CI children whose families have chosen for their child to acquire spoken language skills.

As such, CI children are not being provided the appropriate learning tools/environment (proper use of sound field systems, ceiling tiles to help with noise reverberation and back ground noise). To properly educate a CI child it takes a team of oral DHH educated personnel to use these tools appropriately. An oral DHH teacher has depth of understanding of a teacher's roles, and student roles. Not only do they understand the importance of language acquisition, but they know the steps it takes to get there. This is why this bill is so important. By providing our community with an environment of teachers, and assistants who have knowledgeable use of teaching practices and standards for oral DHH education in CI children, we give these children a chance at a more successful future.

If CI children do not receive the proper planning and care in education their development will be delayed in many areas besides just speech (i.e. depth of understanding, relationship skills). If CI children are not afforded highly qualified oral DHH teachers to educate, test, and provide appropriate interventions, then the CI child will fall short of any projected education goals. These shortfalls in turn can lead to impacts on self-sufficiency in adulthood.

In all, it seems crazy that it is a fight to provide a pathway to the right to speak for disabled CI DHH children in Hawai'i. We all should have the right to communicate in oral language if we choose. By supporting this bill, you will do right by children who want to speak. We must be the voices of those who cannot yet speak. Help our CI keiki become strong successful communicators, and leaders of our community ion future generation. Support HB 2228.

Mahalo for consideration and your time

Andi Pawasarat-Losalio

Kona

HB2228 Submitted on: 2/12/2014 Testimony for HLT on Feb 12, 2014 10:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Len Losalio	Individual	Support	No

Comments: I am in full support of this measure to help Children with these implants. These children have to go away from their homes in Hawaii to receive this special surgery, and then upon successful completion, there is no facilities for them to learn how to speak, here in Hawaii. It becomes a huge burden for the families to have to continue to travel in order for their child to receive proper care. Please support this measure so that these families are not broken up or taken away from their homes. Mahalo Nui Loa, Len H. Losalio

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