

Parent challenges, perspectives, and experiences caring for children who are deaf or hard-of-hearing with other disabilities: A comprehensive review

By

John Whicker<sup>a\*</sup>, Karen Muñoz<sup>a,b</sup>, and Lauri Nelson<sup>a</sup>

<sup>a</sup> Communicative Disorders and Deaf Education, Utah State University, Logan, Utah, USA;

<sup>b</sup> National Center for Hearing Assessment and Management, Utah State University, Logan, Utah, USA

\*Corresponding author: John Whicker, 2620 Old Main Hill, Logan, Utah, 84322;  
[jj.whicker@aggiemail.usu.edu](mailto:jj.whicker@aggiemail.usu.edu)

### **Abstract**

*Objective:* The purpose of this literature review was to explore parent challenges in caring for children who are deaf or hard of hearing with other disabilities and discuss implications for audiologists related to supporting families.

*Design:* A comprehensive literature review was conducted, and through qualitative analysis, emergent themes were identified, and a narrative summary generated.

*Study Sample:* Nine research studies were included in this review. Combined, these studies reflect a sample of 111 children, 23 families, and 41 parents.

*Results:* Three broad themes were identified, and include parent-reported challenges related to family, professional, and child variables. Sub-themes were identified within each broad theme to further describe parent experiences, such as challenges related to decision-making and planning, interprofessional collaboration, and child communication and behaviors.

*Conclusion:* Parents of children with hearing loss and additional disabilities face unique challenges related to family, professional, and child variables that could impact how they manage their child's hearing care.

## Introduction

The World Health Organization (WHO) estimates that nearly 9% of hearing loss in the world occurs in children (WHO 2016), and in the United States, permanent hearing loss is diagnosed in 1 to 3 of every 1000 births (Centers for Disease Control and Prevention [CDC] 2016). Incidence reports related to children with hearing loss who also have other disabilities have been variable (National Deaf Children's Society [NDCS] 2012); however, general estimates indicate 25 to 40% of children with hearing loss have one or more comorbid disabilities (Cupples, Ching, Crowe, et al., 2014; Wakil, Fitzpatrick, Olds, et al., 2014). Understanding the multiple underlying challenges of parents who care for children who are deaf or hard of hearing with other disabilities (D/HH Plus) can aid the pediatric audiologist in providing quality services for this population. How audiologists understand and partner with parents of children who are D/HH Plus could influence how they manage hearing care, and in turn, produce positive intervention outcomes.

The challenge of accepting, adapting, and managing hearing loss has been shown to impact individuals and their families emotionally across the lifespan (Luterman 1999; Hintermair 2006; Quittner, Barker, Cruz, et al., 2010). When additional disabilities are involved, the needs of both parents and children may extend beyond the needs of parents and children with hearing loss alone. This extension of needs could compound burnout for parents or caregivers. Burnout is the result of physical, emotional, and cognitive exhaustion (Melamed, Shirom, Toker, Berliner, & Shapira, 2006). For parents of children who are D/HH Plus, this burnout could impact how they manage their child's hearing care.

Hintermair (2000) found that parents of children who are D/HH Plus experience a significantly increased amount of stress compared to parents of children with hearing loss alone.

Furthermore, families of children who are D/HH Plus may experience chronic guilt (e.g., self-blame for their child's multiple disabilities), and this may affect parental behaviors and interactions with their children (Luterman, 2004). For example, Klein (1977) described a continuum of parent interactions, ranging from a 'helicopter parent' approach to care (e.g., parents allow for the needs and wants of their child who are D/HH Plus to dictate all family functioning), to an alienation approach to care (e.g., parents exclude the child who are D/HH Plus from family activities).

