

CASE EXAMPLES

Implementing the SHINE Component of Early Intervention Services

Case 1: Ricky

Ricky is a healthy two month-old infant who has a profound hearing loss in both ears.

Goal 1, Understanding the hearing loss: In infancy the brain grows at a rapid rate and organizes itself according to its genetic blueprint and the patterns of stimulation found in the environment. Ricky's hearing loss is so severe that his brain cannot receive the information that comes from the voices and environmental sounds of his world. Hearing babies are benefiting from the voices and sounds that are part of their daily routines and the bases of language and speech are already developing in the first few weeks of life. Ricky is a healthy baby and his brain can develop normally if it is provided stimulation in a way that can be used. With the proper use of hearing aids, he can likely receive some parts of speech (i.e., low pitches, low vowels and intonation) as well as a variety of louder environmental sounds. Because Ricky can see, he can benefit from information gained from watching the speaker's face and/or signed language. When presented consistently throughout each day, amplified sound and/or signing can provide Ricky's brain the stimulation it needs to develop language. Early focus on Ricky's ability to communicate will support and boost the development of his ultimate cognitive skills and capabilities.

Goal 2, Role of amplification: The severity of Ricky's hearing loss will prevent him developing verbal language unless intensive intervention occurs. The early use of amplification helps the child adjust to the equipment physically, helps the child experience sound, and supports the possibility of speech development. Verbal language development is only possible for Ricky under very intense and consistent attention to communication with continuous amplification use (hearing aids, tactual devices). Even with hearing aids and intensive intervention, most children with profound hearing loss averaging greater than 90-95 dB will not develop intelligible speech. Only 20% of children with severe to profound hearing loss will develop intelligible speech by age 5 using hearing aids alone. Like all quickly growing babies, Ricky will need to have the ear molds to his hearing aids frequently replaced. The power provided by his hearing aids will cause loud feedback (whistling) if the ear molds are not replaced very often, possibly every three to four weeks during his first few months of life. Even with hearing aids on and functioning, Ricky may be able to detect sounds only when they are within about two to three feet of him. Using the Early Listening Function (ELF) test to determine the size of Ricky's hearing range or "listening bubble" for different voices and in different environments is very important. If the parents pursue oral communication the size of Ricky's listening bubble will define how close caregivers must remain to him throughout his waking hours in order for him to perceive spoken language in a manner conducive to learning the parts of speech he can hear. Cochlear implantation surgery may be an option for Ricky. However, it is not performed before the age of 12 months, and a minimum 6-month use of hearing aids is typically required before implantation can occur. It is critical for Ricky to be developing language in a meaningful manner throughout his first year of life and that these skills be monitored every three or six months.

Goal 3, Facilitate Parent-Child Interaction: All babies benefit from the gestures, facial expressions, cuddling and touching of their caregivers, that accompany the feeding, diapering, soothing, bathing and other routines of daily care. When a baby cannot hear, these visual and touch routines of bonding and communication become the child's primary language experiences. Language development is critical for all children, as language is the "toolkit" for self-expression, self-esteem, academic skills, and social interaction. Children who do not develop language skills have difficulty negotiating their wants and needs, managing their emotions, and succeeding when they enter school. Ricky is still very young, but his brain is searching for the foundations of language even now. It is important for Ricky's parents and other caregivers to receive coaching and encouragement to maximize the communicative impact of their care giving and interaction with Ricky. If they are choosing to use manual communication, with or without spoken language, an introduction to American Sign Language, coaching in the use of signs, and opportunities to meet deaf adults will facilitate the family's understanding of what language is (with or without speech) and the importance of their interactions with Ricky.

Goals 2 and 3 together support the optimum early development for Ricky and should be gently and persistently developed by the family with appropriate intervention. If Ricky's parents do not choose to use amplification devices, their choice should be respected. Foundations of communication development through effective parent-child interactions can help prevent developmental delays for Ricky as well as appropriate bonding and interaction.

Goal 4, Unbiased presentation of communication features and options: As Ricky's parents and caregivers begin to understand his hearing loss they will need assistance in exploring the different communication options available to their family. They will benefit from talking to other families of children who are deaf who have made differing communication option decisions. Use of videos and book materials are likely to be of benefit to Ricky's caregivers as they learn about communication modalities and their use in the development and the education of deaf children. If speech is a goal of Ricky's parents, information on cochlear implantation should be provided. A cochlear implant could improve his chances for developing intelligible speech by age five, especially if follow-up therapy is intensive and the parents are highly involved.

