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"I am the expert" : The Process of Adolescent Transition in the Self-Management of Hearing Healthcare. A Constructivist Grounded Theory Study

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Abstract

Adolescence is a time when adult behaviours become established and adolescents are more able to manage aspects of their health care. Research has examined adolescent transitions to self-manage their personal health care needs associated with chronic diseases. Providing children and adolescents with information about their health is an ongoing process and, as they mature, they should be allowed to take on more responsibility for their health care management. The purpose of this study was to explore the transition for adolescents who are deaf and hard of hearing toward the self-management of their hearing healthcare. A constructivist grounded theory approach was used to develop a model for the transition process. Participants included adolescents with congenital or early-identified hearing loss who communicate via the aural/oral modality, parent(s)/guardian(s) with the role of primary caregiver for a child with hearing loss, hearing resource teachers working within a school board to support students with hearing loss, and audiologists working clinically with adolescents. All participants took part in one-on-one interviews and adolescent participants were asked to complete a take-home journal. Findings from this study informed the development of the constructivist grounded theory model "*I am the expert*" that describes the transition for adolescents in the self-management of hearing healthcare. This model identifies the key themes of *developing ownership*, *managing identity*, *developing advocacy*, and *doing it myself*. Results from this study highlight the support role of parents, audiologists, and itinerant teachers of the deaf and hard of hearing in the transition to self-manage hearing healthcare. Implications for audiology practice and education are provided.

Keywords

adolescent, hearing loss, deaf and hard of hearing, audiology, audiologist, itinerant teacher, self-management, grounded theory

Summary for Lay Audience

As young people get older, it is important for them to begin to take on more responsibilities. This is also true for young people with disabilities, including those with hearing loss. It is important for young people with hearing loss to learn how to self-manage their hearing health care needs. This can include being able to ask questions about their hearing loss, understand their listening needs, advocate for themselves, and manage any hearing devices they may require. Currently, there is not a significant body of evidence that explores how young people learn to take on more responsibility for their hearing needs. In this study, a constructivist grounded theory methodology was used to explore how adolescents transition to self-manage their hearing healthcare. A constructivist theory is concerned with how and why an individual constructs meaning and actions from their own experiences. It can help us to discover the experiences of participants and how their social context, including individuals they interact with, can indirectly and directly impact them. Interviews with adolescents who are deaf and hard of hearing, caregivers of children with hearing loss, audiologists, and hearing resource teachers were analyzed and the grounded theory model "I am the expert" was developed. Four major themes were identified that are important to this transition: *developing ownership*, *managing identity*, *developing advocacy*, and *doing it myself*. Results from this study can help professionals, parents, and educators to better work together to support young people with hearing loss.

Dedication

In Memory

Dr. Mary Beth Jennings

Acknowledgment

I would like to extend my sincere gratitude, to the families, educators, and hearing professionals who participated in this study. Without them, the completion of this study would not have been possible. It was a privilege to learn from their shared stories and experiences.

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List of Abbreviations

ALD   Assistive Listening Devices

AODA   Accessibility for Ontarians with Disabilities Act

CRIDE   Consortium for Research into Deaf Education

D/HH   Deaf and Hard of Hearing

EMA   Ecological Momentary Assessment

FM System Frequency Modulation System

HRT   Hearing Resource Teacher

IHP   Infant Hearing Program

ICF   International Classification of Functioning, Disability, and Health

ICF-CY   International Classification of Functioning, Disability, and Health: Children and Youth Version

IPRC   Identification, Placement and Review Committee

TDHH   Teacher of the Deaf and Hard of Hearing

MCCSS   Ministry of Children, Community and Social Services

SEA   Specialized Equipment Amount

SLP   Speech-Language Pathologist

WHO   World Health Organization

Chapter 1

1   Introduction

Adolescence can be a challenging time for young people as they navigate the transition from childhood to adulthood and experience significant physical, cognitive, emotional and social changes. Adolescents who have chronic health conditions or disabilities, including hearing loss, may face additional struggles and challenges compared to peers who are healthy or do not have disabilities. A review of the literature reveals there is limited research that examines self-management of hearing healthcare for children and adolescents. The chronic illness literature provides evidence for delayed or poor development of autonomy and the implications for self-management of healthcare for children and adolescents with chronic illnesses and disabilities. This can provide some insight to potential challenges that children and adolescents with hearing loss may have transitioning to self-manage their hearing healthcare. There is a significant gap in knowledge regarding the self-management of hearing healthcare for children and adolescents.

1.1   Personal Statement

My early background in the biological sciences exposed me almost exclusively to quantitative inquiry and cultivated within me a very strong post-positivist perspective. However, with exposure to qualitative research and a better understanding of the various paradigms of inquiry I have realized that I have begun to lean strongly toward a more interpretivist perspective.

I have 15 years' experience working as a clinical audiologist with both pediatric and adult populations. I have worked in private practice and hospital settings. For the past four years, I have been on faculty in the School of Communication Sciences and Disorders at Western University, teaching in the Master of Clinical Science audiology program. As a clinical supervisor, I maintain a patient caseload in the H.A. Leeper Speech and Hearing Clinic (Western University) and am an Ontario Infant Hearing Program audiologist.

I am interested in the area of adult and pediatric aural (re)habilitation. I am particularly interested in the experiences of adolescents, who are an underrepresented group in the audiology research literature. Adolescents have very different needs compared to both young children and adults and are at a point in their lives when they need to learn to take responsibility for their hearing healthcare. Many questions remain about adolescents' perceptions of their hearing loss: what responsibilities they have for their hearing health, and how adults support and educate children and adolescents about their hearing loss. Supports may include, managing amplification and assistive listening devices, providing knowledge about different types of technology, and the development of autonomy in young people with hearing loss.

1.2   Research Purpose

This grounded theory study explores the process of transition for adolescents who are deaf and hard of hearing (D/HH) in the self-management of their hearing healthcare, to identify the barriers and facilitators to a successful transition and to examine the role of adolescents, parents, audiologists and teachers throughout this process.

1.3   Research Question

The guiding research question was: "What is the process of transition for adolescents who are D/HH to self-manage their hearing healthcare?"

1.4   Thesis Overview

With these objectives in mind, the chapters in this dissertation will provide the following information:

Chapter 2 explores extant knowledge concerning adolescent development and hearing healthcare. Chapter 3 provides a description of grounded theory methodologies and a rationale for the selection of a constructivist grounded theory approach for this study. Chapter 4 outlines the study design. Chapter 5 provides a detailed analysis of the study findings and Chapter 6 presents the grounded theory model to represent the process of transition for adolescents concerning their hearing healthcare. Chapter 7 and Chapter 8

provide a summary and discussion of study findings, future research directions, and implications for clinical practice.

1.5   Terminology

1.5.1 Adolescents who are Deaf and Hard of Hearing

There is no international consensus on terminology to describe individuals who have hearing loss and preferred terminology varies across individuals who themselves have hearing loss. In a consensus statement for best practices in family-centred care, Moeller et al. (2013), suggests using terms that have a shared understanding and to avoid those that have varied interpretations or are controversial. In the consensus statement, the authors chose to use the terms "deaf" and "hard of hearing" abbreviated as D/HH to be inclusive of all children with varying degrees of hearing loss, from mild to profound (Moeller et al., 2013). Therefore, I have chosen to refer to the participants in my study who have an identified hearing loss as deaf and hard of hearing, abbreviated as D/HH.

1.5.2 Teachers of the Deaf and Hard of Hearing

Educators who work in schools with students who are D/HH are commonly referred to as Teachers of the Deaf and Hard of Hearing (TDHH). These teachers, employed by the school board, often travel between schools to provide services to students and are referred to as itinerant TDHH or shortened to itinerant teachers. The school board I collaborated with in this study uses the term Hearing Resource Program to refer to the special education program for students who are D/HH and uses the broader term Hearing Resource Teacher (HRT) to refer to both teachers that have an itinerant caseload and those who are based in schools. The term Hearing Resource Teacher (HRT) will be used in this document as an umbrella term to refer specifically to my study participants who are either itinerant teachers or based in schools.

Chapter 2

2 Review of the Literature

We know that adolescence is a critical time in a child's life and that he or she faces many obstacles. There are many support programs available for families of young children and infants identified with hearing loss but many of these services are reduced or eliminated, as children get older. However, it is evident that adolescents who are D/HH may face significant challenges and are a group for whom appropriate counselling and support is essential to help them to accept their hearing loss, to meet their communication needs (Elkayam & English, 2003), and to help transition to self-manage their hearing healthcare (English, 2003).

2.1 Adolescent Development

The period of adolescence is commonly divided into three developmental periods: early adolescence (ages 10-13), middle adolescence (ages 14-17), and late adolescence (ages 18 to early twenties) (Smetana, Campione-Barr, & Metzger, 2006). This period is marked by significant physical, cognitive, emotional, social and attitudinal changes. In addition, this stage of life has a significant impact on the development of self-identify, self-esteem, increased decision-making autonomy as well as the self-regulation of behaviour and cognition (Steinberg & Morris, 2001; Zimmer-Gembeck & Collins, 2005). Adolescent-parent relationships also experience a significant transformation as relationships transition from a more hierarchical relationship between parent and child, to a more egalitarian relationship by late adolescence (De Goede, Branje, & Meeus, 2009; Sessa & Steinberg, 1991; Steinberg & Morris, 2001). As this shift in parent-child relationship occurs, adolescents may start to view their peers as more important and influential than their parents (Steinberg & Morris, 2001). However, this increased engagement with peers allows adolescents to fully develop social skills, including empathy, sharing and leadership (Steinberg & Morris, 2001).

The development of autonomy has long been considered one of the most important elements in the transition from adolescence to adulthood (Erikson, 1968; Havighurst,

1948). Autonomy can be defined as the freedom to determine one's own actions and behaviours and/or to be self-governing. In the context of adolescent development, Zimmer-Gembeck and Collins (2005), define autonomy as a widely used term "to refer to a set of psychosocial issues that are of particular importance during adolescence" (p. 176). Historically, many definitions of adolescent autonomy have been used; how autonomy has been defined or explained has depended greatly on researchers' and theorists' own assumptions on the meaning and significance of autonomy during adolescence (Zimmer-Gembeck & Collins, 2005). Contemporary definitions of adolescent autonomy describe it as "an interpersonal process by which the adolescent begins to develop a greater capacity for independent behaviour in the context of continued family connections" (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009, p. 16).

During adolescence, the development of autonomy accelerates significantly due to the rapid physical and cognitive changes occurring, an increase in social relationships, and increased responsibilities (Zimmer-Gembeck & Collins, 2005). This increase in autonomy occurs over several different domains. Sessa and Steinberg (1991) described autonomy as a "multidimensional construct that is manifested in affective, behavioural, and cognitive domains" (p. 42). In the affective domain, adolescents become more emotionally autonomous from their parents and begin to feel more individuated (Steinberg & Silverberg, 1986). This emotional autonomy also involves less adolescent idealization of parents and a decrease in childish dependencies on them (Steinberg & Silverberg, 1986). Behavioural autonomy is described as the development of independent function, including decision making, self-governance and self-regulation (Feldman & Rosenthal, 1991; Sessa & Steinberg, 1991). Finally, cognitive autonomy, as described by Sessa and Steinberg (1991), "is characterized by a sense of self-reliance, a belief that one has control over his or her life, and subjective feelings of being able to make decisions without excessive social validation" (p. 42).

2.2   Theories of Development

Early perspectives of autonomy were based on the psychoanalytic theory of Anna Freud (1958). Psychoanalytic theory describes the development of autonomy as an internal

drive of the individual that leads to a "detachment and disengagement from parental ties and controls" (Zimmer-Gembeck & Collins, 2005, p. 180). Psychoanalytic perspectives consider this detachment from parents as an essential component for an individual to develop autonomy and to be responsible for their own actions, emotions and thoughts (Zimmer-Gembeck & Collins, 2005).

Contemporary researchers built on the psychoanalytic perspective and described adolescent development of autonomy as a process of separation and individuation from parents (see Blos, 1979; Levy-Warren, 1999). The separation-individuation theory has two components where the adolescent separates and individuates from their parents in order for the development of autonomy to occur. The separation aspect requires that adolescents physically and emotionally distance themselves from their parents. Individuation requires that adolescents take more responsibility for themselves and rely less on their parents (Soenens et al., 2007). However, researchers have argued that because an individual is independent, does not mean they are able to regulate their behaviours effectively. Instead, researchers suggest that positive development of autonomy occurs within a supportive parent-child relationship as opposed to the child simply attaining independence (Soenens et al., 2007).

Self-determination theory (Deci & Ryan, 1985; Ryan & Deci, 2000) defines autonomy in terms of self-governance, as opposed to the concept of achieving independence, as described above. Self-determination theory states that all individuals share three basic psychological needs: autonomy, competence, and relatedness (Ryan & Deci, 2000). An ability for individuals to fulfill these basic needs results in increased well-being (Chirkov, Ryan, Kim, & Kaplan, 2003). Specifically, self-determination is defined as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 115). Therefore, within self-determination theory, adolescents who are highly autonomous will make decisions based on awareness of personal interests, values and goals, as well as taking responsibility for those decisions (Soenens et al., 2007). To be considered autonomous, self-determination theory does not require an individual to have achieved independence. On the contrary, Soenens, et al. (2007) argued that a highly independent individual may not necessarily

exhibit a sense of volition if they are not aware of personal values and goals. In contrast, they describe an autonomously dependent adolescent who may exhibit volitional functioning but may still rely on their parents for guidance and support.

The development of autonomy occurs throughout an individual's life span and can increase or decrease depending on changing circumstances in an individual's life. It is considered an extremely important aspect of adolescent development as it allows for an individual to develop a sense of responsibility and self-direction that are needed to transition to adulthood. In an analyses of the concept of adolescent autonomy and its relevance to health behaviours, Spear and Kulbok (2004) argue that due to the very dynamic nature of autonomy, it is relatively difficult to determine absolute conditions that are necessary for the development of autonomy. However, as will be discussed in the next section, autonomy has been associated with the concepts self-identity, self-efficacy, self-esteem, well-being and social competence.

Contemporary perspectives do not view the development of autonomy as relinquishing all attachments with parents and complete independence. Instead, autonomy and attachment are considered of equal importance to the psychosocial adjustment of adolescence (Noom, Deković, & Meeus, 2001). Attachment is defined as the integrity of a relationship and/or the bond present with significant others (Noom, Dekovic, & Meeus, 1999; Weisel & Kamara, 2005). In the case of adolescents, this can include both parents and peers. Autonomy and attachment are not separate entities but are considered important aspects of development and that positive, supportive relationships facilitate rather than inhibit autonomy (Noom et al., 2001). Social interaction, not only with parents but also with peers, is important for the development of autonomy. This social interaction allows adolescents to learn what values and actions are socially acceptable and lead to self-regulated action (Zimmer-Gembeck & Collins, 2005). The promotion of autonomy within a supportive context promotes the development of appropriate social skills, psychological well-being, and the ability for adolescents to engage in responsible and independent behaviours (Noom et al., 2001). A lack of autonomy during adolescence may delay psychosocial development and lead to adolescent engagement in high-risk behaviours (Williams, Cox, Hedberg, & Deci, 2000).

Noom et al. (2001) explored attachment and attitudinal, functional, and emotional autonomy in adolescents. They conducted a survey of 400 adolescents and found that autonomy was associated with positive psychosocial adjustment in the areas of social competence, academic competence and self-esteem. The authors found that adolescents who exhibited high functional autonomy (knowledge of strategies to achieve their personal goals) and who had positive social relationships were more likely to be socially competent. They found that adolescents with high attitudinal autonomy (the cognitive ability to choose personal goals) demonstrated academic competence. Adolescents, who demonstrated high autonomy in all three domains, demonstrated high levels of well-being and satisfaction. Similar findings presented by Reis, Sheldon, Gable, Roscoe and Ryan (2000) found that individuals with higher levels of autonomy reported increased emotional well-being.

2.3   Impact of Disability on Development

The literature suggests that children with disabilities and chronic health conditions may be overprotected by parents and caregivers and are at an increased risk for psychosocial adjustment problems (Kennedy, Sloman, Douglass, & Sawyer, 2007). This may be partly due to an inability to achieve a certain degree of autonomy from parents. Young people with disabilities may require continued dependency on adults for emotional support, financial support, help with self-management, and continued medical care (Friedman et al., 2009). Parents of children with chronic health conditions may feel it is necessary to retain a greater degree of responsibility in the management of a child's health care needs, therefore delaying the transfer of responsibility (Westwood, Henley, & Willcox, 1999). This reluctance to transfer responsibility may be due to parental anxiety as well as adolescent insecurity surrounding autonomy (Westwood et al., 1999). For example, Westwood and colleagues (1999) found that adolescents transitioning from pediatric to adult cystic fibrosis care wanted to make their own decisions regarding their health care, but were reluctant to speak with their doctor alone. In a study of adolescents with Type 1 diabetes, Karlsson, Arman, and Wikblad (2006), suggested that the transition towards autonomy "is characterized as hovering between parental dependency and a willingness to make one's own decision" (p. 568); suggesting that this may lead to confusion

regarding who is responsible for an adolescent's care. However, the chronic illness literature suggests that it is important for adolescents to master the tasks and responsibilities associated with their condition in order to become independent and functioning adults (Westwood et al., 1999). Delaying the attainment of autonomy for adolescents can ultimately decrease an individual's ability to manage their own care and can be associated with negative health outcomes (Bat-Chava, Deignan, & Martin, 2002; Friedman et al., 2009; Lebrun-Harris et al., 2018; Palermo, Putnam, Armstrong, & Daily, 2007; Westwood et al., 1999; White & Cooley, 2018).

Several studies have shown that adolescents with chronic health conditions experience delays in the development of autonomy and related psychosocial constructs. A study of adolescents with spina bifida were found to be highly dependent on their parents for personal care and experienced decreased peer interaction (Davis, Shurtleff, Walker, Seidel, & Duguay, 2006; Friedman et al., 2009). In addition, these individuals were more passive, more dependent on adults for guidance, had decreased decision-making skills, and displayed less intrinsic motivation in school. Similar, results were found in a study of young adults who had grown up with various chronic or life threatening diseases (Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006). In this study, 1158 young adults between the age of 18-30 years of age were administered a questionnaire that measured the achievement of developmental milestones. Results from this study showed that young adults who had experienced chronic illnesses in childhood achieved fewer milestones or were delayed in the development of autonomy, psychosexual development, and social development compared to their healthy peers (Stam et al., 2006).

2.4   Hearing Services for Children in Ontario

Permanent hearing loss is one of the most common congenital disorders (Patel & Feldman, 2011). In Ontario, approximately 3 in 1000 babies are born with a permanent hearing loss or will develop a hearing impairment in early childhood (Bagatto et al., 2020). With the introduction of universal newborn screening in the province in 2002, the majority of children are now identified early in life allowing for early intervention. The Ontario Infant Hearing program (IHP), funded through the Ontario Ministry of Children, Community and Social Services (MCCSS), has designated diagnostic and intervention

centres with access to audiologists who have obtained specialized training in evidence-based diagnostic and intervention protocols. For families who choose oral communication, children will grow up using audition supported with hearing aids and/or cochlear implants where appropriate. These children are followed by an infant hearing program audiologist until the age of 6 years, at which time, they transition to community-based audiology services not funded through Ontario's IHP. Young children also have access to a speech-language pathologist (SLP) through the MCCSS, and if families desire, a family support worker, and a home-visiting teacher of the deaf and hard of hearing from the Ontario Provincial and Demonstration Schools Branch.

The scope of practice for an audiologist includes identification, intervention, and management of hearing loss. This includes the responsibility to provide appropriate counselling regarding hearing loss and interventions, referred to as informational counselling. It is also within audiologists' scope of practice to provide affective or personal adjustment counselling which includes discussing the psychological, social, and emotional impact of hearing loss (Elkayam & English, 2003). Young children and/or those recently identified with a hearing loss may see their audiologist more frequently (as often as every 2-3 months) whereas older children and adults may only visit their audiologist on an annual basis. English & Pajevic (2016) note that often adult-level care has shorter appointment times with the expectation that patients can communicate their needs to their clinician. However, several authors have suggested that clinical audiologists are not providing the extensive level of counselling required for their adolescent clients (Clark & English, 2019; Elkayam & English, 2003). Further complicating the counselling relationship, adolescents who typically see their audiologist infrequently, may not necessarily choose to disclose communication problems or other difficulties and concerns they may have (Elkayam & English, 2003).

2.5 Hearing Loss in the Education Setting

2.5.1 Legislation

In Canada, there are a variety of statutes and regulations at the provincial and federal level that inform an individual's right to equal education. The Canadian Charter of Rights

and Freedoms (S7, Part I of the Human Rights Code, 1990) guarantees an individual's civil, political, and equal rights at all levels of government, including publicly funded schools. Section 15 of the Charter guarantees equal protection to all individuals without discrimination based on disability. In 2007, Canada ratified the United Nations' Convention on the Rights of Persons with Disabilities (CRPD, 2007). This international treaty was designed to "promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". Although the CRPD is not part of Canadian law, it provides an obligation to Canada to uphold the human rights of Canadians with disabilities in all areas of life, including education.

In Ontario, the Ontario Human Rights Code (1990) provides protection for individuals with disabilities from discrimination in "services", including education services. The Accessibility for Ontarians with Disabilities Act (AODA, 2005) provides equal opportunity and inclusion for people with disabilities with the aim to make Ontario fully accessible by 2025. This law mandates that organizations must follow standards to ensure accessibility for people with disabilities. The five standards are: information and communications, employment, transportation, design of public spaces, and customer service. Currently, the AODA does not have a standard for education. As of March 2020, committees have been struck to provide recommendations for an education standard for the AODA. However, organizations that provide schooling in Ontario must still follow AODA standards, which inform areas such as, design of new school buildings, renovations to existing buildings, availability of assistive devices, use of communication supports, transportation to and from school, and teacher training.

Specific legislation pertaining to the right to education in Canadian schools is contained in education acts at the level of the provinces and territories. In Ontario, the Education Act (1990) provides legislation to address the identification and placement of *exceptional pupils* (students with special needs), including the need for special education programs and the development of an Individual Education Plan (IEP). The IEP is a written document that outlines the educational plan for a student based on a thorough assessment of the student's strengths and needs that affect the student's ability to learn and

demonstrate learning. An IEP includes, specific educational expectations, special education programs and services that may be required, and how student progress will be reviewed.

2.5.2 School Settings

Historically, students who were D/HH would attend specialty schools for the deaf. Over the years enrollment in these schools has fallen drastically. In Canada, declining enrollment has been attributed to: changes in eligibility criteria for schools for the deaf, advancements in hearing aid and cochlear implant technology, early identification and intervention programs for childhood hearing loss, changes in legislation surrounding accommodations and education rights, and increased capacity of school boards to accommodate children who are D/HH (Millet, 2018; Powers, 2001).

Modern statistics for students who are D/HH placed in mainstream education settings vary widely for the United States and Europe with values as low as 40% (Verhaert, Willems, Van Kerschaver, & Desloovere, 2008). However, reports of 75-87% of students who are D/HH placed in mainstream classrooms seem to be consistent (Foster & Cue, 2009; Luckner & Bowen, 2006; Powers, 2001). More recently in the United Kingdom, The Consortium for Research into Deaf Education (CRIDE, 2019) reported 84% of children with hearing loss are mainstreamed, with only 3% attending schools for the deaf. It is likely that these statistics hold true for the Canadian context. Unfortunately, this type of aggregate data are available at neither the federal nor the provincial level in Canada (Millet, 2019). For example, the Ontario Ministry of Education has data available for the number of students who are identified as D/HH under the Identification, Placement and Review Committee (IPRC)[1] process and the number of students for whom a Specialized Equipment Amount (SEA)[2] claim has been submitted for assistive listening devices for

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[1] Exceptional pupils (i.e. student with special needs) are identified by an Identification, Placement, and Review Committee (IPRC) (Ontario Ministry of Education, 2007)

[2] Special Equipment Amount (SEA) provides funding to school boards to assist with costs of equipment essential to support students with special education needs, where the need for specific equipment is recommended by a qualified professional (Ontario Ministry of Education, 2018)

use in the classroom (Millet, 2019). However, these numbers may not accurately represent the number of students who are D/HH in Ontario schools. Millet (2019) suggests that IPRC numbers "vastly underestimate the number of students with hearing loss" as not all school boards formally label all students as D/HH. In addition, the SEA numbers for assistive listening technology are not representative, as not all students who are D/HH may use an assistive listening device and not all students requiring assistive listening technology in the classroom setting have hearing loss (Millet, 2019).

Educational audiologists and TDHH often work within the public school system providing support services for young people with hearing loss. Both professionals along with their speech-language pathology (SLP) colleagues work closely with students, parents, teachers, other support personnel, and clinical audiologists to ensure students' hearing and communication needs are met.

The educational audiologist is a regulated hearing healthcare professional who is able to make recommendations for appropriate equipment and/or accommodations for students to ensure favourable listening conditions for optimal communication in school and can fit hearing assistive technology (Johnson, 2000). They also act as a liaison between the clinical audiologist and the school to interpret reports and to ensure that appropriate interventions are in place for the student. The educational audiologist may also be involved in the development of a student's IEP.

TDHH are specialist teachers who collaborate and consult with general education teachers, parents, educational audiologists, and clinical audiologists to provide support for students with hearing loss (Foster & Cue, 2009). They adapt instructional materials to be used in the classroom and suggest methods for classroom teachers to better communicate with students. In addition, they help maintain hearing aids and assistive listening devices, they may conduct an environmental assessment of a student's classroom, develop educational plans, monitor student progress, support development of an IEP, and provide academic support for students.

Both educational audiologists and TDHH play an important role within the school system, ultimately providing support and advocating for students' hearing and

communication needs. Due to their role in the school and classroom they are seen more often and consistently than other hearing professionals (Johnson, 2000). Not all school boards may use this model of student support. Depending on the size and allowable budget, a school board may not have the means to employ an educational audiologist or TDHHs, but may instead have a teacher for students with disabilities who ensures recommended accommodations are in place.

2.6   Aural Rehabilitation for Adolescents

Aural re/habilitation programs, typically conducted by audiologists and/or speech language pathologists, are also available in some settings for adolescents who are D/HH (Alpiner, Hansen, & Kaufman, 2000). These types of programs educate individuals about their hearing loss, provide realistic expectations of amplification, introduce and allow practice of communication strategies, and provide speechreading training (Alpiner et al., 2000; Gagné & Jennings, 2008). Aural rehabilitation programs have been shown to be effective for adults with hearing loss who experience communication difficulties when provided in both individual and group formats (Hawkins, 2005; Sweetow & Palmer, 2005). Although aural re/habilitation programs are available for adolescents, it is not commonly implemented in clinical practice and few research studies examine this area of audiology. In the literature, pediatric aural habilitation often does not differentiate between children and adolescents, and focuses on development of listening and language skills, auditory training, and educational management. However, it is recommended that aural re/habilitation programs for adolescents include communication strategies, life-skills, self-advocacy, basic hearing aid care as well as information about hearing aid technologies and assistive listening devices (Clark & English, 2019, 2004; Edwards, 2007; Elkayam & English, 2003; English, 2003).