Both Klein (1977) and Luterman (2004) concluded that parents of children who are D/HH Plus may require different approaches for communication from providers, as parents may not be emotionally or physically able to adhere to standard treatment recommendations. Thus, understanding the range of challenges of parents caring for children who are D/HH Plus may aid pediatric audiologists in establishing shared goals, and partnering with parents in decision-making and action-planning on behalf of children who are D/HH Plus. Therefore, the purpose of this study was two-fold: (1) to comprehensively review research that has explored parent-reported challenges in caring for children who are D/HH Plus to describe the various aspects of parental burden, and (2) suggest implications for audiologist communication to support the additional needs of these patients and families.

## **Methods**

### **Procedure**

A comprehensive literature review was completed in September-October 2017 to identify journal articles related to parent challenges caring for children who are D/HH Plus. The following databases were used: ERIC, MEDLINE, Psychology and Behavioral Sciences

Collection, and PsycINFO. Key terms for this literature search were: (children OR adolescents OR youth OR child OR teenager) AND (multiple disabilities OR additional disabilities) AND (parent challenges OR parent coping OR parent experiences OR parent perspectives OR parent needs).

The first author identified articles by first screening by title and/or abstract. If articles appeared to meet the inclusion criteria, a full-text review was completed. Inclusion criteria were that the article was (1) published in English, (2) published in a peer-reviewed or editor-reviewed journal between 1976 and 2017, (3) reported findings which included parent challenges, perspectives, or experiences caring for children with hearing loss and an additional, specified disability, and (4) a research study (e.g., not a position paper).

The database search yielded 45 articles, after duplicates were removed. Thirty-nine were eliminated based on an irrelevant title and/or abstract. Full text was reviewed for the remaining six articles. At this stage, three articles were excluded for the following reasons: two were not research studies, and one did not report on findings related to the challenges, perspectives, and experiences caring for children who are D/HH Plus. The remaining three articles were considered relevant, and included in the review. To ensure that all relevant articles were identified, an ancestry search of the references cited in the three eligible articles was completed, and, following the same process as before, six additional articles were found and considered eligible for inclusion. A total of nine articles qualified for this comprehensive review (see Figure 1).

## **Analysis**

The nine articles were reviewed, and a thematic qualitative analysis was completed. Emergent subthemes were identified and recorded in a spreadsheet. These subthemes were then coded for the type of insight that was provided (e.g., working with professionals), and categorized into broad themes. As this review was exploratory in nature, broad themes were not predetermined, but emerged from the subthemes. These themes and subthemes were reviewed and in agreement with the second author of this study. Following agreement, the themes and subthemes were narratively summarized to describe parent challenges, perspectives, and experiences caring for children who are D/HH Plus.

### **Results**

Of the nine articles reviewed, five were studies related to parents of children with cochlear implants and a variety of additional disabilities (McCracken & Tuner, 2012; Mulla, Harrigan, Gergory, & Archbold, 2013; Isarin, van Zadelhoff, Wolters-Leermakers, et al., 2015; Zaidman-Zait, Curle, Jamieson, et al., 2015; Turan, 2016), three were related to parents of children with hearing loss and Autism Spectrum Disorder (ASD; Myck-Wayne, Robinson, & Henson, 2011; Wiley, Gustafson, & Rozniak, 2013; Zaidman-Zait & Curle, 2016), and one study was related to parents of children with dual sensory impairments (hearing loss and visual impairment) (Giangreco, Cloninger, Mueller, et al., 1991). Eight of the studies used a qualitative research design, and one study used a mixed methods design. Combined, these studies reflect a sample of 111 children, 23 families, and 41 parents. A summary of the studies included in this review, including their individual sample sizes, can be seen in Table 1. Three broad themes were identified from the review regarding parental challenges, perspectives and experiences caring for children who are D/HH Plus: (1) *Family variables*, (2) *Professional variables*, and (3) *Child variables*.

### **Family Variables**

Eight of the nine studies identified family variables which presented as challenges in caring for children who are D/HH Plus. The family variables reported included challenges related to (1) decision making and planning on behalf of children who are D/HH Plus, (2) extended family reaction, (3) funding, and (4) the emotional and physical drain of caring for children who are D/HH Plus.

