Hearing Parents Identify Positive Aspects of Parenting a Deaf Child
By Talibah E. Buchanan*

Families with deaf children, like all families, have both positive and negative experiences, but much of the research concerning deaf children and their parents conducted in the last quarter century has focused on the negative impact a child’s hearing loss can have on hearing family members (Brand & Coetzer, 1994; Calderon & Greenberg, 1993; Calderon & Greenberg, 1999; Desselle, 1994; Meadow & Trybus, 1979). Considerable attention has been given to the experience of “shock” and “the grieving process” that hearing parents go through upon learning that their child has a hearing loss (Koester & Meadow-Orlans, 1996). Parents have reported feelings of sadness that their child will never hear a human voice, a piece of music, or something as simple as a cow’s moo (Blackburn, 1999). Many researchers have noted that anger, self-pity, confusion, and guilt are common emotions among hearing parents of deaf children (Greenberg & Kuche, 1993). Some studies have looked at parents’ concerns about not being able to directly share their spoken language with their deaf child (Bodner-Johnson, 2003). Other studies have focused on the confusion and frustration experienced as parents receive mixed messages from professionals about optimal communication modalities.

“It just seems to me that there’s so many people, you know, that have in their own mind what is the right way to educate or the right method of communication and that’s part of what they’re trying to pass on to parents…instead of making something available and saying, ‘OK, these are the things that are available, these are the things that are used, and this is where you can find out about them.’” (parent comment quoted by: Meadow-Orlans, Mertens, & Sass-Lehrer, 2003, p.22)

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New Grant Awarded to Technology Access Program
By Paula E. Tucker*

Better access to communication technologies for people who are deaf or hard of hearing has been one of the most important trends of the past 15 years. Access has come from Internet-borne text and video technologies and from the increased accessibility of broadband services at home and at work, from mobile communications products, and from government policies mandating TV captioning, relay services, and a digital update to the closed captioning system. Many deaf people, particularly the more tech-savvy who live in larger cities, are abandoning their traditional land line telephone services in favor of completely IP-based communications. Hearing people are following them as voice-over IP (VoIP) telecommunications grows. The IP revolution will continue to affect all of us in the coming decade, in ever-changing ways.

Gallaudet’s Technology Access Program (TAP), a research unit within the Department of Communication Studies (and formerly in the GRI) has been working for the past 18 years in the arena of government, industry, and consumer efforts toward continual improvement in access to communications. During this time, TAP has successfully competed for grant funding to support its research, demonstration and evaluation projects. TAP’s newest grant, in partnership with the Trace Center, College of Engineering, University of Wisconsin, Madison, has recently been awarded for their joint project, the Rehabilitation Engineering Research Center on Telecommunications Access (RERC-TA). This

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Such experiences are indeed common and it is only natural that investigators have drawn our attention to them. However, there is a new movement in the field of psychology called “Positive Psychology” that is making deliberate efforts to look beyond the focus on pathology that has predominated discussion to expand our understanding of factors that allow individuals, communities, and societies to flourish. Through this movement, experiences are understood in all their complexity (Seligman & Csikszentmihalyi, 2000). This means acknowledging the existence of serious problems and negative experiences, but not overlooking the many positive things that can occur in even the most challenging of circumstances. It is, after all, the positive things that make challenging experiences seem more manageable.

Positive Psychology is what led one of the Gallaudet University Clinical Psychology doctoral students, Amy Szarkowski, to employ a positive stance in the design of her dissertation 1. She believed that parents of deaf children had positive experiences that were unique results of raising a deaf child. The results indicated that her belief was shared by parents of deaf children that participated in the study.

“It is good for me to think about the positives, because I think it is easy sometimes to get caught up in the little everyday stuff, like the dishes, and changing diapers and stuff like that. So, when I have a chance to sit back and reflect on what it’s like to have a deaf child, it just makes me smile.”

Methodology

Szarkowski designed a study that examined and highlighted the uniquely positive experiences of a hearing parent’s situation that would not have occurred if their child was not deaf. Since more than 90% of deaf children are born to hearing parents and the experiences of hearing parents of deaf children are likely to differ from those of deaf parents of deaf children, only hearing families were included in the study. These families were recruited through advertisements on web pages of parent groups and by word of mouth. The recruitment procedures led to 44 parents inquiring about the study. Out of the 44 parents, Szarkowski selectively chose 10 parent-child pairs for participation. Purposive sampling (purposely selecting specific participants) was utilized in order to be sure that a diverse group was included, although Szarkowski was geographically limited when selecting families.

