

Supporting Families of Children with Auditory Neuropathy

A Sound Foundation
Through Early Amplification
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Children's Hospital Colorado

- Infants are transferred from outside birthing hospitals
60 bed NICU
- Maternal Health Care Unit for low risk maternal patients with high risk neonate/fetus (30-50 deliveries)
- Children are from Colorado, Wyoming, Kansas, Montana, New Mexico, and Nebraska-Rocky Mountain region
- 23 audiologists-9 Networks of Care for audiology
- Identified 100 plus auditory neuropathy since 1999/2000
- Click ABR screening and diagnostic testing before discharge-especially for out of state babies



Children's Hospital Colorado




Supporting families with children who have Auditory Neuropathy Spectrum Disorder ANSD- there is a difference!



Not the same...uncertainty of the child's developmental trajectory

Two distinct populations of ANSD/AN:

- 1) Small population genetic/otoferlin severe to profound, more certainty in how we manage them
 - 2) NICU babies/syndromic/complex medical issues, developmental challenges, multiply involved- other factors that confound the diagnosis of AN
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The challenge

- **Universal agreement** on best treatment options for children with AN has been an **ongoing challenge** for professionals and parents
- Families have faced **contradictory information** regarding the diagnosis, choices in communication, amplification and intervention for their child





Going back and looking ahead

Family interviews were conducted to obtain perspectives and stories from parents as their children with ANSD transitioned from birth-3 and preschool to elementary school and beyond

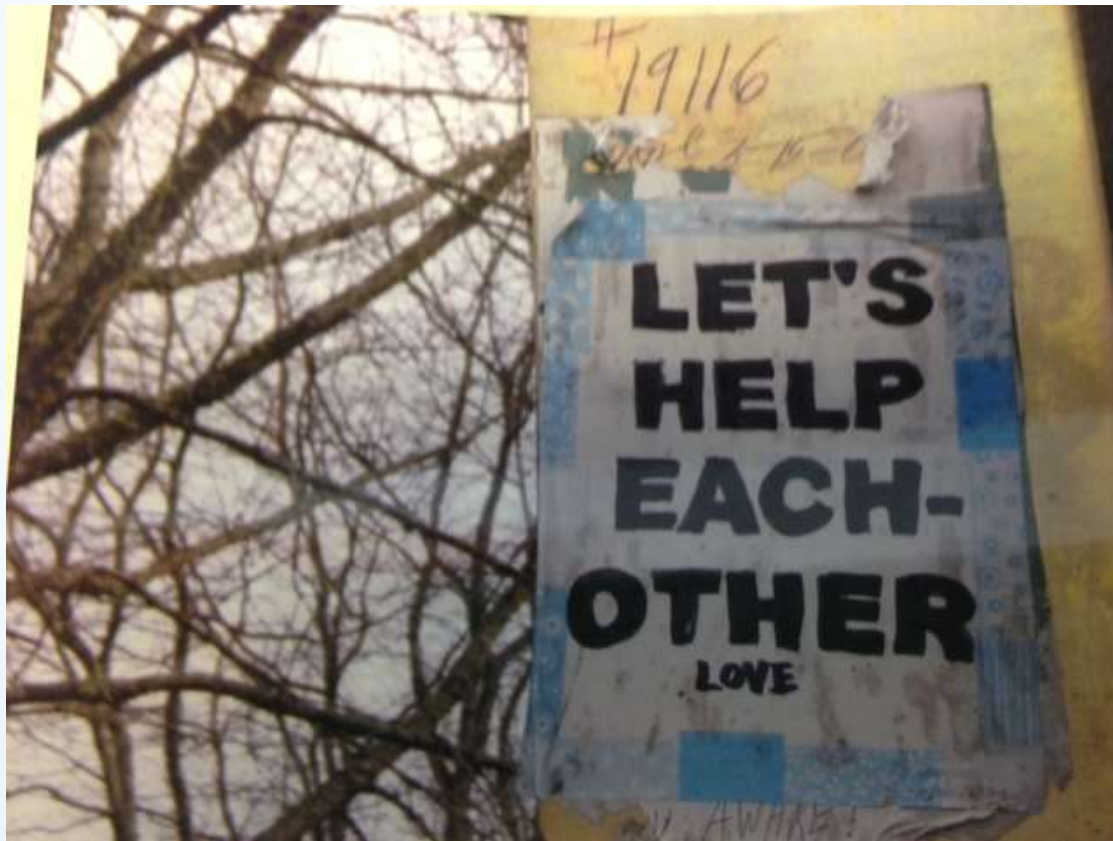
Families shared what helped them begin to understand the complexity of ANSD and increase their confidence to become full partners in their child's care, as well as pitfalls for practitioners to avoid while counseling families