**Decision-making/Planning.** Five studies reported findings related to parent challenges and experiences in decision-making or planning on behalf of their child. Giangreco and colleagues (1991) found that parents felt uncomfortable thinking about the future of their child, for fear of the unknown. Some parents avoided planning for the future as a way of coping with the stress of caring for their child. For some of the parents in this study, thinking of the future sparked feelings of depression – feelings which were compounded when contemplating the care their child would require for a life-time.

Both Myck-Wayne, Robinson, and Henson (2011), and Zaidman-Zait and Curle (2016) reported parent challenges regarding selection of services for their child with hearing loss and ASD. In this study, parents described taking a ‘trial-and-error’ approach to selecting types of services for both the hearing loss and ASD, basing those selections only on the degree of their child’s improvement in behavioral and communication skills. Parents from Myck-Wayne, Robinson, and Henson’s (2011) study described how they prioritized hearing care differently; for example, some of parents valued an emphasis on treating the child’s behavioral issues related to the ASD before attending to the hearing-related issues.

Selecting a mode of communication was a challenging decision for the parents in both McCracken and Turner's (2012) and Zaidman-Zait and Curle's (2016) studies. For these parents, it was unclear as to which method for developing language they should adhere, given their children's complex needs. Some parents felt that spoken language was not possible for their child, whereas other parents chose to employ a combination of sign or gestures with spoken language.

Finally, Isarin and colleagues (2015) found that parents of children who are D/HH Plus, who received cochlear implants, reported difficulty deliberating whether cochlear implantation was right for their child before implantation, given the invasiveness of the surgery, and the lack of guarantee for success. Other parents found this decision difficult, because they considered sign language and Deaf culture as important aspects of their child's identity.

### **Extended Family Reaction**

One study reported findings related to extended family members, and it explored family member reactions to the dual diagnosis of hearing loss and ASD (Wiley, Gustafson, and Rozniak, 2014). Some extended family showed interest and demonstrated a willingness to learn how to effectively communicate with the child; however, other extended family members were in denial, and had difficulty in accepting the needs of the child. Some even advised the parents in ways to manage the child's behavior, without considering the challenges that both hearing loss and ASD present for behavior. Parents reported that these negative reactions changed over time, or as more information (e.g., evaluation reports) was shared to explain the child's condition.



**Funding.** Three studies reported parent challenges related to funding for the needs of children who are D/HH Plus. McCracken and Turner (2012) found that some parents struggled paying for hearing care (e.g., hearing aids, cochlear implants), because of the already burdensome finances related to their child's other medical needs. Zaidman-Zait and colleagues (2015) found that, even though the medical needs of each study participant were funded by the government, parents were charged with the task of managing these funds and completing a significant amount of paperwork.

Zaidman-Zait and Curle (2016) found that many families of children with hearing loss and ASD faced structural changes in their family that impacted their financial stability. For example, several mothers gave up their careers to care for their child full-time. Many families had to relocate to access the specialized services their child needed. Some families even split up to access specialized services (e.g., the mother and child with hearing loss and ASD would live in a different city for the week to attend the child's interventions services, while the father remained in the family's home community to take care of typical family needs, such as caring for the other children).

**Emotional and Physical Drain.** Four studies reported parent experiences related to the emotional and physical drain in caring for children who are D/HH Plus. Turan (2016) found that five mothers of children with cochlear implants and additional disabilities reported the first year of their child's life as 'exhausting' emotionally and physically. For example, one of the mothers described the first year of her child's life in terms of traveling back and forth between hospitals and home multiple times a week for testing, which was complicated due to the child not sleeping. This mother reported sleeping, herself, for only two to three hours most nights to care for her child.

Zaidman-Zait and Curle (2016) found that mothers of children with cochlear implants and ASD experienced emotional drain by taking on multiple roles in the care of their child. Roles, as perceived by one mother, included speech therapist, behavior therapist, teacher, case manager, and service coordinator. One mother stated: ‘I have to be everything and I’m only one person’ (page 5). These burdens led many mothers to express feelings of overwhelm, depression, isolation, and loneliness.

