

## The Impact of Multiple Technologies on Families: Considerations in Real Life

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### Abstract

*This article seeks to articulate the complexity and use of technology in today's world, the parent emotions attached to the experience, and the strategies that audiologists can use to support families as they move between the audiology sound booth and the 'real world'. There have been many studies looking at the use and monitoring by parents of hearing aids in children. This article is written from the parent perspective on that topic. For those of us who provide parent-to-parent support and/or professional-to-parent support, we are the sacred holders of two ideas for families to help them through their day - the miracle of technology and the limitations of technology.*

As a parent of a child who is hard of hearing, I seemingly have a passion for describing to pediatric audiologists the limitations of technology in the 'real world'... I can remember one day leaving the audiologist's office with my 8 year old daughter who had just been fit with the latest digital hearing aids at the time. We spent over an hour of careful fitting and programming, with my daughter assuring our provider that everything sounded fine. I was experiencing new hope that this pair of hearing aids might deliver new sounds and new access opportunities. As we walked out to the car, my daughter said, "Can I take these out now? I hate them." I wasn't prepared for that. We made it home somehow, and through the adjustment period.

As I began to explore this topic on the limitations of technology, I felt it only fair to write about this subject in context to what myself and other parents have also used to describe the use of supports as the 'miracle of technology'. Over the years, with many experiences of raising a child who is deaf/hard of hearing, I can ascribe to the fact that we have had both 'miracle moments' as well as the

frustrations and limitations of technology available to us. We have had moments where my daughter responded to new hearing aids with directional microphone technology, "I can hear in really loud places for the first time!" We have had moments of discouragement knowing that while the technology for something existed, we couldn't afford it. (i.e., water resistant hearing aids so swimming at the pool would create communication accessibility) We have also learned over the years that the sum experience of being deaf or hard of hearing cannot be defined or described only as what piece of technology my daughter uses. As we look at what led to her success in emerging adulthood – from advocating for a successful education, ensuring a good sense of self-esteem and pride in her Deafness, embracing her communication choices in speaking, listening, use of sign language, and different technologies – we have come to realize it wasn't just one thing that led to success. It was being supported in the choices we made at different seasons of life for different reasons – understanding that the complexity of the deaf experience can never be summed up in one simple solution – such as brand new state of the art pink hearing aids....and ultimately, supporting the choices our own daughter now embraces in terms of technology and communication access. We know she will still face challenges in her life – but we also celebrate her success as a beautiful human being - now that is a miracle!

Unlike any time in history, advancements are being made in terms of hearing technologies including the vast array of programmable digital hearing aids, cochlear implants, FM systems, streaming technologies and Bluetooth, etc. The availability and opportunity of ever expanding technology options has far exceeded the old days when a plain, beige, analog hearing aid was the 'offer on the table' in terms of technology solutions for young children with hearing loss.

What are the considerations about how all these new technology options impact families? Studies on hearing aid use and the acknowledgment of the multi-faceted challenges that families face suggest they may benefit from working in partnership with audiologists who have audiologic counseling strategies, to promote consistent device use across a variety of daily situations. (Moeller, Hoover, Peterson, & Stelmachowicz, 2009) Professionals can hone their skills to be sensitive to the possibility of overwhelming families with all the choices laid before them, and considering each family's unique needs.

Or is it possible that audiologists simply recommend "the latest and greatest" in a broadly sweeping way as opposed to individualizing such recommendations? As technology is opening doors for children with hearing loss like never before, there are still day to day, real life considerations: age of the child, culture, cost, and the capacity of the average user to understand and utilize the current technology available. Additionally, technology in and of itself is not the only consideration towards successfully raising a child who is deaf or hard of hearing that needs recognition in the parenting experience, and by the audiologist who support them.

### **The Limitations of Technology and the Miracles of Technology**

One of my favorite quotes comes from Stephanie Olson, an adult user of a cochlear implant who says, "My miracle only lasts as long as my battery supply." When terms such as the 'the miracle of technology' are used to describe today's generation of children who are deaf and hard of hearing, there is no denying that the quality of technology and hearing aid fitting in infants and young children has indeed come a long way. Comprehensive evidence-based guidance for clinicians with regard to maximizing modern hearing aid amplification outcomes for children now exists (Ching, 2012) Parents can be overwhelmed with the bombardment of branding and marketing of new products that promise everything they could possibly need for their child. It is particularly important for parents as they begin to move from identification and acceptance of hearing loss for their child, to communication and technology choices, that there will be clarity and realistic expectations of what technology may and may not be able to offer.

### **Considerations in Real Life**

Realistic expectations and understanding the limitations of technology is not the only thing that parents must process. There are many factors when considering new technology and questions that should be considered. Some of these factors include:

- Parental Acceptance and Support – *if there is resistance to use of technology by a family, is it the device itself or the feelings and emotions associated with its use?*
- Cost – *deciding what to buy, when/ waiting on newer technology, hidden costs.*
- Understanding and using technology – *will a parent be able to use complicated features they have paid for, once home and in day to day usage?*
- Other health problems impacting the child – *will success with technology be impacted when a child has additional health care needs and/or disabilities?*
- Appropriate age range of products – *which features benefit children at what age range?*
- Short term use when waiting on next technologies – *when is it time to invest in new technology and/or wait until next year's version comes out?*
- Technology in different settings – *what is the most advantageous and useful features that a particular child in their unique setting might need?*

### **How Audiologists Can Help: Relationship Building**

Every child and family is unique. It is important for audiologists to ensure that they are supporting the family's individualized priorities, capabilities, and capacity when discussing new technology options and/or consistent use of currently owned products. In order to have a clear understanding of these things, a relationship of trust must be established. (Stonestreet, Johnston & Action, 1991) For parents, they need to feel safe in order to talk about what is and isn't working with their professional partner and a feeling that they will not be judged for what they might perceive as 'failure'.

