



## Children's Hearing Aid Program (UCA 26-10-11): 2017 Annual Report

Requested by:

- Health and Human Services Interim Committee

Prepared by:

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



*Taylor, CHAP Recipient*

## 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 and any out of pocket medical/childcare expenses)
  - Utah resident
  - 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.

**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 Shannon White, 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 Application Coordinator)
- Administrative Assistive Staff



*Hayes, CHAP recipient of softband bone-conduction hearing aids*

## **Children’s Hearing Aid Program FY2017 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 the provided CHAP 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 new pamphlet was created to place in pediatric and audiology 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 diagnosed with hearing loss and reported to their program.
- CHAP brochures and pamphlets are distributed at local audiology, CMV, and/or hearing loss presentations.
- Committee members provide CHAP updates and information at their respective professional and/or public meetings in which they participate.
- Regular CHAP updates and a newsletter were created and sent via email to the Utah Consortium of Pediatric Audiologists (UCOPA) – a listserv for audiologists in Utah who specialize or have an interest in pediatrics.
- CHAP brochures are distributed to Baby Watch/Early Intervention providers across the state.
- CHAP brochures were provided to school districts.
- 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 147 children have requested information for services since the program began accepting applications in November of 2013. Of these, 123 children were approved for services, 19 children did not meet qualification criteria, and 5 children withdrew to date. For FY 2017 specifically, 34 children were approved for services, 3 children did not qualify for services, and no children withdrew from the program.

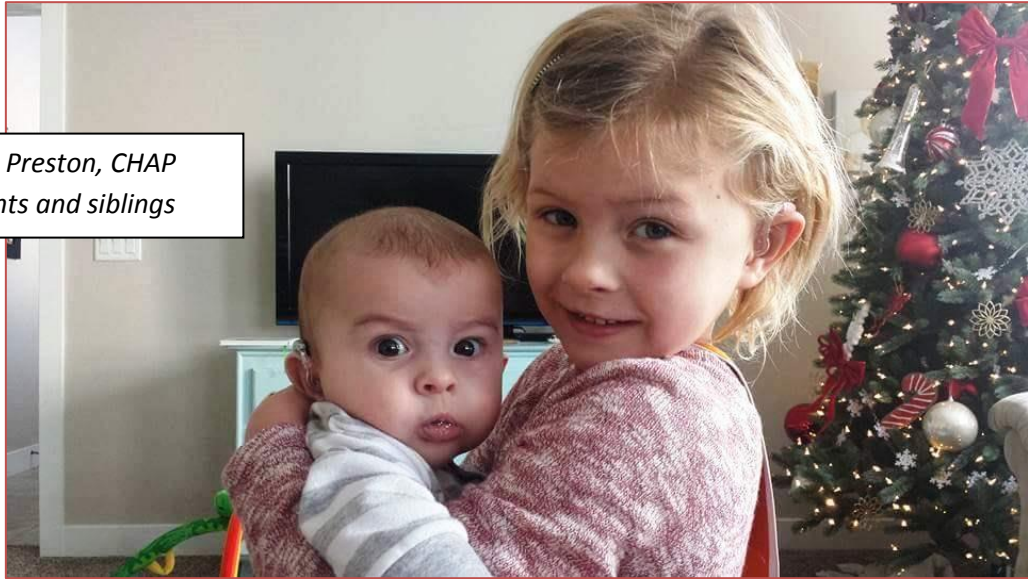
For FY 2017, the average time period needed to turn in and review all documentation was 9 days with the range falling from same-day to 51 days for approval/denial of application. The range for approval varies due to the length of time it takes the participants and providers to gather and turn in *all* required paperwork. In the case of the outlier that took 51 days, the family had switched providers and there was a delay as a new provider was determined. *Once all the documentation is in, the review and approval/denial process is typically less than three working days by UDOH staff.* The process has become more streamlined as the pediatric audiologists who use the program most often 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 the Advisory Committee is currently investigating.