Both McCracken and Turner (2012) and Wiley, Gustafson, and Rozniak (2014) reported on parents’ emotional strain as it related to their children’s diagnostic process. In McCracken and Turner (2012), some parents of children with cochlear implants and additional needs reported that it took years for them to get a referral for cochlear implant evaluation, and to find a cochlear implant center that would consider cochlear implantation for their child. Some parents from this study obtained a referral and evaluation for cochlear implantation; however, near the end of the time-consuming assessment process the parents were informed that their children did not meet cochlear implant candidacy criteria, which impacted parents’ already sensitive emotions.

Wiley, Gustafson, and Rozniak (2014) found that parents of children with hearing loss experienced varied emotional responses to the additional diagnosis of ASD. One family felt left out of the diagnostic process for ASD and were frustrated at the difficult tasks being given to their child as part of the diagnostic assessment, knowing that the child would not perform well because of the hearing loss, and not necessarily due to the suspected ASD. Parents reported feeling that the assessment batteries did not account for their child’s hearing loss-related needs.

### **Professional Variables**

All nine articles identified professional variables that challenge parents of children who are D/HH Plus. The professional variables reported included challenges related to (1) interprofessional collaboration, (2) attitudinal barriers to support, and (3) educational placement and school support.

**Interprofessional Collaboration.** Three studies reported parent challenges related to interprofessional collaboration. Giangreco and colleagues (1991) found parents of children with dual sensory impairments were frustrated with the lack of communication between the number of professionals caring for the several aspects of their children's needs. One parent expressed that each professional seemed to have a different idea about what was right for the child. Parents reported perceiving specialists as professionals with minimal expertise beyond a small area of knowledge. Parents felt they were answering the same questions multiple times to different professionals. Families with a case manager to liaise between professionals experienced greater satisfaction.

Isarin and colleagues (2015) found that the greatest cause of parental dissatisfaction in services was related to a lack of coordination among the different professionals, or even within teams of professionals. One parent stated: 'There were so many doctors and all of them did their own thing' (page 226). Similar to Giangreco's (1991) findings, Isarin et al. reported that when a case manager was used to coordinate information and monitor progress, parents felt more confident they could ask a question, and then be directed to the appropriate professional.

Zaidman-Zait and colleagues (2015) found that the parents of children with cochlear implants and additional needs in their study were stressed in managing the multiple appointments and services their child needed to attend and felt overwhelmed at the number of recommendations made to them from varying professionals. One parent reported being in

meetings with 20 different professionals, each representing the various aspects of the child's care. Parents expressed that it would be helpful for professionals to communicate, coordinate and combine services.

**Attitudinal Barriers to Support.** Three studies provided insight into the attitudinal barriers of professionals, and the extent to which professionals provided support to families. Giangreco and colleagues (1991) found that parents of children with dual sensory impairment noted hesitancy from the vision and hearing professionals respectively. They reported feeling that itinerant visual and hearing specialists were minimally involved with their children when it made sense that they should have been more involved, and the more complex the children's handicaps, the less likely any visual or hearing professional was involved at all. Parents perceived this lack of involvement as being due to the professionals' fear of not knowing something, or coming across as inexperienced; thus, parents supposed, the coping mechanism for professionals was to not work with the child altogether or pretend to know something which they did not.

For both McCracken and Turner (2012) and Turan (2016), parents reported a negative attitude that professionals (mostly physicians or audiologists) displayed related to whether the child with hearing loss and other disabilities should receive a cochlear implant, which impeded parents' efforts in pursuing cochlear implantation for their child, some for years. For example, one of the mothers from Turan's (2016) study reported that a neurologist continually ignored the urgings from both a child's mother and his interventionists to implant him at an early age. By the time the neurologist finally consented, the child had turned 4.

**Educational Placement and School Support.** Six of the nine articles reported findings regarding parent challenges and experiences navigating their child's educational needs.