2.7   Self-Management

Barlow, Wright, Sheasby, Turner and Hainsworth (2002) define self-management as "an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and life style changes inherent in living with a chronic condition" (p. 178). Successful self-management requires an individual to monitor their health condition and

to control the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life (Barlow et al., 2002). Development of self-management of chronic health conditions is associated with improved well-being and increased participation in health care (Sawyer & Aroni, 2005). Although engagement in self-management does not necessarily result in an increase in treatment adherence, it does lead to a better understanding of one's health condition and better commitment to treatment regimens, both of which contribute to improved adherence (Sawyer & Aroni, 2005). The transition to more independent health care is closely associated with autonomy. Adolescents who successfully transition to take on a more independent role in their health care have enhanced autonomy due to an increased sense of personal responsibility and self-reliance (Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Positive autonomy development may also be associated with self-management of health care and positive health outcomes. For example, research looking at adolescent autonomy and chronic pain found that decreased decision-making power for adolescents was associated with increased disability (in this case headache-related functional impairment) (Palermo et al., 2007). This has also been demonstrated in asthma management research where children who were given more responsibility showed greater self-efficacy for asthma management and better adherence to treatment (Ayala, Yeatts, & Carpenter, 2009).

The majority of audiology research does not specifically look at autonomy or the development of autonomy in adolescents who are D/HH. However, it does include studies that look at the development of self-identity, self-efficacy, self-esteem, well-being, and social competence of individuals with hearing loss; all of which have been associated with autonomy. In a review of the literature regarding social-emotional challenges of students with mild to moderate hearing loss, Dalton (2011) suggests that children with hearing loss are at risk for decreased social-emotional functioning, decreased well-being, and decreased formation of identity, all of which are associated with poor development of autonomy in adolescents.

Many children with hearing loss are mainstreamed and experience much of their social interaction with hearing peers. However, several studies indicate that these relationships are not always supportive and many children and adolescents with hearing loss

experience a lack of social acceptance, social isolation, self-consciousness and rejection (Israelite, Ower, & Goldstein, 2002; Kent, 2003; Moeller, 2007). Difficulty with peer relationships for children and adolescents with hearing loss may be associated with poorer social skills due to the decreased ability for incidental learning, decreased ability for social reasoning, and a decreased ability to infer emotions during communication due to their hearing loss (Moeller, 2007; Spangler, 2010). In a study by Israelite et al. (2002), adolescents with hearing loss believed that they lacked knowledge of social rules for communication that their hearing peers utilised, leading to more negative social interactions. Kent and Smith (2006) looked at the impact of peer relationships on children with hearing loss and the development of identity. Results revealed that children with hearing loss who experienced positive relationships with hearing peers were more accepting of their hearing loss and exhibited more self-confidence. However, children with negative relationships had a poor sense of personal identity. The development of poor self-identity can also negatively impact the development of autonomy, as a positive sense of self is required for the successful development of autonomy. Poor social interactions may lead to decreased independence in children and adolescents. Hind and Davis (1998) conducted quality of life measures for children with moderate, severe, and profound hearing impairments. Parents of children with severe hearing impairments in their study reported that the hearing impairment had a significant impact on the child's independence. If adolescents experience more negative social interactions and have fewer same age peers this may increase their dependence on teachers and parents instead of transferring some of their reliance on peers, thus impacting autonomy (Weisel & Kamara, 2005).

Weisel and Kamara (2005) looked at the process of autonomy (specifically attachment and individuation) in 18-35 year old adults who identified as D/HH. They found that deaf and hard of hearing individuals expressed more fear of attachment and more fear of individuation than their typical (normal) hearing peers. They also demonstrated decreased self-esteem and well-being compared to their typical hearing peers. The authors suggest that individuals with hearing loss may have difficulty establishing autonomy during adolescence due to experiences of loneliness, social rejection, social isolation and lower social status due to their hearing loss (Weisel & Kamara, 2005). Michael and Attias

(2016) explored the development of cognitive autonomy in adolescents with hearing loss. Cognitive autonomy is the ability for an individual to evaluate thoughts, voice opinions, and make decisions. They found that perceived social support, particularly from parents, was a predictor of cognitive autonomy in adolescents. In addition, they found adolescents with hearing loss reported lower levels on the cognitive autonomy variable of *voicing opinion*. The authors suggest that adolescents who are D/HH may more often find themselves in contexts where they are unable to express themselves fully due to communication barriers. Results also indicated adolescents who are D/HH had higher levels of comparative validation which may represent lower levels of independent thinking (Michael & Attias, 2016).

It is apparent that adolescents with hearing impairments may be at risk for decreased self-identity, self-esteem, peer support and social competence compared to peers with typical hearing. These concepts have all been associated with autonomy in adolescents. In addition, the chronic illness literature provides several examples of how children with chronic health conditions may experience delays in the development of autonomy and the implications this may have on health management and outcomes. Therefore, it is possible that adolescents with hearing impairments are at an increased risk for delayed or decreased autonomy which may impact their ability to effectively manage their hearing healthcare (English & Pajevic, 2016). Recognizing the impact that hearing loss may have on the development of autonomy is extremely important, primarily due to the significant role that autonomy plays in the transition to adulthood. Delays in the development of autonomy will inhibit successful adolescent transition to become independent functioning adults. Therefore, the development of autonomy has significant implications for adolescent self-management of their hearing healthcare.

Health care practitioners can promote adolescent autonomy within the healthcare setting, which may improve the potential for effective self-management of health conditions. Several authors in the chronic illness literature suggest that it is essential for adolescents to acquire knowledge about their health condition, be involved in the decision-making process and obtain more responsibility in order to promote healthy development of autonomy and self-management of health care (Jurasek, Ray, & Quigley, 2010; Karlsson

et al., 2006; Westwood et al., 1999). It is recommended that providing children and adolescents information about their health should be an ongoing process; providing age-appropriate information about health conditions and associated health care needs at various stages throughout childhood and adolescence. As children mature and demonstrate the ability to manage certain health related tasks, they should then be allowed to take on more responsibility with their health care management. The ability for a young person to be successful in effectively using health knowledge is impacted by their health literacy. Health literacy is defined as the ability for an individual to read, write, understand, derive meaning, and critically evaluate health information (Nutbeam & Kickbusch, 2000). Ultimately, adolescents will be better equipped to self-manage their health care if they are able to: determine when they need to see a healthcare practitioner, ask questions relevant to their health care needs, navigate the healthcare system, schedule appointments, and understand costs that may be associated with their illness and/or disability (Callahan, Winitzer, & Keenan, 2001; Jurasek et al., 2010).

2.8 Transition Planning

Findings from the chronic illness literature can be applied to hearing healthcare and can help us to better understand the implications of hearing loss on adolescent autonomy and self-management of hearing healthcare. It is important to note that there are some significant differences between hearing healthcare compared to the management of chronic health conditions. First, chronic illnesses and associated complications may be life threatening. Inappropriate health management may lead to death or permanent disability, which may pose as a barrier in transition planning. In addition, much of the chronic illness literature focuses on transitioning from pediatric to adult health care services. Although there are some exclusively pediatric audiology facilities, there are many children who obtain their hearing healthcare from clinicians who see both adults and children. Therefore, the transition that is marked by age and the termination of services in a pediatric facility may provide a more apparent timeline for considering adolescent self-management of chronic illnesses, which is not always applicable to audiology.

Awareness surrounding the need for transition planning in audiology is emerging. Pajevic and English (2014) strongly suggest the need for health care transition planning to be considered standard of care for pediatric audiology patients. They proposed a three-stage model for transition planning and developed a set of goals for knowledge and skill development (see Appendix A for a full list of health goals). In addition, they have proposed the use of the World Health Organization International Classification of Functioning, Disability and Health: Children and Youth Version (WHO: ICF-CY, 2007) as a framework for transition planning in pediatric audiology (English & Pajevic, 2016). This is because the ICF-CY provides a model that engages the end-user (in this case the adolescent) and promotes patient education, goal setting, and skill building by identifying areas of activity limitations and participation restrictions that are important to them.

Chapter 3

3 Methodology

This study was conducted using a constructivist grounded theory approach. The following will provide a background to grounded theory, the different schools of grounded theory, details of constructivist grounded theory, and the rationale for the choice of constructivist grounded theory for this study.

3.1 Theoretical and Philosophical Considerations

Different forms of grounded theory have evolved since its development by Barney Glaser and Anselm Strauss in 1967, to better fit the various research paradigms within qualitative research and the ontological and epistemological positions of each (Mills, Bonner, & Francis, 2006b). A paradigm is a set of assumptions, concepts, values, and practices that constitute a way of viewing reality and the social world and in turn provides a philosophical and conceptual framework for the study of the world (Guba & Lincoln, 1994; Ponterotto, 2005). This includes one's assumptions regarding ontology (the study of the nature of being, existence, and reality) and epistemology (the study of the origin, nature, and limits of human knowledge). Ontological and epistemological beliefs create a framework for how one views the world and how research is conducted. Assumptions regarding the nature of reality and how we are able to obtain knowledge sit on a continuum; positivist ideas of objectivity and realism (traditional scientific inquiry) are at one end of the continuum and interpretivist notions of subjectivity and realism (qualitative inquiry, including grounded theory) are at the other (Meston & Ng, 2012). For a table summarizing definitions and relationships of paradigms, ontologies and epistemologies, see Table 1.

Table 1: Philosophical and Theoretical Perspectives and Their Implications for Research (adapted from Meston and Ng (2012)**;** Plano-Clark and Creswell (2007))

Worldview Element	Postpositivism	Constructivism	Pragmatism
Ontology: nature of reality	One reality that we can *strive* to measure	Multiple perspectives, individual realities, that we can *strive* to represent	Singular and multiple realities, depending on topic
Epistemology: the theory of knowledge	Knowledge can be *objectively* found through impartial methods	Researchers and participants co-construct knowledge (knowledge acquisition is subjective)	Collect data depending on "what works" to address a particular research question
Methodology: system of methods chosen	Deductive, predictive, controlled, explanatory (e.g. experimental design; survey research)	Inductive, understanding, meaningful, naturalistic, descriptive (e.g. grounded theory, ethnography, narrative)	Practical, problem solving, addresses the question through appropriate means (e.g. mixed methods)
Methods: the techniques used to gather and analyze data	Questionnaires, statistical analysis	Interviews, focus groups, naturalistic observation, writing, document review	Both quantitative and qualitative methods
Language: how the research is presented	Formal (third person)	Informal (first person, literary, analogical)	Formal or informal

3.2   Development of Grounded Theory

Grounded theory is defined as a systematic, inductive, and comparative approach for conducting inquiry for the purpose of developing theoretical explanations of social processes and to explain issues of importance in people's lives (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Three major schools of grounded theory are recognized, as described by, Glaser and Strauss (Glaser & Strauss, 1967), Juliet Corbin and Strauss (Corbin & Strauss, 2008), and Kathy Charmaz (Charmaz, 2006). These forms have evolved to better fit the various research paradigms within qualitative research and the ontological and epistemological positions of each (Meston & Ng, 2012; Mills et al., 2006b). The following will provide a brief history of grounded theory and discuss the different theoretical and philosophical underpinnings of each.

3.3   Three Schools of Grounded Theory

Previous guides to qualitative research focused on data collection with little guidance for analysis. In the development of grounded theory, Glaser and Strauss, built on the works of earlier qualitative researchers to provide explicit procedures and research strategies that aimed to move qualitative inquiry beyond descriptive studies (Charmaz, 2006). Their work challenged the contemporary views of qualitative research as being unsystematic and less rigorous than quantitative research (Charmaz, 2006). It also encouraged researchers to pursue qualitative research by providing a systematic guide for data analysis (Charmaz, 2006).

Glaser and Strauss' contributions to grounded theory were heavily influenced by their prior experiences. Glaser, trained in quantitative research at Columbia University, contributed his positivist assumptions, inductive logic, and a systematic approach to grounded theory (Charmaz, 2000; Meston & Ng, 2012). Strauss, influenced by symbolic interactionism having studied at the University of Chicago under Herbert Blumer and Robert Park, contributed pragmatist ideas of process, action, and meaning to grounded theory (Charmaz, 2000; Corbin & Strauss, 2008; Meston & Ng, 2012).

Glaser and Strauss would later part ways, as they disagreed with one another regarding the future direction of grounded theory, with Glaser remaining true to the original methodology (Meston & Ng, 2012). Strauss went on to collaborate with Corbin, a nurse with a theoretical orientation in pragmatism and interactionism, and introduced new technical procedures for data analysis in grounded theory (Mills, Bonner, & Francis, 2006a).

Kathy Charmaz, once a student of both Glaser and Strauss, developed Constructivist Grounded Theory by building on the "pragmatist underpinnings in grounded theory and developing it as a social constructionist method" (Charmaz, 2005, p. 509). Charmaz (2006) suggests that the basic components and methods of grounded theory (described in section 3.4) are "neutral" and "flexible" to fit with a researchers own epistemological and ontological beliefs (2006, p. 9).

Glaser has been critical of forms of grounded theory that stray from the traditional grounded theory method (Meston & Ng, 2012). However, the need to redefine grounded theory to reflect philosophical shifts within qualitative research has been acknowledged (e.g. Bryant, 2002, 2003; Clarke, 2003; Meston & Ng, 2012; Seale, 1999).

3.3.1 Glaserian Grounded Theory

Theory generation through traditional, or Glaserian grounded theory, is conducted from a positivist perspective and thought to be reflective of one true reality that is present and must be discovered (Glaser & Strauss, 1967). Glaser also sees the role of the researcher as an unbiased observer. This is evident in the application of theoretical sensitivity where the researcher is recommended to eliminate bias by entering the field without any predetermined thoughts about the research (Glaser & Strauss, 1967). This includes refraining from conducting a preliminary literature review to avoid contaminating the data (Glaser & Strauss, 1967). This is an objectivist perspective, which assumes that the data can be separate from the participant and researcher. Glaser (2002) also holds the positivist view that the researcher is the authoritative expert in the research process; he writes of some grounded theorists "...they forget that the participants are the data, NOT the theorists" (p. 29; emphasis in original).

3.3.2 Pragmatist Grounded Theory

Corbin and Strauss have been described as *relativist pragmatists* (Mills et al., 2006b), generating theory that can explain or predict phenomena (Charmaz, 2006; Corbin & Strauss, 2008; Rennie, 2000). Corbin and Strauss' methods and research strategies are based on pragmatist and interactionist philosophies. Corbin writes that her work has also been influenced by contemporary feminists, constructionists, and postmodernists (Corbin & Strauss, 2008).

In their earlier work Corbin and Strauss seemed to espouse both post-positivist and interpretivist assumptions (Charmaz, 2000). They demonstrate a relativist ontology by rejecting the notion of one true reality and recognizing that individuals may experience the world differently. They also demonstrate interpretivist or critical ideas in recognizing that data analysis includes the researcher's interpretations (Corbin & Strauss, 2008). However, they lean toward a more objectivist epistemology in some of their work when they discuss maintaining objectivity as well as recognizing and minimizing researcher bias (Corbin & Strauss, 2008). It has been suggested that "people can find support for any ontology they wish" in Strauss and Corbin's version of grounded theory (Mills et al., 2006b, p. 28). However, it has been argued that conflicting language in some of Strauss and Corbin's work may simply be evidence of the changing assumptions within qualitative research over time (Meston & Ng, 2012; Mills et al., 2006b).

3.3.3 Constructivist Grounded Theory

Constructivist theory is concerned with *how* and *why* participants construct meaning and actions from their experiences and views the research process as created from shared experiences between the researcher and participants (Mills et al., 2006b). The idea of the co-construction of knowledge between the researcher and participants is at the forefront of constructivist grounded theory (Charmaz, 2006).

Constructivist grounded theory looks to uncover the experiences of participants within a specific social context, including other individuals within that context that may impact the participant directly or indirectly. Therefore, constructivist grounded theory can

explore a particular phenomenon under study, and the hierarchies of power within the context that perpetuate the phenomenon (Charmaz, 2006; Meston & Ng, 2012).

A constructivist approach to grounded theory takes on an interpretivist perspective with a relativist ontology and subjectivist epistemology (Meston & Ng, 2012). Ideas of relativism include recognition of the existence of multiple realities that are dependent on the participants' different perspectives as well as the context in which actions occur (Charmaz, 2006). A subjectivist stance acknowledges that interpretation of the data depends on the researcher's own experiences; the data and analysis can never be independent from the researcher (Charmaz, 2006).

Charmaz also moves constructivist grounded theory further away from that of Glaser, Strauss, and Corbin in the writing of the research. Grounded theory research has been traditionally written in third person. This suggests a positivist/post-positivist perspective, placing the author as separate from the research and maintaining a position of "distant expert" (Mills et al., 2006a). Charmaz (2006), however, states that writing matters and reflects the choices authors make. She encourages authors to include his/her own voice and to acknowledge his/her role in the research experience. Thus, constructivist grounded theory manuscripts can be written in first-person and can use more literary or narrative styles of writing. Authors can utilize various writing techniques such as, rhetorical devices, analogies, or metaphors that can provide richness, stir emotion, and catch a reader's attention (Charmaz, 2006).

3.4   Grounded Theory Methods

The main concepts and methods of grounded theory developed by Glaser and Strauss included theoretical sensitivity, theoretical sampling, constant comparative method of data analysis, coding, memo-writing, and the simultaneous involvement in data collection and analysis. Although all these methods are used in each of the three schools of grounded theory, they are defined and/or implemented differently depending on the type of grounded theory chosen. The following will review the above methods from a constructivist point of view. Table 2 provides a comparison of grounded theory methods across the three schools of grounded theory.

3.4.1 Theoretical Sensitivity

Theoretical sensitivity considers the researchers' knowledge and insight that they bring to the research area. It also addresses how sensitive they are to the complexities present in the participants' words and actions in order to reconstruct meaning from the data (Glaser & Strauss, 1967). Glaser and Strauss (1967) suggest researchers enter the research field without any preconceived theories to ensure sensitivity to the data. However, in constructivist grounded theory, researchers' acknowledge their contribution to the research process and theoretical sensitivity is achieved through reflexivity (Charmaz, 2006).

3.4.2 Literature Reviews

The literature review in grounded theory is greatly debated. Traditional grounded theory suggests delaying the literature review in the early stages of the research to avoid developing preconceived assumptions of the area under study and forcing the data (Glaser & Strauss, 1967). From a constructivist perspective, prior knowledge of the topic and the literature becomes part of theoretical sensitivity. Therefore, prior knowledge of the literature will inevitably influence the research (i.e. the nature of the research question and the type of research that is conducted) and is acknowledged by the researcher (Charmaz, 2006).

3.4.3 Reflexivity

Reflexivity is an important component of constructivist grounded theory. It has been defined as a "...reflective activity within qualitative research" (Neill, 2006, p. 254) that occurs on an effective and affective level. Therefore, reflective thinking can focus on the process of the research (effective level) and on self-awareness on the part of the researcher (affective level) (Neill, 2006). A reflexive stance allows the researcher to examine their own role in the research experience as well as decisions and interpretations made throughout the research process (Charmaz, 2006). This also allows the reader to assess how the researcher's own assumptions influence the research process (Charmaz, 2006).

3.4.4 Memo-Writing

Memo-writing is a reflective tool to examine where the researcher is in relation to the area of interest. It is used to uncover underlying assumptions and biases, making them explicit to both the researcher and eventually to the readers of the study (Mills et al., 2006a). Memo-writing is also used to record the researcher's thoughts about the research process, and to "...remember, question, analyse and make meaning about the time spent with participants and the data that were generated together" (Mills et al., 2006a, p. 11). Memo-writing is considered an important method in constructivist grounded theory that prompts the researcher to analyze the data and codes early in the research process (Charmaz, 2006). The process of memo-writing produces analytic notes that facilitate the development of theoretical categories (Charmaz, 2006). Memos provide an opportunity for making comparisons between data, codes, categories, and concepts and to explore relationships between them (Charmaz, 2006).

3.4.5 Theoretical Sampling

Theoretical sampling is employed for recruitment in grounded theory to forward theory construction and not to be representative of a specific population (Glaser & Strauss, 1967). Charmaz (2006), defines theoretical sampling as "seeking pertinent data to develop your emerging theory. The main purpose of theoretical sampling is to elaborate and refine the categories constituting your theory. You conduct theoretical sampling by sampling to develop the properties of your category(ies) until no new properties emerge" (p. 97).

3.4.6 Theoretical Sufficiency

In grounded theory, it is suggested that data collection should be terminated when theoretical saturation is reached. Theoretical saturation is defined as "when gathering fresh data no longer sparks new theoretical insights nor reveals new properties of [the] core theoretical categories" (Charmaz, 2006, p. 113). This does not mean that the same patterns have been observed multiple times in the data, rather the comparisons between data no longer yields new properties of the categories (Charmaz, 2006). Theoretical

saturation is independent from sample size and achieving saturation is paramount to sample size, allowing sample size to potentially be very small (Glaser, 1992).

Charmaz (2006), states that the term 'saturation' is often used uncritically, which may result in researchers assuming categories are saturated when they are not. She cautions that superficial research questions and uncritical or limited analysis of the data may result in early saturation of categories (Charmaz, 2006). Dey (1999) also challenges the use of the term 'saturation' because achievement of theoretical saturation cannot be demonstrated as it is based on researcher interpretation. Instead, he proposes that in grounded theory, categories are suggested by the data and that researchers instead achieve 'theoretical sufficiency' (Dey, 1999).

3.4.7 Constant Comparative Method

The constant comparative method is the method of analysis used in grounded theory. This inductive process involves making comparisons between the data during each stage of analysis resulting in more abstract concepts and theories (Charmaz, 2006). Glaser and Strauss (1967) outline the defining rule for the constant comparative method: "while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (p. 106). For example, one would compare interview data from the same interview and then compare to subsequent interviews. As categories are developed from the data, theoretical properties of the categories begin to emerge. As coding continues, the unit of comparison changes from comparing data with data to making comparisons between the category properties and the data. This type of comparative analysis looks for similarities and differences within the data and ultimately grounds the researcher's final theorizing in the participants' experiences (Charmaz, 2006; Glaser & Strauss, 1967).

3.4.8 Coding

Charmaz (2006) describes coding in grounded theory as the link between collecting data and developing an emergent theory; it is the first step of data analysis. Coding allows the researcher to define what is happening in the data and to begin to determine what it means. Coding consists of two main phases that include an initial phase which involves

coding for each word, line, or segment of the data which is then followed by focused coding which uses the most frequently occurring initial codes to "sort, synthesize, integrate, and organize large amounts of data" (Charmaz, 2006, p. 46). Finally, in theoretical coding a more sophisticated level of coding is conducted where the relationship between codes is analyzed to develop theoretical integration of identified categories (Charmaz, 2006).

Table 2: Grounded Theory Schools - Comparison of Methodology-Methods

(adapted from Meston and Ng (2012))

	School of Grounded Theory		
Grounded Theory Method	**Glaserian (Glaser and Strauss)**	**Pragmatist (Corbin and Strauss)**	**Constructivist (Charmaz)**
Theoretical sensitivity: what knowledge the researcher brings to the research (beliefs, assumptions, skills)	Grounded theory emerges from the data. Bias is eliminated through constant comparative method. Role of literature review minimized.	Literature and professional experience help guide data collection and analysis. Researcher bias should be minimized.	Researcher should acknowledge role in research process. Reflexivity is important.
Reflexivity: reflective thinking used during the research process	No need for reflexivity Researcher seeks to accurately represent what is occurring. Bias eliminated through constant comparative method.	Important, as researchers may unconsciously affect their participants. Reflexivity may uncover researcher influence and help to minimize influence.	Inherent. Reflexive stance taken throughout process, allows the reader to assess how and to what extent the researcher may have influenced inquiry.
Theoretical sampling: seeking pertinent data to develop the emerging theory	Use of multiple comparison groups, groups provide conceptual and population control to maximize and minimize similarities between groups.	Sampling is dependent on the data, rather than pre-established prior to data collection, flexible and open. Sampling concepts, not participants.	Aim is to develop properties of the developing theory, not to randomly sample population. Seek data to uncover and define categories.
Theoretical saturation: the point at which data collection should be terminated	Occurs when no new relevant data emerges, category properties can withstand variation in context of the phenomenon, relationships among categories are well established.	When properties, dimensions, and variations of categories are well developed. Further data collection and analysis add little or new insight (although variations can always be discovered).	Further data collection and analysis results in no new theoretical insights, nor new properties of core theoretical categories. The term theoretical sufficiency is preferred.

3.5 Methodology Rationale

Audiology research is heavily influenced by positivist and post-positivist ideals and the medical or curative models of health (Gagné, Hétu, Getty, & McDuff, 1995). The professional practice of audiology is based on traditional notions of evidence-based practice that value objective research and notions of absolute knowledge and generalizability of findings. Quantitative research has played a significant role in generating knowledge for audiology practice. However, there are research questions that are better suited to qualitative inquiry. Qualitative research includes a broad range of empirical procedures that are used to describe and interpret the experiences of research participants often in a context-specific setting (Pope & Mays, 1995). For example, questions that attempt to uncover emotions, perceptions, processes, or experiences of individuals in certain situations may be better suited to qualitative analysis compared to traditional quantitative methods (Meston & Ng, 2012). The use of qualitative inquiry has a rich history in the social sciences, nursing, education and some areas of rehabilitation science. Historically, within audiology research the use of qualitative methodologies has been limited but is gaining popularity. Within rehabilitation sciences qualitative research is considered a useful mode of inquiry to help answer important questions about how an individual may experience a particular disability or illness and how an individual's experience may change depending on their, social, economic, or cultural context (Kearney, 2001). As well, qualitative research can also look at how people create meaning from their circumstances (Finlay, 2006). This knowledge is particularly important for individuals with disabilities like hearing loss. How individuals understand their own disability may impact how they cope with their disability and/or affect feelings of self-efficacy for that individual.

The type of grounded theory used in a study is dependent on the research question, the desired resulting theory, as well as the fit with the theoretical and philosophical beliefs of the researcher. The aim of the current study was to explore the process of transition for adolescents toward the self-management of their hearing healthcare. A literature search confirmed that there is emerging interest in this area of hearing healthcare. In addition, current literature in other health fields suggests learning to manage one's health care is a

complex process that involves several factors. Constructivist grounded theory was chosen as I believe a constructivist approach not only fits well with my personal theoretical and philosophical beliefs, but also with the nature of the research question. Grounded theory is an appropriate approach to study my research topic because it is suitable for answering questions about basic social processes (Charmaz, 2006; Glaser & Strauss, 1967) and is appropriate where there is limited pre-existing evidence present in the literature (Stern, 1980). In addition, I am interested in the experiences of adolescents within their specific context or *reality*. All three forms of grounded theory allow researchers to uncover the social processes at work, but constructivist grounded theory also asks *why* that process is occurring. I believe that knowing *why* is an important aspect of the research question as it allows the resulting theory to be clinically relevant and inform the development of appropriate solutions, suggestions, or interventions. Finally, constructivist grounded theory considers and uncovers power hierarchies that are present within the specific context of the phenomenon under study. Considering and understanding the power hierarchies within the context of studying adolescent hearing healthcare is particularly important as there are many individuals in an adolescent's life (for example, parent, educator, or audiologist) who hold positions of power.

Chapter 4

4 Study Design

This study was conducted using a constructive grounded theory approach. Adolescents who are D/HH, parents, hearing resource teachers (HRT), and audiologists were recruited from a Canadian city to take part in interviews regarding adolescent transition toward the self-management of hearing healthcare. Participant recruitment was conducted in partnership with a local school board.

4.1 Ethics

4.1.1 Ethics Approval

Ethics approval (#102820) was obtained for this study through Western University's Health Sciences Research Ethics Board (Appendix B, Appendix C, Appendix D). Once ethics approval was obtained by Western University the ethics application and approval was reviewed and approved by the participating school board.

4.1.2 Ethical Considerations

It is imperative to consider the ethical rights of minors during research studies. All adolescents involved in this study were provided their own letter of information and were asked to sign a separate assent form prior to participating in this study. All adolescent participants were given the opportunity to ask questions regarding the research study prior to the start of interviews. As well, they were given the choice as to whether they would prefer their parents to be present during their one-on-one interview.

