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

2016 Annual Report

Requested by:

- Health and Human Services Interim Committee

Prepared by:

- Utah Department of Health (UDOH)
- Children’s Hearing Aid Program Advisory Committee
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 to provide hearing aids to qualifying children who are 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
  - 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, MS, CCC-A (Audiologist Coordinator)
- Heidi Ellsworth, BS (Administrative Assistant)

**Children’s Hearing Aid Program FY2016 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 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:

- Information on CHAP was provided to the Utah Pediatric Audiology Collaboration group at its last annual meeting.
• 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 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 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 108 children have requested information for services since the program began accepting applications in November of 2013. Of these, 90 children were approved for services, 12 children did not meet qualification criteria, 5 children withdrew, and 1 child is currently in the application process to date. For FY 2016 specifically, 36 children were approved for services, 3 children did not qualify for services, and 1 child withdrew from the program.

For FY 2016, the average time period needed to turn in and review all documentation is 16 days with the range falling from same-day to 161 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 the date of hearing aid fitting. The statistics of CHAP and its participants are as follows:

- Age of hearing aid fitting ranges from 1 to 71 months
- Age of hearing loss diagnosis ranges from 1 week to 54 months
- 64% requested binaural fitting, 18% requested left-ear unilateral fitting, and 18% requested right-ear unilateral fitting
- Participants reside in 47 different cities from 12 different counties throughout Utah
- 25 pediatric audiologists from 11 different audiology clinics have participated
• 61% of the participants are male and 39% of the participants are female
• Possible primary etiology causes for hearing loss include:
  o 38% have unknown cause
  o 19% have family history of hearing loss with no other known possible cause
  o 18% have a syndrome with associated hearing loss
  o 10% due to atresia/microtia
  o 4% due to congenital cytomegalovirus (CMV)
  o 3% due to ototoxic medications (for cancer or infection)
  o 2% due to Connexin 26 mutation (gene associated with hearing loss)
  o 1% due to Auditory Neuropathy Spectrum Disorder (ANSD)
• There are 4 sets of siblings that 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 devices/audiologist 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, 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 2017 to date: 12 applications have been reimbursed; 6 are currently in the reimbursement process; and 8 additional earmold requests have been reimbursed.
  o Total expenditures: $25,816.46
  o Reimbursement costs for devices/services: $24,707.11
  o UDOH administrative costs: $1109.35

• FY 2016: 36 applications and 14 additional earmold requests were reimbursed.
  o Total expenditures: $118,666.59
  o Reimbursement costs for devices/services: $109,359.44
  o UDOH administrative costs: $9307.15

• Previous years (include FY 2014-2015): 35 applications and 5 additional earmold requests were reimbursed.
  o Total expenditures: $91,210.69
  o Reimbursement costs for devices/services: $88,841.53
  o UDOH administrative costs: $2369.16

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.

Jude, CHAP recipient, with his Mom, Kim
Family perception of services and benefits

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My audiologist seemed knowledgeable about the CHAP(P) program and was able to answer any questions that we had.</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>There were no disruptions to my child’s care in working with the audiologist to obtain hearing aids through CHAP(P).</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Obtaining the hearing aids has been important to our child’s speech, language, and listening development.</td>
<td>0%</td>
<td>*7.69%</td>
<td>92.31%</td>
</tr>
<tr>
<td>Our child has benefited greatly from the hearing aid(s) provided by CHAP(P).</td>
<td>0%</td>
<td>*7.69%</td>
<td>92.31%</td>
</tr>
<tr>
<td>Our family’s overall experience with the CHAP(P) program has been positive.</td>
<td>0%</td>
<td>0%</td>
<td>100%</td>
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</tbody>
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Only one family responded as neutral in the above questions and they provided the following comment as to why:

“Our son used his hearing aids for a little over a year and were of great benefit to his speech therapy and other LOL [sic] goals. Recently, his hearing has declined even more and now he receives little benefit from the aids as far as his speech is concerned. They still benefit him in keeping neurons active and in recognizing environmental sounds.”

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:

- “Kids need access to devices for hearing and learning. Special needs kiddos come with expenses that parents usually don’t plan for. Insurance usually covers these needs. However, insurance rarely covers hearing devices! They are necessary and insurances call them elective. We’re thankful for a program that values the needs of our disabled children.”
- “Hearing aids are a very unexpected expense for an already expensive new baby. The program helped us to be able to provide an opportunity to our child that most other families take for granted, to be able to hear.”
• “Discovering that our child had a significant hearing loss was very overwhelming and intimidating to try and rectify. These feelings were magnified when faced with the process and cost of obtaining hearing aids. Through the CHAP program, we were able to consult with an incredibly helpful and knowledgeable audiologist who walked us through the process step by step. They helped us with each part of the application and made sure her hearing aids fit just right after we were approved. This program is such a blessing. We would not have been able to afford these hearing aids without a significant financial burden, so we are so grateful. Our little gal has blossomed over this past year now that she can hear, and she is so excited about her ‘new ears’! Thank you so much!”

• “Because my son qualified for hearing aids, we were able to begin more intense interventions much sooner than if we had to delay the purchase of hearing aids. Once he had his hearing aids, he became a completely different little boy. He felt more comfortable in his surroundings, wasn’t as shy and reserved, and his speech progressed rapidly.”

• “Our child has had dramatic improvement in his pronunciation due to these hearing aids. His speech development is progressing much more quickly since having access to this hearing aid early in life. Had we not had these funds we would have likely waited a little bit longer to give him the hearing aids.”

• “CHAP has allowed us to focus on raising our child and getting her the help she needs now, rather than focus on how to pay for her first set of hearing aids. This has been a huge relief to our family. It has given us the ability to get her hearing aids at a young age so she can begin to develop her speech now.”

• “I am no longer worried that my hard of hearing son will be delayed because we were able to start him with hearing aids at 4 months old. The program has been a major blessing to our family and we are so grateful to have the CHAP program help us. My son is on track with all of his developmental benchmarks and I believe it is because we were able to get his hearing aids. Thank you, thank you!!”

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.
• “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.”

• “I think this is an important program and many insurance companies still will not cover hearing aids, so this is a greatly needed service for families who otherwise cannot afford them but don't qualify for programs like Medicaid.”

• “Such great and quick feedback once application is submitted. Such a huge benefit for these children! And now coverage for osseointegrated* devices is amazing!”

• “There is a pretty quick turn-around, which is great for our families. The application and the payment request is pretty simple.”

*osseointegrated = bone conduction

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.