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Analyzing the self-identities of students with hearing loss and the perceptions of their caregivers/parents assist understanding of and affirming of one another and facilitate students' self-advocacy development. Caregivers/parents must be receptive to how the individual identifies him/herself (Cole & Edelmann, 1991; Jackson, Traub, & Turnbull, 2008; Schlesinger & Meadow, 1972). Disparate views of identity need reconciliation before addressing how to foster self-advocacy. This study examines perspectives of identity related to perceptions of hearing loss in ten participants (i.e., four students and six caregivers/parents). Data collected from in-depth interviews describe how students identify themselves and how their caregivers/parents identify their children with respect to their hearing status. The data of the study showcases three factors that influence which identity type is selected: interactions with others, setting/context, and life experiences. Findings indicate self determined identity types, the notion of identity as a fluid concept, and a sense of management as well as a sense of perseverance exist when selecting an identity type related to hearing loss.

ARE YOU DEAF OR HARD OF HEARING? WHICH DO YOU GO BY:  
PERCEPTIONS OF STUDENTS WITH HEARING LOSS

by

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APPROVAL PAGE

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## **CHAPTER I**

### **INTRODUCTION**

This study explored perceptions of identity related to hearing loss in students with hearing loss who use spoken language and listening who are educated in the general education setting and the perceptions of identity related to hearing loss of the students' caregivers/parents. Approximately 5% of the general population has significant hearing loss (Woodcock, Rohan, & Campbell, 2007) and approximately three per 1,000 newborns in the United States are born with a hearing loss (K. R. White, 2007; U.S. Centers for Disease Control and Prevention, 2009). Moreover, 95% of children with hearing loss are born to hearing caregivers/parents (Calderon, Bargones, & Sidman, 1998; Eleweke & Rodda, 2000; Gallaudet Research Institute, 2001; Jackson, Traub, & Turnbull, 2008; Jackson & Turnbull, 2004; National Institute on Deafness, 2013; Woodcock et al., 2007). It is also estimated that 9–10 per 1,000 children will be diagnosed with hearing loss in one or both ears by school age (Sharagorodsky, Curhan, Curhan, & Eavey, 2010; K. R. White, 2010).

Within the past decade, fewer children have been classified as having profound hearing losses while the numbers of children who have been classified as having mild and moderate losses has increased (Moores, 2004). This fact may partially explain why there is a decrease in enrollment in residential schools for the deaf and why the numbers of children who receive access to communication through spoken language and listening are

increasing due to improvements in medical care and newborn hearing screening (Moore, 2004; K. R. White & Baisner, 2011). More than 80% of all students with hearing loss in the United States attend their local public schools (Gallaudet Research Institute, 2003, 2011). The United States Office of Special Education (U.S. Department of Education, 2004, 2012) found that 85% of students with hearing loss are educated in public schools. These students are usually the only ones in their classrooms, or even schools, who have hearing loss (Bruce-Rosser, 2009). Itinerant teachers of students who are deaf/hard of hearing (TOD/HH) supply services for students with hearing loss by providing individualized student instruction outside of the general education classroom, and by allowing the students with hearing loss to participate in school with their hearing peers (Foster & Cue, 2009; Luckner & Miller, 1993; Yarger & Luckner, 1999).

A person with hearing loss may not identify him or herself as deaf. Factors such as degree of hearing loss, age of onset, type of hearing loss, family history and lifestyle, mode of communication, and community context influences how an individual with hearing loss perceives or identifies him or herself (Humphries & Humphries, 2011). A person with hearing loss may claim an identity that is radically different from other individuals with a similar type of hearing loss. Many factors contribute to and affect adoption of an individual identity and some researchers agree that identities are constructed within multiple communities and contexts. See Appendix A for a chart that outlines characteristics of groups of individuals with hearing loss (Melick, 1999). Many researchers have proposed that individual characteristics contribute to identity

construction such as one's racial or ethnic background and/or hearing or vision abilities (Humphries & Humphries, 2011; Leigh, 2009).

Two aspects of identity, related to hearing loss, that are particularly prominent are the degree to which a person identifies with Deaf culture/community and how a person views his or her hearing loss. Woodward (1972) first made the distinction between deaf (medical view) and Deaf (cultural view). Those who identify with Deaf culture often communicate through American Sign Language (ASL) and may object to the hearing world and people with hearing loss using the speech mode of communication (Gesser, 2007; Padden & Humphries, 2005; Reagan, 1995; Shakespeare, 1996; Shakespeare & Watson, 2002). Conversely, if an individual with hearing loss defines him or herself as having a hearing identity type, then hearing loss would likely be perceived as a medical pathology and the hearing world would be the reference point for normality and health (Ladd, 1991, 2005; Padden & Humphries, 2005; Woodward, 1972). In this instance of relating to the hearing world, value is placed on spoken language, therefore those who categorize themselves as having a hearing identity type might call themselves hearing, hard of hearing, or as someone who has hearing loss rather than classifying oneself as having a deaf identity type.

### **Rationale or Background for the Study**

Analyzing how individuals with hearing loss identify themselves with how others in their lives perceive them is critical if understanding and affirmation of one another can occur because caregivers/parents, teachers, and counselors of students with hearing loss must not assume what is most central to individuals with hearing loss. For example,

others should realize individuals with hearing loss may not necessarily identify themselves as being one of the identity types that have been established in identity studies within Deaf Studies/Deafness literature. Instead, caregivers/parents, teachers, and counselors of students with hearing loss must be receptive to how the individual student identifies him or herself (Cole & Edelman, 1991; Jackson et al., 2008; Schlesinger & Meadow, 1972). This awareness of differing perceptions reflects tenets of the Symbolic Interaction Theory in that individuals may have different interpretations or meanings for the identities they select related to hearing loss.

It is human nature to want to be understood and to view oneself as a whole person rather than isolated features through externally imposed labels and by a singular dimension (i.e., child being seen as more than just as a child having hearing loss but instead being seen as a creative athletic individual who also has hearing loss; Orange, 2003; Zurcher, 1977). The Multidimensional Identity Model speaks to this aspect of wanting to be understood or viewed as a whole, or a sum of multiple parts, rather than solely focusing on one aspect of self. If a disconnect among the self perceptions and others' perceptions exists, the differing views of identity must be reconciled before addressing the issues of how to foster self-advocacy in students with hearing loss.

Aspects of Social Identity Theory that highlight the concept of belonging or "fitting in" with a group relate to the present study in that, if a student with hearing loss does not perceive him or herself as belonging to a group or as "fitting in" then he or she may feel isolated and unacceptable in terms of his or her social identity membership. Therefore, the present study research will help bridge the gap that exists in research regarding

students with hearing loss: how they perceive/identify themselves and how their caregivers/parents identify their sons and daughters with respect to their hearing status.

The existing research indicates a need to determine what identity among individuals with hearing loss means to them so they can choose with which group they most relate or feel a sense of belonging to as is posited in Social Identity Theory. Identifying with a minority group may be beneficial to the person by enhancing self concept and social competence (Bat-Chava, 1994; Gecas & Schwalbe, 1983; Glickman, 1996; Phinney, 1992; Phinney & Alipuria, 1990; Sue & Sue, 1990). However, that identification can also prove harmful to the person if it is viewed as being the only option available. If a person has determined that the minority group holds all of the value for identification, the person is likely to not be as well adjusted socially in the larger world, due to a restriction of other available options for identification and social interaction, yet a strong identification with any group may be more beneficial than no group identification (Cornell & Lyness, 2004).

Although studies have been conducted that examine identity in the psychology, counseling, and Deaf Studies/Deafness literature, the present study seeks to explore the perceptions of identity and hearing loss in students with hearing loss who use spoken language and listening and are educated in the general education setting and their caregivers/parents. Reviewed identity studies largely focused on the biological/medical (deaf) model versus the social (Deaf) model in construction of deaf identities. Areas that were not considered in the related literature or in which weaknesses exist are (a) impact of gender on identity formation, (b) role of ethnicity, (c) the age of identification of

hearing loss, (d) whether or not the participants view themselves as culturally Deaf prior to the study, and (e) viewing identity from the lens of a fluid DeaF perspective applied to the hard of hearing population. The present study seeks to address the last two gaps (listed above) by investigating whether or not the participants will view the student participants as being culturally Deaf. The present study will also examine whether or not perceptions of identity are fluid as outlined by the DeaF perspective (Mcilroy & Storbeck, 2011) by participants sharing if and to what extent hearing loss has an impact in their lives emphasizing the fluid aspect of shifting from one identity type to another (e.g., Deaf identity type in one setting and hearing identity type in another context). For example, a participant may share that hearing loss may not be a factor in determining his or her identity in some interactions with others. However, the participant may share that the hearing loss may have a larger impact in certain settings and in certain roles as described in Symbolic Interaction Theory.

The perceptions of identity and hearing loss of four students and their caregivers/parents will provide a naturalistic backdrop for comparing the perceptions and views of identity in the population of individuals with hearing loss who utilize spoken language and listening to communicate. The implications of these perceptions will provide qualitative data that can be applied to literature in Deaf Studies/Deafness. Moreover, analyzing perceptions of identity and hearing loss within this population, that is, students with hearing loss who communicate using spoken English and listening as their primary mode of communication and who are educated in the general education setting and their caregivers/parents, is sparse in the research in Deaf Studies/Deafness.

There are a variety of ways in which individuals identify themselves through the lens of Symbolic Interaction Theory, Social Identity Theory, and the Multidimensional Identity Model (Mead, 1934; Reynolds & Pope, 1991; Tajfel, 1982; Tajfel & Turner, 1986) as described in the literature in psychology and counseling. Analyzing how students with hearing loss identify themselves and how their caregivers/parents identify these students will extend the literature base of research pertaining to identity within Deaf Studies/Deafness. Applying the construct of identity according to the selected theories listed above from psychology and counseling will enable the researcher to examine whether or not students with hearing loss and their caregivers/parents view identity as being a fluid or a static construct in terms of identity types (e.g., Deaf, deaf, hearing) that have been established within the Deaf Studies/Deafness literature.

### **Statement of the Research Problem**

The present study seeks to analyze identity related to hearing loss. How will the students selected for the study identify themselves in relation to their hearing loss and how will their caregivers/parents perceive them in relation to the hearing loss? Will hearing loss be a salient feature when they describe the identities of the students?

### **Purpose of the Study and Research Questions**

The overall purpose of the study is to discover how the student with hearing loss identifies him or herself and how others in the student's life perceive the student. If there is a disconnect among those perceptions, the differing views must be reconciled before addressing the issues of self-advocacy in the student with hearing loss. Additionally, caregivers/parents, general education teachers, and school counselors can encourage

students with hearing loss to consider the less focused on aspects of their identity while still maintaining care to not make assumptions about identity dimensions (i.e., Deaf identity type versus hearing identity type). As Foucault suggests (as cited in Besley & Peters, 2007), by truthfully and authentically confessing who one is to others, we affirm and own our identity. We need to tell the truth about ourselves and we need to uncover the diversity of deaf/Deaf/DeaF epistemologies (Ladd, 2005).

An analysis of qualitative data in which results from interviews will be used to: (a) produce themes related to identity type and hearing loss, (b) compare students' perceptions of identity with the perceptions of their caregivers/parents, and (c) provide a context for the qualitative analysis. The collection and analysis of interviews will serve as qualitative methods that will provide data relevant to the individuals' aspects of identity. Results from the interviews will be analyzed and relayed in the discussion section. Specific details regarding each individual, his or her caregiver(s)/parent(s), and information related to individual hearing losses will be gained through a demographic information sheet. Trustworthiness will be established by conducting a two-stage pilot study of the interview protocol, by utilizing the NVIVO 10® data managing software to aid in analysis of coding, and by having a second reader, who will also serve as a peer debriefer to the researcher, assist with the transcribing and coding process of the interviews to ensure accuracy, validity, and assist with inter rater reliability (IRR).

The study will address the following research questions:

1. How does a student with hearing loss who uses spoken English and listening as his or her primary mode of communication and who is educated in the

general education setting identify him or herself with respect to his or her hearing status?

2. How do the caregivers/parents of the student with hearing loss identify him or her with respect to his or her hearing status?

The research questions are a result of deductive reasoning in seeking to obtain results that will either supplement or reject the already established identity types within the literature in Deaf Studies/Deafness. Both research questions align with the Symbolic Interaction Theory, Social Identity Theory, Multidimensional Identity Model, and the identity types that have been established within the literature regarding identity in Deaf Studies/Deafness. To conclude, the present study will explore the perceptions of identity and hearing loss in students with hearing loss who use spoken language and listening who are educated in the general education setting and the perceptions of their caregivers/parents. See the glossary in Appendix B for a list of the definitions of terms that will be used throughout the study. Chapter II provides a review of the literature related to perceptions of identity and hearing loss. The chapter opens with the theoretical framework underlying the present research followed by a review of literature regarding identity development. The last section will describe the connection of the theoretical framework within the discipline of Deaf Studies/Deafness.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

This chapter provides a review of the literature for the present study of perceptions of identity and hearing loss. First, the theoretical framework underlying the research will be explained. A review of literature regarding identity development will follow while the chapter will conclude with a connection of the theoretical framework within the discipline of Deaf Studies/Deafness. Various researchers have viewed identity from differing perspectives. Simmel (1971) perceived an individual's identity and individuality as being the product of his or her overlapping ethnic, social, religious, familial, geographic, occupational, and multiple other affiliations. One's self-identity is based on his or her range of multiple intersecting affiliations (Brekhus, 2008; Zerubavel, 2007). Gergen (1991) elaborated on this idea by stating that the modern self is comprised of so many memberships that no single identity membership is likely to comprise a large percentage of a person's overall self and he further posits that authenticity goes beyond assuming that commitment to and pride in one's identity are necessarily the only ways one can claim an authentic identity membership to a marked social category.

#### **Theoretical Framework Underlying the Research**

Constructs of the study of identity from psychology and counseling as well as the literature in Deaf Studies/Deafness will serve as the foundation for the theoretical

framework underlying the investigation. Symbolic Interaction Theory, Social Identity Theory, the Multidimensional Identity Model, and studies of the development of identity from the discipline of Deaf Studies/Deafness will be the lens through which the present study will be framed. See Figure 1 for a visual representation of the theoretical framework for the present study.

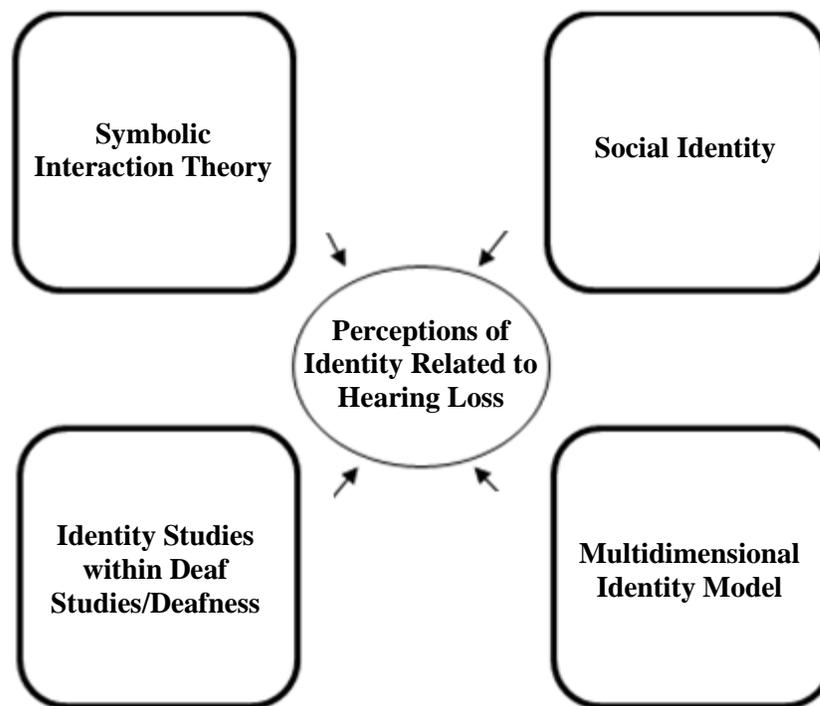


Figure 1. Theoretical Framework.

The lens of Symbolic Interaction Theory, Social Identity Theory, the Multidimensional Identity Model, and constructs of identity from Deaf Studies/Deafness form the theoretical framework for the present investigation. One's perception of identity as related to hearing loss may be affected by the meanings he or she attributes to identities, roles, interactions, and contexts (Symbolic Interaction Theory). One's

perception of identity as related to hearing loss may also be influenced by how one achieves a sense of belonging to or “fitting in” with a group (Social Identity). In addition, one’s perception of identity as related to hearing loss may be contingent upon one’s view of self as a whole versus focusing on isolated features that comprise the individual (Multidimensional Identity Model). One’s perception of identity as related to hearing loss may also be attributed to his or her interpretation of identity types (Deaf Studies/Deafness literature).

The interactions the participants will share via the interview protocol responses will provide detailed information related to hearing loss and their perceptions of identity. These responses constitute the means to apply the identity theories that have been selected as the basis of the theoretical framework for the study. It is through social interactions that individuals derive meanings and make sense of their world as described in Symbolic Interaction Theory. These same social interactions also enable individuals to perceive acceptance or non-acceptance in groups as delineated in Social Identity Theory. Further, the Multidimensional Identity Model emphasizes identity as being fluid as demonstrated through the social interactions of individuals with others in various contexts. Studies from the development of identity in Deaf Studies/Deafness highlight the role of social interactions as central in forming one’s social identity. Thus, the frameworks of Symbolic Interaction Theory, Social Identity Theory, and Multidimensional Identity Model, in conjunction with the identity types as established within Deaf Studies/Deafness, affirm the role of social interactions in forming perceptions of identity by students with hearing loss and their caregivers/parents.

G. P. Stone (1962) proposed that when one has an identity, he or she is situated in social relations and identity is established when others place the individual as a social object by assigning him or her the same words of identity as they appropriate or announce for themselves. For example, a caregiver/parent who identifies herself as hardworking and studious may also identify her son as a persevering student who puts forth his best effort in his studies since the mother is assigning the son the same words of identity she chooses for herself. The self can also be viewed as relatively fluid and defined by the interactional context and the way in which the individual frames or schematically understands the context and the rules of that interactional context (J. M. White & Klein, 2008).

Social identity constitutes verifying one's group membership and receiving acceptance and recognition from others based on one's membership in that group (Brekhus, 2008; Burke, 2004) whereas, personal identities are based on internal personality attributes (Belshaw, 2000) which is congruent with aspects of the Multidimensional Identity Model that have been chosen as a portion of the undergirding framework for the study. Authenticity is an aspect of identity in which disputes (Brekhus, 2003; J. A. Howard, 2000) occur that create tension between 'being' and 'doing' (Mullaney, 1999, 2006; Williams, 2006) when an individual claims an identity that differs from the identity others have conferred upon him or her. For example, individuals who identify themselves as members of a specific religious group may take offense with individuals who are not practicing that faith yet still call themselves members of the group. The individuals who are not practicing their faith may personally

identify themselves as ‘being’ religious but may not attend church functions or ‘do’ or participate in events within the group. Commitment and duration assist the individual in “keeping it real” and are valued as characteristics belonging to truly authentic individuals (Brekhus, 2008; E. E. Jones et al., 1971; Peterson, 2005; Turner, 1976). Such authentic characteristics are seen as the individual being “true” to him or herself as the individual acts in congruency with categories with which he or she most identifies. Authenticity can also be viewed as a commitment to self-values in that an individual is consistently “true” to him or herself and his/her beliefs and values across settings (Erickson, 1995; Hewitt, 2003; H. E. Stone, 1993). For example, a student with hearing loss may describe him or herself as being a hearing person, whereas others who know the student may regard the student as being deaf which may conflict with the student’s perception of his or her identity.

Identity and authenticity are context and setting-dependent (Ethier & Deaux, 1994; Grazian, 2003; Hormuth, 1990) as is put forth in both Symbolic Interaction Theory and Social Identity Theory. Thus, an individual may identify as being one identity in one setting but may select an alternate identity in a different setting. For example, an individual who is of Irish descent may identify as an Irish person at a family reunion but when interacting with friends of other ethnicities elsewhere, may choose to downplay his or her Irish descent. Markedness is defined as an attribute of identity that can be readily observed by others whereas unmarkedness is defined as the attribute of identity that is not typically apparent to others (Brekhus, 2003). For example, upon first meeting an

individual with diagnosis of clinical depression, others may not perceive the individual as having this condition because the depression is unmarked or not readily observed.

Markedness and unmarkedness can vary across time and space in which individuals can emphasize or downplay varying aspects of themselves and their self-identities depending upon different settings or contexts (E. Anderson, 1999; Brekhus, 2003; Grazian, 2003; Renfrow, 2004; Rockquemore & Brunisma, 2001). For example, a student with hearing loss may refer to him or herself as a person with hearing loss but others may perceive the student as a hearing person because he or she has intelligible speech and does not utilize sign language to communicate. Settings or contexts in which individuals may have differing perceptions of identity could include the geographic location, the time, and the social networks in which the individuals are situated (Brekhus, 2008). For example, identity shifts can occur in different contexts such as an individual conducting him or herself in a certain way in the school setting and behaving differently when in the home setting with family.

Life events may alter one's core identity or sense of self so that the past self and the present self have very little in common (Nippert-Eng, 1996; Vinitzky-Seroussi, 1998). Some changing of identity traits or characteristics are seen during moments in life that are viewed as turning points, revelations, transformations, or conversions (Machalek & Snow, 1984). Some individuals claim a new self-identity by constructing a rigid split between their past self and the present self (Mullaney, 2006). Some individuals travel between different selves, roles, and identities, exhibiting a shifting multidimensional identity (Orrange, 2003; Zurcher, 1977). Yet other individuals choose to combine many

attributes and networks at once into a complex multiple attribute social identity. For example, an individual may identify him or herself as being religious, Jewish, and a person with hearing loss regardless of the context, setting, or people with whom he or she interacts. Although there are many models to explain the development of identity available within the psychology, counseling, and Deaf Studies/Deafness literature, the present study seeks theoretical grounding in utilizing interactive components from Symbolic Interaction Theory, Social Identity Theory, the Multidimensional Identity Model, and identity studies from Deaf Studies/Deafness.

### **Development of Identity from the Discipline of Psychology**

#### **Symbolic Interaction Theory**

All situations can be analyzed through a number of different perspectives, each illuminating something more about the aspects of human beings (Charon, 2004). Symbolic Interaction Theory, attributed to the work of George Herbert Mead, originated in the 1920s and 1930s and is a current popular family perspective that focuses on how the individual interacts with others in interpersonal relations to formulate a sense of self and truth in order to adapt to and survive in his or her environment (Blumer, 1969; Brekhus, 2008; Cooley, 1902; Hays, 1977; R. L. Howard, 1981; Mead, 1934). In considering the role of symbols and their meanings Charles S. Peirce (1905), a well known pragmatist and philosopher, developed a theory of signs and symbols in which a symbol is a sign that is agreed upon by convention and for communication to take place, symbols must be shared or commonly agreed on by society. However, a symbol can change as Chomsky (1965) and other linguists discuss in their work when examining the

value of individuals understanding a symbol system and meaning in spite of its changing over time. Thus, interactionism is evident in interpersonal relations when the meaning an individual assigns to something can change even if that meaning does not change for other individuals in a social context. Therefore, within the present study, an interaction can signify one meaning for a participant but the exact same interaction can hold a very different meaning for another participant.

Philosopher William James (1975) developed a notion of self in relation to the environment, and John Dewey (1925), a philosopher and psychologist, developed the concept of mind. In James's notion of self, he proposes that the meaning of ideas and the truth of beliefs are held by an individual and those perceptions have an impact on his or her life. For example, an individual can formulate what it means to have hearing loss which impacts how he or she perceives hearing loss and the effect it has on his or her life. Thus, James suggests that the self has control over thinking; it is never static and always in motion. In Dewey's concept of the mind, he posits that interactions with objects and others drive the thinking of an individual and that thinking can change due to experiences. Consequently, an individual's interactions with the environment and others determine how the individual perceives hearing loss in his or her life or how external factors influence his or her perceptions of experiences with hearing loss. The aspects of nature and nurture as defined by both James's notion of self and Dewey's concept of mind interrelate with the creation of meanings from symbols, interactions with others, and influences of those interactions on the meanings aspects of Symbolic Interaction Theory.

The crux of the Symbolic Interaction Theory emphasizes that shared meanings are portrayed through symbols whereas the verbal and nonverbal actions and communications between individuals are termed interactions. Humans create symbolic worlds and through interacting with one another, these worlds then shape or influence human behavior (Mead, 1934). Symbolic Interaction Theory underscores the relationship among identities, roles, interactions, and contexts (LaRossa & Reitzes, 1993). An individual formulates his or her own role and develops role expectations through interacting with others. Through this social interaction, the individual assigns meaning to the symbols.

According to the tenets of the Symbolic Interaction Theory, an individual creates his or her identity through interacting with others so a child's interactions with his or her caregivers/parents have a significant impact in formulating meaning since caregivers/parents are the child's first teachers or first individuals with whom they interact. These interactions influence how the individual behaves in subsequent interactions. If others with whom an individual interacts disagree with the individual's self-identity or perceptions of hearing loss, this may lead to an individual questioning his or her identity or how he or she defines hearing loss. The Symbolic Interaction Theory views the family as a seminal social interaction group and posits that individuals develop both a concept of self and their identities through social interaction with family members (Burgess, 1925; Handel, 1985; J. M. White & Klein, 2008). Family members are the first individuals with whom a child interacts, thus, families serve as shapers of identity since they are crucial sites of creating and verifying social and shared meanings. Thus, in the

present study, the researcher will examine whether or not self perceptions of the participants align with those of their caregivers/parents by seeking the answers to the research questions posed by the researcher.

In an effort to influence others and gain approval, a child begins to form a social self (Cooley, 1902). The notion of the “looking glass self” posits that it is from contact with others that a child learns to develop a sense of “my” and “mine” as well as to identify with others through a sense of “we” (LaRossa & Reitzes, 1993). This formation of a social self can be likened to a looking glass in which an individual interprets others’ perceptions of him or her and experiences his or her reaction to that assessment by reflecting on his or her behavior (J. M. White & Klein, 2008). The looking glass self emerges in primary groups (e.g., a family), who rely on face-to-face associations that offer the opportunity for relatively permanent, intimate, and cooperative ties (Cooley, 1909). Thus, through empathy, or “sympathetic introspection,” a person is able to become aware of others. Through becoming aware of others, individuals expect certain behaviors from people with whom they interact (R. L. Howard, 1981; Mead, 1934). As the individual extends interpersonal meanings to others, he or she transitions from self as object (me) to self as subject (I). The “Me,” the social self, includes past actions whereas the “I” includes the spontaneous behavior of the immediate and instantaneous present. For example, an individual may think about something happening to “me” compared to something happening as a result because of something “I” did. This cognitive restructuring is evident when an individual discusses what happens to him or her versus what he or she does in an interaction.

Regardless of what has occurred in the past, human action cannot be understood without the subjective interpretations given to situations (Thomas & Thomas, 1928). This inability to separate human action from situations in which they occur is termed the Thomas Theorem or Axiom; if people define situations as real, they are real in their consequences. Individuals determine how they will behave or act in a situation depending on how they perceive the environment (J. M. White & Klein, 2008). Similarly, Burgess (1925) theorizes that the interactions among family members have an impact on how an individual defines his or her identity. Family roles are dynamic rather than static and behavior or reactions of one person in a family can and will change the interactions of other family members. Moreover, social images and conceptions of self and others are not illusions but are factors that provide self-generated motives for action and enable individuals to better interpret the responses of others (Burgess, 1925; Stryker, 1964; Waller & Hill, 1951). For example, a family who views itself as financially stable may feel threatened if one of the caregivers/parents loses a job. The family members may feel as though they are not able to overcome the loss of the job and maintain their financially stable identity. This hardship example affirms the importance of roles on behavior.

Symbolic Interaction Theory places significance on the meanings of human behavior. Cooley (1902) situated meaning in a person's imagination and perception of others, with other people becoming real and meaningful to the extent that a person becomes aware of them. Mead (1934), on the other hand, stressed the inter-subjective basis of meaning and argued that meaning rests in symbols or shared interpretations that

produce a common response in the individual and others. Meanings are thus modified through an interpretive process. Individuals interpret reality through the symbols and the shared social meanings of their culture (LaRossa & Reitzes, 1993). According to Mead, once symbols are learned, the individual uses the vantage point of the generalized other to negotiate the specific meanings of self, others, and the social setting.

Self-values, self-beliefs, self-feelings, and positive self-assessments affect behavior according to the Symbolic Interaction Theory. Additionally, individuals must contend with individual freedom in contrast to constraints imposed by societal norms (LaRossa & Reitzes, 1993). LaRossa and Reitzes (1993) reveal that individuals and small groups are influenced by larger cultural and societal processes so an individual's identity may change based on what occurs in that individual's world. Further, it is through social interaction in everyday situations that individuals work out the details of social structure. The four mutually related concepts, as they pertain to the Symbolic Interaction Theory, are (a) identities, (b) roles, (c) interactions, and (d) contexts.

**Identities.** Within Symbolic Interaction Theory, self-meanings or identities are found in a role and are typically hierarchically organized by salience (LaRossa & Reitzes, 1993). Salience is the probability of an identity being displayed in a given situation or in a variety of situations (Stryker, 1968a, 1968b; J. M. White & Klein, 2008). The greater the prominence of an identity, the more motivated an individual will be to perform and try to excel in expected role-related behaviors (McCall & Simmons, 1978). Within relationships across situations, identity is verified by others and emotions produced in interactions (Stets, 1995) thus, identity influences self-esteem, which is the most

frequently studied aspect of self-concept within Symbolic Interaction Theory. Self-esteem refers to how one feels about oneself (Wylie, 1979) with the desire to acquire and maintain positive self-esteem as powerful motives for behavior. Gecas (1982) reports that self-esteem affects conformity, interpersonal attraction, moral behavior, educational orientations, and various aspects of personality and mental health (Burr, Leigh, Day, & Constantine, 1979; Kaplan & Pokorny, 1969; Rosenberg, 1981; Wells & Maxwell, 1976). In examining differing levels of self-esteem, Luck and Heiss (1972) found that individuals with low levels of self-esteem tended to be characterized as submissive and dealt with depression, psychic anxiety, autonomic anxiety, maladjustment, and vulnerability; whereas, individuals with high levels of self-esteem were characterized as being assertive, adaptable, and displayed low rates of depression, psychic anxiety, and vulnerability.

**Roles.** Shared norms are applied to the occupants of social positions in establishing roles (Heiss, 1981) and are group-held beliefs about how members of a society should behave in a given context. Systems of meaning enable role occupants and others with whom they interact to anticipate future behaviors and to maintain regularity in social interactions (Turner, 1970). Roles specify not only knowledge, ability, and motivation (Brim, 1966), but also expectations about the proper extent, direction, and duration of feelings and emotions (Hochschild, 1979). Past experiences and events may shape roles in the present (Maines, Sugrue, & Katovich, 1983; Wheaton, 1990) whereas current roles may shape experiences. Moreover, behavior once considered as normal is redefined as abnormal in certain roles. For example, caregivers/parents who are

struggling with a child who battles highs and lows due to a manic depressive disorder may view the child's outbursts as normal. Then, once the caregivers/parents have made the decision to medicate the child in an attempt to control the outbursts, the caregivers/parents rationalize that the highs and lows the child faces are abnormal hence the medication.

In Symbolic Interaction Theory, child socialization is viewed as a complex process by which children memorize roles, actively learn various roles, and participate in the formation of their identities (LaRossa & Reitzes, 1993). Gecas and Schwalbe (1986) found that adolescent self-esteem is more strongly related to adolescents' perceptions of parental behavior (control, support, and participation) than it is to parental reports of the adolescents' behavior. This aspect of understanding others is related to Cooley's notion of the "looking glass self" as outlined earlier in this chapter. Rosenberg (1979) revealed that school-aged children's self-esteem was dependent upon the caregivers'/parents' views of the children. Furthermore, the desire to think well of oneself and to protect one's self-concept against change are powerful motivators of behavior. Roles provide rules or expectations of behaviors (J. M. White & Klein, 2008). Without clear expectations shared by both the individual and others, it is impossible for individuals to perform the role or for others to know how their behavior influences the individual (J. M. White & Klein, 2008). Thus, the role of self-esteem is a powerful motivator in forming identity according to Symbolic Interaction Theory.

Role overload or strain occurs when individuals do not have sufficient resources to enact a role or roles. For example, an individual may experience role overload or

strain if an individual tries to identify in more than one category or type of identity. The more an individual perceives consensus in the expectations about a role he or she occupies the less is his or her role strain (Burr et al., 1979). The roles of others may not be perceived as important or relevant to individuals, which may increase their role strain (J. M. White & Klein, 2008). The greater the perceived clarity of role expectations, the higher the quality of role enactment (Burr et al., 1979). However, when a person plays multiple roles, myriad role expectations may contradict one another (J. M. White & Klein, 2008).

**Interactions.** It is through social interaction that individuals apply broad shared symbols and actively create specific meanings of self, others, and situations (LaRossa & Reitzes, 1993). Use of verbal and nonverbal clues convey and announce one's role and identity while at the same time individuals make inferences about that individual's identity (Goffman, 1959, 1978). Goffman (1959, 1978) further highlights the underlying moral character that the person is expected to live up to as well as the rights and responsibilities of his or her validated identity and that others are obliged to respect that identity. The actions, responses, and subjective meanings of other people are another feature of social interaction. Some individuals have more impact on an individual's identity than do other individuals (Hoelter, 1985; Hughes, 1962) such as siblings, peers, caregivers/parents, teachers, and counselors.

**Contexts.** The connections that are made between the individual and society are referred to as contexts in Symbolic Interaction Theory (LaRossa & Reitzes, 1993; Strauss, 1987). How an individual negotiates his or her identity is influenced by the

contexts of the immediate factors that influence the individual's relationships with others (e.g., involvement in extracurricular activities, performance in classroom). Structural contexts represent the interactive environment in which the relationships take place, such as within the community or school.

In summary, the process of an individual creating his or her identity produces emotions that are a result from interactions with others (LaRossa & Reitzes, 1993). Individuals select the role definitions which are most salient, or predominant, to them and then act in accordance to the expectations within these roles (LaRossa & Reitzes, 1993). However, the process of determining these salient role positions, the experience of role strain between various role positions, or the process of achieving role clarity are influenced by identities, roles, interactions, and contexts (LaRossa & Reitzes, 1993). Varying role identities, within an individual, combine to form individuals' expectations and beliefs concerning perceptions of identity as they pertain to hearing loss. As is posited in Symbolic Interaction Theory, individuals determine the salience, or how noticeable or important aspects of their identity roles are, through interactions with others and their environment.

In addition to explaining the relationship among identities, roles, interactions, and contexts, Stryker's (1980) "identity theory" suggests individuals actively infuse roles with identities, commitment, and salience. Rosenberg (1979, 1981) elaborates Stryker's "identity theory" by defining four sets of self-processes: (a) reflected appraisals in which individuals are influenced by the attitudes of others toward self; (b) social comparisons in which individuals evaluate themselves by comparing themselves to certain individuals,

groups, or social categories; (c) self-attributions in which individuals use their own behaviors as a basis for making inferences about self-descriptions or competencies; and (d) psychological centrality, in which self-concept is an organization of components, some of which are the foci of attention and thus are given greater importance. In considering the centrality of family, Gecas and Seff (1990) report that when a person's family is key to his or her self-esteem, family variables (e.g., perceived control over children) will have a strong effect on self-esteem. However, self-esteem is only one aspect of the self that motivates behavior as self-efficacy, the desire to perceive oneself as a causal or originating agent, and authenticity, the desire for meaning and significance, among others, are other significant bases for action (LaRossa & Reitzes, 1993).

Symbolic Interaction Theory has been criticized as utilizing vague and ill-defined concepts but symbolic interaction emphasizes the processes by which meaning is constructed (J. M. White & Klein, 2008). Elsewhere, critics have declared symbolic interactionism as being too focused on the individual and "self as agent" rather than concentrating on the effects of social structure (J. M. White & Klein, 2008). However several aspects of Symbolic Interaction Theory provide a useful construct of analyzing identity in students with hearing loss.

### **Social Identity Theory**

In addition to Symbolic Interaction Theory, Social Identity Theory delineates the relationship between the individual and society and the development of an individual's personal and social identities (C. A. Baker, 2012; Mead, 1934; Tajfel & Turner, 1986). Social identity is defined as the "aspects of an individual's self-image that derive from

the social categories to which he perceives himself as ‘belonging’” (Tajfel & Turner, 1986). Therefore, an individual’s social identity refers to that part of one’s sense of identity that emerges from his or her belonging to a particular group and thus, acts as a locus of interaction between personal and group identity. For example, a caregiver/parent participant may perceive his or her daughter with hearing loss as belonging to a separate group of individuals who are similar to them, with respect to hearing loss, or the caregiver/parent participant may identify his or her child as being hearing and “fitting in” with peers who do not have hearing loss. This perception of social identity and hearing loss, may be evident in the identity terms participants choose to describe themselves and/or the students. Tajfel (1982) further states that an individual’s identity derives from his or her knowledge of membership in a group combined with the value and emotional significance attached to that membership. This extension of Mead’s original definition of social identity includes three facets of social identity: (a) cognitive recognition of belonging to the group, (b) evaluative recognition of the value attached to the group, and (c) emotional attitudes of the group members (Tajfel, 1982; Tajfel & Turner, 1986).

People categorize themselves into groups in an attempt to establish a positive sense of value (C. A. Baker, 2012; Tajfel & Turner, 1986). One way of doing this is to distinguish their membership in a group compared to that of other groups of which they are not members. These distinctions favor the group to which they belong (Mullen, Brown, & Smith, 1992; Tajfel & Turner, 1986). In the present study, it will be of interest to examine with which group the students with hearing loss and caregivers/parents identify the students and explore their attitudes toward others in and outside of that group

based upon the two theories from the discipline of psychology of relevance to this study: Symbolic Interaction Theory and Social Identity Theory.

### **Development of Identity from the Discipline of Counseling**

Identity is complex and multifaceted (Brekhus, 2008) and many models within the counseling literature seek to explore the development of identity. However, one specific model, the Multidimensional Identity Model bears relevance for the study. Social theorists have noted that as society becomes increasingly fragmented, identities become more multidimensional, more complex, less static, and less anchored in social places. Countless social networks, significant others, and generalized others influence self-identities and lead to a self that is pulled in multiple directions leading to no anchored or core self according to Gergen (1991). As a result, some individuals may attempt to bracket these multiple affiliations by shifting from identity to identity and living double or even multiple lives while other individuals may try to bridge affiliations to form one multiply influenced and socially networked self (Brekhus, 2008).

### **Multidimensional Identity Model**

The Multidimensional Identity Model consists of four aspects in which individuals (a) identify with only one aspect of self in a passive manner such as the aspect of self assigned by others such as society, peers, or family; (b) identify with only one aspect of self that is determined by the individual; (c) identify with multiple aspects of self, but choose to do so in a “segmented fashion” frequently only one at a time which is determined more passively by the context rather than by the individual’s own wishes (i.e., in one setting the individual identifies by race, yet in another setting as gay); and (d)

chooses to identify with the multiple aspects of self, especially multiple oppressions, and has both consciously chosen them and integrates them into one's sense of self (Reynolds & Pope, 1991). This pluralistic view of identity is perhaps more aligned with the conceptualization of identity as a result of blending more than one culture (e.g., bicultural). For example, a student with hearing loss may identify as being a member of the dominant or hearing society in Science class where he or she can communicate and interact with peers and teachers without difficulty. However, in social situations such as during lunch in the noisy school cafeteria, he or she may identify as a person with hearing loss due to interactions being affected by the hearing loss.

Proponents of the Multidimensional Identity Model caution that other identity approaches, in counseling, have overplayed the importance of shared minority category membership to an individual's overall conception of self and identity. Others impose a master status perspective on individuals who do not themselves recognize their minority status as the major social determinant of their identity (Brekhus, 2008). An attribute of markedness that is readily visible to others is often assumed to be an individual's "master status" which may contradict that individual's view of him or herself (Brekhus, 2008). Thus features of the Multidimensional Identity Model can be applied to students with hearing loss, who may or may not wear hearing aids and who do not communicate using American Sign Language (ASL).

### **Development of Identity from the Discipline of Deaf Studies/Deafness**

There is no one development of identity model that has been established within the discipline of Deaf Studies/Deafness. Investigations of identity in Deaf

Studies/Deafness have resulted in the designations of four categories to describe an individual with hearing loss. Factors such as degree of hearing loss, age of onset, type of hearing loss, family history and lifestyle, mode of communication, and community context influence how an individual with hearing loss perceives or identifies him or herself. A person with hearing loss may claim an identity that is radically different from other individuals with a similar type of hearing loss and multiple factors contribute to the development of identity of individuals with hearing loss (Humphries & Humphries, 2011; Leigh, 2009).

