A GROUNDED THEORY TO EXPLAIN PARENT PRIORITIZATION OF
HEARING CARE WHEN CHILDREN HAVE DOWN SYNDROME

by
John J. Whicker

A dissertation submitted in partial fulfillment
of the requirements for the degree

of
DOCTOR OF PHILOSOPHY

In
Disability Disciplines

Approved:

Karen F. Muñoz, Ed.D.  Trenton J. Landon, Ph.D.
Major Professor  Committee Member

Michael P. Twohig, Ph.D.  Lauri H. Nelson, Ph.D.
Committee Member  Committee Member

Karl R. White, Ph.D.  Richard S. Inouye, Ph.D.
Committee Member  Vice Provost for Graduate Studies

UTAH STATE UNIVERSITY
Logan, Utah

2020
ABSTRACT

A Grounded Theory to Explain Parent Prioritization of Hearing Care When Children Have Down Syndrome

by

John J. Whicker, Doctor of Philosophy

Utah State University, 2020

Major Professor: Karen F. Muñoz, Ed.D.
Department: Special Education and Rehabilitation

The purpose of this study was to describe the decision-making process parents experience when prioritizing hearing care while caring for children who are deaf or hard-of-hearing with Down syndrome. To achieve this, parents of children who are deaf or hard-of-hearing with Down syndrome were recruited, and in-depth interviews were conducted to develop a grounded theory that may explain the decision-making process for how parents prioritize hearing care and management. Ultimately, 18 mothers of children who are deaf or hard-of-hearing with Down syndrome participated.

Analysis from the in-depth interviews revealed five sub-theories related to how mothers prioritized hearing, hearing aids, communicative development, speech-language intervention, and manual language. From these sub-theories, an overarching theory was generated to describe the factors that influence how mothers prioritize and manage hearing health. The resulting theory
indicated that the higher the extent of professional engagement, parent perception of benefit, parent activation, and engagement of family support, the higher the priority for hearing care and management will be.

The results of this study may inform audiologists and other professionals interacting with this sub-population of parents and children regarding how parent needs and challenges may extend beyond those present when children are deaf or hard-of-hearing alone. This may, in turn, inform how person-centered care is delivered to meet these needs.
A Grounded Theory to Explain Parent Prioritization of Hearing Care When Children Have Down Syndrome

John J. Whicker

The purpose of this study was to describe the decision-making process parents experience when prioritizing hearing care while caring for children who are deaf or hard-of-hearing with Down Syndrome. To achieve this, parents of children who are deaf or hard-of-hearing with Down Syndrome were recruited, and in-depth interviews were conducted to develop a grounded theory that may explain the decision-making process for how parents prioritize effective hearing care and management. The resulting theory indicated that the higher the extent of professional engagement, parent perception of benefit, parent activation, and engagement of family support, the higher the priority for hearing care and management will be.

The results of this study may inform audiologists and other professionals interacting with this sub-population of parents and children regarding how parent needs and challenges may extend beyond those present when children are deaf or hard-of-hearing alone. This may, in turn, inform how person-centered care is delivered to meet these needs.
ACKNOWLEDGMENTS

This dissertation could not have been possible without the help and support of many individuals, whose work, time, expertise, and experiences helped to shape the outcomes of this project. First and foremost is my mentor, Dr. Karen Muñoz whose thoughtful leadership has inspired me since my undergraduate coursework and on to this final part of my graduate experience. Dr. Muñoz was instrumental in helping me decide to pursue a Ph.D. despite my fears and doubts about what the experience would be like. I will be forever grateful for her and her support in this challenging endeavor.

Next, I wish to acknowledge my doctoral committee, Drs. Michael P. Twohig, Karl R. White, Trenton J. Landon, and Lauri H. Nelson. Each member of my committee has played a pivotal role in providing direct feedback to enhance the scope of this dissertation. Beyond that, members of my committee have been accessible, supportive, and insightful in other areas of my graduate experience. A special acknowledgement must be made for Dr. Michael Twohig, who has served as a co-mentor throughout the entirety of my graduate experience.

Through my time in school, I have had the privilege to learn from many distinguished professors and lecturers. Three of those professors have made a huge impact on who I aspire to be, both as a clinician and as a researcher. These professors deserve special acknowledgement, and they include Drs. Elizabeth Preston, Kristina Blaiser, and Colby Tofel-Grehl. In addition, several audiologists have contributed to how I am developing now as a clinician, whose perspective and influence have inspired me and my research. These audiologists include, Drs. Johnnie Sexton, Lindsey Tubaugh, Kathryn Tonkovich, Kayla Hirschmugl, and Michelle
Bunker. I wish to also thank Kathryn Carmina, the Deaf Educator in whose class I volunteered, where this passion truly began.

The data collection and analysis for this dissertation was completed with the aid of Nicole (Nikki) Pearson, who is a doctoral student in the audiology program at Utah State University. Despite her busy academic and clinical schedule, Nikki devoted hours of time to this important project, and I will never be able to thank her enough. I will also never be able to express the appropriate amount of gratitude to the 18 mothers who participated in this study. The data presented in this study does not fully encapsulate the devotion, sacrifice, and love these mothers expressed as they shared their tremendous stories. I wish to particularly thank three additional mothers of children with Down syndrome who were especially supportive during this study: Darcy Hardman, Heather Ripplinger, and Donnel Owen.

I could not have made it through this experience without the love and support of my classmates. I wish to especially thank Faith Thomas, Kandace Jones, Kayla Currier Kipping, and Brenda Smith. You four are powerful women who are going to make a huge contribution to the field. I can only hope that I can be there with you to see the change you can make to improve how we treat individuals with disabilities.

Finally, and with deepest gratitude, I wish to acknowledge the efforts and sacrifices made by my family. To my parents, Jeff and Lynda Whicker, and my parents-in-law, Kenneth and Sheila Stettler – thank you for the support, both emotional and financial, that you contributed to this endeavor. I wish to thank my three boys, Peter, Collin, and Leo Whicker, for consistently shining brightly despite the hard times. Though you’re young, I hope that my time in school is something you can remember and know that I did this for you with all the love in the world.

Most importantly, to my best friend and wife, Lori Whicker: Student life is hard, and I cannot
imagine having endured it with anyone but you. Thank you for putting up with me during my times of stress and fatigue. After all of this, I hope you feel as rewarded as me as, together, you and I make a difference in the lives of children everywhere.

John J. Whicker
CONTENTS

<table>
<thead>
<tr>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
</tr>
<tr>
<td>PUBLIC ABSTRACT</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
</tr>
<tr>
<td>CHAPTER</td>
</tr>
<tr>
<td>I. INTRODUCTION</td>
</tr>
<tr>
<td>II. REVIEW OF THE LITERATURE</td>
</tr>
<tr>
<td>An Overview of Parent Challenges Caring for Children Who Are DHH Plus</td>
</tr>
<tr>
<td>Principles of and Evidence Base for Patient-centered Care</td>
</tr>
<tr>
<td>Application of Patient-centered Care in Audiologic Service Delivery</td>
</tr>
<tr>
<td>Overall Summary and Implications</td>
</tr>
<tr>
<td>Purpose Statement and Research Questions</td>
</tr>
<tr>
<td>III. METHODS</td>
</tr>
<tr>
<td>Grounded Theory</td>
</tr>
<tr>
<td>Participants</td>
</tr>
<tr>
<td>Instrument</td>
</tr>
<tr>
<td>Procedures</td>
</tr>
<tr>
<td>Interpretation</td>
</tr>
<tr>
<td>Reliability</td>
</tr>
<tr>
<td>IV. RESULTS</td>
</tr>
<tr>
<td>Theory – Hearing Care and Management Priority</td>
</tr>
<tr>
<td>Sub-theory 1 – Hearing Priority</td>
</tr>
<tr>
<td>Sub-theory 2 – Hearing Aid Priority</td>
</tr>
<tr>
<td>Sub-theory 3 – Communicative Development Priority</td>
</tr>
<tr>
<td>Sub-theory 4 – Speech-language Therapy Priority</td>
</tr>
<tr>
<td>Sub-theory 5 – Manual Language Priority</td>
</tr>
<tr>
<td>Summary</td>
</tr>
<tr>
<td>V. DISCUSSION</td>
</tr>
<tr>
<td>Study Limitations</td>
</tr>
<tr>
<td>Key Findings</td>
</tr>
<tr>
<td>Clinical Implications</td>
</tr>
</tbody>
</table>
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Whicker, Muñoz, and Nelson (2019) table of studies</td>
<td>6</td>
</tr>
<tr>
<td>2. Overview of the proposed grounded theory process</td>
<td>26</td>
</tr>
<tr>
<td>3. Demographic description</td>
<td>35</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure
1. Coding Scheme ................................................................. 33
2. Overlapping Factors............................................................. 37
3. Hearing Priority Decision Tree.............................................. 45
4. Hearing Aid Priority Decision Tree...................................... 56
5. Communicative Development Priority Decision Tree............... 65
6. Speech-language Therapy Priority Decision Tree.................... 74
7. Manual Language Priority Decision Tree......................... 82
8. Hearing Care and Management Priority Model .................. 84
CHAPTER I
INTRODUCTION

An estimated 25-40% of children who are deaf or hard-of-hearing (DHH) have one or more comorbid disabilities or health conditions (DHH Plus; Cupples, Ching, Crowe, et al. 2014; Wakil, Fitzpatrick, Olds, et al., 2014). These comorbid disabilities and health conditions could impact how parents of children who are DHH Plus understand and accept a diagnosis of hearing loss and, in turn, influence the extent to which parents prioritize hearing care through appropriate device use (e.g., hearing aid wear time), or committed parent skill development (e.g., learning a manual language, troubleshooting amplification equipment). Consistent hearing care can be key to how well children who are DHH Plus develop communication, academic, or other daily living skills. When a child is DHH Plus, however, consistency in hearing care and management may be impaired due to the different challenges faced by parents of children who are DHH Plus.

Few studies have explored the challenges faced by parents of children who are DHH Plus. Such inquiries have reported a variety of challenges that are similar to the challenges reported by parents of children with special health care needs (Whicker, Muñoz, & Nelson, 2019); yet, how those challenges impact hearing care and management priority remains unclear. Furthermore, a wide variety of other disabilities were represented in studies exploring parent challenges; thus, understanding parent challenges related to caring for a group of children who share the same disability type and are DHH is limited and called for.

Arguably, Down Syndrome (DS) may be one of the more common cases encountered by pediatric audiologists when serving children who are DHH Plus. Nearly one in 700 children in the United Stated are born with DS (Parker, Mai, Canfield, et al., 2010; Center for Disease Control and Prevention [CDC], 2019), and nearly 75% of children with DS have hearing loss
Currently, no studies have explored how the complexities of DS, specifically, change how parents prioritize hearing care and management. Aspects of psychosocial well-being, however, have been found to correlate with how parents of children who have DS adapt to the DS diagnosis, which has implications for how parents set achievable goals and follow through on interventions (Truitt, Biesecker, Capone, Bailey, & Erby, 2012). Understanding the impact of challenges associated with caring for a child who has DS on hearing care priority can illuminate and emphasize the need for a person-centered approach to care to meet the diverse needs of families.

Person-centered care (PCC) is regarded as a gold-standard for service delivery in health and allied health care. In a well-regarded framework for PCC, Mead and Bower (2000) emphasize the importance of recognizing both the practitioner and patient as experts with differing needs and should therefore focus on sharing power when making decisions and setting an agenda for care management. Given that audiologists can play a role in supporting how parents effectively manage the hearing care of children who are DHH Plus, understanding this emphasis for PCC and its implications for parent success in hearing care is critical. How audiologists set up their relationship with parents of children who are DHH Plus to follow family needs through shared agenda- and action-planning can have implications for the extent to which parents take effective action in hearing care to optimize their child’s development.

Even with limited research regarding the challenges faced by parents of children who are DHH Plus or parents of children who have DS, prior research has clearly identified challenges faced by parents of children who are DHH. For example, parents of children who are DHH experience challenges related to the acceptance of and emotional adjustment to the diagnosis of their child’s hearing loss (Luterman, 1999; Hintermair, 2006; Quittner, Barker, Cruz, et al.,
For parents of children who are DHH who have opted for amplification to facilitate spoken language development, research has suggested that challenges arise related to learning new skills (e.g., navigating new technology, gaining confidence) and fear regarding social perceptions of their child (Walker, Spratford, Moeller, et al., 2013; Muñoz, Olson, Twohig et al., 2015). These challenges can impact effective use of technology to access auditory input (Muñoz, Kibbe, Preston, et al., 2017). Despite the commonality of these challenges, research suggests that audiologists feel underprepared to address the parent needs that arise from these challenges (Muñoz, Price, Nelson & Twohig, 2017). This point is important, because when a child is DHH Plus, these challenges may be compounded and parent priority for hearing care may change based on the child’s other, possibly more demanding needs – thus, reiterating that audiologists should be prepared to address parent challenges and have collaborative conversations with parents that facilitate optimal shared agenda- and action-planning for care.

Given the need to further understand parent challenges when caring for children who are DS and how those challenges impact consistent hearing health care, the purpose of this study is to develop a grounded theory to explain the decision-making process parents experience when determining how they prioritize hearing care. The outcomes of this study will provide new information and may be used to improve care provided to this population through patient-centered practices to meet parent needs.
CHAPTER II
REVIEW OF THE LITERATURE

When a child is diagnosed with hearing loss, parents may experience several emotional reactions, many of which are reflective of the grief process (Yoshinaga-Itano & DeUzcategui, 2001; Kurtzer-White & Luterman, 2003; Luterman, 2004). When a child is DHH in combination with DS, parents’ emotional reactions and grief may be compounded and, in combination with the child’s other needs, may impact how parents prioritize hearing care differently. How parents prioritize hearing care has implications for language and other developmental outcomes (Tomblin, Harrison, Ambrose, et al., 2015), and emphasizes the need for audiologists to offer a person-centered care (PCC) delivery model to understand and meet parents’ needs to help facilitate appropriate at-home care. Currently, research regarding parent challenges caring for children who are DHH with DS specifically does not exist. Research regarding the challenges associated with caring for children who are DHH Plus, however, may highlight what parents of children who are DHH with DS experience. The purpose of this chapter, therefore, is to: (a) describe the variety of challenges parents of children who are DHH Plus face in the course of caring for their children, and (b) describe the principles and evidence-base for person-centered care and its implications for audiologic service delivery generally, and especially for this subgroup of parents. The proposed study will theorize the factors that influence the decision-making process parents experience when prioritizing hearing care for children who are DHH with DS. This information will inform audiologists working with families and may improve their application of person-centered care throughout service delivery.

An Overview of Parent Challenges Caring for Children Who Are DHH Plus
Estimates of the prevalence of childhood hearing loss with other disabilities have been variable; however, scholars have reported that 25-40% of children who are DHH have other disabilities (e.g., Cupples, Ching, Crowe, et al. 2014; Wakil, Fitzpatrick, Olds, et al., 2014). The representation of types of disabilities is also variable. In a systematic review of literature (n=12 studies), the National Deaf Children’s Society (NDCS, 2012) reported, as other disabilities, speech-language disorders (61-88%), vision impairments (4-57%), neurodevelopmental disorders (2-14%), cerebral palsy (2-13%), Autism Spectrum Disorder (ASD; 2-4%), and pervasive developmental disorders (2%). Additionally, the Gallaudet Research Institute (GRI, 2013) reported, as other disabilities, developmental delays or disorders (17%, n=2,117/12,418), intellectual/cognitive disorders or impairments (15%, n=1,900/12,418), emotional or behavioral disorders (13%, n=1,555/12,418), visual impairments or blindness (11%, n=1,335/12,418), learning disabilities (7%, n=1,282/12,418), and orthopedic impairments (4%, n=857/12,418).