Assumptions should not be made about what a parent can or cannot do. As an example of this, a clinician may label a parent 'non-compliant with treatment recommendations' when there is a realization that hearing aid use is not being used consistently. Upon further dialogue, and through the use of open ended questioning, for example, it may be found that particular setting-specific, child-temperament, or activity-related challenges are oc-

curing, not the parent's lack of follow through in keeping the hearing aids on a young child. Parents often report that things like riding in a car/car seat, loud restaurants, outdoor conditions (windy, wet, hot), and mealtimes are challenging for consistent use of hearing aids. When a child is fussy, tired, sick, mad/tantruming – these are realities in families lives. (Moeller, Hoover, Peterson, & Stelmachowicz, 2009). When families can talk about these things in a safe setting, strategies can be employed to help ensure that consistent use of technology is maximized.

Families may have emotional triggers regarding the use of technology. These can include both ends of the spectrum – unrealistic expectations (“this device will ‘fix’ the hearing loss”) to a belief that their child doesn't need the technology (“my child can hear just fine without it”) In order for an audiologist to challenge these assumptions, the audiologist needs to take the time to ensure that families have the knowledge and understanding of the technology itself, with realistic expectations about what a particular hearing aid can or cannot do. Parental acceptance of the hearing loss is also a process for families. Parents can greatly benefit from parent-to-parent support in processing the impact of hearing loss on their child, and their choices in the journey. On reflection of the early intervention years, families rank parent-to-parent support as one of the strongest measures of family support (Jackson, 2009).

## How Audiologists Can Help: Encourage Family Involvement

Audiologists can support families by encouraging them to actively engage in advocacy out in the real world. They can:

- Partner with families in the educational setting – discussing technology linkages between the home and in the classroom (i.e., will the child's personal hearing aid be compatible with a school purchased FM system?).
- Help families to understand the impact of background noise on speech recognition and hearing aid performance.
- Lend expertise as parents prepare for Educational (IEP) meetings with supporting documentation and testing results.
- Recommend testing that looks at functional hearing in real life settings such as the Functional Listening Evaluation (Johnson and Von Almen, 1997).
- Review student needs in the school based setting.
- Work collaboratively with school personnel.

## The Story of Anthony

Lisa and Brian's son, Anthony, is a middle school student who is hard of hearing with bilateral hearing aids. When Anthony joined the wrestling team, he advocated for his accessibility needs during wrestling matches. Anthony wore wrestling head gear during the meets which limited his access to some of his auditory surroundings, along with the noise in the gymnasium. Accommodations such as the referee using a hand signal when blowing the whistle at the start of a match were utilized, as well as educating Anthony's coach on some strategies about how to communicate effectively in those settings when the use of technology had its limitations. (i.e. the coach demonstrating the needed move from the sideline instead of yelling the move from the sidelines). It wasn't until after a match one night, as the family sat around the kitchen table reviewing a video that Lisa had taken from the stands that an 'aha' moment occurred – in different ways to different members of his family.

As the family watched the video, Anthony asked, while listening to the audio portion of the recording, “Were people cheering me on? Who is that person I hear?” Lisa replied, “Yes, we were all cheering you on. That's me yelling from the stands”. “And that cheer?” he asked. “That is your Grandfather” she replied. “And that one?” he asked. She answered, “That was a woman behind me cheering you on. I don't know who she was.”

For the first time, Anthony realized that there were people cheering for him during that meet. For his parents and siblings, it had never occurred to them that their support, encouragement, energy, and effort at attending the sporting events for their son may not have been fully realized by him due to the limitations of his technology in that setting. Anthony's sisters, who in their day to day lives had gotten used to ‘how well he does with hearing aids’ were awakened to the idea that something so simple, and yet so important in a young athlete's life - cheering from the stands – may have escaped their brother's notice.

While today's technology has advanced and provides access to young children who are deaf and hard of hearing, the limitations of technology can impact a child in ways we underestimate. As quoted from her article, A Note to the Coach by L. Seaver (2005) “Although my child cannot hear you at the plate...on the mat... or from the field...please don't stop yelling for him! Don't let a player's deafness or hearing loss stop you from cheering him or her on. Show that you care, and know that you

are making an impact that will affect this kid positively during the game, during the rest of the school day, and one that will even be felt and recalled positively all his or her life.” Hearing a parent’s cheer from the stand is just a small example of the missed moments that no amount of technology will ever ‘cure’. To understand this as a parent opens up the mind to explore other ways to get information in the world to children who are deaf and hard of hearing. It may be the use of sign language, or taping the cheering to hear later on, or some other means. If missing out on the cheering section during a sporting event is impactful, then considering accessibility beyond the use of technology warrants a parent’s consideration, as well as the professionals who are supporting them.

## Conclusion

Today’s generation of children who are deaf and hard of hearing have unique and unprecedented opportunities to benefit from the miracle of technology. And yet, it is incumbent upon parents and professionals alike to also take into consideration the limits of current technology, and to be open to ensuring appropriate communication access beyond technological solutions. These two truths can co-exist when families are given appropriate support from the professionals who serve them. And in the words of Albert Einstein, “There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.”

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