Melick (1999) conducted a study that explored and revealed meaningful and influential experiences and factors that shaped the Deaf cultural identity of deaf adults who were born into hearing families. The investigation was conducted with participants who had early childhood hearing losses and who were educated in mainstream (inclusive) settings. The following questions were addressed, “How does this group of individuals learn about and become connected with the Deaf culture?”; “What experiences and variables influenced their identification and affiliation with the Deaf culture?”; “Are there common patterns of enculturation this select group of Deaf adults share?”; “How does this group experience the enculturation process?”; and “Do they fall into one of the four types of Deaf identity as proposed by Glickman’s (1996) Deaf Identity Development (DID)?” Interviews were conducted with ten Deaf individuals regarding their experiences. The result of this study was the development of a model that outlines four phases involved in developing a Deaf identity for this segment of the Deaf community. The four phases are: (a) Being an Outsider, (b) Encountering/Connecting, (c)

Transitioning from an Outsider to an Insider, and (d) Self-Definition. This developmental model that is sequential and cyclical was compared and contrasted with Glickman's (1996) DID model. Melick (1999) hypothesizes that this comparison highlights how the model proposed by this study reflects a more comprehensive model of the identity development process of children who are raised in Hearing families, have a hearing loss since early childhood, and are educated in mainstream educational settings.

Likewise, a narrative study conducted by Hole (2007) revealed that living in the world as a Deaf person provides a "different situatedness" or a different experience in which individuals with hearing loss construct their identity. This study sought to answer the question, how does living in the world, different from the hearing majority, influence the ways individuals with hearing loss construct identities? This question brings to mind the relational components of identities, roles, interactions, and contexts within the Symbolic Interaction Theory. Three women, with prelingual hearing loss, or hearing loss before language, participated in this qualitative study by sharing how they incorporated, resisted, and/or rejected various cultural aspects of deafness. The results of this study reveal that four discourses impact identity formation (a) discourses of normalcy, (b) discourses of difference, (c) discourses of passing, and (d) Deaf cultural discourses (Hole, 2007). The author states that discourses of normalcy and discourses of difference led to the construction of identities based on opposites, in a binary relationship where one side of the binary was privileged and the opposite was "othered" (e.g., hearing/deaf, and Deaf/deaf).

These findings from the literature in Deaf Studies/Deafness are congruent with the notion that past experiences, interactions with others, and setting impact how an individual views him or herself as a member of a specific culture as viewed through the theoretical lens of Symbolic Interaction Theory, Social Identity Theory, and Multidimensional Identity Model (Mead, 1934; Reynolds & Pope, 1991; Tajfel & Turner, 1986).

### **Identity Types: Deaf, deaf, Marginal, Bicultural/Dual**

Four identity types (a) Deaf, (b) deaf, (c) marginal, and (d) bicultural/dual have commonly been discussed in the Deaf Studies/Deafness literature (Cornell & Lyness, 2004; Glickman & Carey, 1993; Lane, Hoffmeister, & Bahan, 1996; Most, Wiesel, & Blitzer, 2007; Woodward, 1972).

**Deaf.** Those individuals who identify themselves as Deaf tend to participate in social activities within Deaf culture/community, communicate through American Sign Language (ASL), and may object to the hearing world and using speech due to not viewing themselves as having a disability nor needing to conform to the hearing society (Gesser, 2007; Padden & Humphries, 2005; Reagan, 1995; Shakespeare, 1996; Shakespeare & Watson, 2002). As with any culture, features of Deaf culture can be defined by shared social beliefs, behaviors, art, literary traditions, history, and values. For an individual who identifies him or herself as a member within Deaf culture, these shared cultural features are affected by an individual having hearing loss who may use American Sign Language as his or her primary means of communication (Holcomb, 2013). Feelings of pride and identifying with other individuals with hearing loss who use

ASL as their primary communication mode can be viewed as types of ethnic and cultural identities that reflect tenets of Phinney's Model of Ethnic Identity Development and Berry's Model of Identity from the literature in psychology.

***Phinney's Model of Ethnic Identity Development.*** A well-known model that relates to the development of ethnic identity is Phinney's (1992) Model of Ethnic Identity Development. This model is composed of three elements. The first is the affective component or the measure of how strongly an individual feels a sense of belonging and commitment to his or her ethnic community. The second element of Phinney's model constitutes the cognitive component or the extent to which individuals adopt or are interested in their ethnicity in terms of its history, traditions, and values. The third element of Phinney's model is the behavioral component that accounts for the level of the individual's involvement in activities related to his or her ethnicity (Phinney, 1992). Thus, Phinney's Model of Ethnic Identity Development allows an individual to feel and demonstrate a strong sense of belonging and pride in one's ethnicity through participating in events or activities that revolve around the person's ethnic identity.

***Berry's Model of Identity.*** A second model of identity development of particular interest to the present study is Berry's Model of Identity in which culture is highlighted. Proponents of Berry's Model of Identity consider the value of maintaining one's cultural heritage in juxtaposition with the value that is placed by the individual on developing relationships with the larger society (Berry, 1997). Thus, an individual's identity with a cultural heritage may or may not conflict with the values that culture places on membership of the individual in the larger society.

In many families of origin, children with hearing loss are often the only members of the family with hearing loss which is in contrast to other minority groups in which family members share the same culture with their children (Wright, 1987). Therefore, a Deaf identity type is rarely developed through family-based socialization as would any other cultural identity that is shared through familiar bonds (Atkin, Ahmad, & Jones, 2002). Other purposes of the caregivers/parents are to carry out the transfer of cultural values of honor and shame, identity and religion, obligations and expectations, relationships with kin and gender roles, including sexual morality and knowledge of these fundamental familiar foundations are regarded as essential to family responsibilities (Anthias, 1992; Ahmad, Darr, Jones, & Nisar, 1998).

In addition to achieving the sense of belonging, membership in the Deaf culture/community is achieved through identification with Deaf members of that community, shared experiences, and participation in social activities. However, it is important to note some hearing people who work closely with deaf people are considered members of the Deaf Community (Wright, 1987). Due to such cultural, linguistic, and social variety among individuals with hearing loss, it is necessary for the purposes of researchers to distinguish between the specific Deaf Community within the general deaf population as the presence of hearing loss, in and of itself, is not adequate for membership in the Deaf Community (Ladd, 1991; Padden & Humphries, 2005). When used as a cultural label, the word, deaf, is written with a capital D, and refers to an individual with hearing loss who uses ASL as his or her primary mode of communication as being “big D Deaf.”

“Big D” Deaf identity differs from disabled identity which raises issues related to the use of terminology and labeling in the Deaf Studies/Deafness literature. It has been suggested that the continued use of the word, deafness, holds a negative connotation in that it focuses on something that is missing from a person. Thus, Obasi (2008) asserts that the term, Deaf, with a capital D, should be more widely recognized as a social construct. Most individuals with hearing loss who categorize themselves as being “Big D” Deaf claim to be members of a linguistic and cultural minority and do not perceive themselves as disabled (Emerton, 1996; Sinecka, 2008). The word deaf, itself, invokes different meanings when used by Deaf and hearing people (Erting, 1985; McKee, 2008). McKee (2008) further explains that for individuals who identify themselves as the Deaf identity type, the term conjures a sense of “people like us” who are visually oriented while for individuals with hearing loss who identify with the hearing world, the use of the word, deaf, refers to social and language challenges when interacting with individuals who do not have hearing loss.

Through establishing an identity as a member of the Deaf community, many advantages associated with selecting this identity type can be experienced, such as feeling a sense of belonging, being accepted, and having the means to communicate with and be understood through the use of ASL while feelings of isolation are reduced. Some researchers have suggested that membership in Deaf culture/community can be a protective factor against mental health problems for these reasons (Taylor, 1985).

Those individuals who identify themselves as Deaf tend to consider individuals who are late deafened, hard of hearing, and who use the oral (spoken language and

listening) mode of communication as “hearing people who have lost some of their hearing” because these individuals originally had some prior experience in hearing sound and speech (Ladd, 1991, p. 36). These reference points for normality and health parallel the aspect of Symbolic Interaction Theory that designates an individual constructs the meaning of symbols from interactions even if that meaning differs from the meanings others have constructed of the same phenomenon.

**deaf.** The word, deaf, written with a lower case d, is used to describe the medical pathology of an individual having hearing loss (Ladd, 1991, 2005; Padden & Humphries, 2005; Woodward, 1972). In contrast to the Deaf identity type (Cornell & Lyness, 2004; Glickman & Carey, 1993; Lane et al., 1996; Most et al., 2007; Woodward, 1972), individuals who identify themselves as deaf may perceive deafness as a medical pathology or a disability and use the hearing world as their reference point for normality and health with value being placed on use of spoken language (Beart, 2005; Berkay, Gardner, & Smith, 1995; Ladd, 2005; Woodward, 1972).

The medical view of deafness purports that the pathological absence of hearing is a disability that should be aided through medical procedures, such as the use of hearing aids or cochlear implants, and other medical interventions (e.g., surgery) to improve hearing and ameliorate the loss of hearing. Those individuals who may have pursued such medical interventions are generally not considered part of the culturally Deaf community because they have hearing loss that ranges from mild to profound, they associate mostly with hearing people, and/or they do not use American Sign Language as their primary means of communicating with others (Melick, 1999).

**Marginal.** Individuals who are members of the marginal identity type do not feel a sense of belonging with the Deaf culture/community nor do they believe they are able to operate within the hearing world (i.e., deaf identity type; Glickman, 1986; Most et al., 2007). These individuals may experience difficulties in both “worlds” as a result of deficient social and communication skills (Most et al., 2007; Woodward, 1972). Finally, individuals who identify themselves as the bicultural/dual identity type are able to navigate both the Deaf and hearing worlds hence the duality of the identity type.

In a study that examined the relationship between psychological well-being and self-perception in adolescents with cochlear implants, adolescents answered questions concerning their perceptions of hearing, deaf signing, and orally communicating deaf peers (Mance & Edwards, 2012). Twenty-two cochlear implant users between the ages of 12 and 18 completed questionnaires assessing their anxiety, depression, disruptive behavior, anger, and self-esteem. Results indicated that perceiving oneself as close to any peer, irrespective of which peer, was associated with better psychological well-being in addition to demonstrating a more positive association between perceived degrees of similarity to hearing peers. This sense of belonging with a peer or a group matches constructs of Social Identity Theory in that importance is placed on forming bonds. Individuals who identify as the marginal identity type are unable to form these close bonds with either identity type (e.g., Deaf, deaf). Mance and Edwards (2012) revealed that the more similar to hearing peers the adolescents with implants perceived themselves, the better their overall psychological well-being. In contrast, perceiving

oneself as more similar to deaf signing peers or deaf oral peers was not significantly associated with psychological well-being.

Some people with hearing loss feel that it is better to be a Deaf person who is proud of him or herself as opposed to an imitation of a hearing person who does not feel a sense of belonging to the hearing world or community (Most et al., 2007). The lack of understanding of oneself as a deaf person and the lack of truthful self-evaluation by pretending to be hearing and using bluffing as a coping mechanism are seen by peers and some teachers as an inauthentic representation of self to others in the class (Mcilroy & Storbeck, 2011). These authors further state that lack of or latent unresolved acceptance supports the peer group attitude of exclusion based less on a person's difference of being deaf but more on the person's not fully honest attempt at inclusion by pretending to be hearing.

**Bicultural/dual.** Members of the bicultural/dual identity type tend to use both signed and spoken languages to communicate with others. For those in this category, loneliness is observed especially when individuals experience a deep sense of insecurity of their identity despite being in an inclusive school environment (Glickman, 1996) as has been documented in several identity studies within the Deaf Studies/Deafness literature. Bicultural identity is reserved for those who feel comfortable in both worlds by belonging to the Deaf culture/community but also feeling comfortable with and respecting hearing people which correlates with the Multidimensional Identity Model in that these individuals have various attributes to their identity.

Within the Deaf Studies/Deafness literature, it appears that a necessary feature of biculturalism, especially for adolescents, is the acceptance of one's bicultural identity (Grosjean, 2010). A person's identity can involve more than one culture, and as a result, these individuals, as adolescents, may exhibit more flexible behaviors and are open to more possibilities of defining themselves (Leigh, Marcus, Dobosh, & Allen, 1998; Leigh & Stinson, 1991) in numerous ways similar to aspects in the Multidimensional Identity Model. Elements of Phinney's Model of Ethnic Identity Development and Berry's Model of Identity focus on the relationship between culture and identity surface in a bicultural perspective of deaf identity.

In a study to investigate the Deaf identity and social anxiety of 196 deaf students at a residential school for deaf students, results revealed that Deaf students' bicultural identity was the strongest of the four identity types with the marginal identity type listed as the weakest. Thus, by choosing a bicultural identity, Deaf students may enhance their social activities and reduce their social anxiety (Tan, Chen, & Fang Zhou, 2010) which corresponds with elements of Social Identity Theory (Brekhus, 2008).

Another study examined the relationships between identity orientations and attitudes toward cochlear implants by adolescents with hearing loss (Most et al., 2007). 115 deaf and hard of hearing adolescents completed a demographic questionnaire regarding hearing loss and identity. Results indicated that participants' bicultural (i.e., fitting into both the deaf and hearing worlds) identity was strongest and marginal identity (i.e., not fitting into either world) was weakest. In general, participants expressed positive attitudes toward cochlear implants and a stronger Deaf identity was associated

with less positive attitudes regarding expected cochlear implant effects whereas, stronger bicultural identity was associated with more positive attitudes. Bicultural identity did not contradict the acceptance of cochlear implant technology (Most et al., 2007).

Members of the bicultural identity type participate, to varying degrees, in the two worlds (the Deaf world and the hearing world) by adapting their attitudes, behaviors, and languages to both worlds, and by combining and blending aspects from each world (Grosjean, 2010). Involvement in both the hearing and the Deaf communities appears to be the most ideal identity for deaf and hard of hearing adolescents as shown by Most et al. (2007) who revealed that members of the bicultural identity type demonstrated higher academic achievement, expanded social relations, and held more positive opinions about themselves (e.g., self-esteem). However, for those individuals who choose the bicultural identity, some individuals may struggle to find a balance among different worlds (Nikoloraizi, 2007). Brueggemann's (2009) idea of "inbetweenity" or living "between spaces" frames identity as a quest for belonging instead of a narrow quest for self-definition based on being either deaf or Deaf. "Inbetweenity" or living "between spaces" thus becomes an individual's way of navigating the boundaries of identity and feelings of belonging to either deaf or Deaf groups in certain situations, and not in others (Brueggeman, 2009). This fluidity in identity finding is congruent with proponents of the Social Identity Theory and the Multidimensional Identity Model that focus on whether or not individuals achieve a sense of belonging or fitting in with a group based on interactions with group members.

From the psycho-social perspective, Erikson (1956) defined a progression of psychosocial development during which individuals self-actualize and achieve a sense of “being.” He contends that during the fifth stage of psychosocial development, termed, Fidelity: Identity versus Confusion, which occurs between the ages of 12 and 18, individuals focus on social relationships (Erikson, 1968). It is during this stage that individuals define their place in society and determine their roles, which may or may not differ from what they believed prior to this stage. Individuals depart from the identity that was handed down to them from their caregivers/parents and gravitate toward a new idea of who they are. This departure may be revealed in discrepancies from caregivers’/parents’ views of the student’s identity compared with the student’s perception of his or her identity.

Marcia (2002) expanded Erikson’s fifth stage of Identity versus Confusion by adding four statuses relating to identity development. The first status, foreclosure, occurs when the child accepts caregivers’/parents’ and other authority figures’ views as truth and does not question these beliefs. During the second status, moratorium, the child explores alternatives in a state of crisis and learns and “tries out” a variety of beliefs and values. The third status, identity achievement, takes place during a time in which a child makes commitments and sets goals. During the fourth status of identity development, diffusion, the child lacks identity and demonstrates insecurity about him or herself.

Based upon the previous findings in the Deaf Studies/Deafness literature and Erikson’s Stages of Psychosocial Development (Erikson, 1956/1968), it is important for most individuals with hearing loss to acquire a bicultural identity in developing a

productive, rewarding life according to Holcomb (1997). The process by which an individual with hearing loss achieves a bicultural identity consists of five stages: (a) conformity, (b) dissonance, (c) resistance and immersion, (d) introspection, and (e) awareness (Holcomb, 1997). Conformity refers to the individual accepting the status quo of the dominant culture, in this case, the hearing world. Dissonance occurs when questioning about perceptions occurs and the individual seeks to interact with others who are like him or her with respect to having a hearing loss. The resistance and immersion stage is defined as the period when an individual with hearing loss distances him or herself from the hearing world and begins to associate with the Deaf community in an attempt to take on a Deaf identity. Introspection follows when the individual realizes aspects of both hearing and Deaf identity can be interwoven rather than assuming an identity consists of either one extreme or the other (i.e., Deaf identity versus hearing identity). The final stage, awareness, occurs when the individual is able to interact with both the Deaf community and hearing world. This concept of deafness is related to Multidimensional Identity Model in recognizing that there are multiple aspects to an individual's identity as the individual transitions from one aspect of identity to another.

Development of identity as a Deaf person is often a lengthy process of discovery since only a small number of deaf individuals are born into the culture, and most become a part of Deaf culture during their teenage or young adult years (M. R. Byrne, 1998; Hodapp, 1998; Leigh et al., 1998; Padden, 1996; Parasnis, 1996; Trybus, 1980). This is done through interactions with others and feeling a sense of belonging within the group according to Social Identity Theory. The transition into a Deaf identity occurs during

students' school years; for some, when they moved from inclusive public schools to a separate school for the Deaf (Mcilroy & Storbeck, 2011). Thus, the process of developing a Deaf identity can culminate in an individual's decision to (a) belong to *both* the Deaf and hearing cultures, (b) develop a static identity by choosing to belong solely to the hearing culture, (c) to belong solely to Deaf culture, or (d) belong neither to hearing culture nor to Deaf culture (Brekhus, 2008; Grosjean, 2010; James, 1975).

Grosjean's categorizations and labels correspond to the four identity types as previously defined in this chapter (Glickman, 1986; Ladd, 2005; Most et al., 2007; Woodward, 1972). According to Grosjean (2010), one solution for people born into two cultures is to accept both cultures. However, due to the influence of the labels imposed upon the two cultural groups, many individuals with hearing loss instead choose one of the first three options (i.e., Deaf, deaf, marginal). This assigning of meaning to the identity types borrows from the Symbolic Interaction Theory perspective in that an individual interacts with others in interpersonal relations and draws meaning from those interactions. The meanings based on those interactions (whether they are with people who identify themselves as Deaf, deaf, or the marginal identity type) are shaped by the norms and contexts of the specific culture so that an individual formulates a sense of self in order to adapt to and survive in his or her environment (Blumer, 1969; Brekhus, 2008; Cooley, 1902; Hays, 1977; R. L. Howard, 1981; Mead, 1934).

The importance of helping children who are hard of hearing develop solid identities as deaf persons has been asserted with emphasis on providing deaf children with access to the Deaf culture/community during their early years (Holcomb, 1997).

Holcomb expands the four identity types, as previously outlined, into seven identity categories by which an individual with hearing loss may be characterized based upon the extent of the individual's exposure to Deaf culture/community. These seven identity categories are as follows: (a) balanced bicultural, (b) deaf-dominant bicultural, (c) hearing-dominant bicultural, (d) culturally separate, (e) culturally isolated, (f) culturally marginal, and (g) culturally captive.

According to Holcomb (1997), an individual with hearing loss who identifies as a balanced bicultural individual is one who can interact in both Deaf and hearing worlds whereas a deaf-dominant bicultural individual prefers to interact with the Deaf community but is able to communicate with others in the hearing world. Conversely, a hearing-dominant bicultural individual is one who most identifies with the hearing world and prefers to interact in that world but, if need be, could communicate within the Deaf community. Individuals who identify themselves as culturally separate prefer to interact solely with the Deaf community while individuals who label themselves as culturally isolated feel as though they do not need to interact with the Deaf community at all as they prefer to function only in the hearing world. Individuals within the culturally marginal group do not feel as if they belong in the Deaf community nor do they feel a sense of belonging within hearing society. The culturally captive individual is one who is not aware there is a Deaf community and has had no exposure to other deaf people.

Thus, in order to develop a multiple and fluid Deaf identity, critical self-reflection, and cross-cultural dialogue are two of the narrative tools that individuals with hearing loss can use to become authentic bicultural Deaf individuals, who are deaf in

their own way (Ohna, 2003, 2004) thus, individuals assign their own meaning to the identity development experience through aspects of the Symbolic Interaction Theory. The decision of choosing a culture or identity can affect several areas of the lives of students with hearing loss, including their self-concept and social competence (Foster, 1996; Paul & Jackson, 1993), particularly due to the amount of social interaction usually associated with the four different identity types. Thus, it appears from the research in Deaf Studies/Deafness, that identifying primarily as bicultural will have the most positive outcomes for a person with a hearing loss, due to the enhanced social interaction with both hearing and deaf individuals, and the strong sense of self that follows the exploration and discovery of being a part of two distinct cultures (Cornell & Lyons, 2004; Glickman, 1996; Leigh & Stinson, 1991). Embracing both cultures and/or worlds is congruent with tenets of the Multidimensional Identity Model in that individuals are able to interact in multiple situations through varying aspects of their own identities.

### **Hard of Hearing**

Individuals with hearing loss who choose to identify themselves as having a hearing identity by being able to function within hearing society or they may claim to be hard of hearing rather than deaf (Leigh, 1999, 2009). This category of hard of hearing is not necessarily related to individuals' degrees of hearing loss and is largely based on self-identification (Grushkin, 2003). Some individuals who are hard of hearing also describe themselves as living "between worlds," in conjunction with Brueggeman's (2009) concept of "inbetweenity," because they are neither fully deaf nor fully hearing. This notion correlates with Social Identity Theory in that members of a group can only feel

they fit in if they achieve a sense of belonging through interactions with others. Grushkin's (2003) findings indicate that rather than identifying as the marginal identity type, these individuals prefer to be in a separate and fifth identity group, the hard of hearing identity type. Thus, the hard of hearing identity type acknowledges the difficulty in determining the boundaries between deaf and hard of hearing and indicates these boundaries vary along audiological, cultural, and ideological perspectives. Grushkin also comments on the "fringe status" of hard-of-hearing people within the Deaf community as does Glickman (1986, 1996) who referred to the status of such individuals as "culturally marginal" (p. 124).

The hard of hearing identity type is clearly distinct from the Deaf identity type that is rooted in signed language and Deaf culture. Individuals who identify themselves as hard of hearing use speech, lip-reading, writing, and their residual hearing (hearing that remains) to communicate (Vernon, 2006). For hard of hearing people, the social dynamics and motivation to develop an identifiable and distinct cultural identity are different from those of Deaf people, because of the wide variations in hearing levels and the fact that the social interactions of hard of hearing people occur via spoken language and listening. The lack of a common identity among individuals who identify themselves as hard of hearing, in contrast with individuals who perceive themselves as being Deaf, results in the proposition that there should be a more continuous line of identity possibilities (Laszlo, 1995). Such possibilities include hard of hearing, partially deaf, and profoundly deaf. However, some members of the hard of hearing population may also

possess varying degrees of both spoken language and sign language abilities similar to an individual who identifies him or herself as bicultural/dual.

Within the construct of the hard of hearing identity type, having a mild or moderate hearing loss may affect an individual's speech and language development as well as his or her academic performance. Nonetheless, this is an area (hard of hearing identity type) that has not been portrayed in the literature as often as has the impact of severe to profound hearing loss on an individual's speech, language, and academic progress (Dalton, 2011; Grushkin, 2003; Leigh, 2009; Mcilroy & Storbeck, 2011). Similar to students with profound to severe hearing loss, students with mild or moderate hearing loss may also experience threats to their social-emotional well-being and self-identity formation, and are at risk for psychosocial deficits related to cognitive fatigue, isolation, and bullying (Niskar et al., 2001). While the body of research on deaf and culturally Deaf students is considerable, studies of the academic performance and psychosocial development of students with mild or moderate hearing loss is much less extensive, especially when considering the high degree of inclusion of students with hearing loss in general education settings (Dalton, 2011; Niskar et al., 2001).

This paucity of such research is concerning because students with mild and moderate hearing loss, those who can hear closest to "normal" with amplification or cochlear implants, are at high risk for rejecting listening technology because they can "hear" and are willing to try to "get by" with the hearing they have (Elkayam & English, 2003). To "fit in" with a group of typically hearing children, a child with hearing loss needs to demonstrate age-appropriate social skills, be aware of subtle social cues, and

also possess high self-esteem to admit he or she has a hearing loss. Further, he or she needs to be willing to take the emotional risk of advocating for his or her own communication needs, especially as he or she enters early adolescence and the teen years. Underpinning these skills is a strong self-concept and identity as a person who is likeable and capable (Schlesinger, 1978).

### **“Normal” versus Deaf**

Some studies report that constructions of normalcy, whereby discounting the specifics of a condition is encouraged, allow an individual with a hearing loss to readily blend into the majority or dominant culture that is looked upon as “normal” (Atkin & Ahmad, 2000). Thus, what the individual constitutes as being normal is related to the identities, roles, interactions, and contexts experienced by an individual under the umbrella of the Symbolic Interaction Theory. However, researchers in Deaf Studies/Deafness argue that such an approach implies that caregivers/parents can sometimes fail to recognize the benefits for their children of associating with members of the Deaf identity type and individuals with hearing loss who do not identify with Deaf culture in social interactions as is posited in the Social Identity Theory (Padden & Humphries, 2005; Tajfel & Turner, 1986). Communication technology (e.g., Skype computer software, digital hearing aids and cochlear implants, texting, Internet, assistive listening devices) have had a significant impact on the extent to which an individual with hearing loss can attempt to blend in with what is deemed normal to that individual (Atkin & Ahmad, 2000). For example, the use of hearing aids among individuals with hearing loss has been viewed as controversial by some members of the Deaf community because

the wearing of hearing aids has been considered by some as an attempt to “normalize” deaf people (R. Baker, 1991). This perception that hearing aids normalize children with hearing loss, however, may explain the attraction for many caregivers/parents.

Caregivers/parents may want their child to identify as hearing individuals and be able to fully engage with the hearing world by being able to speak; a task the caregivers/parents and professionals working with children may value in a hearing world in which fluency and clarity in speech is highly preferred (L. Jones, Atkin, & Ahmad, 2001).

Being deaf can result in some forms of disadvantage due to society’s inability to accommodate for differences. Some individuals view deafness as being a personal tragedy, in which deaf people are unable to achieve the same quality of the life as hearing people (Lane, 1993; Rojeck & Collins, 1987). Operating from this perspective, audiologists, teachers of students who are deaf and hard of hearing, and medical personnel form a type of social control, whereby professional assistance, under the guise of good intentions, privileges the hearing world as dominating Deaf culture (Bronfenbrenner, 1979; Lane, 1993; Rojeck & Collins, 1987). In an attempt to sustain a more positive sense of deafness, some schools encourage the use of sign language and Deaf social clubs which provide an environment where other deaf people can meet and celebrate their Deaf identity (Lane, 1993). However, problems may occur because Deaf culture has been slow to recognize cultural diversity (Ahmad et al., 1998). For example, many Deaf individuals prominent in the media are Caucasian (e.g., actress Marlee Matlin, Miss America 1995 Heather Whitestone, Gallaudet University Deaf president I. King Jordan). Assumptions about the Deaf community often imply that all individuals with

hearing loss share a common experience and that only those who recognize and embrace Deaf culture, can be regarded as “real” deaf people (Gregory, Bishop, & Sheldon, 1995; Smith & Campbell, 1997). This belief is now being challenged as the importance of gender, ethnicity, religion, and sexuality (Ahmad et al., 1998) are being recognized and Deaf culture is beginning to accept and accommodate multiple diversities (Corker, 1995; S. R. Jones & McEwen, 2000) and move toward a Multidimensional Identity Model view of interpreting identity.

An alternative way of coping with stigma or threat to one’s identity is to adopt the strategy of “passing” (Renfrow, 2004). This “passing” involves an attempt to remove oneself from the threatened position by gaining access to another group under false pretenses. For individuals with hearing loss this means passing as hearing, or normal, and adopting an “as if” identification with the hearing majority (Breakwell, 1986). Adopting a hearing identity type means placing a high value on the use of speech, isolation from the Deaf community, and the rejection of sign language. Such meanings to interactions, from a Symbolic Interaction Theory perspective, may be seen as a negative attitude toward deafness and as a wish to be “as hearing as possible” (Cole & Edelmann, 1991; Schlesinger & Meadow, 1972). Weinberg and Sterritt (1986), in a comparison of deaf, hearing, and bicultural/dual identities in deaf adolescents, found that a predominantly hearing identity type was consistently associated with poorer academic achievement, social relationships, personal adjustment, and perceived family acceptance; the bicultural/dual identification type was associated with the highest level of outcomes on all measures of psychosocial development. Thus the bicultural/dual identity type can

be interpreted as an individual's acceptance of both the hearing world and an acknowledgment of the challenges of an individual's hearing loss (Cole & Edelman, 1991; Schlesinger & Meadow, 1972).

**Students with hearing loss.** Studies have been conducted with paraprofessionals and teachers with hearing loss to determine the effects of the presence of adults with hearing loss on the identity development of students with hearing loss. Based on a larger study of children with hearing loss who are taught in general education settings and their paraprofessionals, who self-identified as members of the Deaf community, McKee (2008) conducted a case study of a single cochlear implant user (age 10 years old) to examine the role the bicultural identity type played in his life. The student identified himself as a marginal bilingual whereas the adults (e.g., parents, general educator, Deaf paraprofessionals) in the student's life, did not choose the Deaf identity type to characterize the student except for the few times the student interacted with other individuals with hearing loss. Another finding of this case study highlights that identity is contextual and dynamic, which is congruent with the previously discussed aspects of Symbolic Interaction Theory, Social Identity Theory, and the Multidimensional Identity Model.

Through classroom observations and interviews of three teachers with hearing loss who taught preschool children with hearing loss, findings revealed that the teachers taught their students as if they were able learners rather than atypical (Morgan, 2005). The children appeared to develop concepts of self that reflected a Deaf identity type through having a role model with hearing loss and thus not feeling a sense of isolation

within the classroom. To examine peer relations among hearing children and children with hearing loss, 18 students with hearing loss enrolled in first through fifth grades in the general education setting were observed over a two year period (Wauters & Knoors, 2007). Findings revealed that no differences were noted between the children with hearing loss and their hearing peers in terms of peer acceptance, social status, or the number of mutual friendships which led the researchers to declare the students with hearing loss had achieved a sense of fitting in with their hearing peers. Wauters and Knoors (2007) did, however, discover that children with hearing loss had fewer friendships in their social circles when compared with their hearing peers which appeared to affect their identity development in that these students with hearing loss experienced feelings of being “left out” or not able to fit in (i.e., marginal identity type) with social groups at times.

Adolescents with hearing loss, as do all adolescents, navigate the complexities of establishing an identity and relating to others (Phinney, 1992). Thus, during the later elementary and early middle school years, adolescents are trying to reconcile “the person I am” with “the person society expects me to become” (Nikolarazi, 2007, p. 199). Moreover, adolescents with hearing loss establish this new sense of self by using past experiences to guide their anticipation of the future. For those adolescents who have had negative experiences relating to their hearing loss, they may be more likely to identify themselves with their hearing counterparts than with peers who have hearing loss (Nikolarazi, 2007).

In reviewing other development of identity models, it is important to note that identities are not closely tied to single issues and young people and their families might simultaneously adhere to differing identity claims. To this extent, it is not a question of forsaking one claim for another and choosing, for instance, 'deafness' over 'ethnicity,' but to negotiate the space to be deaf and other social constructs as well (L. Jones et al., 2001). This line of thought leads to there being more than one dimension to identity which resonates with the Symbolic Interaction Theory (multiple meanings), Social Identity Theory (sense of belonging to a group), and the Multidimensional Identity Model (multiple aspects of self or identity).

In Gordon's (1998) investigation of self-perception of identity by adolescents with hearing loss, the question, "What awareness and ideas do adolescents (age 13 to 16) with severe and profound hearing loss, attending mainstream schools, have about their developing deaf identity?" was raised. Data were collected through semi-structured interviews with 11 students with hearing loss who were educated for the majority of their time with hearing peers, had hearing caregivers/parents, and had exposure to sign language at school. The results revealed information related to hearing loss, facts about adolescence, feelings and thoughts about hearing loss, perspectives on inclusion, perspectives on disability, family issues, friendships, and school issues. The outcome of the study highlighted the adolescents' alignment with a specific group and proposed that ease or difficulties with communication, together with the participants' previous experiences of friendship and current preferences, combine in influencing their choices regarding group alignment (Hardy, 2010). These interactions influenced the meanings

the adolescents created for symbols in their lives as is stated in Symbolic Interaction Theory. Adolescents with hearing loss who chose a bicultural/dual identity type appeared to demonstrate higher levels of self-esteem and emphasized human activity which has as its goal development of all aspects of the self as an integrated being (Gordon, 1998). Gordon also provided evidence that gender influences the ways adolescents with hearing loss evaluated and rated their sense of self and relationships with others. Male adolescents with hearing loss appeared to evaluate and rate their sense of self and relationships with others as more important and more positive than did female adolescents with hearing loss.

Honda (1999) determined that individuals with more significant degrees of hearing loss tended to have higher levels of deaf identity. This finding was the result of a study in which 303 students with hearing loss participated. The individuals with hearing loss answered questionnaires that consisted of questions relating to ethnic identity, hearing loss, multiple aspects of identity, and self-esteem.

School experiences and interactions with teachers and individuals who identify themselves as hard of hearing appeared to be major influences on establishing identity in a qualitative study that explored the identity construction of seven adolescents who attended special classes for students with hearing loss for part or all of their elementary school years (Israelite, Ower, & Goldstein, 2002). Results of open-ended group interviews and written questionnaires indicated the students strongly identified as the hard of hearing identity type rather than as Deaf individuals which supports the position that a hard of hearing identity type may exist separately from the culturally Deaf identity

type which contributes to the notion of Multidimensional Identity Model in that there are pluralistic views of identity. The authors suggest that individuals who identify themselves as hard of hearing need to connect with other individuals who choose the hard of hearing identity type whether or not they assimilate into the hearing world or decide to participate in both the hearing and Deaf worlds which borrows from the Social Identity framework within the discipline of psychology.

Similar results of individuals identifying themselves as the hard of hearing type rather than the Deaf identity type have been established elsewhere as demonstrated by investigations of adolescent identity and self-concept by Cornell and Lyness (2004). Kent (2003) reported that a significant number of students with hearing loss did not consider themselves to have a disability. Cappelli, Daniels, Durieux-Smith, McGrath, and Neuss (1995) determined students with hearing loss were more likely to be rejected by their hearing peers and display behavioral problems, exhibit low self-esteem, and experience feelings of social isolation. However, Martínez and Silvestre (1995) studied adolescents' with hearing loss concept of deafness in inclusive educational settings and did not find any differences in self-esteem compared with hearing students in their study.

Existing research indicates a need to determine what identity development among students with hearing loss means to their adjustment. Already established in studies with students with hearing loss is the fact that identifying with a minority group may be beneficial to the person by enhancing his or her self concept and social competence (Bat-Chava, 1994; Gecas & Schwalbe, 1983; Glickman, 1996; Phinney, 1992; Phinney & Alipuria, 1990; Sue & Sue, 1990). Alternately, that identification can also prove harmful

to the person if it is viewed as being the only option available especially if a person has determined that the minority group holds all of the value for identification. If this is the case, the person is likely to not be as socially adjusted in the larger world, due to a restriction of other available options for identification and social interaction. However, a strong identification with any group may be more beneficial than no group identification (Cornell & Lyness, 2004).

According to Glickman (1986), the interactions of individuals with hearing loss with peers who are hearing is often strained and frustrating, as adolescents with hearing loss often struggle for communication, understanding, and solid relationships. This interaction with others impacting how students with hearing loss view themselves is similar to the impact of interactions within the Social Identity Theory.

**Identity is fluid and multi-faceted.** The concept of identity being fluid and multi-faceted based upon contexts and interactions with others, as posited in the Symbolic Interaction Theory (Mead, 1934), can be applied to how the terms Deaf and deaf contradict, overlap, coexist, and compete with one another (Skelton & Valentine, 2003). These authors suggest moving away from the binary constructs of deaf/hearing or Deaf/deaf in order to capture the full experiences of living with a hearing loss. Fernandes and Myers (2010) state the need to expand beyond two rigid opposites (binary model of sign versus speech) and accept the complexities involved in identity formation to better understand that individuals with hearing loss have found new identities among the fixed terms (Corker, 1996; Leigh, 2009; Wrigley, 1996). The notion that deaf identity is not a static concept but a complex, fluid, ongoing search for belonging is a novel paradigm that

departs from the binary mode of thinking (e.g., classifying an individual as deaf or Deaf). This perception reflects aspects of the Multidimensional Identity Model and is a crucial factor in examining whether or not an individual chooses a static or fluid concept of identity related to hearing loss.

In a similar fashion, Reagan (2002) employed Michel Foucault's concept of "archeological thinking" as a means of "making it possible to think difference" when organizing a framework for conceptualizing the conflict between the multiple competing social and individual constructions of deaf identity. This concept relates to hearing loss and the four identity types by allowing individuals with hearing loss to have fluid, multiple dimensions or aspects to their identities based on their interactions with others, the roles they assume, as well as the contexts, and the settings in which they interact (Cornell & Lyness, 2004; Glickman & Carey, 1993; Lane et al., 1996; Most et al., 2007; Woodward, 1972). Through these relational concepts of Symbolic Interaction Theory, individuals are able to develop and foster different aspects of their identity through interactions with others.

Fernandes's and Myers's expanded perspective of the deaf identity type was affirmed in an ethnographic study by McIlroy and Storbeck (2011) that explored the identity development of nine participants with hearing loss through the narratives of their educational experiences in either mainstream (inclusive) or special schools for the Deaf. Results suggested that expanding perceptions of the deaf identity type beyond the binary medical (i.e., deaf identity type) and social (i.e., Deaf identity type) conceptualizations of identity creates a postmodern bicultural "dialogue model" that can be a useful

framework in examining the diversity of identities of individuals with hearing loss (Mcilroy & Storbeck, 2011).

The inclusion of the researcher's (Mcilroy) own fluid cross-cultural identity as a bicultural "DeaF" participant in Mcilroy and Storbeck's (2011) study provides an auto-ethnographic gateway into exploring the lives of other deaf, Deaf, or bicultural DeaF persons. Mcilroy and Storbeck define DeaF identity as the cultural space from which individuals with hearing loss transition within and between both the Deaf community and the hearing community thereby encompassing a fluid view of identity in that individuals can move from one identity type to another as they choose depending on the roles, interactions, and contexts or settings in which the individual engages. The capital F highlights the individual's fluid interactions with his or her typically hearing family members whereas during social interactions with peers who have hearing loss who use ASL, the individual is able to fluidly connect and identify with members of the Deaf community/culture which results in a cross-cultural bicultural dialogue between sign language and a spoken or written language (Mcilroy, 2010).

For all individuals, regardless of whether or not hearing loss exists, identity changes across an individual's developmental trajectory. For example, an individual may identify as being deaf during the elementary school years but then he or she may identify as being Deaf during high school due to differences in his or her social and educational experiences and interactions. It is possible that individuals who categorize themselves as having dual or both Deaf and hearing identities perceive challenges or problems as being overcome by themselves, whereas, those individuals with a deaf identity project their

challenges or problems outside themselves onto hearing caregivers/parents, teachers, or the school system, thus “coping” by becoming angry with others who do not have hearing loss (Cole & Edelman, 1991).

**Influence of caregivers/parents on identity development of individuals with hearing loss.** Caregivers/parents are faced with two crucial questions when parenting: to what extent should caregivers/parents accept their children for who they are, and to what extent should they help their children become their best selves (Solomon, 2012).

Solomon reported that many families grow closer through caring for a challenging child by discovering supportive networks or communities of those who are facing the same issues and by becoming advocates and activists themselves to support other caregivers/parents. These shared activities foster the child’s sense of identity. Through generosity, acceptance, and tolerance, children with hearing loss and others in those children’s lives are able to bond and establish and maintain relationships with one another (Solomon, 2012).

Approximately 95% of children who are born with hearing loss are born to caregivers/parents who have no hearing loss (Calderon et al., 1998; Eleweke & Rodda, 2000; Gallaudet Research Institute, 2001; Jackson et al., 2008; Jackson & Turnbull, 2004; National Institute on Deafness, 2013; Woodcock et al., 2007). The transition to parenthood for any caregiver/parent can produce a variety of normative changes within an individual that can affect personality and attitudes (Antonucci, 1985). This change in the caregiver/parent as a result of the child draws from the transactional model of caregiver/parent-child interaction (Sameroff, 2009) which suggests that the

caregiver/parent has an effect on the child while, simultaneously, the child has an effect on the caregiver/parent, an interaction that changes over time. Given this theory regarding caregiver/parent-child interaction, the event of becoming a caregiver/parent and the additional event of discovering a child's hearing loss can produce an effect on the caregiver/parent which would in turn affect the caregiver/parent-child interaction.