Although research exploring parent challenges caring for children who are DHH Plus is scant, a variety of challenges have been found to exist among this population (Whicker, Muñoz, & Nelson, 2019). Only nine studies have reported on parent challenges when caring for children who are DHH Plus, thus highlighting the scant nature of the research that has explored this topic (see Table 1). Additionally, eight of the nine studies were purely qualitative, using a variety of unstructured, semi-structured, or structured interviews. Three broad categories may be considered that are reflective of the range of challenges faced by parents of children who are DHH Plus related to (a) personal and family life, (b) medical and educational services, and (c) child communication and behavior management.
### Table 1

*Table of studies adapted from Whicker, Muñoz, and Nelson (2019)*

<table>
<thead>
<tr>
<th>Authors (year)</th>
<th>Sample</th>
<th>Representation of Disabilities</th>
<th>Findings by Broad Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giangreco (1991)</td>
<td>28 children</td>
<td>Vision impairment</td>
<td>a, b</td>
</tr>
<tr>
<td>Myck-Wayne et al. (2011)</td>
<td>4 children</td>
<td>ASD&lt;sup&gt;a&lt;/sup&gt;</td>
<td>a, b</td>
</tr>
<tr>
<td>McCracken et al. (2012)</td>
<td>12 children</td>
<td>Learning disability; major medical conditions; Cerebral Palsy; visual impairment/blindness; ASD; syndromic/genetic disorders</td>
<td>a, b</td>
</tr>
<tr>
<td>Mulla et al. (2013)</td>
<td>10 children</td>
<td>Syndromic/genetic disorders; ASD; cerebral palsy; visual impairment; intellectual/cognitive disorders; major medical conditions</td>
<td>b, c</td>
</tr>
<tr>
<td>Wiley et al. (2013)</td>
<td>4 parents; 3 children</td>
<td>ASD</td>
<td>a, c</td>
</tr>
<tr>
<td>Isarin et al. (2015)</td>
<td>23 families</td>
<td>Major medical conditions; syndromic/genetic disorders; cerebral palsy</td>
<td>a, b, c</td>
</tr>
<tr>
<td>Zaidman-Zait et al. (2015)</td>
<td>45 children; 23 parents</td>
<td>Learning disability; language disorder; intellectual/cognitive disorders; vision impairment cerebral palsy; ASD; syndromic/genetic disorders</td>
<td>a, b, c</td>
</tr>
<tr>
<td>Turan (2016)</td>
<td>5 mothers</td>
<td>ASD; major medical conditions; syndromic/genetic disorders</td>
<td>a, b</td>
</tr>
<tr>
<td>Zaidman-Zait et al. (2016)</td>
<td>9 mothers; 9 children</td>
<td>ASD</td>
<td>a, b, c</td>
</tr>
</tbody>
</table>

<sup>a</sup> ASD = Autism Spectrum Disorder
Personal and family life. Klein (1977) was the first to comment on parenting behaviors of parents caring for deaf-blind children, describing a continuum of parent interactions ranging from a “helicopter” approach (e.g., letting the needs and wants of the deaf-blind child dictate most or all family activities) to an alienation approach (e.g., excluding the deaf-blind child from family activities). Although a discourse rather than empirical study, Klein (1977) was one of the first to explicitly call for different provider communication approaches when working with parents of children who are DHH Plus, given that parents may not be receptive of or adhere to standard treatment recommendations due to their emotional and physical state.

Parent Burnout. Due to the many needs of children who are DHH Plus, parents may experience an extended level of burnout that goes beyond what parents of children who are DHH experience. Burnout is emotional, cognitive, and physical exhaustion (Melamed, Shirom, Toker, et al., 2006). Many parents have linked burnout to the diagnostic procedures used to identify hearing loss, cochlear implant candidacy, or other disorders for their children. For example, parents in McCracken and Turner’s (2012) study reported a burnout fueled by the extensive process and challenges getting their children referred for, evaluated for, and often rejected from cochlear implantation (McCracken & Turner, 2012). In Wiley, Gustafson and Rosniak’s (2014) study, some parents of children with hearing loss and Autism Spectrum Disorder (ASD) reported burnout due to feelings of being left out of the diagnostic process for ASD, or feelings of doubt regarding the validity of diagnostic assessments when hearing loss was, from the parents’ perception, not accounted for. In Turan’s (2016) study, mothers described the first year of their child’s life as frequent traveling between home and hospital to obtain conclusive testing, which was complicated due to the child’s multiple needs (e.g., child would not sleep for auditory brainstem response testing).
Finally, burnout has also been linked by parents of children who are DHH Plus to the multiple roles parents feel they must take on to care for their children. For example, in Zaidman-Zait and Curle’s (2016) study, roles to which parents referred included behavior therapist, speech-language therapist, case manager, teacher, and service coordinator. In this study, one mother expressed, “I have to be everything and I’m only one person” (page 5). Parents regarded the burden of these multiple roles as causing feelings of depression, isolation, and general overwhelm.

**Planning and Coordinating.** Many parents have reported challenges regarding planning and coordinating for their family on behalf of and around the needs of their children with DHH Plus. For example, parents in Giangreco et al.’s (1991) study reported avoiding thinking about future planning altogether to cope with the stress of managing their child’s day-to-day needs. For some parents in this study, parents were expecting to care for their children for the duration of their children’s life and planning for the future compounded feelings of depression.

Zaidman-Zait and Curle (2016) found many families of children with hearing loss and ASD experienced structural changes in order to accommodate care. For example, several mothers reported giving up their careers to be at home with their children. Additionally, some families had to relocate to less rural areas in order to more easily access specialized services. When families could not relocate, some would split up, such that fathers lived at home with their typically developing children, while the mother and children with hearing loss and ASD lived closer to specialized services during the week.

Finally, finances presented as a burden to many families. McCracken and Turner (2012) found that many parents reported struggling paying for amplification technology due to the high expenditures already made towards the children’s other health care needs. Parents in Zaidman-
Zait et al.’s (2015) study also reported challenges managing government-sponsored funds and the high amounts of paperwork that came with such help.

**Decision-making.** Many parents reported challenges making decisions on behalf of their children with DHH Plus. For example, parents of children with hearing loss and ASD reported difficulty selecting services for their child. Many reported not knowing where to begin and fostered a trial-and-error approach to selecting services that accommodated both their children’s hearing- and ASD-related needs (Myck-Wayne, Robinson, & Henson, 2011; Zaidman-Zait & Curle, 2016).

Parents also reported difficulty deciding on a communication modality for their children. For example, parents in both McCracken and Turner’s (2012) and Zaidman-Zait and Curle’s (2016) studies did not know how much their children’s complex needs would impede their ability to develop communication skills. Some parents felt that spoken language was not an option. Many parents chose a combination of manual and oral language.

For parents in Isarin et al.’s (2015) study, this question of communication modality played a role in deciding whether cochlear implantation was appropriate for their children. For some parents, the complexity of the children’s multiple disabilities raised questions regarding the safety of the cochlear implant surgical procedure and whether the procedure would be successful. Additionally, some parents in this study felt unsure about the appropriateness of cochlear implantation, as they felt that Deafness and sign language was part of their children’s identity.

**Extended Family.** Some parents in Wiley, Gustafson, and Rozniak’s (2014) study reported challenges related to the extended family acceptance and reaction to their children’s dual diagnosis of hearing loss and ASD. According to parents, many extended family members were doubtful and sometimes unaccepting of the additional needs required by the dual diagnosis.
Some extended family would go so far as to suggest to parents different ways to manage the children’s difficult behaviors, without considering the compounded challenges that both ASD and hearing loss contribute to behavior. Parents reported that sharing detailed information with extended family members (e.g., evaluation reports) helped to mitigate some of these reactions and, over time, extended family members became more interested in learning how to help and effectively communicate with the dually diagnosed children.

**Medical and educational services.** Across both medical and educational settings, parents have reported several challenges regarding service delivery. Many parents have provided suggestions for improvement to mitigate such challenges.

**Collaboration.** Parents have reported a lack of collaboration among professionals serving children who are DHH Plus. Parents in Giangreco et al.’s (1991) study expressed frustration when professionals missed opportunities to communicate with one another and parents felt the need to answer the same questions multiple times to different service providers. Similarly, parents from Isarin et al.’s (2015) study reported dissatisfaction with services when there was a lack of coordination. In this study, one parent expressed, “There were so many doctors and all of them did their own thing” (page 226). Indeed, parents from Zaidman-Zait et al.’s (2015) study expressed overwhelm at the need to manage multiple appointments and a number of different recommendations made from the variety of professionals serving their children. One parent revealed that their child received services from 20 different professionals. Parents from each of these studies advocated for case managers to liaise between professionals to improve clarity of information and direct parent inquiries to the appropriate professional.

For parents of children with hearing loss and ASD, challenges for collaboration have been reported regarding the services provided by different education specialists for hearing loss
and ASD (Myck-Wayne, Robinson, & Henson, 2011; Zaidman-Zait & Curle, 2016). Parents in Zaidman-Zait and Curle’s (2016) study reported attempts to help the educators integrate services that met their children’s hearing- and ASD-related needs; however, educators were reported to be nonresponsive to these attempts, perpetuating parents’ frustration.

**Professional Attitudes.** Attitudes displayed by professionals towards children who are DHH Plus have been reported to compound parent challenges across medical and educational settings. For example, parents in Giangreco et al.’s (1991) study perceived itinerant vision and hearing professionals as being hesitant about providing services to their children who are deaf-blind; parents reported that the more complex children’s needs were, the less the itinerant professionals seemed to be involved in their children’s cases. This lack of involvement influenced parents to perceive professionals as inexpert or only narrowly competent in providing services to children who are DHH or blind, and not both.

Parents from Turan’s (2016) study linked professional attitudes to a delay in or lack of adequate educational services. For example, one mother had to appeal to her government’s ministry to get her child a teacher of the deaf to help in her child’s regular education classroom. Another mother reported that her child’s general education teacher outwardly opposed having her child in class and made arrangements to decrease how often the child was in the classroom.

For parents of children who are DHH Plus and seeking cochlear implantation, professional attitudes often impeded the cochlear implantation process (i.e., candidacy evaluation, surgical procedure). Parents from both McCracken and Turner’s (2012) and Turan’s (2016) studies reported that many professionals demonstrated skeptical attitudes regarding the usefulness of cochlear implants given the children’s complex issues. These skeptical attitudes
often slowed significantly (sometimes for years) the process of children receiving cochlear implants, despite the parents’ urging.

*Parent Involvement in Educational Planning and Placement.* Parents of children who are DHH Plus often reported feelings of being left out of educational planning. For parents in Giangreco et al.’s (1991) study, this led to parents feeling as though educational services were not attending to the children’s and families’ individual needs. Similarly, parents from Zaidman-Zait et al.’s (2015) study reported being uninformed regarding their children’s school performance and called for improved school-family correspondence to ensure effective communication. Additionally, parents from Zaidman-Zait et al.’s (2015) study felt that extracurricular activities were limited for their children who are DHH Plus, and any activities that could accommodate their children’s complex needs were expensive.

Parents from Mulla et al.’s (2013) study reported difficulty finding appropriate educational placements for their children who are DHH Plus. In this study, only one of the seven children included was placed in a deaf education classroom and the other six were placed in classrooms serving children with severe learning difficulties. According to parents, these classrooms for children with severe learning difficulties did not provide listening environments that are conducive for hearing loss which they felt limited how well the children’s educational needs were met. In Myck-Wayne, Robinson, and Henson’s (2011) study, only one child with hearing loss and ASD was placed in a classroom that had other children with hearing loss, and the parents had to file for due process in order to obtain this classroom placement.

*Child communication and behavior management.* A few studies have reported parent challenges regarding child communication and behavior management. Most of the studies that reported such findings involved parents of children with hearing loss and ASD, suggesting that
this population of children who are DHH Plus may require additional attention regarding communication and behavior.

**Communication.** For parents from Wiley, Gustafson, and Rozniak’s (2014) study, challenges related to their children’s communication arose from maintaining consistent communication strategies between school and home. For instance, parents reported that the schools emphasized the Picture Exchange Communications System (PECS); however, parents felt their children were better able to communicate in other ways (e.g., total communication), and therefore did not encourage use of PECS at home.

Parents from Zaidman-Zait and Curle’s (2016) study were challenged interpreting their children’s communication. Many children were yet unable to communicate using spoken language, and parents reported being left to interpreting their children’s needs based on facial expressions, crying, and tantrums. Some parents from this study reported significant frustration from these difficult parent-child communication exchanges.

**Behavior Management.** For many parents of children who are DHH Plus, getting their child to wear their amplification devices was much harder than anticipated. For parents from Mulla et al.’s (2013) study, this difficulty perpetuated parents’ feelings of failure. Parents from Isarin et al.’s (2015) and Zaidman-Zait et al.’s (2015) studies reported frustration and desperation managing children’s treatment of cochlear implant devices, which was often damaging (e.g., chewing, throwing). Additionally, many children were reportedly aggressive towards parents when they attempted to place processors.

For parents of children with hearing loss and ASD, challenges were reportedly related to general behavior management. For example, parents from Wiley, Gustafson, and Rozniak’s (2014) study reported a need to have detailed behavior plans, because tasks as simple as
changing hearing aid batteries had the potential to trigger outbursts. For these same parents, behavioral challenges in public were of particular concern, and these parents reported placing a higher priority for social and functional interventions than for academic success.

**Summary of parent challenges.** Parents of children who are DHH Plus experience a variety of challenges related to personal, familial, medical, educational, and behavioral aspects of care. Some of these challenges are nearly identical to the challenges faced by parents of children with special healthcare needs (CSHN). In a national survey of parents of CSHN, more than half reported financial burden due to healthcare costs (56.8%, n=184,043) and required a caregiver to terminate their employment to provide full-time at-home care (54.1%, n=175,294). One-third (33.1%, n=107,350) of those surveyed also reported challenges accessing appropriate educational or other non-medical services (Kuo, Cohen, Agrawal, Berry, & Casey, 2011).

How these reported challenges impact parent hearing care priority remains unclear; yet, consistent hearing care has implications for how these reported challenges might be perpetuated, especially regarding educational achievement, and child communication and behavior management. Further, a lack of interprofessional collaboration may have implications for what parents understand about their children’s needs, and parents may have a minimized perspective regarding the impacts of hearing loss on multiple domains of life, including development, academics, relationships, and even emotions.

**Implications for DS.** The findings and implications regarding parent challenges caring for children who are DHH Plus may also reflect the experiences of parents of children who are DHH with DS, specifically. DS is a chromosomal defect that manifests through a wide range of medical complications and cognitive impairment (Roizen & Patterson, 2003). Medical complications can include congenital heart defects, sleep apnea, vision complications, neurologic
complications, and even thyroid disease (Bull, 2011). Additionally, cognitive impairments can range from mild to severe in degree (Bull, 2011).

When children are diagnosed with DS, parents may feel a variety of strong emotions. For example, in a focus group of 9 fathers of children with DS, fathers expressed the shock and emotional turmoil that came with their children’s birth and the uncertainty of whether their children would live. Fathers also associated the disability with negativity (Takataya, Yamazaki, & Mizuno, 2016). These and other emotions may influence how parents adapt to their children’s conditions and act. For example, in a sample of 546 parents of children with DS, perceived uncertainty about their child’s condition and level of hope were significantly associated with the extent to which parents adapted ($r=0.326$, $p<.01$ and $r=-0.319$, $p<.01$ respectively; Truitt et al., 2012). Additionally, hope was significantly associated with how confident parents were in making plans to achieve goals related to their children’s social skills, behavior, learning, physical health, mental health, and independence (Truitt et al., 2012). In a sample of 553 parents of children with DS, parents who engaged in self-blame for their children’s diagnosis were more likely to experience depressive symptoms ($r=0.350$, $p<.001$) and experience barriers to achieving goals for their children ($r=0.282$, $p<.001$; Van der Veek, Kraaij, & Garnefski, 2009).

How providers seek to understand parents’ emotions and needs when caring for children who are DHH with DS can influence the quality of service delivery to ensure adequate priority for evidence-based at-home hearing health care. Evidence suggests that professionals interacting with parents of children who are DHH alone can play a vital role in helping parents master new care skills (Quittner, Barker, Cruz, et al., 2010) and reduce stress (Jean, Mazlan, Ahmad & Maamor, 2018), which may be compounded for parents of children who are DHH with DS. In the following section, core principles of and evidence base for person-centered care will be
described and their implications for audiologic service delivery will be expounded to understand how such a delivery model may effectively meet the needs of parents of children who are DHH with DS. Although in this context parents are not the patients, their role as primary caregivers for the patient (child who is DHH with DS) may posit parents as direct recipients of care. Family-centered care is a related term and adheres to the same foundational principles as person-centered care. Thus, for this proposal, the term person-centered care will be used throughout.

**Principles of and Evidence Base for Person-centered Care**

**Foundational principles of person-centered Care.** Discussion among scholars regarding person-centered care (PCC) began in the late 1960s, with definitions of PCC continuing to emerge through the 1980s. Early definitions were philosophical, and generally included the idea that physicians should treat each patient individually as a unique being (Balint, 1969), and attempt to view the patients’ medical issue through the patients’ eyes (McWhinney, 1989). In 1976, a seminal text by Byrne and Long, entitled *Doctors Talking to Patients*, introduced the concept of shared power between the physician and patient, including shared decision-making regarding treatment. This concept of shared power became a fundamental aspect of PCC and has been included in all subsequent definitions and models of PCC since its introduction (Mead & Bower, 2000).

In a seminal review of the empirical literature surrounding PCC, Mead and Bower (2000) developed a five-dimensional conceptual framework to describe PCC. Each dimension is labeled as reflecting a nomothetic system of understanding (i.e., systems of understanding that apply to all groups of people) or an idiographic system of understanding (i.e., systems of understanding that apply to individuals). Dimension 1 regards the extent to which physicians attempt to understand their patients from a biopsychosocial, or holistic perspective (nomothetic);
Dimension 2 is the extent to which the physician understands the individual patient (idiographic); Dimension 3 is the extent to which the physician includes the patient in decision-making and accountability (nomothetic); Dimension 4 is the therapeutic quality of the general physician-patient relationship (nomothetic); and Dimension 5 is the quality of the individual physician-patient dynamic (idiographic). Specifically, Dimension 5 recognizes both the physician and patient as unique individuals with different expertise and needs.

