



Children’s Hearing Aid Program (UCA 26-10-11): 2019 Annual Report

Requested by:

- Health and Human Services Interim Committee

Prepared by:

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Kenton, CHAP Recipient

Children’s Hearing Aid Program Annual Report

Purpose of Report:

This report is submitted in response to the following language from HB18 passed by the 2015 Legislature:

“The department shall, before December 1 of each year, submit a report to the Health and Human Services Interim Committee that describes the operation and accomplishments of the program.”

Overview:

The Children’s Hearing Aid Pilot Program (CHAPP) was established in July 2013 by the Utah Legislature with the passage of House Bill 157. The program was then amended during the 2015 legislative session and re-named the Children’s Hearing Aid Program (CHAP) in July 2015 with the passage of House Bill 18.

- HB 18 converted the pilot program into a permanent program and increased the age limit to provide hearing aids to qualifying children younger than six years of age who fit within the following eligibility requirements:
 - Ineligible for full hearing aid coverage by Medicaid, the Utah Children’s Health Insurance Program, or private insurance
 - Meeting financial need criteria established by UDOH (families must fall within 300% of the federal poverty guidelines; this is determined by the families’ reported gross income less any out of pocket medical/childcare expenses)
 - Utah residency
 - Diagnosis of a hearing loss with hearing aid recommendation by an audiologist with pediatric expertise
 - Medical clearance by a medical provider for hearing aid fitting
- Ongoing funding was appropriated by the state from the General Fund Restricted – Children’s Hearing Aid Program Account in the amount of \$100,000 to be used for assistance in funding hearing aids, related equipment, and follow-up services. Some years had a higher budget due to carryover monies.
- An ongoing building block provided additional funding increasing the total appropriation to \$319,800 starting FY2020.
- The Utah Department of Health will provide staff to the Children’s Hearing Aid Program Advisory Committee in order to represent the department and support UCA 26-10-11.
 - Personnel are provided from the Bureau of Children with Special Health Care Needs Early Hearing Detection & Intervention (EHDI) program.

- Due to parent and provider feedback regarding the needs of Utah children with hearing loss per survey responses, the following criteria expansions were presented to the state legislature and became effective July 1, 2015 and July 1, 2019 respectively:
 - Softband bone-conduction hearing devices* became an eligible option in addition to traditional hearing aid requests
 - Additional earmold** coverage was included for three years

*Softband bone-conduction hearing devices are hearing aids that sit firmly on a portion of the skull, typically the forehead or mastoid, via a headband and provide amplification through vibration; these are typically prescribed for children with microtia/atresia and other permanent conductive hearing losses.

**An earmold is a custom molded device that fits inside the ear canal and bowl of the ear. It attaches to the hearing aid to 1) hold it on the child's ear and 2) direct the amplified sound into their ear canal.

Emily, CHAP recipient of a softband bone-conduction hearing aid

The mission of CHAP is to optimize early communication and learning potentials for deaf/hard of hearing (DHH) infants and children by providing access to hearing aids to financially eligible families.



Children’s Hearing Aid Program Advisory Committee

UCA 26-10-11 established the Children’s Hearing Aid Program (CHAP) Advisory Committee to recommend medical criteria, to establish eligibility protocols, and to review rules developed by the Utah Department of Health. The committee must include the following members:

- Pediatric audiologist- currently served by Lindsey Tubaugh, AuD
- Speech-language pathologist- currently served by Brooke Edwards, MS, CCC-SLP
- Certified teacher of the deaf or a listening and spoken language therapist- currently served by Paula Pittman, PhD
- Ear, Nose, and Throat Specialist- currently served by Jeremy Meier, MD
- Parent of a child with hearing loss that is six years or older- currently served by Kim Frandsen (current chair as selected by the CHAP Advisory Committee)

In addition, the Utah Department of Health provides staff to represent and support CHAP that currently includes:

- Stephanie Browning McVicar, AuD, FAAA, CCC-A (Program Manager)
- Jenny Pedersen, AuD, CCC-A (CHAP Coordinator)
- Administrative Assistive Staff – currently served by Joyce McStotts

Children’s Hearing Aid Program FY2019 Activities:

The CHAP Advisory Committee has continued to meet the needs of Utah children by listening to parents, audiologists, and other individuals and bringing their comments to the table for discussion. One big concern was that the number of children requesting services exceeded funding during the fiscal year. Audiologists and other professionals were put in the predicament of putting children on a waiting list until the next fiscal year which is not in alignment with national best practice standards that recommend the earlier a child is fit, the more benefit he/she will receive in all aspects of development. In addition, CHAP had to restrict its services to allow more children access to the program. These restrictions included unilateral (instead of bilateral) fitting for bone-conduction hearing devices, denial of earmold requests, and trial periods for unilateral hearing loss. Due to this, CHAP personnel applied for an ongoing building block starting in FY2020. The program was granted additional funding which has allowed us to remove restrictions to ensure that children are being fit according to the national Joint Committee on Infant Hearing (JCIH) recommendations and to ensure that all eligible children residing in Utah can be served.

Other activities include issuing annual surveys to both families and audiologists requesting feedback on CHAP provided services. With this information, we are striving to continue to improve communication, the application process, and the support of both families and providers.

The CHAP Advisory Committee and the Utah Department of Health have provided public awareness of the program by the following means:

- A testimonial video featuring a family of a child who is a CHAP recipient has been posted on the CHAP website and other appropriate social media sites.
- Various formats of a pamphlet featuring CHAP recipients have been placed in audiology and other pediatric provider offices.
- CHAP brochures and pamphlets are placed in *An Interactive Notebook for Families with a Young Child Who is Deaf or Hard of Hearing* binder that is mailed by the UDOH Early Hearing Detection & Intervention (EHDI) program to parents whose children have been newly diagnosed with hearing loss and reported to their program.
- CHAP brochures and pamphlets are distributed at statewide audiology, CMV, pediatric

provider and EHDI conferences and presentations.

- Committee members provide CHAP updates and information at their respective professional and/or public meetings in which they participate.
- Regular CHAP updates are sent via email to Utah audiologists. CHAP brochures are distributed to Baby Watch/Early Intervention providers across the state.
- The CHAP brochure was updated to reflect program and recipient picture changes.
- The CHAP website continues to be updated and is a comprehensive source for parents and providers: health.utah.gov/CHAP.

Number of children who have received hearing aid devices and/or earmolds:

A total of 242 children have requested information for services since the program began accepting applications in November of 2013. Of these, 204 children were approved for services, 27 children did not meet qualification criteria, and 10 children withdrew to date. For FY 2019 specifically, 43 children were approved for services, 5 children did not qualify for services, and 3 children withdrew from the program.

For FY 2019, all but four of the 47 applications were given an approval/denial response within two weeks of receiving the application. The range for approval varies due to the length of time it takes the participants and providers to gather and turn in *all* required paperwork. Typically, more audiological information is required to determine type and permanency of hearing loss if it takes longer than two weeks or there is a possibility that insurance will pay and it may take a bit to see if that will occur. It's important that all the information is turned in to ensure that CHAP funds are used for kids who truly have a need and fall within eligibility requirements. *Once all the documentation is in, the review/approval/denial process is typically less than two working days by UDOH staff.* The process has become more streamlined as the pediatric audiologists who most often use the program are aware of, and compliant with, CHAP application requirements. We continue to monitor survey results to make the process as easy as possible from both the audiologist and parent perspectives. From the last survey, a comment came up requesting the approval/denial answer be given to parents as well as the audiologist, which UDOH staff promptly began to do and made it a part of the CHAP protocol.

If eligibility is determined, children will have access to hearing aid services for up to three years from the date of the hearing aid fitting. The statistics of CHAP (2013-19) and its participants are as follows:

- Participants resided in 75 different cities from 15 different counties throughout Utah
- All but 7 of the 190 eligible applicants have had private or CHIP insurance, neither of which cover any portion of the costs for hearing aids (the 7 applicants did not have insurance at the time of the application and were ineligible for Medicaid)
- Age of hearing aid fitting ranged from 1 to 73 months
- Age of hearing loss diagnosis ranged from 1 week to 70 months
- 64% requested binaural (both ears) fitting, 19% requested left-ear unilateral fitting, and 17%