Having a child who has a hearing loss creates social and psychological consequences for hearing caregivers/parents (Chamba, Ahmad, & Jones, 1998; Gregory et al., 1995) which include feelings of guilt, frustration, anxiety, helplessness, isolation, and notions of unfairness and resentment. These responses mirror those of caregivers/parents of children with chronic illnesses and disabilities (Beresford, Sloper, Baldwin, & Newman, 1996). Chronic and disabling conditions have an important impact on identity (Atkin & Ahmad, 2000; Schou & Hewison, 1999). Research has shown caregivers'/parents' own responses to hearing loss affects the young persons' views about being an individual who has a hearing loss. For example, in an interview study of perceptions of identity and hearing loss with individuals with hearing loss and their families that asked questions related to ethnicity, religion, gender, racism, and hearing loss, one teenager shared she was aware her caregivers/parents loved her but they had little confidence in her abilities due to her being deaf (Atkin et al., 2002).

Some caregivers/parents who have children with hearing loss seek and encourage involvement with the Deaf community in their children's lives due to believing that children with hearing loss will be more well-rounded and will form relationships with others who are like them. However, some hearing caregivers/parents have reported that

they feel the Deaf community is not very accepting of them or excludes them because they do not utilize sign language with their children (Jackson et al., 2008). These authors conducted interviews with nine hearing caregivers/parents of eight deaf children.

Themes that emerged from the study centered on family experiences such as reactions to diagnosis, decision making, the impact of deafness on family interactions, family time and the child, positive experiences in early intervention, and desired support services.

When asked about their child's self perception or identity, most of the hearing caregivers/parents reported their children perceived themselves as hearing but they also reported varying degrees of awareness of deafness in their children. The awareness of hearing loss varied from a three-year-old child realizing she is different from others but not yet being able to articulate the difference to an 11-year-old child with a cochlear implant who added a cochlear implant to a gingerbread man cookie when baking Christmas cookies (Jackson et al., 2008).

Atkin et al. (2002) report that the concerns of hearing caregivers/parents, as yielded through interviews, focus on issues such as their ability to successfully negotiate transitions they deemed 'normal' for hearing children: a good education; social skills; knowledge of parental religions and cultures; and assuming adult roles like having a job and being married. The hearing caregivers/parents, who participated in the study, expressed, through interviews, that the presence of hearing loss presented additional barriers for their children and, as a consequence, an adolescent participant in the study (child participants ranged in age from 12 months through 19 years old) revealed that her caregivers'/parents' view of deafness undermined her own confidence and made it

difficult for her to sustain a positive self-image. Moreover, the older children participants disclosed their perceptions that their caregivers/parents treated their hearing siblings more favorably and described experiencing a sense of isolation within their families. A theme of a lack of respect in addition to the sense of isolation, when interacting with other individuals without hearing loss, emerged for some of the participants. Finkelstein (1993) describes this feeling as “social death” which leads to individuals with hearing loss classifying themselves as members of the marginal identity type (Glickman, 1986; Most et al., 2007).

According to Wright (1987), caregivers/parents have the greatest impact on the socialization of their children with hearing loss. Direct effects arise because caregivers/parents determine the family climate and the nature of the social interactions within the family while indirect effects occur through caregivers’/parents’ educational decisions. During adolescence, caregivers’/parents’ role in children’s identity development decreases as children begin to seek less approval from caregivers/parents and instead rely on peers as their main reference group (Most et al., 2007).

In addition to the primacy of caregivers/parents, family, language, and education are also influential to the identity development of children (Bronfenbrenner, 1979).

However, the additional presence of hearing loss adds unique pressures to these experiences. Interactions with families help to form and shape the identity of a child with hearing loss and influence whether he or she chooses to relate more with Deaf culture or a Deaf-centered identity or if he or she feels a part of hearing society or forms a hearing-centered identity. Children’s family and school experiences help form identity as it is a

socially constructed process based on past and present experiences (Mcilroy & Storbeck, 2011). Although family, language, and education each influence identity choice, family interaction appears to be most crucial for identity choice (Overstreet, 1999) since generally, if a child with hearing loss felt he or she were the same as his or her hearing family members, he or she constructed a hearing-centered identity and remained in mainstream hearing society through orally communicating. In contrast, if a child with hearing loss viewed him or herself as being different from hearing family members, he or she constructed a Deaf-centered identity, joined the Deaf community, and communicated using ASL. Overstreet's (1999) binary categorizing individuals with hearing loss as identifying as either being a member of the Deaf community or identifying as hearing (i.e., Deaf-centered versus hearing-centered) contrasts with tenets of the Multidimensional Identity Model as described by Reynolds and Pope (1991).

### **Theoretical Model for the Research**

Multiple perspectives of identity development from the disciplines of psychology, counseling, and Deaf Studies/Deafness are blended into a theoretical framework for the present study. In the model illustrating the theoretical framework for the research, identity is viewed as being fluid and constantly changing depending upon an individual's social interactions with others, life experiences, and the setting or context of the individual. See Figure 2 for a visual representation of the theoretical model for the study.

In this figure of the theoretical model for the present study, components or elements of the Symbolic Interaction Theory, Social Identity Theory, and the Multidimensional Identity Model will be the lens through which participants' responses

to the interview protocol will be viewed. Aspects of Phinney's Model of Ethnic Identity Development, Berry's Model of Identity, and tenets of psychosocial development as defined by Erikson may also apply to participant responses. The participants' responses will be viewed relative to findings from identity studies within the discipline of deafness to see whether or not the participants' responses align with the identity types that have been established in Deaf Studies/Deafness literature.

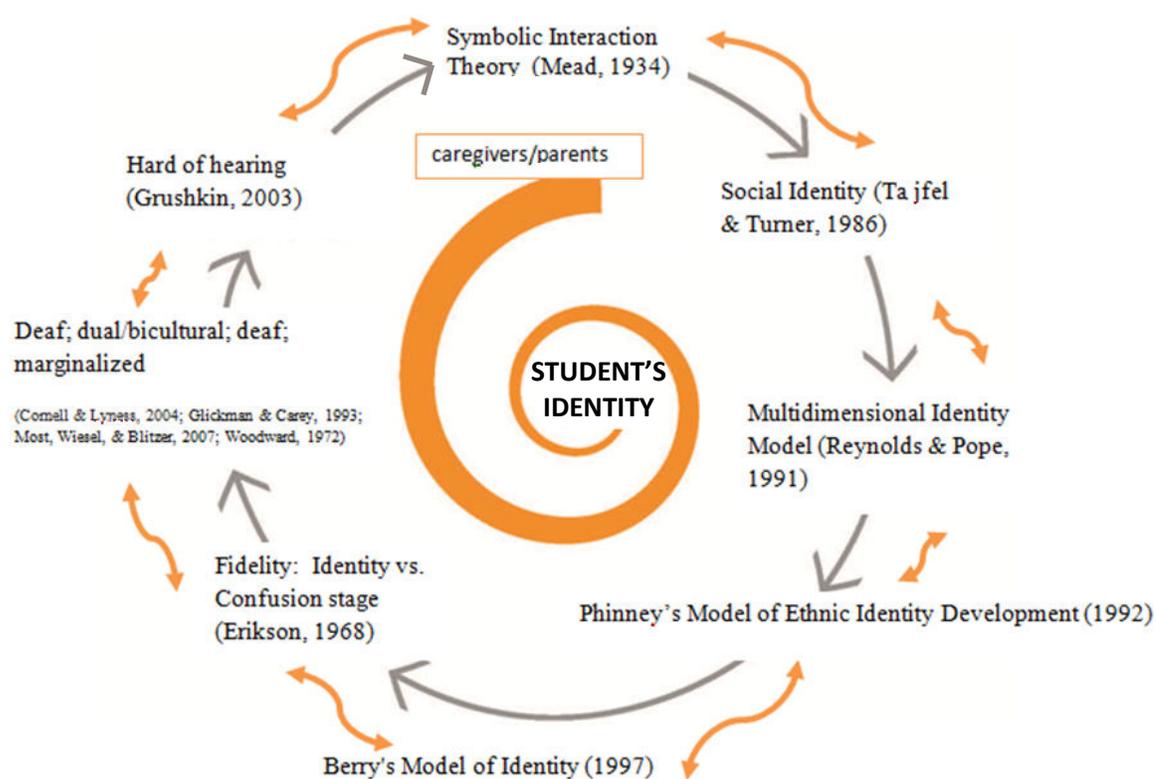


Figure 2. Theoretical Model.

At the perimeter of the theoretical model, the outer wavy lines represent identity as being fluid and constantly changing depending upon an individual's social interactions with others, life experiences, and the setting or context of the individual. The solid

arrows display that identity is viewed as cyclical in nature in its evolving processes that continue to expand as the individual discovers and learns more about him or herself. At the center of the model, a spiral depicts the student's identity as being shaped by the critical influence of caregivers/parents on the development of an individual's identity. The varying thicknesses in lines of the spiral illustrate that the influence of others (in this study the caregivers/parents), can be of greater or lesser influence depending upon timing and circumstances within the individual's world. As shown in the figure of the theoretical model for the present study, an individual's identity is portrayed as an ever changing multi-faceted process.

### **Summary**

The present study analyzes perceptions of identity related to hearing loss in light of interactions with others by using components or elements of Symbolic Interaction Theory, Social Identity Theory, Multidimensional Identity Theory, and identity studies within Deaf Studies/Deafness as a lens through which to view the data yielded through interviews with the participants in the study. Past experiences, interactions with others, and setting impact how and if an individual views him/herself as a member of a specific culture as viewed through the theoretical perspectives of Symbolic Interaction Theory, Social Identity Theory, and Multidimensional Identity Model (Mead, 1934; Reynolds & Pope, 1991; Tajfel & Turner, 1986).

Utilizing aspects of the Symbolic Interaction Theory, the researcher will analyze the data by examining the responses of the participants as they describe how they interact with others in order to adapt to and survive in their environments (i.e., identities, roles,

interactions, contexts; Blumer, 1969; Brekhus, 2008; Cooley, 1902; Hays, 1977; R. L. Howard, 1981; Mead, 1934). The primary element from Social Identity Theory that will be highlighted in the data analysis of the study involves the relationship between the individual and society and whether or not the individual perceives a sense of “belonging” to either Deaf culture or hearing culture or neither cultural group (C. A. Baker, 2012; Mead, 1934; Tajfel & Turner, 1986). Four aspects of the Multidimensional Identity Model that relate to the present study are: (a) individual identifies with one aspect of self as determined by others, (b) individual identifies with one aspect of self as determined by individual, (c) individual identifies with multiple aspects of self but in a “segmented fashion,” and (d) individual has integrated the multiple aspects of selves into one sense of self (Reynolds & Pope, 1991). These aspects of the Multidimensional Identity Model relate to students with hearing loss in that the students might choose to identify themselves based on one aspect of self that is determined by others such as choosing the deaf identity type since the caregivers/parents have identified the students in that manner. In contrast, a student may identify him/herself based on an aspect of self as determined by him/her. For example, a student may identify as strong swimmer or athlete since he/she has chosen to focus on that aspect of self rather than focusing on the hearing loss.

Phinney’s (1992) Model of Ethnic Identity Development allows an individual to feel and demonstrate a strong sense of belonging and pride in one’s ethnicity through participating in events or activities that revolve around the person’s ethnic identity. This relates to Social Identity Theory due to the individual feeling a sense of belonging to his or her ethnic group. Moreover, Phinney’s Model of Ethnic Identity Development

specifically relates to students with hearing loss and their caregivers/parents by a student being able to achieve a sense of belonging and pride in his/her ethnicity (e.g., Deaf culture, Irish heritage) and by participating in events or activities that are related to the ethnic identity.

In Berry's (1997) Model of Identity, an individual's identity with a cultural heritage may or may not conflict with the values that culture places on membership of the individual in the larger society. Berry's Model of Identity specifically relates to students with hearing loss and their caregivers/parents if the student with hearing loss identifies him/herself as Deaf and with Deaf Culture whereas caregivers/parents may place value on the student achieving membership in the larger society (e.g., hearing world). This aspect resonates with Symbolic Interaction Theory in that the individual may construct a different meaning on an interaction or symbol from what society may construct.

Similarly, Erikson (1956) defined a progression of psychosocial development during which individuals self-actualize and achieve a sense of "being." Erikson (1968) contends that during the fifth stage of psychosocial development, termed Fidelity: Identity versus Confusion, 12- to 18-year-old individuals focus on social relationships. This stage of development is congruent with importance of interactions with others in Symbolic Interaction Theory (Erikson, 1968; Mead, 1934). Erikson states that during adolescence, one defines his or her place in society and determines his/her roles, which may or may not differ from what he/she believed prior to this stage. Thus, individuals may depart from the identity that was handed down to them from their caregivers/parents and gravitate toward a new idea of who they are. This departure may be revealed in

discrepancies from caregivers'/parents' views of the student's identity compared with the student's perception of his/her identity.

The literature related to identity development within Deaf Studies/Deafness posits that identity is contextual and dynamic which is in agreement with elements of Symbolic Interaction Theory and Social Identity Theory that will be of focus in the present study. Additionally, identity may change across an individual's developmental trajectory which is in agreement with Erikson's progression of psychosocial development. For example, an individual may identify as being deaf during the elementary school years but then he or she may identify as being Deaf during high school due to differences in his or her social and educational experiences and interactions. Factors such as degree of hearing loss, age of onset, type of hearing loss, family history and lifestyle, mode of communication, and community context have an impact on how an individual with hearing loss perceives or identifies him or herself. A person with hearing loss may claim an identity that is radically different from other individuals with a similar type of hearing loss. Many factors contribute to and affect adoption of an individual identity and some researchers agree that identities are constructed within multiple communities and contexts (Humphries & Humphries, 2011; Leigh, 2009).

Interactions with others affect how an individual sees him or herself and attempts to fit in or belong to a group may occur which speaks to Social Identity Theory where importance is placed on the individual's ability to belong or fit in with a group, whatever that group may be (Burke, 2004). Conversely, interactions with the individual with hearing loss also affect how others perceive that individual and hearing loss. These

interactions affect the meanings individuals construct for interactions as posited in Symbolic Interaction Theory (Blumer, 1969; Brekhus, 2008; Burke, 2004; Cooley, 1902; Hays, 1977; R. L. Howard, 1981; Mead, 1934). In the past, literature within Deaf Studies/Deafness that related to identity argued that individuals with hearing loss would fit into one of four identity types: Deaf, deaf, dual/bicultural, or marginalized (Glickman, 1996; Holcomb, 1997; Most et al., 2007, Woodward, 1972). However, in recent years, a shift has occurred within the literature in Deaf Studies/Deafness toward aspects of the Multidimensional Identity Model in which identity is seen as being fluid and not static while other categories of identity within deafness have emerged (e.g., hard of hearing, hearing, DeaF; Brekhus, 2008; Grushkin, 2003; Mcilroy & Storbeck, 2011).

Although several studies within the Deaf Studies/Deafness literature have examined elements of identity and identity formation, few studies have examined the perceptions of identity of students with hearing loss, who choose to communicate using the oral spoken English mode of communication, who are educated in the general education setting, and their caregivers'/parents' perceptions of hearing loss in their children. Consequently, very few studies have analyzed identity from the more fluid perspective of deafness which breaks away from the binary model of categorizing individuals with hearing loss as Deaf (cultural or social view) or deaf (medical view). Analyzing how students with hearing loss identify themselves with how others in their lives perceive themselves is critical if understanding and affirming of one another is going to occur because caregivers/parents of students with hearing loss must not assume what is most central to individuals with hearing loss. Instead, caregivers/parents of

students with hearing loss must be receptive to how the student identifies him or herself (Cole & Edelman, 1991; Jackson et al., 2008; Schlesinger & Meadow, 1972) as it is human nature to want to be understood and to be viewed as a whole rather than as a part through externally imposed labels and by a singular dimension (i.e., child being viewed as more than just a child having hearing loss but being seen as a creative athletic individual who also has hearing loss).

When considering the various influences on identity, one must consider the encounters one experiences within public and cultural domains, as well as familial contexts. The challenges individuals with hearing loss encounter in a hearing-dominant world shape identity formation (Bat-Chava, 2000; Mcilroy & Storbeck, 2011). Becoming aware of one's D/deafness does not necessarily lead to a deaf identity per se; rather it leads to a realization of one's own personal identity, whatever that may be (Mottez, 1990). Larger critical justice issues related to deafness have important implications influencing the types of knowledge and identities produced not just for deaf students, but for a greater understanding of humankind and our connections to the world (Horejes, 2010). The impact of caregivers/parents on children and adolescents with hearing loss is influential in conjunction with interactions with others in contexts and environments. We would do well to remember that there is more that unites us than divides us (Pray & Jordan, 2010) in spite of the many roles we all play in varying contexts.

Although the research described throughout this chapter represents an awareness of identity within Deaf Studies/Deafness, the focus on fluidity or "in betweenity" among identity types has not been explored with students with hearing loss who utilize spoken

language and listening as their primary mode of communication. Through the present study, the researcher hopes that the findings will contribute to the understanding of how human behavior and experience empower others (Creswell, 2007). Moreover, the present study is exploratory in nature due to the researcher attempting to focus on a new angle within a topic that has been sparsely investigated (Lichtman, 2006; Strauss & Corbin, 1998) due to the low-incidence nature of hearing loss as only approximately 5% of the general population has significant hearing loss (Woodcock et al., 2007). Literature regarding identity development within Deaf Studies/Deafness has predominantly focused on individuals with hearing loss who use sign language as their primary mode of communication, which is a different population from those who would be recruited for participation in the present study.

Thus, the sample from which to study this population of students who have hearing loss, who communicate through speaking and listening, and who are educated in the general education setting is sparse due to being a low-incidence population. Further, implementation of mandatory Newborn Hearing screening has determined that approximately three per 1,000 newborns in the United States are born with a hearing loss (K. R. White, 2007; U.S. Centers for Disease Control and Prevention, 2009). It is also estimated that 9-10 per 1,000 children will be diagnosed with hearing loss in one or both ears by school age (Sharagorodsky et al., 2010; K. R. White, 2010). This fact may partially explain why there is a decrease in enrollment in residential schools for the deaf and why the numbers of children with hearing loss who receive access to communication

through spoken language and listening are increasing due to improvements in medical care and newborn hearing screening (Moore, 2004; K. R. White & Baisner, 2011).

In large part due to early detection of hearing loss and early intervention measures, more than 80% of all students with hearing loss in the United States attend their local public schools (Gallaudet Research Institute, 2003, 2011). The United States Office of Special Education (U.S. Department of Education, 2004, 2012) found that 85% of students with hearing loss are educated in public schools. These students are usually the only ones in their classrooms, or even schools, who have hearing loss (Bruce-Rosser, 2009). Thus, the present study seeks to utilize a sample of students with hearing loss and their caregivers/parents who have not been the focus of research in the literature within Deaf Studies/Deafness. By using this sample, the researcher is able to embrace diverse local worlds, views, and actions of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting (Charmaz, 2005, 2006). Chapter III will outline the methods that will be utilized to conduct the study in an effort to seek answers to the research questions relating to identity and perceptions of hearing loss by students with hearing loss and their caregivers/parents.

## **CHAPTER III**

### **METHODS**

#### **Introduction**

In the present study, the perceived self-identities of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting were compared with how the caregivers/parents of the students with hearing loss identified their sons or daughters with respect to the students' hearing status through qualitative research methodology. The data were compared within the two data sets (i.e., caregivers/parents and students). The transcendental phenomenological paradigm served as a guide to the development of the research questions, the choice of methods employed in the study, and served as a framework for the data analysis. In this chapter, the research framework of the research design will be explained followed by description of the research design and research questions. Next, information pertaining to the participants, data source, and data collection procedures will be presented. The background/bias of the researcher and the description of the data analysis will be explained at the conclusion of the chapter.

Qualitative research methodology utilized in this phenomenological study enabled examination of how one identifies him or herself by providing a "voice" for the participants' experiences he or she expressed during an interview to highlight the details of a situation to better understand the reality of the participants at that moment in time

(e.g., cross-sectional study versus a longitudinal study). As such, the emic perspective, referred to as the insider's or native's perspective of reality (Fetterman, 1998; Patton, 2002), as disclosed in an interview becomes critical when attempting to understand or describe a situation. Moreover, the emic perspective allows for multiple perspectives of reality in a given study. Thus, by conducting interviews with caregivers/parents and students who are bounded by specific selection criteria, the researcher obtained in-depth data from the participants to gather a first-hand account from the participants of their perspectives regarding identity and hearing loss that yield descriptive qualitative data (Creswell, 2007; Kvale, 1996) within the two data sets.

The qualitative method of conducting individual in-depth interviews with the participants was employed in the present study (Schensul, Schensul, & LeCompte, 1999) to not predict what may happen in the future but to provide an understanding of the participants at a particular point in time to describe the phenomenon of perceptions of identity as related to hearing status. The use of interviews in qualitative research also reveals information about happenings the researcher is unable to directly observe (Patton, 2002). For example, only through interviewing caregivers/parents about perceptions of identity and hearing loss in the students can the researcher learn of prior experiences that contribute to definitions of hearing loss and impact of hearing loss on the family unit that may affect how the caregivers/parents identify and perceive their children in relation to hearing loss. Similarly, an interview with a student with hearing loss can reveal to the researcher his or her perceptions of identity and hearing loss by sharing stories of what has occurred as a result of the hearing loss. In considering interviews as a fruitful source

of qualitative data, it is not necessary to interview many key informants to obtain a large amount of information about a subject due to the exploratory nature of the interview process (Schensul et al., 1999). Thus, rich and comprehensive qualitative data can be extracted from a successful interview regardless of the quantity of interviews.

These perceptions were documented through conducting and analyzing individual and separate face-to-face interviews with the students and their caregiver(s)/parent(s). If there is a disconnect among the expressed perceptions of identity, the differing views must be reconciled before addressing issues of how to foster self-advocacy in students with hearing loss (Jackson et al., 2008). Comparing how students with hearing loss identify and perceive themselves with how others in their lives perceive them is critical if understanding and affirming of one another can occur because caregivers/parents of students with hearing loss must not assume what is most central to a student with hearing loss. Instead, caregivers/parents of students with hearing loss must be receptive to how the student identifies him or herself (Cole & Edelman, 1991; Jackson et al., 2008; Schlesinger & Meadow, 1972). By examining how students with hearing loss identify and perceive themselves and how the caregivers/parents of those students identify and perceive their sons or daughters, the findings of the study contribute to the understanding of how human behavior and experience empower others (Creswell, 2007).

The population of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting has not been the focus of research in terms of identity. Current literature within the constructs of self-identity and deafness has determined that students

with hearing loss who use sign language as their primary mode of communication and who are educated in residential schools or self-contained classrooms for the deaf, classify themselves as Deaf, deaf, bicultural/dual, or marginalized (Cornell & Lyness, 2004; Glickman & Carey, 1993; Most et al., 2007; Woodward, 1972). The present study sought to examine which category, if any, students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting best describe the students. If the students in the study do not identify themselves as Deaf, deaf, bicultural/dual, or marginalized, then the study may possibly generate a new category or identity type at the conclusion of the study.

Rather than systematically developing a theory that explains the process, action, or interaction on a topic (e.g., perceptions of identity and hearing loss), the researcher's aim in conducting the study was to examine diverse views of perceptions of identity and hearing loss at that moment by describing the interaction or the phenomenon, which can be done through utilizing a phenomenological inquiry research design approach and conducting interviews with the participants. In the study, the researcher conducted ten interviews with four clusters of participants (i.e., each cluster was comprised of one student and his or her caregivers/parents). The researcher conducted the interviews during one point in time rather than interviewing participants multiple times or over a longer time span. Data were analyzed at the conclusion of the interviews after member checks had been conducted by the participants to ensure accuracy and validity. The researcher of the present study intended to include the information from the researcher field notes (if needed) and documents in the detailed description at the conclusion of the

study in the discussion so the phenomenological inquiry research design approach best aligns with the present study.

### **Research Framework**

The study employed transcendental phenomenology to explore the phenomenology of identity as related to hearing loss in two data sets of students who utilize spoken language and listening as their primary mode of communication and who are educated in the general education setting and of caregivers/parents of the students with hearing loss (Hatch, 2002; Moustakas, 1994). Transcendental phenomenology falls under the constructivist paradigm, which means this form of phenomenology recognizes multiple socially constructed realities and the impact these realities have on the interaction between the participants and the researcher as a co-construction of knowledge (Hatch, 2002).

Edmund Husserl (1931), known for his work in descriptive transcendental phenomenology delineates that the transcendental phenomenology approach is based on the notion that the “relation between perception and its objects is not passive” (Gubrium & Holstein, 2000, p. 488) as transcendental phenomenologists believe human consciousness (i.e., one of the critical ideas of phenomenology) continually relates to human experiences. As a result, consciousness is viewed as being always related to something since consciousness “does not stand alone, over and above experience, more or less immaculately perceiving and conceiving objects and actions, but, instead, exists always ready-from the start-as a constitutive part of what it is conscious of” (Gubrium & Holstein, 2000, p. 488). Gubrium and Holstein elaborate on this concept of

transcendental phenomenology by explaining that Husserl believes human consciousness both constructs and observes the experiences in the world. Further, Husserl's main focus was to explore the phenomena "as they appeared through consciousness" (Lavery, 2003, p. 5). This transcendental approach allows for exploration and description of the phenomenon (i.e., perception of identity related to hearing loss in students and caregivers/parents) through describing the phenomenon with minimal interpretation from the researcher (Lavery, 2003). For these reasons, in the present study, the researcher chose to utilize the transcendental phenomenology approach as outlined by Husserl (1952) and Moustakas (1994) as the theoretical research approach and method of research.

### **Research Design**

Phenomenology is the theoretical construct that served as the qualitative inquiry research design approach that was most appropriate to answer the research questions posed by the study since phenomenology seeks to gain the truth of lived experiences through the consciousness of the experience or participants (Moustakas, 1994). An important aspect of the phenomenological research design or approach is that this design is typically used to highlight the experiences and perceptions of individuals from their own perspectives, which may challenge structural or normative assumptions (Lester, 1999). Phenomenology was the preferred research approach for the current investigation in that the purpose of the phenomenological research approach or design was to identify phenomena through how they are perceived by the individuals experiencing the phenomena (Lester, 1999). Phenomenological principles assert that scientific

investigation is valid when the information gained comes about through rich description that allows for understanding of the essences of experience (Moustakas, 1994). In the phenomenological research design, researchers employ the following qualitative methods to gather data relating to the phenomena of perceptions/experience of the participants: interviews, field notes by the researcher, and subsequently analyzing and sharing the data from the perspective of the participants.

Through the use of a phenomenological research design in the study, emphasis was placed on obtaining and analyzing the participants' personal perspectives and interpretations of identity related to hearing loss. The phenomenological research design or approach also assisted the researcher in drawing out deep issues and making participants' voices be heard and possibly contradicting taken-for-granted assumptions concerning identity by students with hearing loss and their caregivers/parents (Lester, 1999). The participants in the study may share stories and information that may reject or align with the current established identity types within Deaf Studies/Deafness. This process will aid the researcher in understanding the subjective experience and gaining insights into the participants' perceptions concerning their beliefs about the construct of identity in individuals with hearing loss (Lester, 1999; Spradley, 1979).

Selecting the transcendental phenomenological research approach or design enables the researcher to operate from a perspective lens free of preconceptions (Husserl, 1970) and rigorous, semi-structured interviewing of students and their caregivers/parents will allow for construction of new aspects of the perception of identity as related to hearing loss, in which both the researcher and the participant will act as co-constructors

of knowledge (Hatch, 2002). Thus, the researcher collects data from persons who have experienced a phenomenon, in this instance, hearing loss, and then develops a description of their perceptions of the phenomena or essence which van Manen (1990) describes as a “grasp of the very nature of the thing” (p. 177). This description consists of “what” they experienced and “how” they experienced it (Moustakas, 1994). The present study sought to follow this format in that the research questions sought to discover if the students and caregivers/parents chose to identify the students with hearing loss as one of the identity types that have been established in Deaf Studies/Deafness or if the participants created a different identity type (i.e., Deaf, deaf, marginal, dual/bicultural, and hard of hearing; Cornell & Lyness, 2004; Glickman & Carey, 1993; Grushkin, 2003; Most et al., 2007; Woodward, 1972). The study fits into the theoretical research framework of phenomenological methodology due to the specific focus of the study being on the phenomenon of hearing loss and perceptions of identity and hearing loss among students with hearing loss in relation to the perceptions of identity and hearing loss expressed by their caregivers/parents. Moreover, little research exists regarding perceptions of identity in the targeted population of students with hearing loss who communicate via spoken language and listening and who are educated in the general education setting.

However, in phenomenological research, the researcher needs to be very clear about how interpretations and meanings have been placed on findings, as well as making the researcher visible in the “frame” of the research as an interested and subjective individual rather than a detached and impartial observer (Hatch, 2002; Plummer, 1983; Stanley & Wise, 1993). Frames of analysis are conceptual categories that help

researchers look at data and make it possible to move to the next step of creating domains or categories (Hatch, 2002). This was achieved through discussing researcher bias, establishing trustworthiness in the data through peer debriefing, inter rater reliability, and member checks. However, Moustakas (1994), in his view of transcendental or psychological phenomenology, cautions that less focus is placed on the interpretations of the researcher and more attention is given to the description of the experiences of participants. In this caution, Moustakas focuses on one of Husserl's concepts, epoche (or bracketing), in which researchers set aside their own experiences, as much as possible, to take a fresh perspective toward the phenomenon under examination by suspending understandings in a reflective move that cultivates curiosity (Creswell, 2007; Husserl, 1970; LeVasseur, 2003).

In an effort to set aside the researchers' own experiences, Moustakas (1994) describes phenomenological reduction in four steps. First, researchers bracket the focus of the research and set aside all preconceived notions to allow attention to be placed solely on the research within the study which is similar to Husserl's (1970) concept of epoche. Second, researchers horizontalize that data by giving equal value to each participant statement and by being open and receptive to each statement in regards to the phenomenon (e.g., perceptions of identity related to hearing status). In this process, repetitive and irrelevant statements are deleted and the remaining statements or horizons are grouped into themes. These themes will then be the basis for a textural description of the phenomenon by the researcher repeating a pattern of looking and describing multiple times to gather descriptions that illustrate the lived experiences of the participants

(Moustakas, 1994). After this constant process of looking at and describing the participant statements, themes or layers will emerge within the data in the study.

The third step, called imaginative variation, seeks possible meanings through the researcher considering differing perspectives, roles, and functions (Moustakas, 1994). Researchers use phenomenological reflection and imaginative variation to construct structural themes and descriptions from the textural meanings that will share the essence of the experience as shared by the participants (Moustakas, 1994), which borrows from Husserl's concept of *epoche* (Creswell, 2007; LeVasseur, 2003). The fourth and last step in Moustakas's phenomenological reduction process incorporates the synthesis of the textural and structural descriptions to discover the meaning or essence of the phenomenon (i.e., perceptions of identity related to hearing loss). This last description that is produced is called a composite in which the textural and structural descriptions are combined to reveal the essence of the phenomenon being examined. It is during this step that the researcher seeks to bring all fundamental structural and textural descriptions into a combined statement of the essences derived from the experiences of the entire phenomenon (Giorgi, 1997; Moustakas, 1994). Moustakas (1994) cautions that the essences of an experience can never be fully sought; rather, the textural-structural synthesis embodies the essences at a certain place and time from the perspective of a single researcher conducting a study on the phenomenon. The analysis of the data gathered from the two data sets (i.e., students and caregivers/parents) is based on the phenomenological assumption that the world consists of phenomena and experiences that

interact and impact one another to create new knowledge and perceptions (Moustakas, 1994) similar to tenets of the Symbolic Interaction Theory.

In order to be sure the participants' experiences at a particular point in time (i.e., when the study is conducted) were not inaccurately portrayed in the data analysis and results, the researcher worked to ensure the participants' understanding of the research goals prior to the research commencing. These steps were achieved using a written description of the research topic via the recruiting flyer, verbal reviews of the purpose of the research at each interview, member checks of the transcripts, and thanking the participants for their participation throughout the study with thank you notes. The researcher attempted to achieve objectivity at the initiation of the study, prior to taking the steps as outlined above, by describing her own experiences with the phenomenon and bracketing out her views before proceeding with analyzing the perceptions of others (Creswell, 2007).

### **Research Questions**

The present study addressed the following research questions:

1. How does a student with hearing loss who uses spoken English and listening as his or her primary mode of communication and who is educated in the general education setting identify him or herself with respect to his or her hearing status?
2. How do the caregivers/parents of the student with hearing loss identify him or her with respect to his or her hearing status?

## Participants

The issue or concern in the present study was perceptions of identity and hearing loss by students with hearing loss and their caregivers/parents. For the purpose of the study, each student and his or her caregiver(s)/parent(s) comprised a cluster. Participants were four students with hearing loss and their six caregivers/parents for a total of ten participants, which is in congruence with the number of participants ranging from three to ten subjects as deemed appropriate in phenomenology methodology (Creswell, 2007; Polkinghorne, 1989). Thus a total of four students and their six caregivers/parents were recruited to participate in the study.

The participants resided in the northeast United States and were purposefully selected, by age/grade level, to investigate varying perspectives across school ages on the issue or phenomena of their perceptions of identity and hearing loss even though the school contexts of each participant may differ. For example, one student participant was enrolled in elementary school while another student participant was enrolled in upper high school. The student participants were obtained through the researcher consulting with the hearing support itinerant teachers of students who are deaf/hard of hearing (TOD/HH) assigned to the school districts selected for participation in the study. The school districts are located in the south central region of a state in the northeastern United States. There are approximately 13,341 students who live in the three school districts. The three districts were comprised of three high schools, two intermediate schools, three middle schools, and twelve elementary schools. In the state in which the student and caregiver/parent participants resided, an educational structure partnered with school

districts and agencies within the county of the school districts to provide educational services and specialized support to students with special needs including hearing loss.

One of the services this educational structure provides to the school districts in which the study took place is the Deaf/Hard of Hearing (D/HH) Support Program. The D/HH Support Program provides itinerant and classroom hearing support teachers of students who are deaf/hard of hearing (TOD/HH) to the district that participated in the study. After sharing the purpose of the study with the TOD/HH, the researcher and TOD/HH discussed demographic characteristics of potential student and caregiver/parent participants. The TOD/HH reviewed the caseload of the educational audiologist as well as the caseload of the TOD/HH for potential students who met the inclusion criteria for selection as a participant in the study. Purposeful sampling was used to select participants who were able to demonstrate varying perspectives of the perceptions of identities of students with hearing loss. The parameters or the specific boundaries for the clusters are listed below in the selection criteria for the participants. For example, only students with a diagnosis of moderate to severe/profound hearing loss in one or both ears who may or may not wear hearing aids with no significant intellectual disabilities and their caregivers/parents were to participate in the study. The student and caregiver/parent criteria for participating in this study follows:

1. Students had an audiometric diagnosis of moderate to severe/profound hearing loss in one or both ears and may or may not wear hearing aids with no significant intellectual disabilities.
2. Students were fully included in the general education classrooms.

3. Students utilized spoken English and listening as the primary mode of communication.
4. Students currently receive or have received D/HH support itinerant services from the D/HH Support Program within the school system (i.e., since entering public school).
5. Students were the only child in their immediate family with a hearing loss (i.e., siblings).
6. Caregivers/Parents were caregivers/parents of the selected student participants.

Each of the students with hearing loss who met the inclusion criteria was randomly assigned to each general education teacher's class and the caseloads of the TOD/HH prior to the start of the study. From this pool of potential student participants, the researcher selected one student each who met the above criteria and who was of three different academic age ranges (i.e., elementary, lower high school, and upper high school). All four students selected to participate in the study resided in one of the three participating school districts and displayed similar ethnic backgrounds.

In order to conduct the research in alignment with ethical principles, the approval of the Institutional Review Board (IRB) of the university of the researcher, as well as the school boards and educational agency of the participating students' schools, was sought and secured prior to the start of the study. The two TOD/HH within the three participating school districts were given an IRB approved recruiting flyer, that contained an explanation of the study and with the contact information of the researcher, to

distribute to potential participants and requested permission to provide their contact information to the researcher. After obtaining verbal permission, the two TOD/HH provided the researcher with the contact information for each family, or cluster, who expressed interest in learning more about the study. The researcher initiated contact via a telephone call or an email, depending on the family's preferred method of contact.

During the initial contact, the researcher screened participants for eligibility, described the purpose and structure of the study, answered participants' questions, and scheduled the interviews if the participants were eligible and expressed continued interest in participating in the study. A total of seven students and 14 caregivers/parents were originally referred to the researcher by the two TOD/HH. One student and two caregiver/parent participants did not meet the eligibility criteria to participate; one student and two caregiver/parent participants declined to participate; and the researcher was unable to make contact with one student and his caregivers/parents after several phone call and email attempts. Within the clusters of students and caregivers who agreed to participate, two fathers chose to not participate in the study. As a result, a total of six caregivers/parents and four students, comprising four separate clusters, volunteered to participate in the study. See Appendix C for a Participant Demographics Table.

### **Data Sources**

The sources of data for the present study were demographic information forms completed by the caregivers/parents, researcher field notes, and one-time interviews conducted by the researcher with the participants as outlined by Moustakas's (1994) approach to phenomenology. Eisner (1991) and Stake (1995) place value on

observations made in field notes in order to find and describe characteristics of participants. However, Stake (1995) also places importance on all aspects of a participant's experience or perception, including what might not be going well, in an attempt to provide a more holistic view which appropriately matches the intent of the study. For example, in the present study, not only was attention placed on how the students and caregivers/parents identified the students, but attention was also given to the participants' perceptions toward hearing loss (e.g., describing attributes of individuals they would classify as similar or dissimilar from them or their children in terms of identity types).

**Demographic information forms.** Each caregiver/parent participant completed a demographic information form prior to the interview with the researcher. Participants were asked to provide the following information on the demographic information forms related to child's date of birth, age of diagnosis of hearing loss, type/degree of hearing loss and amplification used (if applicable), family history of hearing loss, preferred mode of communication used with the child, length of time receiving D/HH support services, and experiences with hearing loss/individuals with hearing loss prior to child's diagnosis. See Appendix D for the demographic information form.

**Researcher field notes.** Immediately after conducting each interview, when applicable, the researcher made written notes of any features of the interview or the participant that may have influenced the content of the interview (e.g., emotional caregiver/parent, interview was disrupted by a fire drill, biases experienced by the researcher). These researcher field notes, or memos, served as an audit trail in which the

researcher was able to provide additional details, as needed, related to the interviews with each participant (Merriam, 2002). This form of researcher field note taking is defined as salience hierarchy (Emerson, Fretz, & Shaw, 1995; Peshkin, 1988; Wolfinger, 2002) which enabled the researcher to remain fully engaged with the participant during each interview and document any factors that may have had an effect on the participants' responses.

**Interviews with students and caregivers/parents.** The study centered on the phenomenon of the issue that has been selected by the researcher (i.e., perceptions of identity of students with hearing loss). Thus, interviews and observations via field notes made by the researcher during the interviews, with both students who are deaf or hard of hearing as well as their caregivers/parents, served as the primary data source. The primary data source for the study consisted of interviews and conversations that were conducted with four students with hearing loss and their six caregivers/parents for a total of ten interviews. The number of caregiver/parent interviews varied depending on familial circumstances (e.g., marital status, living arrangements) and varied in length from a minimum of 30 minutes to 60 minutes.

Interviews are commonly utilized in qualitative research methodology because they provide direct access to data sources (Creswell, 2007). Individual interviews, conducted with the participants, enabled examination of how one identifies him or herself by providing a "voice" for the participants' experiences (Fetterman, 1998; Patton, 2002) while observations and completion of demographic information forms provided the researcher with information to supplement the "insider" view or perspective that was

gleaned from the interviews. By conducting multiple interviews the opportunity for achieving objective and balanced findings increased (Creswell, 2007; Kvale, 1996) and a large amount of qualitative data was generated. Within the phenomenological research design or approach, multiple-participant research allows for examination of factors that may occur with more than one participant (Lester, 1999).

The protocol for the interviews included questions to facilitate the identification of themes that addressed the research questions of how does a student with hearing loss who uses spoken English and listening as his or her primary mode of communication and who is educated in the general education setting identify him or herself with respect to his or her hearing status and how do the caregivers/parents of the student with hearing loss identify him or her with respect to his or her hearing status. The protocol for the investigation was a semi-structured interview with open-ended questions to offer participants the opportunity to describe their experiences and perceptions specific to the individual students and caregivers/parents selected as participants in the study (Creswell, 2007; Sampson, 2004; Yin, 2003). The interview protocol appears in Appendix E.