SHINE Services: Like many deaf children, if given the opportunity over time, Ricky will show what communication features he needs to effectively understand language and be able to communicate with others. This family may require as much as 6 months of SHINE initial services to understand the hearing loss, use of amplification, communication-interaction strategies, and to become connected with other families who have had a similar experience. The SHINE provider will facilitate meetings between the family and the service providers in the community or other localities in the state that the parents may select for further support and services to support Ricky's communication development. The SHINE provider will continued to be involved with the family to monitor Ricky's progress developing communication skills and his strengths and nonstrengths with visual and auditory input.

Case 2: Sara

Sara is a five month old child who has Down syndrome.

Goal 1, Understanding the hearing loss: Through much repeated testing, Sara's hearing was finally diagnosed as abnormal in the course of the last month. Sara has had frequent ear infections in addition to a moderate sensorineural hearing loss. Communication is a critical foundation to Sara's development of cognitive abilities. Although Sara may have other health issues related to Down's syndrome, the development of her communication ability should also be presented to the parents as a priority. Establishing Sara's ability to communicate will support and boost the development of her ultimate cognitive skills and capabilities. Language experiences and repetition will play a key role in developing Sara's interest and abilities in communication. The SHINE provider will assist Sara's parents and other caregivers in understanding the degree of hearing loss she experiences and how it can change when she has an ongoing ear infection. Sharing the information from Colorado may assist the parents in understanding the benefit of this attention to communication and interaction. (<http://www.colorado.edu/slhs/mdnc/efficacy.html>)

Goal 2, Role of amplification: Continued ear infections are typical for persons with Down's syndrome and will require regular medical intervention. In Sara's case, even when she does not have fluid or infection behind her eardrums she will have a very significant hearing loss. Therefore, use of amplification is necessary if Sara's parents want her to develop an understanding of verbal language. It is important that Sara's physician, audiologist, early intervention providers, parent(s) and caregivers work closely together to monitor Sara's ear problems and to obtain appropriate hearing aids for her as soon as possible. Like other babies wearing hearing aids, Sara's ear molds will need to be replaced frequently. It is important for the SHINE provider to support the parents as Sara is fit with hearing aids and to assist them in recognizing how much more of verbal communication Sara is exposed to when wearing amplification. The parents will need to become skilled in determining the size of Sara's "listening bubble" daily as it may change with the status of her middle ear problems. Hearing aids that have two or more different programs that allow for varying levels of hearing could be of great benefit to Sara, but only if her caregivers are vigilant in monitoring her daily functional hearing and selecting the program that allows Sara the most consistent hearing from day to day. Hearing aids will not replace the need for vigilant medical management of Sara's ear problems.

Goal 3, Facilitate effective parent-child interactions: The SHINE provider will stress the importance of developing effective parent-infant communication strategies. Loving touch, gaining eye contact, and following Sara's lead are critical to stimulating her language and cognitive growth.

Goal 4, Unbiased presentation of communication features and options: By using amplification consistently, children with a moderate hearing loss can perceive all of the speech sounds and have the potential to learn language

in a typical manner. In Sara's case, her moderate hearing loss is sometimes increased due to ongoing ear problems, thus reducing her chances to perceive speech consistently with her hearing aids. Because of the vigilance needed, her parents may prefer to also use sign language with Sara. Although use of sign language may provide a beneficial visual input in addition to her fragmented hearing ability, there is some controversy regarding the benefit of sign language for individuals with Down's syndrome as a means of establishing an initial expressive language. [http://www.tbnet.org/einstein-syndrome/development/sign_language.htm]. In Sara's case, sign language would be considered as an efficient language input that would supplement what language she can hear and not just a means of expressive language. Viewing videotapes on different communication options, discussing information from the internet site, and speaking with other parents of Down's syndrome children may be of benefit to the parents as they consider communication choices.

SHINE Services: Information on hearing loss, support in obtaining and using amplification, and developing effective interaction strategies may take 3-6 months or more of services by the SHINE provider. Connecting Sara's parents with other parents of children with hearing loss as well as other parents of children who have Down's syndrome may be highly beneficial. The SHINE provider will review communication development monitoring checklists with the family to track the amount of communication progress occurring in a 6-month period. Although a 6-month gain in language cannot be expected when there is a cognitive delay, effective stimulation and access to communication should result in continuous growth of language that is equal to the rate of development in other domains.

Case 3: Benjamin

Benjamin is a happy baby who was diagnosed with a mild to moderate sensorineural hearing loss at three months of age.