Giangreco and colleagues (1991) found parents reported feeling uninvolved in educational planning, which often lead to decisions being made by educators that did not meet the child's or family's needs. Similarly, the parents in Zaidman-Zait and colleagues' (2015) study also felt uninvolved or uninformed regarding their child's school life and expressed that effective communication between the school and the family is important to parents. Furthermore, parents of this study expressed concern that extracurricular activities were hard to find for their child with complex needs; when they were found, such programs were expensive.

Mulla, Harrigan, Gregory, and Archbold (2013) reported parents had difficulty finding schools that they perceived to meet the unique needs of their children. Only one of the seven children in this study was placed in a deaf education classroom; the rest were placed in classrooms designed for children with severe learning difficulties. According to the parents in this study, these classrooms did not provide an appropriate listening environment for the children, and therefore the children's hearing needs were not met. Similarly, only one of the four children with ASD and hearing loss in Myck-Wayne, Robinson, and Henson's (2011) study was placed in an educational setting that had other children with hearing loss. To obtain this placement, the parents had to file for due process.

Both Myck-Wayne and colleagues (2011), and Zaidman-Zait and Curle (2016) found that many of the parents of children with hearing loss and ASD experienced little coordination between deaf education services, and ASD services. In these cases, Zaidman-Zait and Curle (2016) reported that some mothers attempted to help educators integrate the child's hearing needs and needs related to ASD. However, some mothers felt that the educators were not responsive to these attempts, causing frustration for parents.

Finally, the mothers in Turan's (2016) study reported difficulty getting their children the services they need in school. One mother had to write to her government's ministry to get her child a teacher of the deaf to help in his regular education classroom. Another mother reported that her child's teacher did not want her child who was D/HH Plus in her classroom and worked to minimize the child's hours in class. The same school required the mother to stay at school with the child in case there was 'any trouble'.

### **Child Variables**

Five articles identified child variables that challenged parents of children who are D/HH Plus. The child variables reported in this review were challenges related to (1) child communication, and (2) behavior management.

**Child Communication.** Three studies reported parent challenges in developing meaningful communication with their child. Wiley, Gustafson, and Rozniak (2014) found parents of children with hearing loss and ASD were challenged in transferring communication strategies used at school (usually the picture exchange communication system [PECS]) into the home. Some parents reported they felt their child was better able to communicate in diverse ways (e.g., writing, total communication), so they would not 'force' PECS, which went against the school's recommendations.

Zaidman-Zait and Curle (2016) found that mothers of children with ASD who were cochlear-implanted were challenged in interpreting their child's wants and needs based from the child's behaviors (e.g., crying, facial expressions, actions), which 'mystified' some mothers, and was the source of considerable frustration. Similarly, Zaidman-Zait and colleagues (2015) found that more than half of the parents they surveyed (60.9%), who had children with cochlear

implants and additional needs, reported communication difficulties related to both the child's general language skills, and the parent-child interactions.

**Behavior Management.** Four studies reported findings related to parent challenges managing their child's behavior. In three of these studies, the children had cochlear implants, and the challenges were related to device wear-time. Mulla, Harrigan, Gregory, and Archbold (2013) reported some parents found that having their child wear their device was much harder than they thought it would be, leading to feelings of failure. Both Isarin et al (2015) and Zaidman-Zait et al (2015) reported parents' feelings of frustration and even desperation as they learned to manage behaviors such as chewing, throwing, or losing processors, and aggressively resisting processor placement.

One study (Wiley, Gustafson, & Rozniak, 2013) found parents of children with hearing loss and ASD faced general challenges to behavior management. Because routines were important to many of the children in this study, tasks such as changing hearing aid batteries required a detailed plan to minimize disruption and child break-downs. Behavior challenges in public settings were especially difficult for these parents, which caused a shift in some of the parents' priorities for help to focus on functional and social skills, and not on academic achievement.