Through the multi-pronged theoretical framework that served as the foundation for the study, and through aspects borrowed from the Symbolic Interaction Theory, along with the phenomenological inquiry research design approach, the researcher assumed that the interview questions held the same meaning and were interpreted in the same way by all responders. Thus, variation in participants' answers to questions should reflect differences in behavior, not in the interpretation of a question (J. M. White & Klein,

2008). Responses might not be based on different reactions to the question but on very different interpretations.

The design of the interview protocol was developed from a review of the literature and several inventories comprised of open-ended questions that have been utilized in other studies related to identity and deafness (Bat-Chava, 1994, 2000; Creswell, 2007; Fischer, 2001; Fischer & McWhirter, 2001; Glickman, 1986, 1996; Glickman & Carey, 1993; Kvale, 1996; Sampson, 2004; Yin, 2003). The questions for the interview protocol for the study were derived after the researcher analyzed several existing scales of identity in the psychology and counseling literature and incorporated additional questions extracted from the literature within Deaf Studies/Deafness (K. Anderson & Arnoldi, 2012; Elkayam & English, 2003; English, 1997). Thus, the questions in the interview protocol were appropriate for the purpose of the study in that participants could answer questions about how the hearing loss may or may not impact their or the students' lives and how the hearing loss may or may not be contributing factors when describing students' identities.

The interview protocol guided topics or subject areas within which the researcher explored, probed, and asked questions that elicited participants' perceptions of hearing loss related to the identities of the students (Patton, 2002). Each of the questions was explicitly worded to ensure each participant was asked the same questions in the same way and in the same order, including the probes. Questions were highly focused to maximize efficiency of time. The same researcher conducted all interviews to prevent variations in how the questions were asked and to ensure that no deviation from the

interview protocol occurred. However, the participants were still able to supply their own words, thoughts, and insights in answering the questions (Patton, 2002).

In designing the interview protocol for the study, the researcher analyzed studies within the discipline of Deaf Studies/Deafness that incorporated interview protocols. When interviewing families of children with hearing loss about aspects of their children's lives, Luckner and Velaski (2004) asked participants eight questions developed specifically for the study. Similarly, when interviewing itinerant teachers of deaf/hard of hearing students about teaching practices, Luckner and Howell (2002) asked participants eight questions developed specifically for the study but allowed for responses to be elaborated upon if the interviewer or interviewee felt that clarification were necessary. Wie, Pripp, and Tvette (2010) utilized a specially constructed interview of ten questions each when interviewing adults with unilateral hearing loss (hearing loss in one ear) on communication and social interactions. Their interview guide was developed especially for the study, as there existed very few relevant self-rating scales addressing the specific problems of the unilaterally deaf listener at the time of the study (Wie et al., 2010). Further, the authors state that in comparison with questionnaires that became available later, the interview guide included questions similar to those presented in a new scale.

Ross and Lyon (2007) explained that some opening questions of the interview protocol used in their study of cochlear implant users and household interactions were devised to "gently initiate the discussion" which could then flow from participants' responses. Basic questions regarding onset of deafness were used to start the interview process but flexibility allowed the participants' own narratives to emerge without the

constraints of a fully structured approach. Interviews broadly followed the chronology of living with profound hearing loss and issues involved in the decisions that were made related to the hearing loss. Luckner and Muir (2001) interviewed students, teachers of the deaf, general education teachers, interpreters, notetakers, and caregivers/parents when investigating factors that contribute to the success of students with hearing loss.

Hadjikakou, Petridou, and Stylianou (2008) utilized caregiver/parent and teacher interviews to glean information related to including students with hearing loss in the general education curriculum. Rugg and Donne (2011) interviewed caregivers/parents to gain insights into the transition process of students with hearing loss. The interview consisted of 18 questions, 12 of which allowed for open-ended responses.

Therefore, the ten initial questions that had been created for the interview protocol to be utilized in the present study are broad to facilitate individual responses by the participants. The interview protocol includes probes to assist with the interviewing process in gathering in-depth comments from the participants (Guest, Bunce, & Johnson, 2006; Schensul et al., 1999). A probe is a neutral question that encourages the participant in the interview to think more deeply, clearly, or broadly about an issue. There were two sets of interview questions: one that was used with the caregivers/parents and one that was used with the student participants in the study. The interview protocol questions are grouped according to similar topics or domains.

Two interview protocol questions (1, 4) relate to general characteristics of identity (i.e., describe yourself/your child, list strengths and challenges), four interview questions (2, 3, 7, 8) pertain to the specific hearing loss and hearing aids, if any, that are worn by

the participant/participant's child (e.g., describe what hearing loss means to you, how often do you/does your child wear hearing aids, does it seem as if others are unable to understand what it is like to have a hearing loss), two interview questions (7, 9) seek information pertaining to participants' experiences (i.e., what advice would you share with others, which identity type would you choose) and two interview questions (5, 6, 10) address challenges and strategies that may or may not arise for the participants as well as strategies of coping with hearing loss (e.g., what helps you/your child to hear better or makes it worse, do you sometimes forget that you/your child have/has hearing loss).

Of the ten questions, four of the questions are classified in the category of the experience and behavior question type (1, 5, 6, 10), three of the questions are classified in the opinion and values question type (2, 7, 9) with one of each of the remaining questions of the following questions types:

- knowledge (question 3),
- background/demographic (question 4), and
- feeling (question 8) (Patton, 2002).

Patton (2002) explains that experience and behavior questions are those that elicit behaviors, experiences, actions, and activities that would have been observable had the researcher been present. Answers to opinion and values question types reveal what participants think about an experience or issue. Knowledge questions measure what the participant knows whereas answers to background/demographic question types aid the interviewer with locating the participant in relation to other individuals. Feeling questions elicit emotions of participants regarding their experiences and thoughts.

Additional probes and support and recognition responses were provided during the interviews, as needed, when participants answer the questions to guide the interview and continue building rapport with the participants. Some examples of probes that were used during the interviews include:

- Would you elaborate on that?
- Can you tell me more?
- Could you say some more about that?
- How did that make you feel?
- If so, how \_\_\_\_\_?
- Oh yes, I see.
- You've been telling me some really important things. How's it going for you?
- I appreciate your willingness to express your feelings about that. You're helping me understand—and that's exactly why I wanted to interview you.

Thus the questions for the students focused on how they perceive themselves in relation to their hearing status whereas the questions for the caregivers/parents focused on how they identify the student with regard to the student's hearing status. It was anticipated that the participant responses will be comparable to one another due to the similarities in the content of the questions and that the responses would yield descriptive data (Bogdan & Biklen, 2003; Creswell, 2007).

In an effort to better understand how the participants identify, perceive, or categorize themselves, or their children, as related to hearing loss, a card sort strategy (Carlone, 2012) was utilized during the interviews in the semi-structured open-ended

interview protocol. The card sort strategy served as a form of “member checking” (Lincoln & Guba, 1985; Maxwell, 2013) in which participants were able to expand on previous answers. After discussing strengths and weaknesses of self (or student), defining what hearing loss means for the participants, and sharing a piece of advice related to hearing loss with another similar individual (i.e., caregivers/parents sharing advice with other caregivers/parents of students with hearing loss, students sharing advice with other students with hearing loss), participants were presented with the card sort activity (Carlone, 2012) in which the categories of D/deaf, hard of hearing, person with hearing loss, hearing, both, and none were written on the cards. A seventh card was left blank so participants could choose to write in a category on the blank card if they chose the “none” card.

Participants were asked to choose, or create and write in, a category that best fit or identified the student with hearing loss based on their perceptions of hearing loss. Participants were reminded that, as with the interview question responses, there are no correct or incorrect answers as the chosen card(s) was or were a reflection of the participants’ perceptions of hearing loss. The researcher explained that the card with the word ‘both’ written on it could be selected if more than one category matched the participant being described while the card, with the word ‘none’ written on it could be selected if none of the provided categories were appropriate. The categories listed on the cards came from identity types listed in the literature from Deaf Studies/Deafness. After participants selected the cards that best fit their perceptions of hearing loss and the participants being described, questions were asked to further expand on the identity type

that was chosen (e.g., “What does it mean to be [identity type here]?,” “Can you give an example of when a person would be moved from this category to that category?”).

Due to the cards containing solely the words for each identity type (e.g., hard of hearing) without any describing characteristics or attributes associated with each identity type, the cards displayed a balance of specificity and ambiguity (Carlone, 2012) which provided the participants with opportunities to elicit participants’ meanings and narratives of experiences related to their perceptions of hearing loss. For example, the card labeled as ‘hearing’ might signify normal or fitting in with others for the participants. Likewise, the card with the term ‘person with hearing loss’ might represent an individual who wears hearing aids who therefore functions as a hearing person while for another participant, the card with the words ‘hard of hearing’ written on it might be selected to describe the same individual. How the participants view or choose these specific categories implied the participants’ notions as to what denotes their perceptions of deafness when examining perceptions of hearing loss in the participants in this study.

The students and their caregivers/parents completed individual interviews with the researcher to allow for a rich corpus of qualitative data. Participants were advised that the interviews would take approximately 30 to 60 minutes each but, in practice, the interviews would only conclude when the participants felt it was appropriate to do so.

### **Data Collection/Procedures**

The present qualitative study utilizing phenomenological inquiry collected data through the demographic information forms, the researcher’s field notes, and through conducting detailed interviews with the participants to obtain the lived experiences

related to perceptions of identity as related to hearing loss of students with hearing loss and also that of their caregivers/parents. The researcher's field notes were written using the researcher's computer and assisted with the bracketing of information (Moustakas, 1994). The phenomenological approach was selected for the study to understand the subjective aspects of the participants from their frames of reference in an attempt to understand the meaning of events and interactions to ordinary people in particular situations (Bogdan & Biklen, 2003). The researcher sought to capture these personal experiences of the participants and to draw out rich descriptions and deep meaning from the participants as they described their perceptions of identity as they pertained to hearing loss and their lived experiences.

Recruitment letters were sent to all eligible participants (i.e., students and caregivers/parents) within the school districts explaining the research project and intent. An ethical consideration critical to the study is harm to the participants through lack of procedures employed to protect the participants within the study (Tracy, 2010). Prior to conducting the research, the researcher secured approval from the Institutional Review Board (IRB) from the schools and from the educational agency in which the student participants were enrolled. For the schools that did not have an IRB, approval was gained from the superintendent and/or the school administrative board. At the time the study was conducted, the researcher was not affiliated with the schools or the educational agency that was recruited for participation in the study, so coercion was not present. Furthermore, the participants in the study were informed of their rights within the study prior to agreeing to engage in the research and prior to each interview conducted.

Student participants who met the selection criteria were interviewed in a private conference room or empty classroom after school had concluded for the day. The interviews with the students occurred after the school day so the students were not “singled out” by participating in interviews with the researcher during class time. Caregiver/parent participants were interviewed at their convenience in a private conference room or empty classroom at each school site. All interviews were conducted by the researcher and each interview lasted between 30 to 60 minutes in length. Interviews were conducted with the participants in a private conference room or empty classroom in the school district where the student is enrolled. The interviews were audiotaped so that they could be transcribed and analyzed (S. R. Jones & McEwen, 2000). The transcriptions were triple checked to provide validity of the transcriptions (Poland, 2003).

If a participant appeared to be upset or uncomfortable from negative emotions or distress about any information he or she disclosed, the researcher would have been able to provide contact information for a counselor and the participant could withdraw from the study at any time without penalty. None of the participants appeared to experience extreme emotions in which a counselor’s information was needed in the present study. Prior to the start of the interview, the participant was informed that he or she could decline to answer any question or conclude the interview at any time. Each interview was recorded, transcribed, and subsequently sent to each participant for proofing as a member check. Member checking is defined as a quality control process by which a researcher seeks to improve the accuracy, credibility, and validity of what has been

recorded during a research interview (Barbour, 2001; M. M. Byrne, 2001; Coffey & Atkinson, 1996; Doyle, 2007; Lincoln & Guba, 1985; Maxwell, 2013; Moustakas, 1994). Once the participants had been invited to read their individual interviews thoroughly for clarity and accuracy to provide additional insight and information (if needed), the researcher then moved forward with the analysis of the data. Obtaining this type of feedback from the participants is a trusted method of establishing validity (Maxwell, 2013; Miles & Huberman, 1994).

### **Background and Bias of the Researcher**

In qualitative research, the researcher is an instrument of analysis, whose stance in relation to the research goals and data should be made explicit. Therefore, it is important to understand the positionality of the researcher in the context of the present study since all research is subject to researcher bias (Morrow, 2005). In order to minimize the bias of the researcher, several strategies were employed in the study such as member checks, use of a second reader/peer debriefer, and triangulation of data sources. These strategies were employed through the researcher “bracketing” and “monitoring of self” (Peshkin, 1988). By creating researcher field notes and using coding logs throughout the process, the researcher was able to state implicit assumptions and predispositions in order to be able to set them aside to avoid having these assumptions and predispositions influence research (Husserl, 1931). Since several factors may influence collection and interpretation of data, such as the researcher’s emotional involvement with the topic, presuppositions formed from reading the literature, and various aspects of interaction with research participants, the researcher was able to control for any bias that may occur

by reviewing literature to gain an understanding of multiple views of the phenomenon (Morrow, 2005).

Morrow (2005) explains that in order for researchers to deal with biases and assumptions that come from their own life experiences or from interactions with the participants, which are often emotion-laden, qualitative researchers attempt to approach their endeavor reflexively. Reflexivity has been defined as “self-awareness” (Rennie, 2004). In the present study, the researcher sought to achieve self-awareness by taking researcher field notes in which the researcher kept an ongoing record of her experiences, reactions, and emerging awareness of any assumptions or biases that arose through interviewing the participants. These notes captured the researcher’s thoughts and served as a way for the researcher to have a conversation with herself and with the interview transcripts without biasing the participants’ responses. These emerging self-understandings of the researcher were then examined and set aside to a certain extent or consciously incorporated into the analysis, depending on the frame of the researcher (Morrow, 2005). A second reflexive strategy that was utilized in the study was to consult with a second reader or peer debriefer (Morrow & Smith, 2000), who served as a mirror, reflecting the researcher’s responses to the research process and who assisted with the coding of the data. Third, the researcher ensured separation or bracketing of the researcher’s bias or experiences from those of the participants by conducting a self-interview (Hycner, 1985; Merriam, 2009). Bracketing did not remove the researcher’s experiences from the present study but rather assisted her in noting areas of bias and allowed the researcher to conduct the interviews without influencing the responses of the

participants. Some ways of not influencing the participants' responses include the researcher avoiding agreeing or disagreeing with the participants since the phenomenological researcher aims to just listen during the interview process (Hatch, 2002; Moustakas, 1994). Further, the chair of the researcher's committee continuously challenged the researcher to assure that the data was being interpreted objectively; this continual feedback served as a form of member-checking.

The researcher is a White female with bilateral severe to profound sensorineural hearing loss, who wears hearing aids in both ears. The researcher communicates with others using spoken language and listening but does know some sign language due to learning it as a requirement of her training to be a teacher of students who are deaf or hard of hearing. Similar to the student participants in the study, the researcher completed elementary, high school, undergraduate, and graduate education programs in the general education setting. Due to these commonalities, the researcher has a shared experience with the student participants. This shared experience proved to be a strength of the study as the researcher was able to connect across a general shared background while still recognizing the uniqueness of the student participants' experiences.

At the age of two, the researcher was diagnosed with severe to profound sensorineural hearing loss in both ears and received amplification via hearing aids at the age of four. The hearing loss is permanent and progressive. Despite this audiological diagnosis, the researcher was labeled as hearing impaired or hard of hearing and she and her caregivers/parents never identified herself as deaf, primarily as the researcher had grown up believing that to be d/Deaf meant that she had to know sign language and

attend a special school. The researcher wore hearing aids in both ears since the age of four, and relied on reading lips and employing other compensatory listening skills to accommodate with hearing missed information. The researcher's main means of communicating was through spoken English and listening after participating in early intervention speech programs from the age of two until the researcher was dismissed from speech services at the age of seven.

As a student with hearing loss growing up in the general educational environment, the researcher excelled academically, graduating in the top 25% of her honors classes in high school, graduating cum laude from her undergraduate program, and graduating summa cum laude with a grade point average of a 4.0 from her Master's program. However, socially, the researcher experienced feelings of loneliness and isolation over the years until she met other students with hearing loss while enrolled in her undergraduate program. During high school, through being active in many extracurricular activities and organizations (e.g., cheerleading, drama club, National Honor Society, yearbook), the researcher formed friendships with a variety of individuals in the general education setting, but it was not until she enrolled in a Deaf Studies/Deafness major in college that she met other similar peers who had hearing loss and utilized spoken language and listening to communicate or who were related to individuals with hearing loss.

While a student in high school, the researcher learned about Gallaudet University, the only liberal arts college for d/Deaf students in the world, and of differing interpretations of what it means to be d/Deaf through various political and social events

that occurred in the late 1980s and 1990s (e.g., the first deaf Miss America 1995 Heather Whitestone, the first Deaf president of Gallaudet University, increase of publicity relating to cochlear implantation and other medical advances). Then, during her undergraduate teacher preparation, the researcher learned about the history of deaf education and the multiple modes of communication available to individuals with hearing loss. Prior to these experiences as an undergraduate student, the researcher never considered herself eligible to attend Gallaudet University or to learn sign language as she identified herself as hearing even when others might have identified her as hearing impaired, deaf, or hard of hearing.

Currently, the researcher identifies herself as a person with hearing loss and hearing, depending on the identities, roles, interactions, and contexts with both typically hearing individuals and individuals with hearing loss. This fluid perspective embraces the DeaF construct of identity as outlined by McIlroy and Storbeck (2011). Although the researcher can and does identify as an individual with hearing loss in some situations, she does not consider herself as being Deaf, according to Holcomb's (2013) definition of Deaf, because she utilizes spoken language and listening as a primary mode of communication and she grew up within a family in which none of her immediate family members also had hearing loss.

The researcher realizes there may be some researcher bias present in the study due to the fact that she has hearing loss and wears hearing aids which may affect the data validation of the present study (Maxwell, 2005). However, bias does not limit the ability to be reflective in that a researcher, through carrying out ethical considerations, is able to

be reflective, think critically about results, and then share those results (Maxwell, 2013; Peshkin, 1988). In addition to having hearing loss, the researcher also has worked as a hearing support itinerant teacher of students who are deaf/hard of hearing (TOD/HH) for eight years.

During the researcher's eight years of experience as an itinerant TOD serving students from birth to 21 years old who had hearing loss and their families, the researcher interacted with students with hearing loss who were educated in the general education setting and who communicated through spoken language and listening and their caregivers/parents. As a TOD with hearing loss, the researcher observed instances during which the students she served experienced differing perceptions of identity, related to hearing loss, from others in their lives (e.g., teachers, peers, caregivers/parents).

While the researcher acknowledges which identity type from the discipline of Deaf Studies/Deafness she chooses for herself based on her professional background/experiences, she is aware of times when this perception of identity has changed over the years and may continue to change depending on her interactions with others and her life experiences. This awareness of her own changing perceptions has led the researcher to the two research questions for the present study that seek to analyze how students with hearing loss perceive themselves and how the students' caregivers/parents perceive the students in relation to hearing loss. Due to the nature of these research questions, qualitative methods were used to obtain the needed data regarding the participants' perceptions of identity and hearing loss at the research sites.

The researcher had some previous background with the research sites due to the researcher having worked as an itinerant TOD for seven years for the educational agency that serves students with hearing loss who participated in the study. However, the researcher had not worked for the educational agency in the schools in which the participants receive services for the past three academic school years, during which time many changes in the staff, children, and families served through the educational agency have occurred. Therefore, while the locations, some individuals, and some practices were familiar to the researcher during the data collection phase of the study, there were no significant relationships between the researcher and the participants. The researcher also did not have prior knowledge of the educational and parenting experiences of the families who participated in the study.

Prior to conducting the interviews, the interview protocol was reviewed and trustworthiness established by conducting a two-stage pilot study of the interview protocol to protect against validity threats. The two-stage piloting process of the interview protocol was conducted with similar respondents the researcher sought for the study as well as with 20 colleagues of the researcher, both within and outside the discipline of Deaf Studies/Deafness with varying backgrounds in teaching, counseling, parenting a child with hearing loss, siblings of an individual with hearing loss, those who have hearing loss themselves, and others who have no affiliation with the discipline of Deaf Studies/Deafness. The objective of this two-stage piloting process was to determine if the interview questions were unbiased, clear, and able to yield information pertaining to the research questions of the study. The quality of the information obtained during an

interview is largely dependent on the interviewer (Patton, 2002), so it was crucial to have others view the interview questions and provide feedback in the first stage piloting process. Some modifications and adjustments were made to the interview protocol based upon feedback that was received. For example, some of the language was simplified, more probes were added, and extraneous or redundant questions were eliminated. Incorporating these changes and conducting the two-stage pilot study of the interview protocol ensured that situational and relational ethics were addressed by the researcher (Tracy, 2010).

Validity of the data collected via the interviews may be compromised by the bias or the reactivity of the researcher (Maxwell, 2013). Some reactivity threats to the research could be derived from the researcher's personal experience as a person with hearing loss and her professional experience as a hearing support itinerant teacher of students who are deaf/hard of hearing (TOD/HH). The researcher may find herself biased toward the participants due to having served as a TOD/HH for eight years. The researcher may also experience biases relating to experiences that are shared regarding the educational experiences of the agency, schools, and support staff where she used to be employed and with whom she used to work. To combat these threats, throughout the data collection procedures of conducting interviews with the participants, the researcher analyzed descriptive data from the demographic information forms, researcher field notes, and the primary data source of individual interviews with the participants. Within the researcher field notes, the researcher made notes of any time she may experience any biases, if any, throughout the process (Peshkin, 1988).

Thus, through monitoring her own thoughts during the interview and transcription process, the researcher was able to better understand and identify her subjectivity (Moustakas, 1994; Peshkin, 1988) as it pertained to the study. The member checks of the information supplied on the demographic information forms and the individual transcripts of the interviews, paired with observations made in the researcher field notes, in conjunction with the primary data source of the interviews, helped to provide data for triangulation of the results (Maxwell, 2013). In order to address the potential researcher biases, if any exist, the researcher employed the following strategies: (a) conduct multiple rounds of listening to the transcripts, (b) utilize a second reader, who does not have hearing loss or wear hearing aids, to check 50% of each of the transcripts for accuracy, (c) employ member checks with the participants through their confirming the content of the individual transcript of their own interview as being accurate as well as member checking the content of the individual composites, (d) read through the transcribed content of the interviews multiple times, (e) utilize a second reader, who does not have hearing loss nor wear hearing aids, to code 50% of the transcripts, and (f) achieve an inter rater reliability score of at least 85% between the researcher and the second reader after utilizing a constant comparative coding process.

The second reader, who served as a peer debriefer, was one of the hearing support itinerant teachers of students who are deaf/hard of hearing (TOD/HH) who assisted with recruiting of participants for the study. This TOD/HH possessed a Master's degree in Deaf Education and taught students who are D/HH for at least five years. This second reader, or peer debriefer (Lincoln & Guba, 1985), was familiar with the issues of identity

and hearing loss that are the focus of the study and helped to ensure the transcribing and coding of the interviews were reflective of the participants' experiences. Finally, the second reader was able to provide a level of external objectivity and a critical eye to remedy any researcher biases or selective interpretation of the researcher.

Another means of developing trustworthiness in the study is through peer review from the dissertation advisor and committee that helped to guide this research process (Merriam, 2002). By sharing the drafts of the methodological process, methods used, and results of the research, the advisor was able to provide the researcher with guidance and feedback on the process. After conducting all of the steps outlined above to establish rigor, trustworthiness, and validity, to further minimize how the researcher's values and expectations might influence the study, the second reader assisted with the transcription and coding processes. In conclusion, the study was directed by the researcher's doctoral committee at the university and the study and research was overseen by the researcher's advisor/chair of the doctoral committee.

### **Data Analysis**

Through conducting in-depth interviews with the participants in the study, access to and information from each participant (i.e., the four student participants and their six caregivers/parents) were acquired and analyzed. Components of the phenomenological inquiry research design approach were appropriately applied in relation to the study (Johnson & Onwuegbuzie, 2004). Phenomenological principles assert that scientific investigation is valid when the information gained comes about through rich description that allows for understanding of the essences of experience (Moustakas, 1994). In the

present study, the analysis of descriptive data from the demographic information forms, researcher field notes, and the primary data source of individual interviews constituted the data sources from which the researcher analyzed data pertaining to perceptions of hearing loss in not only the students with hearing loss but also in their caregivers/parents.

In analyzing the data, each participant was assigned a pseudonym thus data was deidentified and the researcher ensured anonymity of the participants and the research sites. Coded and uncoded paper copy records remained locked in a filing cabinet in the principal investigator's office in the School of Education Building on the campus of the University of North Carolina at Greensboro. Electronic copies were password protected and remained on a closed computer network. All information obtained in this study was deidentified as it was strictly confidential unless disclosure was required by law.

Individual interviews conducted with the students and the caregivers/parents were transcribed by the researcher within 72 hours of completion and then checked for accuracy by the researcher within three weeks because the period after an interview is critical to the rigor, transparency, and validity of qualitative inquiry (Patton, 2002). The interview data, after being transcribed, yielded 194 single-spaced pages. The transcriptions were stored on a computer that is password and firewall protected. Additionally, each interview was saved and a backup file was created and stored on an external hard drive.

In order to ensure accuracy of the researcher's transcription of the interviews, a second reader, or peer debriefer, listened to 50% of each interview and checked the transcript a third time for accuracy (Lincoln & Guba, 1985). The second reader was one

of the hearing support itinerant teachers of students who are deaf/hard of hearing (TOD/HH) who assisted with recruiting of participants for the study. This TOD/HH possessed a Master's degree in Deaf Education and has taught students who are D/HH for at least five years. The 50% selection of the interview that was checked by the second reader was determined by dividing the total number of minutes in the interview in half then dividing that new number in half. This number determined where the second reader was to begin listening in the interview and where to stop listening. For example, in a 40 minute long interview,  $40/2 = 20$ . Twenty was divided by 2 to obtain 10. In the 40-minute long interview, the second reader began listening at the ten minute mark and stopped at the 30 minute mark to listen to 50% of the interview and check for accuracy of the transcription.

After the transcription had been triple checked by the researcher and second reader, each individual transcript was sent to the participants for a member check via email. The participants were given two weeks to review the transcript for accuracy and inform the researcher of any errors. This member check was completed through having each participant review his or her transcribed interview to ensure the trustworthiness of the transcribed interviews and provide triangulation of the data (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Maxwell, 2013). Of the ten transcribed interviews that were emailed to the participants with a request to provide member checking, all ten participants replied to the email request for member checks. All ten of the checked transcripts were accepted by the participants as not needing any revisions or corrections yielding 100% of member checked transcriptions. Subsequently, the

researcher read through the checked transcripts to obtain an overall view of the data and then each transcript was analyzed for thematic coding or identifying pertinent issues or ideas concerning identity related to hearing status. This qualitative analysis procedure adheres to recommendations provided within qualitative research methodology (Miles & Huberman, 1994; Moustakas, 1994).

Prior to the researcher reading through interview transcripts, the researcher reviewed researcher field notes that recorded reactions, if any, to the interview experience with each individual participant. Each of the transcripts was entered into the NVIVO 10® data managing software program to assist the researcher with the data analysis process. In addition to utilizing the computer software program, all transcribed interviews were kept in a binder that was stored in a locked office. Through use of the computer software program and the binder, assistance with organization and management of the data was provided. The binder system also assisted the researcher by allowing for efficient retrieval of the data when it was necessary for the researcher to refer back to the transcripts during data analysis.

Specifically, within the phenomenological approach, data analysis occurred through use of Moustakas's (1994) phenomenological approach to data analysis. First, the researcher listed all statements relevant to the participants' experiences as revealed to the researcher during the interviews in the transcribed data by typing the transcripts verbatim from the audio files. The researcher looked at every statement relevant to the questions that were asked to bracket the researcher's views or preconceptions. This process, called horizontalization, enabled the researcher to assign each comment or

horizon of the experience made by the participant an equal value. These comments were highlighted within the binder on the printout of the transcript for each participant. These comments were then placed into the NVIVO 10® data managing software and coded by the researcher and the second reader to achieve an IRR score of at least 85%. Second, the researcher listed all non-overlapping, non-repetitive statements which were the invariant and consistent horizons of the experiences as shared by the participants. This was done by underlining all the relevant statements and highlighting each non-repetitive concept within the computer software program. During this step of the data analysis process, the researcher asked two questions of the data: (a) does the expression capture an element of mattering, or being an invariant constituent, that is “necessary and sufficient” which will aid in the understanding of the phenomenon?; and (b) is it possible to label the expression? If the expression can be classified, it is considered “a horizon of the experience” (Moustakas, 1994, p. 121)? If the expressions did not meet these two requirements, the data were eliminated (Moustakas, 1994). Similarly, expressions that were not clearly and plainly articulated or communicated were eliminated and not included in the data analysis. Meaning units were created via careful scrutiny (Moustakas, 1994) of the number of times and context in which meaning occurred. These horizons were unique to the individuals and, with the use of the NVIVO 10® data managing software, these comments were organized via a coding summary report.

Third, the researcher grouped these invariant horizons into categories or themes by using inductive reasoning or a “bottom up” approach, a theoretical underpinning of phenomenology, by analyzing what emerged from the data (Moustakas, 1994). The

researcher then clustered the meaning units together into categories to look at the data from a whole picture perspective. Clustering is the process when germane theme meanings naturally cluster together or, in other words, whether there seems to be some common theme or essences that unite several discrete units of relevant meaning (Hycner, 1985). As a form of validation in this process, the relevant expressions were checked by asking two additional questions: (a) Are the expressions completely and clearly articulated in the complete transcript?; and (b) Are the expressions “compatible” and clearly communicated? If the expressions are not compatible or clear, they were eliminated (Hycner, 1985; Moustakas, 1994). These clustered categories were organized into a coding list through the use of the NVIVO 10® data managing software. The researcher worked with these invariant horizons and themes to create an individual textural description, or what happened, of each participant’s experience, as revealed during the individual interviews, including verbatim examples. Creation of the individual textural descriptions was done by analyzing the coding and using the NVIVO 10® data managing software to assist with text-based data analysis (e.g., word search and line-by-line coding comparison). The researcher continually checked back with the transcript and meaning units to ensure that the participants’ views, rather than the researcher’s view, were expressed in the phenomenological data analysis of the study. The researcher next constructed an individual structural description, or how the phenomenon was experienced, of each participant’s experience drawn from the individual textural description. Creswell (2007) describes these descriptions as being thick descriptions of

what the participants experienced in that noteworthy themes and statements from the data are used.

Once the structural descriptions of each participant's experience were created, the researcher constructed a textural-structural description of the meanings and essences of each participant's experience, including the categories or themes with which to tie the information together. These individual textural-structural descriptions were sent to each participant for a second level member check to ensure accuracy and strengthen trustworthiness, transparency, and validity. All ten participants responded to this member check and reported to the researcher the descriptions were accurate so 100% of the textural-structural descriptions were verified by the participants in the present study. After the member checks were completed, the researcher then combined the individual textural-structural descriptions to develop a composite description of the similar essences of the lived experience for all participants as a whole (Moustakas, 1994) by the researcher looking at and reporting on only the common or universal experiences/ essences. Aspects of the experience which are common or universal to all the participants are invariant or consistent structures and reveal the essence of the experience. Creswell (2007) refers to this last step in the data analysis process as the essential invariant structure. This step was developed to establish the fundamentals of the phenomenon, as experienced by the participants, through the combined description and focus on the participants' common experiences related to the phenomenon being explored (i.e., perceptions of identity related to hearing loss). This process centered on the participants' common experiences via thick description which helped the researcher

understand the core meaning of the phenomenon in the present study. Thus, the findings of this data analysis consisted of the composite description across all of the participants and are filled with “sufficient examples . . . to give the reader confidence that the researcher’s assertions about the topic at hand are supported by the data” (Hatch, 2002, p. 225). A review of how the researcher will operationalize Moustakas’s transcendental phenomenological process and data analysis (1994) will be provided at the beginning of Chapter IV.

Each interview was read multiple times to gain a solid understanding or sense of what was included in the data set and to identify themes and patterns useful for describing and explaining perceptions of identity and hearing loss (Gall, Borg, & Gall, 1996; Hatch, 2002). These issues or ideas that emerged from the data were compared with the information revealed in the other interviews within the two data sets (i.e., caregivers/parents and students). The data from the interviews of the caregivers/parents were compared with one another while the data from the interviews of the students were compared with one another. Through the use of individual interviews across the two data sets, data analysis was productive since the researcher was able to locate each participant’s answer to the same question at a more efficient rate of speed (Patton, 2002). When analyzing the data, the researcher coded the content of each transcribed interview by emerging themes utilizing the NVIVO 10® data managing software which assisted the researcher to cross-compare first and second rounds of coding with the coding of 50% of the transcribed interviews that was completed by the second reader/peer debriefer. Before the second reader began to code the data, a three-hour training (with the

researcher) was provided to ensure the second reader understood the coding procedures and a 95% inter rater reliability between the researcher and the second reader was achieved. Through the use of inductive analysis of the data from the participant interviews, the researcher started with specific elements provided by the participants and found connections among them before pulling the pieces together into a general meaningful whole to learn more about the phenomenon of perceptions of identity related to hearing loss (Glaser & Strauss, 1967; Spradley, 1979). Further, inductive analysis of data is suitable for studies relating to discovery of meaning, such as those relating to symbolic interaction, in which case the present study does (Hatch, 2002).

Throughout the inductive data analysis, coding classifications were compared between the researcher and the second reader and differences were discussed and reconciled during the final stage of the data analysis. Throughout the coding process, the initial codes were altered, modified, added to, or deleted as determined by the researcher (Brantlinger et al., 2005). The researcher and the second reader developed definitions for the final coding list. The data were then independently re-coded by the researcher and the second reader, utilizing the final coding list from which the inter-rater reliability of the coding process was determined. Brantlinger et al. recommend the inter rater reliability score between the researcher and the second reader be at least 85% or higher. Upon completion of the coding between the researcher and the second reader, an IRR score of 98.92% was achieved which meets the standard.

The transcript of each interview was analyzed using constant comparative coding (Creswell, 2007) and initial open codes were developed from the primary research

questions for the study (Miles & Huberman, 1994). As themes emerged from the data of the participants' interviews, the initial open coding index was altered and examples that defined each category were included. Upon secondary or axial coding, data were then aggregated and organized into more refined codes. The data were coded and recoded independently using the final thematic categories by the researcher and the second reader at least twice until at least 85% inter rater reliability was achieved (Brantlinger et al., 2005).

The constant comparative process included reviewing and reorganizing the coding index throughout the analysis process until a final set of coding categories was developed. Data were analyzed using the constant comparative method to capture the multiple but equally applicable and legitimate aspects of individual experiences and perspectives (Johnson & Onwuegbuzie, 2004). This constant comparative method enabled the researcher to compare each unit of data with every other unit of data, both in and between coding categories, in order to uncover similarities, differences, and consistencies of meaning expressed by each participant. Regarding the participant groupings, the researcher analyzed the data sets separately (i.e., caregiver/parent participants versus the student participants) in order to create a more homogenous sample and to align with one of the theoretical underpinnings of phenomenology (Moustakas, 1994). Data were further compared by classifying and organizing information by codes that were grouped into broader categories or themes. From these themes, patterns were identified to examine similarities or differences in how students with hearing loss who use spoken English and listening as their primary mode of communication and who are

educated in the general education setting identify themselves with respect to their hearing loss and in how do the caregivers/parents of the students with hearing loss identify their sons or daughters with respect to their hearing status. Key themes and issues were identified as they pertained to the theoretical framework of the study utilizing the data analysis procedures as described in this chapter (Hatch, 2002; Lester, 1999; Moustakas, 1994; Spradley, 1979; Strauss & Corbin, 1990).

Triangulation of the data analysis occurred by comparing and contrasting multiple sources of data for common themes and findings (Creswell, 2007). The study achieved triangulation through the researcher coding the interview data at two separate points in time that occurred within one week of each other by employing NVIVO 10® data managing software. The cross checking of the researcher's two initial codings with the initial coding of 50% of each transcribed interviews by the second reader at a third separate point in time occurred at least one week after the second coding was completed by the researcher in order to calculate inter rater reliability or IRR (Miles & Huberman, 1994). This coding process was repeated at least once to ensure a second coding by both the researcher and the second reader to assist with the constant comparative coding procedure. Upon completion of the coding between the researcher and the second reader, an IRR score of 98.92% was achieved. Further, the following validation strategies (Creswell, 2007) were included to contribute to the credibility and dependability of this phenomenological study: (a) rich, thick descriptions; (b) clarification of the researcher role and potential bias; (c) description of the participants; (d) identification of methods for data collection and analysis; (e) evidence of member checks by individuals involved

in the study (i.e., checking of transcripts and of textural and structural descriptions); and (f) peer reviews.

Analysis of the qualitative data in the present study yielded findings related to perceptions of hearing loss, the impact of hearing loss on the family and in the school setting, as well as interactions with peers. The purpose or intent of the study is to describe perceptions of identity and hearing loss in students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting. Additionally, the role of the study is not to generate replicability, but rather it is to describe the environment through those who experience it; hence, the phenomenological research design was selected to examine the similarities among participants in order to permit a description of the essence of the phenomenon of perceptions of identity related to hearing status (Giorgi, 1997). Through using a qualitative research perspective and the phenomenological approach in the study, the researcher relied on the views of the participants for credibility as the only justifiable evaluator of the results. Therefore, the use of member checks was critical to ensure the participants agreed with the researcher's analysis adding to the transparency, rigor, and trustworthiness of the study (Barbour, 2001; M. M. Byrne, 2001; Carlone, 2012; Coffey & Atkinson, 1996; Doyle, 2007; Fleming, Gaidys, & Robb, 2003; Lincoln & Guba, 1985; Maxwell, 2013; Merriam, 2002; Miles & Huberman, 1994).

Rigor of the data analysis was established through trustworthiness, demonstrated by transcribing interviews and use of inter rater reliability, credibility, confirmability through member checks and proofing, and objectivity through peer debriefing

(Brantlinger et al., 2005; Fleming et al., 2003; Maxwell, 2013; Merriam, 2002).

Researcher reflexivity was reached by aiming to achieve an epoche as prescribed in the phenomenological approach or research design through the researcher approaching each interview with a mind free of biases, preconceived interpretations, and/or expectations. Further, including a subjectivity statement disclaimed the researcher's perspective and assisted the researcher with embracing the naturally occurring subjectivity. Before the data collection process began, the researcher revealed her bias in the Background and Bias of the Researcher section included in the present study. The researcher answered the same questions asked of the participants and researcher field notes were maintained throughout the interviewing process to prevent personal researcher bias from entering into the data analysis. Themes were developed from the participants' data and rich thick descriptions were created. Specific quotations from the participants were implemented into the narrative supporting each theme. Multiple examples of the essence of each theme were also included in the results. The researcher engaged peers in reviewing the themes and narrative descriptions. In addition, the researcher requested each of the participants to review the themes and narrative descriptions. The feedback provided by peers and participants provided additional validity to the findings of this phenomenological study. A second level member checking was utilized by the participants being provided with analyzed data so they could validate the conclusions and interpretations made by the researcher. Of the ten composite descriptions that were emailed to the participants with a request to provide member checking, all ten replied to the email request. One participant requested a minor language and grammatical change

while the remaining nine participants accepted the analysis without any revisions or corrections. Additional qualitative research standards were met by inviting peer debriefing from the researcher's committee members and through the prolonged recursive engagement with the data from the interviews.

The results of the data from the transcendental phenomenological analysis are presented in Chapter IV according to themes based on the literature review as well as from the key issues that emerged from the participants' descriptions of the phenomenon or essence of their lived experiences regarding perceptions of identity related to hearing loss (Hatch, 2002; Lester, 1999; Moustakas, 1994). Chapter IV begins with four examples of textural and structural descriptions (i.e., two from each data set of students and caregivers/parents) to demonstrate the transcendental phenomenological data analysis process. The researcher then presents the results of the phenomenological study by describing the essence of the phenomenon of perceptions of identities related to hearing loss as it emerged from the data across both data sets of participants. Chapter V concludes with a synthesis of the findings of the study by highlighting connections between these findings with those in the literature, the implications for practice and research, as well as limitations of the current study.

## **CHAPTER IV**

### **RESULTS**

#### **Introduction**

This chapter presents the findings of a transcendental phenomenological study (Moustakas, 1994) on the perceptions of self-identities of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting as well as the perceptions of the caregivers/parents of the students with hearing loss through qualitative research methodology. Through a detailed and in-depth examination of the perceptions of identity related to hearing loss of the students and their caregivers/parents, insights into their perceptions of identity and meaning associated with those perceptions and experiences are provided. Chapter IV presents the results of ten individual interviews conducted with six caregiver/parent participants and four student participants. The data from these interviews seeks to answer the research questions by exploring and examining perceptions of identity as they relate to hearing loss in students who use spoken language and listening as their primary mode of communication and who are educated in the general education setting.