Combined, these five dimensions interact with a variety of physician and patient factors that can influence the extent to which services are person-centered (Mead & Bower, 2000). Factors for both parties can include attitudes, knowledge, and values. They may also include individual factors (e.g., gender, age, ethnicity), cultural factors, professional factors (e.g., incentives, accreditation), and third-party factors (e.g., interruptions, time, workload).

**Evidence base for person-centered care.** Not until the mid-to-late 1980s did empirical data begin to emerge regarding the effectiveness and importance of PCC in practice. In the following subsections, key seminal articles regarding PCC in general medical practice will be briefly reviewed. These articles were some of the first to explore, establish, or synthesize data to support the need for PCC.

**Patient Satisfaction.** Roter, Hall, and Katz (1987) recruited 43 male primary care physicians, each of whom provided services to two simulated patients presenting with symptoms of chronic obstructive pulmonary disease (COPD). The purpose of this study was to determine whether correlations existed between levels of patient satisfaction and patient information recall. Additionally, this study sought to determine whether correlations existed between levels of patient satisfaction and patients’ overall impressions of physicians.
The simulated patients with COPD were trained by a multidisciplinary team to accurately talk about their histories and symptoms. After each encounter, the simulated patients were asked to complete multiple questionnaires to understand their perceptions of different levels of satisfaction with care. These levels included: (1) global satisfaction, (2) task satisfaction, and (3) humaneness satisfaction. The questionnaires were also used to understand the stimulated patients’ general impression of the physician (i.e., angry, bored, or calm). Finally, the simulated patients were also given an opportunity to recall as much as they could regarding what the physician said.

Each encounter was audio-visually recorded. Findings revealed that global and task satisfaction were significantly correlated to patient recall of information (0.38, p<.01 and 0.54, p<.001 respectively). Furthermore, global, task, and humaneness satisfaction were significantly correlated to overall patient impression of the physician, such that the less angry, less bored, and calmer a physician was, the more satisfied the patient was across the three satisfaction domains.

Next, Hall and Dornan (1988) conducted a meta-analysis of studies that quantitatively measured patient satisfaction with general medical care, and correlated patient satisfaction with at least one variable. Two-hundred and twenty-one studies were included in analysis, and each study was coded relating to the aspect of care that was inquired regarding patient satisfaction. Eleven aspects of care were identified, and each aspect was ranked from highest patient satisfaction to lowest patient satisfaction. Results indicated that patients tended to be most satisfied with overall quality of care, followed by physician humaneness and competency. Patients were least satisfied with how physicians address psychosocial aspects of medical issues. A limitation with these data is that only seven of the 221 studies inquired regarding patient
satisfaction with how physician addressed emotional concerns, which might explain these results.

Williams and Calnan (1991) surveyed 454 patients to determine the extent of patient satisfaction with medical care from their general practitioner (GP). Findings revealed that 95% of participants were overall satisfied with care; however, 38% felt unable to discuss personal problems related to their medical issue, 26% were unsatisfied with the level of information they received regarding their medical issue, and 25% were dissatisfied with the amount of time spent with their GP. Further, this study analyzed the association of physician communication, quality of the physician-patient relationship, and the quality of professionalism exhibited by the GP to overall patient satisfaction. Findings indicated that a significant positive relationship existed between all three variables and patient satisfaction (0.64, p<.001; 0.61, p<.001; 0.58, p<.001 respectively).

**Patient Engagement.** Kaplan, Greenfield, and Ware (1989) conducted a randomized control trial measuring the effectiveness of a physician training to improve sharing of individualized information and using behavioral strategies to promote patient engagement in care. Patients were sufferers of ulcer disease, hypertension, diabetes, and breast cancer (N=252). Prior to physician training, baseline data were retrieved regarding patient health (e.g., blood glucose levels, blood pressure, complications), and control of appointment (e.g., patient assertiveness to seek information and take part in decision-making). Post-intervention, the same measures were obtained, and results revealed a significant increase across all dependent variables. Furthermore, data were obtained regarding the relationship between “good health” (e.g., less days missed from work, less functional limitations) and patient control. Findings
indicated that patients who were more in control of the appointment than patients who were not had significantly improved health.

Finally, Zolnierek and DiMatteo (2009) conducted a meta-analysis of studies conducted to analyze the relationship of physician communication to patient engagement: specifically, adherence to treatment recommendations. One-hundred and twenty-seven studies were included in the analysis. Results indicated that how well physicians communicated had a significant positive correlation to how much patients adhered to treatments. In contrast, poor communication resulted in a 19% higher risk of nonadherence. Furthermore, this meta-analysis found that physicians who were trained to use good communication were 1.62 times more likely to have adhering patients than physicians who received no such training.

**Summary of evidence for patient-centered care.** Evidence from the preceding articles support the need for and effectiveness of PCC. Specifically, the data indicate that how physicians interact with patients can influence patient satisfaction with care, patient engagement in care including adhering to treatment recommendations, information recall, and the quality of the physician-patient relationship. In the following section, I will discuss the application of PCC in audiologic service delivery.

**Application of Person-centered Care in Audiologic Service Delivery**

Audiology is an allied-health profession. As such, audiologists are daily interacting with individuals affected by auditory or vestibular disorders. Given this interaction, PCC has a direct application in audiologic service delivery. Evidence has shown that patients with hearing loss are impacted physically, emotionally, socially, and even vocationally by their hearing loss (e.g., Luterman, 1997; American Speech-Language-Hearing Association [ASHA], 2004; Preminger &
Meeks, 2010; Pronk, Deeg, Smits, et al., 2014). These impacts may pose a variety of barriers that impact how patients manage their hearing care.

For parents of children who are DHH, several factors may influence how parents learn and manage their children’s hearing health, including age (e.g., infants present greater challenges for consistent care compared to older children; Walker, Spratford, Moeller, et al., 2013), depression (Muñoz, Olson, Twohig, et al., 2015), and the quality or quantity of information parents are given (Muñoz, Rusk, Nelson, et al., 2016). Walker et al. (2013) reported a majority of parents (84%, n=112/133) overestimated how much their children used their hearing aids each day by approximately two hours. Furthermore, Muñoz et al. (2015) found that only 35% of parents (n=12/55) reported their children wear their hearing aids during all waking hours, and infants/toddlers (age 7-35 months) only wore their hearing aids on average 4.6 hours per day, which is significantly less than the recommended 10 or more hours per day for optimal language development (Tomblin et al., 2015).

Given that disabling hearing loss is most often a chronic condition requiring rehabilitation, how audiologist use a person-centered approach to care has implications for how patients are able to (1) cope with and understand their diagnosis, (2) learn new skills to effectively manage their hearing care, and (3) develop self-advocacy skills to effectively communicate and/or work in a hearing world. For the scope of this study, it may be appropriate to speculate a fourth implication: person-centered care may help parents of children who are DHH with DS place adequate priority on consistent hearing health care.

**Implementation of PCC: Current Practice in Audiology**

Research regarding the quality of audiologist-patient communications and the extent of person-centeredness is limited. However, to the extent that such research does exist, evidence
reveals a gap between the ideal person-centered communication and how audiologists communicate with patients (across the life-span) during audiologic encounters. For example, Grenness, Hickson, Laplante-Lévesque, et al., (2015a, 2015b) found that audiologists tended to dominate the communication dynamic by asking closed-ended questions and responding to questions with biomedical language, and overall speaking as much or more than the patient. Furthermore, both Ekberg, Grenness, and Hickson (2014) and Coleman, Muñoz, Ong, et al. (2018) found that audiologists tended to ignore patients’ emotional concerns or respond to emotional concerns with technical information.

Although these studies demonstrate that the audiologist-patient communication dynamic does not reflect optimal PCC, audiologists have indicated they value PCC (Laplante-Lévesque, Hickson, & Grenness, 2014) and desire to increase their person-centered competencies through more training (Meibos, Muñoz, Schultz, et al., 2017). These preferences for PCC are an indication that audiologists recognize the broad functional impacts of hearing loss and the need to view patients holistically throughout assessment and treatment. In fact, the ASHA (2018) scope of practice for audiology includes consideration of the World Health Organization’s (WHO) International Classification of Functioning (ICF; WHO, 2001) to guide how goals are set with patients to (1) increase functioning and (2) facilitate a more collaborative practice with other professionals to engage patients and families.

The ICF essentially acknowledges two components of disability: (1) the impact of impairment on basic functioning and (2) the influence of contextual factors. With such descriptions and classifications, audiologists may more easily foster a communication with patients that facilitates a person-centered delivery model to meet the variety of unique needs individuals have. An ICF core set was developed for hearing loss which includes a total of 117
categories that represent the body function (e.g., attention, memory, emotional), body structure (e.g., external ear, middle ear, inner ear), participation (e.g., communication, family relationships, community life), and environmental (e.g., technology for communication, societal attitudes) impacts of hearing loss, and can be used to guide professionals and others in understanding the impact of hearing loss (Danermark, Granberg, Kramer, et al., 2013).

By using intentional, person-centered skills to check patient understanding, allowing for patients to ask questions, and checking in on how patients are feeling, audiologists can know what patient skills need to be strengthened to promote higher self-efficacy, and what barriers patients might face that impede their ability to cope with and manage the nuances of their hearing loss. Thus, through PCC, patients may be more likely to adhere to the rehabilitation program (e.g., use their amplification devices), and improve the aspects of their lives that have been impacted by hearing loss.

Given the variety of needs and challenges experienced by parents of children who are DHH Plus, the implications of PCC are emphasized, as parents’ needs and challenges may require a different pace for audiologic intervention than typical. Further, should parents have low priority for evidence-based hearing care at home, it is likely that this low prioritization may be perpetuated if parents are not allowed to contribute to the communication exchanges by describing their feelings and needs, and setting shared goals to enhance appropriate hearing care.

**Overall Summary and Implications**

The purpose of this chapter was to review pertinent literature to describe (a) parent challenges when caring for children who are DHH Plus and (b) the principles and evidence base for person-centered care, and its implications for audiologic service delivery, especially for this subgroup of parents. This chapter has emphasized the minimal amount of existing data regarding
parent challenges when caring for children who are DHH Plus. While this small amount of information does highlight the possibility of compounded challenges, the other disabilities represented were widely variable, and little is yet known regarding the influence of challenges on consistent hearing care at home for groups of children who share the same disability type and are DHH. To enhance the literature, this study aims to explore how hearing care priority is impacted when children are DHH with Down syndrome. The results of this study will add new information to the literature to both (a) describe parent challenges and (b) describe how those challenges influence parent prioritization of evidence-based hearing care among parents of children with Down syndrome. This new information may provide insight for audiologists regarding areas of importance when communicating with and making recommendations to this population of parents. By understanding the challenges surrounding adequate hearing care when caring for children who are DHH with DS, audiologists may have increased sensitivity and empathy, and foster a more patient-centered communication.

**Purpose Statement and Research Questions**

The purpose of this study was to develop a grounded theory to describe the factors that influence the decision-making process parents experience when determining how they prioritize hearing care and management. This purpose will be achieved by answering the following research questions:

RQ1: What factors, if any, influence how parents of children who are DHH with DS decide to prioritize hearing health care?

RQ2: What decision-making process, if any, do parents of children who are DHH with DS experience when prioritizing hearing health care?
CHAPTER III
METHODS

The purpose of this study is to develop a grounded theory explaining the decision-making process parents experience when determining how they prioritize hearing care for children who are DHH with DS. Ethical approval from the Utah State University Institutional Review Board was obtained prior to conducting this study.

Grounded Theory

This study will use a qualitative design with grounded theory as the approach for inquiry. Grounded theory is moving beyond the narrative description of a phenomenon by explaining (i.e., theorizing) the process for, or actions related to, a phenomenon which can be linked (i.e., grounded) to data (Corbin & Strauss, 1990; Creswell & Poth, 2018). Two primary perspectives for grounded theory exist (Creswell & Poth, 2018): one perspective adheres to a more systematic structure and process for collecting and interpreting data (Corbin & Strauss, 2008), while the other (constructivist grounded theory) adheres to a more flexible structure to emphasize the values, beliefs, or ideologies of the participants rather than on the strict methods of the research (Charmaz, 2014). In the systematic perspective, concept is the basic unit of analysis (Corbin & Strauss, 1990), whereas in the constructivist perspective, social situation is the basic unit of analysis (Clarke, 2005). Although both perspectives are well-respected, each with strengths and credibility, this researcher will adhere to the systematic approach to grounded theory as described by Corbin and Strauss (1990, 2008), which requires a constant and systematic comparison of observed events, actions, or interactions to reduce researcher bias or underdeveloped theorizing.
A grounded theory approach is appropriate for this study for the following reasons: (a) while it may be speculated that parents prioritize hearing care based on the challenges associated with caring for children who are DHH with DS, no data exists to support this, and (b) a grounded theory to explain the decision-making process parents experience when determining how they prioritize hearing care may lay a foundation for influencing factors that may be quantitatively explored in future studies (e.g., predicting consistency of hearing health based on severity or other aspects of DS using statistical methods). An overview of the process for grounded theory is provided in Table 2, which is adapted from descriptions provided by both Corbin and Strauss (1990, 2008) and Creswell and Poth (2018).

Table 2

Overview of the grounded theory process

<table>
<thead>
<tr>
<th>Steps</th>
<th>Actions</th>
</tr>
</thead>
</table>
| Identify the phenomenon of interest | • Review literature  
• Determine whether an explanation (theory) for the phenomenon (hearing care priority when children who are DHH with DS) already exists |
| Sampling                       | • Identify the concepts, properties, or dimensions that describe the phenomenon  
• Identify the theoretical sample that represents these concepts, properties, or dimensions |
| Constructing instrument        | • Develop questions which focus on understanding how parents of children who are DHH with DS experience the process of prioritizing hearing care and identify the steps in that process |
| Gathering and interpreting data | • Conduct interviews  
• Integrate interpretation in phase with data collection  
  • Memoing |
| Code data                      | • Open coding  
• Axial coding  
• Selective coding |
| Conceptualize                  | • Diagram data to reflect core category, categories, and subcategories  
• Summarize the theory |
Participants

One of the core principles of grounded theory is that sampling and recruitment do not occur based on specific groups of individuals; rather sampling is based on concepts, properties, and dimensions of the phenomenon of interest (Corbin & Strauss, 1990). For this study, the phenomenon of interest is parent prioritization of hearing care when children are DHH with DS. Concepts, properties, and dimensions of this phenomenon may include an integration of, (a) hearing health care, (b) hearing loss with Down syndrome, and (c) incidences/events associated with caring for a child who is DHH with DS. From these, a theoretic sample is selected which best represents the phenomenon. For this study, the theoretic sample is parents of children who are DHH with DS.

Inclusion criteria. In this study, parents of children who are DHH with DS will be recruited for participation. Parents may include any primary caregiver of a child who is DHH with DS (e.g., foster parents, grandparents). Additional criteria are: participants must be proficient in English language (all interviews will be conducted in English), and participants must reside in the United States.

Sample size. Because the sample is theoretical, no definitive number of individuals may be determined; rather, data collection ceases upon data saturation (i.e., no more new, relevant information is being identified through the data collection process). For example, Landon and Schultz (2018) reached saturation after querying as few as eight individuals. Typical sample sizes, however, include 20 to 30 sources of data (Cresswell & Poth, 2018). Data saturation was indicated once an interview did not reveal any new information when compared to the previous interviews. Specifically, saturation was indicated when the experiences described during an interview were coded into already-existing categories and sub-categories, with no newly-
emerging category or sub-category. To enhance the transferability of this study’s results, three subsequent interviews were completed after saturation was indicated to confirm whether any new information could be coded into new categories or sub-categories, which would contraindicate saturation. For this study, saturation was indicated after interview 15 and confirmed after interview 18.

Instrument

A demographic form was be completed by each participant to describe representation of individuals interviewed (see Appendix A). This study used in-depth interviews to gather data. In-depth interviews allow the researcher to adjust questioning based on individual responses, which is a critical piece of ground theory (Corbin & Strauss, 1990). For example, if one participant speaks of a particular event or expresses a particular challenge, subsequent interviews with other participants might include questioning to determine if that event or challenge is consistent across cases, and if not, why. Each interview, however, used “stem” questions to elicit initial responses. They are:

1. Tell me about what it’s like caring for a child who has hearing loss and Down Syndrome.
2. One a scale of 1-10 (10 being very important, 1 being little or not important) how important are hearing aids to you?
3. How much does your child use his/her hearing aids?
4. One a scale of 1-10 (10 being very important, 1 being little or not important) how important is learning a manual language to you?
5. How much time do you spend learning a manual language?
6. One a scale of 1-10 (10 being very important, 1 being little or not important) how important is your child’s communication to you?
7. How much time do you spend using strategies with your child to facilitate communication?

8. One a scale of 1-10 (10 being very important, 1 being little or not important) how important is your child’s speech intervention?