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

- All but 3 of the eligible applicants have had private or CHIP insurance, neither of which cover any portion of the costs for hearing aids (the 3 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 65 months
- 68% requested binaural (both ears) fitting, 17% requested left-ear unilateral fitting, and 16% requested right-ear unilateral fitting
- Participants resided in 58 different cities from 12 different counties throughout Utah
- 28 pediatric audiologists from 11 different audiology clinics have participated
- 53% of the participants were male and 47% of the participants were female
- Possible etiologies for hearing loss included:
  - 24% have an unknown cause
  - 19% have a family history of hearing loss
  - 18% have a syndrome with associated hearing loss
  - 12% have atresia/microtia (physical ear defects)
  - 7% had long-term NICU stays
  - 5% have congenital cytomegalovirus (CMV)
  - 5% 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

- 0.5% have an enlarged vestibular aqueduct (LVA/EVA) (physical inner ear disorder)
- 0.5% have a metabolic disease
- 0.5% have an absent cochlear nerve
- There are 8 sets of siblings that received services from CHAP

*Ari and Preston, CHAP recipients and siblings*



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

Eligibility Requirements

Children eligible for services must be tested, diagnosed with hearing loss, and have hearing aids recommended by an audiologist with pediatric expertise. The child must then have the hearing loss medically cleared by a medical provider. In addition, CHAP recipients under 3 years of age must be receiving or in the process of applying for Type-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

## 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 two years, both audiologists and parents have referred others 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 milestone delays and the need for long-term services). On the other hand, this also means that our funds are used up more rapidly. In FY 2017, there were five children whose hearing aids had to be delayed due to insufficient CHAP funds. Currently in FY 2018, CHAP reimbursement funds have been expended greater than what is to be expected for the half-way mark of the current fiscal year. This funding shortfall was discussed at great length during the last Advisory Committee meeting and will continue to be discussed at subsequent meetings. Some options that have been discussed are continuing until monies run out for the fiscal year then delaying children having access to hearing aids; removing some of the benefits from the program such as the one year coverage of earmolds; limiting the coverage to softband bone-conduction devices to only one ear; only covering unilateral fittings, and requesting additional monies. Any option that decreases program benefits will be detrimental to the children we serve. At present, average monthly expenditure according to need is about \$15,000. The legislative sponsor of this program has been apprised of these financial concerns.

- FY 2018 to date: 18 applications have been reimbursed; 4 are currently in the reimbursement process; and 17 additional earmold requests have been reimbursed.
  - Total expenditures: \$72,231.60
  - Reimbursement costs for devices/services: \$67,656.59
  - UDOH billed administrative costs: \$4575.01
- FY 2017: 34 applications and 17 additional earmold requests were reimbursed.
  - Total expenditures \$122,069.92
  - Reimbursement costs for devices/services: \$115,053.06
  - UDOH billed administrative costs: \$7,016.86
- Previous years (include FY 2014-2016): 73 applications and 19 additional earmold requests were reimbursed.
  - Total expenditures: \$204,953.92
  - Reimbursement costs for devices/services: \$193,277.61
  - UDOH billed administrative costs: \$11,676.31

**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, with her dad*

2017 Family perception of services and benefits

	Disagree	Neutral	Agree
I/We feel confident in our audiologist’s expertise.	0%	5%	95%
The application to receive hearing aids was clearly written and easy to understand.	0%	5%	95%
Obtaining the hearing aids has been important to our child’s speech, language, and listening development.	0%	5%	95%
Our child has benefited greatly from the hearing aid(s) provided by CHAP.	0%	5%	95%
Our family’s overall experience with the CHAP program has been positive.	0%	5%	95%



A few families responded as neutral in the above questions and they provided the following comments as to why:

- “We were only confused on some of the details we needed to give with the financial part of the application.”
- “My audiologist was slow to respond to emails and provide answers to our questions. She also ordered the wrong hearing aid and had to re-order which delayed receiving the hearing aids. But it all worked out in the end. However, we do not see the same audiologist.”

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.

