



# Children's Hearing Aid Program (HB 18): 2015 Annual Report

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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 that is to provide hearing aids to qualifying children who are younger than six years of age through the following eligibility requirements:
  - Ineligible for hearing aid coverage by Medicaid or the Utah Children’s Health Insurance Program
  - Meeting financial need criteria established by UDOH
  - Utah resident
  - Diagnosis of a hearing loss with hearing aid recommendation by a pediatric audiologist
  - Medical clearance for hearing aids by a medical provider
- 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 HB18.
  - Personnel are provided from the Bureau of Children with Special Health Care Needs.

## **Children’s Hearing Aid Program Advisory Committee:**

HB18 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 Mike Page, AuD, CCC-A, (current chair as selected by the CHAP Advisory Committee)
- Speech-language pathologist- currently served by Carrie Pereyra, MS, CCC-SLP
- Certified teacher of the deaf or a listening and spoken language therapist- currently served by Lauri Nelson, PhD
- Ear, Nose, and Throat Specialist- currently served by Jeremy Meier, MD
- Parent of a child that is six years old or older that has hearing loss- currently served by Kim Frandsen

In addition, the Utah Department of Health provides staff to represent and support HB18 that currently includes:

- Stephanie McVicar, Au.D., FAAA, CCC-A (Program Manager)
- Jenny Pedersen, MS, CCC-A (Coordinator)
- Courtney Steele, BS (Administrative Assistant)

## **Children’s Hearing Aid Program FY2015 Activities:**

The CHAP Advisory Committee has continued to expand 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 issued surveys to both families and audiologists requesting feedback on the provided CHAP(P) services. Due to this information, the following criteria expansions were presented to the state legislature and became effective July 1, 2015:

- Program moved from a pilot to an ongoing program
- Age of eligibility was 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 aids became an eligible option as a requested hearing aid device

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

- *From CHAPP to CHAP: A Quarterly Education series* that was hosted by Primary Children’s Hospital. Representative Rebecca Edwards, Dr. Stephanie McVicar, and Jenny

Pedersen presented information and data on varying aspects of the CHAP program, including audiology-related legislative issues, the development and logistics of CHAP, and the statistics of the participants.

- At the Utah Department of Health's Utah Early Hearing Detection and Intervention Conference, *CHAP Updates*, discussing the recent changes of the program, was presented by Jenny Pedersen.
- 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 to parents whose children fail their newborn hearing screening and are subsequently diagnosed with hearing loss.
- CHAP brochures and pamphlets are distributed at local audiology 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 are 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 is advertised in newsletters for pediatric medical care providers.
- The CHAP website has been re-designed 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 71 children have requested information for services since the program began accepting applications in November of 2013. Of these, 54 children were approved for services, 11 children did not meet qualification criteria, 5 children withdrew, and 2 children are currently in the application process to date. The average time period needed to turn in and review all documentation is 21 days with the range falling from same-day to 99 days for approval/denial of application. The range for approval varies due to the length of time it takes the participants to gather and turn in *all* required paperwork. Once all the documentation is in, the review and approval/denial process is typically less than three working days. If eligibility is determined, children will have access to services for up to one year from date of fitting.

The statistics of CHAP and its participants are as follows:

- Age of hearing aid fitting ranges from 2 to 55 months (mean is 17.11 months)
- Age of diagnosis ranges from 1 week to 52 months (mean is 7 months)
- 73% requested binaural fitting, 19% requested left-ear unilateral fitting, and 8% requested right-ear unilateral fitting
- Participants reside in 41 different cities from 10 different counties throughout Utah
- 18 pediatric audiologists from 9 different audiology clinics have participated
- 65% of the participants are male and 35% of the participants are female
- Etiology for hearing loss includes:
  - 35% have unknown cause
  - 17% have family history of hearing loss with no other known possible cause
  - 15% due to atresia/microtia
  - 15% have a syndrome with associated hearing loss
  - 7% due to ototoxic medications (for cancer or infection concerns)
  - 5% due to congenital CMV
  - 4% due to Auditory Neuropathy Spectrum Disorder (ANSD)
  - 2% due to Connexin 26 mutation (gene associated with hearing loss)
- 11% of the participants also have a sibling that has received services from CHAP

### **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 and by offering families support, 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 services, administrative costs, and the total cost expenditures. Administrative costs were not used or used sparingly for the first two years as UDOH staff were unsure of how much would be available after reimbursement costs were distributed and wanted to be able to accommodate all eligible applicants. In addition, over the past year there has been an increase in CHAP applications and requests for information which has increased the amount of work time associated with the program.