9. How much time do you spend collaborating with your child’s speech interventionist?

   How much time do you spend transferring skills learned in speech therapy to the home?

10. Tell me about the family support you receive. How has family support influenced your decision for hearing care priority?

11. Tell me about the professional support you receive. How has professional support influenced your decision for hearing care priority?

**Procedures**

To cast the widest net possible for diversity, an invitation explaining the scope and intent of this study was posted to Facebook support pages dedicated to parents of children with Down syndrome (e.g., Parents of Children with Down Syndrome, Parents of Children Born with Down Syndrome; see Appendix B). The invitation instructed interested, eligible participants to contact the researcher by private email to express their interest. Eligibility was confirmed through the same communication venue. Once eligibility was confirmed, a link to an online Qualtrics survey was emailed to the participants. This survey included an informed consent (see Appendix A), and parents were asked to indicate whether they agree or disagree with the letter and their intention to participate. The survey included questions to gather demographic data. Once the survey was completed, the researcher scheduled a telephone interview with the participant. Interviews occurred at a maximum of two per week from March through September 2019 to allow for
sufficient flexibility in time for the concurrent analysis and coding that occurred with grounded theory.

**Interpretation**

All interviews were audio-recorded with a digital recorder while conversing with the telephone on speaker. Each interview was transcribed verbatim for interpretation. Consistent with a systematic grounded theory approach, the researcher completed a three-tier coding process, which occurred throughout data collection. Figure One provides a schematic to demonstrate this process.

**Open coding.** During this phase of coding, transcripts were broken down to identify events, actions, or interactions, and compared one against another to determine similarities and differences. Based on these similarities and differences, each event, action, and interaction were conceptually labelled to group each into categories. For example, a researcher might observe several events, actions, or interactions that are all pointing to “medical priority”. As Corbin and Strauss (1990) note, a primary characteristic of this phase of coding is the recurrent and systematic comparing between events, actions, or interactions to reduce risk of bias as researchers categorize data.

**Axial coding.** During this phase of coding, researchers delineate, from the observed categories, the contexts, conditions, actions, or outcomes associated with each. For example, a researcher might examine “medical priority” to understand “the conditions that gave rise to that kind of [priority], in what context it was carried out, by what action/interactions did it occur, and what were the consequences?” (Corbin & Strauss, 1990, pp. 423).

Corbin and Strauss (1990) note that, during the axial coding phase, observations may vary, and researchers must adjust their inquiry to understand why. For example, while some
children who are DHH Plus have other medical needs regarding which some parents express high priority, it may be that other parents who also have children with medical needs do not express such high priority. Understanding why some parents do or do not express high priority on medical needs can make for a more conceptually dense category and, in turn, a conceptually dense theory.

**Selective coding.** Finally, in the selective coding phase, researchers identify a core category that unifies all other categories. The core category is used to conceptualize the resulting theory. Common in grounded theory, a diagram is used in integrating the categories to establish the core (Corbin & Strauss, 2008). Corbin and Strauss (1990) point out that the core category should be the most abstract, to widen the applicability of the discovered theory.

**Memoing.** Perhaps the most characteristic aspect of grounded theory is memoing (Corbin & Strauss, 1990, 2008; Creswell & Poth, 2018). Unlike other qualitative designs wherein data are analyzed after collection has been completed, grounded theory requires that data analysis commence with data collection. This is made possible through memoing. Memos are on-going inferences that the researchers make about their observations. They may be considered iterative, such that inferences may be made after one interview and then shaped throughout subsequent interviews to more accurately describe and link events, actions, or interactions to one another. It is during the memoing process that initial categories emerge, integrate, and link themselves to concepts. Neglecting to thoroughly memo each interview may result in an underdeveloped theory.

**Reliability**

Corbin and Strauss (1990, 2008) recommend that multiple researchers code interviews to ensure richness of interpretation by including multiple perspectives for interpretation. Thus, the
data from this study were coded and interpreted independently by two researchers (the candidate and another graduate student researcher). The graduate student researcher was trained by the candidate regarding the three-tiered coding process described. Prior to official data collection, two pilot interviews were conducted, wherein the candidate confirmed the graduate student researcher’s competencies and reliability in assisting with this endeavor.

At each phase of coding, the researchers met to compare, contrast, and discuss findings. Differences in language for labelling and categorizing existed between the researchers; however, such differences in language were evaluated for overall meaning and researchers created a consensus for how categories and subcategories were worded. No substantial differences in how the content was interpreted by the researchers existed.

**Member checking.** Member checking is an important step in confirming the accuracy of researcher interpretation. For this study, member checking was completed at the end of each interview, wherein the candidate summarized the contents of the interview and asked parents for clarification, additional information, or corrections, if necessary.
Figure 1

Coding Scheme

Note: Developed from Creswell and Poth, 2018.
CHAPTER IV
RESULTS

Data saturation was indicated after interview 15 and confirmed after interview 18. Table 3 provides a demographic description of the participants in this study. All participants were mothers of children who are DHH with DS. Geographic representation includes one midwestern state and two western states in the United States. Of those mothers interviewed, 44% (n=8) represented males that were DHH with DS, and 56% (n=10) represented females. Four mothers did not disclose the age of their child; of the 14 mothers who did, ages ranged from 16 months to 20 years of age, with an average of 8.3 years (SD=5.5 years). Sixty-six percent (n=12) of participating mothers indicated their age to be between 31 and 50 years old. Income reported by the participating mothers was variable, with 44% (n=8) indicating a salary of more than $80,000 annually. Similarly, 44% (n=8) reported they obtained a graduate degree. Interviews lasted, on average, 36.4 minutes (SD=7.5 minutes; Range=21-51 minutes).

Theory – Hearing Care and Management Priority

Findings from the interviews revealed that, within the general framework of hearing health priority, five sub-theories were uncovered to explain factors that influence parent prioritization for hearing health management. These include their priorities related to: (1) hearing, (2) hearing aids, (3) communicative development, (4) speech-language therapy, and (5) using a manual language. For hearing aids, communicative development, speech-language therapy, and manual language, mothers were asked to indicated how important each was important to them on a scale of 1-10, with 10 suggesting high importance, and 1 suggesting little importance. Based on mothers’ response to this question, and in conjunction with their expressed experiences, priority for each element was inferred as either low, moderate, or high. For
example, mothers may have indicated hearing aids to be 10, highly important; however, they reported hearing aid use to be low. Thus, the incongruency between the expressed value and the practice inferred priority for hearing aids to be moderate.

**Table 3**

*Demographic description (N=18).*

<table>
<thead>
<tr>
<th>Demographic</th>
<th>% (n)</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>100(18)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parent Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20</td>
<td>0(0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-30</td>
<td>11(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-40</td>
<td>33(6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41-50</td>
<td>33(6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;50</td>
<td>23(4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PNA</td>
<td>0(0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$20,000</td>
<td>11(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$21-40,000</td>
<td>23(4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$41-60,000</td>
<td>0(0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$61-80,000</td>
<td>11(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;$80,000</td>
<td>44(8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PNA</td>
<td>11(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School/GED diploma</td>
<td>5(1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>17(3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baccalaureate degree</td>
<td>23(4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>44(8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational training</td>
<td>11(2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PNA</td>
<td>0(0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Child Age (years)</strong></td>
<td></td>
<td>8.3</td>
<td>5.5</td>
<td>16 months – 20 years</td>
</tr>
<tr>
<td><strong>Child Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44(8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>56(10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Interview Length (minutes)</strong></td>
<td>36.4</td>
<td>7.5</td>
<td>21-51 minutes</td>
<td></td>
</tr>
</tbody>
</table>

PNA=Preferred not to answer

From the analysis, four overlapping factors were present across each sub-theory that were consistent with a high parent-reported priority for hearing health. These included mother’s
perception of (a) the extent of professional engagement, (b) benefit for child outcomes, (c) their own activation, and (d) the extent of family engagement (See Figure 2).

Thus, an overarching theory suggests that the higher the extent of engaged professional support, perception of benefit for child, parent activation, and family engagement, the higher the priority for hearing care and management will likely be. Each sub-theory will be expounded to describe the factors explained by parents that influenced them in having a high priority for hearing care and management.

Sub-theory 1 – Hearing Priority

Sub-theory. Factors that were consistent with hearing as a parent-reported priority included their perception of (a) engaged professional support, (b) the benefit of hearing as it relates to development, (c) their own activation, and (d) family engagement. Thus, it is theorized that the higher the extent of engagement professional support, perceived benefit of hearing, parent activation, and family engagement, the higher the priority for hearing will likely be.

Comments related to hearing priority were those regarding the timeliness of hearing loss identification and/or follow-up monitoring of hearing acuity. Figure 3 depicts a decision-making tree to reflect how the researchers interpreted the thoughts and experiences described by participating mothers related to their decision-making process for hearing priority. Through their shared experiences, it was clear that no mother indicated hearing as being altogether unimportant; thus, it was inferred that any level of priority requires a general value for hearing. For some mothers, it was clear they experienced a fluctuation of how hearing was prioritized over time, based on their individual circumstances. This fluctuation was captured and is described under the category “shifting priority”.
**Low priority.** Four mothers expressed low priority for hearing. Reasons to explain this decision included (a) presence of complex medical concerns, (b) poorly engaged professional support, (c) parent fatigue, (d) limited parent activation, and (e) poor family engagement. Each of these is expanded below.
**Medical Concerns.** Some parents noted their low priority to be related to their child’s complex medical conditions. For example, Mom 5 reported how her daughter had serious congenital heart defects that required immediate attention. She explained:

> [My daughter] didn’t pass her newborn hearing screening. But she was tiny. She was 4 lb 15 oz, so everything was just small. And they didn’t really like, at that point, say it was because of Down syndrome or anything. It was just . . . It wasn’t really the priority with her heart issues.

Similarly, Mom 6 reported hearing loss as being low priority, due to her son’s breathing issues and concern for possible heart defects. She reported:

> Hearing loss was probably the last thing I was thinking about. Now that I have this child, what was I going to look for? It was probably heart. Well, and he had the breathing problem. So, then I thought, oh brother, breathing and heart problem – just what we need. Those were probably the top things on my mind at the time.

**Engaged Professional Support.** One parent (Mom 2) linked her low priority for hearing to her experience with the newborn hearing screening process and interactions with the hospital staff. She reported that her child failed her first newborn hearing screen attempt, yet the hospital staff told Mom 2 that she did not need to return for follow-up testing until 3 months later. From there, the mother reported being given inconsistent information about her child’s hearing. The result was that the mother did not push to have her daughter’s hearing acuity assessed in a timely manner. She explained:

> And so we went back in three months, and I don’t really remember exactly why they wanted 3 months, and then they wanted 6 months . . . Oh, they’re like, oh she can hear [at 3 month follow-up], and then they’re like, well you know what come back at 6 months.
So, then we came back at 6 months and they’re like, oh no she can’t hear in both ears.

So, now I’m at the point, well which ones accurate?

**Parent Fatigue.** Mom 5 linked fatigue as another reason for her low priority for hearing. She described how her daughter could not have her heart defect fixed until 7 months old, due to the invasiveness of the heart surgery required. After it was all over, the mom recalled feelings of burnout, which caused she and her husband to put off having her daughter’s hearing tested until she was nearly 18 months old:

*So, then after that [heart surgery], we were just kind of trying to recover and have a normal life for a while. We honestly just swore off doctors. Like, we don’t want to deal with this [hearing loss] right now.*

**Parent Activation.** Mom 6 described a low motivation to monitor her child’s hearing, indicating her doubt regarding the accuracy of his failed newborn hearing screen. She also expressed her feeling that her child does “well enough”. She explained:

*[My son] gets his point across. He sings, he dances. He can pretty much do everything.*

*He loves sports. So, because he’s so . . . He has so many experiences, that hearing loss is probably the last thing on the list.*

**Family Engagement.** Finally, Mom 6 described her husband’s lower level of involvement as partly influencing her decision for low hearing priority. She explained:

*I feel that he could have been a lot more . . . Well he’s been a workaholic because I think he shies away from it [helping]. He knew that what I was doing was correct. But he didn’t want to get involved, because it just took so much of his time.*

**Moderate priority.** Only one mother considered her priority for hearing to be moderate, which is to say that hearing is part of her focus, but not a top priority. Specifically, Mom 3
indicated that hearing loss did not seem as important as her daughter’s other medical issues and hoped the failed hearing screen would resolve on its own. She explained:

I would say the hearing thing seems to be kind of less of an issue at times, you know. With DS, there’s a lot more concerning issues most of the time. Like her physical milestones and . . . we do a lot of other therapies that aren’t focused on hearing. So, I think hearing – the hearing loss – is kind of in the background most of the time. We still do all of her hearing stuff, but as far as, in combination with the DS, it’s not as big of a priority as it probably should be most of the time.

**High priority.** Eleven mothers ranked hearing as a top priority. Reasons to explain this decision included (a) engaged professional support, (b) high parent activation, and (c) recognition of the role of hearing on child development. Each is expanded below.

**Engaged Professional Support.** The role of the professionals interacting with the family was crucial for many mothers. For example, Moms 9, 10, 17, and 18 reported being given explicit instructions on where to go and how to set up follow-up diagnostic evaluations for their child after failed newborn hearing screen attempts, which they reported helped to fuel their priority for understanding their child’s hearing needs.

Mom 7 was particularly influenced by her Early Intervention provider, who carefully explained hearing loss and its impact on child development. She explained:

Our [EI] specialist has been such a huge help for me. Like, as far as helping me make decisions based off of . . . you know like his hearing loss, and the importance of his hearing loss, understanding, you know what he’s able to hear and what he’s not able to hear. She’s definitely been a huge support for us.
Moms 11 and 13 linked their respective providers’ accessibility as reasons for their high hearing priority. For example, Mom 13 described: *If I need something, I can just pop in . . . The hospital has a portal, so if I have questions, I can send questions to the portal.*

**Parent Activation.** One mother demonstrated her high hearing priority through descriptions of her and her husband’s actions to ensure that their child’s hearing was being closely monitored. Specifically, Mom 4 sent her husband to a parent conference for parents of children with DS where he learned about the frequent middle ear infections common among children with DS, which prompted them to closely monitor their daughter’s middle ear health and hearing. She described:

*My husband went to a conference up at [University]. They just had a whole bunch of ENTs come and do a conference for like other medical professionals and parents of kids with DS. And so, we were like, oh, you should go to that. That would be really helpful. They were going to discuss all of these things that you should have done on your child. And hearing was one of them, a swallow study was one of them. It was just a whole bunch of stuff, so we just did it all. And that’s when we found out she had fluid in her ears, and she got ear tubes. That was kind of the first thing we did.*

**Perception of Benefit.** Finally, Mom 8 expressed her motivation for high hearing priority given how she perceives hearing to be beneficial, or rather her appreciation of the impact of hearing loss on child development. She stated:

*From my perspective, the hearing loss was a really big hit, because I knew that [my child] was already at risk for having trouble learning, because of the developmental delays that come with Down syndrome. And then knowing that he wasn’t hearing on top of that, just had me really freaked out that my child wasn’t going to be able to learn. I*
mean, the hard part for the hearing loss – the biggest problem I was having accepting the hearing loss was knowing that his learning was going to be that much more impacted.

**Shifting priority.** For two mothers, priority for hearing shifted from low to high throughout their respective journeys. Reasons offered included elements related to (a) engaged professional support and (b) parent activation.

**Engaged Professional Support.** Mom 12 described how her daughter failed her newborn hearing screen, but they did not pursue follow-up diagnostic care because the nurses caring for the child prior to discharge gave the parents false excuses for why the child may have failed the screening. She described:

*My daughter was not diagnosed with a hearing loss until she was a year old. And that was after multiple failures at those early newborn hearing screens. The nurses and the hospitals and everyone just gave an excuse for failing. Like, oh she’s congested, or oh she was fussy, or oh she was sucking on a pacifier. You know, that’s why she failed, that’s why she failed.*

The result was that the mother did not think she needed to pursue follow-up hearing testing, thus monitoring hearing acuity was a low priority initially. However, the mother further explained:

*We finally realized at age one that we couldn’t make excuses for it anymore, and my pediatrician pushed to do a sedated ABR. And that was when they discovered that she was born with a mild to moderate bilateral hearing loss.*

Thus, after time, it appears the mother took intentional action to follow-up on her daughter’s failed newborn screening, inferred a shift from a low priority to high.
**Parent Activation.** For Mom 7, due to medical concerns, hearing was “put on hold” while her son had procedures completed to repair a heart defect and an obstructed airway. Despite this, she independently took action to ensure that hearing testing was completed. She reported:

*He did fail his newborn hearing screen, but there were a lot of other medical complications going on that influenced us to push off following up on that. He needed to have a procedure done to help him breathe. And he spent almost six months in the cardiac intensive care unit. And so, because of all those things, hearing things were put on hold. But at about 6 months, I did ask for a follow-up screening, and they got through about half of it before he became too wakeful to finish it. So, I had push for an ABR that finally happened in conjunction with the tongue-clipping procedure at 18 months old.*

**Sub-theory 2 – Hearing Aid Priority**

**Sub-theory.** Factors that were consistent with hearing aids as a parent-reported priority included their perception of (a) engaged professional support, (b) family engagement, (c) the benefit of hearing aids, and (d) the quality of child behaviors. Thus, it is theorized that the higher the professional and family engagement, the perceived benefit of hearing aid use, and the quality of child behaviors, the higher the priority for hearing aids will likely be.

