

# 2023 South Dakota Newborn Screening Advisory Committee Meeting

## Public Comment

### Written Public Comments

- Carri Crum, Vermillion, SD
  - a. In South Dakota, we have made great strides the past decade to catch up with implementing things that have long been the standard in other areas of the country. One area in which we have made progress but still needs improvement is hearing health care for children. This starts with mandatory newborn hearing screenings, not just simply a recommendation for hearing screenings. A World Health Organization Report from 2017 entitled, "Global costs of unaddressed hearing loss and cost-effectiveness of interventions," states that an estimated 360 million people worldwide have hearing loss. According to the Centers for Disease Control and Prevention, in 2019, over 98% of newborns were screened for hearing loss, and almost 6,000 infants were identified with a permanent hearing loss. Hearing loss affects brain development, language, speech, ability to communicate, learning, socialization, mental health, productivity, academic achievement, and so much more for children, followed up with job opportunities as adults. It is imperative that children born with hearing loss are identified at birth so that early intervention can begin.

I am speaking from the heart on this topic. My husband and I have lived and breathed this journey for the past 12 years. We have three children, all of which were born in Iowa, as we live near the border. Two of them passed their newborn hearing screenings with flying colors. Our youngest did not. She was "referred" on one ear, and she passed the other ear. As is common, the hospital staff told us to follow up later because she probably had "junk" in her ears from birth. We followed up over the course of two months, although not taking things seriously since our other two children had normal hearing. Eventually, our daughter passed the ear that was originally referred, and then was referred on the ear that originally passed. Because she had passed each ear once, they told us she was probably fine. The system failed our daughter, and as parents we were uneducated regarding hearing loss and the importance of following up with further hearing tests. Our daughter is profoundly deaf. Profoundly. Her hearing loss was not identified until we began to question her hearing at her 9 month well check. After visits with multiple audiologists and doctors, her hearing loss was finally identified at 13 months. She received her first cochlear implant at 17 1/2 months and her second one at 25 months. Because her hearing loss was not properly identified at birth, we have spent the past 11 years trying to "catch up" to her normal hearing peers in areas like speech, language, literacy, academics, and social skills, among other things. She is still lagging behind, and we, along with her team of professionals, are still working hard to get her caught up. Early identification is critical for children with hearing loss. South Dakota desperately needs mandatory newborn hearing screenings and a solid policy for following up on questionable screening results.

If the quality of life of our children in South Dakota is not reason enough to implement mandatory newborn hearing screenings, consider the costs associated with hearing loss. According to the American Cochlear Implant Alliance, the cost of hearing loss for a child with prelingual deafness exceeds \$1 million. The report I previously referenced from the World Health Organization states that the cost to the health-care sector is estimated to be \$67-107 billion worldwide for providing hearing loss care and hearing equipment. The cost to the education sector is \$3.9 billion for children 5-14 years old, assuming that only children with moderately severe loss require educational support. Loss of productivity accounts for \$105 billion in cost annually, while societal costs add another \$573 billion each year. The report states, "Early identification of hearing loss through screening of newborns, schoolchildren and adults over 50 years of age is found to be cost-effective. In neonates, universal screening strategy yields good economic returns in the long term." Under the recommendations section of the report, it states, "Hearing loss must be addressed as a public health issue."

As a parent, and as a South Dakotan, I am asking you to invest in our children by making newborn hearing screenings a mandatory part of the Newborn Screening Panel. Our children are the future of South Dakota. Please help ensure they have a bright future from the very beginning.

Sincerely, Carri Crum Vermillion, SD

- Brad Bies, Yankton, SD  
Committee Members,

I'm the parent of a nearly three-year-old deaf child, who uses cochlear implants. My wife and I are hearing, as are more than 90% of all parents of deaf children, so we knew very little about hearing loss before it impacted a member of our family. During this review process I'm confident that experts will share statistics about the current gaps in testing and intervention in South Dakota, and how important early diagnosis and intervention in the first three years is for deaf individuals. I'd like to share a little bit about how that impacts families.

Newborn hearing screening and diagnosis is critical, in part, because outside of some narrow specialties, very few medical professionals are well trained in identifying a child with a differing hearing status. Parents are even less prepared to recognize the signs. Our son, like most deaf children, is a great mimic. He could react to situations in ways that even made other caregivers doubt his diagnosis. A child lost to testing is likely a child that won't be identified until they fail to start speaking two years later. That's months and years of lost intervention, critical time lost.

Raising a deaf child is a change of lifestyle, not a course of treatment. In the past as a culture we've medicalized deafness. There is a medical component, but this is really about language acquisition. Early medical identification is the first, most critical step, because it is the gateway to language.

Our son uses bilateral cochlear implants to access sound, and from sound is learning spoken language. He's not cured; we're not trying to cure his deafness. However, with early detection and parent education, we have chosen a path to spoken language for our son, and that path includes realistic expectations for success. If not for early diagnosis we would have lost months or even years. The critical time for language is the first three years, and a child not identified until after he or she is three years old will struggle with language (manual or spoken) probably for their entire time in school. Children like our son can't afford to lose that time.

Our son was referred on his newborn hearing screen from the hospital, ABR tested over several weeks, diagnosed and fitted with hearing aids during his third month, and bilaterally implanted and activated at about 15 months. Our family chose a listening and spoken language route, with support from American Sign Language. With intensive intervention and family support, he's now on par with his same-age peers' language development. Our family was lucky, but families shouldn't have to be lucky. The benefits of mandatory universal early hearing testing and diagnosis are not disputed both for families and the medical/educational system.

