



## Children’s Hearing Aid Program (UCA 26-10-11): 2018 Annual Report

Requested by:

- Health and Human Services Interim Committee

Prepared by:

- Utah Department of Health (UDOH)
- Children’s Hearing Aid Program Advisory Committee



## Children’s Hearing Aid Program 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 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.
- 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:
  - The age of eligibility increased from under 3 years of age to under 6 years of age
  - Additional earmold\* coverage was included for one year
  - Softband bone-conduction hearing devices\*\* became an eligible option in addition to traditional hearing aid requests

\*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.

\*\*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.

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.

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



**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 Tubaug, 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 (current chair as selected by the CHAP Advisory Committee)
- Parent of a child with hearing loss that is six years old or older- currently served by Kim Frandsen

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

### **Children’s Hearing Aid Program FY2018 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. The CHAP Advisory Committee also issues 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 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 was created to post on the CHAP website and other appropriate social media sites.
- Various formats of a pamphlet featuring CHAP recipients were created to place in audiology and other pediatric provider offices.
- Applications that could be filled out online were created and posted on the website to make it easier for families to fill out and e-mail the forms to their audiologists.
- 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 website continues to be updated and is a comprehensive source for parents and providers: [health.utah.gov/CHAP](http://health.utah.gov/CHAP).

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

A total of 198 children have requested information for services since the program began accepting applications in November of 2013. Of these, 167 children were approved for services, 23 children did not meet qualification criteria, and 8 children withdrew to date. For FY 2018 specifically, 34 children were approved for services, 4 children did not qualify for services, and 2 children withdrew from the program.

For FY 2018, the average time period needed to turn in and review all documentation was 9 days with the range falling from same-day to 55 days for approval/denial of 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. In the case of the outlier that took 55 days, more audiological information was required to determine type and permanency of hearing loss. It took the audiologist about 5 weeks to gather the necessary information and turn it in so the application could be fully processed. 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 and 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 the 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 application forms be available to be filled out online, which UDOH staff was able to accommodate and set up on the website for easy access.

If eligibility is determined, children will have access to audiological services for up to one year from the date of the hearing aid fitting. The statistics of CHAP (2013-18) and its participants are as follows:

- Participants resided in 65 different cities from 13 different counties throughout Utah
- All but 4 of the eligible applicants have had private or CHIP insurance, neither of which cover any portion of the costs for hearing aids (the 4 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
- 68% requested binaural (both ears) fitting, 17% requested left-ear unilateral fitting, and 15% requested right-ear unilateral fitting
- 32 audiologists with pediatric expertise from 13 different audiology clinics have participated
- 53% of the participants were male and 47% of the participants were female

- Possible etiologies for hearing loss included:
  - 26% have an unknown cause
  - 17% have a family history of hearing loss
  - 19% have a syndrome associated with hearing loss
  - 13% have atresia/microtia (physical ear defects)
  - 8% had long-term NICU stays
  - 4% have congenital cytomegalovirus (CMV)
  - 4% have had ototoxic medications and/or radiation (for cancer or infection)
  - 4% have Auditory Neuropathy Spectrum Disorder (ANSD)
  - 2% have a Connexin 26 mutation (gene associated with hearing loss)
  - 2% have had meningitis
  - 1% have had a head trauma
  - 0.3% have an enlarged vestibular aqueduct (LVA/EVA) (physical inner ear disorder)
  - 0.3% have a metabolic disease
  - 0.3% have an absent cochlear nerve
- There are 9 sets of siblings that received services from CHAP



*Evie Shawcroft, CHAP recipient, with her sisters*

## **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 all 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): this is a one-time benefit per eligible ear
- Earmolds for one year from the hearing aid fitting
- Follow-up services from a managing audiologist with pediatric expertise for one year from the hearing aid fitting date

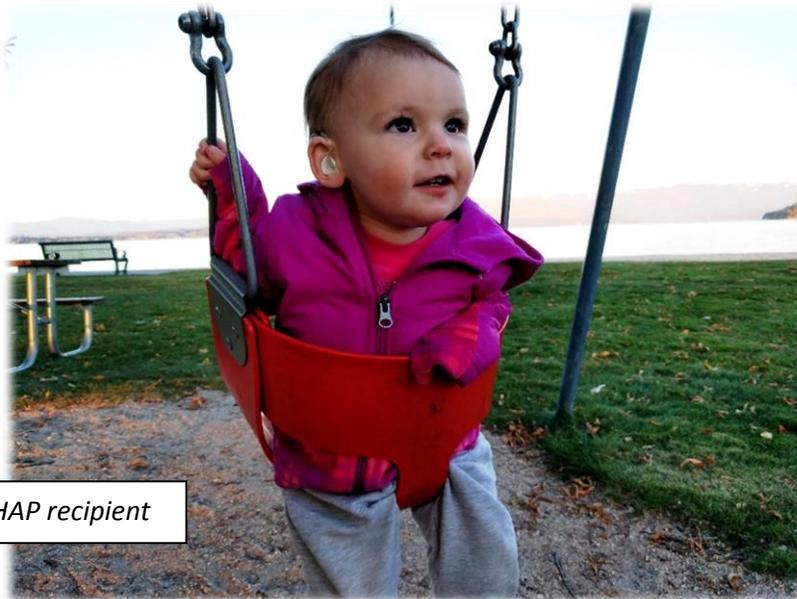
## **Cost of providing hearing aids and associated costs through CHAP:**