requested right-ear unilateral fitting

- 38 audiologists with pediatric expertise from 15 different audiology clinics throughout Utah have participated
- 55% of the participants were male and 45% of the participants were female
- Possible etiologies for participant hearing loss include:
 - 26% have an unknown cause
 - 18% have a family history of hearing loss
 - 16% have a syndrome associated with hearing loss
 - 13% have atresia/microtia (physical ear defects)
 - 9% had long-term NICU (neonatal intensive care unit) stays
 - 3% have congenital cytomegalovirus (CMV)
 - 3% have had ototoxic medications and/or radiation (for cancer or infection)
 - 4% have Auditory Neuropathy Spectrum Disorder (ANSD)
 - 1% have a Connexin 26 mutation (gene associated with hearing loss)
 - 2% have had meningitis
 - <1% have had a head trauma
 - 1% have an enlarged vestibular aqueduct (LVA/EVA) (physical inner ear disorder)
 - <1% have a metabolic disease
 - <1% have an absent cochlear nerve
 - <1% have middle-ear abnormalities
- There are 13 sets of siblings that received services from CHAP

*Jayden and Dashell, brothers
and CHAP recipients, before nap...*



...after nap

Eligibility requirements and services offered for children who qualify for CHAP:

Eligibility Requirements

Children eligible for services must be evaluated, diagnosed with hearing loss, and have hearing aids recommended by an audiologist with pediatric expertise. The child must have the hearing loss medically cleared by a medical provider. In addition, CHAP recipients under 3 years of age must be enrolled or in the process of applying for Part C Early Intervention services. Early intervention services will increase the impact and benefit of the hearing aids by monitoring the child's development, supporting communication, and by offering families information, modeling, and training.

Provided services

- Hearing aid(s) and accessories as applicable: this is a one-time benefit per eligible ear
- Earmolds for three years from the hearing aid fitting
- Follow-up services from a managing audiologist with pediatric expertise for three years from the hearing aid fitting date

Cost of providing hearing aids and associated costs through CHAP:

The following is a list of the reimbursement costs for devices/audiologist services, administrative costs, and the total cost expenditures. There has been an increase in CHAP applications and requests for information which has increased the amount of staff time associated with the program. In the past year, audiologists, ENT physicians, early intervention providers, and parents have shown increased awareness in CHAP and have been referring infants and young children to the program which has increased the number of applications. In addition, there has been an increase in collaborative care among different professionals to ensure children are meeting CHAP requirements and being fit as early as possible. This has been wonderful as more children can utilize the program to receive hearing aids and in turn, be enrolled in Early Intervention (both of which are vitally important to help decrease the risk of developmental milestone delays and the need for long-term services). With the addition of the ongoing building block starting FY2020, we can ensure that all eligible children referred from the above providers can receive services through CHAP without the concern of a waiting period. Below are the expenditures for current and previous fiscal years:

- FY 2020 to date: 14 applications have been reimbursed; 8 are currently in the reimbursement process; and 9 additional earmold requests have been reimbursed.
 - Total expenditures: \$45,202.94
 - Reimbursement costs for devices/services: \$36,786.08
 - UDOH billed administrative costs: \$8,416.86

- FY 2019: 38 applications and 19 additional earmold requests were reimbursed.
 - Total expenditures \$139,133.61
 - Reimbursement costs for devices/services: \$128,681.53
 - UDOH billed administrative costs: \$10,452.08
- Previous years (FY 2014-2018): 147 applications and 63 additional earmold requests were reimbursed.
 - Total expenditures: \$473,184.57
 - Reimbursement costs for devices/services: \$443,268.40
 - UDOH billed administrative costs: \$29,916.17

Family perception and comments:

All families whose children have participated in the program are asked on an annual basis to complete a brief online survey regarding their experiences with the CHAP program and the impact that the program’s services have had on their child and family. The survey was designed by the Advisory Committee, and families have the opportunity to opt in or out of having their comments published or to remain confidential, if so desired.



Jude, CHAP Recipient with Down Syndrome

Family perception of services and benefits

	Disagree	Neutral	Agree
I/We feel confident in our audiologist's expertise.	0%	12.5%	87.5%
The application to receive hearing aids was clearly written and easy to understand.	0%	0%	100%
Obtaining the hearing aids has been important to our child's speech, language, and listening development.	0%	0%	100%
Our child has benefited greatly from the hearing aid(s) provided by CHAP.	0%	0%	100%
Our family's overall experience with the CHAP program has been positive.	0%	0%	100%

Any questions that come our way on any part of the application are answered quickly as we strive to make the process as easy as possible (while still obtaining required elements) for both parents and providers.