The qualitative data from these ten individual semi-structured interviews will be compared within the two data sets (i.e., students and caregivers/parents). The transcendental phenomenological paradigm served as a guide to the development of the

research questions, the choice of methods employed in the study, and served as a framework for the data analysis. The results of the data from the transcendental phenomenological analysis of the data in the study will be presented in Chapter IV according to themes based upon the literature review as well as from the key issues that emerged from the participants' descriptions of the phenomenon or essence of their lived experiences regarding their perceptions of identity related to hearing loss (Hatch, 2002; Lester, 1999; Moustakas, 1994).

Chapter IV begins with individual profiles of all ten participants followed by four examples of textural and structural descriptions (i.e., two from each data set of students and caregivers/parents) to demonstrate the transcendental phenomenological data analysis process. The researcher then presents the results by describing the essence of the phenomenon of perceptions of identities related to hearing loss as it emerged from the data across both data sets of participants. After the initial analysis of each interview and a creation of the individual textural, structural, and composite descriptions (Moustakas, 1994), the themes across all participants were identified in order to arrive at the essence of perceptions of identity as they relate to hearing loss. Individual profiles, individual textural descriptions, and individual structural descriptions identify the “relevant, validated invariant constituents and themes” of the perceptions of identity as related to hearing loss (Moustakas, 1994, p. 21). Individual profiles provide demographic data for each of the participant clusters (i.e., students and their caregivers/parents). The demographic data was obtained from the demographic information form completed by the participants prior to the interviews.

Through the process of phenomenological reduction the researcher attempted to fully grasp the nature of the phenomenon, perceptions of identity as related to hearing loss, and then completely and clearly describe what was seen (Moustakas, 1994). Using the relevant, validated invariant constituents and themes, the researcher constructed the individual textural descriptions to examine what constitutes each participant's experience with perceptions of identity and hearing loss and the meaning each participant assigned to his or her experiences. Verbatim explications from the transcribed interviews have been provided as evidence of the experience in the participants' own words. All of the data was initially coded by utilizing the NVIVO 10® data management software. The non-repetitive and relevant comments or horizons of the experience made by the participants were combined and coded into meaning units or themes (Moustakas, 1994). Thirty-seven meaning units were identified across all participants. The meaning units were then categorized into fifteen subthemes and ten broader themes to yield and describe the three essences of the phenomenon of perceptions of identity related to hearing loss.

Using the individual textural descriptions and imaginative variation, the individual structural descriptions were constructed to offer "a vivid account of the underlying dynamics of the experiences" (Moustakas, 1994, p. 135), and portray the "themes and qualities that account for the 'how' feelings and thoughts connected with (the experience), and what conditions evoke (the experience)" (Moustakas, 1994, p. 135). Structural statements relate to contexts and influencing situations which relate to the experience. The purpose of these textural and structural descriptions is to arrive at the essence of the participants' perceptions of identity related to hearing loss, their lived

experiences, and the ultimate meaning they ascribe to their perceptions of identity related to hearing loss. Further, within the participant clusters, the researcher analyzed and presents the perceptions of identity of the student and his or her caregiver(s)/parent(s). Table 1 operationalizes the relevant terms, experience, and context used in the textual and structural analysis of the study.

Table 1

Operationalizing Moustakas's Transcendental Phenomenological Process and Data Analysis (1994)

<b>Type of Coding</b>	<b>Definition</b>	<b>How Researcher Identified It</b>	<b>Coding Examples</b>
Epoche/ Bracketing	Researcher's personal perspectives and preconceptions	Reflecting on personal experiences and memories	Stay objective; this is not my story
Significant Statement	Relates to participants' experiences, and/or contexts of participating in the phenomenon of perceiving identity as related to hearing loss	Compared all units of meaning to research questions; labeled relevant interview data as "Significant Statement" and no longer considered the irrelevant statements	Interactions Contexts/Settings Belonging Differing Identity Types/Fluidity
Textural	"Experience" data; phrases refer to what perceived identity is, or to something that is consistently experienced in identifying oneself as related to hearing loss	Transcribed data contained: 1) A personal pronoun with identity type, 2) Along with phrases indicating the identity type	Wearing of hearing aids Sharing information or explaining about hearing loss Normal

Table 1

(Cont.)

Type of Coding	Definition	How Researcher Identified It	Coding Examples
Structural	“Context” data; the interrelated conditions in which something exists or occurs, usually “settings” or physical or emotional “situations”	<p>Transcribed data contained:</p> <ol style="list-style-type: none"> <li>1) Reference to a setting or situation that influenced the participant’s experience of identity as related to hearing loss.</li> <li>2) Reference to a specific “context” that underlined the identity experience, such as               <ol style="list-style-type: none"> <li>a) Knowledge of child, child’s hearing loss, and/or special education;</li> <li>b) Informal or formal networks;</li> <li>c) Facilitators and/or barriers to perceiving identity.</li> </ol> </li> <li>3) Any emotional “situation” describing why participants acted as they did.</li> </ol>	<p>School setting</p> <p>Home setting</p> <p>Community setting</p> <p>Accommodations</p> <p>Family members</p> <p>Teachers</p> <p>Coaches</p> <p>Peers</p> <p>Audiologist/ Otolaryngologist</p> <p>Support network</p> <p>Because</p> <p>Lack of knowledge related to hearing loss</p>
Invariant Meaning Units	Non-repetitive and non-overlapping significant statements; data which most clearly describe aspects of “experience” and “context”	Reviewed all significant statements with similar themes; assessed them for clarity and inclusiveness; identified most clear and inclusive as the invariant meaning unit	<p>Themes of:</p> <ol style="list-style-type: none"> <li>1) fluidity</li> <li>2) versatility/sense of belonging</li> <li>3) normal/hearing</li> <li>4) perseverance</li> <li>5) adjustment</li> <li>6) acceptance/person first</li> <li>7) resiliency</li> <li>8) advocacy</li> <li>9) respect/as the need arises</li> <li>10) management</li> </ol>

To support the findings and illustrate the depth of each theme direct quotation excerpts from the transcribed interviews from the transcribed interviews are presented. Individual profiles of the clusters of participants are provided followed by four illustrations of the first level of the phenomenological analysis. Similar to Lee and Koro-Ljungberg (2007), the examples contain the textural and structural descriptions and showcase the broad range of perceptions of identity related to hearing loss of the participants in each data set (i.e., students and caregivers/parents). The narrative then presents the results of the phenomenological study by describing the essence of the phenomenon of perceptions of identity related to hearing loss as it emerged from the data across all participants within the two data sets (i.e., students and caregivers/parents).

### **Individual Profiles of Participant Clusters**

#### **White Family: Matthew's Individual Profile**

Mark is a married father of two children who resides in the same school district where his children attend school. He is married to Jessica, another caregiver/parent participant in the present study. Mark's oldest child, Barry, is in the 11th grade, is 17 years old, and has been diagnosed with moderate to severe sensorineural hearing loss in both ears.

Barry wears behind the ear hearing aids in both ears and has received Deaf/Hard of hearing (D/HH) support services in the general education setting since Kindergarten (i.e., for the last 12 years). With pride in his voice, Mark described Barry as "a great kid who is very good at sports, likes his friends and teammates, and has a good heart."

**White Family: Jessica's Individual Profile**

Jessica is a married mother of two children who resides in the same school district where her children attend school. She is married to Mark, another caregiver/parent participant in the present study. Jessica's oldest child, Barry, is in the 11th grade, 17 years old, and has been diagnosed with moderate to severe sensorineural hearing loss in both ears. Barry wears behind the ear hearing aids in both ears and has received D/HH support services in the general education setting since Kindergarten (i.e., for the last 12 years). Through being talkative throughout the interview and displaying an outgoing personality, Jessica, related her son, Barry, is a "great kid who is a sweetheart."

**White Family: Barry's Individual Profile**

Barry is 17 years old and the oldest child in his family of an older brother, younger brother, mother, and father. His caregivers, Mark and Jessica, also participated in the study. He lives with his family in his home in the same school district where he attends school. He has been diagnosed with moderate to severe sensorineural hearing loss in both ears. Barry wears behind the ear hearing aids in both ears and has received D/HH support services in the general education setting since Kindergarten (i.e., for the last 12 years). Polite and friendly, Barry revealed he "enjoys playing outside, baseball, playing with his little brother and friends, and doing fun things."

**Sand Family: Scott's Individual Profile**

Scott is a married father of three children who resides in the same school district where the children attend school. Scott is married to Kate, another caregiver/parent participant in the present study. Scott's youngest child, Danny, is 12 years old and is

enrolled in the fifth grade. He has a diagnosis of moderate to severe sensorineural hearing loss in both ears and has a history of fluctuating hearing levels. He wears hearing aids in both ears and has received D/HH support services in the general education setting since the third grade (i.e., for the past two years). In a calm and assertive manner, Scott described his son as being

very intelligent, perceptive, empathetic, and different than any other kid I've known. He's very disciplined and listens a lot. He asks great questions, reads a lot, and picks up vocabulary. He pays attention, is smart, and a really good kid. There is never a time he's not paying attention.

#### **Sand Family: Kate's Individual Profile**

Kate is a married mother of three children who resides in the same school district where her children attend school. She is married to Scott, another caregiver/parent participant in the present study. Kate's youngest child, Danny, is 12 years old and is enrolled in the fifth grade. Danny has been diagnosed with a moderate to severe sensorineural hearing loss in both ears and has a history of fluctuating hearing levels. He wears hearing aids in both ears and has received D/HH support services in the general education setting since the third grade (i.e., for the past two years). With a smile on her face, Kate described Danny as being "a very pleasing child who likes to make sure everyone is happy. He's outgoing, kind, a leader, and has high expectations for himself! We call him an 'old soul' and he is very brave and talkative."

#### **Sand Family: Danny's Individual Profile**

Danny, a 12-year-old fifth grader, is the youngest child in his family of an older brother, older sister, mother, and father. His caregivers, Scott and Kate, also participated

in the study. He lives with his family in his home in the same school district where he attends school. Danny has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and has a history of fluctuating hearing levels. He wears hearing aids and has received D/HH support services in the general education setting since the third grade (i.e., for the past two years). Talkative and inquisitive by nature, Danny calls himself “open minded and imaginative” and while he struggles with writing, he enjoys giving speeches.

#### **Coral Family: Shannon’s Individual Profile**

Shannon is a married mother of two children who resides in a differing school district where her oldest son attends school. Shannon’s oldest child, Devin, a 16-year-old who is enrolled in the ninth grade, has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and wears hearing aids in both ears. Her son has received D/HH support services in the general education setting since he was three years old (i.e., for 13 years). With tears in her eyes, Shannon described Devin as being “a caring child who looks out for his sister even if they don’t get along sometimes. He puts on a front at times and acts like he doesn’t care about things but deep down, I know he really does.”

#### **Coral Family: Devin’s Individual Profile**

Devin, a 16-year-old, is the oldest child in his family of a younger sister, mother, and father and is the ninth grade. He lives with his family in his home which is not located in the same school district where he attends school. He has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and wears hearing aids.

Devin has received D/HH support services in the general education setting since he was three years old (i.e., for 13 years). With a sense of independence and tossing his hair out of his eyes, Devin described himself as a teenager who enjoys driving, playing video games, spending time with his friends and girlfriend, hunting, fishing, and other social activities (e.g., talking, hanging out with friends in the lobby). He commented that he does not enjoy nor like school.

### **Day Family: Eileen's Individual Profile**

Eileen is a married mother of three children who resides in the same school district where her children attend school. Eileen's oldest child, Larry, a 15-year-old who is enrolled in the ninth grade, has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and wears hearing aids. Her son has received D/HH support services in the general education setting since Kindergarten (i.e., for the past ten years).

In a thorough and thoughtful manner, Eileen described her son as being

tender hearted and sensitive in spite of putting up a wall with some people. He can be lazy through not applying himself at school but he does love to read books he's interested in on his own time. He struggles with organizational skills and studying habits and can be hardheaded but with maturity, he may outgrow this.

### **Day Family: Larry's Individual Profile**

Larry, who is 15 years old, is the oldest child in his family of two younger brothers, mother, and father. He lives with all of them in his home which is located in the same school district where he attends school. Larry has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and wears hearing aids in both ears. He has received D/HH support services in the general education setting since Kindergarten

(i.e., for the past 10 years). Friendly and at ease during his interview, Larry revealed he enjoys riding dirt bikes, following the Ravens football team, music, and video games. He is interested in social studies but struggles with math in school.

### **Sample Textural Descriptions and Sample Structural Descriptions**

#### **Mark: A Father's Perception of Identity as it Relates to Hearing Loss**

**Mark's individual profile.** Mark is a married father of two children in the White Family. This family resides in the same school district where the children attend school. He is married to Jessica, another caregiver/parent participant in the present study. Mark's oldest child, Barry, a 17-year-old who is in the 11th grade, has a diagnosis of moderate to severe sensorineural hearing loss in both ears. Barry wears behind the ear hearing aids in both ears and has received Deaf/Hard of hearing (D/HH) support services in the general education setting since Kindergarten (i.e., for the last 12 years). With pride in his voice, Mark described Barry as "a great kid who is very good at sports, likes his friends and teammates, and has a good heart."

**Mark's individual textural description.** Mark describes his son's strengths as being "very personable and a kid others enjoy being around" with weaknesses revolving around academics at times. Although Barry is a strong student, his father revealed there are times he has to work hard to achieve his grades. When discussing the impact of hearing loss on Barry's life through using a pie analogy in which Mark had to determine how large of a slice of the pie to designate as impact of hearing loss, Mark said,

when I think of my son, the first thing that comes to mind certainly is not his hearing loss. There are a lot of other things I think about when I think of him such as how smart he is, how well liked by his peers he is, and how proud I am of

him. Yes, there would be a small part of the pie that makes up my son that would go to the hearing loss but that's just one part of who he is and I think he may be a better kid today because of it.

Mark further explained that the hearing loss is a part of who his son is and that the pie slice attributed to hearing loss is perhaps more for how he and his wife “react to the hearing loss” since Barry has always dealt well with the hearing loss according to his father.

As a parent of a teenage son with hearing loss who wears hearing aids in both ears, when asked what one piece of advice he would share with other caregivers/parents of children with hearing loss, Mark responded by saying,

I would tell them to try to integrate their children and make them as normal as possible where there's not a spotlight on them or there's not something that's drawing attention to the fact that they have hearing loss but to just try to make them as normal a kid as possible.

Mark clarified that when he stated normal in the context of his interview, he meant the term, hearing. He suggests the caregivers/parents treat their children with hearing loss as children who do have “full hearing” because his son is “as normal as can be given his limitations or his challenges that come out of the hearing.”

However, when presented with the card sort activity that contained the list of identity types and asked to select an identity type that best matches his son, Mark chose the person with hearing loss identity type rather than the hearing (i.e., normal) identity type. The reason for doing so is because Mark views his son primarily as a person first followed by the hearing loss as is evident by his response, “One, he's a person. Two, I'm

thinking of it as he certainly does have hearing loss and I know the hearing is not coming back because the hearing loss is a permanent condition.” Mark also shared that the identity type of person with hearing loss is “a more clinical term” in his eyes because he “has had to deal with the issues and challenges that arise from Barry’s hearing loss” as his caregiver/parent.

Mark differentiated between the person with hearing loss and hard of hearing identity types by saying the hard of hearing person would be

someone who I was trying to speak to who couldn’t hear me necessarily but they didn’t have any amplification. For me, the hard of hearing identity type could almost kind of shift in that the person could use sign language but could also speak depending on his or her background.

When discussing the deaf identity type, Mark explained his perception that people who are deaf may use sign language to communicate or may “not have a voice to speak with but they are certainly able to communicate through signing.”

Further, Mark said he would categorize his son as a person with hearing loss but that the category or identity type would change based on the environment his son is in and his ability to hear in the varying environments. He also revealed his son may select a differing identity type from what he, as his father, chose by saying, “Barry sees himself as perfectly normal and actually gets frustrated when my wife and I try to accommodate or try to give him a little extra help.” Mark explained that

there are definitely times when I don’t think of the hearing loss in certain situations. It comes back to me when we have to make accommodations for his hearing loss but you know through the normal day and normal routine, I may go a couple days without noticing he has a hearing loss.

Conversely, Mark shared that even though his perception of his son's identity or the way he categorizes his son may change depending on the situation or with whom his son interacts, his son's "hearing loss is a permanent condition. You know, he is someone who has experienced hearing loss and it will be with him for the rest of his life." In spite of the permanency of the hearing loss, Mark shared that through the use of technology (i.e., hearing aids), Barry can successfully communicate with others. He commented Barry's "hearing aids allow him to hear perfectly normal." Technology that has assisted Mark's son, both in the past and at present, include sound field amplification systems in his classrooms, hearing aids, and a vibrating shaker alarm clock.

When discussing interactions with his son, Mark spoke of accommodations and explaining to others what is needed for his son to be successful in school, the community, and when communicating with others. However, Mark believes while caregivers/parents should do "whatever it takes" to create a positive communicative environment for their children with hearing loss, "there should be no difference in the caregivers'/parents' approach in how they deal with their children with hearing loss." Mark spoke of the importance of not creating extra attention around his son's hearing loss by "shining a spotlight on it or singling him out" and also explained his son may have a better handle or understanding of the experience than his wife and he do. Mark shared his son "is a lot better at dealing with it than his Mom and I are and I'm proud of who he is and who he has become in spite of his hearing loss." Mark also shared that his son's hearing loss is "definitely something that has affected me a lot more than it may have affected my son" since the hearing loss has always been a part of his son's growing up and part of his life

so his son may not have noticed the hearing loss as much as his wife and he have noticed it. For instance, Mark explained that although Barry's immediate family (i.e., mother, father, little brother) recognize the accommodations that are successful for Barry to communicate with them, sometimes his extended family may forget or not recognize the impact of the hearing loss due to not being around his son as much as his immediate family is, something Barry may not be cognizant of when interacting with extended family.

Within the immediate family in the home setting, Mark revealed it is not uncommon for his wife and he to wonder if Barry is really not hearing what is being said or if he is ignoring his parents as a typical teenager might do. He also revealed how surprising it can be that Barry misses some of the everyday noises and listening exchanges within the home by saying,

sometimes it's shocking in how different he is from someone without a hearing loss. Things like our security system and sometimes, the alarm goes off and it's quite loud. There are times that he's just sleeping away and I know I can go out of his room and he not even know I was there. We have also noticed that we need to get Barry's attention to talk to him, especially when we're downstairs and he's upstairs. That can certainly be a bit of a challenge.

Mark also spoke of the successful ways his son has of compensating for what he auditorially misses within the home setting.

Barry has gotten really good at his own internal alarm clock . . . so he's been really good at getting himself up now. Barry will also be able to respond to us or answer a question if we project our voices or have him face us or look at us when talking.

Within the school setting, Mark shared positive instances of relating to teachers, speech therapists, and coaches when working with his son's hearing loss over the years by saying, "I think we've been very lucky with folks we've interacted with because I think they get it and understand my son's needs." Mark had positive experiences with his teenage son's school district over the years by saying that he and his wife would "make sure Barry can hear his teachers and he is accommodated for by putting him in the position to do that, if he hasn't already, to help him to hear better." Mark also mentioned this sort of parental advocacy for his son at school took place more often in the past than it currently does now at the high school due to his son now advocating for himself. Mark also discussed the benefit of accommodations (intended for his son) on his peers within the classroom by saying,

when Barry was younger, he got preferential seating and the school put in an audio or speaker system that allowed him to hear the instructor better. We were told the amplification would be of benefit to not only my son but to all the students in the classroom since it helped all of them to hear and not be distracted by background noises.

Another positive within the school setting for Mark was to receive support from Barry's classroom and hearing itinerant teachers and speech therapists "to make sure Barry received the skills and instruction he needed" to succeed.

Mark related a story regarding his son's current baseball coach in which his son and the coach have a rapport with one another and are able to talk about his hearing loss,

His current coach will give him a hard time at times where he doesn't quite do something that the coach wanted such as not doing the play the way he wanted him to and the coach will joke with Barry and say do you have the hearing aids

on? Not in a mean way but more of a are you hearing me, are you getting what I'm saying kind of way.

Additionally, Mark discussed the impact of Barry's hearing loss on his son's identity within the community setting by sharing that

when Barry is in a really crowded situation or there is any loud noise in the background, it can be difficult for him to communicate due to the fact that he is not picking up different things as opposed to when he can in a quiet setting.

However, when in a quiet setting, Mark wondered if others would realize his son has a hearing loss due to Barry's excellent use of compensatory listening skills, "honestly, in those quiet settings, if someone didn't know Barry, they would probably walk in and not notice he had any kind of problems." Mark further shared that his son does understand and recognize that when he is in a loud situation or a distracting setting that he may need to utilize accommodations to help him access communication within the various community settings.

In looking at interactions with peers, Mark described his son as a "very good friend and great kid whom other kids like to be around" and explained Barry's friends have been understanding and are "very good in working with Barry and his hearing loss since his friends accept him as he is." Mark shared his son's friends have similar qualities as his son through playing baseball together. For this particular group of friends, Mark said they help his son when he misses information from their coach and they are very supportive. Mark pondered whether his peers with whom he comes into daily contact "might not realize the impact of Barry's hearing loss" since they are so

accepting of him and do not appear to focus on that aspect of his son. Mark also shared there are other students enrolled at Barry's school who have hearing loss but that his son is not friends with them.

Mark revealed that in his interactions with others regarding his son's hearing loss, some folks may view his son as inferior,

in my experience, when I tell people about Barry and his hearing loss, the immediate reaction is he's not as intelligent as someone else. I find it interesting that I can tell someone my kid needs glasses and it's like oh ok, no big deal. Then I tell them my kid has hearing loss and it's oh how's he doing in school and there's this immediate stigma or aura to hearing. It's like he's not as good as the next person or he can't have a good IQ since he has hearing loss.

Through this statement, Mark revealed his belief that "hearing loss is not as socially accepted as needing corrective lens or glasses" in his experiences.

**Mark's individual structural description.** The description of Mark's interview is focused on the notion of acceptance as a person. Mark emphasized that despite his son's hearing loss, Barry has been able to be successful within his evolving environments in communicating with others, sometimes through the use of technology and other accommodations, which helps Barry to be seen as "normal," or a person without hearing loss, in the context of this interview. Rather than focusing on the hearing loss and defining his son by this attribute, this parent chose to focus on the other features that define his son and view him as a person first (e.g., baseball player, hard worker, friendly). This belief was evident when Mark described hearing individuals by referring to them as "individuals without hearing loss" and to say "individuals with hearing loss" instead of saying "deaf individuals" or "hearing impaired individuals." By positioning these words

from a standpoint of person-first and using person-first language, Mark reiterated his preference for viewing and accepting a person by his overall self (e.g., the kind of person his son is) rather than focusing on individual singular attributes of identity (e.g., hearing loss) .

However, in spite of Mark's view of identifying his son primarily as a person first, this father displayed awareness of the permanency of his son's hearing loss and recognized the hearing loss will not be restored or improved over time. Mark expressed his son's ability to compensate for his hearing loss does evolve or change based on the interactions with others and environments in which communication is occurring. For example, in certain environments (e.g., quiet classroom), Mark may identify his son as a normal person or a person with full hearing identity type versus as a person with hearing loss identity type in more distracting situations (e.g., noisy restaurant and trying to place his order with a server). Throughout the interview, Mark wondered if there were times when his son honestly did not hear the information or if he was choosing to ignore it as typical adolescent behavior. In the times when he knew his son was not hearing correctly, Mark expressed shock at just how much information his son was unable to hear. When discussing characteristics of the deaf identity type, Mark defined use of sign language as a salient trait.

Regardless of which identity type was selected for his son by others, his son, and himself, this father expressed a sense of gratitude for his son's teachers, coaches, and others in that they seemed to understand what was needed for his son to be successful in this world. Conversely, Mark reported he experienced the perception of others viewing

his son as inferior due to having a hearing loss. A stigma or type of aura seems to act as a shroud to the hearing loss as it is not as socially accepted as vision loss might be in the eyes of this father. Mark expressed frustration over others viewing his son as less than others solely based on the fact his son has hearing loss throughout the interview. Yet Mark also shared his sense of pride over his son's accomplishments and use of compensatory listening skills in spite of the challenges Barry faces as a result of the hearing loss. Mark further hypothesized his son may be a better person due to experiencing hearing loss in his life.

#### **Kate: A Mother's Perception of Identity as it Relates to Hearing Loss**

**Kate's individual profile.** Kate is a married mother of three children in the Sand family. This family resides in the same school district where the children attend school. Kate is married to Scott, another caregiver/parent participant in the present study. Kate's youngest child, Danny, a 12-year-old who is enrolled in the fifth grade, has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and has a history of fluctuating hearing levels. He wears hearing aids in both ears and has received D/HH support services in the general education setting since the third grade (i.e., for the past two years). With a smile on her face, Kate described Danny as being "a very pleasing child who likes to make sure everyone is happy. He's outgoing, kind, a leader, and has high expectations for himself! We call him an 'old soul' and he is very brave and talkative."

**Kate's individual textural description.** In terms of his hearing, Kate recognized the impact of hearing loss on identifying her child before he received hearing aids by

saying his “hearing was not normal and if you asked him a question, he did not answer because he did not hear the questions but he is better about it now with his hearing aids.” Kate shared that her son’s confidence and self-esteem seemed to increase after he started wearing his hearing aids in the third grade and was able to hear better and was also able to more readily access communication. Kate reflected that her son’s hearing aids are an extension of him through this example,

we went to the allergist recently and he had to take the hearing aids out so they could look at his ears. When they were done, Danny popped the hearing aids right back in and said the hearing aids were a part of him; they make up who he is.

Kate further revealed there are times when others seem to overlook her son’s hearing loss and they “don’t realize how much work it takes for him to hear; they don’t realize how hard he is working to communicate with others on a daily basis.” She disclosed others seem to think he’s “normal due to his wearing his hearing aids and being able to communicate as if he had 100% hearing” by using his compensatory listening skills. While others may identify her son as having a hearing identity type, for this mother, her son is a person with hearing loss and hard of hearing. According to Kate, the person with hearing loss identity type matches the “actual physical medical problem while the hard of hearing identity type goes with what happens as a result of the hearing loss.” Kate also explained how, for her, the hard of hearing identity type is a result of hearing loss. She said, “my son is hard of hearing *because* of his hearing loss.” Regarding the deaf identity type, Kate views individuals who would identify themselves as the deaf identity type as not being able to hear at all, even with use of hearing aids.

Kate spoke about how her son's identity type can change depending on the situation and with whom he is interacting by saying he is a leader in some aspects but in other circumstances can display low self-esteem. She also shared that due to her son's strong speech skills, others have a tendency to not realize he has hearing loss,

they listen to Danny and as far as his speech goes, we have worked so hard on it. It is very very good and really hard to pick out that he has a hearing loss because I stayed home for 17 years with him. His older brother, sister, and I worked and worked with his speech to try to get it to where he is right now. So many people think how can he be hard of hearing? How can he have moderate to severe hearing loss and that bad?

Kate also explained how those who are not around her son a lot may have a tendency to forget the impact of his hearing loss on communication,

I think other people do forget sometimes. Other family members and those who aren't around him all the time because we will hear them say at family functions, oh my gosh, so sorry, I forgot and they'll come around to the front of Danny and talk to him face to face.

In thinking about the long term and impacts of hearing loss on her son's ever shifting identity type, Kate, shared, "if anything, his hearing loss is going to get worse. So the hearing loss might create more challenges as he gets older. Driving, being in more crowds, and different settings will create new challenges." Kate reflected that although others' perceptions of her son's identity type can be fluid and change, for her as Danny's mother, the hearing loss

is always right there with me. It's always right there with us at the forefront that we always remember when we're in the car and things like that, we have to always turn around and talk to him. It is really ingrained in our family.

As a family, all members work together to meet Danny's "special need." Kate further shared that she "doesn't think there will ever come a time that this awareness will go away" as Danny matures to adulthood because "the hearing loss is never going to get better." In spite of the permanency of hearing loss, Kate spoke of her son's hearing loss as "not being new or unusual for the family due to having a niece with hearing loss." She also explained hearing loss in regards to her son was not currently seen as an "obstacle. When he was younger, it was more of a challenge, especially before he received his hearing aids, because the hearing loss did create some problems." When asked for one piece of advice to share with other caregivers/parents of children with hearing loss, Kate advised the caregivers/parents to "be diligent and to not let others tell them the hearing loss is not a big deal." Kate also spoke of concern over transition when Danny is older by saying, "I'm not going to be around as much so he is going to have to take on more responsibilities."

In thinking outside the family, Kate commented her son "works well with older people; sometimes he works better with older people than with those in his peer group" and reflected that this trait is not a bad thing, "he would rather sit down and talk with an adult versus a child his own age but he still gets along with peers in his own age group in spite of this preference." In describing Danny's friends, Kate said they are "outgoing and active. They stick up for him if someone does say something about his hearing" and let others know what accommodations they need to make to communicate with Danny (e.g., looking at Danny when talking, use repetition). Kate shared that her son has a lot of

acquaintances with a very strong group of close friends and that he gets along with a variety of different people since “it seems like everyone likes Danny.”

Even though Danny is currently doing well socially, Kate discussed the struggles her son went through to communicate with others prior to diagnosis of hearing loss and receiving hearing aids,

He worked so hard to try to hear people and it was exhausting for him. It was one of those things I could never understand why he was so tired all the time. He would come home, and by 7:00, he was in bed asleep and I didn't know why. Well, it's because he was expending so much energy trying to hear. After receiving his hearing aids, we still struggled with the communication when we would go places and he still wasn't talking and I would have to explain why he isn't talking. Or I asked the question why isn't he answering me? I think having to explain it to everyone was one of the biggest challenges.

In cases where she was to explain to others what was happening, Kate cited having patience and being willing to explain the situation to the people around you as being two primary ways of dealing with these scenarios.

Thinking back to prior to diagnosis, Kate spoke of how before her son was diagnosed with hearing loss, the otolaryngologists had written off her concerns by saying “the older siblings were talking for Danny” and that was why he was not talking as much as she expected. As a result, “a lot of time was lost and Danny did not speak for a long time” so Kate advised other caregivers/parents who may think their children have a hearing loss to persevere and be diligent in seeking medical opinions. Once diagnosis was established, Kate shared the following as accommodations that have assisted Danny in the past and currently, allow for speech reading, have a clear view of the face,

advocate by explaining his needs and about hearing loss, and asking questions about what was said.

**Kate's individual structural description.** The description of Kate's interview is focused on the notion of perseverance and adjustment. Kate emphasized that despite difficulties in obtaining a diagnosis of her son's hearing loss, Danny has been able to be successful within his evolving environments in communicating with others, sometimes through the use of technology and through using compensatory listening skills. Throughout her interview, Kate focused on how much a part of her son hearing loss is (e.g., hearing aids are an extension or part of her son), even if others did not realize how much work it took on her son's part to fit in with the hearing world.

Kate perceives a person is hard of hearing as a result of having hearing loss. She views the hard of hearing identity type as being the action in a person having a difficult time hearing or comprehending language due to having a degree of hearing loss. However, this difficulty or being hard of hearing can be assisted with accommodations and through the support of friends. Kate shared that her son's friends have been crucial in providing assistance and support when he has trouble hearing in the environment. Due to this difficulty in some situations, Kate explained her son's identity type related to hearing loss may shift depending upon the situation, environment, and interactions with others. Similarly, as her son gets older, this mother expressed a desire for her son to be independent and to handle transitions in spite of the presence of his hearing loss since she and her husband will not always be there to support their son.

**Danny: A Student's Perception of Identity as it Relates to Hearing Loss**

**Danny's individual profile.** Danny, a 12-year-old, is the youngest child in the Sand family. This family is comprised of an older brother, older sister, mother, and father. Danny's caregivers, Scott and Kate, also participated in the study. Danny lives with his family in his home in the same school district where he attends school. Danny has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and has a history of fluctuating hearing levels. He wears hearing aids in both ears and has received D/HH support services in the general education setting since the third grade (i.e., for the past two years). Talkative and inquisitive by nature, Danny calls himself "open minded and imaginative" and while he struggles with writing, he enjoys giving speeches.

**Danny's individual textural description.** Danny revealed he has "big goals in politics and history and big ideas in life in terms of a job or a career." Hobbies and interests of Danny include sports, karate, and debating. With regard to hearing status, Danny described those with a hearing identity type as being average since there is no hearing loss in these individuals. In spite of this criterion, Danny identifies himself as the hearing identity type at times even though he himself has hearing loss and wears hearing aids. Danny shared that "people are mean sometimes because I have the hearing aids or because I have hearing loss." When people ask why he wears hearing aids, Danny will find himself in an informational role educating others about his needs, "I tell them I can't hear well and the hearing aids help me hear better so they understand why I have hearing aids after that." Danny recommends students with hearing loss to try hearing aids, or surgery if it will help them to hear, if that is what they would like.

According to Danny, when he wears his hearing aids, he considers himself to be a member of the person with hearing loss identity type. He also stated a person with hearing loss could also be “someone who does not need hearing aids who could communicate through speech.” When presented with the card sort activity that contained the list of identity types, Danny was not familiar with the hard of hearing identity type as can be seen in this quotation, “I don’t think I have trouble hearing with my hearing aids in so I don’t fit in with the hard of hearing identity type.” When discussing the deaf identity type, Danny explained a “person who is deaf would not be able to hear sounds or they can hear sounds but they are unable to understand what is being said.” Danny also said that if he were to not wear his hearing aids, then he would identify himself as the deaf identity type. Further, for Danny, to be deaf means sign language would be used to communicate with others.

Regardless of selected identity type, Danny explained that there are times he does forget he has hearing loss “but then something comes up that would remind me” such as someone asking him what he has in his ears or having a hard time hearing information in a conversation when he is upstairs and the speaker is downstairs or vice versa. Moreover, no matter which identity type is selected, Danny advised to not “stay one identity type forever” in that a person with hearing loss can be many different identity types in spite of having hearing loss through using compensatory listening skills and wearing hearing aids. He said he “sometimes forgets I have hearing aids because I hear and think I am hearing everyone well compared to when I was younger before I had hearing aids when I would completely miss what was said.”

When discussing interactions with his caregivers/parents and siblings, Danny explained “my family is used to my hearing loss. I don’t think they mind repeating things to me at all.” Danny also shared he has a cousin who also has hearing loss but he described her hearing loss as “worse than mine because without her hearing aids in she can’t hear whereas I can hear a little bit.” He explained that he sees her at family functions every now and then.

Outside the family unit, within interactions with peers, Danny spoke about an instance of being bullied due to having hearing loss but was clear that individuals with hearing loss are not always singled out for that reason. In cases of peers teasing him, he shared that “puts it out of my mind. If it happens, then I confront them and talk with them. If it happens again, then I will tell the teacher because she won’t stand for that.” Danny spoke of his friends and explained “we have a good amount of differences and likes. We usually play Xbox or Playstation, like certain shows and games but we also have some differences too.” Some of the differences Danny revealed between his friends and him are that his friends may react to things differently in anger while Danny is of a more calm nature. Danny also explained he is a “hard worker and strives to get good grades in school while my friends would rather play games than do homework.”

Danny discussed instances where his peers have asked him about his hearing aids and hearing loss and will try to educate them, “I try to explain to them about my hearing aids and tell them what they are for to help them understand.” Accommodations that have been and are currently successful with Danny are to ask for repetition and check for understanding and to keep spare hearing aid batteries on hand for his hearing aids.

Danny observed adults sometimes have a better understanding than his peers. Danny revealed that due to his hearing loss, he may sometimes struggle with making new friends and his confidence level may be impacted by the hearing loss.

Speaking to the struggles with self-esteem or confidence in himself, Danny expressed worry over being perceived as a nuisance with others, “Sometimes I feel that I’m a bother since I have to ask what did you say a lot and people have to keep repeating things.” Danny also shared his frustrations over “when people are not willing to repeat themselves and when they say I should have been listening so they don’t have to repeat themselves.” Danny recommended that, during these times of frustration, students with hearing loss should “keep friends with hearing loss, if you have any, close to you because if something were to happen and you don’t know what to do then you could ask them for advice” as a type of emotional support system. Danny also urged students with hearing loss to

move on with their lives. Deal with the hearing loss and then try to be president of your class, or try out for band and chorus, or do sports; it doesn’t matter what you do but just try and move on so you don’t get stuck and not see where you can go!

Even though he is in fifth grade, Danny has already given thought to what he would like to do once he is finished with his schooling. He has plans to be a politician or a professor someday. However, that does not mean he has not worried about the steps it will take to reach those goals,

I’m worried that people will not be willing to repeat things and help me to hear missed information at the middle school or the high school. What if they won’t

put up with my hearing loss? I'm sure they will but I'm still afraid for people to not be as receptive to it as they are in the elementary school.

**Danny's individual structural description.** The descriptive structure of Danny's interview is focused on the notion of ambition. Danny stressed the importance of accepting oneself as is and then moving on and accomplishing goals, whatever they may be. He spoke of the fluidity of the identity types based on the environment and people with whom he is interacting and advised individuals with hearing loss to not become fixated on type but rather on what he or she can do in spite of obstacles or challenges. This elementary student struggled with issues related to low self-esteem and self confidence as a result of the challenges he has faced or the teasing he has endured from peers in the past but currently serves as an educational advocate to others within the school and community settings. Danny shared examples of informing others of his hearing loss, the purpose of his hearing aids, and accommodations that are successful for him. With regard to hearing status and throughout his interview Danny spoke about the differences in identity types and which ones best described him (i.e., hearing identity type in most situations, person with hearing loss when he is wearing his hearing aids, deaf when he does not have his hearing aids in) but he was unaware of the hard of hearing identity type and characteristics of members of that identity type.

### **Devin: A Student's Perception of Identity as it Relates to Hearing Loss**

**Devin's individual profile.** Devin is the oldest child in the Coral family and is 16 years old. This family consists of a younger sister, mother, and father and is the ninth grade. Devin lives with his family in his home which is not located in the same school

district where he attends school. He has been diagnosed with a moderate to severe sensorineural hearing loss in both ears, and wears hearing aids in both ears. Devin has received D/HH support services in the general education setting since he was three years old (i.e., for 13 years). With a sense of independence and tossing his hair out of his eyes, Devin described himself as a 16 year old who enjoys driving, playing video games, spending time with his friends and girlfriend, hunting, fishing, and other social activities (e.g., talking, hanging out with friends in the lobby). He commented that he does not enjoy nor like school.

**Devin's individual textural description.** With regard to hearing status, Devin defined individuals as being hearing if they were “totally normal and didn't have to do anything.” He explained not only can he communicate with deaf individuals through sign language but he can also “talk with normal people, especially at home and in my neighborhood.” Devin has often found himself in the role of explaining the different identity types to his hearing peers, “if they don't have the experience then I tell my friends and explain how I can be both by using my voice with them but communicating through sign language with the deaf students.” Devin also recognized the impact hearing aids have on him in dealing with his hearing loss and in allowing him to fit in with the hearing identity type.

According to Devin, a person with hearing loss “might not be able to interact with other people in different groups.” When presented with the card sort activity that contained the list of identity types, Devin chose the hard of hearing identity type “because there is not [a] person who is hard of hearing with hearing loss since you're

going to be hard of hearing, deaf, or hearing.” Devin also said since he could communicate with others orally (e.g., using his voice) and via sign language, then the hard of hearing category would go between hearing and deaf since he could communicate with individuals from both groups. Devin spoke of an advantage to falling in the hard of hearing category as being able to serve as an interpreter. Through signing for individuals with hearing loss, Devin is able to prevent their feeling isolated and he serves as the bridge or connector between deaf individuals and hearing individuals.

Devin spoke of having one foot in the deaf world and one foot in the hearing world in that he is able to communicate with both groups of people (i.e., oral communication and sign language). He explained he can be both deaf and hearing at the same time due to this communicative ability even though he identifies himself as being the hard of hearing identity type, “I can hear but I can still communicate with deaf people and not have to be all selfish and be a normal hearing person. I can fit in both worlds, which is awesome.” He credits this versatility to blend in with both groups to his hearing aids and further to his caregivers/parents for buying them for him,

My parents encouraged me to wear my hearing aids to make me hear and all that so I’m just like, it’s almost a gift for me since I can do both [communicate with deaf and hearing people] now. Or I can act as an interpreter since I can hear what they’re saying and sign to them.

When discussing the deaf identity type, Devin commented,

well, for me, it would suck to be deaf in my opinion because I see how much my deaf friends miss by not being able to hear anything. School is harder and life would be harder. It might be hard to get a job because some guy might be like oh, I don’t want this guy because he’s deaf or I don’t want this guy because he can’t

do anything. I wouldn't want to be deaf because for me, it feels to me like the world has shut down on me no matter how hard I work.