Goal 1, Understanding the hearing loss: Benjamin's parents have seen him respond to their voices as they hold him and to other sounds that occur close to him. Because of this, the parents doubt the importance of the diagnosis of Benjamin's hearing loss. Indeed, parents of children with mild hearing loss have a tendency to have a longer emotional adjustment period to the presence of their child's hearing loss than do those parents of children with greater degrees of hearing loss. In the past only about one half of children with mild hearing loss wore hearing aids at school age due to lack of parental "buy-in" and non-support of amplification use at home. This places the child with the mild to moderate hearing loss at extremely high risk for language delay, and social skills deficits, as well as reading and other academic deficiencies. The SHINE provider's involvement with this family is critical in helping the family understand what this degree of hearing loss means to the Benjamin's ability to understand his world. Use of audiotapes to simulate hearing loss, earplugs simulating mild hearing loss, and extensive use of the Early Listening Function (ELF) test to determine the size of Benjamin's "listening bubble" as he responds to sounds at different distances will assist the family and caregivers in understanding the developmental effects on language, speech, cognitive development and socialization from the reduced stimulation that occurs with a mild or moderate degree of hearing loss. It is also critical for Benjamin to receive hearing evaluations at three month intervals. Some children have progressive hearing loss that appears to be mild or unilateral in early infancy but progresses in their first years of life. A progressive hearing loss would pose more significant amplification and communication challenges during which the parents would need to be supported.

Goal 2, Role of amplification: Supporting the family as the child goes through the hearing aid fitting process is critical, as they may not be motivated to obtain hearing aids for the child. This may be due to their not being able to recognize any hearing problem at home and/or the degree to which they have accepted the hearing loss. A critical part of parental acceptance of amplification is getting them to have Benjamin use properly fitted hearing aids at home and then reintroducing the contrived listening activities of the ELF test as a means to determine the benefit of the hearing aids to "open up Benjamin's world." Again, identifying any sign that the hearing loss may be progressive is critical to preventing valuable time being lost in adjusting the hearing aids to the auditory deficit.

Goal 3, Facilitate effective parent-child interaction: As a child with a mild to moderate hearing loss, Benjamin may be able to learn speech and language without amplification, but at a much slower rate than children with normal hearing. Encouraging the use of effective parent-interaction communication strategies in addition to use of amplification will go far in preventing any delays in speech and language development for Benjamin. It is important for the parents to recognize that gaps in development can be prevented, but only if Benjamin is provided full access to communication.

Goal 4: Unbiased presentation of communication options: Once the parents realize the limitations of the hearing loss and the need for consistent hearing aid use, Benjamin will likely learn spoken language in a very natural manner and at a typical rate, as long as the parents are within the child's "listening bubble" or hearing range. Few children with mild, moderate, or moderate-severe degrees of hearing loss require visual communication options (ASL, Cued Speech, Manually Coded English) to develop language as long as they are provided communication access to hearing through the consistent use of hearing aids with appropriate intervention. Viewing videotapes on the effects of hearing loss and communication with children who are hearing impaired may be of benefit to Benjamin's caregivers along with written materials such as the children's book "Oliver Gets Hearing Aids." It is imperative for the SHINE provider to work together with the parents in the communication development monitoring procedures every three to six months in order to identify if any communication delays have become evident. If there is audiometric evidence that the hearing loss may be progressive, it is critical that the parents be kept apprised of different communication features that can be combined into different communication options. In this way, the parents may be aware of the possibility of adding visual communication features and/or additional auditory based intervention if Benjamin's hearing loss progresses.

SHINE Services: Depending on the level of acceptance of the parents to the child's diagnosis of hearing loss, the SHINE provider may need to provide as little as two months of service, to four to five months of service. It is possible that the family will need no direct services other than SHINE initial services, communication monitoring by the SHINE provider, and support in transition to school unless communication or other delays are identified. If the parents have become highly involved and supportive in meeting Benjamin's hearing and communication needs, it is probable that he will not require special education support services upon school entry. However, as a child with a permanent hearing loss, he will require classroom accommodations so that he can access verbal instruction and class discussions in a typically active classroom (i.e., FM system, appropriate classroom acoustics).

Case 4: Emily

Emily had a hearing loss identified in the right ear at her newborn hearing screening. After ruling out ear infection as the cause, a severe sensorineural hearing loss was diagnosed.