Personal information was collected for contact purposes only and was not shared with individuals outside of this study. Contact information and video recordings are stored in a secure location at The University of Western Ontario. Interview transcripts were de-identified. Participants were informed that recorded data would be retained for 10 years, at which time it would be destroyed.

4.2   Research Team

The research team consisted of myself, three researchers from the Faculty of Health Sciences at Western University, and student research assistants. As noted in my personal statement (section 1.1), I have a background as a clinical audiologist with pediatric and adult populations, having worked in both private practice and hospital settings. I am currently a faculty member in the School of Communication Sciences and Disorders at Western University where I divide my time between teaching, clinical supervision, and research. Dr. Mary Beth Jennings' background is in clinical audiology and her research explored aural rehabilitation outcomes for adults with hearing loss, stigma and disclosure of hearing loss, as well as assessing workplace accessibility for adults with hearing loss. Dr. Cheesman's research studied hearing loss in older adults, including speech perception and effects of listening in noise. Both Dr. Jennings and Dr. Cheesman were on faculty in the School of Communication Sciences and Disorders and affiliated with the National Centre for Audiology. Dr. Marilyn Evans is a registered nurse affiliated with the Arthur Labatt Family School of Nursing. Her research explores maternal newborn health, patient centred care, and global health, with an interest in qualitative methodologies. The student research assistants were students in the Masters of Clinical Science program in audiology at Western University who volunteered or worked in Dr. Jennings laboratory.

4.3   Participants

Participants for this study included adolescents who are D/HH, their parents and/or guardians, clinical audiologists practicing in the community, and HRTs. These particular individuals were chosen to participate in this study because they all play a significant role in a child's hearing healthcare. A total of 24 individuals participated in this study.

4.4   Participant Recruitment

Participant recruitment was conducted in partnership with a local school board and through the community.

4.4.1 School Board

Once ethics approval was obtained through Western University, the school board reviewed the approved ethics and I was provided with a liaison at the school board to assist with recruitment. I was invited to a meeting with the HRTs working within the school board, arranged by my liaison. At this meeting, the HRTs were briefed on the research study and were provided information packages to distribute to families of adolescents who are D/HH (Appendix E, Appendix F). HRTs were also invited to participate in the study and were provided the letter of information for adult participants (Appendix E). The school board was provided posters to advertise ongoing recruitment (Appendix G, Appendix H). Interested participants were to contact me by phone or email. HRTs who assisted with recruitment were not obligated to participate in this study.

4.4.2 Community Audiologists

The letter of information for adult participants was distributed to community audiologists, outlining the opportunity for their participation in the research study (Appendix E). They were also asked if they would consider sharing the information package to interested families on their caseload or post the advertisement poster in their clinic. Audiologists who assisted with participant recruitment were not required to participate in the research study and those that did choose to participate were not obligated to recruit their own patients.

4.4.3 Families

HRTs and community audiologists distributed information packages to families of adolescents with hearing loss attending elementary and secondary schools within the school board. Interested families were instructed to contact me directly by telephone or email. Two hundred information packages for families were distributed through the school board and local clinics.

4.5   Participant Demographics

4.5.1 Adolescent Participants

Nine adolescents (5 males, 4 females), ranging in age from 10 to 17 years (average age 13.5 years) participated in this study. Criteria for participation included individuals who had been diagnosed with a permanent, congenital or early identified, hearing loss and communicated through the aural/oral modality with English as their first language. Early identified hearing loss was defined as identification of hearing loss prior to entry to school. Participants with co-morbidities were not excluded from this study. However, participation was dependent on the young person's ability to take part in the one-on-one interview and to complete the take-home journal. Degree and configuration of hearing impairments ranged across participants, from mild to profound, including both bilateral (7 participants) and unilateral hearing losses (2 participants). Four participants wore binaural hearing aids, 1 wore a CROS[3] hearing aid, and 1 had a cochlear implant (unilateral). Three participants did not use hearing aids or cochlear implants but used hearing assistive technology in the classroom at school. All adolescents were followed by their own audiologist at the time of this study.

4.5.2 Parent/guardian Participants

Nine parents/guardians (all female) participated in this study. Inclusion criteria included proficiency in English and having the role of primary care giver for a child with hearing loss. Eight individuals were the mothers of the adolescent participants, and one individual was a female family member who acted as primary guardian.

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[3] Contralateral routing of signal (CROS) system is used when one ear presents with normal hearing and the other ear has very little residual hearing and is un-aidable. A microphone/transmitter is worn on the worse ear and transmits the signal to a hearing aid on the good or better ear.

4.5.3 Hearing Resource Teachers and Audiologists

Three clinical audiologists (1 male, 2 female) and three HRTs (all female) participated in this study. Clinical audiologists and HRTs were working with children within the age range under study at the time this study was conducted.

4.6 Data Collection

Consent forms were signed by all participants prior to participation in this study and adolescent participants signed an assent form (Appendix K and Appendix J). Parents were asked to complete a release of information form to allow access to adolescents' audiometric results (Appendix K). A brief case history was conducted for adolescent participants (Appendix L).

4.6.1 Interviews

I conducted all interviews either at the National Centre for Audiology (NCA), Western University, at a participant's home or office, depending on the preference of the participant. One-on-one, in depth semi-structured interviews were conducted with all participants (see Appendix M, Appendix N, Appendix O for all interview guides). Interviews were approximately 1 hour in length. All interviews were audio recorded and interviews conducted at the NCA were also video recorded. Video recordings were done to allow us to view participant body language and facial expressions during the interview to assist with interview transcription if the case arose where audio recordings were difficult to interpret. Interview guides were developed by the research team, questions were adapted as subsequent interviews were completed to address new concepts or ideas that emerged. The line of questioning during interviews was flexible because various topics arose spontaneously during the interviews.

4.6.2 Journals

Adolescent participants were given the opportunity to complete a take-home journal to write down their thoughts about their hearing loss and how they manage their hearing loss, once the interview was complete (Appendix P). Journals had prompt questions, as well as a section where the young person could write on any topic of their choosing.

Young people were also provided the option to draw pictures, instead of writing, to share their thoughts or feelings. None of the young people who completed the journal chose to draw. Journals were accompanied with a self-addressed envelope with postage for participants to return once complete. Participants were also provided the option to return the journal themselves at the H.A. Leeper Speech and Hearing Clinic at Western University or I could pick up the journal from a location that was convenient for the family (e.g., home, place of work). However, only five of nine journals were returned; one family requested I pick up the journal, one family returned the journal to the H.A. Leeper Speech and Hearing Clinic, and three families returned the journal by mail. I sent a reminder by email and telephone to three of the four families with outstanding journals; one family was contacted by telephone only. A reminder to return completed journals was provided 1 week, 3-4 weeks, and 2 months post interview.

4.7   Data Management

Transcripts from interviews were transcribed verbatim and uploaded to Nvivo 10 data analysis software (QSR International Pty Ltd., 2010). I trained a student research assistant and together we transcribed the interviews. I reviewed all audio recordings and transcriptions to ensure accuracy of transcriptions. Journal entries were electronically scanned and uploaded to Nvivo 10. Nvivo 10 software was used solely to aid in the organization of data during analysis and was not used for automated development of themes.

4.8   Data Analysis

Data collection and analysis occurred concurrently which allowed for the data to guide future data collection and informed subsequent interviews (Charmaz, 2006).

4.8.1 Constant Comparative Method

The constant comparative method (described in section 3.4.7) was used to examine relationships within and across codes and categories identified in the data. This entailed coding the data and comparing interview statements within the same interview and then

making comparisons of statement across interview data. This was an iterative process that occurred throughout data collection and analysis.

Initial line-by-line coding of the interview transcripts, as described by Charmaz (2006), was conducted. Charmaz suggests coding the data as actions as a way to stay true to the data (Charmaz, 2006). Therefore, coding used the participants own words found in the text that were representative of the experience being coded as well as to use action words for these initial codes to help realize the social processes underlying the experience. During the second phase of coding (focused coding) the initial codes were sorted and grouped to see which initial codes were able to best categorize the data completely (Charmaz, 2006). This "phase" of coding did not occur linearly, some focused codes were developed earlier and others were developed later in the research process. During this process, codes were synthesized into larger categories. However, in some instances large categories were later divided into smaller separate categories as analysis continued. Once the coding was refined, theoretical coding involved analysis of the data to further explore the relationships between codes and to elevate the data to a conceptual level. The research team met several times during the coding process to discuss the emerging codes and categories. At each phase of coding, research team members would review interview data and representative quotes independently in attempt to avoid bias and to reveal any discrepancies in the interpretation of participant meaning.

4.8.2 Diagramming

Charmaz (2006) suggests that diagrams "offer concrete images of our ideas…providing a visual representation of categories and their relationships" (pg. 117). Diagramming was utilized at several points during data analysis. It was used during focused coding to help organize the data, illustrate potential processes present in the participants experiences, and to observe relationships between codes and categories. Finally, during theoretical coding an interpretive model was developed to provide a meaningful representation of the data.

4.8.3 Reflexivity and Memo-Writing

I engaged in reflexivity through memo-writing and discussion with supervisors and committee members during data collection and analysis. This reflexivity allowed me to acknowledge and address personal biases during the research process. Memo-writing was completed after each interview to help revise the interview guide. Memo-writing was also completed after meetings with the research team to further develop ideas that were broached during discussion. Memo-writing was conducted during data analysis to document ideas and emerging relationships between concepts and categories, eventually informing the grounded theory. Participant statements were integrated into the memos, which eventually developed into the findings section of this document.

4.8.4 Theoretical Sufficiency

Theoretical sampling was used to reach theoretical sufficiency as described by Charmaz (2006). Theoretical sufficiency was declared and data collection ceased when subsequent interviews did not result in the identification of novel concepts, categories, or their properties. Early analysis during the data collection process and memo-writing helped to identify gaps in the data and informed future interview directions and testing of emerging theories. Memo-writing also allowed me to uncover and acknowledge my own biases regarding developing categories and theories. It also was used to ensure categories were not closed or considered redundant prematurely. Interviews later in the research process elicited limited or no new/novel categories, and redundancies began to emerge. However, these interviews were used to confirm or test emerging theories.

4.9 Quality Criteria

It is important to provide appropriate criteria for which a study can be evaluated. Charmaz states that "criteria for evaluating research depend on who forms them and what purposes he or she invokes" (2006, p. 182). Charmaz suggests four quality criteria for use in grounded theory studies: credibility, originality, resonance, and usefulness.

To ensure the criteria of *credibility* has been met the researcher should: achieve intimate familiarity with the setting or topic under study, ensure data are sufficient as to merit any

stated claims, conduct systematic comparisons between observations and between categories, and develop categories that cover a wide range of empirical observations (Charmaz, 2006). The researcher must also develop strong logical links between the gathered data, the argument, and analysis (Charmaz, 2006). Finally, the research should provide enough evidence to allow the reader to form an independent assessment and agree with the researcher's claims. For the current study, credibility was achieved through engagement with participants who had lived the experience under study and in-depth interviews from a range of participants (including young people who are D/HH, parents, audiologists, and HRTs). The use of two data sources (interviews and journaling), the use of direct quotes from participants, as well as input and feedback from the research team members also contributed to credibility.

To achieve *originality* categories offer new insights to the topic under study, provide social and theoretical significance as well as challenge, extend, or refine current ideas concepts and practices (Charmaz, 2006). To determine originality, once data analysis was complete, I returned to the literature to look for similar findings using the results of this study to determine how these findings contribute to extant knowledge on this topic. Novel findings from this study are addressed in the discussion section of this manuscript.

Charmaz (2006) suggests that to support the criteria of *resonance*, developed categories should portray the fullness of the studied experience, and the analysis offers individuals a deeper insight into individuals lives and worlds. Data collected across three groups of stakeholders allowed for richness of data in which we could observe agreement and sharing of beliefs from different perspectives. As themes emerged, those ideas and concepts informed the interview guide for future interviews with subsequent participants to ensure they resonated with them as well. During interviews, clarification was sought to ensure understanding of participant statements. Concepts were developed and described using participants own words paraphrased from the interview transcripts.

Finally, to satisfy the criteria of *usefulness*, grounded theory analysis should provide practical and useful interpretations, provide categories that suggest generic processes, and examine these processes for tacit implications (Charmaz, 2006). The research should also

spark research in other substantive areas, contribute to knowledge, and contribute to the betterment of the world. The usefulness of this study is addressed in the discussion and conclusion section of this manuscript where I offer an interpretation of the results and how these results can inform future research studies and clinical practice.

Chapter 5

5   Key Findings

Through analysis of interviews with adolescents who are D/HH, hearing resource teachers (HRT), and audiologists the core grounded theory concept of "*I am the expert*" and four key concepts were identified: *developing ownership*, *managing identity*, *developing advocacy*, and *doing it myself*. Table 3 summarizes the identified categories and their subcategories. This section will describe and illustrate each of the above-mentioned categories and subcategories that support the *"I am the expert"* model using the participants own words.

Table 3: Summary of Identified Concepts and Categories

Concept	Categories and subcategories
Developing ownership	Building knowledge • Knowing myself • Sharing knowledge Making my own decisions • Sharing decision making • Compromising • Developing trust
Managing identity	Evolving identity Disclosing hearing loss Having a sense of belonging
Developing advocacy	Speaking up Standing out Nurturing advocacy
Doing it myself	Checking in and letting go Moving on

5.1   Developing Ownership

This category describes how developing a sense of ownership toward their hearing loss and devices contributed to a young person's ability to self-manage their hearing healthcare. Subcategories were as follows: building knowledge and making my own decisions (Figure 1).
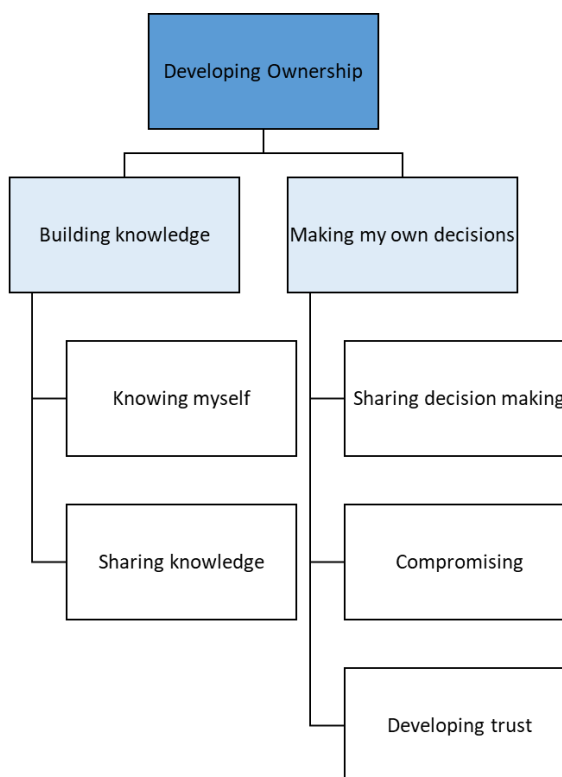
Figure 1: Categories and Subcategories: Developing Ownership

5.1.1 Building knowledge

The importance of young people understanding their hearing loss and realizing the benefit of devices prescribed to them contribute to building a knowledge base regarding their disability.

Knowing myself

Young people in this study believed that it was important to understand their hearing loss, what caused their hearing loss, and the impact of hearing loss on daily life. Adolescent 2

stated: "*It's one thing to know you have a hearing loss, but it's another thing to know what causes it, like where it is in your ear.*"

An HRT discussed how often a lack of understanding of the hearing loss can contribute to negative feelings on the part of the individual. She stated: "*And what comes up is that they don't know what caused the hearing loss, and some of the kids feel bad about it.*"

The HRT went on to discuss the importance of young people understanding their listening needs:

> *I look in more generalities, so for me the challenge isn't the audiogram…I would rather them say what they need and don't need rather than 'oh I have a moderately severe sloping hearing loss', or you know 'I have a high frequency [loss]', because people don't understand that. I'm not sure they get it, 'okay in this environment I don't hear, this environment I hear, this helps me, this doesn't help me' (HRT 1).*

Young people in this study also voiced their desire to know more about the progression of their hearing loss, one individual stated:

> *I guess the only thing [I would like to know] is whether my hearing would keep failing because I only got the cochlear implants because my hearing was failing, like getting worse. So I would like to know if that's still happening (Adolescent 4).*

Young people are often unaware of the implications of their loss. One HRT stated:

> *I think it is important that they understand their hearing loss, and what kind of a hearing loss they have, and the degree of hearing loss. We talk about what kinds of strategies are important for advocating for yourself. So I think the earlier the better. Often they don't know anything. They know they have a hearing loss and that they need whatever equipment they may have, but they don't understand the implication of their hearing loss (HRT 2).*

Building knowledge surrounding their hearing loss helps young people to make informed decisions regarding treatment and management. They showed a desire to use assistive

devices when a perceived benefit was experienced when using them. Adolescent 5 reflects on her decision to use assistive technology in high school and would continue using it if it provided benefit:

> *We talked about that, and we're bringing the FM system[4]. I kind of didn't want to, but then I thought to myself, well what if I miss something, I don't want to do that. School's really important to me, so I said, well I will try it and if the first year I say to myself well ok maybe I should, I'll continue using it. But if I don't really need it and I'm okay without it, then I'll talk to my mom about it (Adolescent 5).*

We see this same sentiment reiterated by a young person who chose not to continue to use a device at school because she did not see the perceived benefit:

> *Yeah they thought that I should use it [FM system] so they tried to get me to try it out for a bit. So I tried it out for a week or two but I decided it wasn't worth the advantage, or it wasn't necessary to help me succeed in school (Adolescent 4).*

Sharing knowledge

Knowledge building does not occur in isolation; hearing professionals and parents spoke of the importance of educating young people about their hearing disability. An audiologist spoke of the importance of providing appropriate information or information they can understand regarding their hearing loss and/or the progression of their loss:

> *Every once in a while, a child will surprise me because they will all of sudden say, maybe when their parent isn't around, 'Will my hearing get better?' It's like they*

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[4] Remote microphone hearing assistance technologies are a type of hearing assistive technology which includes a broad range of devices that can be used to overcome listening difficulties caused by distance and noise. They are often utilized in classroom settings. In the past, most systems were based on Frequency Modulation (FM) technology and were called FM systems. Today, many systems no longer use FM technology however, although incorrect, they continue to be colloquially referred to as FM systems. Commonly, the teacher will wear a microphone around his/her neck and the teacher's voice is transmitted wirelessly to the child's hearing aids via an integrated receiver.

really haven't accepted it or didn't really know that it's a permanent type of hearing loss (Audiologist 1).

An HRT spoke of her role in educating young people:

I figure that's my role, to help the kids to understand their hearing loss. So when I go in and I find out that they don't know much, that's where we focus (HRT 2).

Family support plays a significant role in a young person's interest in understanding their hearing loss and acquiring knowledge. One audiologist reflected on the importance of the family in supporting knowledge acquisition about the hearing loss:

I find that it varies tremendously depending on the child and it's not just the child, it's more the families. There are some families for who that is part of the process, that the child and the family become very knowledgeable. Then there are others who show or express no interest, even when you provide that information, you don't sense that information is being integrated. There are those who could certainly talk about their hearing loss and ask a lot of questions along the way and sort of build their knowledge both, from me and from other sources, and there are others who I think don't have a good handle on that at all (Audiologist 2).

In this study, most young people raised concerns regarding a lack of understanding of the status of their hearing loss and the desire for more information. In particular, several participants noted that they would like their audiologist to provide them with more information. One young person reflected on her desire to better understand her hearing loss and the progression of her hearing loss, and wondered if this was information her audiologist could give her:

[I would like] more information about how it [the hearing loss] is dropping. My mom says that I have a high frequency [loss], like more trouble in the high frequencies or something. If [the audiologist] just explained that a little bit better. But also, how moderate or severe it is. Like if she just talks about that or if she thought that [the hearing loss] would go down more maybe. I don't know if they can say things like that (Adolescent 1).

Adolescent 1 went on to express her desire for the audiologist to better explain her hearing loss and real world implications:

> *Maybe if there was more information about my hearing loss itself, what it meant. Like, maybe if [the audiologist] explained the audiogram a little bit better. I mean, it is kind of a complicated thing. My hearing itinerant explains it to me sometimes but, I mean, I know what's left, left is like X's, and O's or whatever, right's the other one. Like I understand that, but put it into more of a real-life world.*

Professionals and families discussed the struggle with finding the time and place to provides young people with the information they may desire given the infrequency of appointments and time constraints within audiology appointments. One HRT comments on these challenges and the growing importance of the role teachers of the deaf and hard of hearing play in a child's circle of care.

> *I think things are changing, that the audiologist is involving the kids a little more, but again their time is so tight for appointments. Because I'm seeing a child all year long, you can kind of build it up [the child's knowledge] step by step. While the audiologist might not know where the child is at, I'm talking to the child without the parents (HRT 3).*

However, young people in this study stated that they did not feel they had the opportunities available to discuss their hearing loss. In her journal entry, adolescent 1, when asked "Do you feel you get to ask all the questions you want to when you see your audiologist?" wrote:

> *No, I feel like time is limited and half the time your hearing aids are out. I wish technical advances were talked about, new products, explanation of other information on audiograms or a comparison. That's not given. Mostly just 'Your hearing dropped', don't know why. It's brief and unclear. I feel like the audiologist doesn't really care about how it personally affects you but maybe they don't need to.*

Parents and hearing professionals also spoke of their role in supporting young people in in realizing the benefit of prescribed devices. One mother discussed the difficulty of having her daughter realize the benefit she received from wearing her devices because young people may not have the life experience to know what they are missing. When her daughter was not wearing her devices, it was difficult to convince her of what she was missing:

> *The hearing thing wasn't as clear because she's like, 'No, I have no problem, I can hear you, you don't have to yell at me.' But maybe she didn't see it our way, where maybe it wasn't the first time we were calling out to her, it was the third time we were calling out to her. Her father and I kept repeating to say, 'Honey you didn't hear us the first time we called you.' (Parent 2)*

Parent 1 went on to say: *"when someone's telling you, you didn't hear me the first or second time, she probably didn't believe us."*

When it came to using devices, the adolescent's choices were often impacted by severity of hearing loss, their perceived benefit of devices, and support from home and school. One HRT spoke of the difficulty she has with getting children to use devices when they do not receive consistent messaging from home:

> *Parents think hearing aids and FM [systems] are very important at school but when you come home you can take them off. And I'm like why, you need it all the time, 24/7. It's not just at school, it's the over-hearing, you're not hearing what's being said. And then, it has implications as the kids get older. They don't see the need to wear hearing aids and FM systems because they don't wear it at home, so why bother wearing it at school. They want to be like the other kids, so they don't want to be different.*

She went on to say that for those children with less severe hearing losses, the benefit of using the devices is not as apparent for the parent and child compared to those with a more severe loss and who are unable to function without their devices:

I find my mild to moderate, conductive, and unilaterals - those are my tough ones. Can't get them to wear the hearing aids at home. Even the parents don't buy into it. That's where I think more education needs to happen, knowing that hearing aids are for overall better living, healthier life (HRT 2).

Hearing professionals spoke of their role to help inform device use for young people. One HRT stated:

Get the FM system on the kids early and have them hear the difference between an FM system versus no FM. Then they learn 'Oh okay this is why I have an FM' and talking about why you have an FM. Like the kids kind of [say] 'Well I can hear' and it's like 'Well, yes you can hear but the FM system is for so you don't have to work so hard to hear in the classroom. So that, you know, the signal goes directly to your hearing aids or cochlear implants so you don't have to strain to listen.'...It's getting the kids used to wearing the FM as soon as possible, hearing the difference between an FM versus no FM (HRT 2).

5.1.2 Making my own decisions

The importance of allowing young people to make their own decisions was often reiterated from both the adult and adolescent perspective although parents were often hesitant to allow such decisions to be made. Three subcategories are as follows: sharing decision making, compromising, and developing trust.

Sharing decision-making

All participants spoke of the importance of sharing the decisions making process with young people. An audiologist spoke of how she advocates for a team approach when making decisions regarding a young person's hearing loss and use of devices:

I try to approach it, especially as the children approach the adolescent years, I try to let them know that it's kind of like a team approach; their parents, me, their teacher, their itinerant teacher, and them. It's really five different people on the team and we should try to make decisions together and of course as the child gets

older then they have to make more of the decisions and I've certainly had that conversation with lots and lots of kids. You know by the time they hit high school I let them know nobody can force you to do anything anymore, you have to make those decisions yourself (Audiologist 1).

One parent spoke of how important it was for children to make their own decisions and allowing them to have some control in decisions regarding their hearing healthcare. She reflected on how important it was for her son to get to choose the colour of his hearing aids and earmolds:

At first, when [he] first got to pick his molds out, my thing was okay let's just go with beige, it's going to blend in, nobody's gonna notice them. Not that that was a big deal to us, but this way they're not going to stand out. Well [he] wanted red and blue, whatever colour was going to make everybody notice. I've spoken to parents about that too and they've said the same thing: 'No Bobby's going to get beige', and I'll say 'Well no, it's okay. That's how they can be creative and that's how they're going to be accepting if it's something that they've got control over' (Parent 6).[5]

One adolescent discussed her decision to terminate hearing aid use and how her parents were accepting of her decision:

They wanted me to continue trying, of course, because they were like it will help you. I was just like I know you think it will help me, but I'm telling you right now it's not. All it's making me, is getting me distracted and bigger headaches. Sometimes my mom would say 'Oh we'll just get it turned down even more'. But you need it at a certain level so you can hear more, not the same level as you are without them. I'm like it's just going to be too distracting. My parents were accepting of that, and eventually I just stopped wearing them (Adolescent 2).

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[5] Name has been changed to maintain confidentiality

Compromising

The concept of compromise was often reiterated by parents and hearing care professionals regarding decision making. A HRT discussed the importance of allowing an individual to make his or her own decisions but agreeing on a compromise that the adolescent, parent, and/or teacher can agree on to alleviate some of the anxiety that may be present:

> *Especially the kids in grade 7 and 8, they tell me they don't want to wear the FM system. I will say, you need to show your teacher and your parents that you can do well without it. If your marks start to slip then you need to go back to wearing it (HRT 2).*

An audiologist also discussed the strategy of compromising with young people, to find a solution that the adults and young people involved can agree on.

> *Well, okay, so you've got a 16 or 17-year-old who decides not to wear their hearing aids to school and you make that an issue. How do you police it? So, okay, fine, all you can say is you should be wearing a hearing aid. Or, it will be beneficial if you wore the hearing aids rather than should. You try to avoid that directive conversation, but hearing aids should be beneficial. To the other extent, you may look at, okay, what don't you like, and what's the compromise around what you don't like. We have different options now. You can't eliminate the fact that they're there but you can make the ergonomics somewhat more appealing to the child…you're not limited nowadays with a custom product's non-use of assistive devices because you simply now have access to that.*[6] *Now, whether you can talk a child into that or not, or an adolescent or a young adult, I shouldn't use the phrase talk into, but help them to understand. Certainly, the custom products become an option for children (Audiologist 3).*

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[6] In the past only behind the ear hearing aids could be coupled with various hearing assistive technologies and the sometimes more discrete custom products could not.