Family comments

Families are given the opportunity to provide their thoughts, both positive and negative, regarding the CHAP program. The comments are almost entirely positive in nature with support for continuation of the program and with families reporting benefit and progress due to the fitting of the funded hearing aids. Representative comments include the following:

- “Those involved in the program are very helpful. They made the financial burden of trying to get hearing aids seamless. The program took away stress and worry knowing my child didn't have to wait to get hearing aids since we couldn't afford them without assistance.”
- “Without this program we could not have afforded hearing aids for our child. Our child has made great progress since receiving his hearing aids.”
- “Our son would have been delayed in receiving his hearing aids or our family would have taken on a greater and stressful debt burden to provide them had it not been for this program.”
- “We are over the moon! Thank you thank you thank you! We are excited for Kenton to get new hearing aids. He's doing really well with his speech and I know it's thanks to these wonderful devices. What a miracle program chap is!”
- “Thank you so much! You have no idea how much this means to us. I am so grateful for this program! There was no way that we could've afforded hearing aids and because of you guys my little boy will be able to hear! Thank you!”
- “It has been 4.5 years since receiving his hearing aids and he is now successfully in main

stream kindergarten loving every minute and while he still needs some speech therapy it is nowhere near what he would have needed had his hearing aids been delayed. Thank you so much for the program!!!”

- “Since receiving my daughter’s hearing aids through CHAP she does so much better in school and in social situations. We are seeing her personality start to really blossom. She would tend to hold back because she couldn’t be engaged in conversations fully since she couldn’t hear everything. We are so grateful for CHAP and the resources it provides to our family.”

Audiologist comments:

As audiologists are a big part of the hearing aid purchase and fitting process and may have to offer their services at a discounted rate, they are also given the opportunity to respond to a survey on their experiences and how the CHAP program has impacted their patients and respective families. As with the family comments, the responses are almost entirely positive and show a support for the program as well. Representative comments include the following:

- “This program provides amplification to patients whose families could not afford it! Application process is easy to follow and complete.”
- “There have been so many children that would have not been fit with hearing aids because of CHAP. Jenny is extremely helpful and timely with questions or processing applications.”
- “It's a great option for families. I think many of these families would choose not to proceed with hearing aid use if this wasn't an option.”
- “...CHAP helps provide crucial assistance to children who have a hearing loss, whose families are unable to afford this need on their own. It gives the child the ability to develop speech and language skills and prepare to enter the school system. Early intervention is critical in helping the child with a hearing loss to develop as or close to their normal hearing peers.”
- “CHAP has changed the lives of a number of families I work with.”
- “I honestly cannot come up with anything to improve CHAP. It has changed so many lives.”

Parents and audiologists are contacted to follow-up on any concerns conveyed in the surveys. One possible improvement that was suggested by parents was to contact both the parents and the audiologists with an approval/denial. Previously we have contacted only the audiologist as they work closely with the family. Due to these comments we have started contacting parents as well which has been beneficial for both the parents and CHAP personnel. We are given more opportunities to interact with the families and to respond to questions or concerns much sooner.

Expected outcomes and public benefit:

Numerous outcome studies have clearly established that the earlier a child can be fit with appropriate amplification, the greater their potential for typical speech and language development, social skills, academic achievement, and future vocational skills. Typical areas of concern for a child with hearing loss

that can go unnoticed include behavioral, cognitive and academic, speech-language and communication, mental health, and social skills. Studies have shown that early amplification and appropriate Early Intervention services save significant costs ranging from \$200,000 up to \$1,000,000 per individual that are associated with special education services and the potential need for long term societal services. Accordingly, there are two outcome goals that the CHAP program is ascribing towards:

1. An increased number of Utah children with hearing loss will have access to and be appropriately fit with bilateral or unilateral hearing devices.
2. An increased number of eligible Utah children with hearing loss will be enrolled in Early Intervention services.

Through CHAP, families in need have early access to appropriate amplification for their infants and young children diagnosed with permanent hearing loss to enhance their ability to communicate and to promote healthy developmental milestones. Early amplification and appropriate Early Intervention services save significant costs associated with special education services and the potential need for long term services, thereby reducing financial burden on the public.



Ari, CHAP recipient