Mothers were asked how important hearing aids are to them on a scale of 1-10, with 10 being highly important, and 1 being little nor not important. Mothers were also asked to talk about how much the hearing aids were used. Figure 4 depicts a decision tree to reflect the comments and experiences shared regarding how mothers prioritize hearing aids. Similar to *Hearing Priority*, no mother indicated that hearing aids hold no importance or priority to them; thus, inferring that any level of priority requires a general value for hearing aids. Otherwise, based on mothers experiences, their priority for hearing aids was inferred as either low,
moderate, or high. For some mothers, it was clear they experienced a fluctuation of how hearing aids was prioritized, based on their individual circumstances. This fluctuation was captured and is described under the category, “shifting priority”.

**Low priority.** Seven mothers indicated that hearing aids hold a low priority for them. Reasons offered included elements related to (a) engaged professional support, (b) perception of hearing aid benefit, (c) child behaviors, (d) family preference for communication, and (e) parent hesitancies. Each are described below.

**Engaged Professional Support.** Four mothers linked their low priority for hearing aids to the type of professional engagement they received. For example, Moms 2 and 14 reported their audiologists told them that their child would not benefit from hearing aids, even though Mom 2 reported her child “couldn’t hear in either ear”, and Mom 14 reported her child to have “80% hearing loss” in one ear. Mom 2 said:

*I mean, if there was ability with the hearing aids, then I would advocate for that to help. But since the audiologist said there’s nothing that’s beneficial, then I’m like okay. The audiologist said there’s no benefit. There’s no benefit to having the hearing aid. And so, I’ve already, you know, with the audiologists have talked, every time we had a test or something like that, I’ve always asked, does she need the hearing aid? Will they help her? Will they support her outside? And often the audiologist would say no, they don’t.*
Figure 3

Hearing Priority Decision Tree

Note: Dotted line infers secondary decision making to influence shifting priority
Mom 14 reported that, because her child was so late identified with unilateral hearing loss, the audiologist did not recommend hearing aids. She reported:

Well, the audiologist that we spoke to also said he [the child] couldn’t even talk if it would help, because they felt like after 8 years that his brain had already figured out how to hear with one ear. So, the hearing aids would be more of an annoyance to him, you know. So, I mean we thought about it quite seriously, and we finally decided not to do it.

For Mom 5, hearing aids were made a low priority due to a lack of information from the professionals following the diagnosis of hearing loss, influencing how urgently parents pursued amplification for their daughter. She explained:

And then we just, when were in there for recovery [following tube placement], and the audiologist – someone – came and told us that she would qualify for a BAHA band and kind of barely talked about it. So, then we were back to Google again. They never really told us if it was a brain thing, because it does use a cochlear . . . I don’t know how to explain it . . . Like if it was an inner ear thing, or if it was a developmental thing with the brain. So, we don’t really know, just because her ear canals are just so small.

Finally, Mom 6 reported being given the option to continue using the hearing aids or not from her education team. She explained:

He was passing all the things he had to pass off as a kindergartner. You know, and he was doing all his speech things pretty well. He was very cooperative in school and things. But, you could tell it was just like . . . They [education team] didn’t feel like his hearing loss was so bad that he needed them to function daily. So, they just said, it’s okay, you choose. I was like, if we can choose, then he doesn’t have to wear them!
Perception of Benefit. Moms 10, 16, and 18 reported low priority for hearing aids, because they do not consider hearing aids to be beneficial for their child. For example, Mom 10 reported:

*I guess I feel like she can hear well enough, and the bother of it [hearing aids] was such a pain, that it’s just not worth it to me. And as far as her speech goes, I don’t feel like her speech is that great, and I don’t think it has much to do with her hearing. I just think she can’t, like her mouth . . . Her tongue is so big, her muscle tone is so low, um, her . . . She just can’t move her mouth, she’s not that coordinated. So, she can’t really speak, but I think it’s more of DS thing than a hearing thing.*

From this description, Mom 10 seems to acknowledge her child’s speech delay, but links it to the child’s accompanying craniofacial anomalies, rather than to hearing loss. Similarly, Mom 16 links her child’s unilateral hearing loss to the decision to make hearing aids a low priority. She stated: *But, her hearing loss, because she still has hearing in her right ear, she seems to hear fairly well, and does really well in school and speech because of it.* Conversely, Mom 18 reported low priority simply because her son’s hearing loss is so profound, she thinks of hearing aids as more a formality while her son undergoes the candidacy process for cochlear implantation. She stated: *We do have hearing aids – they haven’t worked very well . . . so we haven’t been using them.*

Child Behaviors. Mom 14 linked her low priority for hearing aids, in part, to her child’s problem behaviors already experienced with getting him to use his eyeglasses. For example, she reported:

*We did think of hearing aids. You know, a hearing aid in that ear. But . . . he wears glasses. His vision is pretty poor. And we had a really hard time getting him to keep the*
glasses on and everything. And I just . . . you know, he would throw them when he was younger and everything. So, we decided at that point not to do a hearing aid or anything.

**Child Preference for Communication.** One mother (Mom 2) reported that she valued hearing aids for other children with hearing loss; however, both parents are Deaf and the family preference for communication is American Sign Language. She did report that the child has hearing aids, but because of the modality of communication, their use is limited.

**Parent Hesitancies.** Mom 16 listed a few reasons why her priority for hearing aids is low. She reported that hearing aids are in consideration; however, she reported a concern about the cost of hearing aid equipment, and fear for how her child might treat the hearing aid equipment, given the high expense. In addition, mom is hopeful that a surgery can fix her child’s conductive hearing loss. She explained:

> They have recommended a hearing aid for that left ear a couple of times. So far, I’ve been reluctant to do it, because she tends to throw things when she gets angry, like her glasses. And I don’t want to have that to be a source of something to be chucked and lost, and/or broken. Hearing aids are super expensive. So, we did talk a little bit about doing a hearing aid. Either that or a Baha this last week. But she—we kind of are going to hold off a little bit, because she’s also battling off some sinus infections. We’re trying to clear that up and figure that out, because we may end up with surgery for that. And, there’s a chance, if we can get that cleared up, that we may just do the surgery to patch the ear and hope that that will fix it. If not, then we’ll probably go down the route of a hearing aid for hopefully a temporary fix until we get the other thing patched. So, it’s kind of on hold for a minute.
Moderate priority. Five mothers indicated a moderate priority for hearing aids. Reasons included (a) medical concerns, (b) child behaviors, and (c) family engagement. Each is expanded below.

Medical Concerns. Three mothers linked medical concerns to their decision to make hearing aids a moderate priority. For Mom 3, she explained that her daughter’s heart and feeding issues take priority and managing hearing aids is sometimes put on hold. For both Moms 7 and 11, their child’s middle ear health, specifically, limited how much parents enforced the use of hearing aids. Mom 11 explained:

Because of her severe ear infections, there’s been times we were having this—for about a month and a half just recently, we had to take out one hearing aid because of the ear infections. It’s been months at a time. When she had that MERSA infection, it was two months before they could get it cleared up. She had to go through infectious disease.

Child Behaviors. Four mothers described how their child’s behaviors influenced how much priority they placed on hearing aids, and specifically, hearing aid use. For example, Mom 3 explained:

It’s not as big of a priority as it probably should be most of the time. Just making sure the hearing aids are in all the time. And, too, she has a little bit of a sensory problem with the hearing aid. So, ripping them [hearing aids] out all the time, and throwing a big fit. She does better now, but in the beginning, she kind of . . . she really didn’t like getting her hearing aid put on.

Similarly, Mom 5 reported that when her daughter comes home from school, managing behaviors to keep the hearing aids on becomes a “pick-your-battles" decision-making process. She reported:
[My daughter is] super stubborn, and it’s hard for her to . . . She wears them [hearing aids] the whole time at school, and she doesn’t wear them at home. So, it’s more just the . . . It’s not worth the fight at home. She screams. She says no, no, no, and . . . She just has a mind of her own.

Mom 1 reported a similar “pick-your-battles” scenario. Regarding her son’s hearing aid use outside of school, she stated:

It’s probably a 9 or a 10 [priority level in school], just because I know that to learn he needs to hear and that’s where he’s, you know, that’s where the intensive learning happens as far as one on one and him getting all of the actual teaching moments. When we’re at home or on vacation or things like that, it’s . . . it’s [hearing aid priority] lower down there. In fact, we . . . I don’t push the hearing aids after school because he often times ends up just throwing them somewhere and then it’s . . . we’re trying to find them the next morning for school. Compliance is probably the biggest thing. We kind of have to pick our battles, and so would I rather him be wearing his hearing aids or running wild out in the streets? Well, I’d rather him be safe at home and not wearing his hearing aids than out in the you know, well he’s got his hearing aids on but he’s running wild out down the road.

**Family Engagement.** Moms 1 and 5 reported that the minimal family support they receive influenced their decision to make hearing aids a moderate priority. For Mom 1, she reported that she felt she is the only one working to manage her child’s difficult behaviors related to his consistent hearing aid use. She explained:

Like, my husband is really good to kind of help and support on that, but he’s not usually here, so he’s not super available for that. Like, I just don’t have as much support at home
as I do like as he would at school. Siblings are like, ‘oh, he took his hearing aids off we don’t care’ kind of thing. Or no one else is here to help me with it.

Mom 5 reported that, generally, her extended family are encouraging of her daughter’s hearing aid use; however, due to intimidation, they are not helpful maintaining consistent hearing aid use. The result is that hearing aids are not enforced when the daughter is away from the parents. Mom 5 described:

Like if they [my children] spend the night [at grandparents’ house] and I want her to be able to hear at my mom’s house, she [grandma] doesn’t want to put them on there.

Because they’re so expensive that she’s kind of intimidated to move them. Which I get.

Because they are very expensive.

**High priority.** Four mothers expressed a high priority for hearing aids. Reasons provided included (a) engaged professional support, (b) parent perception of benefit, (c) family engagement, and (d) good child behaviors. Each is expanded below.

**Engaged Professional Support.** Three mothers linked their high priority for hearing aids to the strong professional engagement received from various providers. For example, Mom 3 reported that her Early Interventionists took seriously mom’s goal for her child to develop spoken language, and consistently provided Mom 4 with helpful explanations and tips for how to increase spoken language development through hearing aid use. Similarly, Mom 7 recalled her Early Interventionist impressed the “importance of [my son] needing hearing aids”.

Mom 9 reported how her audiologist encouraged high hearing aid use. She reported:

[Hearing aids] are very important. Because what they told us was, have [my son] wear them as much as he can. Especially because it’ll help with clarity of sound, and also for
safety. Because he doesn't hear the soft sounds as well. And to keep the . . . for him to have as much awareness over time, the more he wears them.

**Perception of Benefit.** Moms 7, 12, and 13 described their priority for hearing aids as high due to their perception of how beneficial hearing aids have been for their children’s outcomes. For Mom 7, the priority is connected to her priority for her son’s communication development through spoken language, as she considers hearing aids to be the medium through which to maintain that goal. For Mom 12, hearing aids are vital to her daughter’s listening experience. She explained:

*The hearing aids help her to hear clearly. And help her to be more attentive to what’s going on around her. As much as I joke and say that she suffers from selective hearing loss, she does have a hearing loss. And so, if we are in a situation that it’s critical that she hears clearly, like at school, out in public, where I need her to hear me . . . in groups, at parties, in social settings, things like that, it is vital that she has those hearing aids in.*

Similarly, Mom 13 describes her daughter’s hearing aids as non-negotiable. She described:

*Having the hearing aids then provides her with more learning opportunities. I mean, just even when she got her hearing aids, her own vocalizations – even though they’re not true words – her own vocalizations have increased. The variety of vocalizations also has increased . . . Yeah, so I mean, when we wake up in the morning, we get about 5:30 or 6:00, and her hearing aids go in . . . To me, it’s non-negotiable. You know, her glasses and her hearing aids – it’s non-negotiable. They stay on. If she takes them off, they go right back on.*
**Family Engagement.** Two mothers reported family engagement played a role in their decision to make hearing aids a high priority. For example, Mom 3 described how her husband’s contribution in managing her child’s behaviors with hearing aids helped to increase hearing aid use. She explained:

> When my husband gets home – he, you know, I’ll even tell him: okay, it’s your turn to get after her, because I’ve been doing it all day. And he does, he’s really good about that. I know that he is there, and as far as when she acts out and pulls the hearing aid out, when he’s around, he definitely steps up, steps in.

For Mom 9, even though her husband is sometimes unsupportive of her son’s hearing aids, her own mother’s lived experience with childhood hearing loss made the grandma a great family resource to promote hearing aid use. Mom 9 stated:

> I grew up in a house, my mom used hearing aids. And my mom helps, too. I mean, as far as putting them one and making them stay on. You know that sort of thing. So, it actually runs . . . You know, and I just feel like, I’m not going to take anything away that will help him.

**Child Behaviors.** Finally, Mom 9 reported that her child tolerated hearing aids well, which contributed to his consistent use of hearing aids. Mom 9 reported:

> The only reason he takes them off is when they don’t work, when the battery is dead. That’s his way of telling you, hey the battery doesn’t work. The only other reason he might pull it out is if like he’s hungry, or he wants to get your attention . . . but no, he wears them. What they told us is for him to wear them as many hours in the day as you can. So, I put them on like his clothes, basically is how they taught me to do it.
Shifting priority – high to low. Only one mother reported a shifting of hearing aid priority that started high and decreased. Mom 8 explained the primary reason to be an improvement in her son’s hearing. She explained:

Today, I would say it’s probably more around like a 4, because I know that he’s hearing better without it. Before, when his hearing was a lot worse . . . I don’t know, they used to be a lot higher of importance when his hearing loss was worse.

Shifting Priority – low to high. Two mothers reported their priority for hearing aids shifted from low to high. For Mom 15, the reason provided was limited understanding of her daughter’s hearing loss, and a change in her perception of how beneficial hearing aids were to her daughter. She explained:

I had hearing aids, but I just didn’t put them on her, because I thought she could hear fine. Because I could talk to her and she would pay attention. I would talk to her, and she would look at me. And whenever I did tell her, hey do this, she would do it. So, I knew she could hear, but I just didn’t know it was that bad.

For Mom 15, teachers also played a role in shifting the priority for hearing aids to be higher and for making the most efficient use of hearing aids in the school setting. She explained: [The teachers are] super supportive. In case I lose, or I forget [the hearing aid], they usually call me and tell me. So, it’s always on her, it’s always on her. So, if I forget it, they usually remind me. Hey, where is it, or are you bringing it, or . . . And they actually had somebody come in to talk to them to explain how to use it, how it works with her . . . it was like a little seminar, I guess, where like all the teachers that were in . . . Whoever
wanted to be in the seminar to learn more about her hearing aids, just so everyone is on the same page.

For Mom 17, her priority for hearing aids shifted from low to high because of shifting recommendations provided by audiologists, despite her son’s moderate degree of hearing loss since birth. She reported:

*So, when [my son] was discharged from the hospital they did a hearing test and let me know that he did fail his hearing, you know the newborn hearing test, and that we would need to follow-up with audiology. And, when we went to the audiologist, they told me he definitely had some sort of hearing loss. However, due to our insurance, they didn’t really play it off like it was a really big deal, or that he would ever be a candidate for hearing aids, so unfortunately he did go unaided for a very long time, because I was actually told that he was not a candidate for hearing aids. I honestly think that they just — you know, I was a young mom. And I think that they think I couldn’t afford them. And, that my insurance wasn’t going to pay for them. So, I honestly believe, unfortunately, that they said that because he wasn’t you know . . . there wasn’t . . . he wasn’t going to get them. Had I known that he could have benefitted from hearing aids, I absolutely would have moved the mountains to make sure he received what he needed.*
Figure 4

Hearing Aid Priority Decision Tree

Note. Dotted line infers secondary decision making to influence shifting priority
Sub-theory 3 – Communicative Development Priority

**Sub-theory.** Factors that were consistent with communicative development as a parent-reported priority included their perception of (a) their own activation, (b) their goals for communication, (c) benefits of communicative development, and (d) the extent of family engagement. Thus, it is theorized that the higher the parent activation, the caliber of goals for child’s communicative development, and family engagement, the higher the priority for communicative development will likely be.

Mothers were asked how important communication is to them on a scale of 1-10, with 10 being highly important, and 1 being little nor not important. Mothers were also asked about how much time they feel they spend facilitating communicative development for their child. Figure 5 depicts a decision tree to reflect the researcher’s interpretation regarding how mothers prioritize communicative development. No mother indicated that communicative development holds no importance or priority to them, inferring that any level of priority requires a general value for communicative development. Unlike Hearing and Hearing Aid priority, priority for communicative development was less variable, and for most mothers a high priority was inferred. A couple mothers did, however, suggest communicative development priority to be either low or moderate.