### **Discussion**

The purpose of this comprehensive review was to explore and describe challenges parents experience when a child has hearing loss and other disabilities, and to discuss implications for pediatric audiologic practice to effectively meet the unique needs of these families. The comprehensive review of the literature identified nine articles that conducted research in this

area. The small number of articles found suggests that this topic area is under-investigated; however, most of the studies were published recently (eight of the nine within the last six years), indicating an increased recognition of the importance of understanding issues to better support families of children who are D/HH Plus. Although a wide variety of medical, developmental, and intellectual disorders are represented in the combined sample of individuals included in these studies, not all disabilities are represented (e.g., social emotional disorder, mood disorders).

Findings from the review suggested one overarching implication for audiologists' consideration regarding the potential impact of additional disabilities on parent burnout, and ultimately how parents of children who are D/HH Plus manage their child's hearing care. Although parent burnout is commonly experienced by many, including parents of children with hearing loss alone, this review identified the extent of challenges that may substantially perpetuate the level of burnout for parents of children who are D/HH Plus. This was made clear in the way several of the parents in these studies attributed their physical, emotional, and cognitive exhaustion to navigating the multiple roles required to meet the considerable number of recommendations and expectations of many different healthcare and educational professionals. Burnout could lead to feelings of anxiety or depression. Audiologists can screen for these and make appropriate referrals to ensure that parents are receiving the support they need (Muñoz, McLeod, Pitt, et al., 2017).

Audiologists should recognize that, for parents of children who are D/HH Plus, challenges may be more complex and take more time to work through than for children with hearing loss alone. Furthermore, these parents may have pressing concerns that extend beyond their child's hearing needs. Through counseling to elicit these pressing concerns, audiologists can engage in a shared decision-making process to ensure that audiologists' actions are



congruent with the families' goals related to caring for children who are D/HH Plus. By engaging in shared decision-making, audiologists may better address many concerns pointed out in this study related to deciding a communication modality for the child, determining the parents' financial priorities, or understanding the child's behaviors and strategies that can be incorporated to handle poor behavior. In this way parents may be more empowered to act, thus increasing likeliness of positive outcomes for their child who are D/HH Plus.

Many of the challenges reported in this review are similar to the challenges reported by parents of children with special healthcare needs (CSHN). For example, Kuo, Cohen, Agrawal, and associates (2011) found in a national survey of parents caring for CSHN that more than half experienced health-care related financial burdens (56.8% n = 184,043) and/or required a caregiver to stop working to care for the child (54.1%, n = 175,294). Additionally, one-third of the parents (33.1%, n=107,350) reported difficulty accessing non-medical services (e.g., education services).

Understanding the multiple challenges parents face in caring for children who are D/HH Plus can inform audiologists regarding how to better collaborate and communicate with parents and other professionals. Based from this review's findings, how audiologists share information with parents and with other professionals may influence parents' perceptions on quality of care that, in turn, may influence how much parents respect and trust their child's audiologist. Audiologists should consider developing a system to ensure that quality resources are provided to parents (e.g., handouts, online learning). Additionally, audiologists (including educational audiologists) should ask parents how they would like information streamlined to other professionals in a way that avoids confusion among parties (e.g., through a case manager or care coordinator). For audiologists working in hospital settings, taking the time to coordinate

appointments to line up with the child's other medical or rehabilitative appointments may help relieve some burden to parents.

Furthermore, how audiologists assess for hearing loss in children with disabilities can play a role in parents' confidence in test results. Children with multiple disabilities may not condition well to behavioral testing, thus impeding the reliability of traditional audiometric testing. Poor communication and poor testing can result in parents attempting to manage their child's needs on their own. When parents attempt to manage their child's need alone, they may introduce other challenges associated with delayed or suboptimal service delivery, given that the child is not receiving specialized early intervention or other services in a timely manner.

Further research is needed in this area to understand how parents of children who are D/HH Plus prioritize hearing care differently from parents of children with hearing loss alone. From this review, minimal information was found regarding parent challenges related to child communication development, which is a crucial aspect of hearing loss; thus, further research to explore communication development in children who are D/HH Plus, and related parent challenges, is warranted. Additionally, further research is needed to explore audiologists' perspectives in working with children who are D/HH Plus, and to understand what educational supports (e.g., graduate training, continuing education) audiologists need to effectively address parent challenges.