Devin also said individuals who identify themselves as deaf typically do not wear hearing aids or cochlear implants. Knowing sign language enables a person to fall between identity types according to Devin and this knowledge does not necessarily mean a person who can communicate via sign language would fall in the deaf identity type. A person fluent in sign language would be able to interact with deaf people and also with hearing people as reported by Devin.

Devin perceives individuals who identify themselves as the deaf identity type will be isolated in spite of working hard to belong to a group or blend in with the hearing world by saying, "I feel like the world would be shutting down on you and you can't hear anything whereas if an individual is hearing, then it's the opening of everything."

Devin viewed identity as being fluid by being able to interact with a variety of individuals at home and in school by stating, "you can blend in and be in different groups and interact with different people. You would have more friends that way too" by being friendly with individuals in many different groups. Devin expanded on this distinction between groups by sharing he can "communicate with deaf friends by using sign language and I can hang out with these other friends by using my voice while I can be me when hanging out with the hard of hearing kids." Devin shared that he has been asked to explain these differing identity types by his peers. A story he relates,

At lunch the other day, I got asked, what's it like being hard of hearing? I said it's fine right now and he asked why. It's because I can interact with both people,

hearing and deaf. I'm in the middle so I can talk with you but when you leave, I can talk to this other guy with my hands.

Devin also spoke about seeing others shift identities by saying, "I've seen some hard of hearing people who just want to be with hearing people and some hard of hearing people who just want to go with the deaf people." He also views the hearing world as identifying him as deaf while he would identify himself as hearing. However, Devin shared that even though he may identify himself as hearing, that the hearing loss is "always there in the back of your mind" since he has had the hearing loss for so long since he was a small child.

When thinking about interactions with caregivers/parents, Devin expressed gratitude toward his caregivers/parents for buying and encouraging him to wear his hearing aids when he was younger. He believes the hearing aids are a large factor in why he identifies himself as a hard of hearing identity type. He recognized not all of his friends or peers had the same experiences with their caregivers/parents. Beyond interactions with caregivers/parents, Devin listed the following activities he enjoys when interacting with his peers, "hanging out with my friends, going out with my girlfriend, talking with my friends, and hanging out in the lobby" of the high school between classes. In the home setting, Devin enjoys playing with friends in his neighborhood and has bonded over things they have in common with each other. When issues surface related to his hearing within his social circle, Devin mentioned his peers may sometimes neglect to provide accommodations in assisting him with hearing. His peers may forget Devin needs to be seated near the speaker or have a view of the face to speechread as this

statement from Devin reflects, “my friends are always like what are you looking at? That’s when I say I’m looking at your lips.” Devin also talked about times when his hearing peers seem to forget he has hearing loss by not accommodating to his needs when conversing,

I told my buddy how he was talking to the other people when I was trying to listen but I couldn’t hear. My buddy didn’t understand what the big deal was because they all think I can just be part of the group when I really am not hearing much of what is being said.

Another listening challenge Devin encounters when he interacts with others, is when

others talk real soft or if they don’t attempt to talk to me at all because they think I can’t hear them. They don’t care about you. They think ah, he’s deaf or he’s hard of hearing so why would I care and try to get his attention when I could talk to someone else who can hear me. They don’t want to deal with having to see face to face or moving from one corner of the room to the other to talk. If that is how they are, then I don’t care either. I will just leave.

Accommodations that have been and are currently successful with Devin are reading lips, seeing the speaker’s face, being close to the speaker, reduced background noise, clear view of the speakers’ lips (e.g., no beards, goatees, or mustaches), talking at an appropriate volume, and including Devin in the conversation.

When asked what one piece of advice he would share with another student who had hearing loss, Devin said he would tell them he understands what it is like “so they don’t feel lonely and they can be with somebody else who also has hearing loss.” Devin also spoke of a sense of isolation in regard to himself in comparison with others due to

his ability to communicate with both hearing and deaf individuals since he did not fit in with either identity type but rather was in his own separate group.

**Devin's individual structural description.** The descriptive structure of Devin's interview is focused on versatility and a sense of belonging. Devin spoke of his belonging to two different identity types by calling himself hard of hearing. He explained the hard of hearing identity type is able to "walk the line" because he can communicate with individuals in the deaf identity type group and with individuals in the hearing identity type group. He enjoyed this aspect of himself in that he could have friends from both groups but also discussed the drawback of not having a defined group to belong to as a member of the hard of hearing identity type. This teenager also spoke of the importance of feeling a sense of belonging to eliminate the feelings of isolation one may feel as an individual with hearing loss in a hearing world.

Devin viewed his hearing aids as a gateway to the hearing world and expressed appreciation his hearing loss was not more severe. He recognized the importance of functioning hearing aids in allowing him to blend in with individuals who do not have hearing loss. With parental involvement from a young age, coupled with use of technology, Devin was able to establish an identity type of hearing in most situations. Devin perceived being deaf as a negative in that members of a deaf identity type would feel separated and distinct from the hearing world and may even struggle with finding jobs and accomplishing other transition goals as a result of hearing loss or others' perceptions of hearing loss. Devin spoke of these differing perceptions of identity

throughout his interview in that others may identify him as a particular identity type he does not necessarily identify himself as.

### **An Overview of Participants' Selected Identity Types**

The participants' perceptions of identity related to hearing loss varied across data sets (i.e., caregivers/parents and students). These perceptions clearly influenced how they responded to the interview questions and, in turn, how each of these perceptions contributed to the findings. Participants presented with a vast range of experiences and a plethora of perceptions on identity especially in how they defined the identity types related to hearing loss. Although differing in the definitions of identity types of hearing loss and deafness based on personal experiences and backgrounds the participants viewed themselves, or their children, as "normal," "regular," or of the hearing identity type, as is illustrated in the following sections. The richness of their perspectives and experiences enhanced the description of the essence of perceptions of identity as related to hearing loss.

The differences in meanings of identity types as perceived by the participants became most evident when discussing identity type related to hearing loss and interactions with others in their environments. The caregivers/parents who identified their children as members of the hearing identity type or normal were adamant about treating their children as if they were like other children who did not have hearing loss. The students who identified themselves as members of the hearing identity type emphasized the importance of wearing hearing aids to gain access to sound and

communication which therefore enabled them to participate as hearing members of society in most situations.

Across both data sets, participants held differing views of what each identity type meant for them. Consequently, these perceptions demonstrated contrasting connotations of what each identity type meant. For example, one mother viewed being called the hard of hearing identity type as being a negative insult because for her, individuals who are hard of hearing do not advocate for themselves. Yet another mother explained that her son is hard of hearing as a result of his hearing loss and she did not associate a positive or negative connotation to that identity type. Across data sets, participants agreed on various aspects of identity related to hearing loss through discussing experiences or situations in their lives. For example, three of the four student participants and all six caregiver/parent participants mentioned communicating via sign language as a salient trait or characteristic of an individual who would identify him or herself as a member of the deaf identity type.

All of the participants, irrespective of identity type selected by the participants, acknowledged the impact of hearing loss on an individual's identity. Permanency of hearing loss, adjustment by the family and others who interact with the child through providing accommodations, and management of the technology that assists with hearing and access to communication were some of the many factors that the participants mentioned in their conceptualizations of individuals with hearing loss. In spite of these factors, children were still viewed as members of the hearing identity as is evident by one father when he explained his son was "as normal as can be given his limitations or his

challenges that come out of the hearing” (Mark). One of the student participants supports this notion by sharing that when he wears his hearing aids, he considers himself to be a person with a hearing identity rather than a person with hearing loss identity type, by saying, “I’m not really a person with hearing loss because I have hearing aids which help to make me like a hearing person” (Larry). The next section of this chapter provides a description of the essence of perceptions of identity related to hearing loss.

### **The Essence of Perceptions of Identity Related to Hearing Loss**

The next section of the findings describes the essence of perceptions of identity related to hearing loss in both data sets (i.e., students and caregivers/parents). During the ten individual interviews, it became evident that interactions with others and the contexts or environments in which communication occurred played a critical role on perceptions of identity related to hearing loss within both data sets of participants (i.e., students and caregivers/parents). Fluidity or being able to move from one identity type to another emerged within the data. Management and resiliency, in the sense that participants were able to provide information regarding their hearing losses to others in an informational role, surfaced as themes related to perceptions of identity and hearing loss. Other themes from the data will be provided in the remainder of this section through rich excerpts from the interviews.

The majority of participants discussed their perceptions of the hearing identity type as being “normal” which was defined within the context of the study (i.e., a person with no hearing loss was deemed hearing or normal). However, for some of the participants (i.e., three students and two caregivers/parents), a particular emphasis was

placed upon the importance of being able to function within the dominant hearing world through use of technology such as hearing aids, sound field amplification systems, and cochlear implants as can be seen by this quotation from a mother participant, “with the hearing aids Barry fits into the hearing identity category due to his hearing aids bringing his functioning up to normal capacity.”

The following section will present data that emerged from the ten individual interviews. Three critical essences emerged for these participants regarding perceptions of identity related to hearing status: (a) self determined identity type; (b) notion of fluidity; and (c) a sense of management and resiliency. The following quotation from one student participant, Barry, encompasses these three essences,

I can explain that I can still hear a little bit without my hearing aids in, just not as well as other people can hear. I’m not going to give them like percentages of what I can hear or when I’m taking hearing tests and stuff like that . . . but I will use the deaf identity type at times because I guess people understand or recognize someone who’s deaf even though I don’t see myself that way.

### **Self Determined Identity Types**

**Hearing.** All of the participants referred to the hearing identity type as that of the normal or regular individual or that of a typically developing and fully hearing person. Even though the four student participants who were diagnosed with a hearing loss they and their caregivers/parents categorized themselves as members of the hearing identity type in most situations. Three caregivers/parents emphasized that despite their sons’ hearing losses the boys have been able to be successful when communicating with others within their evolving environments, through the use of technology or other

accommodations. Through using a strengths-based or positives-based attitude, caregivers/parents enable their sons to be seen as “normal,” or as individuals without hearing loss. Mark also explained that “with the hearing aids Barry fits into the hearing identity category due to his hearing aids bringing his functioning up to normal capacity.” Scott stated multiple times throughout his interview that his son “can hear just fine even though I don’t know the specifics of his hearing loss.” He also revealed there are times when it is easy to overlook his son’s hearing loss and

very easy to just treat him like a kid with no issues since his hearing loss isn’t that severe in the way it is managed right now with hearing aids. He deals with his hearing loss so well. We’re lucky his hearing is not 100% impaired.

As a parent of a teenage son with hearing loss who wears hearing aids in both ears, when asked what one piece of advice he would share with other parents of children with hearing loss, Mark responded by saying,

I would tell them to try to integrate their children and make them as normal as possible where there’s not a spotlight on them or there’s not something that’s drawing attention to the fact that they have hearing loss but to just try to make them as normal a kid as possible.

This father suggests that parents treat their children with hearing loss as children who do have “full hearing” because his son is “as normal as can be given his limitations or his challenges that come out of the hearing.” Mark also revealed his son may select a differing identity type from what he, as his father, might choose by saying, “Barry sees himself as perfectly normal and actually gets frustrated when my wife and I try to accommodate or try to give him a little extra help.”

Another instance of differing perceptions of identity regarding the hearing identity type was evident during Shannon's interview when she explained that there is often a gap among her perception of identity of her son with others' perceptions of identity of her son. She attributes this disconnect to her background knowledge of her son's abilities,

I know that he's not totally deaf but if I were to talk to people about him, and if I said he was hearing, I think that would be misleading because when you list someone as hearing, you assume they hear everything you say.

In contrast, Kate revealed there are times when others seem to overlook her son's hearing loss and they "don't realize how much work it takes for him to hear; they don't realize how hard he is working to communicate with others on a daily basis." She asserted others seem to think he's "normal due to his wearing his hearing aids and being able to communicate as if he had 100% hearing" by using his compensatory listening skills. She also shared that due to her son's excellent speech intelligibility, others have a tendency to think he does not have hearing loss,

they listen to Danny and as far as his speech goes, we have worked so hard on it. It is very very good and really hard to pick out that he has a hearing loss because I stayed home for 17 years with him. His older brother, sister, and I worked and worked with his speech to try to get it to where he is right now. So many people think how can he be hard of hearing? How can he have moderate to severe hearing loss and that bad?

Regarding the hearing identity type, Eileen recognized the impact hearing loss has on identifying her child before he received his hearing aids by saying,

if you tried to talk to him without his hearing aids in, forget it, because he could not hear. Once he got his hearing aids, it was easier to communicate with him and

he doesn't play the game of oh, I can't hear you, I'm deaf or anything like that so it's just he's a normal kid and we treat him that way. We treat him as we would any other kid in our home.

Eileen also made the clear distinction that she

really truly sees Larry primarily as hearing and I also look at him as hard headed *not* hard of hearing. I also don't look at him as a person with hearing loss because he hears everything we say with the hearing aids in and even without them in during the right situation. I mean if you're in a noisy room, he's not going to pick up everything you say. He wants so badly to be seen as normal. I see him as a hearing person but how he interacts with people will make you think of the hard of hearing identity type or someone with hearing loss or being impaired. When he has problems, that's when we bring up or talk about the hearing loss, like well, he doesn't have his hearing aids so just talk a little bit louder.

Eileen also shared her view of a person with a cochlear implant as being a member of the hearing identity type as well since they are "hearing things."

Eileen emphasized that the use of technology, such as hearing aids, further adds to the perception of her son as being a member of the hearing identity type. By wearing his hearing aids he is able to hear information and communicate using speech,

The hearing aids blend in with his hair and his speech is so clear. A lot of people on the outside don't realize he has hearing loss and would probably put him in the hearing identity type category if they had to choose between deaf and hearing.

Scott recognized the impact of hearing aids on viewing his son as having a hearing identity, "Through using his relatively simple hearing aids, he sounds normal, and he can hear just fine." Scott also clarified that when he uses the term, fine, he means "average or gets by" and that his son, Danny, is able to fit in or "function mostly normally" within the hearing world. In contrast, throughout her interview, Danny's mother, Kate, focused on

how integral her son's hearing loss is to his identity type (e.g., hearing aids are an extension or part of her son), even if others did not realize how much effort her son expends to fit in with the hearing world.

The student participants were in agreement with their caregivers/parents on their perceptions of hearing aids influencing the identity type they selected for themselves. Barry emphasized that in spite of having hearing loss since birth, and wearing hearing aids, he views himself as a hearing person in most situations, in large part thanks to the involvement of his parents in obtaining resources and providing him access to communication. Barry also recognized that even though he considers himself as a member of the hearing identity type, his hearing loss is a part of him and contributes to his overall perception of himself. This can be seen in Barry's comments regarding participating in the study, "the whole conversation today, definitely, helped me in the fact that I can appreciate and recognize everything that I am" in regards to hearing loss and identity by thinking about "the parts that make me me."

Danny recognized the importance of his wearing hearing aids to maintain his hearing identity type. Devin also viewed his hearing aids as a gateway to the hearing world. He acknowledged the importance of functioning hearing aids in allowing him to blend in with individuals who do not have hearing loss. With parental involvement from a young age, coupled with use of technology, Devin was able to establish a hearing identity type for himself in most situations.

Another student participant focused on an individual's ability to communicate with the hearing world as a defining attribute of the hearing identity type. Larry

highlighted the fact that as long as an individual can communicate with others in the hearing world, no matter the communication mode (e.g., signing versus speaking), then this individual can be defined as having a hearing identity type because he or she is able to communicate. According to Larry, when he wears his hearing aids, he considers himself to be a person with a hearing identity rather than a person with hearing loss identity type, “I’m not really a person with hearing loss because I have hearing aids which help to make me like a hearing person.” He also said a person who communicates using sign language would have a hearing identity type since this person is able to “fit into the hearing world by communicating using a different mode.” Similarly, Barry shared his belief that everyone with hearing loss will fall into a hearing identity type by saying, “from my perspective, everyone falls into the hearing category because each person is hearing as much as he or she can, even if it’s just a little bit.”

*Other technology (hearing aids, cochlear implants, sound field amplification systems).* When selecting the hearing identity type, technology was a defining factor for all the participants. Hearing aids were specifically mentioned as tools which enabled the students and caregivers/parents to identify the students as members of the hearing identity type even if others did not view these students as members of this category or identity type. In spite of the permanency of the hearing loss, a father participant, Mark, shared that through the use of technology (i.e., hearing aids), Barry can successfully communicate with others since Barry’s “hearing aids allow him to hear perfectly normal.” Technology that has assisted Mark’s son, both in the past and at present, include sound field amplification systems in his classrooms, hearing aids, and a vibrating

shaker alarm clock. Barry's mother, Jessica, acknowledged that technology has assisted her son with communicating with others regardless of his identity type, and shared the analogy she uses to explain her son's hearing loss to others by saying, "As soon as Barry is around walls or out of range, he'll have more difficulty hearing but we often say that he wears hearing aids as people wear glasses in order to function appropriately."

Jessica also suggested that if Barry were unable to benefit from wearing hearing aids that his hearing loss would have a larger impact on his life and that he might not necessarily fall into the hearing identity type since the hearing loss "would impact his functioning and the impact of his hearing loss would be greater than it is now." She emphasized that technology needed to be functional in order for it to be valuable and that she hopes to see continued improvements and advancements in hearing aids and listening technology. In terms of her son's hearing loss, Kate recognized the impact of hearing loss as contributing to her son's identity and interactions with him prior to his using his hearing aids by saying his "hearing was not normal and if you asked him a question, he did not answer because he did not hear the questions but he is better about it now with his hearing aids."

Shannon shared a story concerning when she and her husband initially obtained hearing aids for their son, Devin. In order to help Devin communicate with others by providing access to sound and influencing others' perceptions of her son as a hearing individual, Shannon spoke of how she, as Devin's mother, had to challenge the system in providing the best technology for her son,

when he was three years old, I took him to an office to get his first pair of hearing aids. This was back in the day, when he had Medicaid, so the state did not pay for digital hearing aids. They only paid for analog hearing aids which were \$300 and were junk. The hearing aid provider actually said to me, well, he's little and he doesn't know what he's missing and I was appalled. I thought are you kidding me? Devin has an entire life of learning ahead of him. Why would I give him the cheapest thing you're giving me when digital hearing aids are available? My husband and I bought Devin digital hearing aids. We never went through the state. We laid out the \$5,000 and bought the best hearing aids we could buy. When you lose your hearing at age 65, and you miss a word in a sentence, you can kind of figure out what people are saying, but not when you are three!

Therefore, Shannon and her husband sought out ways to increase their son's access to sounds and communication through acquiring technology.

An added benefit to use of listening technology as described by another mother was evident when Kate shared that her son's confidence and self-esteem seemed to increase after he started wearing his hearing aids in the third grade. She explained her son was able to hear better and also able to more readily access communication. Kate reflected that her son's hearing aids are an extension of him by sharing a story about a recent trip to an otolaryngologist's office,

we went to the allergist recently and he had to take the hearing aids out so they could look at his ears. When they were done, Danny popped the hearing aids right back in not wanting to leave them out any longer. He said the hearing aids were a part of him; they make up who he is.

Another mother, Eileen, echoed this sentiment by sharing that her son's hearing aids are "a part of him and that when she looks at her son, she views the hearing aids as an extension of him."

Not all of the caregivers/parents reported positive instances of hearing aid use in their children. Eileen conveyed that although her son started wearing hearing aids around the age of four or five that now, as a teenager, there are times he does not wear them, “He says he doesn’t need to wear his hearing aids.” There have been times where he has not worn the hearing aids and “used them as an excuse” to not do something if he did not hear what was said. In addition to going through stages of not wanting to wear the hearing aids, Eileen also talked about the evolution of hearing aid technology over the years in that her son

has a choice of colors that match skin tone or hair color. When he was younger, he used to have the colorful ear molds and had red, green, white, red, and blue but now his ear molds are a frosty white and are translucent so they are not as noticeable, which he likes.

She also reflected that her son’s glasses sometimes interfere with his hearing aids and cause irritation at times but that he is more concerned about the “social pressure” in sticking out from his peers through wearing hearing aids since he wants to be viewed as hearing or normal. Conversely, this same mother participant reported there are times her son may remove the hearing aids or “turn them off if he’s trying to block out sounds because he’s tired or he’s trying to read and he doesn’t want any distractions.”

The student participants placed importance on utilizing the listening technology consistently in order to maintain their hearing identity types as illustrated by Barry, “I’m going to say I do have, I am a person with hearing loss but then I’m also going to say that when I have my hearing aids in, I’m almost the same as a person with hearing.” When the technology (i.e., hearing aids) does work properly, little to no attention is given to his

hearing loss according to Barry. “There are definite times when I have my hearing aids in that I don’t pay attention to my hearing at all and it doesn’t bother me or I don’t think about it at all.” However, when the hearing aids malfunction, the hearing loss has more of an impact on Barry’s life and he may function more so as a person with hearing loss in those situations.

Devin credits his ability to blend in with people who have no hearing loss to his hearing aids and further to his parents for buying them for him when he was small,

My parents encouraged me to wear my hearing aids to make me hear and all that so I’m just like, it’s almost a gift for me since I can do both [communicate with deaf and hearing people] now. Or I can act as an interpreter since I can hear what they’re saying and sign to them.

Hearing aids have been very beneficial to Danny as well. So much so that he recommends students with hearing loss try hearing aids, or surgery if it will help them to hear, as the following quotation illustrates,

I would tell other students with hearing loss to ask for, get help for the hearing loss if they wanted hearing aids or to maybe do something, some kind of surgery. I don’t know, I am not a big medical guy but if that is what they would like to do, they could.

Danny emphasized this is a personal decision the student and his or her family needs to make as he recognized wearing hearing aids may not be everyone’s first choice.

Larry recognized that his hearing aids help him to have a hearing identity type but he shared that he sometimes wishes his hearing aids were less noticeable,

sometimes I wish they were smaller because some people think it is weird I have hearing aids because they don't know what they are. They just think that these things are sticking out of my ears or something like that. That's why I like having my long hair because they can cover the hearing aids and no one sees them. I sometimes wonder what it would be like to just not have to have hearing aids. However, when I explain to others what they are, people usually are understanding about my hearing loss.

Larry also explained that while he engages in hearing aid maintenance, it is not a favorite activity of his to do, "sometimes I have to turn up the volume to hear people, and keep the tubes clean so wax doesn't get stuck in them, and changing the battery is a pain; I can't stand that." In spite of not enjoying this type of advocacy for himself, Larry still engages in hearing aid maintenance.

*Advocate for accommodations.* Nine of the participants (i.e., all four students and five of the caregivers/parents) placed value on other means of advocating for students with hearing loss and gaining accommodations to ensure access to communication and sounds. Scott discussed compensatory listening skills that have worked well for his son, Danny. He reported that his son pays attention and asks for clarification when he is unsure of information he has heard. Danny's mother, Kate, spoke of the role of her son's friends in advocating for Danny. In describing Danny's friends, she said they are "outgoing and active and they stick up for him if someone does say something about his hearing." She also explained Danny's friends let others know what accommodations they need to make to communicate with Danny (e.g., looking at Danny when talking, use of repetition). Once the diagnosis of hearing loss was established, Kate shared accommodations that have assisted Danny both in the past and currently (e.g., allow for speechreading, advocate by explaining her son's needs and about hearing loss in general).

Eileen revealed some of the same accommodations as previously listed by other participants and added the following accommodations, “ensure the student gets the equipment and accommodations needed to be successful at whatever he or she does in life.”

Jessica also discussed the role of using compensatory listening skills in her son’s life and the impact it had on making hearing loss be manageable by saying, “if he could hear it precisely, he’ll usually respond the first time.” She explained her son makes good use of these compensatory listening skills by saying, “he’s very good at when he doesn’t hear the information and another student will chime in and say, Barry, someone’s talking to you. That doesn’t irritate him when his peers help him out like that.” She also remarked on her son’s use of compensatory listening skills from a young age by saying,

even when he was young, he picked up on the skills of watching what everyone else does first to know what is happening. He has learned to follow through and he still does that even as he has gotten older but again, I can’t contribute it all to his hearing where he will first want to figure things out and then jump in because it is also a personality attribute of his.

Due to his excellent use of compensatory listening skills, Jessica commented on how others her son interacts with seem to forget he has hearing loss, “I do know other people forget about it. I don’t think they pay attention until a scenario comes up and it’s really just them trying to figure it out and I’ve become more understanding of that.”

Shannon expressed concern over upcoming transitions related to employment even if her son does advocate for himself as she feared her son may face discrimination due to his hearing loss and lamented the fact that parents of hearing children do not have

to consider the impact hearing loss may have on their children's career choices based on perceptions of others. As her son gets older Shannon expressed a desire for her son to be independent and to handle transitions in spite of the presence of his hearing loss since she and her husband will not always be there to support their son. She asserted that

as he's getting older, we're starting to talk about getting a job and things like that. You would like to think prejudice and discrimination are not out there but as he's gotten older, I just hope his hearing impairment does not impact getting a job and what kind of job he can get. I get really discouraged sometimes, as a parent, because he could do so many things! Even if he does face some difficulty, we're going to keep trudging on and go for it but these are definitely things you don't think about when you have a child who can hear because you just assume the child who can hear will get a job.

Kate also spoke of concern over transition when her son, Danny, is older by saying, "I'm not going to be around as much so he is going to have to take on more responsibilities." In thinking about the long term and impacts of hearing loss on her son's ever shifting identity type, Kate shared, "if anything, his hearing loss is going to get worse. So the hearing loss might create more challenges as he gets older. Driving, being in more crowds, and different settings will create new challenges." Eileen, expressed that her main desire for her son at this time in his life relates to advocating for himself during transition, "I want to make sure he gets what he needs so he can be a productive adult. I want him to advocate for himself and to be a person who can handle and take care of himself."

Within the student data set, all four students spoke of the importance of advocating for accommodations related to their hearing losses. Barry demonstrated understanding of the impact his hearing loss has when he shared that he misses

information due to concentrating or focusing on the task at hand by explaining how he gets very involved with what is occurring in his environment to the point that he may inadvertently miss hearing something due to focusing his energy elsewhere. Although he appreciates others continuing to try to gain his attention before speaking to him, Barry explained, “Normally, if I don’t hear what is being said the first or the fourth time, then I’m probably not going to hear you at all so you probably shouldn’t keep yelling my name.” Alternatively, Barry would rather others tap him on the shoulder or move closer to gain his attention and talk with him. Other accommodations that have been and are currently successful with Barry are for others to gain his attention before talking with him, to repeat information, to use preferential seating (e.g., sitting within six feet of the primary speaking area in a classroom), and for Barry to position himself so that he can hear information such as “making sure I’m on this side where I hear better when the person is talking.”

Accommodations that have been and are currently successful with another student, Devin, are for him to read lips, to have a clear view of the speaker’s face, to be close to the speaker, reduce background noise, ensure a clear view of the speaker’s lips (e.g., no beards, goatees, or mustaches), talk at an appropriate volume, and to include Devin in the conversation. When issues arise related to his hearing within his social circle, Devin mentioned his peers may sometimes neglect to provide accommodations in assisting him with hearing. Devin hypothesized his friends may forget he needs to be seated near the speaker or have a view of the face to speechread as this statement from Devin reflects, “my friends are always like what are you looking at? That’s when I say

I'm looking at your lips.” Devin also talked about times when his hearing peers seem to forget he has hearing loss by not accommodating to his needs when conversing,

I told my buddy how he was talking to the other people when I was trying to listen but I couldn't hear. My buddy didn't understand what the big deal was because they all think I can just be part of the group when I really am not hearing much of what is being said.

Additional listening challenges that have emerged for Devin, when interacting with others, is when

others talk real soft or if they don't attempt to talk to me at all because they think I can't hear them. They don't care about you. They think ah, he's deaf or he's hard of hearing so why would I care and try to get his attention when I could talk to someone else who can hear me. They don't want to deal with having to see face to face or moving from one corner of the room to the other to talk. If that is how they are, then I don't care either. I will just leave.

When interacting with others, accommodations that have been and are currently successful with a different student participant, Larry, are for him to ask for repetition, to keep his ears and hearing aid tubes clean, have a quiet background setting to assist in hearing what is being said, and to keep spare hearing aid batteries on hand for his hearing aids. However, Larry explained there are times he does forget he has hearing loss and needs accommodations such as “when I'm talking to my friends in the hallway at school.” The fifth-grade student participant, Danny, reported accommodations that have been and are currently beneficial for him are to ask for repetition, check for understanding, and to keep spare hearing aid batteries on hand for his hearing aids for

when he needs to replace the batteries. Danny observed adults sometimes have a better understanding of his needs or accommodations than do his peers.

Speaking about his struggles with self-esteem or confidence in himself regarding accommodations for his hearing loss, Danny expressed worry over being perceived as a nuisance with others, “Sometimes I feel that I’m a bother since I have to ask what did you say a lot and people have to keep repeating things.” Danny also disclosed his frustrations over “when people are not willing to repeat themselves and when they say I should have been listening so they don’t have to repeat themselves.” Danny recommended that, during these times of frustration, students with hearing loss should “keep friends with hearing loss, if you have any, close to you because if something were to happen and you don’t know what to do then you could ask them for advice” as a type of emotional support system.

**Person with hearing loss.** Five of the caregiver/parent participants expressed a hesitancy to view the students as being members of the individuals with hearing loss identity type. Mark, shared that the identity type of person with hearing loss is “a more clinical term” in his eyes because he, as Barry’s father, “has had to deal with the issues and challenges that arise from Barry’s hearing loss.” Conversely, Barry’s mother, Jessica, when asked to select an identity type that best matches her son, chose the person with hearing loss identity type after initially displaying some resistance to choosing any identity type related to hearing. Jessica expressed that her son is a “great kid who is a sweetheart but if I had to address the hearing, then I would choose person with hearing loss.” The reason for this choice is because Jessica views her son as a “person with

hearing loss but that's simply how I'm describing his hearing, not him." Shannon demonstrated her hesitancy in selecting the person with hearing loss identity type for her son by explaining that when she thinks of the term, person with hearing loss, she usually thinks of older people rather than her son.

As with the hearing identity type, there were some disconnects between perceptions of others and caregivers/parents' perceptions of their children's identity type regarding the person with hearing loss identity type. While others may identify her son as having a hearing identity type, for Kate, her son is a person with hearing loss and hard of hearing. According to this mother, the person with hearing loss identity type matches the "actual physical medical problem while the hard of hearing identity type goes with what happens as a result of the hearing loss." Eileen explained that she also associates the term, hearing impaired, with the person with hearing loss identity type. She remarked, "if there's someone who's using sign language as they're talking, regardless of how his or her voice may sound, then I would put him or her in either the hearing impaired or person with hearing loss identity type categories." Further, Eileen expressed hope that one day her son will advocate for himself and therefore move from the hard of hearing identity type to the person with hearing loss identity type since she felt that an individual who identifies as a person with hearing loss would more readily advocate for his or her hearing needs.

This sense of reluctance in selecting the person with hearing loss identity type was not present in three of the student participants; however the students depicted varying descriptions of what an individual with hearing loss may or may not look like.

According to Barry, a person with hearing loss communicates in the same manner as someone without hearing loss does. He further stated, “I chose the hearing loss identity type for myself because that is the term I was raised with” but also explained, “I probably would consider myself almost deaf if I couldn’t wear hearing aids and have a conversation with you as I am doing now.” Later on in the interview, Barry described himself as a “hearing loss person.”

Echoing Barry’s belief that his needing to wear hearing aids to communicate caused him to identify himself as a person with hearing loss identity type Danny also shared that when he wears his hearing aids, he considers himself to be a member of the person with hearing loss identity type. Danny also expanded this description of an individual with hearing loss by stating a person with hearing loss could also be “someone who does not need hearing aids but who could still communicate through speech.”

Conversely, Devin explained a person with hearing loss “might not be able to interact with other people in different groups.” Devin did not select this identity type for himself since he is able to communicate and interact with other people via speech and signing. When discussing other identity types besides the hearing identity type (e.g., hard of hearing, person with hearing loss, deaf), Larry made the distinction between a person with hearing loss identity type and a person he would categorize as deaf by saying these two categories are not synonymous with one another.

**Hard of hearing.** Nine of the participants (i.e., five of the caregivers/parents and all four of the students) described a varying range of characteristics or traits that they believe define the hard of hearing identity type. Kate perceived a person is hard of

hearing as a result of having hearing loss. She views the hard of hearing identity type as being the result of a person having hearing loss and thus experiencing difficulty with hearing or comprehending language due to having a degree of hearing loss. She said, “my son is hard of hearing *because* of his hearing loss.” Mark also focused on the action part of listening when he discussed the hard of hearing identity type. Mark differentiated between the person with hearing loss and hard of hearing identity types by saying the hard of hearing person would be

someone who I was trying to speak to who couldn’t hear me necessarily but they didn’t have any amplification. For me, the hard of hearing identity type could almost kind of shift in that the person could use sign language but could also speak depending on his or her background.

Jessica also felt individuals within the hard of hearing identity type might not necessarily make use of technology to communicate with others. She explained the hard of hearing identity type as being an appropriate description of individuals with whom she “may have more difficulty communicating with and who may live without hearing aids.” Jessica further asserted, “I don’t like the medical terminology. In my mind, the terms hard of hearing and deaf are medical and signify disability which does not describe my son’s capability.” Another father participant, Scott, expressed the same thought process regarding disability being associated with the hard of hearing identity type by saying, “If I’m hard of hearing, I’ve got some hearing loss *and* there is a problem.”

Not every caregiver/parent associated the hard of hearing identity type as not being a good fit with his or her child. In defining identity types that best match her son, Shannon initially made no distinction between the hard of hearing identity type and

person with hearing loss identity type. She selected hard of hearing since, when using sign language, she knows how to sign “HH” for hard of hearing rather than signing the phrase, “person with hearing loss.” This same mother also explained the reason why she had initially selected the hard of hearing identity type for her son. She explained that the hard of hearing identity type is the terminology that has always been used in the school setting and on legal paperwork with her son, “In school, he’s always identified as hard of hearing on his Individualized Education Plan (IEP). That term [hard of hearing] has been used rather than person with hearing loss.” Shannon also described the hard of hearing identity type as being a better identity type for her son due to others’ perceptions of what it means to be hard of hearing, “When you identify someone as being deaf or hard of hearing, people realize that these folks don’t always hear you. I’m not sure how many people realize even if these folks heard you, they don’t understand you!”

According to Eileen, her son is not a person with hearing loss because he is able to hear everything that is said to him. For this mother, the reason she associates her son with the hard of hearing identity type is because for her,

the person with hearing loss identity type advocates for him or herself. I think, as a person with hearing loss, if he can’t hear something, he would tell you or be upfront about it. Not to say the first time when you meet but in the first instance of not being able to hear, the person with hearing loss would say, you know, I may not catch everything you say, I need to look at your face and read your lips and you know, if I’m talking to you, I’ll say I’m sorry, I can’t hear what you said can you repeat that? Larry is not advocating for himself, because he fights it so hard and he doesn’t tell anybody so they just think he’s hard of hearing versus a person with hearing loss.

Due to this line of thought, Eileen explained how for her, the hard of hearing identity type is a negative insult because the person in this category or identity type does not self advocate.

The student participants also expressed differing perceptions of what qualifies an individual as being identified as hard of hearing. Barry, an 11th grader, was not familiar with the hard of hearing identity type as can be seen in this quotation,

Hard of hearing; is that a term for something? Like is that hearing loss is hard of hearing? I have not heard of this term before but I would interpret it as someone who has a hard time hearing, which is almost the same as a person with hearing loss.

The fifth grade student participant also did not have a familiarity with the hard of hearing identity type as is evident in this quotation, “I don’t think I have trouble hearing with my hearing aids in so I don’t fit in with the hard of hearing identity type.”

Larry explained that his perception of an individual who would identify him or herself as hard of hearing would “be somebody that has trouble communicating and constantly ask for repetition. They would be able to talk with people but would have a hard time hearing the conversation since they can’t hear very much.” This aligns with many of the perceptions of the caregivers/parents regarding this identity type in that the focus is on the physical act of hearing or mishearing information.

Devin, a ninth grader, displayed a completely different perspective from his fellow student participants on the hard of hearing identity type. He spoke of his belonging to two different identity types by labeling himself hard of hearing and explaining by fitting into the hard of hearing identity type he is able to “walk the line”

and communicate with individuals in the deaf identity type group and also with individuals in the hearing identity type group. He enjoyed this aspect of himself in that he could have friends from both groups but also discussed the drawback of not having a defined group to belong to as a member of the hard of hearing identity type. He did not feel the hard of hearing identity type was as clearly defined as the other identity types (e.g., hearing, deaf). This teenager also spoke of the importance of feeling a sense of belonging to eliminate the feelings of isolation one may feel as an individual with hearing loss in a hearing world.

Devin also shared that since he could communicate with others orally (e.g., using his voice) and via sign language, then the hard of hearing category would go between hearing and deaf if he were to create a scale or continuum to demonstrate the relationships among the identity types. He chose to place the hard of hearing identity type in the middle since he could communicate with individuals from both the deaf and hearing identity types. Devin spoke of his advantage in fitting in to the hard of hearing category because he is able to serve as an interpreter for his friends who communicate via speech and/or sign. Through signing for individuals with hearing loss, Devin is able to prevent their feeling isolated and he serves as the bridge or connector between deaf individuals and hearing individuals. In this manner, Devin spoke of having one foot in the deaf world and one foot in the hearing world because he is able to communicate with both groups of people via oral communication and sign language. Devin explained he can be both deaf and hearing at the same time due to this communicative ability even though he identifies himself primarily as being the hard of hearing identity type, “I can

hear but I can still communicate with deaf people and not have to be all selfish and be a normal hearing person. I can fit in both worlds, which is awesome.”

**Hearing impaired.** Three caregiver/parent participants talked about the hearing impaired identity type throughout their interviews. This identity type was not provided in the card sort activity in which students and caregivers/parents completed in choosing the identity type that best described the student with hearing loss yet these caregivers/parents spoke about this identity type based on their experiences. Jessica elaborated saying she “would only use the hearing impaired identity type only if she were completing special education paperwork” for her job due to working in the education sector. She emphasized she would not use this identity type to describe her son. Similarly, Eileen raised the point that the hearing impaired identity type is used on school paperwork, “hearing impaired is used on the Individualized Education Plans (IEPs) and we hear hearing impaired a lot so that is something I throw out from time to time.” Eileen explained that with the hearing impaired identity type there is “some level of sound.”

Shannon at first selected the hard of hearing identity type for her son but upon second thought later in the interview shared,

Originally, I said my son was hard of hearing, which is similar to the person with hearing loss identity type but I would probably, now that I said the words hearing impaired, if I was going to describe my son to you, I would say my son’s hearing impaired. I would actually say that. I would not say hard of hearing.

Due to her first-hand knowledge of all that her son mishears every day, Shannon chose to define her son by his hearing abilities (i.e., hearing loss) rather than focusing on the other characteristics that define her son (e.g., outdoorsman, teenager).

Shannon conveyed mixed feelings on selecting the hearing impaired identity type to describe her son,

It's almost embarrassing to say that when I think of my son, a large part of what I think about him falls into the hearing impaired category because I hate to see that I think of him so strongly as that rather than seeing him as a fisherman or a teenager. I would love to say I don't see him as hearing impaired and I overlook it but the reality of it is I do see him as hearing impaired because I have been in so many situations where it has affected us. We, the family, have to deal with it. You can't just ignore it and say it isn't there because it is there on a daily basis. It's not here today and gone tomorrow.

Shannon also wondered how her son's teachers view and identify him and speculated, "I think his general and special education teachers would identify him as being hearing impaired."

**deaf (medical).** Nine participants (i.e., five caregivers/parents and four students) viewed the deaf identity type as being primarily related to no or minimal access to sounds and use of sign language to communicate with others. When discussing the deaf identity type, Jessica explained that for her, people who are deaf may "have no or minimal auditory hearing or they could hear sounds but could not discriminate between sounds, they may use sign language to communicate, or may not receive speech." Moreover, Jessica suggested members of the deaf identity type would "need accommodations to communicate with others" in order to access information. Another mother participant, Shannon, delineated between groups of her son's friends by saying there are those who can hear and those who are unable to hear. The latter group she categorized as falling under the deaf identity type.

Shannon also shared had she only two choices (i.e., deaf or hearing) to select from in describing her son's identity as it pertained to hearing loss, then she would select the deaf identity type. Shannon elaborated on this choice by saying,

I know he's not totally deaf but if I were to talk to others about my son, and said he were hearing, I think that would be misleading because when you list someone as hearing, you assume they hear everything you say but when you identify someone as being deaf or hard of hearing, people realize they might not always hear what was said.

Shannon further explained her perception of how people who are deaf communicate is through "use of sign or lipreading."