Parent Survey

- What support or information was helpful to your family after you learned about your child's hearing loss and the diagnosis of AN?
- What could the professionals have done differently?
- Looking back, is there anything that you as parents would have done differently for your child?
- What advice would you give to families with children who have auditory neuropathy?
- Are there any memories or experiences where you could see how AN impacted your child at home or school?

Thank you to the families that
shared their comments and
experiences





Common themes:

1. The desire to know what their child is hearing
2. “I felt that I have always had to seek information myself and then find the professionals who were willing to help me.”
Parent to parent support is critical and alleviates the desire to search for support through the internet.
3. “I am always explaining auditory neuropathy to other professionals.”
4. Professionals may not be knowledgeable about all of the tools for communication
5. Consistent and effective communication is a challenge
6. People tend to underestimate my child



Birth to Three Years

“The time spent on counseling during appointments was time well spent.”

Family dynamics –understanding the diagnosis

“Maybe this will get better.”

“This could be part of God’s plan to heal our child.” **How do we encourage parents to make empowering decisions with their faith and their treatment team?**

Health issues

Early Intervention-language, speech and babies, communication options, global development

“It was hard to be told that my observations were wishful thinking.”





Birth to Three years

- Conflicting information-What is the best option for the best outcomes rather than “wait and see”
 - Confidence in technology
 - Hearing aids
 - Cochlear implants
- *“I was so scared to lose what hearing my child had.”*
- Teaming- “In the beginning I didn’t understand the value of collaboration until my child started school; then I was glad to have had that experience to meet my child's needs.”





Preschool Years

- Separation anxiety-preschoolers tend to be more dependent on the parent (mom) for clarification
- Parents developed an awareness of when their child was hearing well
- Developmental delays become more obvious





Preschool Years

- Beginning skills in parental advocacy and involvement
- *“People will help your child if they know you.”*
- Increased confidence *“WE are the team.”*
- Cochlear implants around four years of age: *“I wish we would have done it earlier.”*





Elementary Years

- Self advocacy skills –need to be incorporated into the child's Individual Education Plan
- The child needs to learn to develop an awareness and recognize when they are not hearing well
- Strategies for tough days
- Creative outlets/sports





Elementary Years

- Fluctuation in hearing impacts social skills
- Challenges hearing in background noise begin to emerge
- Social skills
- “What are the goals for our child-what can we expect?”





Transitioning from Elementary to Middle School

- School placement and support services may look different
- Battle of the FM/note takers
- Training teachers and parents/obtaining missed information/clarification





Transitioning from Elementary to Middle School

- Exhaustion from being in listening situations all day long, day after day
- Fluctuations/hearing days = **temper**
- *“The fluctuations in his hearing are evident in his temper when he comes from school”.*
- Journaling





Transitioning from Elementary to Middle School

- Biographical power point/involvement in their own IEP's
- Independence/freedom/privacy
- Increased social issues –siblings *“I can hardly wait to be old enough to live by myself.”*





What didn't help...

- Wait and see
- Wishful thinking
 - *"It was hard to be told that my observations were wishful thinking".*
- The number of professionals working with my child that didn't understand AN
- The number of appointments
- Depending on the internet for information *"I was sad when I read about some cases of AN resolving itself. I wish I had been told that might be a possibility."*
- Not receiving a referral for vision- *"We didn't fully understand vision as it pertains to communication."*





What didn't help...

Judgment on school of choice

- Private vs. public
- Smaller classes
- More control with the teachers/classroom adaptations
- Teaching methods/philosophies vs. school support services

Judgment of choices and decision making process

- We as professionals learn about families by not passing judgment



We are learning!

- Recognizing strengths
- Involvement of parents
- Parent observations and feedback
- Highly recommend speech therapy and monitoring language development



We are learning!

- Working closely with schools
- Collaboration: multiple therapists/specialists with early interventionists
- *“Hope didn’t get me through understanding hearing loss and deafness.*

People did—People got me through it.”



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