Children in the study were prelingually deafened with a hearing loss of 70 dB or greater in their better ear. They ranged in age between one and fourteen years. Some children used amplification devices, others used a cochlear implant, and still others did not use assistive technologies. Communication mode was not an exclusionary factor, as families self-identified as using Oral Speech, ASL, Cued Speech, and Total Communication. The parents who participated had no significant hearing loss and communicated to the researcher via spoken English. Each parent was a biological parent of the child. Seven mothers and three fathers participated. Though parents with more than one deaf child were included, these parents were asked to focus their responses on experiences with their first deaf child.

Through demographic questionnaires, interviews, observations, and journal entries, information about

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parenting a deaf child was obtained. The interviews, which Szarkowski audiotaped and later transcribed, ranged from 45 minutes to just under 2 hours, with an average of 1½ hours per interview. Although preliminary questions asked about the unique and positive aspects of raising a deaf child, parents were given ample opportunity to discuss difficulties and express a full range of thoughts, ideas, or opinions. During a second home visit, Szarkowski gave parents an opportunity to add any thoughts that had come to mind since her first visit and to verify or correct her understanding of their perspective. Each parent-child pair was also observed on two occasions, doing different activities, in sessions lasting from 1 to 2 ¼ hours.

Finally, parents kept a journal of reflections on their positive parenting experiences, the child’s recent developmental changes, and any noticeable patterns that had developed in their interactions with their child.

Parents’ Experiences

Once all of the data were collected, Szarkowski looked for recurrent themes and found 42 topical areas which were believed to directly affect the ability of the parent to have a positive parenting experience. A few quotes may suggest the kinds of positive experiences expressed by parents of deaf children.

**The Child.** Parents from the study often indicated that they believed they “really” knew their child, and attributed that in part to the fact that their child was deaf.

“I’m actually very thankful to have had a daughter who is deaf. I feel like I know her better than if she would have been hearing. Maybe that is because we spend so much time together, or so much effort in teaching her language, but I feel a bond with her that I don’t think would be there if she could hear.”

“When I found out he was deaf, I wondered if I knew him at all. I had been talking to him and he never even heard me. But now I really think I do, and I wonder if hearing parents really, really, really know their kids. I feel so lucky for that.”

The children were praised for their skills and attributes and parents admitted that it was difficult to know the extent to which the child’s attitudes and disposition were related to hearing loss, role modeling, or genetics. Regardless, parents stated that their child was simply a “great kid.”

“He is funny, comical, and delightful. I don’t know how different he would be if he could hear, but I wouldn’t want to find out. He is simply a great kid, and I am proud to be his mother.”

**Advocating.** Many of the parents suggested that becoming an advocate for their child was an empowering experience. While they acknowledged that it can be difficult, they also believed that it made them feel closer to their child and more involved in the child’s life.

“At first, advocating for her was hard, and it felt tiring. Now I see it as an opportunity to teach other people about deafness and what deaf people need. I realize that most people aren’t being mean when they don’t provide her with what she needs to understand, they just don’t know what to do. If I can advocate for (daughter’s name), then I can maybe even make things better for other deaf kids.”

**Providing Services.** Parents in the study were generally very concerned with obtaining the best quality care for their deaf child. Families had moved for services, or were considering moving for services to areas they perceived as more “deaf friendly.”

“We moved here from the Northeast. It was a difficult decision, but we would do it again in a heartbeat. Moving here was the best thing for [daughter’s name]. Having the services here that she needs means that she doesn’t feel like a freak, like she used to when we had to drive for a couple of hours to get her to appointments. She leads a healthy and normal life now. Other kids go to the doctor; she just goes to the ear doctor. No big deal.”

**Support.** Parents that participated in support groups with other parents reported the substantial assistance they received and indicated that this was the most important action they took in their child’s early life.

“Then we met the group, and that was great. I wouldn’t have wanted to go through this without them. They have been so much support. I’ve made good friends, and have people who understand what I am going through. There are good things about all things, definitely. The parent’s group is definitely one of the good things about having a deaf child. They were great.”