Scott viewed individuals who would identify themselves as the deaf identity type as having a more severe hearing loss than his son currently has, "Somebody who is deaf is clearly deaf and has issues with picking up on any sounds at all. Sign language would more than likely be their language of choice." Likewise, Kate viewed individuals who would identify themselves as the deaf identity type as not being able to hear at all, even with use of hearing aids. Eileen echoed this perception by stating individuals with the deaf identity type would not be able to hear anything at all "because verbal cues or sounds are not coming through" and these individuals would most likely communicate through sign language.

Within the student data set, the student participants generally agreed with the caregivers/parents in that they also attributed lack of hearing sounds and using sign language to communicate to members of the deaf identity type. Larry explained a "person who is deaf would not be able to talk, would not be able to hear cars nor music,

and would probably use sign language to communicate.” Danny commented that a “person who is deaf would not be able to hear sounds or they can hear sounds but they are unable to understand what is being said.” Danny also said that if he were to not wear his hearing aids, then he would identify himself as the deaf identity type. While this particular student suggested he might be a member of the deaf identity type had he not been able to benefit from wearing hearing aids, another student, Barry, explained that while there are some differences among those he would classify as deaf in comparison to him, he can also relate to these individuals. Barry explained he may have more in common with individuals who have a more profound hearing loss than he by stating, “some people might be worse off in hearing loss than you; some people are almost completely deaf and still might do some of the things like I do. I know there are deaf baseball players.” He defined the deaf identity type as being for folks who are unable to hear at all or who have lost their hearing later in life who typically communicate through sign language and through reading lips.

Devin viewed being deaf as a negative in that members of a deaf identity type would feel separated and distinct from the hearing world and may even struggle with finding jobs and accomplishing other transition goals as a result of hearing loss or others’ perceptions of hearing loss. When discussing the deaf identity type, Devin commented,

well, for me, it would suck to be deaf in my opinion because I see how much my deaf friends miss by not being able to hear anything. School and life are harder for them. It might be hard to get a job because some guy might be like oh, I don’t want this guy because he’s deaf or I don’t want this guy because he can’t do anything. I wouldn’t want to be deaf because for me, it feels to me like the world has shut down on me no matter how hard I work.

Devin also shared his view of individuals who identify themselves as deaf typically do not wear hearing aids or cochlear implants.

### **Fluidity**

Eight of the participants (i.e., three students and five caregivers/parents) explained the identity types may differ or change based on interactions with others, the settings, and contexts or may be fluid or not static. This fluidity was achieved through use of compensatory listening skills and perceived roles or expectations of the students and of others. Mark marveled at his son's ability to compensate for his hearing loss and expressed that the identity type he would select for his son does evolve or change based on the interactions with others and environments in which communication is occurring. Thus, in certain environments (e.g., quiet classroom), Mark may identify his son as a normal person or a person with full hearing identity type versus as a person with hearing loss identity type in more distracting situations (e.g., noisy restaurant and trying to place his order with a server or noisy gym during basketball practice). Barry's mother, Jessica, also explained that the way she views her son, in relation to his hearing loss, "is not set since it could be fluctuating since the family does not experience many scenarios where the hearing is a problem."

During her interview, Shannon reported her view on identity as being fluid due to experiences and education she had acquired over the years,

I've seen my son gain the skills through interacting with different people which in turn had an effect on his identity type, whatever that may be. For example, at the age of three or even younger, he didn't have the skills to clearly speak or to be understood through speech yet, so I would choose a different identity type for him then compared to what I would choose for him now. I think with education, the

more he knows and the more I know, the better we communicate. I can see where my perception of his identity changes a little because I remember back in the day where my husband and I took sign classes and I knew as much sign as Devin and his friends with hearing loss because they were very little. Back then, they could come over to the house and I could ask if they were hungry or understand if they said they had to go to the bathroom and I could communicate with them. Over time circumstances, people we're interacting with, and different activities have changed and they now know more sign than I do.

Kate, another mother participant, also spoke about how her son's identity type can change depending on the situation and with whom he is interacting by saying he is a leader in some aspects but in other circumstances can display low self-esteem.

Eileen also spoke about how her son's identity type can change depending on the situation and with whom he is interacting by saying he will say he can't hear when he is in trouble but at other times saying he can hear fine. She disclosed her son "will struggle in a noisy classroom and not be able to pick up on everything that is said" but in quiet settings, that he will be able to hear. She also remarked that she "doesn't define Larry as a specific identity type but that when he's not paying attention she will ask if he has his hearing aids on and is he paying attention." Additionally, Eileen spoke about the impact of her son's hearing loss changing from day to day, "It's going to vary on a daily basis depending on with whom he is interacting, the environment, the setting, and the noise levels."

The student participants displayed an awareness of fluidity when discussing identity types they selected for themselves. When the hearing aids malfunction, Barry may view himself as a different identity type, that of person with hearing loss. Throughout his interview, Barry spoke of fluidity through his perception of identity for

himself changing depending on his environment (e.g., quiet classroom versus noisy ball field), interactions with people, and context. Barry also illustrated this concept of fluidity by referring to himself as members of multiple identity types over the course of his interview (i.e., hearing, person with hearing loss, and if necessary, deaf) when describing himself. Moreover, Barry explained that depending on with whom he interacts, aspects of his personality or identity may shift or be more fluid. For instance, when conversing with a particularly outgoing friend, Barry may not be as talkative, yet with another group of friends who are of a more quiet nature, Barry will initiate conversation and be a leader within the group. Also, when people have to repeat themselves or seek to gain Barry's attention when communicating with him and when Barry has to attend appointments related to his hearing, his hearing loss has a greater impact on his identity and he may change his label or how he identifies himself at those times. He stated, "Depending on the context and the interaction and what's happening in my environment, the impact of my hearing loss may be bigger or smaller and it is kind of always changing."

When discussing the impact of hearing loss on his life through using a pie analogy in which Barry had to determine how large of a slice of the pie to designate as impact of hearing loss, Barry said,

the hearing loss would be small only because the only times I need to recognize, or not recognize, the hearing loss is when I'm needing to recognize the hearing loss through missing information or having to go to a meeting or an appointment because of the hearing loss.

Barry further disclosed the hearing loss is "part of what makes me" and does not make up all of him. Barry explained that "depending on the context and the interaction of what's

happening in my environment, the hearing loss sliver or slice of the pie may get bigger or smaller since it is always changing.” Barry also spoke about the fact that even though his perception of his identity or the way he categorizes himself may change depending on the situation, his hearing loss has always been a factor in his life, even if a seemingly insignificant one. He says,

I mean there are definite times when I have my hearing aids in and I don't pay attention to my hearing at all. And it doesn't bother me or I don't think about it at all. It just kind of, I've always had hearing loss, it's never not been there.

Like Barry, Danny also selected multiple identity types to best describe him (i.e., hearing identity type in most situations, person with hearing loss when he is wearing his hearing aids, deaf when he does not have his hearing aids in) but he, like Barry, was unaware of the hard of hearing identity type and characteristics of members who would fit in that identity type. In contrast, a student participant, Devin, identified himself as being a member of the hard of hearing identity type in most cases. Devin explained not only can he communicate with deaf individuals through sign language but he can also “talk with normal people, especially at home and in my neighborhood.” This ability contributed to Devin's view of identity as being fluid by his being able to interact with a variety of individuals at home and in school by stating, “you can blend in and be in different groups and interact with different people. You would have more friends that way too” by being friendly with individuals in many different groups. Devin expanded on this distinction between groups and his ability to interact with them by sharing he can “communicate with deaf friends by using sign language and I can hang out with these

other friends by using my voice while I can be me when hanging out with the hard of hearing kids.” Devin also spoke about seeing others shift identities by saying, “I’ve seen some hard of hearing people who just want to be with hearing people and some hard of hearing people who just want to go with the deaf people.”

Irrespective of selected identity type, another student participant, Danny, explained there are times he does forget he has hearing loss “but then something comes up that would remind me” such as someone asking him what he has in his ears or having a hard time hearing information in a conversation when he is upstairs and the speaker is downstairs or vice versa. Moreover, no matter which identity type is selected, Danny highlighted the need to not focus specifically on the identity type by advocating fluidity of identity types. He advised to not “stay one identity type forever” in that a person with hearing loss can be many different identity types in spite of having hearing loss through using compensatory listening skills and wearing hearing aids. Additionally, Danny said he “sometimes forgets I have hearing aids because I hear and think I am hearing everyone well compared to when I was younger before I had hearing aids when I would completely miss what was said.”

Four of the caregivers/parents, while recognizing the fluidity aspect of identity by acknowledging the identity types are not set and they can change on a daily basis, also spoke of the hearing loss in terms of it being permanent and constant. This notion was evident in a father participant’s interview. In spite of Mark’s view of identifying his son primarily as a person first, this father also displayed awareness of the permanency of his son’s hearing loss and recognized the hearing loss will not be restored or improved over

time as is evident by his response, “One, he’s a person. Two, I’m thinking of it as he certainly does have hearing loss and I know the hearing is not coming back because the hearing loss is a permanent condition.” Conversely, Mark shared that even though his perception of his son’s identity or the way he categorizes his son may change depending on the situation or with whom his son interacts, his son’s “hearing loss is a permanent condition. You know, he is someone who has experienced hearing loss and it will be with him for the rest of his life.”

Barry’s mother also viewed or identified her son primarily as a person first while also demonstrating awareness of the impact of hearing loss on the family and on her son. She shared that even if the hearing loss is not prominent or at the forefront all of the time due to use of compensatory listening skills and optimal listening environments, she “doesn’t think there is ever a time” her husband and she “ever forget Barry has a hearing loss” in their lives but she described the family’s management of the hearing loss as “a way of life.”

Shannon also spoke of the permanency of her son’s hearing loss and of the impact it has had on the family unit during her interview. In spite of not describing the specifics of his son’s hearing loss, Scott did highlight the fact that his son’s hearing loss is permanent and will always be present in the lives of his family. Scott shared that the family has adjusted over the years and will continue to provide support to Danny as he grows into a teenager and adult. He also raised the point that his son’s hearing loss “is not something Danny can overcome. It is something he will deal with long term” since the hearing loss is permanent and is “never going to get better.” Speaking about the

permanency of the hearing loss, Scott spoke of his son's hearing loss as being a "challenge and something added to deal with" in raising his son compared to his other children. Danny's mom, Kate, reflected that although others' perceptions of her son's identity type can be fluid and change, for her as Danny's mother, the hearing loss

is always right there with me. It's always right there with us at the forefront that we always remember when we're in the car and things like that, we have to always turn around and talk to him. It is really ingrained in our family.

As a family, all members work together to meet Danny's "special need." Kate further shared that she "doesn't think there will ever come a time" that this awareness will go away as Danny matures to adulthood because "the hearing loss is never going to get better." In spite of the permanency of hearing loss, Kate spoke of her son's hearing loss as "not being new or unusual for the family due to having a niece with hearing loss."

For two of the mother participants within the caregiver/parent data set, discussion of the hearing loss in general was fluid depending upon their and their children's interactions with others, contexts, and settings. The descriptive structure of Jessica's perception of her son's identity related to his hearing loss focused on respect and dealing with hearing-related issues as the need arises. Jessica shared that while she and her family do not downplay or ignore her son's hearing loss, they have made a conscious decision to discuss the hearing loss as the need arises out of respect to not only her son but to others who have weaknesses of any sort, which would encompass all of humanity according to Jessica. Throughout her interview, Jessica stated multiple times that she and her husband have made the conscious decision to not discuss their son's hearing loss with

others in an effort to “start everything regularly without saying he has a weakness” by highlighting his strengths and only choosing to discuss the hearing loss as the “need arises” with others. Conversely, she explained the hearing loss does not have as much of an impact on her son’s life in certain situations therefore discussion is not centered on the hearing loss and only comes up “as the need arises.” For instance, when describing her son to others, Jessica does not start the interaction or exchange with talking about her son’s hearing loss but will bring it up should he be in a situation when he misses information or accommodations do need to be made as a result of his hearing loss.

Jessica, who is involved within the education sector, reflected on the educational process in working with students who have special needs. She felt those in education should approach the issues at hand in a more positive way by stating,

in education, we feel the need to let everyone know the strengths and weaknesses of the students. However, my husband and I feel the opposite. So we will go to parent meetings with the teacher and say, the teacher needs to get to know Barry and then we’ll touch base with Barry in a month or so and see kind of how things are impacting him. We do not want to start off the situation by saying oh, he’s a child with a hearing loss because that’s not who he is.

This approach recognizes the fluidity of describing their son as a certain way in one context and another way in a differing context as the need arises.

Eileen also explained that in new interactions or settings with new people, she and her family do not start the exchange by discussing Larry’s hearing loss, “we don’t come in the door and say oh, he has hearing aids, you need to do this, that, and the other. There is no need to prep them for something that may not even apply.” Eileen also expressed that for her family,

Larry is a normal kid in our family. He's not identified as anything different but we do have to clarify sometimes for the new folks coming in just because they don't understand why he's not replying and I think their perception is either he's not paying attention or he's being disrespectful.

so as the need arises Eileen shared they will explain to others about the hearing loss.

**Interactions with caregivers/parents, siblings, other family members.** All ten of the participants in the study discussed the impact that interactions with others had on selecting identity types as related to hearing loss. For the caregivers/parents the interactions with their children with hearing loss were of focus while within the student data set, interactions with caregivers/parents dominated the student interviews. Additionally, interactions with other children, siblings, and other family members were discussed.

Throughout his interview, Mark wondered if there were times when his teenage son honestly did not hear the information or if he was choosing to ignore what he heard as a typical adolescent might do. In the times when Mark knew his son was not hearing correctly, he expressed shock at just how much information his son was unable to hear. A mother participant, Shannon, also wondered if her son honestly did not hear the information or if he was choosing to ignore it as typical adolescent behavior. Likewise, Shannon expressed surprise at just how much information her son was unable to hear or misinterpreted in everyday conversations.

An area that affects another father's perception of his son's identity as it relates to hearing loss is that of family involvement. Throughout his interview, Scott commented that familial involvement is key to success for his son. He advised other parents of

children with hearing loss to be consciously involved and present in the raising of the children and accommodating for their hearing needs. Through being present and actively involved with raising his son, the other father participant, Mark, also shared that his son's hearing loss is "definitely something that has affected me a lot more than it may have affected my son" since the hearing loss has always been a part of his son's growing up and part of his life so his son may not have noticed the hearing loss as much as his wife and he have noticed it. For instance, Mark explained that while Barry's immediate family (i.e., mother, father, little brother) recognize the accommodations that are successful for Barry to communicate, sometimes his extended family may forget or not recognize the impact of the hearing loss due to not being around his son as much as his immediate family is, something B may not be cognizant of when interacting with extended family.

Regarding immediate familial interactions, a mother participant spoke of Barry as being a "very good son and big brother" when discussing scenarios and interactions that have come up with her son. Jessica also reported that Barry is very involved with baseball, which the family readily supports. She revealed her son "is wonderful in dealing with his hearing loss" and that the hearing loss has been more of a weakness for her husband and her since Barry "has a great disposition where he doesn't get agitated or yell" about having hearing loss. In times where Barry does need discipline or when dealing with behavioral issues, Jessica mentioned,

Barry doesn't want the voice to be raised. He doesn't understand why the voice needs to be raised when we need to correct something. Raising the voice does not

work for him so he doesn't necessarily need that from us but I can raise my voice ever so slightly and talk strongly like this and that's not yelling for Barry.

As parents, Jessica wondered had she and her husband had "prior knowledge of hearing loss, they might have picked up on it earlier in Barry's life" in terms of diagnosis of hearing loss during preschool.

When discussing interactions with her teenage son, Shannon spoke of the everyday challenges of parenting a child with hearing loss,

His hearing loss has made our family life very difficult. I wish we had a camera in our dining room to document our dinner times because there are so many times at meal time we will have a discussion as a family and he'll make a comment that is totally irrelevant to what is being said. The things he will say will be totally on a different subject and the point is that he thinks we're talking about something else or he has heard something else and I'm like oh my gosh, he's not even on the same page as us. Sometimes it's funny and then other times it's very sad because you realize oh my gosh, he hasn't got what we're saying.

Shannon also spoke of growing pains in raising an adolescent who happens to also have hearing loss,

The hearing loss has made the normal transitions more difficult over the years. When he was little, we tried to teach him certain words. He said a lot of words incorrectly or dropped the ends of the words when he would speak. He would only say the first half of the word and you had to constantly say no, that's not what it was. In the same respect, we know a lot of words can mean different things but Devin might only know one meaning. He has gotten better at it over the years with a lot of explaining of language and explaining what you're explaining! I might have to repeat the information in a different manner with a different word but Devin is so verbal and doesn't have a speech impediment like most hearing impaired would have, and with his hearing aids being covered, most people would not even notice he has hearing loss until he responds in a certain way. I will have to repeat a question or a missed word for him to help him communicate with others. This is why the hearing loss is not something my husband and I have overlooked since we live with this reality every single day.

You have to deal with it and can't just ignore it. It is not fun and has been really hard.

Reflecting on personal experiences with her son, Shannon spoke of the shock and surprise of learning her son was diagnosed with hearing loss due to his use of compensatory listening skills,

I can remember when the audiologist came in and said, he can't hear. I was like oh my God, what do you mean. I was in denial because he was three and I was certain he was answering us when we talked to him and showed the audiologist. She said he's reading your lips. I thought what do you mean? He's three. Who reads lips at three?! He can't read lips! We would talk to him like this (covering mouth with paper) and he never responded so that's when I knew the audiologist was right.

Shannon and her husband then began to advocate for their son and work to grant him access to sounds and communication through technology.

Scott also highlighted advocacy as an essential component to raising his son with hearing loss. Scott credited his wife's involvement with his son's success, "My wife takes such good care of helping him deal with the hearing loss and I do as well." This accommodating style is evident in Scott's response to being asked to share one piece of advice with other parents of children with hearing loss, by Scott saying these parents will need to "be patient in terms of how they interact with their children. Be patient with how he or she develops and make a conscious choice to be involved with your children."

Reflecting on the family unit and his son's place in it, Scott shared that his son with hearing loss is the sum of the whole family, "As I watch my oldest daughter and then my older son, and then Danny, and I think about my wife and I, he is really everything a

blending of all of us.” Danny’s mother, Kate, explained how those who are not around her son as often as the immediate family (i.e., father, mother, older brother and sister) may have a tendency to forget or overlook the impact of her son’s hearing loss on communication,

I think other people do forget sometimes. Other family members and those who aren’t around him all the time because we will hear them say at family functions, oh my gosh, so sorry, I forgot and they’ll come around to the front of Danny and talk to him face-to-face

or carry out other accommodations.

Eileen described interactions with her son as being confusing at times when Larry would mishear information, “He would say things and we would say what are you talking about because what he said didn’t match up with what we were saying.” In contrast, Eileen revealed there are times “with and without hearing aids in” her son can hear “just fine.” She also shared that due to this ability, there are days she may forget Larry has hearing loss especially when Larry is able to hear her voice or his little brother’s voice easier than his father’s voice due to differing pitches and frequencies of spoken voices. When asked for one piece of advice to share with other parents of students with hearing loss, Eileen spoke of how parents of children with hearing loss should not engage in “special treatment or feeling sorry for your child and letting them use hearing loss as a reason why they can’t do something or why they should get out of doing something.” She felt the children with hearing loss should be treated as any other child in the household and should not receive preferential or special treatment on account of the hearing loss. Eileen explained she and her family treat her son in the same manner as

anyone else in that the hearing loss is just one part of him and not the whole. Along this same line of thought of not providing special treatment of the child with hearing loss,

Mark explained that

there are definitely times when I don't think of the hearing loss in certain situations. It comes back to me when we have to make accommodations for his hearing loss but you know through the normal day and normal routine, I may go a couple days without noticing he has a hearing loss.

On the other hand, Mark believes while caregivers/parents should do "whatever it takes" to create a positive communicative environment for their children with hearing loss, "there should be no difference in the caregivers'/parents' approach in how they deal with their children with hearing loss." Mark spoke of the importance of not creating extra attention around his son's hearing loss by "shining a spotlight on it or singling him out" and also explained his son may have a better handle or understanding of the experience than his wife and he do.

When thinking about interactions with his caregivers/parents, Devin expressed gratitude toward his caregivers/parents for buying and encouraging him to wear his hearing aids when he was younger. He believes the hearing aids are a large factor as to why he identifies himself as a hard of hearing identity type and had it not been for his caregivers/parents providing him with his hearing aids he would not have had the same opportunities to access communication. He recognized not all of his friends or peers had the same experiences with their caregivers/parents.

Larry explained there are times when he is wrestling with his siblings or playing, that he may forget about his hearing aids and they may end up breaking due to rough and

tumble kind of play with siblings. Danny commented that his siblings also do not place too much attention on his hearing aids by explaining, “my family is used to my hearing loss. I don’t think they mind repeating things to me at all.” Danny wondered if his family was comfortable with his hearing loss and need of accommodations due to an extended family member also having hearing loss by sharing that he has a cousin who also has hearing loss. He described her hearing loss as “worse than mine because without her hearing aids in she can’t hear whereas I can hear a little bit.” He explained that he sees her at family functions every now and then.

When discussing interactions with his caregivers/parents, Barry explained his caregivers/parents help him to recognize when he has missed hearing information,

My parents told me yesterday that during the game, Coach was trying to get my attention when I was sitting on the bench. He had wanted me to tell somebody something and yelled my name like eight times but I didn’t turn at all.

Barry’s caregivers/parents sometimes act as the liaison or link between others and their son to ensure he has heard what was said.

**Interactions with peers and others.** All ten of the participants expressed that interactions with peers and others in the students’ lives affected the identity type the students and the caregivers/parents selected for the students with hearing loss. However, irrespective of which identity type was selected for his son by others, his son, and himself, Scott expressed a sense of gratitude for his son’s teachers, coaches, and others in that they seemed to understand what was needed in terms of accommodations for his son to be successful in communicating with others. In commenting on his son’s interactions

with peers, the other father participant, Mark, described his son as a “very good friend and great kid whom other kids like to be around” and also expressed that Barry’s friends have been understanding and are “very good in working with Barry and his hearing loss since his friends accept him as he is.” Mark shared his son’s friends have similar qualities as his son through playing baseball together. For this particular group of friends, Mark said they help his son when he misses information from their coach and they are very supportive. Mark pondered whether his peers with whom he comes into daily contact “might not realize the impact of Barry’s hearing loss” since they are so accepting of him and do not appear to focus on that aspect of his son. Mark also shared there are other students enrolled at Barry’s school who have hearing loss but that his son is not friends with them.

In spite of his son’s acceptance by his peers, Mark revealed that in his interactions with others regarding his son’s hearing loss, some may view his son as being inferior due to having a hearing loss,

in my experience, when I tell people about Barry and his hearing loss, the immediate reaction is he’s not as intelligent as someone else. I find it interesting that I can tell someone my kid needs glasses and it’s like oh ok, no big deal. Then I tell them my kid has hearing loss and it’s oh how’s he doing in school and there’s this immediate stigma or aura to hearing. It’s like he’s not as good as the next person or he can’t have a good IQ since he has hearing loss.

Through this statement, Mark revealed his belief that “hearing loss is not as socially accepted as needing corrective lens or glasses” in his experiences. A stigma or type of aura seemed to act as a shroud to the hearing loss as it is not as socially accepted as vision loss might be in the eyes of this father. Mark expressed frustration over others

viewing his son as less than others solely based on the fact his son has hearing loss throughout the interview.

In recalling interactions between his son and his coaches in extracurricular sports, Mark related a story regarding his son's current baseball coach in which his son and the coach have a rapport with one another and are able to talk about his hearing loss,

His current coach will give him a hard time at times where he doesn't quite do something that the coach wanted such as not doing the play the way he wanted him to and the coach will joke with B and say do you have the hearing aids on? Not in a mean way but more of a are you hearing me, are you getting what I'm saying kind of way.

Additionally, Mark discussed the impact of Barry's hearing loss on his son's identity within the community setting by sharing that

when Barry is in a really crowded situation or there is any loud noise in the background, it can be difficult for him to communicate due to the fact that he is not picking up different things as opposed to when he can in a quiet setting.

However, when in a quiet setting, Mark wondered if others would realize his son has a hearing loss due to Barry's excellent use of compensatory listening skills, "honestly, in those quiet settings, if someone didn't know Barry, they would probably walk in and not notice he had any kind of problems." Mark disclosed that his son does understand and recognize that when he is in a loud situation or a distracting setting that he may need to utilize accommodations to help him access communication within the various community settings.

Barry's mother, Jessica, irrespective of which identity type was selected for her son by others, her son, and herself, expressed a sense of hypersensitivity or emotionality on the part of her husband and her as Barry's parents and that this may, in part, contribute to her worry about upcoming transitions related to college and her son's interactions with others. Jessica explained her husband and she may be more sensitive about the hearing loss and how others react to it than their son but that they are improving in this area over time. When interacting with others, Jessica explained her son does not seem to be as sensitive about his hearing loss as his parents may be in most situations but he may grow frustrated when something is attributed to his hearing loss that he may not necessarily agree with in some cases. When asked about perceptions of others regarding her son and hearing loss, Jessica shared her husband and she are

more aware of it than Barry. Barry takes on the 'it is what it is' attitude and people respond to that. I understand some folks may joke about the hearing loss, and they are trying to process that information. Every once in a while, my husband and I will get irritated because someone's trying to figure out why Barry is not responding and they may say stupid things as they're trying to figure it out.

Jessica also spoke about how everyone has something they are dealing with in their lives and for her family, it happens to be her son's hearing loss.

Irrespective of class size, Jessica explained her son does very well with peers letting him know when he has missed information or if someone is trying to gain his attention. She also revealed Barry's close friends share similar interests due to spending so much time together playing baseball. Barry also has friends in different groups due to his being understanding and diverse according to Jessica. Jessica also shared an

acquaintance of Barry has hearing loss but the two peers are not close friends. Within Barry's social circle, Jessica spoke of the variety of friends and peers her son associates with by saying,

he's diverse. He fits into different groups without too many problems. He's very accepting and wouldn't argue with kids to get pushed out of the group. He can move around so I would say he's diverse, understanding, and goes with the flow.

Jessica revealed some struggles over the years with Barry's teachers in the school setting. These struggles pertained to the teachers' perceptions of her son as related to his hearing loss through saying,

At first look, actually in any look, I have had some teachers tell me he doesn't have hearing loss. I remember in 1<sup>st</sup> grade, his teacher saying Barry doesn't have hearing loss and I said, I would like to sit across from you and tell you that he's like any other kid but I'm telling you he does have hearing loss.

A more positive experience with the teaching staff shared by Jessica reveals how critical perceptions can be,

A teaching assistant in Barry's preschool was the one who brought the hearing loss to our attention. She was a helper in the classroom and noticed he was missing information here and there. It all made sense when she brought these instances up in a conversation with us and it led to our getting him tested and diagnosed with a hearing loss.

Because Jessica and her husband have made the "conscious effort to start everything normally" by not informing teachers, speech therapists, and coaches of their son's hearing loss, some interactions with these individuals have been filled with awareness and understanding once they do learn the specifics of Barry's hearing loss.

They've actually been very receptive of the explanation. Like, oh, I could see that happening every once in a while or oh, yeah, I can *not* stare at my clipboard when I'm giving the group basketball announcement. Or I do wonder why Barry maybe kind of squeezes to the front to get the visual.

In reflecting on the preferred communication styles among his caregivers/parents and coaches, Jessica shared that Barry would rather have his coaches yell at him during times of discipline versus his parents "talking strongly" when reprimanding him in the home. "He does like to be yelled at on the field. He wants to be yelled at on the field because he says when he gets yelled at, it's quick and precise and he knows what to correct." Jessica also explained how Barry's coaches will sometimes ask Barry if his hearing aids are on when questioning a play or move Barry has made,

Barry has expressed to us that he is okay with the coaches doing that. However, if he feels the play that is called into question has nothing to do with his hearing then the coaches asking if his hearing aids are on is off-center for him

and Barry may be irritated by this action, according to his mother.

Jessica remarked that over the years of sports involvement, she and her husband have had to

have side conversations with the coaches to explain Barry's needs. One coach, in particular, made a comment at a banquet that threw us off a shade. We ended up talking to the coach about it. In retrospect, I don't think anyone else even picked up on it but it was my husband's and my emotionality to the hearing loss that caused us to pick up on it. After talking to the coach, of course he said, oh, no, that was not my intent kind of thing but we are more hypersensitive than Barry is. We are more emotional about the hearing loss than Barry is and are more sensitive to outside statements than he is. We're getting a little better with that over time.

An example of interacting with coaches and other parents occurred during a baseball game recently. Jessica explained,

Barry's hearing aid battery died and he didn't have one. He got thrown out of the game because he missed a call because the coach yelled but that happens. First off, because it wasn't necessarily due to his hearing loss. In this case, he just didn't have the baseball IQ to figure that out. So a couple of the parents obviously know of the hearing loss. Two said to me, I told the coach his hearing aid battery wasn't working correctly and I said ok, great. Then they said, tell him again and I said no. It is Barry's responsibility to tell his coach. If Barry's hearing aid is not working and Barry needs a battery, he needs to go tell his coach.

Similarly, Jessica shared a story of discussing the impact of hearing loss on her son with a basketball coach,

When we started basketball with some new coaches this year, we didn't bring the hearing loss up until there was a scenario several weeks into camp where Barry was describing it to us. He wasn't aware he wasn't hearing which is the hardest part. In the translation, we said, Barry, that was a hearing issue and he said, you think? And then he puts it together but he will never first say it's his hearing. He will first say he's engaged and focused in the activity and it didn't register.

Jessica also shared her concern as her son begins to look at colleges and whether or not his hearing loss will have a greater impact, even if that impact is the perception of future coaches rather than what is actual reality for Barry.

I am concerned, and this will be the Mom type of sensitivity coming out here, that when coaches for baseball start looking for him, that there may be no prior knowledge with a student with hearing loss and they may be hesitant to have him come to their college but they could be hesitant for a multitude of reasons not necessarily because of his hearing loss.

Kate discussed the difficulty in her son accessing communication as a result of having hearing loss or being a member of the hard of hearing identity type. However, she explained her son can be assisted with accommodations and through the support of friends. Kate shared that her son's friends have been crucial in providing assistance and support when he has trouble hearing in the environment.

Shannon experienced a lack of exposure or knowledge of interacting with individuals with hearing loss on the part of others. Regarding her son's hearing loss, Shannon reflected, "there are lots of people, in my perception, whether I'm accurate or not, there are lots of people who can overlook my son's hearing loss." She also felt that strangers may be less than understanding of what it is like for Devin and for her family when living with Devin's hearing loss, "I would say 100% of the time, other people don't get it. Now, my friends who have been with me a long time and have been around me a long time, they get it" or have a better understanding of what it is like. She attributes this lack of understanding to "little exposure to hearing loss and language and how much influence language has on your life. People don't really stop to think how we learn to talk, learn how to read, and how much language impacts life."

Outside the school setting in the community setting Shannon revealed that her son, when interacting with others, will say things are

boring. Through the years, my husband and I have come to learn that when something is boring in Devin's book, it usually means he didn't understand what was going on so we kind of have to interpret that the word boring might mean he didn't know what the people were saying in the conversation.

Within the home setting, Shannon commented speculated that Devin may have more access to communication compared to settings within the community in the following examples,

At home, he is able to hear better where things aren't loud and there aren't a lot of people. However, if we are in a restaurant where the music is really loud and the silverware is clinking, he will struggle to hear the conversation at the table. If we're in the community swimming pool, he really struggles with communication, since he does not wear his hearing aids in the pool.

Some interactions with teachers in the school setting have proven humorous yet eye-opening. Shannon shared a story about an interaction with one of her son's teachers regarding vocabulary,

It has taken a lot of time and a lot of work to improve his vocabulary. He would use words inappropriately until he understood the correct use of the word. One time, when we went to the 8<sup>th</sup> grade middle school night to meet the teacher, Devin said to the teacher, you're pathetic! I was thinking oh my gosh! He's pathetic, are you kidding me?! So we laughed it off but later in the car, I said to Devin, you called your teacher pathetic? He said, yeah, Mom, he's pathetic! I said, could you give me another word for pathetic to which Devin said funny! I said oh my gosh, you used the word pathetic when you meant the teacher is really funny.

When discussing involvement of others with his son, Scott described his son as "empathetic, intelligent, perceptive, and willing to hang out with anyone as long as they treat him well. He has friends of all types and doesn't hang out with just one particular group of people." Scott also shared an instance in which his son's teammates overlook his hearing loss at times but reported that after initial information sharing, Danny's peers seem to pay no attention to the hearing loss due to his son's use of compensatory

listening skills. Scott also related stories of his son struggling to hear information during sports when the helmet interferes with his hearing and he is unable to hear the coach or umpire. Beyond sports, when selecting friends to associate with, Scott emphasized close knit relationships yielded more acceptance of his son's hearing loss,

If you look at our family, everybody obviously understand Danny's hearing loss, particularly due to Danny's cousin also having hearing loss. When you look outside of the family and go into just friends area, we have a limited batch of friends because we choose who we hang out with or socialize with and they all understand the hearing loss and it's not an issue. Then you go into stranger mode and a stranger or somebody may just come in and have to be reminded of Danny's hearing loss.

In thinking outside the family, Kate commented her son "works well with older people; sometimes he works better with older people than with those in his peer group" and reflected that this trait is not a bad thing, "he would rather sit down and talk with an adult versus a child his own age but he still gets along with peers in his own age group in spite of this preference."

Even though Danny is currently doing well socially, Kate discussed the struggles her son went through to communicate with others prior to diagnosis of hearing loss and receiving hearing aids,

He worked so hard to try to hear people and it was exhausting for him. It was one of those things I could never understand why he was so tired all the time. He would come home, and by 7:00, he was in bed asleep and I didn't know why. Well, it's because he was expending so much energy trying to hear. After receiving his hearing aids, we still struggled with the communication when we would go places and he still wasn't talking and I would have to explain why he isn't talking. Or I asked the question why isn't he answering me? I think having to explain it to everyone was one of the biggest challenges.

In cases where she was to explain to others what was happening, Kate cited having patience and being willing to explain the situation to the people around you as being two primary ways of dealing with these scenarios.

Eileen revealed her son “struggles with identity and has a tendency to take on the persona of whoever he is following in music, acting, or songwriters as some of his peers also do.” Eileen commented on times she has shared with her son that

he can like that music but he needs to be himself and does not have to try to change himself to be just like the person, whether it is a famous person or a ‘cool’ kid in school” when interacting with others.

She stated Larry has been ostracized for wearing glasses, hearing aids, and being slightly overweight. In spite of these instances of bullying as reported by mom, she shares that Larry still “tries his hardest to fit in” with his peers.

In thinking about social situations, a student participant, Barry, differentiated between interactions with others and interactions with his peers with regards to discussing his hearing loss. He shared he does not mind when his peers talk about his hearing loss but he would prefer others he is not as familiar with to not discuss the topic. He said, “My friends can bring my hearing loss up and I’m fine with it. I’m just more comfortable with them.” He also explained he has a peer buddy support system in which his friends will let him know of missed information in class or on the baseball field and said that this accommodation works very well for him. Personality differences are also a factor within interactions with peers as can be seen in this quotation,

It drives me crazy at lunch when we're all sitting there at the table and we don't talk at all. Other tables notice and I'm like, come on, and I try to bring up a conversation but it's hard when the others don't talk at all but some of my other friends I hang out with are very talkative and I don't have to be the leader or start the conversation with them.

When discussing his friends, Barry revealed his peers and he are more alike due having a shared interest in playing sports and socializing well with one another. He also recognized the value in having friends who were different from him.

When comparing his hearing loss to the hearing abilities of others, Barry explained that the fact that others can hear better than he can does not bother him too much. Rather, what does irritate him is when others bring up the hearing loss rather than focusing on what he can do as revealed in this notion, "If nobody else brings it up then it doesn't bother me but if someone says something about it then it gets, I get really insecure about it." Barry went on to state he would rather others know about his hearing loss but to not bring it up in conversation. "I guess I would rather everybody be aware of like, if I don't hear them, everybody's aware that oh, maybe he doesn't want to talk about it and then no one will have to feel uncomfortable."

Beyond interactions with caregivers/parents, Devin listed the following activities he enjoys when interacting with his peers, "hanging out with my friends, going out with my girlfriend, talking with my friends, and hanging out in the lobby" of the high school between classes. In the home setting, Devin enjoys playing with friends in his neighborhood and has bonded over things they have in common with each other. In looking at his social circle at school and elsewhere, Larry explained he does not have many friends but he does have a core group of good friends with whom he associates.

Danny, the youngest student participant in the study, shared that “people are mean sometimes because I have the hearing aids or because I have hearing loss.” Within interactions with peers, Danny spoke about an instance of being bullied due to having hearing loss but was clear that individuals with hearing loss are not always singled out for that reason. In cases of peers teasing him, he shared that he “puts it out of mind. If it [teasing] happens, then I confront them and talk with them. If it happens again, then I will tell the teacher because she won’t stand for that.” Danny spoke of his friends and explained “we have a good amount of differences and likes. We usually play Xbox or Playstation, like certain shows and games but we also have some differences too.” Regarding selecting an identity type related to hearing loss, Danny also urged students with hearing loss to

move on with their lives. Deal with the hearing loss and then try to be president of your class, or try out for band and chorus, or do sports; it doesn’t matter what you do but just try and move on so you don’t get stuck and not see where you can go!

Through this statement, Danny stressed the importance of accepting oneself as is and then moving on and accomplishing goals, whatever they may be.

**Other personality attributes.** All of the participants described personality attributes that also contributed to the identity of the students with hearing loss in addition to the hearing loss. Mark describes his son as “a great kid who is very good at sports, likes his friends and teammates, and has a good heart” with his strengths as being “very personable and a kid others enjoy being around” with weaknesses revolving around

academics at times. While Barry is a strong student, his father revealed there are times he has to work hard to achieve his grades.

Shannon shared that her son has a big heart in spite of not being able to relate to others at times,

He would give you the shirt off of his back to a point but he can also be very rigid in that he only thinks about things from his perspective and can have a hard time relating to others at times.

Shannon also described her son as being very active in outdoor activities such as hunting and fishing.

Scott revealed his son is

very intelligent, perceptive, empathetic, and different than any other kid I've known. He's very disciplined and listens a lot. He asks great questions, reads a lot, and picks up vocabulary. He pays attention, is smart, and a really good kid. There is never a time he's not paying attention.

Danny's mother, Kate, described him as being "a very pleasing child who likes to make sure everyone is happy. He's outgoing, kind, a leader, and has high expectations for himself! We call him an 'old soul' and he is very brave and talkative."

Eileen characterized her son as being "tender hearted and sensitive in spite of putting up a wall with some people. He can be lazy through not applying himself at school but he does love to read books he's interested in on his own time. He struggles with organizational skills and studying habits and can be hardheaded but with maturity, he may outgrow this." In regards to the impact of hearing loss, Eileen explained her son's hearing loss is a "big portion of the pie that makes up my son but there are also

other things that make up Larry” which reflects her philosophy of viewing her son primarily as a person rather than focusing on the hearing loss.

The student participants demonstrated a wide variety of interests, hobbies, strengths, and weaknesses. Barry, a student participant, revealed he has a “good family that consists of my mom, dad, and little brother.” He “enjoys playing outside, baseball, playing with his little brother and friends, and doing fun things.” In thinking about personal strengths, Barry said, “I’m a good listener, not actually hearing people but I can listen to people talk and interpret what they’re saying. I like being around people and I give good advice” although he can “get nervous in a crowd” but he does “socialize well” in spite of a little shyness. He explained that “it takes me longer to warm up to people” in some social situations but that he can also be talkative at times. Devin described himself as a 16-year-old freshman who enjoys driving, playing video games, spending time with his friends and girlfriend, hunting, fishing, and other social activities (e.g., talking, hanging out with friends in the lobby). He commented that he does not enjoy nor like school.

Larry explained that hearing loss does not define him as he would rather individuals be defined by their actions and whether or not they are kind to others. Rather than focusing on the hearing loss as making up the whole person, this teenager spoke of hearing loss as being a singular dimension of identity throughout his interview. Larry conveyed he enjoys riding dirt bikes, following the Ravens football team, music, and video games. He is interested in social studies but struggles with math in school. Danny commented he has “big goals in politics and history and big ideas in life in terms of a job

or a career.” Hobbies and interests of Danny include sports, karate, and debating. He calls himself “open minded and imaginative” and while he struggles with writing, he enjoys giving speeches.