### **Conclusion**

Parents of children who are D/HH Plus face multiple underlying challenges that are not all related to hearing. These challenges include factors related to family, professional, and child

variables, and could impact how much, or how effectively parents manage their child's hearing care.

### References

Center for Disease Control and Prevention. Hearing loss in children. Available at:

<https://www.cdc.gov/ncbddd/hearingloss/research.html> [Accessed Nov 29 2017].

Cupples L., Ching T., Crowe K., Seeto M., Leigh G., Street L., Day, J., Vivienne, M., and

Thomson, J. (2014). Outcomes of 3-year-old children with hearing loss and different types of additional disabilities. *J Deaf Stud Deaf Educ*, 19 (1), pp. 20-39.

Giangreco, M., Cloninger, C., Mueller, P., Yuan, S., and Ashworth, S. (1991). Perspectives of parents whose children have dual sensory impairments. *J Assoc Pers Sev Handicaps*, 16 (1), pp. 14-24.

Hintermair, M. (2000). Children who are hearing impaired with additional disabilities and relates aspects of parental stress. *Excep Children*, 66 (3), pp. 327-332.

Hintermair, M. (2006). Parental resources, parental stress, and socioemotional development of deaf and hard of hearing children. *J Deaf Stud Deaf Educ*, 11 (4), pp. 493-513.

Isarin, J., van Zadelhoff, I., Wolters-Leermakers, N., Speksnijder-Bregman, M., Hannink, M., and Knoors, H. (2015). A world of difference. Parental perspectives on cochlear implantation in deaf children with additional disabilities. *Deafness Educ Int*, 17 (4), pp. 219-230.

Klein, C. (1977). Coping patterns of parents of deaf-blind children. *Am Ann Deaf*, 122 (3), pp.

310-312.

Kuo, D., Cohen, E., Agrawal, R., Berry, J., and Casey, P. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*, 165 (11), pp. 1020-1026.

Luterman, D. (2004). Counseling families of children with hearing loss and additional disabilities. *Volta Rev*, 104 (4), pp. 215-220.

Luterman, D. (1997). Emotional Aspects of Hearing Loss. *Volta Rev*, 99 (5), pp. 75-83.

McCracken, W., and Turner, O. (2012). Deaf children with complex needs: Parental experience of access to cochlear implants and ongoing support. *Deafness Educ Int*, 14 (1), pp. 22-35.

Melamed, S., Shiron, A., Toker, S., Berliner, S., and Shapira, I. (2006). Burnout and risk of cardiovascular disease: Evidence, possible causal paths, and promising research directions. *Psych Bulletin*, 132 (3), pp. 327-353.

Mulla, I., Harrigan, S., Gregory, S., and Archbold, S. (2013). Children with complex needs and cochlear implants: The parent's perspective. *Cochlear Implants Int*, 14 (S3), pp. S38-S41.

Muñoz, K., McLeod, H., Pitt, C., Preston, E., Shelton, T., & Twohig, M. (2017). Recognizing emotional challenges of hearing loss. *Hear J*, 70 (1), pp. 34-37.

Myck-Wayne, J., Robinson, S., and Henson, E. (2011). Serving and supporting young children with a dual diagnosis of hearing loss and ASD: The stories of four families. *Am Ann Deaf*, 156 (4), pp. 379-390.