Developing Trust

Most parents discussed the need to trust their child's decision. Most often, this came up with a child's decision to not use devices as they got older. One parent reflected on a conversation with her daughter surrounding her decision not to use hearing assistive technology at school after her parents had gone to some lengths to ensure teachers at her school would use it. The parent stated: *"And now she's not even wearing it. She said to me, 'Mom, I'm the one with the hearing impairment, not you.' And I was like okay, you know, you're a good judge (Parent 4).*

The same parent went on to say:

> *I am trying to let her make her own decisions. Like now, as we've hit the, and I wouldn't even say it's the wall or anything because there are so many other good things about her. I mean she just brought home a whole history assignment all level 4's. You know, you don't get those marks if you're not hearing anything…she's still managing top marks. I wish she would use her FM more with her friends and stuff because I think she wouldn't miss out so much on things. But it's gotta be hard, you know? (Parent 4).*

Another parent reported that her child did not get to be part of the initial decision-making process to wear hearing aids. Her parents made that decision for her when she was younger, and now believed, at this point in her life, that she needed to trust her child to make her own decisions:

> *But I had to trust her because I realized I never asked her. I said you go ahead and do what you're doing and she goes, 'Mom, I don't need those hearing aids. I can do this' (Parent 2).*

An HRT reiterated the importance of letting young people make their own decisions:

> *That's the bottom line, it's the path they take, might be different then what we think they should take, but it's the path they take it's not our path…It's control, they want control to a certain degree and they have none (HRT 1).*

5.2   Managing Identity

This category describes concepts that were associated with how young people identified themselves as individuals with hearing loss. Subcategories were as follows: evolving identity, disclosing hearing loss, and having a sense of belonging (Figure 2).
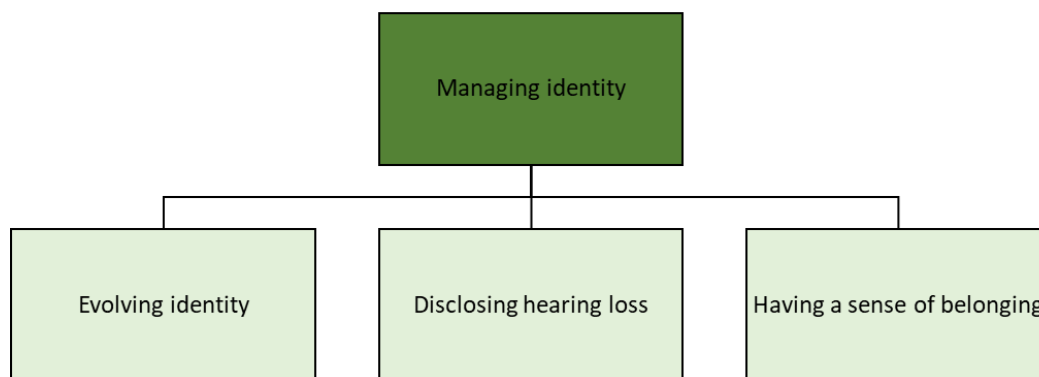
Figure 2: Categories and Subcategories: Managing Identity

5.2.1 Evolving identity

How young people perceived and identified themselves as a person with a hearing loss was an important concept identified in this study. Perceptions of personal identity, whether negative or positive, tended to evolve over time. Young people commented how they may have felt differently about their hearing loss at other times in their life. One adolescent reflected that she viewed her hearing loss more negatively when she was younger:

> *When I was younger I would be shy, but since high school I've been trying to be*
> *more social. I would assume my shyness was a result of not being able to hear*

well, it would be difficult to have a conversation with people. When I was younger it used to be more of a disability but now I don't feel as different (Adolescent 4).

Another individual reflected on a very different experience; one in which her hearing loss was less of an issue than in the present:

I think when I was younger I didn't think about it as much. Like when I went to VOICE activities and that, I think I just had a good time![7] I always had hearing aids, everyone knew about it, I didn't really think about it (Adolescent 1).

Young people often commented that their hearing loss was part of who they were and made them special and/or unique, for example:

No one has actually had hearing aids like me [at school] so, it kind of makes me feel special (Adolescent 5).

I feel that I am fortunate that I only have a moderately-severe loss and not a profound loss. I feel that my hearing loss is a part of me and makes me who I am today (Adolescent 1, journal entry)

It's always been a part of me. It kind of makes me who I am (Adolescent 1).

Parental support and attitudes seemed to have a significant impact on how adolescents identified as a person with a disability and/or perceived their loss as a disability:

I guess when you have a hearing loss and you're born with it, you don't really know what it's like to have perfect hearing, right? My parents, they never treated it like a disability. They just said, 'Oh, you have this so we'll get you the resources that you need to cope. You just go to school and study'. There wasn't really a negative thing about it. (Adolescent 2).

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[7] VOICE For Deaf and Hard of Hearing Children is an organization committed to providing support, education, and advocacy for deaf and hard of hearing children and their families.

Some of the older adolescents reflected that having a hearing loss and working through some of the challenges associated with it helped shaped their identities and who they are today:

> *I feel that I can do everything and anything someone without a hearing loss can do because my hearing loss doesn't affect my walking and talking, and I can overcome any obstacle (Adolescent 3, journal entry).*

Adolescent 1 wrote that working through her own challenges has made her more understanding and accepting of the struggles that others may face:

> *I feel that some days I wish I didn't have a hearing loss because that would make everything easier to do. But I know life isn't about being easy, and I have accepted and work with the challenges I face with my hearing loss. I also feel that having a hearing loss makes me more understand[ing] and accepting of other[s].*

5.2.2 Disclosing hearing loss

Young people in this study made decisions whether to disclose their hearing loss and discussed the perceived and/or real social implications of disclosing their hearing loss. Even those individuals who were open and comfortable in discussing their loss often made choices as to when and if they disclosed their hearing loss in certain situations. Some young people reported they were judged and/or perceived negatively by others because of their hearing loss.

> *Bottom line people judge me every day and make comments about it and I just have to deal with it (Adolescent 1, journal entry).*

Another participant discussed how his typical hearing peers perceived his hearing loss negatively which he found frustrating and caused him to give up trying to have others understand:

> *They think I have a mental problem sometimes. I don't take that as offensive but I'm like, 'I just have a hearing loss, it's rare, so I can't help it' (Adolescent 7).*

When asked how he felt when these misconceptions were made, he replied: "*I'm like, just never mind.*"

In response to negative feedback from others, young people chose to be selective in disclosing they had a hearing loss. The following individual did not wear hearing aids and chose not to disclose her hearing loss due to past negative experiences, she shared: "*I'm trying to keep it a secret so nobody knows.*" When asked why she wanted to keep it secret she reported the following experience: "*When I was like in kindergarten, I told them 'I have a deaf ear'; they laughed at me*" (Adolescent 8).

Some participants noted that the uncertainty of others' reactions can inhibit them from disclosing their hearing loss. One young person reflected on an interaction with a classmate at school who also had a hearing loss but seemed unwilling to discuss or disclose his hearing loss. She reflected that she understood the individual's reluctance to bring attention to his own loss due to fear that he may be mocked or singled out:

> *I remember this one kid and I'm like, 'Do you have hearing aids?' and he just walked past and was like, 'I'm not getting into that'. I [thought] that's strange, he just walked away and didn't even answer me and you know I wasn't being nosy, I was just saying, 'hey do you have hearing aids?' because I've seen that his teacher needed to wear an FM system. But I kind of understood that too 'cause you know sometimes they're afraid you're going to be like, 'Oh, ha ha ha' (Adolescent 5).*

Another individual voiced his concern surrounding his fears in wearing his hearing aids to high school the following year. He was unsure how individuals he did not know might react when they saw him wearing hearing aids. He shared his plan that he would carry them in his pocket when in the hallway and only wear them when in the classroom. When he was asked why he did not want to wear them he responded: "Because *in high school, there's bigger kids*". When asked if he thought they would react negatively he replied "*Probably, yeah*" (Adolescent 3).

Other families in this study went through similar issues at different ages:

> *We went through a big issue of him not wanting to wear it when he went to Beavers, because it set him off, because he was different. So we discussed it with his speech pathologist and she had us write up a little caption about [his] special ears that he could take and give to the Beaver leaders to read, you know so that they could answer any questions from any of the other kids (Parent 1).*

> *Well I knew that with [her], going into grade nine, it's all about the visual. Let's be honest, right? I mean, not that [she] is that kind of a girl, she's not high maintenance, she's a little bit sporty, a little bit artistic, but you're still going to worry about how you look. You're still going to worry about how you're perceived by the other grade nines. So it's that first year of going to high school, there was no way she was going to wear them (Parent 2).*

Young people who may not have previously experienced negative reactions from others regarding their hearing loss and/or wearing hearing aids, may anticipate negative reactions from others. This may cause them to worry about attracting unwanted attention from their peers and may inform their to decision to not disclose their loss or to not use their hearing devices.

Young people in this study indicated that at some point it was inevitable that they would have to disclose their hearing loss. One individual stated that hearing aids are visible and people are curious to know what they are for:

> *Well, they ask me right away, maybe when they see this part of my head [pointing to ears]. So, they'll see the ears and they'll wonder what's in there, so they'll end up asking me, 'what are those in your ears man' and I'll go 'those are hearing aids bro' (Adolescent 6).*

Others agreed that hearing aids often draw questions from others. However, Adolescent 4 reported that if someone did not notice her hearing aids right away she would not feel it necessary to bring up her hearing loss:

I guess usually most of the time they see and they're like, 'Are those hearing aids or something?', then yeah. But no, I don't usually tell them until there's something important that I need to tell them about. (Adolescent 4).

However, young people commented that they believed they were in control of when and how they disclosed their hearing loss and often reported the benefits of disclosing. One participant indicated she was very open about disclosing her hearing loss but was selective in when she disclosed:

I think I'd get to know them a bit. If they're like 'Hey I called you, and you didn't hear me' or something, I'm like 'Oh sorry I just have a slight hearing loss, I'll tell you about it sometime', or something like that. I don't say it right off the bat. Usually, I get to know the person more, and then I'll reveal it (Adolescent 2).

Another participant indicated that she is also selective in how she discloses her hearing loss preferring to get to know someone first:

Depending on the situation, I take a different approach. With friends, I don't mention it, I don't want them to treat me differently. I prefer they get to know me first before possibly pre-judging. Telling people is not always important to me and I am not always comfortable. I do like to educate people, but not all the time (Adolescent 1, journal entry).

Young people are also aware that there are situations where it may be beneficial to disclose a hearing loss:

I guess if they need to know then I could tell them. I guess it's more like something like they should know. I shouldn't be shy about saying that, like it would be more beneficial to say it than not or whatever (Adolescent 4).

5.2.3 Having a sense of belonging

Young people reflected that they did not want to be different and wanted to belong to a group. Positive and negative interactions with peers seemed to influence how individuals perceived their hearing loss and influenced their choices to disclose their hearing loss. All

children interviewed attended mainstream schools and thus had a peer group of predominately typical hearing individuals. Young people recounted both positive and negative experiences with peers:

> Where I went to school, I went to like a rural school so like everyone was really nice. I was never teased or bullied about my hearing loss. So, I mean, I didn't really have to think about it. I had the FM system but that was about it...it never really bothered me so much (Adolescent 1).

However, the same individual wrote in her journal: "*I have a friend that makes deaf jokes about me in front of me*" which highlights social struggles a young person may face even when they admit they are in a positive environment.

The importance of being accepted by a peer group was evident and having a level of comfort that allowed children to be themselves and feel understood was important. One young person spoke about how his close friends know how to accommodate his communication needs:

> They know to speak clearly when I am around. If I come into the conversation they would know to help me catch up on what's going on and whatever. And if I don't hear something they can repeat themselves. They don't get annoyed as easy, repeating things, they don't get annoyed or tired repeating stuff (Adolescent 4).

Adolescents also noted that although their regular peer group may not include other young people with hearing loss, it was important for them to meet other young people who were D/HH. This allowed them to share the unique hearing loss experience. One young person discussed how she believed it was important to meet someone who had similar experiences with hearing loss to hers:

> I think it is [important] because it's not nice to have everything bottled up inside of you. If I have a problem with it, I'd say oh I hate it when I can't hear a teacher and they won't speak up louder. My friend is like oh my god, I hate that too. We'll go off a bit like that so it's nice to have someone to talk to that's in that

similar situation because not everybody can respond the way you want them to (Adolescent 2).

When asked what else they were able to share she replied:

Well, pretty much anything. I can just treat them like a regular best friend. She wears glasses, and I wear glasses. She has a hearing problem, and I have a hearing problem so we're pretty close. We talk about anything and everything (Adolescent 2).

She continued to discuss the importance of young people who are D/HH having the opportunity to meet and interact with others with hearing loss:

Even if you are coping well, I think it's nice for everybody to have someone to talk to because like I said it's not nice to not have everything bottled up inside. It's a great stress reliever too. My parents, they love me to death, and I love them to death. They would try to understand and they would, but it's still not to the same as somebody who has hearing loss (Adolescent 2).

Parents and hearing professionals also discussed the importance of young people meeting others who are D/HH. Parents agreed it was an opportunity for children to share their experiences, one parent stated the importance of a one day event organized by the school board for students to have the opportunity to interact with other young people with hearing loss:

I think it's good. Even if they're not interacting with them on a daily basis, even this one day thing is good, so that they can see that there are other kids like them. They can share ideas like, 'This is how I hook my iPod up' and 'this is how I do this' and 'look what you can do with that.' So I think as far as that goes, I think that's good (Parent 5).

An HRT shared her experience that young people are eager to meet others with hearing loss:

What I found, was last year every single student was telling me, from I think 8 years old and on, that they want to meet someone else with a hearing loss, more than ever before. The kids don't ever see anyone, even a teenager, with a hearing loss or hearing aids and being proud of it (HRT 3).

She went on to explain the high school students she works with do have some interaction with individuals who are also D/HH. The school board organizes a day for students with hearing loss to socialize and meet one another. Students who are D/HH from the nearby college are asked to volunteer for the day. She recounts some advice one of the volunteers gave the younger students:

There was one very attractive young lady and someone asked "Do you wear your hearing aids all the time?" and she responded "Yes! If someone has a problem with it they're a jerk. These are like jerk-detectors, that's part of me if they have a problem with it I'd like to find out right away." So the kids were surprised. (HRT 3).

An audiologist reiterated the sentiment that it may be important for these young people to have someone they can relate to:

I think there's a lot of shared learning in that and somebody that they can relate to. Sometimes it is hard to put those opportunities in place, but I do think that it can be quite valuable, and especially when you're trying to share or give them information that they don't want to hear. Sometimes they're more willing to listen to that from somebody who shares their experience in some way (Audiologist 2).

Regardless of the strength of their peer group, adolescents struggled with their communication difficulties and feeling left out due to their hearing loss:

Well it doesn't really bother me when I have to wear hearing aids but it does kind of bother me that I can't hear as well as others. (Adolescent 6).

One individual reflected that she did not enjoy swimming with friends as she feels she misses out with the social interaction:

I recently realized how much I don't like swimming, I can't hear anything to play the games. I am at the age where we just tread water and talk, I can't hear anything, it's very frustrating and I feel excluded, yet nothing can be done (Adolescent 1, journal entry).

The same individual also wrote about struggling through other social situations:

I can't whisper and I don't always hear everything and I don't like asking people to constantly be repeating. Like, if I miss the punch line of the joke [I] fake laugh my way through it (Adolescent 1, journal entry).

Parents also were concerned that their child would miss out socially due to their hearing loss. One parent shared:

In high school there's a lot more going on so he's you know, potentially missing a lot of other things because a lot of information is conveyed on the PA system.[8] You know, it's hard for a hearing person to understand and hear all of that. So he has missed things like track and field try-outs and stuff like that (Parent, 5).

An HRT spoke of her concerns regarding children wearing a hearing assistive technology in the classroom may be isolating them from their peers:

I have one student in particular, and [with the] FM they feel they're missing out. Even though the hearing aid is supposed to pick everything up, that FM takes priority when that teacher is talking. But if there's some sort of discussion about the party last night over here and they can't pick it up. If they take the FM out they'll get to be part of it. I think there's a real, you know, gang mentality. Teenagers travel in packs. I think they feel they're losing out on that so that's part of the challenge too I think. So with the FM, they're so plugged into the teacher that the social part [is missed], which is huge at that age (HRT 1).

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[8] Public address system (PA system)

Similarly, the same teacher shared a conversation with a student that highlighted the concerns of missing out in social situations and missing conversation due to a hearing loss.

> *I had one girl say, because she was complaining, she was a bus student and she said the noise on the bus was bothering her. I thought, oh I said you can take your hearing aids out on the bus 'well then I'll miss what they're talking about and they'll be talking about me'. So it's like okay, it has nothing to do with the noise on the bus it has to do with you think kids are talking about you and you can't hear them (HRT 1).*

During adolescence, young people also begin to explore intimate relationships and are interested in dating. It is a challenging time for most adolescents but can even be more so for young people navigating this with a disability. Parent, adolescents, and hearing professionals spoke of this. One parent voiced the concerns that she had for her daughter dating:

> *I worry about relationships with her. I would hate for her to not have a relationship with someone because they were afraid of her hearing loss. You know what I mean? But then, someone said, you know, if they can't handle that then you don't want them anyways. And I said, yeah, you're right. I'm sure there will be a time when the hair goes down completely and you know, at university and when you get to meet people without showing them (Parent 4).*

One audiologist (Audiologist 2) recounted a story in which a young male patient shared his insecurities about his hearing loss while speaking with a male student clinician who also happened to have a hearing loss. In the exchange, the young patient asked the student if he had a girlfriend. The student clinician replied that he did not and then asked the patient if he had a girlfriend, he responded *'Yeah, but I never wear my hearing aids when I'm with her.'*

One young person reflected on dating and how she does not have the same opportunities as her friends due to her hearing loss:

I feel like guys judge me because I wear hearing aids. They don't want to date because I wear hearing aids and their friends will make fun of them. I have never dated anyone, only been asked out once, no guys talk to me, unlike all my friends (Adolescent 1, journal entry).

5.3   Developing Advocacy

This category describes young people developing self-advocacy skills. All participants expressed the importance for young people to be able to advocate for themselves and their unique listening needs. Subcategories are as follows: speaking up, standing out, and nurturing advocacy (Figure 3).
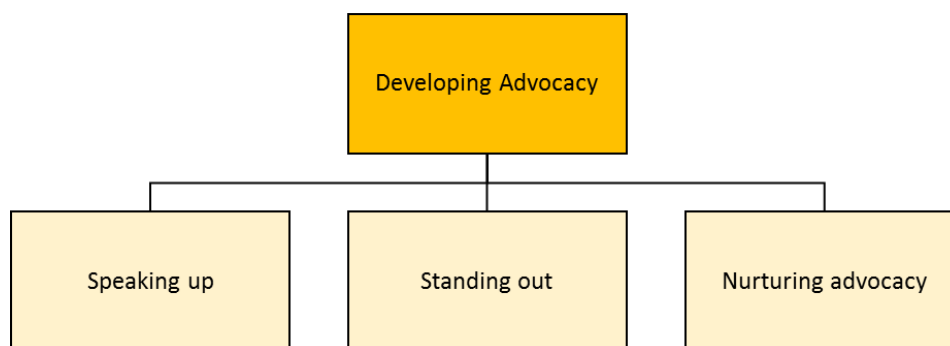
Figure 3: Categories and Subcategories: Developing Advocacy

5.3.1 Speaking up

Young people in this study voiced an awareness of needing to be able to advocate for themselves even if they were not always comfortable with it. One participant, although her mother continued to advocate for her, noted that it was important that she begin to do this for herself but stated: *"I'll start doing it when I get older"*. When asked why she thought it was important to do so, she replied: *"because I can speak up for myself" (Adolescent 2)*. Older adolescents reflected on the importance of being an advocate for oneself and the knowledge that they are the only ones that understand their needs and need to articulate that to others. When asked what her advice would be to other young people regarding this issue one young person said:

I would say you need to put yourself out there if you need it. To be able to raise your hand and say, 'you know what, this needs to happen.' You know they don't take charge because it's not theirs, it's your problem. I did have trouble with that because, like I said, I was really shy and I like to have my mom around. So I would say, you gotta get used to being able to speak up for yourself (Adolescent 5).

One participant in her journal entry wrote about her struggles in advocating for herself in situations where she did not hear well, but did not always feel she could ask for clarification and described her feeling associated with that.

It makes it difficult, challenging, and frustrating to talk with other people. I always feel like I am not hearing everything, but I shouldn't ask what was said. It helps you hear [to ask others for repetition] but it's still difficult, humiliating and frustrating (Adolescent 1, journal entry).

Others suggested that it was easier to advocate for oneself when they were not the only individual to benefit from the request. For example, one young person spoke of speaking up in class to request a teacher to wear the microphone for the hearing assistive technology system, which was in place to assist more than one student in the classroom.

One time I had a really snappy substitute teacher in elementary school, she didn't want to wear the FM system. She was like 'oh, I'll just project my voice louder'. I'm like, 'I'm sorry, but it's not only me. There are other students in this classroom that need it'. My real teacher actually talked to her, and she apologized (Adolescent 2).

The same individual goes on to explain:

When there's a group of people, it's more in demand for that device to be used. It's not just one person so it definitely increases the need and the realization by the teacher that oh I need to use this. Sometimes I'd be shy about it, but having to ask people - to remind them, learning about my hearing loss disabilities, and then telling people about it like 'oh can you wear this, not only for me but for someone

else.' As I said earlier, about the camaraderie-ship, not just being alone, it really made me uncomfortable going outside my personal bubble saying can you wear this to help me (Adolescent 2).

Hearing healthcare professionals indicated that there was a significant range in how well children will self-advocate for themselves. Both audiologists and hearing resource teachers noted that they found young people with more severe losses were better able to advocate for themselves as they could not cope as well as those with less severe losses. One audiologist noted:

The child with a more severe [loss], say moderate to moderately severe or severe loss and they've worn their hearing aid since they were infants. They can't go without them, and they know it and say that (Audiologist 1).

An audiologist also noted that children who were more aware of their listening needs and the benefits of advocating for themselves were also more successful:

Some are incredibly good self-advocates and others are not very aware, not really promoting their own needs or even necessarily aware of their own needs. Particularly when it comes to high school age, you know there is all the issues around 'I don't want to be singled out, I don't want to be known in this group'. So they're either out there advocating because they know that's to their benefit or they haven't reached the stage where they understand the connection between what the equipment or whatever it is they may have is to their success overall. They haven't made those connections yet (Audiologist 2).

Like typical hearing adolescents, young people with hearing loss appeared to exhibit self-advocacy as they were transitioning out of high school. This was articulated by a parent as she discussed her daughters improved advocacy skills as she was preparing to apply for university:

She wouldn't go out of her way when she was younger, she wouldn't want that attention. Now she knows the stakes are higher, because now she's preparing for university. Everything for her now is getting ready for university. And she knows

that when she's done high school, we [will] have to pay for [university]. So, it's like, ok, now the stakes are higher, so now everything has to be appropriate. So, if there was something that was lacking in her hearing, she knows that she would have to say it now (Parent 2).

5.3.2 Standing out

Young people voiced concern with bringing attention to their disability. The decision to not advocate for themselves was possibility due to concerns of standing out or being different from their peer group. One parent, when if asked if her child would tell the teacher if she was having difficulty hearing or if her hearing assistive technology was not working, replied: *"For some years I don't think she did, because she didn't want to be kind of, you know, stand out"*. The same parent went on to say:

She understands it, she knows it's important. She's just, I guess, self-conscious about asking. Why, I don't know. I think I'm assuming that it's because she'll stick out. You know, being noticed that she didn't get it. She really, really wants to just fit in (Parent 3).

An audiologist reiterates this point:

So, every child in the classroom is an individual, we need to accept you. But on the other side, those teenagers are still saying I just want to be part of the group. I don't want to stand out. I don't want to be noticed (Audiologist 3).

The following audiologist has noticed that many children start developing good advocacy skills as they reach 12-13 years of age, however upon entering high school they no longer want to stand out and will often refrain from advocating for themselves:

Grade 6 or 7, I think that's an area where kids are just getting really good at [advocating for themselves] and then in high school they don't want anybody to know. The ones who don't want to advocate for themselves because they don't want anybody to know, they don't want to stand out. So yeah it's really tough. I find that there's a few years, especially grade 9 and 10, where if we can just get

them through, that's what we have to do. By the time they hit grade 11 and 12,
very often they've changed and they've realized that they have goals, want certain
things, and to get there, there are some things they have to do (Audiologist 1).

5.3.3 Nurturing advocacy

Both parents and health care providers discussed the importance of modeling or
encouraging advocacy in young people. One audiologist discussed how difficult it can be
for young people to advocate for themselves and encouraging them to do so:

You know if someone's kind of shy and doesn't want to advocate for themselves, I
mean they wouldn't do it even if they didn't have the hearing loss. The fact that
they have a hearing loss makes it that much harder. Although, it's that much more
important for them to learn; so I mean I would try to encourage them to do small
steps (Audiologist 1).

The same audiologist believed that working with children to identify strategies for
advocating for themselves was helpful for children when a situation did arise, she stated:

I encourage the child, no matter what age they are, if they identify a problem to
me I would say to them 'What do you think we can do, or what is the solution, can
you talk to your teacher?' And quite often they will, they'll try it. Quite a few of
them will try themselves. Sometimes they don't want their parent to advocate for
them, which is good, that's good, they'll advocate for themselves (Audiologist 1).

One parent also discussed the struggles of her child overcoming shyness in order to
advocate for herself. The parent discusses how this was raised at a school meeting:

We also talked at that meeting about her advocating for herself and that's a little
hard for [her]. She's the one that has to let her teachers know when something's
not working, or it's not on, or she didn't get it. So, she has to be a little more
proactive about that. I think she wants to do it, but she keeps saying 'Oh mom I'm
really, really shy.' (Parent 3).

Another parent spoke of working with her daughter to advocate for herself at school when she was not able to hear what the teacher said: *So hopefully we made her stronger to feel she can speak up. Because no one else is going to do it for you (Parent 2).*

However, having the sense they were a role model for others also promoted advocacy skills in young people. One young person reflected on having the opportunity to speak to her class about her hearing aids when she first received them. Her hearing resource teacher had suggested she speak to the class about the device so everyone would know what it was for. Although, she reflected that she was very shy she was grateful for the opportunity and was happy that she had agreed to present to her class:

> *I think it was a good idea and you know I always like to be a role model. So yeah. I like the decision that I made (Adolescent 5).*

Hearing health professionals commented that children who experienced positive re-enforcement for self-advocacy or had positive role models for advocacy at home and school were better self-advocates, two audiologists reflected on this point below:

> *If a child has a sibling [with hearing loss] it's been much more successful. If a child has a parent with a hearing loss they seem to have that confidence. (Audiologist 1)*

> *I feel that not only is it the family, but there is a huge part that's played by the professionals in the school system. So again, it is very dependent upon who those children have come in contact with (Audiologist 2).*

Providing the opportunity for children to advocate for themselves was found to be important. However, young people at times received negative responses in their attempts at self-advocacy. One parent indicated how important it is to recognize when children are attempting to advocate for themselves, to acknowledge the attempt and to reinforce those skills:

> *I think she makes the attempt, but then nothing happens, or it happens but it's still not right. And then to do it again, is just too much. It needs to be recognized as*

'Okay wow, she asked'. It's kind of brushed off as 'Yeah, yeah, we'll fix it, or
we'll get to it, or it's your responsibility.' I don't think they understand how huge
it is (Parent 3).

Another parent recounted a similar experience where her child's attempts to articulate her
needs and be an advocate for herself were not recognized. In this case, the young person
asked the classroom teacher if he would wear the microphone for the hearing assistive
technology that was an accommodation for her in the classroom.

Well, the talking to the teacher part, that was challenging. She's hit grade 9 and I
said to the LST⁹, I very much think she needs to be an advocate for herself.
However, she's a 14-year-old girl, she had the courage to go ask this man to wear
it, and now he's telling her in front of all her friends that he doesn't need to
because he's loud enough. What kind of message does that [send]? (Parent 4).

However, parents and professionals need to relinquish some control to allow children to
work on their advocacy skills, even if they don't agree with what adults may feel is in the
best interest of the child; one audiologist noted:

The first advocacy is when they say to their parents or to me 'I don't want to use
the FM system.' We want them to advocate for themselves but we can't always
say 'Oh, but wait we want you to do [this]' (Audiologist 1).