**Low priority.** Mom 10 was the only mother to report a low priority for her child’s communicative development. Although her child did not have other complex medical needs, she reported communication to be a sort of afterthought, with the child’s general health being the primary focus. In her words:

*My daughter* doesn’t always know what she wants. I mean, she’ll sign what she wants over and over. And it’s sometimes something that she can’t have, or you know we can’t
do it at that time. So, she'll sign it and sign it and sign it, and it's not possible. So, she
doesn't understand “not now” or “later” or “I understand you, but no”. So . . . I mostly
feel like I'm just keeping her alive. And, communicating a little bit on the side is kind of
nice. But you know as far as keeping her alive, I don’t need to communicate too much
with her to do that. So, it’s not . . . It would be nice, but it’s so . . . It’s not totally
necessary. I mean, there are a lot of kids who don’t talk, and they’re kept alive. So, I
would say it’s not totally important, because she doesn’t always make sense when she’s
signing, you know . . .

From this statement, it seems that Mom 10 considers her daughter’s communicative
ability, as well as her drive to keep her healthy and alive, when determining her priority level for
communicative development.

**Moderate priority.** Mom 9 indicated she highly valued communication; however, she
commented on her limited time spent facilitating communication development with her son.

[Communication is] important to me, because I want [my son] to be able to fend for
himself and communicate, and ask for what he wants, and advocate, all those things. And
it worries me. But then my friend who has a daughter with DS, she said she just made it
where [her daughter] couldn’t get what she wanted without asking for it somehow,
whether it was just sign, or verbal, or whatever. And I probably need more push on that.
Like I need maybe to be tougher like that mom, because this is my last kid. I kind of wuss
out, kind of give in. I was one of those moms, for what it was worth – and I did it with the
other kids, too – I always anticipated their needs before they asked for it. Because I
thought, someday they’ll grow up and they won’t need me to do that. But the difference
is, and what I have to remind myself all the time, is those kids could still tell me what they
wanted in speech. This kid’s [with DS] not as verbal. So, I might be doing him a
disservice not making him ask for it, or worse. I do need to be tougher about that. But,
you know, you do what you can.

From this, it is clear Mom 9 recognizes how she can improve to better facilitate her son’s
communicative development. For example, when speaking of strategies to encourage
communication, Mom 9 further explained:

*I probably need to use more of those. I think that when he’s in school they’re doing it. I
think at home, I often feel like he’s already had a full day, just kind of let him get what he
needs. Now, what I have started to do – and this probably isn’t good either – I might
leave stuff where I know he knows where to find it. So, he doesn’t have to ask for it, he
can just get up and get it himself. You know, like if it’s his veggie sticks, or whatever. So,
I probably need to have more strategies. You know . . . I probably do need to do more of
that.*

**High priority.** Sixteen mothers suggested a high priority for their children’s
communicative development. Reasons to explain why communicative development was such a
high priority included (a) parent activation, (b) parent goals, (c) perception of benefit for the
child, and (d) family engagement. Each is expanded below.

*Parent Activation.* When asked about priority for communicative development, most
mothers responded by listing specific action they have taken to enhance their children’s
communicative abilities. Moms 1, 6, 7, 11, 12, and 16 reported they use their daily routines and
interactions to intentionally facilitate communication with their children. For example, Mom 6
explained:
I spend most of the time [facilitating my son’s communication]. Because I was a home mom, and most of the kids were at school. so instead of like . . .they even offered the bus. But most of the time I would take him, because it was just so fun to see him progress. And it was just a lot more fun to be one-on-one. I felt like I wanted to be one of the facilitator people.

Regarding time spend facilitating communicative development, Mom 12 reported:

It’s really hard to say, because it’s just built into what we do. I mean, we’ve been living with this for 16 years, so I just do it and I don’t even realize I’m doing it. You know, working things like making her look at us. When I really want her to pay attention, I say look at me. Look at me. And that to me is a strategy. Repeating things for her, having her repeat back to me. Having her agree – so, when I ask her to do something, I don’t walk away until she says ‘okay, mom’. And I think that that’s a communication strategy. So, I don’t know . . . it’s just all day constantly.

Similarly, Mom 16 said:

It’s hard to put a number to it, because I feel like it’s just constant throughout the day. I mean, she’s in school for a lot of the day now, and I’m at work for the time that she’s at school. But when we’re home, we’re talking to her. And anytime we’re talking about things we’re talking to her, or you know, she’ll sit, and she likes to watch [TV show] and she learned lots of stuff from that. And, she reads, like if she’s bored, she’ll sit down and read and I feel like that’s helping her too. So, I feel like it’s all the time. But, I guess, specifically sit-down with her, we sit down and read 20 minutes/day. And I sit down and
do homework with her. So, that’s like 15-20 minutes every day during the school year.

So, I don’t know how to give a number to that.

**Parent Goals.** Nine mothers reported their priority for communicative development as high due to specific goals they have for their children. For example, Moms 3, 5, and 7 reported they want their child to develop strong communicative skills in order to develop quality social relationships. Mom 3 stated:

*I guess it’s just one of those social things, because she has DS, I want her to be able to be social, and . . . like if she can’t communicate well, if she can’t speak well – then that just limits her even more in her social abilities and other aspects of her life as she gets older.*

Similarly, Mom 5 explained:

*I want her to be able to interact with her typical peers. And I know that they kind of treat you different if you . . . honestly my goal is to not have her sound like she has DS, which sounds horrible, but I know that she will have an easier time. Just, I’m trying to work on her articulation now, so that she understands that she can use her mouth for words . . . [I want] people besides me to understand her, and not have to like translate everything for her, and be right there so that people will know what she’s talking about.*

Connected, but different from the mothers’ social goals for their children, Moms 1, 4, 7, and 15 reported a general goal for their children to communicate their basic needs and share experiences. For example, Mom 4 explained:
We just wanted her to be able to tell us like, what she did at school, or you know, things that she likes to do . . . We always just thought that she could get through life a lot easier if she could tell people what she needed, what she wanted, or as far as frustration at home, like, telling us why she’s upset. You know, I feel like communication just solves a lot of issues.

Mom 15 explained:

I know talking is going to help her a lot. Knowing what she wants, and eventually having her opinion on stuff. And it’s really important for her to talk, because if somebody hurts her, I’ll know somebody hurt her, because she’ll tell me. If she’s in pain, I’ll know she’s in pain because she’ll tell me. It’s just super important for her to speak, because I know she’ll grow older. And I want her to work. I want her to be independent just the way she is now, but without speak[ing] it’s going to be a lot harder. So, I just need her to speak.

Moms 8, 11, and 12 both reported their children’s difficulty with communication as the drive for prioritizing it. For example, Mom 11 stated: I think that’s the toughest area that she struggles with initially. She’s having trouble physically with the gross and fine motor. Moms 9 and 12 expounded their experiences. Mom 9 stated:

[Communication is important] because he’s going to have to work harder to learn to communicate than most kids. Between having DS, having hearing loss, and having a cleft palate . . . so he’s at disadvantage for the cognitive component because of the developmental delays associated with DS. He’s at a disadvantage for the receptive component because of the hearing loss. He’s at a disadvantage for the expressive component because of the . . . he has difficulty with sound production because of the cleft
palate. Even though the cleft palate’s been repaired, he still is very nasally and a lot of
his sound production comes through his nose. So, he has a lot working against him. So,
teaching him ways to communicate and how . . . you know, and more than that, just
teaching him about communication is always been a really really high priority for me.

Similarly, Mom 12 explained:

*I mean, [communication is] the most important thing, because that is truly what is
holding my daughter back from being successful and being independent is her
communication, her ability to communicate. It is the single thing that is holding my child
back. So, everything that we do, any support that we have out there that will help us to
help her improve her communication, we do it.*

**Perception of Benefit.** Seven mothers described different benefits they perceived that
were linked to their children’s communicative development. Moms 13, 14, 16, and 17
specifically reported their children’s communicative development minimized problem behaviors.
Mom 15 explained: *[When my son communicates], he’s happier. It also is a happiness factor. If
people understand him, it makes him a lot happier than if they don’t, he gets very frustrated.*
Mom 16 simply stated: *If we can communicate [with my daughter], it’s a lot easier. We don’t
have the tantrums and fights.* Similarly, Mom 17 expounded:

*Well, I think communication for everyone . . . if you have a child or adult who can’t
communicate, that leads to, you know, behavior problems, leads to frustration. Not being
able to let your parent know, I really want to eat a hamburger. So, it is so important to
communicate, because that is the basis of life. Once he was able to communicate more,
we saw less behavior problems, we saw less frustration.*
Finally, Mom 18 reported a benefit of generally increased quality of life. She explained:

*I just think it’s so important to set my son up for success in any way as possible. I want him to succeed. I want him to have a good quality of life, in however way that may be. And, I want him to be able to count on us and everything like that and depend on us. And we depend on him, too, you know. So, it’s important for him to grow in that way.*

**Family Engagement.** Two mothers linked family support to their high priority for communicative development. For Mom 2, hereditary Deafness runs in the family, and she reported that both sides of her daughter’s family support a variety of communication modalities. She described:

*We have a Bi-Bi language home, like I said. My husband’s family is completely Deaf . . . And my family is primarily hearing. So, we have both. And, as far as her grandparents, you know they speak, and they’re very supportive if we sign, or [if] we speak. And then when we go to my husband’s parents, and they’re very supportive as well. And they, my husband’s parents, sign to her. And she’ll sign right back. She’ll have full on conversations back and forth with you know her grandparents, she understands them.*

Mom 15 reported her own mother to be persistent in her encouragement to have Mom 15 facilitate communication with her daughter. She explained:

*[My mom], she’s like, you need to spend more time with her, you need to talk to her more, you need to practice, you need to do this. She’s like, I’m pretty sure if you were with her, take at least 10-20 minutes just talking conversation-wise with her, her [communication] would improve.*
Figure 5
Communicative Development Priority Decision Tree
Sub-theory 4 – Speech-language Therapy Priority

**Sub-theory.** Factors that were consistent with speech-language therapy as a parent-reported priority included their perception of (a) their own activation, (b) engaged professional support, (c) their goals for spoken communication, and (d) family engagement. Thus, it is theorized that the higher the parent activation, the extent of engaged professional support, the caliber of goals for spoken language development, and family engagement, the higher the priority for speech-language therapy will likely be.

Mothers were asked how important speech-language therapy is to them on a scale of 1-10, with 10 being highly important, and 1 being little nor not important. Mothers were also asked about how much time they feel they spend transferring skills learned in therapy into the home. Figure 6 depicts a decision tree to reflect the researcher’s interpretation regarding how mothers prioritized speech-language therapy. No mother indicated that speech-language therapy holds no importance or priority to them, inferring that any level of priority requires a general value for speech-language therapy. Based on mothers experiences, however, a low, moderate, or high priority was inferred. Figure 6 depicts a decision tree to reflect the researcher’s interpretation regarding how mothers prioritize manual language. Priority levels are expounded below.

**Low priority.** Three mothers indicated their priority for speech-language therapy to be low. Two reasons were uncovered to explain this decision: (a) low parent activation, and (b) poorly engaged professional support.

**Parent Activation.** For one mother (Mom 15), low priority was indicated by her limited activation as demonstrated by her simply unknowing whether her daughter was receiving speech-language therapy services in school. When asked, she explained:
I don’t know, actually. I know my son did it, because he was not speaking, so he was pulled out to get it. I’m not sure about [my daughter]. I know she gets pulled out of normal classes when she doesn’t pay attention, or if she needs a break, they’ll pull her out. But I don’t know if they do anything else after that. I know that they just call it ‘specials’, but I don’t know what ‘specials’ are.

**Engaged Professional Support.** For Moms 10 and 17, low priority was influenced by professional services which they felt did not effectively benefit their children. For example, Mom 10 explained:

＞I had given up, because I tried a few different speech therapists and different programs, and I didn’t really see any benefit. So, I had kind of given up – but then I heard of someone else recently, so I got hooked up with that. So, I still try . . . the difficulty is, there are a lot of great SLPs [speech-language therapists] out there, and they know a lot, but it’s working with the Down syndrome that’s the hard part, because they are just hard to work with. And so, it’s hard to find an SLP who knows how to make them work and doesn’t just sit down and wait for them to cooperate. So, it’s finding that person, and that’s really hard.

Similarly, Mom 17 reported:

＞To be completely honest, I don’t value the speech therapy from the school district. I don’t think that they are working with [my son] in the right manner. He has apraxia and a lot of therapists don’t believe in that. Like I appreciate them, but I’m not going to push for more speech therapy or anything like that, because they just don’t . . . if they were working on techniques for his specific condition, then I think I’d be more . . . I’d rate it
higher. But I think that the speech therapists in the district are just kind of like trying to get hours done and then move on to the next.

**Moderate priority.** Eight mothers considered speech-language therapy to be a moderate priority. Reasons to explain this decision included, (a) limited parent activation, (b) inconsistently engaged professional support, (c) family preference for communication modality, and (d) parent fatigue. Each is described below.

*Parent Activation.* Three mothers indicated limited parent activation that seemed to infer a moderate level of priority for speech-language therapy. Specifically, Moms 2, 4, and 5 consented for their children to receive speech-language intervention services in the school; however, they rarely corresponded with the speech-language therapist to understand the focus of interventions to transfer skills to the home. For example, Mom 2 simply stated: *You know, I actually don’t speak with the speech therapist. They email me if they have any questions. [My daughter] enjoys going.* Similarly, Mom 5 reported:

*I don’t feel like we know what’s going on, except for when we go to IEP meetings. We have a binder that we go back and forth with her main teacher. And so, if I have some questions, that’s how we communicate.*

*Engaged Professional Support.* For Mom 13, professional engagement played a role in how highly they prioritized speech-language therapy. Like Moms 10 and 17, who held a low level of priority, Mom 13 reported actively pursuing speech-language services, depending on who provided the services. She explained:

*Honestly it depends on the individual who is providing [the speech-language therapy]. So, you know, somebody who – you know, it’s important for me, that AAC [augmentative and alternative communication] should be their area of expertise. But I know the speech
pathologist that’s working this summer at school does not have knowledge of AAC and has very limited sign language knowledge. You know so . . . In that regard how functional are the sessions [with that therapist], versus someone who is very proficient in that?

**Family Preferences for Communication.** For Mom 2, speech-language therapy held a moderate level of priority for speech-language therapy simply because the child’s preference for communication modality was American Sign Language (ASL). She explained:

> So, I can hear a little bit, but I don’t understand it all. So, for me, with communication with [my daughter], it’s going to be in sign. So, I’d rather have ASL for our communication between the two of us. If she was to talk to me, I will have to figure out, you know . . . read her lips, and figure out what is it she’s trying to tell me. And, that will happen every once in a while, where she will try to say something to me. And I have to sit there and study her. And if I don’t understand, I’ll ask her brothers and sisters ‘What is she trying to say?’

**Parent Fatigue.** For Mom 8, speech-language therapy is valued, but the frequency that her son receives therapy is seldom and reportedly influenced by her level of burnout, given his need for services from a wide variety of professionals. She described:

> [The professionals] want to come more. I know it would be beneficial to him if they came more. But I can’t. I have to draw the line. Because he has so many medical visits also. And then I work. So, I just . . . I have to draw the line. And [the speech therapist] is open, like I’ve texted her before with questions and stuff. Same with his feeding therapist. You know, they’re open to communicating with me outside, and they’re always open to have a second visit in the month. But I just can’t do it. I’m too overwhelmed. I have to set a barrier, a boundary to protect my sanity.
**High priority.** Seven mothers indicated their priority for speech-language therapy to be high. Reasons to explain this decision included (a) high parent activation, (b) parent goals, and (c) family engagement. Each is described below.

**Parent Activation.** Six mothers reported a high level of activation and involvement with speech-language therapy. For example, Mom 1 reported a background as a speech-language therapist, and actively works on speech goals in the home. She explained:

*Again, because of my background, and I know a little bit of what I’m doing, I try to work on [my son’s speech goals] all the time. Like, kind of reinforcing certain sounds. Trying to reinforce longer sentences and things like that. And that’s only because of my background and I kind of know what I’m doing.*

For Mom 3, involving herself in her daughter’s interventions, including speech-language therapy, is considered her primary role. When talking of her involvement, she described:

*I mean, it’s fun for me. And I see the, I see how applicable it is and how we can use it in every day. So, yeah, it’s very important for me to be involved. If I’m not involved, then it’s not going to be happening on . . . You know, like I said, throughout the day when those opportunities arise. And it’s my job – I see it as being my job, not theirs.***

Moms 9, 12, and 14 reported making corresponding and collaborating with their children’s speech-language therapists their prerogative. For example, Mom 14 described:

*The speech therapist should always be at the IEP [Individualized Education Program]. And they would communicate with me and I would communicate with them other times if we needed to. I would go into the classrooms and talk to them and just see. I always wanted to make sure he didn’t have behavioral problems in any of his classes. And sometimes when you’re in something like speech, where is can be a little more*
frustrating, those problems can come out. So, I always made sure that the speech therapist knew that the behavior was important.