- National Deaf Children's Society (2012). Prevalence of additional disabilities with deafness: A review of the literature. Available at: <http://www.ndcs.org.uk/document.rm?id=7558> [Accessed 29 Nov 2017].
- Quittner, A., Barker, D., Cruz, I., Snell, C., Grimley, M., Botteri, M., and CDaCI Investigative Team (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. *Parent Sci Prac*, 10 (2), pp. 136-155.
- Turan, Z. (2016). Cochlear implanted deaf children with additional disabilities: The mother's perspective. *Int J Med Med Sci*, 8 (7), pp. 66-74.
- Wakil, N., Fitzpatrick, E., Olds, J., Schramm, D., and Whittingham, J. (2014). Long-term outcome after cochlear implantation in children with additional disabilities. *Int J Audiol*, 53 (9), pp. 587-594.
- World Health Organization (2016). Childhood hearing loss: Strategies for prevention and care. Available at: <http://apps.who.int/iris/handle/10665/204632> [Accessed 29 Nov 2017].
- Zaidman-Zait, A., Curle, D., Jamieson, J., Chia, R., and Kozak, F. (2015). Cochlear implantation among deaf children with additional disabilities: parental perceptions of benefits, challenges, and service provision. *Deaf Stud Deaf Educ*, 20 (1), pp. 41-50.
- Zaidman-Zait, A., and Curle, D. (2016). Complexity: an interpretative phenomenological analysis of the experiences of mothers of deaf children with cochlear implants and ASD. *J Health Psychol*, doi:10.1177/1359105316646171

## Tables

Table 1. Table of Studies

<i>Year/First Author</i>	<i>N*</i>	<i>Disabilities included</i>	<i>Instrument</i>
1991/Giangreco	28C	Vision impairment	Semi-structured interviews
2011/Myck-Wayne	4C	ASD	In-depth interviews
2012/McCracken	12C	Learning disability; lung disease; tracheotomy; kidney disease; tube fed; Cerebral Palsy; hypotonia; hypertonia; blind/visually impaired; ASD; Vacterl syndrome; Mitochondrial cytopathy; Ip36 deletion	Unstructured interviews
2013/Mulla	10C	Down syndrome; ASD; cerebral palsy; CHARGE syndrome; visual impairment; severe learning disability; severe/chronic epilepsy	Semi-structured interviews
2013/Wiley	4P; 3C	ASD	Focus group/Structured interviews
2015/Isarin	23F	Cytomegalovirus; CHARGE syndrome; cerebral palsy; meningitis; Down syndrome; twin-twin transfusion syndrome; Noonan syndrome	In-depth interviews
2015/Zaidman-Zait	45C; 23P	Learning disability; language disorder; cognitive delay; vision impairment cerebral palsy; ASD; Down syndrome; fetal alcohol syndrome	Questionnaire
2016/Turan	5M	ASD; mental/motor disability; Williams syndrome; cytomegalovirus	Semi-structured interviews
2016/Zaidman-Zait	9M;9C	ASD	Semi-structured interviews

\* ASD = Austim Spectrum Disorder, C = children, F = families, P = parents, M = mothers

\*\*Severe learning disability in European literature is indicative of an intellectual disability

Table 2. Themes and Subthemes

<i>Themes</i>	<i>Subthemes</i>	<i>Studies</i>	
Family Variables	Decision-making/planning	Giangreco (1991) Myck-Wayne (2011) McCracken (2012) Isarin (2015) Zaidman-Zait (2016)	
	Extended family reaction	Wiley (2014)	
	Funding	McCracken (2012) Zaidman-Zait (2015) Zaidman-Zait (2016)	
	Emotional and physical drain	McCracken (2012) Wiley (2014) Turan (2016) Zaidman-Zait (2016)	
	Professional Variables	Interprofessional collaboration	Giangreco (1991) Isarin (2015) Zaidman-Zait (2015)
		Attitudinal barriers to support	Giangreco (1991) McCracken (2012) Turan (2016)
Educational placement and school support		Giangreco (1991) Myck-Wayne (2011) Mulla (2014) Zaidman-Zait (2015) Turan (2016) Zaidman-Zait (2016)	
Child Variables	Child communication	Wiley (2014) Zaidman-Zait (2015) Zaidman-Zait (2016)	
	Behavior management	Mulla (2014) Wiley (2014) Isarin (2015) Zaidman-Zait (2015)	



**Figure 1**