One HRT spoke of the difficulty that parents have in relinquishing control and allowing
children to make mistakes and learn from those mistakes:

I don't know if there's a good age for them to say 'okay I can advocate for
myself', a lot of it is parent driven, some of the parents are the advocates and
don't back away until quite a late age, others are very good. If you have mommy
and daddy save you your entire life, the real world has no safety net. You know
what they need, this is their way to be in control, let them do it. They need to

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⁹ Learning Support Teacher (LST)

sometimes fail in order to realize, you know depending on the child, but sometimes they have to fail, misread a conversation, not hear anything, to realize 'oh wait a sec I did miss out on that'. But yeah, I think parents can be detrimental in saving too much you know, I always say they're special but not that special (HRT 1).

An audiologist spoke of the key role HRTs have played in working with children and developing advocacy, above and beyond what the audiologist is able to do.

…they do a very good job of it. They are very good at it and they are often seeing those children once a week. So, that's the luxury that they have because they have more regular contact. They know that child in a different way than I might because I see them less often. With that sort of regular contact, you could work at something together. They're very good at working on self-advocacy and independence with devices and so on. When kids come for appointments, sometimes I will send the itinerant an email after and say 'Wow, thank you, this child is independent with getting their hearing aids in. That's amazing'. And it's not been through me, it's really been their hard work that's achieved that with the family or the child. And often it's just with the child because the parents don't tend to be at the school during the itinerant's time with that child. So, they often form this nice relationship because the parent isn't part of it. They get their own little relationship going that doesn't get [affected] by what the parents' agenda is or what the parent wants for their child (Audiologist 2).

5.4   Doing it Myself

This category describes how young people integrate hearing loss into their daily life by managing the responsibilities that are directly related to their hearing loss. It also addresses developing daily life skills that may require modifications compared to typical hearing peers due to the hearing loss. Subcategories are: checking in and letting go and moving on (Figure 4).

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│ Checking in and   │  │    Moving On       │
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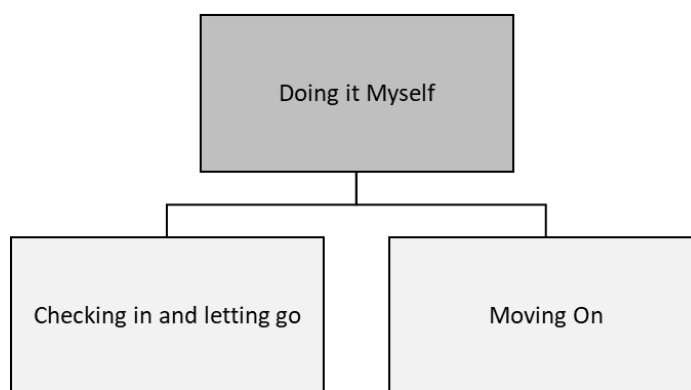
Figure 4: Categories and Subcategories: Doing it Myself

5.4.1 Checking in and letting go

All participants recognized that it was important for young people to learn to manage and maintain devices. Participants often referred to a process of sharing responsibilities between parent and child. As a young person becomes more competent and demonstrates the ability to manage aspects of their hearing healthcare responsibilities can move to the child, with the parent checking-in to provide support and oversight when needed.

Hearing care professionals discussed trying to encourage active participation from young people in sharing responsibility for managing their hearing loss and devices:

> *I like a child to do as much as possible, depending on the age and ability. When we fit hearing aids in this clinic we spend quite a bit of time fitting the hearing aids but then showing the child and the parent how to take care of them (Audiologist 1).*

An HRT reiterated the importance of instilling a sense of responsibility at a young age so children are able to manage their hearing aids when in school:

> *We try to get the kids to do as much as possible. I used to work with the preschool students; that was the 2 and 3 year olds. I would have them check their batteries and learn how to put the batteries in properly. I think the earlier you show the kids, the easier it is for the children. Because when they get into the classroom they need to be able to change their batteries when it happens, like if it dies on them they need to be able to do it right then and there you can't wait until the end of the day or when you go home. So, I think the earlier the better (HRT 2).*

Parent 4 remarked that her child's audiologist would encourage her child to take responsibility for her hearing aids. She reflected on how the audiologist addressed the situation when her daughter received new hearing aids: '*Here it is, this is yours, here's the box you put it all in there it's all your stuff'. So I thought, okay that's good (Parent 4).*

Although all professionals stated that they encouraged independence from children, this independence must be supported and supervised by adults in order to be successful. Audiologist 2 stated:

> *But certainly, with the younger elementary kids I think that it's asking a lot. Yes, we want them to be independent but we would like them to be supported in their independence (Audiologist 2).*

Another audiologist in this study discussed the importance of engaging children and adolescents during their appointments so they feel involved and part of the process, and in turn providing an example for parents in allowing their child to take on more responsibility:

> *You want them to engage and talk about what you're doing and how they feel about what you're doing. In that regard, you are hopefully facilitating some independence in terms of the child's responsibility. And hopefully, the parents will see over time that no, they can't always be putting that earmold in, that child*

should be putting it in. They develop independence even though the parent is still sort of supervising (Audiologist 3).

Young people in this study commented that they were supported by their parents when learning to care for their devices and responsibility was shared between parent and child. One young person commented on how her mother would show her how to care for her hearing aids and would remind her when to clean them:

She'd show me, and it got just sort of natural and then it just came to me. And then it's like brushing your teeth in the morning, you can't really forget (Adolescent 3).

I think it was like grade three or four, she'd always remind me when to clean them (Adolescent 3).

Well my mom told me you know when you have hearing aids it's like glasses you need to clean them once and a while, you have to take extra care with them. So I understood that right from the beginning (Adolescent 5).

Adolescent 4 explained how his parents would involve him in troubleshooting problems when his hearing aids were not working:

I guess if something happens I should tell them and then they will try to figure out what the problem was. And then, they would fix it. But they would make sure they showed me how they fixed it so I could fix it myself. They were always trying to have me figure out how to do it myself.

However, if children are not supported by adults (e.g. parents and/or teachers) it is very difficult for them to be successful in learning to manage their hearing loss. Hearing professionals reflected on experiences where children were not supported and it becomes a barrier for a young person learning to manage their own hearing loss:

I would say that I have a couple of students where when their batteries die they don't have extra batteries with them. So, I am supplying them with batteries even

though the parents are responsible for supplying their own personal hearing aid batteries. I find that frustrating, so that's a barrier (HRT 2).

Audiologist 2 reiterated the importance of children to have support from the adults in their lives and that once a child shows some independence their needs to be some oversight to ensure a task it getting done. The audiologist used an example of a child forgetting to plug in their hearing assistive technology system at school at the end of the day:[10]

We are teaching the child to take those actions and be responsible for those things. There still needs to be somebody who's backing that up, and it seems though if a child shows a little independence then they're quickly left with the task, so it does come as an issue. The child forgot, and it didn't get plugged in, now they have no FM today. So, I do feel that the teacher, I really do think that it ends up being the teacher who has to give that task a little bit of oversight. (Audiologist 2)

All participants spoke of adults providing oversight for young people to support them in managing their new responsibilities, an audiologist explained:

That is a big responsibility that you're asking of some very young children sometimes. Sure, they can do all those procedures, but then you're checking to make sure that that's happening and that it's happening in the way that it's supposed to happen (Audiologist 2).

One parent recalled having to remind her child to properly care for her hearing aids:

Yeah, and we would have to remind her. I would hear her dad going after her 'You put those things in the jar' you know. Stuff like that. And of course, with her

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[10] Systems are usually rechargeable and require recharging over night to be functional for the following day.

earliest set, they were probably a lot worse for moisture and stuff like that, but
now I have nothing to do with that part of it (Parent 4).

As young people demonstrate their ability to take on a particular responsibility or manage
a particular aspect of their hearing loss successfully, parents may begin to relinquish that
responsibility. An HRT described it as a negotiation between parent and child:

So I think it's a negotiation with the parents, you know over time they could see
that the child is becoming more independent with it. And I think the kids
demonstrate 'Oh I can do it' and then the parents are like 'Oh, okay, I can give
that responsibility to my child.'

Participants often commented on a process of adults "checking in and letting go" when
young people began to take over various responsibilities regarding their hearing loss. One
parent explained checking in to see if her child's hearing aids had been cleaned:

I kind of checked when she was doing it, but not very often. She was good about
that. [Now it's] her responsibility, yeah. So, the only thing we have now is her
telling me when the batteries are all gone (Parent 3).

A hearing professional commented that a young person's success in managing their own
hearing healthcare is dependent on the parent's willingness to let go. Audiologist 3
explained:

Parents and their willingness to let go, and let the child, and insist on the child,
managing their hearing loss, their hearing aids, their earmolds, care and
maintenance, FM at school (Audiologist 3).

Eventually parents must relinquish responsibilities to their child, although tasks may not
be completed as they would prefer them to be. Parent 3 commented that she would
encourage her child to clean the hearing aids more often, but she was aware that it was
her daughter's responsibility. She stated: "*I would encourage her to clean them more*
often and to clean her ears more often. But it's not, I mean, I don't want to turn it into

nagging.'' Parent 4 also commented: "*I personally would keep my molds a lot cleaner than she does''*, but was aware that it was no longer her responsibility but her daughter's.

Most parents commented that in many cases they were no longer responsible for aspects of device care because they were no longer the expert. Their child was more up to date on the latest technologies. Parent 4 commented:

> *I have no idea anymore. Like even now, they come with, I didn't even know it had a name, the Bluetooth thing that will hook up. So, she got that with the last one, but even prior to that she was hooking her [music] up to her FM and the TV. I had no idea what she was doing. And I mean, I guess I could've, because at the start we did all that stuff, but I just thought it's your thing (Parent 4).*

All participants expressed the need for parents to maintain some involvement in supporting their child. Adolescent 1 wrote in her journal:

> *I feel that I am mainly responsible for everything with my hearing aids. I don't think I need more responsibilities to do it all. Other than making appointments and washing the molds. I am still a teen, I don't have a car to get to the audiologist that's why I don't make the appointments (Adolescent 1, journal entry).*

However, parents commented on their apprehension in letting their child take on more responsibility. Parent 4 commented on the concern she felt when allowing her child to take on more responsibility for caring for assistive technologies due to her young age until the school reassured her otherwise.

> *I talked to her itinerant ay that time and said, 'Really, she's 7.' At first this was my attitude. The itinerant and the teacher said, 'We think that she's responsible enough.' I guess I was afraid she going to be missing her recess because she's going to be busy doing this stuff. But in the end, you know, they assured me she'll have the time. It turned out they just saw that she is that kind of organized, responsible kid. I think it was a great thing, now that I look back at it. I'm glad*

they pushed for it because she is responsible. Then she was always responsible for her FM at school, putting it on the charger and doing all those things (Parent 4).

HRT 1 stated that giving young people new responsibilities *"depends on the family"* and *"family involvement and to a certain degree, what they have accepted"*. She gives an example of a young person for whom earmold insertion was done by the parents: "*I've had a grade seven student that the parents put the hearing aids in, they don't know that that's not normal, they have no sense of normalcy"*.

However, when parents fail to allow their child to take on more responsibility it can be difficult for healthcare professionals to intervene, as Audiologist 3 explained:

> *When you see that parent who simply dictates every move around what happens, now, how do you change that? The parent is the one who is responsible for the child. If things aren't getting done, I don't think you can say to a parent, well, you know, you're really too intrusive with this child. How well is that going to balance? (Audiologist 3).*

For some families the cost of the technology can be a barrier for allowing a young person to manage their own devices. HRT 1 commented that parents often are concerned with the cost to replace technology and therefore, *"not wanting the child to touch the technology."* HRT 1 went on to say: *"I always say parents not wanting their kids to manage their own technology is a big barrier."* Similarly, Audiologist 1 commented: *"We stress to them that they're expensive and they have to be careful with them but at the same time I think more of a problem is maybe parents and/or teachers"* concerned with the child losing or damaging the devices.

Similarly, Audiologist 2 shared an example of a situation where a child is made to take off their hearing aids on the bus for fear that they may be lost on the way home:

> *Most often the parent is trying to do what they feel is in the best interest of their child. A good example is a child that I saw recently, the parent is just so concerned about the loss or damage of those hearing aids that they interfere with the child's independence and establishment of those kinds of processes. And you*

know that's not really helping the child. The child is not yet at the point where they are willing to sort of go, 'No I need my hearing aids on the bus more than ever'. It's interfering with that child sort of understanding why they need them and the routines around that (Audiologist 2).

Audiologist 1 commented: *but for most kids hearing aids are important to them so they take some kind of pride in taking care of their hearing aids and usually they are quite devastated when something happens to them (Audiologist 1).*

5.4.2 Moving on

In addition to responsibilities inherent to hearing device use, must learn specific life skills that allow them to grow their autonomy and independence. Participants described particular concern with moving away from home, and acquiring skills surrounding telephone use and waking up to an alarm clock

Adolescent, parents, and hearing professionals in this study all spoke of telephone use. A recurring point of interest was the lack of telephone use by young people, due to the use of other technologies, predominately text. When the topic of using the telephone with hearing devices arose, many young people admitted to limited use of conventional telephones. Adolescent 1 stated: "*Like nowadays I find you don't really use the telephone. On my cell phone, I have unlimited texting and on the phone I really only talk to my grandparents*". Adolescent 4 similarly commented *"Well if anyone ever wanted to call me or something, they usually just text me, so I never really have to talk on the phone."*

Many young people often stated that they did not have problems on the phone but were really not using the technology. Audiologist 1 commented *"A lot of teenagers say 'oh yeah there's no problem'"* using the telephone, "*but they're texting all the time*"; not using the telephone to speak. *S*tatements by young people indicated that there may be some difficulties using conventional telephones as Adolescent 6 shared this example of using the telephone:

Nope, I have no problems. Sometimes people just speak quietly. Like for example, my mom called the other day, she was speaking all quietly so I just told her to hang on a second. I tried turning the volume up on the phone, but it was full volume, so she just spoke louder (Adolescent 6).

One parent commented on some of the issues her daughter had using the telephone:

Talking on the phone is a nightmare. She doesn't do that, kids don't do that these days anyway (Parent 4).

Hearing professionals admitted that telephone use was an area that possibly needed more attention. HRT 1 commented that she may not address it enough with the children she worked with:

I do ask, but probably not enough. I should probably have some sort of checklist at the front of everyone's file. I will ask when the kids are getting old enough, where they might be going to birthday parties, sleep-overs, talking to grandma (HRT 1).

Another HRT commented on the importance of telephone use and wished that it was an area that audiologists would focus more on. HRT 2 stated: *"It is all over the board and I wish that audiologists would talk about it more because it is important."* She went on to say: "*I think it is important to get that experience and getting comfortable talking on the phone and getting comfortable toggling between programs" (HRT 2).* An audiologist reiterated that telephone strategies are often not addressed until it becomes a necessity: "*I do think that sometimes we forget about it and we just don't address it at all, until suddenly they ask 'Oh, how do you manage on the phone?" (Audiologist 2).*

Parents and hearing professionals commented that some strategies used by young people are not successful. Many participants spoke of using a speaker phone or parents making phone calls. Hearing resource teachers commented that these strategies do not allow for privacy. HRT 2 was surprised other strategies are not utilized, as she commented: *"You don't want everybody else to hear"* your telephone conversation. HRT 3 noted a lack of awareness by parents regarding various devices that can be used by their child to hear on

the telephone and often act as a barrier to developing autonomy in this area. HRT 3 commented:

> *I think parents, the majority think, 'Oh, if my child can't talk on the phone then I will, or I'll be right beside them.' They don't know about all the devices, accessories, to have your child be independent (HRT 3).*

Parents and professionals in this study were concerned that young people will be unable to be successful telephone users as they have not had the opportunity to practice those skills. HRT 2 commented:

> *I don't think they have a clue. I think hard of hearing kids are going to start avoiding the phone because they haven't had those skills on the phone to make a play date. I can think of a kid and I'm not sure she's ever talked on the phone, she said 'Why would I, I can email and I can text' (HRT 2).*

HRT 1 commented that she encourages parents to encourage their children to make appointments in order to practice phone skills: *"I've said to parents, can you try to have them make it? To struggle on the phone?"(HRT 1).*

Adult participants in this study believed that young people do not yet see a need to be able to speak on the telephone. Audiologist 2 commented:

> *It's an interesting dilemma in this day and age because they really don't see it as a need, or important. They don't perceive that they need to use the phone and maybe they won't right? I don't know, but I think that they should still be able to use the telephone. You know it is still a standard piece of equipment that we use in our environment (Audiologist 2).*

Alerting devices were also discussed by most participants. In particular, individuals spoke of the ability for a young person to be more independent and to wake up in the morning on their own to an alarm. Audiologists and HRTs in this study commented that often parents have the responsibility of waking up children, even as they get older, as

opposed to them using an alarm. Audiologist 2 commented on parents taking on that responsibility:

> *I think for a lot of those children, especially as the degree of hearing loss becomes more severe, that the parents tend to take on that role. They don't even think, 'Oh wait a minute, I am not giving this child independence', just 'I've got to wake them up' (Audiologist 2).*

Parents and adolescents often commented that it was easier for parents to wake them up. Adolescent 1 commented on trying to us a regular alarm clock but that "*it never worked*" and instead, *"just relied on my parents to make sure that I was up."* Parent 1, who also was responsible for waking her child in the morning, commented on her child waking up independently to an alarm clock or alternative device: "*I've really never thought of it because I didn't think he'd actually hear it*" (Parent 1).

Audiologists in this study stated that often families did not necessarily see it as a priority for their child to wake up on their own. Audiologist 2 commented: "*they don't see it as being abnormal that the child doesn't get themselves up in the morning because it just becomes part of what they do*" (Audiologist 2). Similarly, Audiologist 1 reflected:

> *I haven't been quite as successful in that area as I would like. I would like the kids to wake-up to alarms, but it's the cost and whether their parents feel it's, well, affordable or important enough (Audiologist 1).*

Often families may not realize the benefit of assistive devices or that they are available. When devices are discussed families may feel that they are not necessary. Audiologist 2 commented that "*families tend to say, 'Oh we don't need that, we don't need that', is the response you get*" when discussing alerting devices. Audiologist 2 went on to say:

> *And I guess what I do is sort of put it out there and make sure that they at least know that there's that sort of equipment available. Many people with hearing loss don't even know that you can purchase it, a special alarm clock. They are just not even aware that it exists (Audiologist 2)*

The more severe losses I try to sort of start and mention assistive devices whether they'll be alerting type devices. You know the child is young enough that it's still, yes right now, you are always there. You are there to wake them up. If there's a fire you know hopefully you're there to get them out of bed. But I try to make them minimally aware that these things are available (Audiologist 2).

Some young people in this study did use alerting devices. Adolescent 1 commented: "*Well the regular alarm clock doesn't wake me up, but I have like the bed shaker that I put under my pillow, it always works" (Adolescent 1).* Audiologist 2 commented on families who have explored alternative devices: *"It tends to be those same families who strive for independence for that child, and so they've explored that and they've gone down that route.*

However, those families who were familiar with various alerting devices commented that they received the information about devices from events or organizations for people who are D/HH. Parent 4 commented that she "*found out about those things at conferences and would come home and tell her"* daughter. Adolescent 1 indicated that she had heard about various devices through events hosted by organizations for deaf and hard of hearing individuals:

I might have heard about it through VOICE at one of the presentations we saw there, or it could have been a "Hearing Day". I think the one day we had a tech specialist come in and show us all these different products (Adolescent 1).

Often, the use of alerting devices was not implemented proactively but came out of necessity. Audiologist 1 noted:

I have some young kids, and especially if they start to work, it seems like if they have a job that they have to get up for then all of a sudden it's more important that they need some sort of wake-up alarm system. But for school, I don't know, parents are still in a wake-them up stage (Audiologist 1).

Similarly, an HRT noted a young person's urgency for finding a solution to wake up on their own when they are going away from home for the first time: "It's d*efinitely more important once they're going to university, it's like "Help, what do I need?" (HRT 3).*

When participants spoke of adolescents gaining independence, a recurring theme was the milestones of transitioning to high school or post-secondary school. Those participants moving on to high school spoke of added responsibilities of managing equipment, finding needed resources, and advocating for themselves. Adolescent 5 commented:

> *My mom said that when I'm at high school the teachers won't be coming to you, that you need to go to them if there's a problem. So, that's another thing, you know, I have to be able to go to them (Adolescent 5).*

Similarly, a parent spoke of the added responsibility on her child going to high school:

> *I guess maybe just his responsibility of keeping himself organized carrying the FM system around to the classes with him and you know encouraging the teachers to put it on and use it (Parent 6).*

Participants already in high school spoke to looking forward to going to post-secondary education and the implications for them; including being away from home, requiring special accommodations, and the responsibility that entails. Parent 5 discussed her desire for her child to go to university but voiced concerns that he is unable to wake up to an alarm and he relies on his mother to wake him up. This was not an issue with her eldest child, who had typical hearing:

> *This is a huge concern of mine because his brother has gone away to university, and he is quite capable of doing well at university. I will encourage him to go to university but my biggest worry is that he will not be able to get out of bed, so we may have to schedule late classes.*

Similarly, parent 2 commented that her daughter was eager to go to university but she will have to find accommodations that work for her:

"I said you're going to be taught in a different fashion now. She's eager, but that whole big classroom, she's going to have to find what's going to be good for her. But I have full confidence that [she] will do the right thing, because she wants to do so well there."

Audiologists and HRTs commented that they often discuss with young people what type of environment they will be in at university and how that will impact their listening needs. Audiologist 2 commented:

There's often a discussion around, you know, what type of program you're going into, what type of classrooms. Are they going to be in a class of 500 or are they going to be in a class of 20?

Adolescents in this study were aware of some of the different leaning environments present at university and the potential challenges. Adolescent 2 commented: *"The only thing that might be worrying is if I were to sit at the back because I know the classrooms are way, way bigger."*

All participants commented on the challenges for a young person going away to school and ensuring they have the resources they require to be successful. Adolescents spoke of some awareness of the resources that may be available to them. Adolescent 2 commented:

My resource teacher has said there are definitely resources that you can use at university that will help you with your hearing disability and all of that. I'm like ok, but if I were to go into a class, I would just do what I usually do. I'd sit at the front and we would be able to have laptops too so that helps a lot, I'd sit at the front and ask the teacher if he can repeat something or ask my classmate. I'd just go into my usual routine. I'm in class so let's do this (Adolescent 2).

The above participant when asked if the types of supports available at the university level were important to her when choosing a College or University commented:

I've looked into it a little bit, but as I said I don't really consider it a disability-disability. I'm more like it's just an everyday thing. I would definitely consider it if the university I looked at had certain programs that would benefit people with hearing loss. I know there are certain scholarships for certain disabilities and stuff like that. I would definitely utilize that. In terms of university and program, yeah I would look into that, but in the end I think it would be the university that would best suit what I want to go into over what resources they have (Adolescent 2).[11]

Adolescent 1 commented:

Well from VOICE conferences I know that I've learned that you can get like either scribes or notes from your professor, you just have to ask, but you have to go to the special health department or something. I'll obviously seek more information as I get older because I want to [make] use of those, say that I need this help because of my hearing loss. That way it would be more beneficial than trying to hear the whole thing, and writing notes, and fail the whole thing (Adolescent 1).

Adolescent 4 commented:

I haven't really thought a lot about university. But, I went to this seminar, they were talking about like what you're going to do after high school and they were talking a lot about people who take notes for you. And I guess I should probably find a friend in the class or have somebody to do that with me. I don't think I will be having too much problems in that. (Adolescent 4).

Hearing resource teachers and audiologists discussed the challenges for adolescents transitioning to post-secondary education. In particular, they noted the importance of young people being aware that some resources are available to them. Audiologist 2 commented on this:

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[11] Referring to resources for students with disabilities

Making them aware that the university would have an office for students with disabilities. That they know if they need resources that they may have to go and speak with them in terms of what resources are available at the university for them. So, whether it's note takers, we've talked about note takers as an alternative to FM because there's a real resistance to FM at university level.

However, often there are challenges to accessing these resources. HRT 1 commented that young people she has worked with in the past have "*had to fight for every adaptation or accommodation that needed to be done*" at the university level.

Challenges regarding the funding of devices was also discussed by the hearing professionals. HRT 2 commented on the funding of assistive technology for post-secondary students:

They will have to access that. Like, it comes down to the funding. It's no longer covered by the school board. So, how do you access an FM system? Do you go through the ministry of community social services or does the university provide it? So, I'm finding the universities have their own criteria for being identified as having a hearing disability. So, I think it's a different process in university (HRT 2).

Similarly, Audiologist 2 commented:

These are things you are going to have to go to the university and ask about and find out because their funding models are quite different. This is what I've discovered over the years, trying to get things like an FM funded for them when they're at that level is actually quite challenging.

Parents in this study realized that their child would have to advocate for themselves at this level to obtain the appropriate resources. Parent 4 noted:

I'm already prepping her. As much as she's an advocate for herself, I'm already saying, you know, you are going to want these things, they're going to give you extra exam time, and they're going to give you a different room to write in.

However, transitioning to university may be challenging as many students are used to having a certain level of support at the elementary and high school level that is often not offered or readily available in post-secondary institutions. Audiologist 2 reflected:

> *I think what tends to happen is that not until they get there they really can wrap their heads around what their needs are. They can't anticipate the different listening challenges necessarily between what they've had for all of their schooling and what they are going to have now. So sometimes it isn't until they get there that they realize.*

HRT 1 noted that the transition can be difficult and suggests that a smaller institution or attending a community college first as a transition year may be beneficial for students with disabilities.

> *[Community] college is a step above high school and not into the melting pot of university where you just swim and hope you don't drown. So for many of my kids I kind of recommend college for a year. I had hearing kids for 10 years prior to this and not all kids, even though academically they might be ready for university, they're not as mature. You need to be strong and very much an advocate. Now the kids who us their FM regularly in high school they might be ready depending on who they are but, you know what, college isn't bad for you. It might be a little smaller and they take care of you a little bit more (HRT 1).*

Adults in this study commented on the independence required by young people as they decide to leave home to go away to school and the ability to navigate both the education and healthcare systems while away from home.

> *I guess at that point you do really hope that those young people have reached the place where they can figure out what their needs are, that they know who to contact, or where to begin the process of finding out how to begin if [they have a] problem (Audiologist 2).*

Chapter 6

6   The Grounded Theory: "I am the expert"

Overall, I am the expert, because <u>no one</u> knows your hearing loss better than you do.

Adolescent 1, journal entry

6.1   Description of the Theoretical Model

In exploring the process of transition toward the self-management of hearing healthcare, the core category *"I am the expert"* and the key concepts of *developing ownership*, *managing identity*, *developing advocacy*, and *doing it myself* were identified. The core category of "I am the expert" represents the process for adolescents as they move into the role of "expert" in managing their hearing healthcare needs. However, there is a process of realization of their expertise, as they grow into the role with support from their parents, teachers, and health care professionals. Figure 5 illustrates the *"I am the expert"* model.