Having family support was viewed as critical for many parents raising deaf children. Many parents felt that it lessened the impact of the stressors associated with parenting a deaf child.
“I think it really helps to know that I’m not alone. When I think about it, I have a husband who’s involved, a family that is concerned, a support group that understands me, and friends whose lives are similar to mine. All of those things help to make this parenting thing so great.”

**Communication.** The issues of communicating with a deaf child are quite complex and the families that participated in Szarkowski’s study utilized different communication modes. Although admitting to struggles, many of these families found a positive way to view communicating with their child.

“Asl has been very difficult to learn. It is not easy, and it requires so much time and effort. I also think it is a beautiful language and hope to someday be fluent at it so that I can effectively communicate with my daughter when she grows up.”

“I know with my son, he was labeled severely to profoundly deaf. Yet, with his hearing aids he can respond to oral speech quite a bit. He listens auditorily and is also oral. He talks quite a bit actually.”

**Advice.** Finally, having been through difficult times, adjustments, joys, and accomplishments with their deaf children, parents were eager to share their insight with other parents.

“I think that parents need to know that every child is unique. Having a deaf child is an opportunity to be exposed to things that, without him, you would never experience. Enjoy it!”

**A Balanced View**

Analyzing what parents said during their interviews, wrote in their journals, and demonstrated through interactions with their deaf child led Szarkowski to develop a continuum-based model of parenting experiences that roughly encompasses three categories. Positive Parents were consistently positive in their interview responses, written work, and observed behavior. They could rapidly and easily identify the positives of raising their deaf child. Interestingly, these parents were also flexible and seemed not to mind altering previous decisions to better meet their child's needs. Struggling Parents were hopeful that positives would eventually outweigh negatives but they described an equal number of positive and negative experiences. Not So Positive Parents had greater difficulty identifying positive experiences and grappled with maintaining consistency between their verbal or written responses and their behavioral interactions with their child.

With these differences in mind, it appears that the ability to report and substantiate positive experiences, while still recognizing different life circumstances, influenced the degree of parental satisfaction with raising a deaf child. Szarkowski's parenting model, in other words, allows for the normal "ups and down" of parental experiences and therefore creates a balanced view of parenting deaf children in which both positive and negative experiences are acknowledged. In her dissertation, Szarkowski expresses the hope that an understanding of her model may encourage parents to increase the overall frequency and intensity of the "Positives" associated with parenting a deaf child.

**References**


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grant, funded by the National Institute on Disability and Rehabilitation Research (NIDRR), an agency of the United States Department of Education, will support both TAP and the Trace Center to study new issues related to accessibility, with the ultimate goal of making emerging telecommunication products and systems directly usable by people who are deaf, hard of hearing, or who have other disabilities. The five-year grant is for $850,000 per year, divided between Gallaudet and the University of Wisconsin.

The Gallaudet research team is led by Dr. Judy Harkins, co-principal investigator of the RERC-TA, and director of the Technology Access Program, as well as a professor in the Department of Communication Studies. Working with Dr. Harkins are Cary Barbin, senior research engineer, Linda Kozma-Spytek, research audiologist, and Paula Tucker, research associate. At the Trace Center, internationally known for its 30 years of work on access to information technologies, computers, kiosks, and telecommunications, the grant is led by Dr. Gregg Vanderheiden, director of the Center and professor of Industrial and Biomedical Engineering.

Quantified Performance Evaluation

In order to determine whether a product is accessible or “usable” by people with disabilities, government and industry look for ways to measure, or quantify, a product’s accessibility. Product developers also want to know what types of access strategies work best and are preferred by people with disabilities. In addition, consumers are interested in research-based information that can help them determine which products will best meet their needs.

Video Parameters for IP Video Relay Interpreting and Low-Effort Conversation. The dream of deaf people to communicate over the Internet using a signed language has become a reality for many in the Deaf community. However, signed languages put a high load on the video communication system because of the unusually vast number of changes between frames, including both large, sweeping movements and small, fast movements, such as those used during fingerspelling. The quality of video varies based on variables that are within the user’s control, such as lighting and camera choice, and variables that the user cannot control, such as bitrate and packet loss on networks. As more choices have become available to consumers, there has been an increase in confusion as to how to maximize performance, with limited information available. In the previous RERC-TA, in collaboration with Swedish developer Gunnar Hellström, a video assessment tool was developed to measure key parameters in received video—such as frame rate and resolution—when ASL is used. In the current project, we will calibrate the assessment levels with user judgments of quality, evaluate video communication products currently on the market, and study user controllable variables for their ability to transmit fingerspelling intelligibly.