For Mom 12, although her relationship with the speech-language therapist was strained, and speech-language therapy services provided to her daughter were not perceived as sufficient, she demonstrated a high priority for speech-language therapy by actively seeking independent testing to file for due process. She explained:

*When we got into the school district, the SLP was worthless. I almost took the district to due process because of her speech services. We had an independent speech evaluation. Actually, we had two of them done in the fifth grade. And both independent evaluations said that if [my daughter] had received the speech articulation support she had needed all along, then she would not have had as delayed of speech that she had.*

Despite this apparent frustrating experience, Mom 12 further described developing a positive and highly collaborative relationship with her daughter’s speech-language therapists in Middle and High School. She reported:

*So, in Middle School and High School there’s been quite a bit of collaboration. There’s been strategies that they’re using at school, they would communicate with us, and we would try to reinforce them at home. We would try to create this seamless connection between home and school and back again. There were things we were doing at home that were successful, they would do at school, and vice versa.*
Finally, Mom 18 reported that, although her son is not currently receiving speech-language therapy until after his cochlear implantation, she highly values speech-language therapy and fully intends to seek such services once activation of the cochlear implant has taken place.

**Parent Goals.** Five mothers attributed their high priority for speech-language therapy to their goals set for their children’s outcomes. Specifically, Moms 1, 11, 12, and 14 linked their high priority to the same high priority they held for their children’s communicative development; thus, some of their comments were quite similar. For example, Mom 1 reported:

*I know that speech, being able to communicate. . . if [my son] can’t communicate he gets frustrated and things don’t go as well. And it affects him being able to . . . it’s kind of like the foundation for his success in other things, I feel like.*

Similarly, Mom 12 explained:

*It’s all about communication. [My daughter] has to be able to communicate with us and we have to understand what she’s trying to say. And it’s not just us, right . . . I could totally be an enabler and let her get away with sloppy, lazy speech, because I know what she’s trying to say. But it’s critical that other people who aren’t around her on a regular basis can understand what she’s trying to say.*

Mom 9 simply stated her priority for speech-language therapy is tied to her goal for her child to communicate using spoken language. She stated:

*Well, I want him to speak. Again, I go back to that. And, so I hope, and I’m hopeful, that the more speech therapy, the more socialization, the more inclusion in school, the more hearing kids talk, is all going to hopefully help to where he’s going to eventually speak.*
**Family Engagement.** Mom 14 reported how her children and husband have played roles in support a high priority for speech-language therapy. She explained:

Okay, [my son] is the youngest of five siblings, so youngest of six. When he was born, my oldest was 17. We had one 17, 15, 13, and 11 [years old]. So, the teenagers were fantastic helpers, especially the girls, doing therapy with [my son] and trying to get him to do the things that the therapists . . . Because you have OT [occupational therapy], PT [physical therapy], speech therapy . . . You have all these things that you’re working with at the same time. They were great at helping. And my husband’s fantastic. He would take off for doctor’s appointments. We’re a good team. He still works really well with [my son]. So, I’ve had great family support.
Figure 6
Speech-language Therapy Priority Decision Tree
**Sub-theory 5 – Manual Language Priority**

**Sub-theory.** Factors that were consistent with manual language as a parent-reported priority included their perception of (a) benefit for the child’s communicative development, (b) their own activation, (c) engaged professional support, and (d) the child’s preference for communication modality. Thus, it is prioritized that the higher the perception of manual language benefit, parent activation, the extent of engaged professional support, and child’s preference for manual language, the higher the priority for manual language will likely be.

Mothers were asked how important manual language is to them on a scale of 1-10, with 10 being highly important, and 1 being little nor not important. Mothers were also asked about how much time they feel they spend/spent learning a manual language for themselves. Figure 7 depicts a decision tree to reflect the researcher’s interpretation regarding how mothers prioritize manual language. Similar to *Communicative Development* priority, manual language priority showed a limited amount of variability, as most mother indicated a shifting priority for manual language, from high to low. No mother indicated that manual language holds no importance or priority to them, inferring that any level of priority requires a general value for manual language. Interestingly, no mother suggested manual language to be always a low priority. Some mothers did, however, infer a moderate or high priority. Priority levels are expounded below.

**Shifting priority – High to low.** Ten mothers (Moms 1, 3, 4, 5, 7, 8, 11, 12, 14, and 16) reported their initial priority for manual language to be high and then shift to low. Reasons identified to explain this decision included (a) parent goals for spoken language and (b) child development.

**Parent Goals.** For Moms 1, 3, 4, 8, and 12, manual language held a high priority while they supplemented spoken communication when children were younger. Eventually, however, mothers pushed away from manual language to emphasize their goal for spoken language
development. For example, Mom 1’s son began to show some verbal language skills but relied too heavily on manual language to communicate. She explained:

*We did a lot of signing in the beginning, so if you would have asked me this when he was like 1 or 2 years old, I would have probably given it a higher number. It has fallen in importance because he has used more speech. We kind of pushed away from it because he seems to almost cling to signs. There are still signs that he uses with words. Like, ‘mom’ and ‘dad’. He almost always uses the signs when he says the words. But we kind of pulled back on it, because . . . he’s always going to need someone to help interpret for him if he’s going to use signs. I want him to be as independent as possible, so we pulled back on the signs and started to emphasize verbal more.*

Similarly, Mom 12 explained:

*Sign language was a huge importance, I mean it was like off-the-scale important to us when [my daughter] was, you know, from a baby to 3rd or 4th grade. Because that’s how she communicated. And that’s how we communicated with her. [But] for a while, it became her excuse not to speak. And so, we’ve started weaning her off of sign language, because that was the easy way out for her. But in society people don’t speak sign language, and so we want her to be an independent communicator when we’re not around. And so that’s why we are really pushing her speech.*

**Child Development.** Like the previous set of mothers, Moms 5, 7, 11, 14, and 16 held a high priority for manual language to supplement communication when children were younger. For this group of mothers, however, it was the children’s development of spoken communication that shifted the high priority to low. For example, Mom 14 explained:
We don’t use a whole lot of signs at this point. But, when [my son] was younger, we would not have been able to communicate very well with him. We probably just used sign. You know, we would speak with him. But he would sign back until he was 8. So, the first 8 years, we used the total communication completely. Then, he started getting some verbal words. So, we would slowly cut down on the signing as the years went on.

Likewise, Mom 16 described:

So, back then [manual language] was huge. Like, 10 for sure. We loved using it. And it was huge for [my daughter] as far as communication goes, because she can communicate with us, and we can communicate back with her, and we didn’t get the frustration. So, it was it was huge when she was learning to speak, because speech came slower for her. Now, it’s like, we don’t need it at all, it’s not a priority at all. She’s very very verbal.

**Moderate priority.** Two mothers indicated a moderate level of priority for manual language. Reasons to explain this decision included (a) parent value for communication and (b) parent activation. Each is explained below.

**Parent Value.** Mom 9 reported that, although her preference for her child’s communication is spoken language, she understands that manual language can be used to facilitate communication when her child can not speak. She explained:

> [Manual language] would be really important to me. It’s just that I only learned what I learned. But I’m not great at learning a foreign language, and that is, to me, like a foreign language . . . So, I’m trying really hard, and I need more practice. But, I have enough to get through the day . . . I would rather [my son] speaks, but if that’s his way of
using his hands, trying to tell me something, I’m still going to let him use all that he has to tell me what he needs.

**Parent Activation.** For Mom 15, manual language was inferred as being a moderate priority. When asked how important manual language is to her, she explained:

*Super, because my biggest issue with [my daughter], I could say, is just knowing what she wants. When she was younger, and she wouldn’t, like, speak and stuff, it would be so hard for me to feed her because she’s so picky. And so, I would never know what to feed her. So, now that she’s actually speaking or signing, she’ll tell me what she wants to eat.*

Despite this high value, however, Mom 15 reported not learning sign language herself, and only learning words as her daughter learns them. Thus, despite the high appreciation for a manual language, the limited effort to learn it and efficiently use it indicates the priority for manual language to be moderate.

**High priority.** Six mothers indicated a high priority for manual language. Reasons to explain this decision included (a) high perception of benefit, (b) high parent activation, (c) engaged professional support, and (d) child preference for manual communication. Each is expounded below.

**Perception of Benefit.** Moms 6, 10, 13, 17, and 18 linked their high priority to how they perceive manual language as benefiting their children’s ability to communicate. For example, Mom 13 explained how she appreciated manual language as a visual reference for when communicating with her daughter. She stated:

*I mean, I can sign something, and [my daughter] will follow through with it. You know, some of the basic things: stand and sit, and you know even doing a directed point. So, to*
give her that visual attention, even if she doesn’t hear it, she understands some of those simple things. Also, I also believe, visually, you know it stays longer. I can, you know, hold the sign in a position. I can just kind of hold it there, and not verbally say anything. And it’s there for her to continue to reference to, versus a word, you keep repeating it, they’re going to have to restart processing.

When asked why manual language is so important, Mom 10 declared:

Because that’s the only way that [my daughter] communicates to us. She gets really frustrated if she can’t – sometimes she really wants something, and it’s not too often. But sometimes she really wants something, and so she has no way to communicate and she’s crying all the time, which does happen.

**Parent Activation.** Moms 6, 10, 13, and 17 reported taking quick initiative to learn a manual language in order to facilitate communication with their children. For example, Mom 13 was a special educator, and she relied heavily on both her professional experiences and community resources to learn a manual language. She explained:

I mean, when I started, I learned my [state] regional signs, and then we moved up here to [another state], I had another student who was Deaf and had an interpreter, and so I had an interpreter in my room, and she was constantly teaching us. And then, we are very lucky to have [program] here in [state] and they offer free sign language classes to families of any child who is DHH, or I also believe they also do it for kids who do not need spoken language, even though they’re hearing. And for some of the other students, I have participated in those in-home group sessions . . . I used to go to a Deaf camp at the state school for the Deaf, and they told me I was a pretty good signer.
Similarly, Mom 17 described:

*I mean I’m always reaching out and trying to learn more. I’m not fluent in sign language by any means. I can definitely get by, you know, signing with somebody who is DHH. They might laugh at me, because it’s different. But I have taken college courses. I have taken online courses. I have reached out to Deaf culture people with Deaf events. I have spent pretty much [my son’s] whole life trying to learn more.*

**Engaged Professional Support.** For Moms 6 and 18, the Early Interventionists played a role at helping mothers maintain a priority for manual communication. For example, Mom 6 explained:

*Well we had the [early interventionists] come to our house, and they would show us [manual language]. I think it was twice a week, I don’t remember. At least it was once a week. And they gave you little stickers and we would practice with them. It was really helpful.*

Likewise, Mom 18 described:

*We have our EI [Early Intervention] team. And they really set me up right off the bat with Deaf culture, and she’s been really great. She now comes once a week. And she’s been definitely encouraging me to . . . different kinds of way to use sign language or has taught me different signs that I need to be using. And has definitely also told me just of like a variety of different programs and whatnot, of what to expect.*

**Child Preference.** One mother indicated her priority for manual communication is high, because her child showed a preference for manual communication. Specifically, for Mom 2, American Sign Language is the primary mode of communication used in the family, given both
parents are Deaf. Although her daughter’s siblings are hearing, Mom 2 reported that her daughter with Down syndrome prefers to communicate in sign language.
Figure 7
Manual Language Priority Decision Tree
Summary

*The Hearing Care and Management Priority Model.* From the five sub-theories related to how mothers prioritize hearing care and management, four elements emerged consistently across experiences as being linked to a high priority. These included (a) engaged professional support, (b) high parent perception of benefit, (c) high parent activation, and (d) high family engagement. Thus, it is theorized that each of these elements, when in place together, influence high parent priority for overall hearing care and management. For a visual conception, this theory is modeled in Figure 8. The four key elements mentioned influence high hearing care and management priority. The arrows used in this model are to indicate the dynamic nature of the factors that influence any level of parent priority. In the model, the factors that are represented further away from high priority are the elements inferring both low and moderate priority.
Figure 8

Hearing Care and Management Priority Model
CHAPTER V

DISCUSSION

The purpose of this study was to develop a grounded theory to describe the factors that influence the decision-making process parents experience when determining how they prioritize hearing care and management while caring for children who are DHH with DS. The remainder of this manuscript will discuss (a) study limitations, (b) key findings, (c) clinical implications, and (d) future research.

Study Limitations

Because a grounded theory design is qualitative, it is not possible to generalize the findings revealed in this study (Creswell & Poth, 2018). Even if this study were not qualitative, generalization would be difficult given the homogenous nature of the theoretic sample used. For example, unintentionally, all participants in this study were mothers and almost half of participants reported a high annual income and education level. Several considerations for how parents determine priority for effective hearing care and management may be left undiscovered as a result of lacking diverse backgrounds. Additionally, recruitment was mainly limited to individuals with internet access, as the bulk of recruitment happened over social media. It could be that parents of children who are DHH with DS without internet access or who do not join Facebook support groups could have influenced the scope and directions of the results reported. Thus, results of this study should be transferred (as in the case of qualitative data) from subject to subject with caution.

Another design limitation that may impede the quality of the results presented is researcher bias, given that this research study was born of the candidate’s clinical assumption
that parents of children who are DHH with other disabilities prioritize effective hearing care and management differently, as other, possibly more complex needs of the children may take precedence. The purpose of the systematic approach used in this study was to mitigate researcher bias through constant and iterative comparisons of events, actions, or interactions described by mothers, and confirm whether observations are consistent or variable across conditions through data saturation. Furthermore, data were coded independently by two researchers and noted to be consistently within high agreement, given the predicted variation in semantics.

**Key Findings**

Four elements were uncovered to theorize how and when parents highly prioritize hearing care and management. These include engaged professional support, a high perception of benefit for the child involved, high parent activation, and engaged family support.

**Professional engagement.** In healthcare, how providers interact with patients has shown to influence patient outcomes (Brown, Stewart, & Ryan, 2003; Zolnierek & DiMatteo, 2009). For mothers in this study, professionals included a wide range of providers (e.g., physicians, audiologists) and others (e.g., Early Interventionists) who offer services to families of children who are DHH. Interestingly, comments from mothers regarding professional interactions were often about how information was shared and recommendations made. This has implications for how mothers are able to establish a relationship of trust with their providers to ensure adequate follow-up care (Gabay, 2015). For example, some mothers reported being misinformed regarding the need to follow-up on failed newborn hearing screens, and some were provided inconsistent recommendations for treatment (e.g., told their child did not need hearing aids from one audiologist, then recommended hearing aids by another).
To optimize information delivery, and therefore increase chances for patient adherence to
treatment, researchers have identified key elements that may be incorporated to influence
successful provider-patient communication. For example, in a systematic review, Bauer, Thielke,
Katon, and associates (2015) identified the following key elements in regard to communication
for management of chronic disease: (a) person-centered care as implemented through a
coordinated, team-based approach, (b) evidence-based decision making, with evidence explained
to patients, (c) measurement-based care to make as-needed adjustments to treatments, (d)
population-based care to provide outreach to loss-to-follow-up patients, and (e) accountable care
to ensure effective service delivery and enhanced patient outcomes. Furthermore, in a recent
empirically based synthesis of the chronic care model to treat hearing disorders, Convery,
Hickson, Keidser, and Meyer (2019) emphasized the importance of marrying both the clinical
infrastructure (i.e., delivery design, decision support, information systems, and self-management
support) with community programs and advocacy groups to enhance outcomes. Overall,
experiences related by mothers in this study agree with both Bauer et al. (2015) and Convery et
al. (2019), given that, mothers who reported their providers to broadly engage in such practices
described (e.g., making clear recommendations [evidence-based decision making], addressing
mothers’ concerns [person-centered care, accountable care], referring mothers to supportive
resources [combining clinical infrastructure with community programs]), tended to report a
higher priority for hearing care and management.

Perception of benefit. In this study, how mothers perceived elements of hearing care as
beneficial to their children influenced how highly they prioritized that element. This
phenomenon is consistent with the Health Belief Model, a widely recognized model for health-
related action. In this model, the extent to which recipients of care take action to manage their
health conditions is contingent upon (a) their motivation to make the health issue relevant to themselves by (b) recognizing the health condition as a threat to some aspect of their wellbeing, and (c) believing that a treatment will benefit them and reduce the threat to wellbeing (Rosenstock, Strecher, & Becker, 1988).

For mothers in this study, this model may apply in respect to their management of their children’s hearing loss. For example, for some mothers, the mild nature of their child’s degree of hearing loss, or the unilaterality of their child’s hearing loss, impeded how they perceived hearing loss to be a threat to their child’s development. This, incidentally, seemed to bar their perception for how helpful hearing aids can be. Conversely, most mothers easily understood the threat to their children’s wellbeing when communicative development was impaired. Many reported that, how their child learned to communicate, would influence their future social, economic, and even emotional wellbeing. Thus, this perceived threat to their children’s wellbeing seemed to enhance how mothers took action to facilitate communicative development.