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, many audiologists, parents, and early intervention providers have been referring infants and young children to the program increasing CHAP awareness and applications. In one aspect, this is 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). On the other hand, this also means that our funds are depleted more rapidly. In FY 2018, there were eleven children whose hearing aids had to be delayed due to insufficient CHAP funds and 20 children that audiologists reported that they didn't refer to CHAP due to the lack of current funds. The CHAP Advisory Committee took steps to tighten eligibility and decrease services in order to serve the maximum amount of children within the available budget; however, this is not in the best interest of Utah children who have been diagnosed with a hearing loss. Some of the steps put into place include limiting the coverage of softband bone-conduction devices to only one ear and requiring a trial period for unilateral fittings. In August, a building block application was turned in to request ongoing additional funding.

- FY 2019 to date: 16 applications have been reimbursed; 9 are currently in the reimbursement process; and 9 additional earmold requests have been reimbursed.
  - Total expenditures: \$49,118.99
  - Reimbursement costs for devices/services: \$45,337.72
  - UDOH billed administrative costs: \$3,781.27
- FY 2018: 40 applications and 27 additional earmold requests were reimbursed.
  - Total expenditures \$146,160.73
  - Reimbursement costs for devices/services: \$134,937.73
  - UDOH billed administrative costs: \$11,223.00
- Previous years (FY 2014-2017): 107 applications and 36 additional earmold requests were reimbursed.
  - Total expenditures: \$327,023.84
  - Reimbursement costs for devices/services: \$308,330.67
  - UDOH billed administrative costs: \$18,693.17

**Family perception and comments:**

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



*Pearl, CHAP recipient*

2018 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.

2018 Family comments

Families were 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:

- “My son had liver cancer as an infant and has hearing loss due to some of the chemotherapy drugs he received. We were already struggling financially with the debt burden of his cancer treatment and he needed these hearing aids to allow for proper hearing and speech development. 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!!!”
- “I am greatly appreciative of the CHAP program. My son was diagnosed with mild bilateral hearing loss. Our family has seen a vast improvement in his speech and hearing. We would hope that the legislature continues funding that could potentially help others as much as we have been helped.”
- “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.”

- “CHAP has made such a huge impact to our lives in providing hearing aids for my son! Tears were brought to my eyes when I heard we were approved! There are so many special appointments and expenses related to hearing aids and hearing loss and it can get difficult! CHAP is important to us because it literally is the difference in my son hearing or not hearing! We will be forever grateful for this program!”
- “This helps families and children whose insurance won’t cover hearing aids. Ultimately it provides a priceless gift to us who in the beginning didn’t plan on this (unexpected) expense. It has given our child a better ability to develop her speech and balance being able to hear fully!”
- “Insurance covers nothing on hearing aids so CHAP helps so much! The kids already go through so many special appointments so it’s a huge stress relief on the parents!”
- “It all comes down to money and racking up significant medical costs since our future is unknown with a child having MED13L (a rare genetic disorder). This program is the ONLY program that has given us a little relief in medical bills, so thank you!!!”
- “No child should have to go without being able to hear. Since most insurance plans don’t cover hearing aids the financial burden is put on parents. CHAP makes it possible so children don’t have to go without due to the cost.”

#### **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 were 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:

- “As stated above, it 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 is so easy to work with. Jenny does an amazing job. CHAP is my go-to when a family doesn't have coverage. It's changed the lives of a number of families I work with.”
- “I can't say enough good things about CHAP. They are generous, easy to work with, and make a true difference for families.”
- “This is a life line for so many families. There are no other options that are nearly as good as CHAP.”
- “Kids need these aids and families cannot afford it. CHAP helps SO MANY KIDS!!!”
- “This is a wonderful program, and it would be a great loss to cut its funding.”

Parents and audiologists are contacted to follow-up on any concerns conveyed in the surveys. One possible improvement that was suggested by multiple parents and pediatric audiologists was extending the age limit to include children older than six years old.

**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



*Taylor, CHAP recipient, fit at one month of age*

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.