Technical Parameter Requirements for Accessible Videotelephony by Hard of Hearing Consumers.

Although deaf consumers have embraced videotelephony, this technology has not yet been widely adopted by hard of hearing individuals. Video phones would seem a natural medium for telecommunication for hard of hearing users, since being able to see the face of the speaker can provide a significant enhancement in comprehension of speech. The levels of performance necessary for a system to be useful for this purpose have not yet been studied. This project proposes to establish benchmarks for frame rate, resolution, and audiovisual sync, relative to individuals’ ability to understand speech with the supplemental full-motion video.

Shown above is a frame from the Video Assessment Tool. Cary Barbin, TAP senior research engineer, is shown signing the letter Y, in the word NYC. On-screen graphics support scoring of the video for frame rate, resolution, and missing letters in fingerspelling.
Electromagnetic Interference

Many hearing aid and cochlear implant users notice a buzzing sound when using a wireless phone. The problems associated with this “buzz”, caused by electromagnetic interference (EMI), can range from an annoyance when making a call, to the inability to use a wireless phone at all. Several projects have been designed to support government and industry in resolving these problems.

Hard of Hearing User Tool for Evaluation of Phone Audio and Usability. With the variety of wireless phones on the market, it is often difficult for hearing aid or cochlear implant users to find a handset that best meets their needs. This project will develop an evaluation tool that hearing aid and cochlear implant users can use to select an appropriate wireless phone.

Cordless Phones and Hearing Aid Interference. Although the FCC has required cordless phones to be hearing aid compatible for 15 years, the newest digital models are causing interference that makes them incompatible. This project will take objective measurement of the output of a number of different types of hearing aids when coupled to cordless phones. Subjective measures will also be collected to determine the relationship between user ratings and phone characteristics, such as transmission frequency and the nature of the audio interference. These results will be provided to industry standards groups and the FCC.

Wireless Phones and Hearing Aids: Lab and Field Validation of New FCC Requirements. In 2003, the FCC decided that some cell phones must be hearing aid compatible and that industry must provide information to consumers on compatibility. Industry is now working on implementation of the rule, and technical testing methods are being adjusted. The RERC-TA will conduct a study to validate the new techniques and determine if they can predict users’ satisfaction with audio performance of combinations of cell phones and hearing aids in field conditions. Also studied will be the usability of wireless phones by cochlear implant users, who are covered by the FCC hearing aid compatibility rule but not by the technical testing procedures. RERC-TA researchers will also continue to be active participants in related industry forums.

Access to Emerging Telecommunication Technologies

The goal of the RERC-TA is to look for ways to build accessibility features into mainstream products so they can be used by everyone, without the need to purchase additional equipment to make the product usable. It is much easier to eliminate technological barriers while products are in development, rather than trying to find solutions after the product is on the market. The projects described below will address these issues in the areas of emergency communications, text communication, and cross-disability access to digital communication technologies.

Accessible Emergency Notification and Communication Solutions Summit. Since September 11, 2001, the need for accessible emergency services and communications has increased. The RERC-TA will hold a summit meeting on this issue at Gallaudet University. The focus will be on technological solutions to this issue and will allow stakeholders and technology experts to share their concerns and expertise. One goal is to create a literature on the topic so that responders and network planners can better incorporate accessibility into their emergency services.

Cross-Industry Road Map for Transition to Universal Text for Conversation. One of the most complicated issues is how to transition from analog text conversation technology on traditional telecommunications networks to a form of IP text conversation that takes advantage of the IP environment. Ways are being sought to mix text and voice on a call, without prematurely cutting off those users who are still using TTYs over analog phone lines. This project will attempt to develop and document a plan to guide policymakers in implementing a coordinated approach that will provide a workable IP text solution. The approach will make use of open industry standards to permit text users to converse internationally and across different networks and hardware.