**Parent activation.** Related to perception of benefit and its link to the Health Belief Model is the extent to which parents take action to maintain a priority for hearing care. Understanding the influence behind parent activation is an important element in identifying and addressing potential barriers parents may face that impede their motivation to pursue and maintain quality care in the home environment. Evidence has indicated the extent of patient (or, in this case, parent) engagement can enhance health outcomes and experiences, as well as make health care more cost efficient (Hibbard & Greene, 2013). To this end, some research has been conducted to understand factors that influence how parents manage healthcare for children with medical needs. For example, Pennarola, Rodday, Bingen, and colleagues (2015) analyzed parent activation over a six-month period for 198 parents providing care to children who had undergone
a hematopoietic stem cell transplant. Their findings indicated that older parent age was significantly associated with lower parent activation scores, while duration of the child’s condition and parent emotional functioning were significantly associated with higher activations scores at the start or end of the child’s treatment, respectively. Interestingly, clinical events, such as worsening complications, did not change parent activation.

Although research exploring parent activation among parents of children who are DHH is limited, some similar findings related to how parents provide care through hearing aid use have been identified. For example, low hearing aid use has been associated with younger child age (Walker, Spratford, Moeller, et al., 2013), and mothers’ depression (Muñoz, Rusk, Nelson, et al., 2016). Additionally, Muñoz and colleagues (2016) found a quarter of their study participants participants (27%, n=318) reported that difficult child behaviors explained low hearing aid use for their children. Unlike Pennarola and colleagues (2015), however, clinical events, such as the degree of hearing loss, do influence device use, such that children with milder degrees of hearing loss showed lower device use (Muñoz, Rusk, Nelson, et al., 2016).

**Family engagement.** That family engagement was found to play a role in explaining how parents prioritize hearing care and management is consistent with previous research related to family support and health management. For example, family support has been shown to enhance how patients adhere to treatment regimens or recommendations. In a meta-analysis of 122 studies, DiMatteo (2004) found that those individuals who received family support to manage their diabetes showed 27% higher adherence to treatments. In a more recent review of empirical literature looking at the effects of family support while managing diabetes, Miller and DiMatteo (2013) indicated that, while the benefits of family support are evident, the mechanism for how family support is effective is yet unclear. For example, family support can have negative
outcomes when family members are critical or nagging (Carter-Edwards, Skelly, Cagle, & Appel, 2004), or when family members are particularly demanding (Gallant, 2007).

In audiology, no studies exist that explore the role of family support on outcomes for adherence to recommendations. One study, however, found patients reported the perception of family members being involved in audiology appointments as potentially beneficial, given the support they could provide (Reynolds, Yoho, Muñoz, & Pitt, 2019). Understanding how family support can be structured to enhance optimal outcomes for parents of children who are DHH with or without other disabilities is warranted in future research.

**Clinical Implications**

Understanding the factors that explain how parents decide to prioritize effective hearing care and management has important implications for clinical practice. The foremost implication relates to how audiologists and other providers can develop partnerships with parents of children who are DHH with other disabilities in order to understand the challenges and barriers associated with a minimal priority for hearing care. For example, while for some mothers, other complexities existed and took precedent over hearing-related needs, it is clear from this study that most mothers valued communicative development and desired for their child to become efficient in their spoken or manual language. Thus, the value for hearing care and management was there, yet the priority varied dependent on the factors described.

Through intentional counselling (e.g., open-ended questioning, validating difficult emotions, reflecting experiences and concerns, shared planning), audiologists can illuminate these incongruencies (i.e. value versus practice) and bring them to parents’ attention. This can open opportunities for clinicians and families to more directly talk about the challenges parents
are facing that impede how they are able to adhere to their own values for why their child’s hearing-related needs may matter to them. By focusing on parents’ values, clinicians can guide parents in overcoming barriers to make the appropriate changes in order to take actions aligned with their value for their child’s ability to develop communication. Values-based conversations are consistent with evidence-based strategies for helping individuals make behavior-based changes, such as Acceptance and Commitment Therapy (Hayes, Luoma, Bond, Masuda, & Lillis, 2006) and Motivational Interviewing (Rollnick, Miller, & Butler, 2008).

Counseling strategies are particularly important, as, per the limitations described, inferring how parents prioritize hearing care and management is risky, given that priority likely changes from day to day, and is the result of factors not illuminated by this research design. Therefore, making clinical assumptions about how parents prioritize hearing care and management based on whether professional engagement, perception of benefit, parent activation, and family support are in place could be over-simplified. Clinicians should be careful to understand the full scope of parent experiences, needs, and routines. Open-ended questioning and reflection can aid the clinician in comprehending parents’ true feelings and perception for how they are prioritizing hearing care and management.

By engaging in such a person/family-centered approach to care, audiologists may more easily partner with parents to set appropriate goals for improvement, and connect parents with meaningful resources, such that priority for hearing care and management may elevate, despite the other needs. Appropriate goals are measurable and time-bound. They can include an increase in time spent using strategies to enforce longer device use, learning a manual language, or collaborating with speech-language therapists to optimize spoken language development. Meaningful resources can include a variety of supports ranging from evidence-based online
tutorials to enhance parent learning, or parent groups to connect parents to peer support. Resources can be provided in multiple modalities, including written information, such that parents can refer to resources as needed, rather than waiting for their next audiologic appointment to address unanswered questions or obtain clarification.

As theorized in the results of this study, how audiologists and other providers inform and support parents of children who are DHH with other needs (in this case, Down syndrome) can play a role in shifting the level of priority parents attribute to hearing care and management. Specifically, by developing a strong provider-parent partnership, a high priority for hearing care and management may be attainable through consistent and collaborative care to enhance (a) timeliness of hearing loss identification and intervention, (b) audibility through amplification technology and/or exposure to manual language, and (c) effective and frequent involvement in therapeutic interventions, including speech-language therapy.

**Future Research**

The goal of a grounded theory design is to establish a conceptual framework for future research. This study was prompted by the need to illuminate challenges that impede how parents are able to prioritize and manage hearing care when children who are DHH have other disabilities. This study focused solely on children who are DHH with Down syndrome. Future studies may expand on the findings reported in this paper by evaluating and theorizing how parents of children who DHH with other types of disabilities determine to prioritize hearing care and management priority. For example, a variety of craniofacial anomalies, often syndromic (e.g., Treacher Collins syndrome), have strong implications for overall child health and wellbeing that may similarly influence whether hearing-related needs are given appropriate attention. Additionally, nearly 1 in 59 children with and Autism Spectrum Disorder (ASD) has a
hearing disorder (Gallaudet Research Institute, 2011). The behavioral implications for ASD, such as problem behaviors triggered by sensory input, may influence parents to lower the priority for consistent amplification device use.

From the conceptual framework developed through the grounded theory design, future studies could expand on the present findings by developing instruments to quantify hearing care and management priority. By creating such instruments, other research may be conducted to comprehensively understand what factors influence hearing care and management priority, and how such priority may be effectively enhanced.

**Conclusion**

Parents of children who are DHH with Down syndrome have a wide variety of challenges and experiences that influence what level of priority they attribute to hearing-related needs. This study theorized that the higher the extent of engaged professional support, the extent of how parents perceive benefit, the level of parent activation, and the quality of family engagement, the higher the priority parents place on hearing care and management. Audiologists and other providers may consider ways to approach their service delivery to create partnerships with parents to maintain a high priority for hearing care despite children’s additional complex needs.
REFERENCES


National Deaf Children’s Society (2012). Prevalence of additional disabilities with deafness: A review of the literature. Available at:
https://www.ndcs.org.uk/media/1829/ear_foundation_additional__disabilities__literature_review.pdf [Accessed 28 Jan 2020].


Appendix A

Demographic Form
Appendix A: Demographic Form

Please indicate the following:

Are you a parent of a child who is deaf or hard-of-hearing with Down Syndrome?

☐ Yes
☐ No

Are you a mother/father/other primary caregiver (please circle one)?

If other primary caregiver, please specify: ____________________________

Are you a male/female (please circle one)?

Do you identify as White/LatinX/Asian/Black or African-American/Multiracial/Native or Indigenous (please circle one)?

Please indicate (circle one):

<table>
<thead>
<tr>
<th>Your age</th>
<th>Your child’s age</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20 years</td>
<td>0-5 years</td>
</tr>
<tr>
<td>21-30 years</td>
<td>5-10 years</td>
</tr>
<tr>
<td>31-40 years</td>
<td>11-15 years</td>
</tr>
<tr>
<td>41-50 years</td>
<td>16-20 years</td>
</tr>
<tr>
<td>&gt;50 years</td>
<td>&gt;20 years</td>
</tr>
</tbody>
</table>

Please indicate (circle one):

<table>
<thead>
<tr>
<th>Annual Income</th>
<th>Level of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$20,000</td>
<td>High School diploma or GED</td>
</tr>
<tr>
<td>$21,000-40,000</td>
<td>Some College</td>
</tr>
<tr>
<td>$41,000-60,000</td>
<td>Baccalaureate Degree</td>
</tr>
<tr>
<td>$61,000-80,000</td>
<td>Graduate Degree</td>
</tr>
<tr>
<td>&gt;$80,000</td>
<td>Vocational Training</td>
</tr>
</tbody>
</table>
Appendix B

Invitation Letter and Informed Consent
Appendix B: Invitation Letter and Informed Consent

Dear Parents/Guardians,

Is your child Deaf or Hard-of-hearing with Down Syndrome? If so, researchers at Utah State University invite you to share your experiences pertaining to how you manage hearing care or communication at home. If you’re interested, you may contact the researcher listed below by email, and we will schedule a telephone interview with you. Interviews may last anywhere from 40-60 minutes, depending on how much you want to share. The experiences you provide will be published to help audiologists and other hearing professionals understand your needs better; however, your identification and the identification of your child will be kept confidential.

If you wish to participate, please email the researcher listed below:

JJ Whicker, PhD Candidate
Utah State University
Communicative Disorders and Deaf Education
2620 Old Main Hill, Logan UT 84322
jj.whicker@aggiemail.usu.edu

Karen Muñoz*, EdD
Utah State University
Professor, Department Head
Communicative Disorders and Deaf Education
2620 Old Main Hill, Logan UT 84322
Karen.munoz@usu.edu

*Karen Munoz is the faculty advisor on this research project
A GROUNDED THEORY TO EXPLAIN PARENT PRIORITIZATION OF HEARING CARE WHEN CHILDREN HAVE DOWN SYNDROME

Introduction
You are invited to participate in a research study conducted by Karen Muñoz, a Professor in the Department of Communicative Disorders and Deaf Education at Utah State University, and John Whicker, a Ph.D. candidate in Department of Special Education and Rehabilitation. The purpose of this research is to describe the decision-making process parents experience when prioritizing hearing care while caring for children who are deaf or hard-of-hearing with Down Syndrome. Your participation is entirely voluntary.

This form includes detailed information on the research to help you decide whether to participate. Please read it carefully and ask any questions you have before you agree to participate.

Procedures
Your participation will involve a telephone interview lasting approximately 40-60 minutes (depending on how much you want to share) to understand how you manage hearing care or communication at home for your child who is Deaf or Hard-of-hearing with Down Syndrome. If you agree to participate, the researchers will also collect demographic information to describe your age, your child’s age, your relationship to the child, your race/ethnicity, your annual income, and your level of education. We anticipate that 20-30 people will participate in this research study.

Risks
This is a minimal risk research study. That means that the risks of participating are no more likely or serious than those you encounter in everyday activities. The foreseeable risks or discomforts include loss of confidentiality, or discomfort answering certain questions during the interview with the researcher. In order to minimize those risks and discomforts, you may choose when or when not to respond during the interview. If you have a bad research-related experience or are injured in any way during your participation, please contact the principal investigator of this study right away at (435) 797-9234 or karen.munoz@usu.edu.

Benefits
Although you will not directly benefit from this study, it has been designed to learn more about how parents with children who are Deaf or Hard-of-hearing manage hearing care when children also have Down Syndrome.

Confidentiality
The researchers will make every effort to ensure that the information you provide as part of this study remains confidential. Your identity will not be revealed in any publications, presentations, or reports resulting from this research study. However, it may be possible for someone to recognize your particular situation.

We will collect your information through audio recordings, along with brief demographic information. Interviews will be transcribed word-for-word in a Word document. All data including recording and interview transcriptions will be securely stored in a restricted-access folder on Box.com, an encrypted, cloud-based storage system, and in a locked drawer in a restricted-access office. All recorded data will be destroyed one year following the completion of this study. This form will be kept for three years after the study is complete, and then it will be destroyed.

It is unlikely, but possible, that others (Utah State University, or state or federal officials) may require us to share the information you give us from the study to ensure that the research was conducted safely and appropriately. We will only share your information if law or policy requires us to do so. If the researchers learn that you are going to
engage in self harm or intend to harm another, state law requires that the researchers report this behavior to the authorities.

Voluntary Participation & Withdrawal
Your participation in this research is completely voluntary. If you agree to participate now and change your mind later, you may withdraw at any time by informing the researchers by email or verbally of your intention to cease participation. If you choose to withdraw after we have already collected information about you, we will destroy your interview recording and transcripts and not include any part of your interview in analysis. If you decide not to participate, any services you may receive from Utah State University Pediatric Audiology Clinic will not be affected in any way.

IRB Review
The Institutional Review Board (IRB) for the protection of human research participants at Utah State University has reviewed and approved this study. If you have questions about the research study itself, please contact the Principal Investigator at (435) 797-9234 or karen.munoz@usu.edu. If you have questions about your rights or would simply like to speak with someone other than the research team about questions or concerns, please contact the IRB Director at (435) 797-0567 or irb@usu.edu.

Karen Muñoz, Ed.D.
Principal Investigator
(435) 797-3701; karen.munoz@usu.edu

John Whicker, Ph.D. Candidate
Student Investigator
(801) 645-1405; ji.whicker@aggiemail.usu.edu

Informed Consent
By ticking “I understand my participation is voluntary, that I may withdraw at any time, and I AGREE to participate” below, you agree to participate in this study. You indicate that you understand the risks and benefits of participation, and that you know what you will be asked to do. You also agree that you have asked any questions you might have and are clear on how to stop your participation in the study if you choose to do so. Please be sure to retain a copy of this form for your records.
CURRICULUM VITAE

John J. Whicker

Education

May 2015 – Bachelor of Science in Communicative Disorders from Utah State University

August 2019 – Doctor of Audiology from Utah State University
    Clinical Research Project: Counseling Training in Audiology: A Syllabi Review
    Advisor: Dr. Karen Muñoz
    Defense: February 2017

December 2019 – Doctor of Philosophy in Disability Disciplines from Utah State University
    Dissertation: A Grounded Theory to Explain Parent Priority for Hearing Care and Management When
    Children are Deaf or Hard-of-hearing with Down Syndrome
    Advisor: Dr. Karen Muñoz
    Defense: December 2019

Certifications


Clinical license for the State of Utah. Awarded August 2019


Employment History

08/19-Present: Primary Children’s Hospital - Audiologist
06/18-07/19: National Center for Hearing Assessment and Management, Utah State University – Research Assistant

Primary Research Interests

1) Patient- and family-centered models for service delivery in pediatric audiology
2) School-to-work transition for youth who are deaf or hard-of-hearing
3) Psychosocial impact of pediatric hearing loss on parents when children are deaf or hard-of-hearing with other disabilities

Refereed Publications


**Other Publications**


**Publications in Preparation**


**Presentations**

Auditory Processing Disorders: Considerations for Your Protocol. Invited oral presentation at Primary Children’s Hospital, Department of Rehabilitation, Audiology Faculty Meeting (September 2018).


**Grants**

Utah State University Research Catalyst Grant
Role: Co-investigator
Principal Investigator: Dr. Karen Muñoz
$20,000

A Randomized Control Trial to Determine the Effects of an EHealth Program on Knowledge, Skills, and Attitudes for Parents of Children Who Are Deaf or Hard-of-hearing

Editorial Experience

April 2017 – Present: Editorial Board; Thieme Publishing; MedOne ComSci Online Education Portal

Teaching Experience

Fall 2018: COMD 3700-001 Basic Audiology (Lead teacher)
Fall 2018: COMD 7470-001 Counseling in Audiology (Co-teacher)
Spring 2019: COMD 3700-001 Basic Audiology (Lead teacher)
Spring 2019: COMD 6850-LB1 Listening and Spoken Language Seminar (Co-teacher)

Service

January 2020 – Present: Board of Directors, American Speech-Language-Hearing Association Political Action Committee
January 2020-Present: Audiology Advisory Committee, American Speech-Language-Hearing Association
November 2018 – Present: Co-founder, The Girl with the Million-dollar Face Advocacy Team
July 2017 – July 2019: Vice President for Student State Officers Audiology, National Student Speech-Language-Hearing Association Executive Council

Memberships

September 2017 – Present: Utah Speech-Language-Hearing Association – student member
May 2017 – Present: Educational Audiology Association – student member