### 2017 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 show that families are pleased with the benefits of the program. Representative comments include the following:

- “The impact the program has had on our lives is immeasurable. Our child can HEAR! To see him not struggle as much is such a gift. He's just happier in general with life. School, friends, family; it all just comes easier now. How can you put a price on that? I am so grateful to the CHAP program for giving my child a better opportunity to succeed.”
- “Having CHAP allowed us to focus on our daughter rather than the stress of affording hearing aids. (We didn't know our daughter would have hearing problems until after birth). It also allowed us the financial space and time to save up for upcoming expenses for our daughter rather than exhausting all of our funds on the first hearing device. Now, we have a plan to afford the costs coming our way instead of playing catch up and relying entirely on financial aid.”
- “We have two beautiful daughters who both were born with bilateral hearing loss. Even though we have insurance, our insurance provider does not cover any hearing related services. Hearing aids/audiology services are very expensive. We fall in a specific income bracket where we do not qualify for Medicaid, yet are not wealthy by any means, and if it wasn't for this program we would have a very heavy financial burden to carry. But thanks to CHAP now we can focus our time, energy, and resources on helping our children grow and develop. We are so grateful for CHAP and the early intervention that we have received for both our girls. We believe that a direct result of having had our children fitted for hearing aids so young (2 months old and 3 months old respectively), they have not had any delayed speech. We often hear from our audiologists and other

family and friends how amazed they are that our daughters don't have any speech impediments due to their hearing loss. We thank CHAP for getting them into hearing aids so young and for all the help we have received from our early intervention teams. Thank you CHAP for all you have done for our two daughters and for our family!"

- "My daughter grins from ear to ear when I put her "ears" on every morning. I am able to tell her that I love her now! We are so thankful for the CHAP program and the hearing aids they provided for our daughter."
- "The impact CHAP has been on my family has been incredible. I know we could have eventually found a way to pay for hearing aids somehow, but finding out your child has a hearing loss is a hard thing to swallow. And then to find out the cost you'll be paying on hearing aids every 3-5 years is another hard thing to swallow. Having an organization that pays for your first pair is such a burden lifter and a good way to ease people into this new road we have to walk. Organizations like this need to stay. It helped me realize there is still good in the world."
- "It was very helpful to have access to this program so that we could get a hearing aid for our child right away. Without this program we would have had to wait and save up the money for it. It is also helpful to have ear molds covered as well. I also think it is great to work with early intervention to make sure that our daughter has stayed on track developmentally so I like that it is a required part of the program."
- "I was just grateful that we were notified about CHAP immediately after the diagnosis. The audiologist had everything I needed for it. I filled it out and they did everything else. It was such a smooth, easy process during our stressful time with handling our baby's situation. Another positive thing about CHAP is that we were able to switch audiologists and still have everything work out smoothly with them."
- "Knowledgeable providers helping us through a scary maze to help our baby. Caring follow up that helped answer our questions in a clear understandable way."

#### **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.

- "If CHAP was no longer funded, many children throughout Utah would not get amplification they needed, particularly children needing bone conduction devices. This would substantially change the quality of their life, for the rest of their life, as delayed amplification has significant negative impact."

- “It helps get kids access to amplification when they do not have coverage for hearing aids.”
- “The application process is fast. Once the application is in we hear back very quickly regarding whether families qualify. I’m so glad the criteria was expanded to cover 5 year olds. Many children in this age range need new hearing aids before they are 5 if they were fit as infants. It has been very beneficial for families.”
- “Whenever I have questions, I have always had immediate feedback from the department of health. Reimbursement process has been easy. I love that even bone conduction hearing aids are available.”

Possible improvement suggested by multiple pediatric audiologists included:

- Extending the age limit to include all children up to 18 years old.

Parents and audiologists are contacted to follow-up on any concerns conveyed in the surveys.



**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. Early amplification and appropriate Early Intervention services save significant costs associated with

special education services and the potential need for long term 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 will 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. The provision of hearing aids in eligible young children reduces the need for long term services. As stated above, research has shown that the earlier a child can be fit with appropriate amplification, the greater the potential for typical speech and language development, social skills, academic achievement, and future vocational skills. 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.