Over the course of a young person's life, they exhibit growth and development in ownership of their disability through building knowledge about their hearing loss, coming to understand their listening needs, and realizing the impact hearing loss has on daily life. We see an evolution in their self-identity that is impacted by personal experiences and shapes how they identify themselves as a person with hearing loss, how they feel they are perceived by others, and how they "fit in" within their school and community at large. The development of positive self-advocacy skills is critical for young people to ensure they have their needs met as they learn to navigate the world more independently.
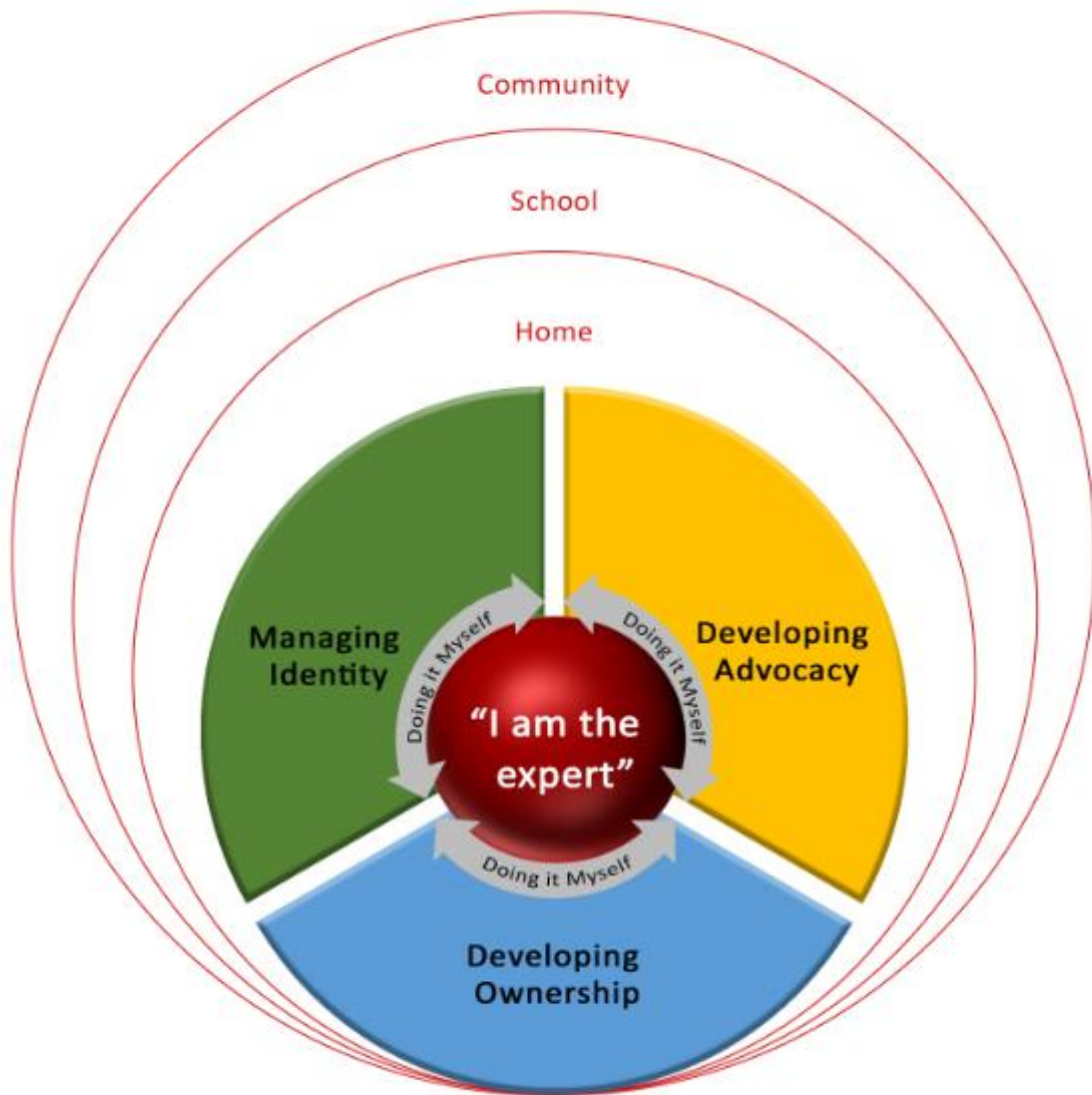
Figure 5: The "I am the expert" Model. A grounded theory of adolescent development toward self-management of their hearing health care

The ability for young people to take on more responsibility and to have greater autonomy in managing their hearing health, characterized by *"doing it myself",* is influenced by their sense of ownership, their ability to manage their identity, and development of self-advocacy skills. As with many developmental processes, this process is non-linear. Findings suggest young people can experience progression and regression.

The ability for young people to self-manage their disability does not occur in isolation and occurs within the greater context of a young person's life. Thus, we see a significant influence from not only parents and family, but this study also highlights the impact of a young person's school and community. The context can, and will, most likely change throughout a child's life (for example, as they get older, change schools, family dynamics and/or social dynamics change). The context of a child's life dictates the type of supports available to the child and family, the types of social interactions (whether positive or negative) a young person will experience and potentially the opportunities to work on skills development. This will significantly shape their development and in turn their success in the self-management of their hearing healthcare.

The "I am the expert" grounded theory model developed to describe a young person's transition in their hearing healthcare is supported by Bronfenbrenner's Ecological Systems Theory. Bronfenbrenner (1979, 1986) describes a framework of child development where individual development is influenced by the environment and the evolving interaction between the two. Of importance for individual development is how the individual perceives that environment.

Bronfenbrenner (1979) describes the ecological environment as a "set of nested structures, each inside the next, like a set of Russian dolls" (p. 3). At the centre is the individual and their immediate context (microsystem) and then moving outward to more abstract concepts of context and environment, noting the interconnectedness and influences of each environment on an individual (meso- , exo-, and microsystems). The microsystem is an individual's immediate "setting" or environment, which includes direct interactions with others. A mesosystem is defined as a "system of microsystems" (Bronfenbrenner, 1979, p. 25) in which an individual actively participates. An exosystem

refers to one or more settings, that does not directly involve the individual, but may indirectly impact the individual or be impacted by the individual. In the context of child development, Bronfenbrenner (1979) provides examples of the microsystem "setting" such as, home, day care, and school. Bronfenbrenner notes the building blocks of the microsystem are *activity* and *interpersonal relations* (Lewin, 1931, 1935) and *role* (Mead, 1934; Thomas & Thomas, 1928). In Bronfenbrenner's framework, these refer to an individual's participation or engagement within a context (activity), the interactions between individuals within a specific context (interpersonal relations), and the "expectations associated with a position in society" (role), for example, the role of student, parent, or teacher (Bronfenbrenner, 1979, p. 25). The mesosystem would be the interaction between home, school, or peer groups, while the exosystem may include a parent's work place. Finally, the macrosystem, furthest from the individual, refers to the societal, cultural, political and/or ideological influences that impact and shape the settings of the micro- and mesosystem levels.

The "I am the expert" grounded theory model identifies the importance of the interrelatedness between contexts and relationships in the process of transition for young people in managing their hearing healthcare. In this model, we identified home, school, and community as important settings in the micro and mesosystem.

Chapter 7

7   Discussion

7.1   Self-Management of Hearing Healthcare

The findings from this study provide insight into the process of transition for adolescents toward the self-management of their hearing healthcare, and the role of parents, educators, and health professionals. The ability for individuals to manage their own health care needs is a *lifelong* process that far exceeds the confines of adolescence. However, during childhood and adolescence, a strong foundation is required to ensure young people are able to become successful adults in managing their health care needs. In order for young people to move toward greater autonomy in their hearing healthcare and successful self-management as adults, this study identified the following areas of importance in the journey to becoming *the expert*: developing ownership, managing one's identity, developing self-advocacy skills, and emerging autonomy.

The ability to self-manage personal health care is inextricably linked with personal autonomy. The development of personal autonomy and the ability to self govern is associated with enhanced self-management of health care and more positive health outcomes (Ayala et al., 2009; Palermo et al., 2007). The sense of personal responsibility and self-reliance that a young person may experience with more independence surrounding health care can in turn contribute to an enhanced sense of autonomy (Rosen et al., 2003).

The properties of the above concepts identified in the current study are specific to the adolescent participants who are D/HH. However, in the chronic illness and disabilities literate the concepts of ownership, personal identity, personal advocacy, and personal autonomy are associated with positive self-management of health care (Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Lebrun-Harris et al., 2018; Westwood et al., 1999).

7.2 Ownership of Hearing Loss

It is fundamental for individuals, including young people, to have a sense of ownership surrounding their hearing disability. In the current study, developing ownership was identified as a foundation to the transition process to "becoming the expert" in self-managing one's hearing healthcare. Ownership is known to be an important part of health care; the chronic illness literature tells us that "active participation in negotiation of treatment plans helps young people to take back some ownership and control of the disease from the parents" and contributes to adherence to treatment plans (Yeo & Sawyer, 2005). English (2003) suggested that assuming ownership of hearing loss is a significant milestone for adolescents who are D/HH. She suggested that hearing loss is "owned" by parents and during adolescence, this ownership must transition to the child and thus gradually gaining the confidence needed to be one's own advocate. Dilollo (2006) noted that rehabilitative efforts in adults with hearing loss may be hindered by lack of ownership. Similarly, studies that explored the transition to self-manage chronic health conditions or other disabilities identify ownership as a key factor in self-management of health care (Giarelli et al., 2008).

In the current study, a key aspect of ownership was gaining knowledge of one's own hearing loss and listening needs. This included knowledge regarding etiology of hearing loss (if known), progression, and degree of the hearing loss. However, perhaps more important was a young person's ability to understand the impact of hearing loss on their communication and listening needs, as well as realizing the potential benefit of using assistive technologies. The importance of not only gaining knowledge was noted, but the process of obtaining that knowledge. Parents, HRTs, and audiologists were key sources of knowledge for young people and contributed to building a young person's knowledge base. The sharing of information with young people regarding their hearing loss is important and should be considered a fundamental aspect of care. Studies surrounding chronic health conditions have stated that knowledge acquisition regarding a disease or disability is important for transitioning to self-manage one's health care and that it is important for young people to begin this process early on (Bollegala & Nguyen, 2015; Levy et al., 2020)

Many young people expressed the need to know more about the "real life" implications of their hearing loss. In this study, several adolescent participants noted a lack of information provision by healthcare professionals regarding their hearing loss. For some participants, this lack of information perpetuated anxiety or worry regarding the potential for progression of hearing loss. Unfortunately, lack of information was often interpreted as a lack of time, care, or necessity on the part of their audiologist.

In the current study, young people's ability to identify the benefit (or lack of benefit) of intervention plans for their hearing loss (e.g. device use) contributed to better understanding of the rationale for their intervention plans and allowed them to make more informed decisions regarding their own hearing healthcare. Expanding their knowledge about their hearing loss provides young people with the knowledge and resources to begin to make their own decisions surrounding their hearing healthcare, providing them with a sense of control. This agrees with studies that look at change in the therapeutic process, taking ownership of the problem and an understanding of the problem is required in order to provide a solution or move forward (Yalom & Leszcz, 2005). In addition, it is important for young people to understand the rationale for intervention and associated options in order to take part in the decision making process. (Yeo & Sawyer, 2005)

In the current study, parents, educators, and audiologists believed that children did not have a frame of reference as to what they may be missing in daily life or in the classroom when not wearing their hearing aids. In particular, the severity of hearing loss played a role in young people realizing the impact assistive technologies play in their lives. Participants noted that young people with milder losses could 'get by' better than individuals with more severe losses and/or the benefit of device use was not as apparent for those with milder losses. Historically, research looking at the effects of mild and unilateral hearing losses are much less understood and intervention plans have not been as defined for these degree of losses (Fitzpatrick et al., 2016). This has often resulted in less consistent device use for young people with minimal or mild hearing loss compared to their peers with more severe hearing losses (Walker et al., 2013). However, studies suggest that children with minimal and mild hearing loss are also at risk for speech and

language delays, as well as academic, social, and behavioral difficulties (Hogan, Shipley, Strazdins, Purcell, & Baker, 2011; Lieu, Tye-Murray, & Fu, 2012; Tharpe, 2008). The findings from the current study further strengthens the need for professionals to remain engaged with young people and their parents not only in the early years but throughout adolescence, providing more specific counseling, as well as finding ways to demonstrate the benefits of hearing aid and assistive device use.

Developing decision-making autonomy was also identified as an important aspect of ownership and moving toward effective self-management. Participants in this study all described a process of shared decision-making between young people and the adults in their lives. Many participants shared the theme of trust and compromise in allowing young people to make their own decisions, often, this was surrounding device use. Children who may have once obediently worn hearing aids and used assistive technologies in the classroom in elementary school may begin to choose otherwise. Allowing young people to make their own decisions with knowledge of the associated consequences was an important aspect of giving young people control of their disability. Allowing young people to make their own decisions, helps them to build the skills necessary to make health care decisions as an adult with the "safety net" of parents and teachers. One can argue that there are likely significant advantages to engaging children who are D/HH at a younger age allowing for young people to make mistakes without more significant consequences.

Many of the adults in this study noted that as children mature and demonstrate the ability to manage certain health related tasks they should be allowed to take on more responsibility with their hearing healthcare management. Ultimately, adolescents should be better equipped to self-manage their health care if they are able to determine when they need to see a healthcare professional, ask questions relevant to their health care needs, navigate the healthcare system, schedule appointments and understand costs that may be associated with their illness and/or disability (Callahan et al., 2001).

7.3   Adolescent Identity Management

The concept of identity implies an awareness of the self and refers to how one is labelled in a social context (Gill, 1997). All relate to an individual's ability to manage their identity and to control how they are viewed or perceived by the outside world. The development of poor self-identity can negatively impact the development of autonomy as a positive sense of self is required (Zimmer-Gembeck & Collins, 2005). Positive self-identity development for youth with a disability can be complex and personal identity development in children with hearing loss can be at risk (Kent & Smith, 2006). In the current study, it was evident that personal identity development was important to how young people identify themselves as an individual with a disability, and how they transition to manage their hearing healthcare. Through their own reflections, young people reported that their perceptions of their hearing loss evolved over time and their experiences with hearing loss significantly shaped their identities. Many young people in this study were relatively positive about how they perceived themselves as an individual who is D/HH indicating how it made them unique, stronger from overcoming challenges, or more understanding of others with differences. However, when the topic of disclosure of one's hearing loss was broached it was made more evident that young people actively engaged to manage and maintain control over how they were perceived in the world. Even those young people who had relatively positive perceptions of their hearing loss and had not had negative interpersonal experiences were acutely aware that they were different and of the consequences that being different had. The complexities of these concepts are evident in their discussions about developing positive traits but also understanding that having a hearing loss does have a societal stigma associated with it. This agrees with previous studies reporting that young people with hearing loss are concerned about social acceptance and being teased or embarrassed at school (Punch, Creed, & Hyde, 2005) and will resist self-identifying with the risk of being "less than normal" (Kent & Smith, 2006).

Hearing loss is generally recognized as an invisible disability. Individuals with a concealable stigmatizing trait, like hearing loss, can decide if and when they choose to reveal their disability (Jennings, Southall, & Gagné, 2013; Ragins, 2008). Strategies

utilized by an individual in identity management are on a continuum from full disclosure of a stigmatizing trait to "passing" where complete non-disclosure is chosen (Croteau, Anderson, & VanderWal, 2008; Jennings et al., 2013; Ragins, 2008). In the current study, adolescents spoke of deciding who to tell and when to tell them about their hearing loss. This agrees with research literature that indicates decisions regarding disclosure of a stigmatizing trait occurs with each social interaction, with individuals weighing the benefits and risks of such a disclosure (Ragins, 2008). It is suggested that for an individual with an invisible stigma who has not disclosed, there is a potential for lack of control over the disclosure process (Rose & Ragins, 2017). Jennings et al. (2013) noted that in the case of a hearing loss, depending on the challenges of the communication environment, a hearing loss may unintentionally be revealed. This lack of control over disclosure may in turn increase an individual's fear or anxiety regarding the disclosure of a stigmatizing trait (Rose & Ragins, 2017). In addition, the choice to not disclose a hearing loss, could negatively impact relationships; impacting the ability to form a close relationships due to the fear of facing social rejection or damaging relationships when disclosure does occur (Ragins, 2008). For children, and in particular adolescents, this may be of particular concern as social interactions within peer groups can be complex and dynamic at this age, and peer acceptance is important as will be discussed below.

Peer acceptance is important to the development of personal identity during the adolescent years and is integral to healthy social-emotional development (Kent & Smith, 2006). Poor peer interactions can lead to challenges in personal identity development and social-emotional well-being. Studies have indicated children who are D/HH can experience deficits in social skills and social interactions compared to typically hearing peers (Davis, 2006; Israelite et al., 2002; Rich, Levinger, Werner, & Adelman, 2013; Stinson, Whitmire, & Kluwin, 1996). Other studies have suggested individuals who are D/HH may have fewer quality friendships than hearing peers, are more frequently rejected by peers (Nunes, Pretzlik, & Olsson, 2001; Rich et al., 2013; Stinson et al., 1996) and experience feelings of loneliness (Kent, 2003). However, other studies suggest no differences in social competency compared to hearing peers. Batten et al. (2014) conducted a systematic review exploring social interactions between children with hearing impairment and their hearing peers. A lack of consensus was noted among

research studies, although there was agreement across studies that a child's communication competence is positively associated with social interactions with hearing peers (Batten et al., 2014). Eriks-Brophy et al. (2012) studied a group of adolescents and young adults to investigate integration of children with hearing loss in mainstream schools. In contrast to previous studies, results suggested that participants were not socially isolated or experienced any negative impact to their self-esteem.

D/HH participants in the current study were all in mainstream schools and reported to be in peer groups of children with predominately typical hearing. Both positive and negative peer interactions were reported. Many participants reported a sense of belonging within their close group of typically hearing friends and expressed that they were being supported by them. Participants also noted that close friends were aware of some of the communication strategies that might be used and that these friends would be patient if a communication breakdown occurred. However, some adolescent participants voiced concern regarding socialization, missing out, and struggling with communication in various social interactions. For example, one participant no longer enjoyed swimming as a social activity as an inability to wear her hearing aids at the pool left her unable to communicate effectively with her peers. Another noted missing out when friends or classmates were whispering. Problems that children and adolescents who are D/HH may experience with social participation have been reported in the literature (e.g. Punch & Hyde, 2011; Zaidman-Zait & Dotan, 2017). Zaidman-Zait and Dotan (2017) examined everyday stressors for D/HH adolescents in mainstream high schools. Adolescents reported that they were not fully able to participate in leisure activities like their hearing peers, specifically referring to listening to music and taking part in athletics where hearing aids cannot be worn. In addition, missing out on social conversation and not being able to hear well was of concern to young people in this study. This can impact what activities or social contexts a child may decide to join. This agrees with studies reporting adolescent difficulties in social and group conversations (Renée Punch & Hyde, 2011; Zaidman-Zait & Dotan, 2017).

Participants who were D/HH in the current study noted incidents of receiving unwanted/negative comments or negative attention due to their hearing loss or wearing of

hearing aids. These types of interactions can affect a child's self-esteem and in turn, self-identity. It can also influence the decision whether to disclose a hearing loss to their peers and/or the timing of disclosure. Studies have shown that children with hearing impairments reported higher incidents of bullying than their hearing peers (Kent, 2003; Warner-Czyz, Loy, Pourchot, White, & Cokely, 2018). Warner et al. (2018) looked at the incidence and type of bullying that occurred for youth and adolescents with hearing loss. Adolescents with hearing loss self-reported a higher incidence of bullying compared to hearing peers (50.0% and 28.0% respectively) and more frequently experienced teasing and social exclusion compared to hearing peers (Dalton, 2011; Kent & Smith, 2006; Warner-Czyz et al., 2018). Children in the current study also shared their perceived stigma toward their hearing loss. They described "knowing" that others may judge or think negatively of them or their abilities due to their hearing loss. This perceived stigma may impact how a child identifies as a person who is D/HH and could influence decisions regarding device use. This seemed particularly true for children entering new social situations (e.g. entering high school). Studies have also suggested that young adults may reject wearing hearing aids due to perceived stigma, cosmetic reasons, or peer acceptance (Cameron et al., 2008; Cienkowski & Pimentel, 2001).

Many participants in the current study indicated how important it is for young people with hearing loss to interact with other D/HH peers and to be provided with an opportunity to engage with others who have had similar life experiences. Young people noted that these interactions could provide them with opportunities to share experiences and feelings that neither their parents nor their typically hearing peers could understand. Parents and professionals also believed that an older peer who has navigated various social and academic experiences with a hearing loss or wearing hearing aids could provide mentorship and insight. Previous studies have reported the importance of experiences with hard of hearing peers in identity construction for adolescents with hearing loss (Israelite et al., 2002) and can help to 'normalize' their experience (Kent & Smith, 2006). Similarly, studies suggest that individuals may feel a greater sense of belonging with peers who share the disability experience (Salmon, 2013) and that interactions with hearing impaired peers can provide social support and identity validation (Zaidman-Zait & Dotan, 2017). Punch and Hyde (2011) also suggested that

supportive hearing friends could ameliorate negative social consequences due to a young person's hearing difficulties.

An emerging area of interest in this study is the impact of hearing loss on dating. In the current study, young people who are D/HH perceived hearing loss and hearing aid use as less than desirable, putting them at a disadvantage to their hearing peers when it came to dating. Parents in the current study also voiced concerns for their children that they would feel left out of the dating experience. Dating is an important aspect of adolescent development. Romantic relationships and the quality of the relationships in adolescence impact the development of romantic self-concept, feelings of self-worth, personal identity, and can impact adult romantic relationships (Connolly et al., 2014; Kansky & Allen, 2018). There is little evidence of the impact of hearing loss on the development of romantic relationships in adolescence. However, a meta-analysis of those with physical or sensory disabilities found individuals to be less successful in forming romantic relationships (Pinquart & Pfeiffer, 2015). The authors hypothesised that this could be due to the negative affects a sensory impairment has on communication with other individuals (Pinquart & Pfeiffer, 2015). A study exploring everyday stressors in adolescents who were D/HH, found romantic relationships to be a stressor (Zaidman-Zait & Dotan, 2017). However, romantic relationships were found to cause less stress than concepts related to peers, school, and the future (Zaidman-Zait & Dotan, 2017).

7.4 Adolescent Advocacy

It is integral for young people with disabilities to develop self-advocacy skills to facilitate transition into adult life and to manage their hearing healthcare needs. Few studies have focused on self-advocacy in adolescents who are D/HH (Michael & Zidan, 2018). Self-advocacy is generally defined as the ability to "effectively communicate one's wants and needs" (Test, Fowler, Wood, Brewer, & Eddy, 2005a). Self-advocacy has been linked to positive self-concept, leadership ability, sense of belonging, informed decision-making, and the ability to access required supports and services (Doren & Kang, 2016; Paradiz, Kelso, Nelson, & Earl, 2018). Self-advocacy is a skill that needs to be developed and young people require the tools, including a sense of ownership and an understanding of there needs, to be successful advocates for themselves (Test et al., 2005a). Test and

colleagues (2005) developed a conceptual framework of self-advocacy for students with disabilities with four components; *knowledge of self, knowledge of rights, communication,* and *leadership.* Test noted that knowledge of self and rights were the foundation to self-advocacy "because it is necessary for individuals to understand and know themselves before they can tell others what they want" (p. 45). Individuals then must be able to communicate information effectively regarding their disability and personal needs. Finally, leadership enables a person to move from advocating for themselves to developing advocacy for others with similar needs. The link between development of self-advocacy skills and successful transition into adult life by students with disabilities has been documented (Test et al., 2005a). Previous studies have shown that student success in a general education classroom is tied to the ability to self-advocate (Luckner & Muir, 2001).

In the current study, participants understood the importance of being able to articulate their needs when it came to their hearing loss but were not always or consistently put into practice. They spoke of needing to "put yourself out there" as others will not advocate for them and that they have the right to various accommodations, particularly in the classroom. Barriers to self-advocacy included the concern that advocating for oneself would single them out and/or have them seen as different from their peer group. Again, the idea of being perceived as different was a significant barrier to young people in this study. Participants also spoke of feeling self-conscious when needing to ask for accommodation or even for clarification in the event of a communication breakdown. One participant articulated that it could at times be "frustrating and humiliating" to ask for repetition or clarification of what was said. It was also noted that group advocacy was easier than personal advocacy.

Audiologists and HRTs spoke of the importance for young to people to work on advocacy skills early on. However, they also noted that they have observed that advocacy skills and the desire to advocate for oneself waxes and wanes over the developmental trajectory. Students who may have once shown positive development in personal advocacy may appear to regress. It was suggested that this more often occurs as children entered adolescence and/or upon entry to high school. Possibly, these changes in

behaviour may be influenced by changing dynamics in peer groups and the growing importance of image and personal identity during this time. Behaviour change may also be influenced by a new school environment (e.g. with new teachers, new social groups, an older adolescent population, and new social expectations). It was also noted that young people who are not fully aware of their personal listening needs might not be able to make the connection between personal advocacy and having their needs met, therefore having no framework for the benefits of personal advocacy. For young people who have not demonstrated good or consistent advocacy skills, the need for personal advocacy may be event driven. For example, in this study one mother discussed how her daughter is more likely to advocate for herself now that she is preparing to apply for post-secondary education, as the consequences for not doing so are much higher.

Advocacy skills can be taught and modelled. In this study, parents and teachers were found to play a significant role in the development of advocacy skills in young people with hearing loss. Audiologists, parents, and HRTs spoke of the importance for young people having the opportunity to practice these skills, and in particular from a young age. Previous studies with students who are D/HH have noted similar findings suggesting advocacy skills are largely influenced by the students' environment, including their relationship with their parents, teachers, and other authority figures (Luckner & Muir, 2001; Michael & Zidan, 2018; Test, Fowler, Wood, Brewer, & Eddy, 2005b). Studies suggest that self-advocacy for children with disabilities is important across the life-span, but development of skills should begin early on to facilitate transitions as they get older (Test et al., 2005a). Unfortunately, it is suggested that the development of self-advocacy skills and providing opportunities for young people to self-advocate are frequently not included in the instruction of, or intervention for students with disabilities (Roberts, Ju, & Zhang, 2014).

Lack of instruction may be a contributing factor for poor personal advocacy development. In this study, the HRTs reported working on self-advocacy skills with children as an important part of their role. They also reported they had more opportunities to work on these skills with young people compared to audiologists. Audiologists also noted the importance of building these skills but cited lack of time and few appointments

to be able work on this consistently. It was noted that it very much depends on the environment of the child and how supportive parents, teachers and other adults are in providing opportunities for practicing advocacy skills outside of instructional time to solidify skills. Gordey (2018) explored self-determination in children who are D/HH and also noted the importance of the relationship between teachers of the D/HH and students who are D/HH. He found they were instrumental in supporting parents, classroom teachers, and students with hearing loss.

Authority figures were noted as potential barriers to self-management skill development. Audiologists and itinerant teachers noted that parents, although well-meaning, can be a barrier to self-management. They may not encourage children to voice their own needs and continue to play the role of primary advocate for their child. Research has found that this could be related to the fact that parents of children with disabilities, including those with hearing loss, may become overprotective. They may be reluctant to allow for more independence or feel that they have to protect their child (Sexton, 2017). Respecting and listening to a young person's attempts at advocacy was also noted in the current study. Participants spoke of situations where young people attempted to advocate for themselves and were instead dismissed or overruled by an authority figure. In one example, a student reminded her teacher to wear the microphone for the hearing assistive technology that was an accommodation for her in the classroom. The teacher dismissed her request and replied that he spoke loud enough and that it was not required. The consequence of this type of situation is multi-faceted. This student was able to identify her listening needs, recognized the need for accommodation, identified her rights to the accommodation in the classroom, and was able to articulate that to her teacher. In dismissing attempts at advocacy, it is reinforcing negative results, and possibly making it less likely that a young person will risk advocating again. This situation also highlights an individual's perceived needs and their rights for classroom accommodation. It is not uncommon for teachers in mainstream classrooms to be unfamiliar with adjustments they may need to make in their teaching to accommodate a student who is D/HH (Zaidman-Zait & Dotan, 2017). They may also not be familiar with the use of and/or need for hearing assistance technology for students (Jamieson, Zaidman-Zait, & Poon, 2011). This is not necessarily specific only to teachers, but includes other authority figures in a child's life (e.g. coaches, professors,

instructors). It is important for those in a position of authority/power in a child's life to be able to identify when a young person makes attempts at self-advocacy and when they see this happening, to provide appropriate responses. If the intended outcome of advocating for oneself is realized, or deemed successful, by that individual they will more likely advocate for themselves in the future.