Goal 1, Understanding the hearing loss: Much like Benjamin's parents, Emily's parents have seen her respond to sounds around her. One out of seven children found to have hearing loss in one ear at birth, develop a hearing loss in their better hearing ear in the first three years of life. Because of this, it is important for Emily to have her hearing tested every three months by the audiologist. Hearing tests are also recommended for all siblings if their hearing status is not already known. Regardless of her responsiveness to the sounds around her, having a hearing loss in her right ear and causes Emily to be at ten times the risk for school learning problems than her peers with two normal hearing ears. Any communication that is at a distance or in the presence of background noise will likely be challenging, if not meaningless to Emily, especially when she is very young. The SHINE provider will best assist the parents in understanding Emily's hearing needs by allowing them to use one earplug and experience the affects of unilateral listening for themselves. Additionally, using the contrived ELF listening activities will likely reveal the distance that Emily begins to falter in receiving sound, and the degree to which background noise can interfere in the reception of desired speech or sounds. An ear infection in her better hearing ear will cause Emily difficulty in hearing and tuning into the speech around her. Little ear problems can turn into significant listening, speech, and language development problems. Emily's parents need to be aware of how she is hearing and go to the doctor for prompt treatment if an ear problem is suspected.

Goal 2, Role of amplification: Wearing an earplug in one ear for an extended time is an experience that may help Emily's parents recognize that there is a hearing problem present and allow them to be more willing to consider having a hearing aid fit to her right ear. It is important to consider stimulating the poorer hearing ear, especially when **one out of seven children who have unilateral hearing loss will end up with a hearing loss in both ears.** Amplifying Emily's poor hearing ear will stimulate the development of that auditory nerve so that, if she loses hearing in her better ear, both ears will be as functional as possible. Children with severe to profound degrees of hearing loss in their worse hearing ear are typically considered to be poor amplification candidates due to the amount of distortion that is likely to be present in the perceptual ability of that ear. Children with moderate to severe degrees of hearing loss in the poor ear are considered good candidates because that degree of hearing loss often has little additional distortion. Having symmetrical hearing, or a balance between the two ears, allows people to understand speech more accurately when background noise is present and to localize sound. Also, if hearing loss does begin to occur in the better hearing ear a progression of hearing loss in the poorer hearing ear is also possible. For children who have hearing loss that progresses to a profound level of deafness, early stimulation of the hearing nerve is critical

and highly beneficial to potential performance with a cochlear implant, should it become an option. If the child is a hearing aid candidate in the poorly hearing ear, the ELF should be used to determine the listening distances and situations that are impacted by the hearing loss before amplification. Repeating the ELF activities with a hearing aid can be useful to the parents in pinpointing the real benefit of amplification to Emily's picking up language incidentally. Reportedly, parents notice that their child with unilateral hearing loss has more difficulty listening in noise or at a distance when they are around two years old.

Goal 3, Facilitate effective parent-child interaction: Assisting the parents in understanding effective parent-infant communication, the need to allow Emily true access to incidental language opportunities, and to pay attention to her developing understanding of conversation building and unspoken social interaction rules may be very beneficial in preventing future difficulties. Understanding the subtleties of communicating effectively with an infant or toddler will benefit the parent's attention to Emily's rate of language development. Surprisingly, even with one good hearing ear, 1/3 of children with unilateral hearing loss, especially if a severe to profound degree, will **develop expressive and receptive language delays (25th percentile or lower)** by the age of three. Not surprisingly then, about 1/3 of children with hearing loss in one ear will require special education support services in school. Along with having weaker language skills, it is surmised that many school delays are due to children missing subtle communication exchanges and social interactions. Communication between young children often occurs in the presence of background noise and across distance; listening situations that are typically more challenging for children with hearing loss, including those with hearing in only one ear. This can lead to a child's lowered self esteem as they feel outside of these peer interactions or may even begin to think that other children are talking about them. This is also true for children with mild degrees of hearing loss, such as Benjamin.

Goal 4: Unbiased presentation of communication options: Children with unilateral hearing loss will learn language through exposure to verbal communication in their environment, without the need for visual communication systems. Therefore, the SHINE provider will likely mention that there are different communication options and that Emily should not need them as long as she has no other developmental issues.

SHINE Services: The SHINE provider may need to provide one to three months of support to Emily's family. Again, it is imperative for the SHINE provider to work with the parents in the communication development monitoring procedures in order to identify if any communication delays are evident. It is possible that the family will also choose to have no direct services other than SHINE initial services and communication monitoring by the SHINE provider. Assuming that SHINE early intervention services will assist the parents in preventing delays from developing, it is likely that Emily who has a unilateral hearing loss will transition into typical school programs without a need for preschool or kindergarten special education support although 504 accommodations will usually be needed (i.e., sound field amplification, appropriate room acoustics).