South Dakota is one of a shrinking number of states not mandating the newborn hearing screening. That alone isn't a reason, but it is indicative of a plurality of other states recognizing the benefits and prioritizing a population that has historically faced serious disadvantages from late identification and lack of intervention. We "treat" deafness with language, either spoken language or manual languages (sign languages). The "treatments" are well known and easy to implement, the gap we have is in identification and referral to intervention. This is a solvable problem with the resources we have available to us today.

Brad Bies  
Yankton, SD

**Public Comment for the Newborn Screening Advisory Committee**

My name is Jill Scott and I am the parent of a child with bilateral profound hearing loss. I am advocating that the newborn hearing screening be added to the required list of testing performed on South Dakota for all children as listed on the RUSP. I support this test due to providing the opportunity for every child, regardless of their hearing status, to be able to reach their highest potential in life. Early access to language needs to happen for all children whether spoken or signed.

As adults, a basic human right we all seem to take for granted is the right to communicate with others. Whether this communication is an oral/spoken language, ASL or other visual language, we have the right to communicate.

Early hearing loss identification is so important. The website *Success for Kids with Hearing Loss* states “The ability of a baby’s brain to change with learning is what is known as neuroplasticity. During normal brain development the first information to be processed by the baby’s young brain is sensory information. Baby’s brains are “pre-wired” to accept and process sound. Babies with typical hearing, actually begin to “hear” before they are born - at 20 weeks gestation. At birth, babies already prefer listening to their mother’s voice, to their native language, to people talking rather than noise, and to songs or stories that they heard before they were born.

### **Brain development and hearing loss from birth**

The brain is the true organ of hearing – the ears only transmit sounds to the brain. Babies born with hearing loss are not starting from the same point as a child with typical hearing:

- (1) they have missed out on 20 weeks of typical development of their auditory brain pathways before birth
- (2) they have missed out on auditory neural development that could have occurred after birth, before their hearing loss was diagnosed, and
- (3) they have missed the typical development of the auditory brain pathways that could have occurred after birth up until the time a child hears sound consistently by wearing hearing aids during all waking hours.

Hearing loss in babies has been called a “**neurodevelopmental emergency.**” This is because there is an optimal time in a baby’s brain development for important, meaningful auditory neural connections to form – and that time is during the first three years of life (especially the first year). The baby’s brain must be exposed to meaningful sounds consistently in order for these auditory neural pathways in the brain to develop. If a baby does not hear sounds well, or is only exposed to just a little bit of sound or speech during his/her early years of life, a permanent, reassignment of the child’s auditory brain cells. If the brain is not stimulated by sound it will reorganize itself through synaptic pruning to maximize processing through other senses – primarily vision. The visual centers of the brain will compete for ‘real estate’, eventually also using the space of the auditory brain centers unless consistent auditory stimulation is received by the auditory brain pathways. In other words, the baby’s brain continues to develop and use the meaningful sensory information that it gets. However, if there is no sound information getting to the brain, those auditory neural branches will be pruned away and the neural branches that support the available vision information will be strengthened. This competition continues throughout the first three years of life. After about 3 ½ years of age, the brain has considerably less flexibility to develop effective skills to process auditory information. This is why children who have hearing loss that is identified late have a much harder time learning to listen and speak proficiently. How brains develop directly relates to a child’s development of communication skills. The brains of children born with severe to profound hearing loss who do not use hearing aids or a cochlear implant(s) will naturally become organized so that the children can use their vision as efficiently as possible to develop a visual mode of communication. If the communication occurring consistently around them from a young age is a meaningful visual language, like American Sign Language, their brains will quickly learn ASL as their native language. The “pre-wiring” in the brain for listening and spoken language learning will be reassigned – or changed - for other functions over time, until the auditory brain centers are no longer readily available to receive and use sound stimulation. Those neural connections and “brain space” are then typically used for processing the available and meaningful visual information.”

Full article: <https://successforkidswithhearingloss.com/wp-content/uploads/2011/08/Brain-Development-Hearing-Loss.pdf>

This information can be echoed through the National Institute of Health. Well known medical facilities such as Mayo Clinic and Cleveland Clinic have studies showing the impact of early hearing loss identification and treatment including access to language. The Center on the Developing Child at Harvard University is also a great source of information regarding the brain's plasticity and development. Boston Children's hospital website echoes "Early intervention services can play a critical role in helping young children develop language and communication skills."

Through my participation with the O.U.R. Project of Hands & Voices Headquarters, I have come to learn that my child is at a 3-4x higher rate of abuse and neglect because of his communication difficulties related to deafness and additional delays. This is information that no parent wants to hear, but parents of deaf and hard of hearing children need to be offered this information and tools to support them.

Through my volunteer work with Hands & Voices in South Dakota as well as working with Outreach Consultants from SDSA, the culture that goes along with Deafness has been introduced to not only our son, but our whole family. This work has also introduced to us several Deaf Adults who serve as role models for our son.

The professional collaboration I have been involved with also includes emphasizing the phrase "Don't wait, re-evaluate." This falls under the EHDI guidelines of 1-3-6. Just as you would not wait to see a physician and seek immediate treatment for a heart condition, why would you wait and see if the hearing loss would get better? You seek treatment. You seek out resources. If your child was having a visual impairment, would you wait to get them a pair of glasses to help them access the world through sight? No, you would seek a tool and treatment to help them succeed.

If children are not early identified with a hearing loss and families are not given access to all available resources from the earliest time possible, are we truly giving children in our state the chance to reach their highest potential?

Thank you.