7.5 Emerging Autonomy

Through the process of building on the various domains, young people become more able to take on responsibility regarding their hearing healthcare needs (doing it myself). This was observed in the process of *checking in and letting go,* related to managing responsibilities directly related to hearing loss (in this study, it was most commonly related to hearing aid, or other hearing device, use and maintenance) and finally, *moving on*, by gaining greater autonomy.

The literature states that adolescents must begin to assume more responsibility for the self-management of their hearing healthcare (English, 2003). This may include understanding their hearing status, recognizing changes in hearing, basic hearing aid care, knowing when they need to see a clinician for a hearing assessment, scheduling appointments and recognizing when hearing technology is not working and needs to be repaired.

Hearing aids and/or other listening assistive devices require daily maintenance and care. In addition, hearing technologies are expensive which can add an additional care burden. When children are young, parents are responsible for all aspects of care. As children get older, participants in this study described a process of shared responsibility between parent and child; evolving over time with a reduction in parental oversight. Participants in this study noted barriers to this process, in particular lack of opportunities to practice tasks, and at times parental reluctance to relinquish their role as the individual with primary responsibility. This is of particular importance as children begin to spend less time with their parents, begin to be away from home over night, and eventually move away from home for work or school.

Independent telephone use in young people who are D/HH was noted as an area of concern by parents and professionals in this study. Young people in this study reported limited phone use; texting has limited the need for young people to use conventional telephones. However, parents and professionals were concerned at an inability for young people to use a conventional telephone, which is a skill (although some would argue a diminishing necessity) required in some cases for employment purposes, and making appointments. Texting in general, has provided opportunities for individuals who are D/HH, to communicate more easily than a traditional landline or cell phone may allow. However, research has shown that texting has now not only reduced telephone conversations, but also in-person conversation. Studies have shown that individuals with typical hearing avoid conversation and/or have a fear of in-person conversation due to texting availability. Face-to-face conversation develops interpersonal skills, teaches children to think and apply reason, and to self-reflect (Turkle, 2011). However, other studies have shown online communication with friends can have a positive impact on adolescent identity and strengthen existing friendships (Davis, 2013). One worry is that young people, in general, will fail to acquire skills in decoding inflection and facial expressions. Young people who are D/HH are already at risk for missing the subtleties of communication and it is interesting to consider the greater impact texting may have on social development for this population. However, it is important to note that communication through texting may put young people who are D/HH on an even playing field with their typical hearing peers.

The ability for a child to wake up independently in the morning was also discussed. Strategies shared by many families was that parents made it their responsibility to wake their child in the morning, even into adolescence. They reasoned that their child could not hear an alarm or that specialty alarms for individuals who are D/HH did not work for them. Alerting devices were not often seen as a priority for families, audiologists did not always provide information about them, or it was not seen as a necessity. Parents relinquishing this waking responsibility was often event-driven (e.g. the result of their child moving away from home to work or to acquire a post-secondary education). It would be beneficial for young people to become comfortable with alerting devices and

find one that works for them before the necessity of these devices is needed. This in turn may alleviate some of the stress of leaving home for them.

The importance of young people developing independence and autonomy is important. Studies have shown that overprotection, and lack of independence can negatively affect the autonomy of individuals with disabilities. In general, parents who demonstrate typical parenting behaviours would exhibit behaviours that were developmentally appropriate for their child, help their child navigate common challenges and provide appropriate boundaries (Gagnon & Garst, 2019). Children, whose parents exhibit these types of typical behaviours, have been found to have greater rates of wellbeing, academic success, and lower rates of maladaptive behaviours (Darling, Cumsille, Caldwell, & Dowdy, 2006). However, over-parenting, defined by parent over-involvement that is developmentally inappropriate (Lemoyne & Buchanan, 2011), has been linked with several negative outcomes in children, adolescents, and young adults (Burke, Segrin, & Farris, 2018; Gagnon, Garst, Kouros, Schiffrin, & Cui, 2020). Studies suggest children who experience over-parenting may have reduced autonomy, poorer academic performance, lower levels of self-esteem, poor peer relationships, higher rates of anxiety and depression, and higher levels of substance abuse (Butner et al., 2009; Gagnon et al., 2020; e.g. Lemoyne & Buchanan, 2011; Schiffrin et al., 2014; Wong, Hickson, & McPherson, 2003). This may also include less than expected development in the areas of independence, confidence, and social skills (e.g. Lemoyne & Buchanan, 2011; Schiffrin et al., 2014). Gagnon et al. (2020) examined the associations between child disability and parent-reported over-parenting, autonomy granting, and affect management of parents of children with and without disabilities. They concluded that over-parenting is more prevalent among parents of children with disabilities. The researchers suggest that this may be due to the need for parents of children with disabilities to advocate for their child to ensure they receive equal opportunities to their peers and that it "may provide the proper balance needed to counteract some of the deleterious effects associated with childhood disability (Gagnon et al., 2020, p. 422). Although adolescents and children with disabilities may require additional supports, ultimately inappropriate levels of oversite may negatively affect a child's development.

7.6   Community Context

The often-quoted proverb "it takes a village to raise a child" speaks to the importance of community in a child's development. Adolescent transition to self-manage health care including hearing healthcare does not occur in isolation. Participants in this study spoke of family, peers, audiologists, HRTs, classroom teachers, extracurricular instructors, and society as a whole playing a role in how a young person identifies as an individual with a disability, gains knowledge about their needs associated with their hearing loss, acquires advocacy skills, and develops autonomy. Adult participants in this study spoke of the, at times, perilous balancing act of building trust and allowing the young person to make their own decisions. Professionals and parents spoke of the need for consistency, in particular between home and school, concerning expectations for a young person around device use, autonomy, and self-advocacy. A lack of consistency, to any degree, was a cause for concern and provided mixed messages for a child. Adults recognizing a child's efforts to advocate for oneself or become more autonomous is crucial and those efforts should be acknowledged.

When is the right time to introduce new skills, encourage autonomy, and work on self – advocacy? It is agreed that although it is highly individual per child, this should occur early and often in a child's development. Unfortunately, a common thread throughout was the amount of time professionals have available during appointments with their D/HH patients/clients. Audiologists spoke of the limited time they had with young people; only a couple of appointments throughout the year where often the priorities are to complete a hearing assessment and review hearing technologies. Young people noted they often felt rushed in appointments and did not always receive the information they needed or were seeking. This study noted the significant importance of HRTs in a young person's life, who may see a child more frequently. Families and audiologists often rely on teachers of the D/HH to take the lead in developing self-management skills and fostering autonomy with device use. Successful development depends on communication between parents, educators, and hearing professionals to ensure consistent messaging and skill development.

7.7 Self-Determination

Promoting self-determination for individuals with disabilities is considered best practice (Wehmeyer & Abery, 2013). Self-determination, was defined in Chapter 1, as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005). Self-determination has been identified as important to the successful transition to adult life (Luckner & Sebald, 2013). Self-determination theory is an organismic theory of human motivation and personality development" (Ryan & Deci, 2017, p. 3). The three factors found to enhance intrinsic motivation, self-regulation, and well-being are competence, autonomy, and relatedness. Ryan and Deci (2000) state that when these factors are not supported, individuals may experience diminished motivation and well-being. The concept of *competence* suggests that individuals must develop various competencies (or skills) and the intrinsic reward for efficacy drives motivation (Ryan & Deci, 2017). The concept of *relatedness* refers to the need for humans to feel belonging. They further describe that there is a "basic need to feel responded to, respected, and important to others" and the desire to avoid "rejection, insignificance, and disconnectedness" (Ryan & Deci, 2017, p. 96). Finally, *autonomy* is the desire for an individual to be self-regulated; the need to feel they are in control of their own lives and behaviours. Ryan and Deci (2017) describe autonomy as the central construct of self-determination theory, and note that these concepts are interdependent. For example, competence is fully realized when an individual feels "efficacy for an activity that they have initiated or willingly undertaken" (Ryan & Deci, 2017, p. 97). Similarly, individuals will feel relatedness if there is willingness to relate to one another. Relatedness will not be achieved if an individual senses an individual was not "autonomously motivated" (Ryan & Deci, 2017, p. 294).

For children with disabilities, development of self-determination within the family context and education setting has been identified as critical for successful transition to adulthood (Shogren, 2013; Shogren & Turnbull, 2006; Wehmeyer, 2014). There is a paucity of research in the area of self-determination for children with hearing impairment (Luckner & Sebald, 2013). Dalton (2011) suggested that students with mild and moderate hearing losses face social emotional challenges in the classroom and provided

suggestions for classroom teachers to support the self-determination concepts of relatedness, competence, and autonomy. Sebald (2013) surveyed teachers of the D/HH and concluded that although the teachers believed self-determination to be important to include in a curriculum it is not always applied. Their research results suggested that one-third of the teachers in the study were itinerant teachers, having limited direct contact with students, thus impacting their ability to control curriculum. As mentioned previously, Gordey (2018) explored the concept of relatedness between teachers and hard of hearing students in mainstream classrooms and found that parents and itinerant teachers of the D/HH are integral in ensuring needs of children are met and in turn promoting development of self-determination. Other studies have noted the relationship between higher levels of self-determination in university students with hearing impairments and their ability to successfully integrate or adapt to a university environment (Cheng & Sin, 2018). Miller, Dorn and Luckner (2019) found a correlation between self-determination and the quality and quantity of friendships among students with hearing loss.

It is evident that there are connections between the core concepts of the grounded theory model "I am the expert" (*developing ownership, managing identity, developing advocacy,* and *doing it myself*) and the concepts of *competence, relatedness, and autonomy* that are at the foundation of self-determination theory.

In the current study, the concept of competence was reflected in the categories of *doing it myself, developing advocacy,* and *developing ownership.* Successful demonstration of skills in caring for devices was motivation to have responsibility move to the young person. Young people demonstrated competence in building knowledge surrounding their own hearing loss and listening needs, to inform decision-making related to their hearing and hearing healthcare. Competence was also demonstrated in the development of advocacy skills to ensure their needs are met.

Relatedness was a common thread throughout this study; the importance of the relationship between young people and their parents, peers, teachers, and healthcare providers is evident in each of the core categories. Managing identity relies on

individuals having a sense of belonging and feeling supported. Developing ownership related to hearing healthcare relies on building knowledge and shared decision-making between a young person and adult. Within self-determination theory the role of a parent in providing autonomy support includes the provision of structure which comprises providing relevant information (Ryan & Deci, 2017). Similarly, within healthcare settings supporting patient autonomy includes providing and sharing appropriate information (Ryan & Deci, 2017). Allowing for compromise and developing trust can provide the young person a sense of importance and being respected which are constructs of relatedness. Developing advocacy was found to rely on adults nurturing a young person's attempts at advocacy and respecting their identified needs. Finally, doing it myself, relies on building trust with the young person and providing support.

The third concept of self-determination theory, autonomy, is also supported in this grounded theory study. Young people noted the importance of autonomy and being in control of their own lives. This included concepts such as decision-making, disclosing hearing loss, advocating for personal needs and healthcare needs. Autonomy was always discussed in the context of being supported by adults in the child's life, whether it was parents, educators, or hearing professionals. Studies of self-determination consistently note the importance of the family and school context in the development of self-determination and Ryan and Deci (2017) state that parental support of autonomy is important for child development and well-being.

7.8   Enacting the "I am the expert" Model

The World Health Organization International Classification of Functioning, Disability, and Health, more commonly referred to as the International Classification of Functioning or ICF (WHO, 2001) provides a framework for considering the effect of health condition on functioning, disability, and health. The ICF is comprised of two parts: 1) dimensions of health, which include body function and structures as well as activities and participation, and 2) contextual factors, specifically environmental and personal factors. An individual's state of health is determined by how the dimensions of health interact with one another and the individual contextual factors (Gagne, Jennings, & Southall,

2021; WHO, 2001). See Appendix Q for an illustration of the interactions between components of the ICF model.

The ICF (WHO, 2001) defines activity as the execution of a task or action and an activity limitation as the difficulty an individual may have in executing that task/activity. Participation is defined as involvement in a life situation and a participation restriction is the difficulty or problem one may experience in involvement in a particular life situation (See Appendix R for a list of definitions for terms used in the ICF). Although, the ICF differentiates between activity/activity limitations and participation/participation restrictions, it may be difficult to determine what should be defined as an activity or participation (Gagné et al., 2021). Gagné et al. (2021) suggests that for the purposes of rehabilitation there is not a significant advantage to determine if a given behavior is an activity or participation. The WHO (2001) has also developed a coding structure to classify various health conditions. The codes were designed to provide a common language and framework for the description of health conditions across various disciplines (Gagné et al., 2021). The ICF can be used across rehabilitation sciences as a framework for identification of problems, understanding context, and goal setting (Gagné et al., 2021). Gagné et al. (2021) has suggested the use of the ICF in adult aural rehabilitation to identify the most important activity limitations or participation restrictions an individual may experience to develop rehabilitation goals.

In 2007, the WHO released the ICF: Child and Youth Version (ICF-CY) that "was sensitive to the physical, social, and psychological characteristics unique to children and youth" (WHO, 2007, p. xiii). Development of the ICF-CY included modifying or expanding current descriptions, assigning new content to unused codes, modifying inclusion and exclusion criteria, and expanding qualifiers to encompass developmental aspects (WHO, 2007). Therefore, the ICF-CY expands coverage of the ICF to include "body functions and structures, activities, participation, and environments specific to infants, toddlers, children, and adolescents" (WHO, 2007, p. xi). As with the ICF, the ICF-CY is a useful framework to identify, describe, and monitor health conditions, but specific to the pediatric context.

English and Pajevic (2016) suggests using the ICF-CY as a tool to standardize transition planning in audiology for adolescents and their families. In their paper, English and Pajevic (2016) illustrated how the ICF-CY can be used as a framework to identify and track development of health literacy skills.

The ICF-CY could be used as a tool to help understand and enact the "I am expert" model. Audiologists and educators could use the ICF-CY framework to explore the various domains of the "I am the expert" model, and identify activity limitations/participation restrictions, environmental factors and personal factors across domains and contribute to the development of shared goals.

Chapter 8

8   Conclusion

This grounded theory study explored the process of transition toward the self-management of hearing healthcare for young people who are D/HH. The grounded theory model, "I am the expert" illustrates the process of this transition and suggests four core concepts: developing ownership, managing identity, developing advocacy, and doing it myself. The model not only illustrates these significant processes, but identifies the importance of context and the influence home, school, and community have at the micro- and mesosystem levels (Bronfenbrenner, 1986). In addition, the "I am the expert" model embodies concepts of self-determination theory: competence, relatedness, and autonomy (Ryan & Deci, 2017). This final chapter will discuss contributions to the field of audiology, strengths and limitations of the study, and future research directions.

8.1   Implications for Practice

Results from this study suggest that to develop the knowledge and skills to successfully manage their hearing healthcare, young people who are D/HH must be offered interventions that address their needs and provided the appropriate supports from parents, educators, peers, and hearing healthcare providers.

Families and caregivers play a critical role in child development and the process of transition to self-manage their hearing healthcare. Clark and English (2019) describe parents as "shapers" in the development of self-concept in children with hearing loss, a description which is equally applicable in the context of the current study. This study also highlighted the role of HRTs and audiologists in supporting young people who are D/HH and their families. Teachers of the deaf and hard of hearing are, and should remain, an integral part of the education environment for young people who are D/HH. However, not all school boards employ these specialty teachers. Some boards may have limited staffing, and cuts to education budgets often disproportionately affect special education programs. With limited or reduced staffing these types of programs are less able to provide education and skill building for students, as the limited time available is often

needed for basic device management. Continued advocacy on behalf of parents, educators, and healthcare providers is required to ensure these positions continue to be funded.

Audiologists and young people who are D/HH also reported less time available for education and counselling, due to length and infrequency of audiology appointments. Audiologists may instead consider scheduling appointment times specifically reserved for developing and managing skill-sets, or discussing a young person's needs without the burden to complete a hearing assessment or hearing aid review. Aural rehabilitation groups are another way that audiologists can provide patient education opportunities while being mindful of the time constraints of a busy audiology clinic. Although, more commonly targeting older adult populations they are still not ubiquitous in private practice and less common for adolescent populations. This type of programming would allow opportunities for young people to meet peers who are D/HH, to learn from one another, and share experiences. Aural rehabilitation program curriculum often include self-advocacy training which audiologists in this study noted they often did not have time for in regular clinical practice.

Parents and professionals in this study supported developing health literacy in young people who are D/HH. Developing the required skills and knowledge to allow young people to better understand their hearing and listening needs helps them become more engaged in shared decision-making processes. As they get older, young people need to be given opportunities to take part in the decision-making process surrounding their healthcare needs. However, results from this study suggest listening needs and benefits of device use (whether hearing aids or other assistive technologies) were not always well understood by young people. Finding different or multiple ways for audiologists and educators to better communicate or demonstrate listening needs and real-word implications may be useful. For example, the use of a familiar sounds audiogram[12],

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[12] A familiar sounds audiogram overlays the frequency and intensity of the sounds of speech as well as everyday sounds on a standard audiogram to illustrate what sounds an individual may or may not be able to hear due to a hearing loss.

hearing loss simulation, or the use of speech in-noise-testing. Some educators and clinicians do utilize these strategies, but they are not necessarily part of standard practice. Emerging technologies like ecological momentary assessment (EMA) analysis may be useful in the future to help young people to define and describe difficult listening situations. EMA can sample an individual's moment-to-moment experience and behaviours in a real-world context through their hearing aids. Paired with subjective feedback (e.g. questionnaires or surveys) it can provide passive and interactive data for a specific context (Glista et al., 2020).

Parents and professionals need to support a young person's developing autonomy by providing opportunities for adolescents to be involved in their hearing healthcare, encouraging them to actively participate in appointments, and parents reducing their own interactions during these encounters. This study also highlighted the importance of young people developing skills to care for their own devices, using the telephone and waking up on their own to an alarm clock. These discussions were often event driven in the context of young people transitioning to high school or post-secondary education, or getting their first part-time job. Some families noted that they did not have knowledge of available devices and sought information from sources other than the audiologist. Both audiologists and teachers of the deaf and hard of hearing may consider introducing alternative listening/alerting devices and discussing connectivity options as children begin to approach adolescence, to allow for a smoother transition when the need for these technologies should arise.

Ensuring open communication and dialogue across all stakeholders would be beneficial, as the need for consistent messaging regarding expectations for young people was noted in this study. To achieve this, families and professionals can focus on developing shared goals across disciplines. This will ensure that messages and/or skill development is consistent and shared.

Finally, this study may inform curriculum development for clinical audiology programs and continuing education for clinical audiologists. Content focused on adolescent

development, adolescent self-advocacy, transition planning, and clinically relevant tools that can be used to support transition planning for adolescent patients.

8.2   Future Research Directions

Further research is required to confirm these grounded theory findings on a greater level as findings from the current study are representative of students from one school board in a more urban centre of Ontario. Future studies should look at the experiences of younger and older individuals and to see if the "I am the expert" model applies to their lived experiences. As well, it would be interesting and advantageous to examine how the "I am the expert" model applies to adolescents with hearing loss and other existing co-morbidities. Future studies might also include fathers or male caregivers and whether they provide novel insight. Further exploration of supports for young people who are D/HH should be conducted, perhaps they will help us better understand how these supports affect health behaviours in this population. Further exploration to identify if and how, severity of hearing loss, unilateral versus bilateral losses, or device use may affect self-management of hearing healthcare in the adolescent population.

8.3   Strengths and Limitations

Limitation for this research study require acknowledgement. First, participants self-selected for inclusion in this study. In particular, families who participated may be those that have had different experiences or more extreme experiences (very positive or very negative) than those who would choose not to participate. Additional participant factors, including socioeconomic status, comorbidities, etiology or age of onset of hearing loss were not considered which may influence the transition process. Interview data are reflective of the participants' personal experiences and may not be the experience of all young people who are D/HH, parents, audiologists, or HRTs. Participants were asked to speak of their current experiences but also of past experiences for which they would be relying on memory of past events. Only female parents/guardians agreed to be a part of this study; fathers or male guardians may have provided a different perspective.

Families were recruited from generally a small geographic region and from one public school board in Ontario. Generally, participants lived within or just outside an urban centre. It is unknown if individuals who live in rural and/or more remote locations may have different experiences. They may not have the same access to hearing healthcare services, and/or the same supports within their school board. Finally, this study did not select participants based on degree of hearing loss, did not differentiate between unilateral or bilateral hearing losses in the exclusion criteria, or whether the individual used amplification.

Children and parents were generally interviewed separately allowing for open and honest dialogue from both parties. However, young people were given the preference to have a parent/guardian present during an interview if it made them more comfortable. In this study, two adolescent interviews were held with parents present. In these two cases, parent presence could have impacted how a young person chose to respond to interview questions. All adult participants were interviewed independently.

This study has significant strengths. Interviews were conducted with four different groups of stakeholders, including adolescents, parents/guardians, audiologists, as well as hearing resource teachers, providing a richness of interview data. The inclusion of hearing resource teachers in this study was novel as few research studies include input from this group. The benefit of multiple stakeholders provided opportunities to address topics that arose with one group, across groups to compare or contrast different perspectives. This also allowed for a cross-check to determine if novel topics were of importance for another group. Finally, adolescents were provided more than one avenue to share their experiences, through one-on-one interviews and a written journal. I believe that journal entries, in some cases, may have provided a more thoughtful reflective answer. Young people had the opportunity to reflect on the interview, and to have time and space when completing their entries in the journal without the pressure of an interview setting.

8.4 Summary

In summary, the transition to the self-management of hearing health care does not happen over-night. Rather, it should be viewed as a life-long process that can change over time

depending on life circumstances, and hearing health status. There is a need for greater awareness of the needs of young people who are D/HH and how they develop the self-management skills required to manage their hearing healthcare as they move into young adulthood. Parents, educators, and clinicians provide critical support and guidance to young people. However, greater and more consistent dialogue between all parties would benefit everyone. Often, professionals are working in silos and may not always be aware of what another professional may be working on. Young people who are D/HH require professionals to work together and share goals to better support their development. They require professionals to foster trusting relationships with their patients/clients and require quality time to have questions addressed and needs met. Finally, young people require space and time to practice and develop new skills with a "safety net" and, when they are ready - to let them do it themselves, because they are the expert.

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Appendices

Appendix A: Knowledge and skills health goals (Pajevic & English, 2014)

- Explain Degree and nature of hearing loss

- Explain functional impact of hearing loss

- Describe and apply assistive technologies and communication repair strategies

- Case history information:

    - Etiology of hearing loss

    - Family history (hearing loss and other health concerns)

    - Blood type

    - History of injuries, illnesses, surgeries, and additional health concerns

    - Current and past medications

    - Names, contact information of health-care providers, insurance, emergency contact information

- Fill out intake, self-assessments

- Maintain health records

- Keep health information and other private data (Social Security number ,etc.) secure

- Know basic health terminology

- Schedule and keep track of appointments

- Explain legal rights and accommodations relative to health care

- Explain confidentiality and the patient-health care provider relationship

- Describe patient autonomy and patient rights

- Explain location, intensity, frequency of pain, and other symptoms

- Understand explanations, instructions, options and recommendations

Appendix B: The University of Western Ontario Health Science Research Ethics Board, Ethics Approval Notice

Western Research

Use of Human Participants - Ethics Approval Notice

Research Ethics

Principal Investigator: Dr. Mary Beth Jennings
File Number:102820
Review Level:Delegated
Approved Local Adult Participants:60
Approved Local Minor Participants:60
Protocol Title:The process of transition for adolescents in the self-management of their hearing healthcare: Examining the barriers and facilitators to a successful transition
Department & Institution: Communication Sciences and Disorders,Western University
Sponsor:
Ethics Approval Date:August 22, 2012 Expiry Date:August 31, 2014
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		
Advertisement	Advertisement Short Version	
Advertisement	Long Version	
Letter of Information	Adults	2012/06/25
Letter of Information	Child	2012/06/25
Other	Consent Form	2012/06/25
Assent		2012/06/25

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Appendix C: The University of Western Ontario Health Science Research Ethics Board, Approval Notice for minor revisions.