Ubiquitous (Readily Achievable) Conversational Text. This project is aimed at developing the techniques, code modules, and drivers necessary to make IP text telecommunications technically feasible on IP phones. Working with industry and non-profit organizations
world-wide, the RERC-TA will also be exploring and documenting the steps needed to create a harmonized international text conversation capability.

**Beyond Text: Total Conversation Reference Design and Open Software Library.** For individuals with multiple communication disabilities, such as hearing, speech, and cognitive disabilities text is not always an appropriate, or accessible, alternative means of communication. For these individuals, accessible multi-media communications will be important to provide “total communication” – independent of disability type – with anyone. This project will develop specifications, identify existing standards and codecs, code key components, create software reference implementations, and then package and release them as open source materials (software whose source code is in the public domain and can be changed to meet the needs of individual users) to facilitate worldwide compatible implementation of accessible multimedia conversation.

**Cross-Disability Accessible Telecommunication Reference Materials and Guidelines.** The focus of this project is the problem of creating mainstream phones that are usable by people with all types of disabilities. This project will gather the best known features and techniques of telecommunication technology, along with their testing data, and prepare integrated packaged code modules to implement them, as well as supporting materials to facilitate the transfer and integration of the techniques by industry. This project truly encapsulates the goal of the RERC-TA – to find ways to make standard telecommunication products directly usable by people with all types and degrees of disability.

More information about this work is posted on two websites: http://tap.gallaudet.edu and www.trace.wisc.edu. Paula Tucker can be contacted at Paula.Tucker@tap.gallaudet.edu.

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**Larry Siegel the 2004-2005 Powrie V. Doctor Chair**

Larry Siegel, a special education attorney and partner with the California-based law firm Zatopia & Siegel who has over 25 years experience working with the Deaf community, is the GRI’s Powrie V. Doctor Chair of Deaf Studies for the 2004-2005 school year. During his time at Gallaudet, Siegel has been developing a book on deaf and hard of hearing children’s right to communication and language and is working with others involved in a National Deaf Education Project (NDEP) on the development of a “communication-driven educational paradigm” for reform in deaf education programs nationwide. NDEP was founded by Siegel in 1998 on the belief that accessible language and communication are inherent rights of all Americans and should be supported by all American institutions, including educational institutions. This right is “a foundational concept upon which program goals must be set and program components built.” Under Siegel’s leadership, NDEP has become a collaborative project of the American Society for Deaf Children (ASDC), the Conference of Educational Administrators of Schools for the Deaf (CEASD), the Convention of the American Instructors of the Deaf (CAID), the National Association of the Deaf (NAD), Gallaudet University, and the National Technical Institute for the Deaf (NTID).

Siegel has long been concerned about the inequities that result when deaf and hard of hearing children are deprived of the kinds of language and communication access taken for granted by hearing individuals. The book he is developing, tentatively called “The Importance of and Right to Communication,” will include chapters by numerous recognized academic and community leaders, exploring the subject of communication access from an educational, historic, linguistic, legal, international, artistic, communal, familial, cultural, economic, and psychological perspective. In his proposal for the Powrie Doctor Chair, Siegel wrote that this book will “assert with energy and academic rigor why communication is so important for all human beings and in particular, for deaf and hard of hearing individuals.”

Siegel says that although communication is central to all human growth, it is not adequately recognized as a “starting point” in American education. Under the Individuals with Disabilities Education Act (IDEA),
for example, schools are required to “consider” the communication needs of individual students, but decisions regarding the communication “method” used in instructing deaf students are implicitly allowed to be based on what can be most conveniently arranged for at the school rather than on the communication needs of the child. Because schools have such leeway in determining how they will accommodate deaf students, many legitimate concerns of deaf children and their parents may be ignored. When decisions are made during IEP meetings, the desire of a deaf student for qualified teachers who are fluent in sign language, a sufficient number of peers with similar communication needs, or requests for qualified/certified interpreters, are often disregarded.

Siegel’s long-range goal is to change the requirements of the IDEA in ways that will help ensure deaf and hard of hearing students’ access to communication. “If communication is fundamental to the human experience and impacts on virtually every moment of our day,” Siegel says, “it must become an unquestioned right under IDEA and not left to the whims of an IEP team who may not understand the issue at hand. Specifically, if parents determine that their child should be instructed in ASL or with a qualified interpreter or go to the state school or have more than one language/communication-compatible peer, then those things should be the right of the child.”

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