- FY 2016 to date: 11 applications have been reimbursed with 5 currently in process.
  - Total expenditures: \$46573.35
  - Reimbursement costs for services: \$42408.29
  - UDOH administrative costs: \$4165.06
- FY 2015: 20 applications were reimbursed.
  - Total expenditures \$61,7444.09
  - Reimbursement costs for services: \$59,374.93
  - UDOH administrative costs: \$2369.16
- Previous years (include FY 2014): 18 applications were reimbursed.
  - Total expenditures: \$29,466.60
  - Reimbursement costs for services: \$29,466.60
  - UDOH administrative costs: \$0.00

**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 the 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.

Family perception of services and benefits

	Disagree	Neutral	Agree
My audiologist seemed knowledgeable about the CHAPP program and was able to answer any questions that we had.	0%	0%	100%
There were no disruptions to my child’s care in working with the audiologist to obtain hearing aids through CHAPP.	0%	0%	100%

	Disagree	Neutral	Agree
Obtaining the hearing aids has been important to our child's speech, language, and listening development.	0%	*14%	86%
Our child has benefited greatly from the hearing aid(s) provided by CHAPP.	0%	*14%	86%
Our family's overall experience with the CHAPP program has been positive.	0%	0%	100%

\*Only one family responded as neutral in the above questions and they provided the following comment as to why:

“We are EXTREMELY grateful for the hearing aids provided to my infant son!! Without them, we would have been so worried and overwhelmed with his hearing loss and the financial burden of purchasing hearing aids, especially needing to fit him with his first pair within 3 months of his diagnosis. He has been a roller-coaster of hearing testing because his hearing loss has been hard to pin down. This is why I say "neutral" to "has he benefited from his hearing aids". We haven't consistently known if the settings were what he needed for sure, because month to month his results were all over the chart either from ear infections or other physiological factors. However, there is no doubt that our family has been BLESSED by CHAPP! We absolutely needed help in that time of worry and confusion when we were scrambling to find a way to fit him with aids, and do all we could to be proactive rather than waiting for a delay to show up in his speech/development. Thank you! Thank you!!!”

### 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:

- “We are swamped by all the bills and paperwork that go along with our son and it is so nice that CHAPP does all that for us. Really so huge to not have to worry about that.”
- “It made hearing aids affordable for our child. It covers a gap where the current insurance coverage fails families.”
- “Maybe make the general public more aware of the program. We think it is so important for families with children who have hearing loss to know about CHAPP. It also is important for families who don't have children with hearing loss to know what amazing things you guys are doing.”
- “Continue the program for children older than age 3. Discounted hearing aid accessories (sleeves, bonnets, stick and stays etc.), or assistance to find the best place to purchase

them. Educate hearing aid dealers, etc. on hearing aids and needs for infants and small children.”

- “Every child needs access to sound as a basic, essential part of their successful development, perhaps even more critically than other things. CHAP provides a way to give them this crucial tool early enough so they have the very best chance at not getting behind in speech and learning. Since hearing aids are very very expensive, at best, parents would need to save up for a few years. CHAP allows a child to not have to wait to hear!!!! And hopefully by the time they need their second pair, their parents have been given enough time to provide them themselves. I love love love this program!”
- “Insurance will NOT give anything for hearing aids. They will not pay one penny! So families with children that have hearing loss are forced to either go in debt, ask friends and family for money, or just not give their children the hearing aids they so desperately need. It is so sad to think of how many kids are probably getting so behind on their language acquisition because insurance will not help their parents with the expensive burden of hearing aids. Without the legislature helping fund CHAPP, our little guy would have been one of those kids.”
- “Through this program we were able to get the dual BAHA system as opposed to the single BAHA. The dual BAHA has helped him so much. It is incredible. He went from not saying anything to finally saying sentences. He is happier because he understands his older brother and sister when he plays. His ability to communicate has increased tremendously in a short period of time. The fact that the state has this program has helped us financially. We were able to avoid debt and we can use the savings for the implants that (our son) will get once he is 5 yrs old. This program is probably the best government program and the first we have ever qualified for. I’d like to know how I can help make this an ongoing program so that other families can benefit .”

#### **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.

- “CHAPP provides access to hearing aids for children that otherwise would not likely benefit from them. It is good that the audiologist provides some documentation of follow up.”
- “The application turn around time is very fast, which is great. I have had three children who received greatly needed assistance last year through CHAPP and I plan on recommending it for more children.”

- “It is such a huge benefit to so many families and children. It is life changing for these kids.”
- “I have seen many families benefit from this program and would be devastated if it didn't continue to be funded. I think this is a very necessary program for families here in Utah.”
- “Very easy to use and a great resource for patients that really need hearing aids.”

**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 aids.
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.