Western   Research Ethics
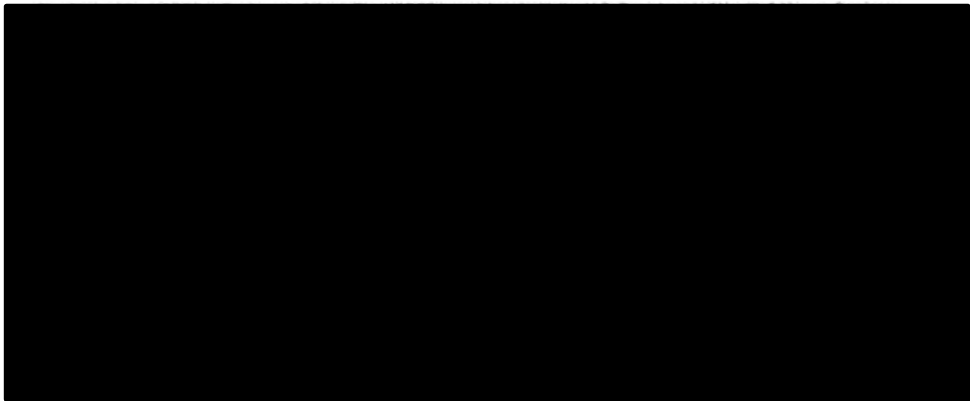
Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Marybeth Jennings
File Number:102820
Review Level:Delegated
Approved Local Adult Participants:60
Approved Local Minor Participants:60
Protocol Title:The process of transition for adolescents in the self-management of their hearing healthcare: Examining the barriers and facilitators to a successful transition
Department & Institution:,Western University
Sponsor:
Ethics Approval Date:November 07, 2012 Expiry Date:August 31, 2014
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Letter of Information & Consent	Letter of Information for Adult Participants - Minor revisions to "Information Letter for Adult Participants" to be consistent with the "Information Letter for Child Participants". An addition has been made only to the "Study Procedure" section, the following addition was made: "Interview questions will ask about, for example, when should a child begin to manage aspects of their own hearing loss and who has responsibility for the care and maintenance of a child's hearing aids (if they wear them)? Changes have been highlighted in yellow on the attached Letter of Information.	2012/09/25

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.
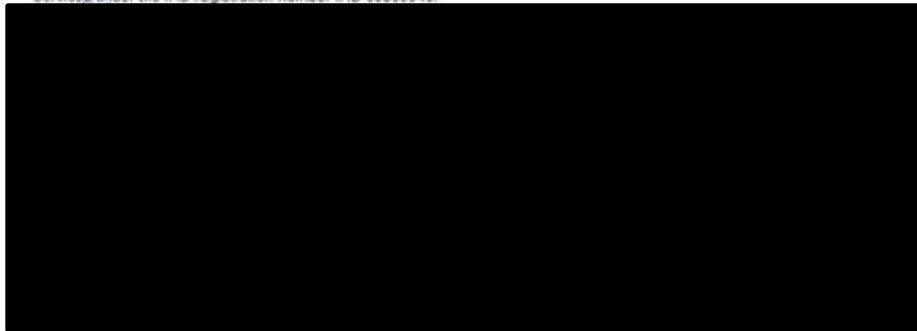
Appendix D: The University of Western Ontario Health Science Research Ethics Board, Amendment Approval Notice

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Amendment Approval Notice

Principal Investigator: Dr. Marybeth Jennings
Department & Institution: ,Western University

HSREB File Number: 102820
Study Title: The process of transition for adolescents in the self-management of their hearing healthcare: Examining the barriers and facilitators to a successful transition
Sponsor:

HSREB Amendment Approval Date: November 06, 2014
HSREB Expiry Date: May 31, 2015

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Revised Study End Date		

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the amendment to the above named study, as of the HSREB Amendment Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review. If an Updated Approval Notice is required prior to the HSREB Expiry Date, the Principal Investigator is responsible for completing and submitting an HSREB Updated Approval Form in a timely fashion.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.
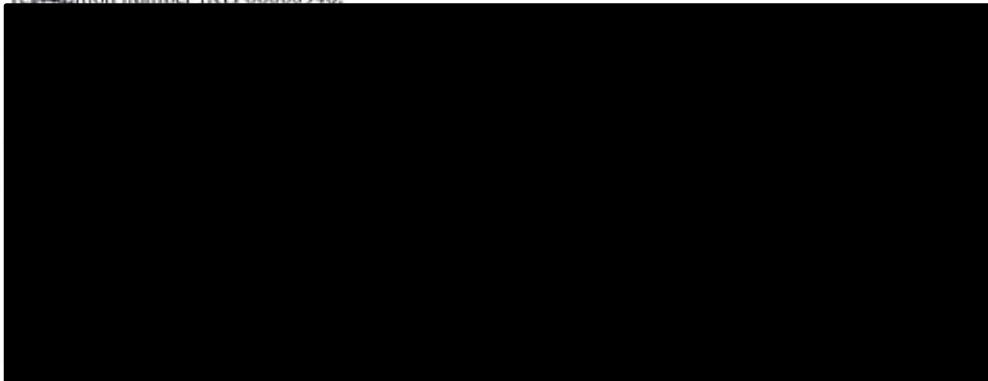
Appendix E: Letter of Information for Adult Participants

![Western HealthSciences logo]

Letter of Information for Adult Participants
(Parent/Guardian, Itinerant Teachers and/or Audiologists)

Study Title: The process of transition for adolescents in the self-management of their hearing healthcare
Principal Investigator: Mary Beth Jennings, PhD
Co-Investigator: Margaret Cheesman, PhD
Co-Investigator: Christine Meston, MSc

Introduction
You are invited to participate in a study that looks at how children and adolescents transition to self-manage their hearing health care. We are looking for individuals to participate who are parents/guardians, itinerant teachers, or audiologists of children with hearing loss. You must be able to read, write, and converse in English. If you are an itinerant teacher or audiologist, you must be working with children with hearing loss between 10-18 years of age. The purpose of this letter is to provide you with information required for you to make an informed decision regarding participation in this research. Please take the time to read this letter and if you have any further questions and/or may be interested in participating in this study please contact the co-investigator for this study:

Study Procedure
If you agree to participate in this study you will be asked to participate in at least one interview session at the National Centre for Audiology at Western University or by telephone. Interviews will be approximately 30-60 minutes in length. Interview questions will ask about, for example, when should a child begin to manage aspects of their own hearing loss and who has responsibility for the care and maintenance of a child's hearing aids (if they wear them)?

Possible Risks and Harms
There are no known, or anticipated risks or discomforts associated with participating in this research study.

Possible Benefits

You may not directly benefit from participating in this study but information gathered may provide benefits to society as a whole, which may include helping us to better understand how children transition to self-manage their hearing health care.

Voluntary Participation

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on any services you may obtain from Western University or future participation in research studies. However, any data collected to that point, except for personal identifying data will remain in the study.

Compensation

Free parking will be provided for any interviews held at the National Centre for Audiology, Elborn College, at Western University.

Confidentiality and Consent

Personal information is collected for contact purposes only and will not be made available to anyone outside of this study. Contact information will be kept in a secure location at the National Centre for Audiology at Western University that is monitored by a security system. Data will be retained for 10 years, after which time it will be destroyed. While we will do our best to protect your information there is no guarantee that we will be able to do so. The information obtained in this study will be used for scientific purposes and may be included in scientific reports. Participants' names will not be used in any publications of this study. Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

If you have any questions about your rights as a research participant or the conduct of this study you may contact: The Office of Research Ethics, at

This letter is yours to keep for your personal records.

Sincerely,

Participant Initials_____

Appendix F: Letter of Information for Parent/Guardian of Child Participants

Western
HealthSciences

**Letter of Information for
Parent/Guardian of Child Participants**

Study Title: The process of transition for adolescents in the self-management of their hearing healthcare
Principal Investigator: Mary Beth Jennings, PhD
Co-Investigator: Margaret Cheesman, PhD
Co-Investigator: Christine Meston, MSc

Introduction
Your child is invited to participate in a study that looks at how children and adolescents transition to self-manage their hearing health care. We are looking for individuals 10-18 years of age who have a hearing loss and who are in elementary or secondary school. Participants must be able to read, write, and converse in English. The purpose of this letter is to provide you with information required for you and your child to make an informed decision regarding your child's participation in this research. Please take the time to read this letter and if you have any further questions and/or may be interested in participating in this study please contact the co-investigator for this study:

Study Procedure
If you agree to participate in this study your child will be asked to participate in at least two interview sessions at the National Centre for Audiology at Western University or at your child's school. Interviews will be approximately 30-60 minutes in length. Interview questions will ask about, for example, what role your child takes in the management of their hearing loss and who has responsibility for the care and maintenance of your child's hearing aids (if they wear them). At the first interview, your child will be given a journal to answer questions about their hearing loss. This journal will be completed at home and handed in when your child returns for the second interview.

Possible Risks and Harms
There are no known or anticipated risks or discomforts associated with participating in this research study.

Possible Benefits
Your child may not directly benefit from participating in this study but information gathered may provide benefits to society as a whole which may include helping us to better understand how children transition to self-manage their hearing health care.

Voluntary Participation

Participation in this study is voluntary. Your child may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on any services you or your child may obtain from Western University or future participation in research studies. However, any data collected to that point, except for personal identifying data, will remain in the study.

Compensation

Free parking will be provided for any interviews held at the National Centre for Audiology, Elborn College, at Western University.

Confidentiality and Consent

Personal information is collected for contact purposes only and will not be made available to anyone outside of this study. Contact information will be kept in a secure location at the National Centre for Audiology at Western University that is monitored by a security system. Data will be retained for 10 years, after which time it will be destroyed. While we will do our best to protect your child's information there is no guarantee that we will be able to do so. The information obtained in this study will be used for scientific purposes and may be included in scientific reports. Participants' names will not be used in any publications of this study. Representatives of Western University Health Sciences Research Ethics Board may contact you or require access to your child's study-related records to monitor the conduct of the research.

If you have any questions about the rights of yourself or your child as a research participant or the conduct of this study you may contact: The Office of Research Ethics, at

This letter is yours to keep for your personal records.

Sincerely,

Participant Initials_____

Appendix G: Recruitment poster - long version

Research participants are needed for a study to investigate:

How children and adolescents transition to self-manage their hearing loss

We are looking for children and adolescents (10-18 years of age) who have a hearing loss to participate in our study. We are also looking for parents/guardians, itinerant teachers, and audiologists of children with hearing loss to participate as well.

This study is being carried out by researchers from The National Centre for Audiology at Western University. During this study you will be asked to participate in at least one interview approximately 30-60 minutes in length. If you are interested in participating in this study or would like more information, please contact:
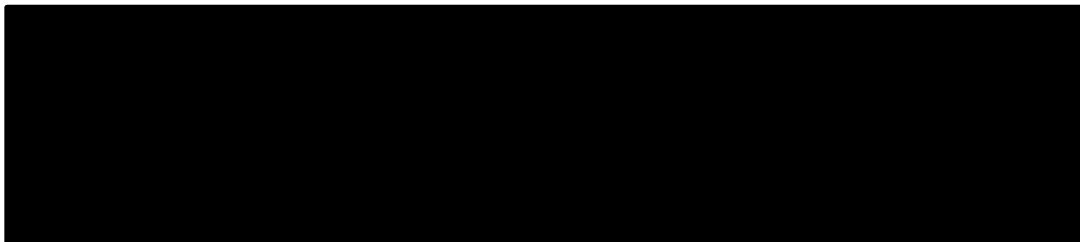
Appendix H: Recruitment Poster - short version

Research participants are needed for a study to investigate:

How children and adolescents transition to self-manage their hearing loss

We are looking for children and adolescents (10-18 years of age) who have a hearing loss to participate in our study. We are also looking for parents/guardians, itinerant teachers, and audiologists of children with hearing loss to participate as well.

You will be asked to participate in at least one interview. If you are interested in participating in this study or would like more information, please contact:
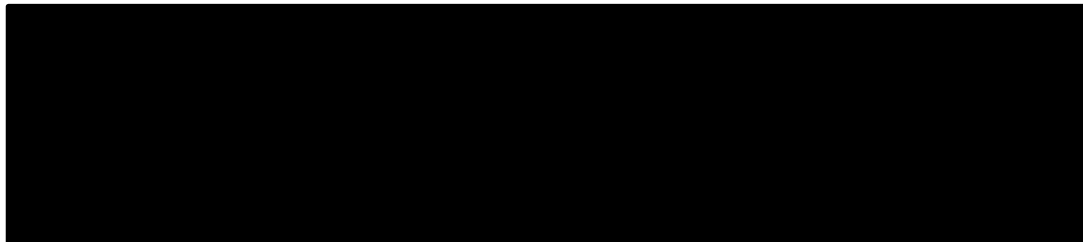
Appendix I: Participant consent form

<u>Consent Form</u>

Project Title: The process of transition for adolescents in the self-management of their hearing healthcare

Principal Investigator: Mary Beth Jennings, PhD
Co-Investigator: Margaret Cheesman, PhD
Co-Investigator: Christine Meston, MSc

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Child's Name: (if applicable) _____

Parent/Legal Guardian/Legally Authorized Representative **Print**: _____

Parent/Legal Guardian/Legally Authorized Representative **Sign:** _____

Parent/Legal Guardian/Legally Authorized Representative **Date:** _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

Appendix J: Assent Letter

<u>**Assent Letter**</u>

Project Title: The process of transition for adolescents in the self-management of their hearing healthcare
Principal Investigator: Mary Beth Jennings, PhD
Co-Investigator: Margaret Cheesman, PhD
Co-Investigator: Christine Meston, MSc

1. **Why you are here.**
   We would like to tell you about a study that will look at how children and teenagers with hearing loss begin to make their own decisions and take more responsibility for their hearing loss. We want to see if you would like to be a part of this study.

2. **What will happen to you?**
   If you want to be in the study you will be asked to answer some questions that the researcher will ask you about your hearing loss.

3. **Will there be any tests?**
   No, there will not be any tests.

4. **Will the study help you?**
   No, this study will not help you directly but in the future it might help other children and teenagers who have hearing loss.

5. **What if you have any questions?**
   You can ask questions at any time, now or later. You can talk to the researchers, your family or someone else.

6. **Do you have to be in the study?**
   You do not have to be in the study if you do not want to do this. If you do not want to be in the study, just say so. Even if you say yes now, you can change your mind later. It is up to you.

I want to participate in this study.

Print Name of Child _____   **Date**_____

Signature of Child _____

Age _____

Signature of Person Obtaining Consent _____

Appendix K: Consent for release of information

National Centre for Audiology
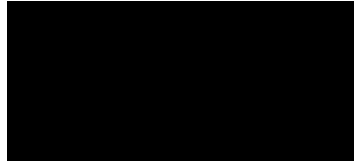
Consent to Disclose Personal Health Information
Pursuant to the Personal Health Information Protection Act, 2004 (PHIPA)

I _____, authorize
(Print parent/guardian's name)

_____
(Print name of health information custodian)

to disclose personal health information for,

_____ consisting of:
(Print child's name)

_____ Most recent audiogram _____
(Describe the personal health information to be disclosed)
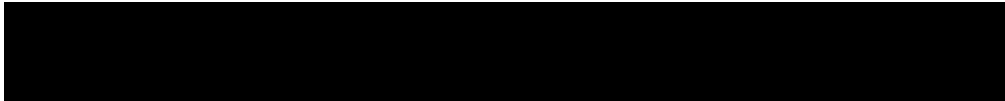
Authorizer's Name: _____

Address: _____
           Street   City/Prov.   Postal Code

Home Telephone: _____ Work Telephone: _____

Signature: _____   Date:_____

Witness Name: _____

Address: _____
           Street   City/Prov.   Postal Code

Home Telephone: _____ Work Telephone: _____

Signature: _____   Date:_____

Page 1 of 1   Version Revised: 06/25/2012

Appendix L: Case history form

<u>Child Participant Information</u>

Today's Date:_____

Name: _____
       Last Name   First Name

Date of Birth: _____

Address: _____
         Street No. and Name   City/Prov.   Postal Code

Telephone: (_____)_____E-mail: _____ Other: _____
----

1. Age hearing loss was identified_____

2. In which ear(s) do you have a hearing loss: Left   Right   Both

3. Is one ear worse than the other?   Yes   No

    If yes, which one?   Left   Right

4. What is the severity of your hearing loss?_____

5. Do you use hearing aids?   Yes   No

    If yes, in which ear(s)?   Left   Right   Both

6. How long have you been using hearing aids?_____

7. Do you have an itinerant teacher at school that you see regularly? Yes   No

8. Do you use an FM system at school?   Yes   No

Appendix M: Interview Guide (Children 10-18 years of age)

Interview Guide: Children 10-18 years of age.

These questions have been developed as a guide for the interviews. However, due to the nature of interviews as well as the chosen methodology of grounded theory, questions may be asked that are based on topics that arise during the interview or new questions may be developed for subsequent interviews after the initial interviews.

Introduction:
Hi, my name is Christine, I have invited you here to help me learn how young people take responsibility for their own hearing loss. I'd like for us to talk about you and your hearing loss. Sometimes I'll ask some questions. If you don't want to answer a question you don't have to. If you need a break, let me know and we can take a break.

Probe Questions:

1. Please tell me a little about yourself. For example, how old you are, what grade you are in, what are your favourite hobbies.

2. Why did you decide to take part in this study?

3. How do you feel about your hearing loss/hearing aids?

4. What do you feel other people think about your hearing loss/hearing aids?

5. When you meet someone new do you tell them you have a hearing loss?

6. How do you tell people about your hearing loss?

7. If you have difficulty understanding when someone is talking, what do you say to them? Do you tell them about your hearing loss?

8. Do you use an FM system at school?

9. What do you do if the FM system is not working one day?

10. How do you wake up in the morning? Do you use an alarm clock?

11. Are you able to hear ok on the telephone? Do you answer the telephone at home? Do you use the telephone at home? Can you hear the telephone ring?

12. Can you tell me what type of hearing loss you have?

13. Do you know how much hearing loss you have?

14. Can you tell me when you had your last hearing test? How often do you go see your audiologist?

15. Who arranges for you to go see your audiologist?

16. What do you do if you think your hearing aid is not working?

17. How do you know if your hearing aid is not working?

18. What if your hearing aid stops working at school?

19. Whose job is it to changes your hearing aid batteries?

20. Who is responsible for carrying spare batteries when you go out?

21. Who is responsible for cleaning your hearing aids?

22. Can you tell me how to clean your hearing aids?

23. Can you tell me how old your hearing aids are?

24. What do you talk about with your audiologist when you get your hearing tested?

25. Who goes with you when you go see your audiologist?

26. Does your parent/guardian go in to see the audiologist with you or do they wait in the waiting room?

27. Do you get to ask your audiologist questions about your hearing loss or your hearing aids?

28. Is there anything you wish you could talk to your audiologist about that you have not asked them?

29. When you have a problem with your hearing aids, do you usually explain the problem to your audiologist or does someone else?

30. At what age did you start doing the following by yourself: changing batteries, asking the audiologist questions, calling the audiologist yourself, cleaning hearing aids etc. (if applicable).

Appendix N: Interview Guide (Parents/Guardians)

<u>**Interview Guide: Parents/Guardians**</u>

These questions have been developed as a guide for the interviews. However, due to the nature of interviews as well as the chosen methodology of grounded theory, questions may be asked that are based on topics that arise during the interview or new questions may be developed for subsequent interviews after the initial interviews.

Probe Questions:
1. Does your child explain their hearing loss to others when needed?

2. Does your child wake up on their own to an alarm clock or does someone in the house wake him/her?

3. Who is responsible for the care and maintenance of your child's hearing aids?
4. Who is responsible for changing hearing aid batteries?

5. Who is responsible for carrying spare hearing aid batteries, when you and your child go out?

6. What does your child do if their hearing aid is not working?

7. What do you do if your child's hearing aid is not working?

8. Who is responsible for making appointments to see the audiologist?

9. When at the audiologist's office does your child have the opportunity to ask questions to the audiologist?

10. If your child has concerns about his/her hearing or hearing aids do you explain the problem or does your child?

11. Are there any hearing or hearing-related tasks that you feel he/she should be doing on his/her own and are not?

12. When do you expect your child to take on more responsibility for their hearing loss/hearing aids management?

13. How do you think this may be achieved?

14. Has your role and your child's roles changed over time? When did these changes occur? What motivated these changes?

15. Do you discuss roles and responsibilities between yourself and your child with your child's audiologist?

16. As your child gets older do you feel that you allow them to take on more responsibility regarding the management of their hearing loss?

17. How do you decide when to allow your child to take responsibility for certain tasks? Is this discussed with your child's audiologist or itinerant teacher at school?

18. Have you had any challenges with negotiating responsibilities between yourself and your child surrounding the management of your child's hearing loss?

14. How do you decide to allow your child to take on more responsibility? Based on age, demonstrated ability? Where there specific milestones?

Appendix O: Interview Guide (Audiologists and Hearing Resource Teachers)

<u>Interview Guide: Professionals</u>

These questions have been developed as a guide for the interviews. However, due to the nature of interviews as well as the chosen methodology of grounded theory, questions may be asked that are based on topics that arise during the interview or new questions may be developed for subsequent interviews after the initial interviews.

Probe Questions:

1. Do you think most children/adolescents are able to adequately describe their hearing loss?

2. Do you feel that they can explain their communication needs and advocate for themselves?

3. What do you feel are some of the greatest barriers to children managing their own hearing loss?

4. Do you feel they are able to ask relevant questions pertaining to their hearing loss and/or hearing aids?

5. What are your expectations for the care and management of a hearing aid by a child/adolescent?

6. What are your expectations regarding hearing aid batteries and responsibility for carrying spare batteries for children and adolescents?

7. Do you communicate with children and families regarding expected goals for children managing aspects of their hearing loss?

8. What are your expectations regarding children asking questions during their appointments with their audiologist?

9. What would you expect a child to be able to do if his/her hearing aid is not working?

10. Do you feel children are able to describe problems they are having with their hearing aids?

11. What would you consider are your responsibilities regarding negotiating responsibilities of hearing loss and/or hearing aids management between parents and children?

15. How would determine a child is ready to take on more responsibility? Based on age, demonstrated ability? Are there specific milestones?

Appendix P: Take-home journal

Title of Journal:

_____

Your Name:

_____

Date Completed:

_____

What should I write about?

This journal is for you to write about things we talked about during the interview. You can also write about things that you wanted to talk about, but only remembered after the interview was done.

Some pages have questions for you to answer. There is a place for you to write an answer, there is also space for you to draw a picture if you want. If you draw a picture, please explain to me what the picture is about. Some pages I left blank so you can write anything you want. If you run out of space you can add extra pages.

There are no right or wrong answers. I am interested in your opinions and feelings.

Can I get help to answer the questions?

Please complete the journal on your own and answer the questions in your own words; I want to know what **you** have to say! It is alright to ask your parents or someone else if you need help to understand the questions.

When do I write in the journal?

You can write in the journal anytime you want, but please complete the journal before you return for your next interview.

Confidentiality

What you write is confidential and I will not tell other people about what you wrote in your journal. Please write your name on the front of the journal. You can also give your journal a unique title if you want.

If you have any questions feel free to contact me:
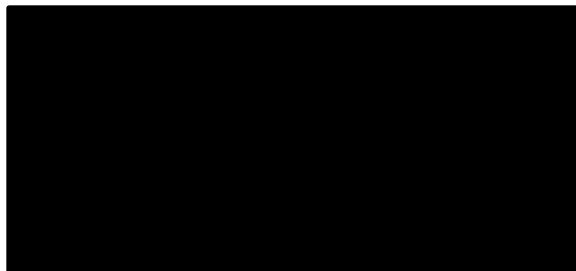
Thank you for all your help!!

1. Tell me how you feel about your hearing loss.

_____

_____

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If you want, you can draw a picture below about how you feel about your

hearing loss. Please explain your picture in words on the lines below.

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_____

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2. In your own words, explain what type of hearing loss you have.

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3. How does your hearing loss affect your ability to hear sounds and

people talking?

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_____

If you want, you can draw a picture below about how your hearing loss affects your ability to hear. Please explain your picture in words on the lines below.

_____

_____

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_____

4. When you meet someone new, how do you tell them about your

hearing loss?

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_____

If you want, you can draw a picture below about how you tell other people about your hearing loss. Please explain your picture in words on the lines below.

_____

_____

_____

5. What do your friends know about your hearing loss?

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_____

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6. What do you do if you think that you are not hearing as well as you usually do?

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If you want, you can draw a picture below about what you do if you think

that you are not hearing as well as you usually do? Please explain your

picture in words on the lines below.

_____

_____

_____

7. What do your friends do when you are not hearing well?

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8. Do you feel that you get to ask all the questions you want to when you see your audiologist? Please explain.

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9. In your family who would you say is the "expert" about your hearing

loss? What makes this person the "expert"?

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If you want you can draw a picture below about who you think in your family is the "expert" about your hearing loss. Please explain your picture in words on the lines below.

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_____

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_____

10. Are there some things you feel you can't do or that an adult does for

you because you have a hearing loss? Please explain.

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11. Who is responsible for cleaning your hearing aid(s)?

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_____

_____

Explain how you would clean your hearing aid(s).

_____

_____

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_____

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_____

12. Who is responsible for checking your hearing aids when you think they

are not working well? What does this person do?

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_____

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13. If your hearing aids are not working what would you check first or what

would you do?

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14. If you have a problem with your hearing aids, who usually explains the

problem to your audiologist?

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15. Do you think you should be given more responsibility for managing your

hearing loss or taking care of your hearing aids(s)? Please explain.

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The following pages have been left blank for you to write about anything you want about your hearing loss, wearing hearing aids, what responsibilities you have for managing your hearing loss or taking care of you hearing aids.

_____

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Appendix Q: The International Classification of Functioning, Disability, and Health (ICF) Model, interactions between ICF components (WHO, 2001)
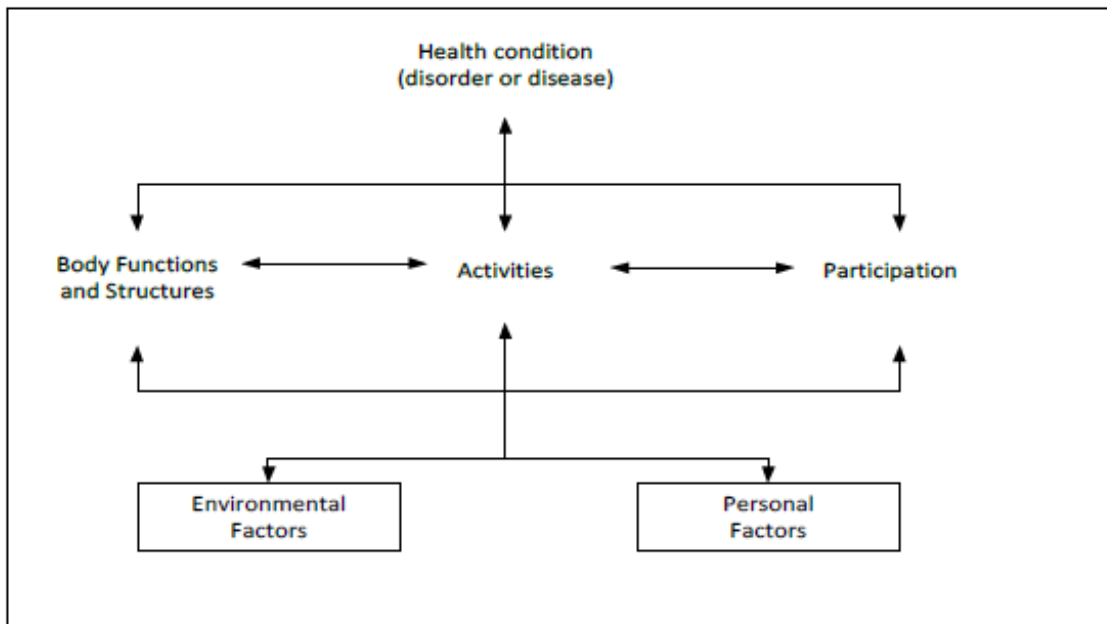
Appendix R: Definition of terms used in the International Classification of Functioning, Disability, and Health (ICF: WHO, 2001)

Body Functions: the physiological functions of body systems including psychological functions).

Body Structures: Anatomical parts of the body such as organs, limbs and their components.

Impairments: Problems in body function and structure such as significant deviation or loss.

Activity: The execution of as task or action by an individual.

Participation: Involvement in a life situation.

Activity Limitations: Difficulties an individual may have in executing activities.

Participation Restrictions: Problems an individual may experience in involvement in life situations.

Environmental Factors: The physical, social, and attitudinal environments in which people live and conduct their lives. These are the barriers to or facilitators of the person's functioning.

Curriculum Vitae

Name: Christine Meston

Post-secondary Education and Degrees:

The University of Western Ontario
London, Ontario, Canada
2021, Ph.D.
Health and Rehabilitation Sciences, Hearing Science

The University of Western Ontario
London, Ontario, Canada
2003-2006, M.Sc.
Communication Sciences & Disorders, Audiology

The University of Western Ontario
London, Ontario, Canada
1997-2001, B.Sc.
Honors Ecology and Evolution

Honours and Awards

Ontario Graduate Scholarship
2012-2013

Queen Elizabeth II Graduate Scholarship in Science and Technology (Declined)

Ontario Graduate Scholarship in Science and Technology
2005-2006

Related Work Experience:

2017 to present   Lecturer and Clinical Supervisor (Faculty)
School of Communication Sciences and Disorders
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2016-2017   Clinical Supervisor - Audiology (Limited Duties)
School of Communication Sciences and Disorders
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2013   Research Associate
Centre for Education Research and Innovation
Schulich School of Medicine & Dentistry
The University of Western Ontario

2012-2017	Course Instructor (Limited Duties) School of Communication Sciences and Disorders The University of Western Ontario
2011-2015	Audiologist London Hearing Centre, London, ON
2009-2011	Graduate Teaching Assistant School of Communication Sciences and Disorders The University of Western Ontario, London, ON
2009-2011	Graduate Research Assistant HearCare Audiologic Rehabilitation Laboratory National Centre for Audiology The University of Western Ontario
2007-2009	Audiologist North York General Hospital, Toronto, ON
2006-2007	Audiologist Hearing Solutions, Toronto, ON

Book Chapter:

Jennings, M.B., & Meston, C.N. (2020). Coping with hearing challenges at work. In M. Valente & L.M. Valente (Eds.), *Adult Audiology Casebook*. Thieme Medical Publishers. 241-245.

Peer Reviewed Journals:

Arntfield, S., Parlett, B., Meston, C.N., Apramian, T., & Lingard, L. (2016). A model of engagement in reflective writing-based portfolios: Interactions between points of vulnerability and acts of adaptability. *Medical Teacher,* 38(2), 196-205

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