Case 5: Leon

Leon's hearing problem was evident at birth because he was born with only nubs for outer ears.

Goal 1, Understanding the hearing loss: When born, Leon's ear atresia was assumed to cause hearing loss. Audiologic evaluation was needed to determine if Leon had hearing loss in his hearing nerves, or only conductive hearing loss due to the absence of outer ear, which blocked access to the sound pathways. Evaluation was completed at ten weeks of age. Leon had no sensorineural hearing loss that would cause distortion of sound or real deafness other than a moderate hearing loss across all pitches. In addition, Leon had no other facial abnormalities that would have suggested the presence of some syndrome. Leon would be a good candidate for ear surgery that would open up his ear canals and likely restore normal or near-normal hearing ability. However, this surgery is not performed until children are at least five to six years old and Leon needed to begin learning language now! In cases like Leon's, parents may believe that since hearing will be fine after the surgery, there is no need for intervention because the child will catch up once the ear is structurally normal. Unfortunately, this is not the case. Lack of intervention can cause significant delays in language learning and result in lifelong educational delays. The SHINE provider can help the parents to understand the hearing loss by holding demonstration conversations with them as they wear sound protection earmuffs over earplugs. This provides a mild to moderate degree of conductive hearing loss that is not quite as much hearing loss as Leon's maximal conductive loss, but portrays the muffled quality of this type of hearing loss. Working with the parents on the ELF to determine the size of Leon's "listening bubble" under various conditions will also assist them in understanding that Leon can hear at near distances in quiet, but that his access to typical conversations is very limited without amplification.

Goal 2, Role of amplification: Because Leon has no outer ears or access to his ear canals, traditional behind-the-ear hearing aids cannot be worn. A bone conduction hearing aid would allow Leon to hear within normal hearing levels. This type of hearing aid is a thimble-sized bone vibrator that must be held tightly to the skull, typically behind either ear. The cochlea is encased in bones behind both ears and a bone conduction hearing aid will deliver sound signals through the bones to both cochleas. The challenge to using a bone conduction hearing aid is to keep it on the child's head, as the vibrator is not very comfortable to wear and is more difficult to keep in place than behind-the-ear hearing aids. A bone conduction hearing aid vibrator is usually kept in place with a metal headband, but can also be attached to a small baseball-type cap or to a stretchy headband, a favorite for girls. The benefit of a bone conduction hearing aid is simple to demonstrate. When the parents have earplug or sound muffs in place, or fingers in their ear canals, the bone vibrator can be pressed to a mastoid bone behind one ear and the person will hear the clearly amplified sound.

Goal 3, Facilitate effective parent-child interaction: Because the bone conduction hearing aid can provide clearly amplified sound at normal or near-normal hearing levels (20-25 dB), if the bone conduction aid can be kept on Leon, he will typically learn language and speech at a normal rate. The parent's will benefit from understanding the importance of effective communication strategies, especially for those times when Leon does not have the bone conduction hearing aid on, such as when he is waking up or bathing.

Goal 4, Unbiased presentation of communication options: Like Benjamin and Emily, Leon will learn verbal language and speech through day-to-day exposure like children with normal hearing and will likely not need sign language to access communication. If the parents are interested in using sign language, hopefully in addition to the bone conduction hearing aid, it can only benefit Leon's early language development. Use of sign language by normally hearing children in the first year of life has been found to result in higher levels of expressive language usage once they begin to talk. Leon's parents may be interested in viewing a video that describes the benefits of signing to babies.

SHINE Services: Once Leon's parents understand his hearing ability and the need to compensate for the hearing loss until surgery to construct his outer ears can be performed, then facilitation of using the bone conduction hearing aid in daily situations is the biggest challenge. The SHINE provider may spend two to four months with Leon's parents assisting them in getting the bone conduction hearing aid on Leon successfully and having it worn throughout the day. It would be of benefit to the family to be in contact with other families who have experienced using bone conduction hearing aids, whose children have had reconstructive surgery, and who can provide support and understanding to Leon's parents. Communication development monitoring at least every 3-6 months is critical.

Every child is an individual and each family has their own dynamics. SHINE is an introduction to early intervention services with the purpose of providing families with support, basic information, and unbiased descriptions of communication options. Once this is accomplished, whether it takes one month or six months, the family will transition to whatever ongoing services are appropriate and will continue to receive regular communication development monitoring at six month intervals from the SHINE service coordinator.