### **Management and Resiliency**

Within seven of the participants (i.e., four students and three caregivers/parents) a sense of management and resiliency was evident through the participants describing how they deal with the hearing loss and carry out their roles as informants in sharing specifics about the hearing losses, details about what helps to assist hearing, and bouncing back or being resilient in adversity. Jessica spoke of the management of the hearing loss being a way of life for the family and her son and the hearing loss was made to be a workable scenario through utilizing resources, gaining background information, and through a support network. Jessica disclosed the advantages of her son being able to benefit from technology by saying the technology “makes his hearing loss very manageable.” While the hearing loss is well managed within the family through buying and keeping hearing aid batteries on hand and making appointments with the audiologist and otolaryngologist, Jessica stated the hearing loss is “not prominent” in their lives since it is “just a part of what we do” in everyday living. Managing of Barry’s hearing loss requires that she not only make appointments with audiologists and otolaryngologists but also requires her to navigate insurance policies and companies according to Jessica. When asked to think back to the initial time of diagnosis and what one piece of advice she would share with other parents of children with hearing loss, Jessica responded by saying,

I guess the first thing is to just start talking about it. Encourage the parents to get the resources their children will need, and try to grow in background knowledge. I would also be sure to tell the parents this is something to deal with, it can be managed, and raising a child with hearing loss is a workable scenario.

Jessica clarified that telling parents who are raising children with hearing loss that this is a workable scenario was not to “minimize the hearing loss but to explain that it can be managed” with the appropriate resources in place. She also said that the very first thing she would do if she were in a situation where she were faced with parents who had just found out their child had hearing loss would be to “sit and talk a while” to provide emotional support for the parents, such as how Dr. Gates had done for her in the past.

Jessica shared a personal example of how she drew support from her son’s educational audiologist during the early stages of diagnosis of hearing loss by saying,

my connection was Dr. Gates. We needed Dr. Gates at that time Dr. Gates came into our lives. She was concrete and I don’t want to say aggressive but she was concrete and sure. Things get foggy when you first begin to figure things out and it was Dr. Gates who broke things down for us. We needed Dr. Gates; we didn’t know that but she was the one who we needed.

Over time, the support from Dr. Gates was not needed as Barry got older and the hearing loss was well managed through use of compensatory listening skills and advocating for himself.

The structure of Scott’s perception of his son’s identity related to his son’s hearing loss can be described as one of management as well. Throughout his interview, Scott focused on how well managed his son’s hearing loss has been due to use of technology (e.g., hearing aids), the family accommodating for Danny’s challenges that

arise from the hearing loss, and his son's excellent use of compensatory listening skills. As a result, Danny is able to manage his hearing loss to the point that he is able to function within a hearing world. Scott explained that had the hearing loss been more severe, this father would view his son's hearing loss as a disability. According to Scott, his son is a person with hearing loss but is "not a person with a disability because the hearing loss is well managed." Scott explained that, for him, if the special need does not "affect quality of life" then it is not a disability. He explained how he compensates for his son's hearing loss by "speaking louder and being more pointed in conversations with him." While at first these accommodations could be seen as challenging, Scott explained that these modifications are "something you adjust to and our family is fortunate that we're familiar with this stuff due to having had another family member (a niece) who has hearing loss and uses cochlear implants so she gets along very well." When describing how Scott manages his son's hearing loss, he described the importance of ordering batteries and scheduling and attending appointments with audiologists and otolaryngologists.

Scott spoke highly of his wife's nurturing and aiding their son in managing his hearing loss, scheduling appointments with the audiologist and otolaryngologists, and providing hearing aid batteries. This dynamic was also evident when Scott shared that his wife knew more specifics concerning Danny's hearing loss than he, as the father. The description of Danny's mother's interview is focused on the notion of perseverance and adjustment. Kate emphasized that despite difficulties in obtaining a diagnosis of her son's hearing loss, Danny has been able to be successful within his evolving

environments in communicating with others, sometimes through the use of technology and through using compensatory listening skills.

Similarly, a story conveyed by Shannon illustrates the positive impact of her son, Devin's, teachers on her experience of raising a child with hearing loss,

His classroom teacher from when he was three years old, gave me a poem. She was a teacher of the deaf and in charge of the hearing impaired classroom. Devin had so many struggles then. She gave me a poem that basically went on and said about how things will be so difficult and at the very end of the poem, it said and God gave him to you. God knew He needed somebody really strong to be DC's mother at this point and I'm probably one of the strongest women I know. What I've been through, my friends would never have made it. But I got him [Devin] and it's going to be a challenge but you know what, I'm a girl who's up for the challenge.

**Role as informational source.** It was not uncommon for student participants to state they served as an advocate or informant in describing their hearing losses or accommodations that assist them with hearing and accessing communication with others. However, one student participant, Danny, struggled with issues related to low self-esteem and self confidence as a result of the challenges he has faced or the teasing he had endured from peers in the past due to wearing hearing aids or having hearing loss. Danny currently serves as an educational advocate to others within the school and community settings. Danny also shared examples of informing others of his hearing loss, the purpose of his hearing aids, and accommodations that are successful for him. When people ask why he wears hearing aids, Danny will find himself in an informational role educating others about his needs, "I tell them I can't hear well and the hearing aids help me hear better so they understand why I have hearing aids after that." Danny discussed instances

where his peers have asked him about his hearing aids and hearing loss and will try to educate them, “I try to explain to them about my hearing aids and tell them what they are for to help them understand.”

In a similar fashion Barry finds that he explains to others about his hearing loss and how much he can or cannot hear in everyday terms rather than speaking in audiological terms.

I can explain that I can still hear a little bit without my hearing aids in, just not as well as other people can hear. I’m not going to give them like percentages of what I can hear or when I’m taking hearing tests and stuff like that. I will use the identity type of deaf because I guess people understand or recognize someone who’s deaf even though I don’t see myself that way.

Devin acknowledged that he often finds himself in the role of explaining the different identity types to his hearing peers, “if they don’t have the experience then I tell my friends and explain how I can be both identity types [hearing or deaf] by using my voice with them [hearing people] but communicating through sign language with the deaf students.” Devin shared that he has been asked to explain these differing identity types by his peers. A story he relates,

At lunch the other day, I got asked, what’s it like being hard of hearing? I said it’s fine right now and he [the peer] asked why. I said it’s because I can interact with both people, hearing and deaf. I’m in the middle so I can talk with you but when you leave, I can talk to this other guy with my hands.

Through these types of exchanges with his peers, Devin is able to inform his peers about the differing identity types and how he perceives himself.

**Advocacy.** One student participant expressed how he acts as an advocate in multiple ways. Larry disclosed that he has been able to be successful within his evolving environments in communicating with others, sometimes through the use of technology and through using compensatory listening skills however Eileen, his mother, would like to see him advocate for himself more often. She would like to see him “put aside his stubbornness and speak up when he has issues hearing someone” and to let others know of accommodations that are successful for him.

Within the caregiver/parent set, advocacy emerged as a critical component in raising a child with hearing loss. Several of the caregivers/parents expressed their desires for their sons to increase their self-advocacy skills, especially as they mature and transition to a higher level of schooling. Jessica made clear her expectations that her son is held accountable for hearing aid maintenance and advocating for his needs during his interactions (e.g., dead hearing aid battery during a baseball game, informing teachers of accommodations as the need arises). Jessica insisted Barry needs to be responsible for his hearing aids (e.g., changing hearing aid batteries, keeping them out of reach of the family dog, and wearing them every day). Shannon maintained a perception of her son’s identity related to his hearing loss as being one of resiliency and advocacy. Throughout her interview, Shannon focused on her ability to overcome challenges within the family and in everyday living that presented as a result of her son’s hearing loss. She recounted a story about the support she received via a preschool teacher through receiving a poem about the upcoming challenges she would face as a mother of a child with hearing loss. This action may have set the stage for the parental involvement she was about to embark

on as she spoke of the need for parental advocacy of children with hearing loss particularly with the school and medical personnel. Such advocacy involved access to appropriate technology, such as digital hearing aids, and to provide opportunities for her son to grow in acquiring language, vocabulary, and communication skills.

Shannon also spoke about how perceptions of Devin's identity may change depending on familiarity with Devin, "People who know him, like friends, would know he doesn't hear sometimes and perceive him differently than people who don't know him, like strangers." Shannon explained as her son got older, he increased use of his compensatory listening skills,

When he was little, if he didn't hear you, he wouldn't say anything but as he got older, he has been able to speak more for himself by saying I didn't hear you or what did you say by asking for repetition. But we went many years where he didn't ask any of that and kind of ignored it. He's gotten better at it. I don't know how often he does that. I don't know if there are times that he doesn't hear things and he doesn't want people to know about the hearing so he just ignores it. I really don't know, with his friends, how often that might happen.

Shannon also highlighted the importance of serving as her child's advocate

all of the time because nobody else is going to look out for him and nobody else is going to take on the schools, the doctors, the teachers, therapists, principals, and drivers. Nobody else is going to do it. It's hard and tiring but the children are given to you for a reason and you don't know why but if you don't fight for them, nobody else is going to fight for them so parents of children with hearing loss need to advocate for them all of the time. Those parents will need to keep their chins up and deal with the many things that will come up along the way!

A challenge of being a parent of a child with hearing loss regarded transportation and school placement according to Shannon,

Every year, we still have to deal with this issue. The bus company is a perfect example because we live in a district separate from the district where he attends school. They try to put him on a bus that he would ride for over an hour and every year, I fight that by saying we're not doing this and I'm not making my child ride the school bus for more than an hour. I'm not going to have that happen.

In terms of advocacy within the school setting, Mark, had positive experiences with his teenage son's school district over the years by saying that he and his wife would "make sure Barry can hear his teachers and he is accommodated for by putting him in the position to do that, if he hasn't already, to help him to hear better." Mark also mentioned this parental advocacy at school took place more often in the past than it currently does at the high school level due to his son now advocating for himself. Mark also discussed the benefit of accommodations (intended for his son) on his peers within the classroom by saying,

when Barry was younger, he got preferential seating and the school put in an audio or speaker system that allowed him to hear the instructor better. We were told the amplification would be of benefit to not only my son but to all the students in the classroom since it helped all of them to hear and not be distracted by background noises.

Another positive experience within the school setting for Mark was to receive support from Barry's classroom and hearing itinerant teachers and speech therapists "to make sure Barry received the skills and instruction he needed" to succeed.

Scott explained that his son's management of the hearing loss through compensatory listening skills coupled with his wife's assistance and "everybody else working around him you get to kind of the core of the way I and my wife think is we're

all responsible for the way in which we conduct ourselves in the world.” Thus, this father believes very strongly in his son’s advocating for himself. Irrespective of identity type or so-called label, Danny is seen as a contributing member of the family who succeeds at communicating with others. Scott shared his view on using labels to identify people in the following statement,

I believe that we’re all accountable for our behavior and the way and things we get in this world. We are all accountable for that and there are way too many labels. There are too many crutches in America and while sometimes they are deserved, there are many times they are misapplied and overused. I don’t want and would certainly not expect Danny to use the labels or crutches to get anything he wants.

Conversely, when asked for one piece of advice to share with other parents of children with hearing loss, Danny’s mother, Kate, advised the parents to “be diligent and to not let others tell them the hearing loss is not a big deal” implying that students with hearing loss may need additional support.

Eileen expressed frustration over her son’s lack of self-advocacy within the community setting,

When Larry gets his hair cut, you know if they’ll talk or they’re blow drying his hair and there are all kinds of noises or they’re standing behind him, he’s not going to hear them but he doesn’t say anything. If they’re talking behind him above his head and he has taken out the hearing aids so they can wash and cut his hair, he needs to ask them to talk a little louder so he can hear them but he doesn’t.

This mother participant hypothesized toward the end of her interview that if her son progresses from the hard of hearing identity type to the person with hearing loss identity

type he would then be advocating for himself due to her defining the person with hearing loss individual as someone who advocates for him or herself.

Chapter IV presented detailed findings and support as evidenced through the data analysis regarding the perceptions of identity and hearing loss in students with hearing loss who use spoken language and listening who are educated in the general education setting and the perceptions of their caregivers/parents. The chapter included individual participant personal profiles and demographic information, descriptions of the identity types related to hearing loss as identified by the participants within the two data sets (i.e., students and caregivers/parents), quotations from the participants to support the identified emerging themes and significant statements within the data. The three critical ideas or essences that emerged for these participants regarding perceptions of identity related to hearing status included: (a) self determined identity type; (b) notion of fluidity; and (c) a sense of management and resiliency. Chapter V will conclude the study with a synthesis of the findings by highlighting connections within the findings and those in the literature, limitations, and implications for practice and future research.

## **CHAPTER V**

### **DISCUSSION AND IMPLICATIONS**

#### **Introduction**

Through a detailed and in-depth examination of the perceptions of identity related to hearing loss of the students and their caregivers/parents, insights into their perceptions of identity and meaning associated with those perceptions and experiences were revealed. Chapter IV presented the results of ten interviews conducted with four students and six caregivers/parents. These participants were recruited through the itinerant TOD/HH in the participating school districts located in the south central region of a state in the northeastern United States. Data from these interviews sought to answer the research questions by exploring and examining perceptions of identity as they relate to hearing loss in students who use spoken language and listening as their primary mode of communication and who are educated in the general education setting. The present study addressed the following research questions:

1. How does a student with hearing loss who uses spoken English and listening as his or her primary mode of communication and who is educated in the general education setting identify him or herself with respect to his or her hearing status?
2. How do the caregivers/parents of the student with hearing loss identify him or her with respect to his or her hearing status?

Three critical ideas emerged for these participants regarding their perceptions of identity related to hearing status were as follows: (a) self determined identity type; (b) notion of fluidity; and (c) a sense of management and resiliency. Chapter V concludes the study with a synthesis of the findings by highlighting connections of the results with those as reported in the literature, the limitations of the study, and implications of the findings for practice and future research.

The theoretical framework for the present study incorporated tenets of Symbolic Interaction Theory, Social Identity Theory, the Multidimensional Identity Model, and identity studies from the literature in Deaf Studies/Deafness. According to Symbolic Interaction Theory from the literature in psychology, all situations can be analyzed through a number of different perspectives, each illuminating various aspects of the human experience (Blumer, 1969; Brekhus, 2008; Charon, 2004; Cooley, 1902; Hays, 1977; R. L. Howard, 1981; Mead, 1934). The identities, contexts, roles, and interactions with one another all have an effect on the meaning individuals attribute to an experience, event, or person and in formulating an identity. As is posited in Symbolic Interaction Theory, individuals determine the salience, or how noticeable or important aspects of their identity roles are, through interactions with others and their environment. For instance, in the present study, the participants varied in their descriptions of the impact of hearing loss or how noticeable the hearing loss was in their lives depended upon factors such as their interactions with others, the setting or environment in which they interacted with others, and their life experiences.

In addition to Symbolic Interaction Theory, Social Identity Theory delineates the relationship between the individual and society and the development of an individual's personal and social identities as related to a sense of "belonging" to a group (C. A. Baker, 2012; Mead, 1934; Tajfel & Turner, 1986). Therefore, an individual's social identity refers to that part of one's sense of identity that emerges from his or her belonging to a particular group and thus, acts as a locus of interaction between personal and group identity. For the caregivers/parents in the present study who identified the students as being individuals with hearing loss, the caregivers/parents viewed their children as belonging to a group comprised of individuals with hearing loss thus casting the students into a different group from themselves. Yet for the caregivers/parents who perceived the students as being hearing and "fitting in" with peers who do not have hearing loss, the students with hearing loss were members of the same group they would select for themselves (i.e., normal, regular, or hearing). This perception of social identity and hearing loss, is evident in the identity terms participants chose to describe themselves and/or the students (i.e., hearing, person with hearing loss, hard of hearing, hearing impaired, deaf). This is congruent with Tajfel's (1982) findings that state that an individual's identity derives from his or her knowledge of membership in a group combined with the value and emotional significance attached to that group membership. These factors may contribute to the extent to which the participants felt a sense of belonging within the group they selected or chose to categorize themselves or the students.

Identity is complex and multifaceted (Brekhus, 2008) and many models within the counseling literature seek to explore the development of identity. However, one specific model, the Multidimensional Identity Model bears relevance for the present study. Countless social networks, significant others, and generalized others influence self-identities and lead to a self that is pulled in multiple directions leading to no anchored or core self according to Gergen (1991). As a result, some individuals may attempt to bracket these multiple affiliations by shifting from identity to identity and living double or even multiple lives while other individuals may try to bridge affiliations to form one multiply influenced and socially networked self (Brekhus, 2008).

This pluralistic view of identity is perhaps more aligned with the conceptualization of identity as a result of blending of more than one culture (e.g., bicultural). For example, one of the student participants in the present study identified himself as being a member of the dominant or hearing society when he is able to hear instruction without any major accommodations in his classroom and is able to communicate and interact with peers and teachers without difficulty. However, in social situations when explaining his hearing loss and needs to other peers, he may identify himself as being deaf due to the understanding levels of the peers with whom he is interacting.

Investigations of identity in Deaf Studies/Deafness have resulted in the designations of four categories to describe an individual with hearing loss. Scholars have identified the following identity types: (a) Deaf, (b) deaf, (c) marginal, and (d) bicultural/dual in the Deaf Studies/Deafness literature (Cornell & Lyness, 2004;

Glickman & Carey, 1993; Lane et al., 1996; Most et al., 2007; Woodward, 1972). It is critical to note a person with hearing loss may claim an identity that is radically different from other individuals with a similar type of hearing loss and multiple factors contribute to the development of identity of individuals with hearing loss (Humphries & Humphries, 2011; Leigh, 2009).

The notion of fluidity has so far been limited to Deaf students (Mcilroy & Storbeck, 2011). Consequently, the literature regarding students with hearing loss traditionally relied on Glickman's (1996) model of identity types. For example, for students with hearing loss, researchers defined individuals with hearing loss as being members of the Deaf, deaf, marginalized, and dual/bicultural identity types (e.g., orienting towards the culturally Deaf identity type; Cornell & Lyness, 2004; Glickman & Carey, 1993; Lane et al., 1996; Most et al., 2007; Woodward, 1972). This culturally focused definition (i.e., Deaf identity type) does not address what identity means for students with hearing loss who use spoken English and listening as their primary mode of communication and who are educated in the general education setting and for their caregivers/parents. A broader conceptualization utilizing aspects of the Symbolic Interaction Theory, Social Identity, and the Multidimensional Identity Model that encompasses attention to other attributes or aspects of identity leads to a fluid or multidimensional identity type contingent upon contexts/environments, interactions with others, and previous experiences that is similar to the DeaF model of identity posited by Mcilroy and Storbeck (2011).

For example, applying this broader conceptualization of identity to the students with hearing loss in this study and for their caregivers/parents, relying on the Deaf identity type to describe themselves and/or their children posed at least two challenges. First, as the participants revealed, the students with hearing loss did not know sign language, with the exception of one out of the four participant clusters. Yet all of these students were reported to be the only individuals with hearing loss in their immediate families and for three of the four clusters, in their classrooms, so it may be possible they may feel a sense of isolation or as if they are marginalized. Second, for other students with hearing loss, the Deaf identity type may be misleading for them because they may choose to identify themselves by some other attribute or characteristic of themselves or may perceive their hearing loss as having a tertiary or small impact on their lives. This was evident when the participants discussed how large of a pie slice or portion they would designate as being related to hearing loss if they had to create a pie chart of characteristics or traits to describe themselves. Nearly all of the participants in this study attributed the hearing loss, or how much time they focus on the hearing loss, a small sliver of the pie chart. Caregivers/parents demonstrated a tendency to make the pie slice a bit larger in comparison to the student participants. When describing themselves, student participants, and the majority of the caregiver/parent participants, chose to describe the students by using adjectives (e.g., great, kind, curious) focusing on accomplishments of the students (e.g., hard worker, good student) rather than dwelling on the hearing loss.

For example, in viewing the self as a whole, when discussing the impact of hearing loss on his son's life through using a pie analogy in which the caregiver/parent participant (Mark) had to determine how large of a slice of the pie to designate as impact of hearing loss, Mark explained the hearing loss is a part of who his son is and that the pie slice attributed to hearing loss is perhaps more for how he and his wife "react to the hearing loss" since his son has always dealt well with the hearing loss according to his father. He stated,

when I think of my son, the first thing that comes to mind certainly is not his hearing loss. There are a lot of other things I think about when I think of him such as how smart he is, how well liked by his peers he is, and how proud I am of him. Yes, there would be a small part of the pie that makes up my son that would go to the hearing loss but that's just one part of who he is and I think he may be a better kid today because of it.

Another caregiver/parent participant (Eileen) agreed with Mark by explaining she views her son as a whole and she does not necessarily associate the hearing loss as the only feature of her son. A student participant, Larry, with regard to hearing loss, also described himself as a "regular person because hearing loss doesn't mean anything in terms of how I define or identify myself. I would think of me first, not the hearing loss." Larry further explained that his perception of "regular is that it doesn't matter if you have glasses, wear hearing aids, or braces, but what does matter is if you are nice to others or not."

Thus, in any case, misunderstanding identity perceptions on the part of the students and/or the caregivers/parents may influence their interactions with others. Analyzing how individuals with hearing loss identify themselves with how others in their

lives perceive them is critical if understanding of and affirming one another can occur because caregivers/parents, teachers, and counselors of students with hearing loss must not assume what is most central to individuals with hearing loss. For example, one student participant clearly explained he does not view himself as a member of the deaf identity type but rather labels himself as a hearing person (when he wears his hearing aids) and as a person with hearing loss when he is unable to hear information. When explaining specifics about his hearing loss to others, however, he categorizes himself as a member of the deaf identity type since it helps others to understand his needs even though he does not necessarily view himself as being deaf. This example from the present study illustrates the importance of others realizing individuals with hearing loss may not necessarily identify themselves as being one of the identity types that have been established in identity studies within Deaf Studies/Deafness literature. Instead, others, such as, caregivers/parents, teachers, and counselors of students with hearing loss must be receptive to how the individual student identifies him or herself (Cole & Edelmann, 1991; Jackson et al., 2008; Schlesinger & Meadow, 1972). This awareness of differing perceptions reflects tenets of the Symbolic Interaction Theory in that individuals may have different interpretations or meanings for the identities they select related to hearing loss.

The present study bridges the gap that exists in research regarding students with hearing loss: how they perceive/identify themselves and how their caregivers/parents identify their children with respect to their hearing status. The present study investigated whether or not the participants view the student participants as being culturally Deaf.

The present study examined whether or not perceptions of identity are fluid as outlined by the Deaf perspective (McIlroy & Storbeck, 2011) through participants sharing if and to what extent hearing loss has an impact on their lives. For example, although the student participants shared that hearing loss was not a large factor in determining their identity in some interactions with others, they reveal that the hearing loss may have a larger impact in certain settings and in certain roles as described in Symbolic Interaction Theory which demonstrated fluidity among identity types. The following sections outline the three essences regarding perceptions of identity related to hearing status that emerged in the present study: (a) self determined identity type; (b) notion of fluidity; and (c) a sense of management and resiliency.

### **Essence 1: Self Determined Identity Types**

Although each student participant in the present study had a diagnosis of moderate to severe sensorineural hearing loss and wore behind the ear hearing aids in both ears, the majority of the students and caregivers/parents agreed that although the hearing loss itself remained static, the impact of hearing loss on their perceptions of identity varied. Perceptions of identity were complex with some participants explaining that their perceptions of their or their children's identity varied depending upon his or her interactions with others, the contexts/settings in which they interacted with others, and the individual meanings associated with identity type.

During the course of the study, it became clear how each participant's self determined identity type, prior experiences, and their own definition of what it means to live with hearing loss distinctly guided how they approached the interview questions. In

order to describe the phenomenon of perceptions of identity related to hearing loss, it was critical to include the perspectives of students who were of three different academic age ranges (i.e., elementary, lower high school, and upper high school) and the perspectives of their caregivers/parents. Although the students were the only individuals within their immediate families who had hearing loss (i.e., siblings and caregivers/parents), the caregivers/parents varied in exposure to and experiences with others in their lives who had hearing loss (i.e., coworker, elderly caregiver/parent, a niece, no prior experience) prior to their children being diagnosed with hearing loss.

Irrespective of identity type selected by the participants, a recurring theme across both data sets (i.e., students and caregivers/parents) emerged in that the individual determines the identity type. Participants spoke of how their perceptions may differ from what others perceive. For example, one cluster, the White family (i.e., Jessica, Mark, and their son, Barry), spoke of their frustration with others' differing perceptions of Barry's hearing loss. Jessica related she and her husband, Mark, are improving in the area of accepting others' differing views of their son based on his hearing loss. Mark raised the belief that a stigma shrouds hearing loss in that others have lower expectations of his son once they realize he has hearing loss. Barry explained how he will sometimes grow upset with others being quick to classify a response, or lack of response, to his hearing loss when other factors may have been the reason why he missed information rather than his not hearing it.

The participants' self determined identity type encompassed the full spectrum of identity types: hearing, person with hearing loss, hard of hearing, hearing impaired, and

deaf (medical), or none of the provided identity types. All of the participants aligned the hearing identity type with their perception of what it means to be a “normal or a regular” person in society (e.g., having no hearing loss) at one end of the spectrum. See Figure 3 for a depiction of the selected identity types by each participant cluster. The circles that overlap display similar identity types. The circles that do not overlap represent differing perceptions of identity selected by the student and caregiver/parent participants.

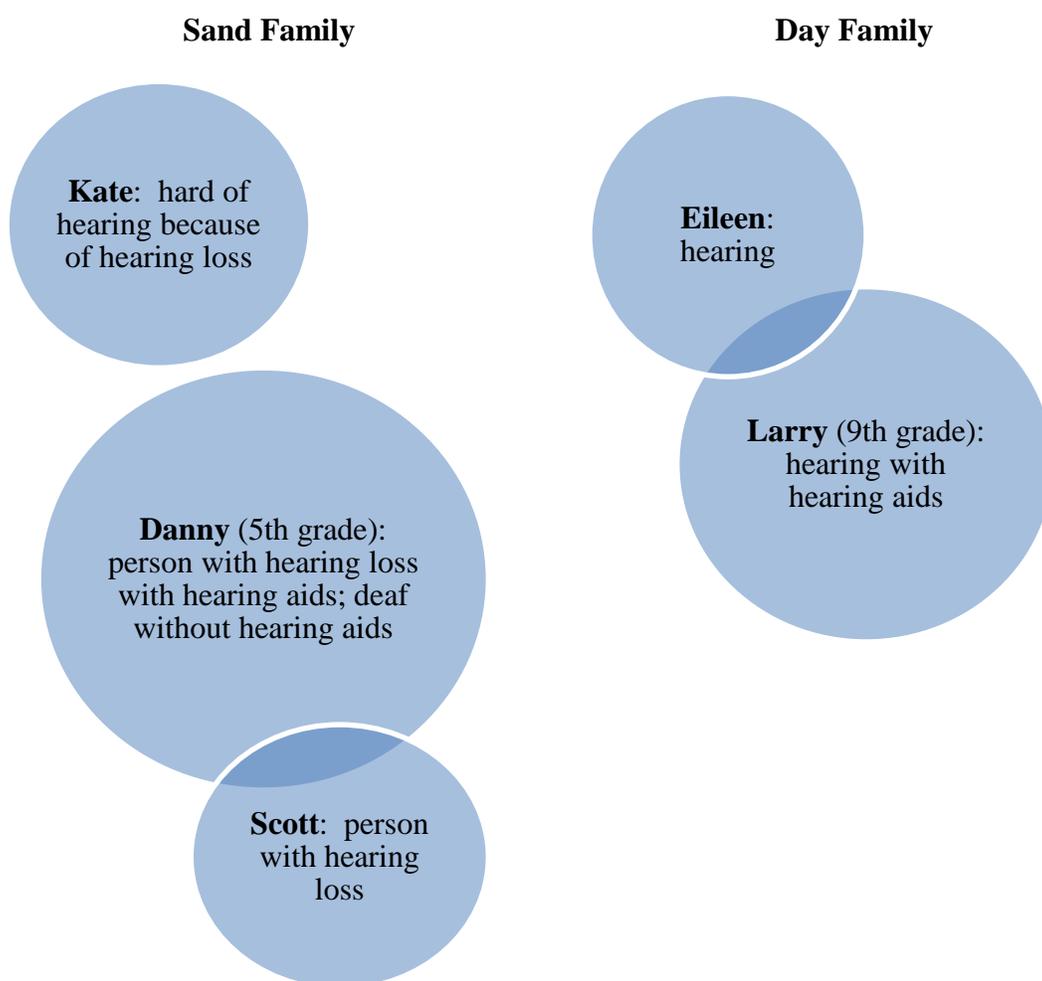


Figure 3. Participant Clusters of Self Determined Identity Types.

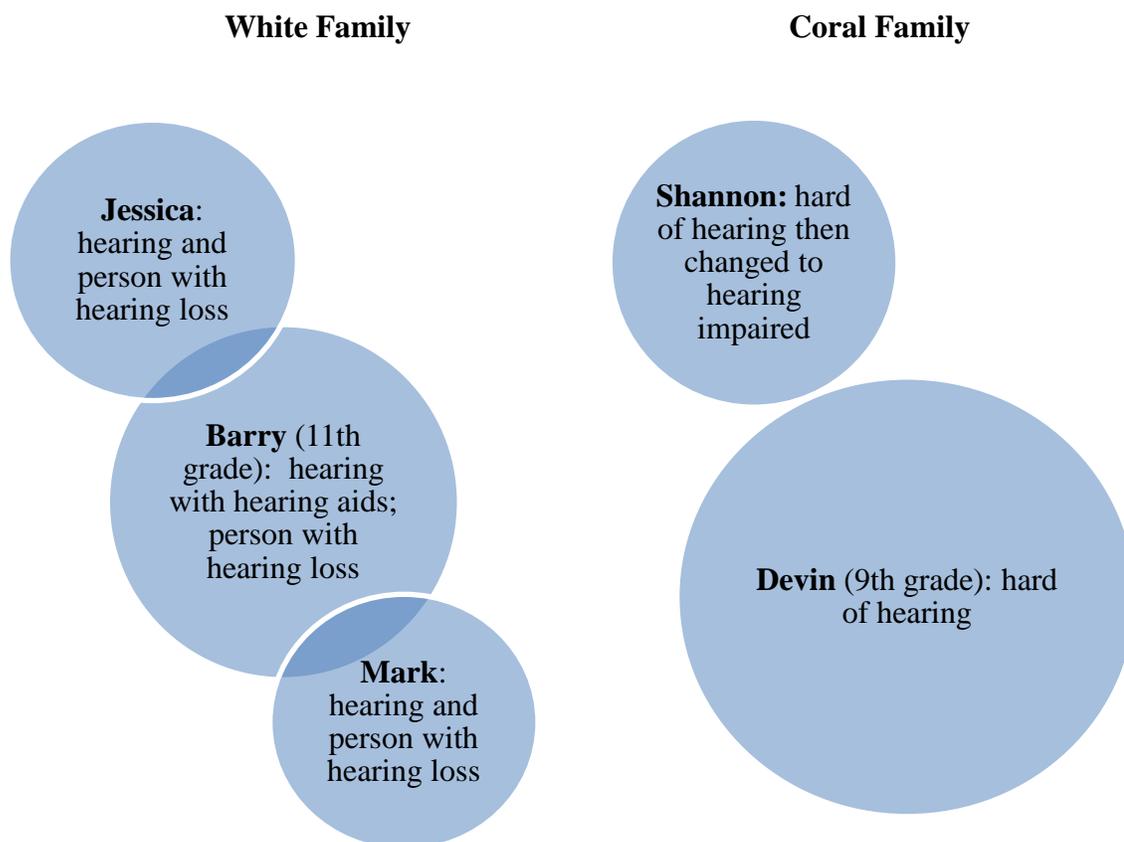


Figure 3. (Cont.)

**Hearing.** All of the participants, across both data sets, defined the hearing identity type as being the normal or regular type in that individuals in this category do not have hearing loss and communicate using spoken language and listening. All of the student participants wore their hearing aids consistently as reported by each of the ten participants. Of the four student participants, two (Barry, Larry) categorized themselves as being a member of the hearing identity type when they wear their hearing aids. Of the six caregiver/parent participants, two caregivers/parents (Jessica, Eileen) reported they identified their sons as being members of the hearing identity type. For Jessica and Eileen, who viewed their sons as members of the hearing identity type, feelings of pride

and identifying with other individuals who do not have hearing loss can be viewed as types of ethnic and cultural identities that reflect tenets of Phinney's Model of Ethnic Identity Development and Berry's Model of Identity from the literature in psychology.

*Other technology (hearing aids, cochlear implants, sound field amplification systems).* All of the participants spoke of the value of listening technology in allowing the students to function within the dominant hearing society by providing access to communication and sounds. Findings from the present study indicate parental involvement regarding technology from a young age are key to establishing a hearing identity type or being able to function within the dominant hearing society. Among all four student participants, a recurring theme of parental involvement from a young age was critical to the students establishing a hearing identity type. Even though he did not select the hearing identity type for himself, Devin spoke with gratitude of his parents' involvement in obtaining his hearing aids in that they assist him with being able to communicate with members of the hearing identity type. Several student participants stated they were thankful to caregivers/parents for obtaining and providing hearing aids from a young age to ensure oral communication could occur.

Some students and caregivers/parents discussed how if the students were not able to benefit from the use of listening technology then their perceptions of the students' identities might change. For example, Jessica stated had Barry not been able to benefit from use of his bilateral behind the ear hearing aids, then she might reconsider her labeling him as both a person who is hearing and a person with hearing loss and instead classify him as a deaf person. Eileen echoed this perception by saying that if her family

would have had to learn sign language in order to communicate with Larry then she would not view him as a hearing person but instead she would view him as a deaf person. Eileen also shared that when she looks at her son, she views his hearing aids as being a part of him. Another caregiver/parent participant, Kate, expanded on this notion by saying her son views his hearing aids as an extension of himself. She spoke of the family joke that her son's hearing aids are his "ears." Thus, these two mother participants viewed their sons' hearing aids as being a part of their children.

*Advocate for accommodations.* The use and advocating for listening accommodations enabled the student participants to successfully participate within the hearing world. The participants felt strongly that by advocating for the needs of the students that others' perceptions of the students' identity might more closely align with those of the students of themselves. One student participant (Devin) shared his belief that others may not provide accommodations because they think he is unable to hear them anyway while another student participant (Barry) expressed frustration over others assuming he is not hearing due to lack of accommodations, by stating,

not everything is related to hearing. Sometimes I am focusing or paying attention to something to the point of blocking out distractions. Some people don't provide accommodations because they think you can't hear them anyway. Perceptions are that some people just don't care or want to help or I may be a nuisance or bother asking people to make these accommodations for me.

One caregiver/participant (Mark) emphasized that despite his son's hearing loss, Barry has been able to be successful within his evolving environments in communicating with

others, sometimes through the use of technology and other accommodations, which helps Barry to be seen as “normal,” or a person without hearing loss.

**Person with hearing loss.** Of the four student participants, two (Barry, Danny) categorized themselves as being a member of the person with hearing loss identity type. Danny made the distinction of classifying himself as such when he wears his hearing aids. Of the six caregiver/parent participants, half (Mark, Jessica, Scott) reported they identified their sons as being members of the person with hearing loss identity type. This finding is in agreement with research that has found caregivers/parents tend to identify their children as deaf if they are students in a residential school or in a self-contained resource room. The student participants in the present study are students enrolled in general education settings where caregivers/parents are less likely to select the deaf identity type when describing their children (Shaver, Marschark, Newman, & Marder, 2013).

Yet one caregiver/parent (Jessica) expressed her hesitancy to use the person with hearing loss identity type due to the term focusing on the hearing loss or the clinical aspect of it. She explained that by saying her son is a person with hearing loss, she is focusing on the actual medical “problem” and not on the individual nor her son. Her son, Barry, and two other caregiver/parent participants (Scott, Eileen) also focused on the term, hearing loss, as representing a disability in a way. These three participants, in particular, emphasized that although they did not view the hearing loss as being a disability, they speculated others may perceive the hearing loss as a medical issue or a disability by saying the hearing loss was “almost a disability” for others. One of the

father participants, Scott, explained initially he was hesitant to use the person with hearing loss identity type to describe his son, Danny. This reluctance was due to his view that his son never lost the hearing to start with as he was born without hearing. This literal approach to this identity type may explain why some people might not use it especially if the hearing loss has been present since birth.

**Hard of hearing.** This identity type was the least known among the student participants. Three of the four student participants (Barry, Danny, Larry) asked for further clarification as to what the hard of hearing identity type might entail. Only one student participant (Devin) selected this identity type for himself, thus presenting himself as an outlier in the present study. He explained that being a member of the hard of hearing identity type meant he could relate to members of the hearing identity type and members of the deaf identity type due to his ability to use American Sign Language and spoken English. Thus, he perceived himself as communicating with others and acting as a bridge between the two worlds or groups by aligning himself with either one (Hardy, 2010). Likewise, Devin's mother, Eileen, initially reported her son was a member of the hard of hearing identity type but later changed the label to the hearing impaired identity type. Another caregiver/parent (Kate) also selected the hard of hearing identity type for her son but distinguished he is hard of hearing as a result of having hearing loss. Eileen also spoke of viewing her son, Larry, as being hard headed not hard of hearing in that he can be quite stubborn at times to which she attributes that to personality rather than hearing ability. Two common themes related to the hard of hearing identity type were evident. The first was the belief that a person who would be identified as hard of hearing

might not necessarily wear hearing aids. The second common theme related to the hard of hearing identity type focuses on whether or not the individual has difficulty with hearing or communicating with others.

**Hearing impaired.** Shannon's rationale for changing the identity type she selected for her son, Devin, from hard of hearing to hearing impaired was based on the knowledge that he misses a great amount of information on a daily basis. Shannon shared that she has seen firsthand how much her son's hearing loss has affected his life. For her, the term hearing impaired, signified that the hearing loss had a stronger degree of impact on her son's life and the lives of those around him than the hard of hearing identity type. It is noteworthy that the term or identity type, hearing impaired, was not listed as an option during the card sort activity and was generated by this mother when she selected an identity type for her son.

**None/Marginal (created own label).** One participant out of the ten, Jessica, selected the none category for her son when describing his identity type. Jessica was hesitant to describe her son strictly by his hearing loss. She instead wanted to describe Barry as a "great kid" which means she selected the none identity type in the card sort activity. However, when prompted to view her son from the perspective of hearing loss, she selected two identity types: a person with hearing loss identity and hearing. Jessica's experience does not represent the essence of the participants but it is of interest to note this particular caregiver/parent participant initially did not want to define her son by his hearing loss. Yet, when asked to describe the extent and percentage to which her son's

hearing loss impacted her overall view of him, when describing him using a pie analogy, she attributed a large slice of the pie to hearing loss (i.e., 70%).

**Both/Dual/Bicultural.** Although recognized and identified within the literature in Deaf Studies/Deafness, the identity type of both/dual/bicultural did not emerge within the present study with the exception of one student participant, Devin. He described himself as being a member of the hard of hearing identity type because for him, that identity type signified he was able to interact with members of the hearing and deaf identity types. In the card sort activity, Devin was presented with the varying identity types. Rather than selecting the both/dual/bicultural identity type card, he instead selected the hard of hearing identity type card. In doing so, Devin positioned the hard of hearing identity type as being midway between the hearing and deaf identity types. His defining the hard of hearing identity type in this way represents what the both/dual/bicultural identity type means in that members of this identity type can belong to more than one identity type. The literature within Deaf Studies/Deafness tends to situate the both/dual/bicultural identity type as being a member of both the hearing and the deaf identity types (Grosjean, 2010; Holcomb, 1997). However, Devin did not state he was a member of each identity type but that he belonged to the hard of hearing identity type which he defined as having the potential to be able to fit in within both identity types. Conversely, he clearly segregated himself from the hearing and deaf identity types and instead placed himself in the hard of hearing identity type as a separate standalone category.

**Deaf (cultural).** None of the ten participants in the present study selected the Deaf identity type or mentioned any of the other characteristics typical of the Deaf identity type as described in the Deaf Studies/Deafness literature. The two defining characteristics of the Deaf identity type for the participants in the present study were communicating through sign language and having minimal to no access to sound. These characteristics differ radically from what has long been believed within the Deaf Studies/Deafness literature in that although hearing people may think that Deaf people's goal is to be included in society, it may be possible that Deaf people's goal is one of maintenance of boundaries between cultures and a search for accommodation that allows the Deaf person to remain true to the self (Humphries, 1996). This widely believed view was not found to be expressed by any of the participants in the study.

The development of one's identity as a Deaf person is often a long process of discovery because only a small number of deaf individuals are born into the culture and most become a part of Deaf culture during their teenage or young adult years (M. R. Byrne, 1998; Hodapp, 1998; Leigh et al., 1998; Padden, 1996; Parasnis, 1996; Trybus, 1980). More often than not, the transition into a Deaf identity has been found to occur during their school years; especially when they transitioned from inclusive hearing schools to a school for the Deaf (Mcilroy & Storbeck, 2011). The student participants in the present study were born of hearing caregivers/parents and the clusters or families were not immersed in Deaf culture nor did they attend schools for the Deaf. These caregivers/parents and students associate with members of the mainstream hearing society (e.g., in their communities and schools) and they made the decision to raise their

children to prepare them for the world around them (i.e., hearing identity type versus the Deaf cultural identity type). Three of the student participants in the present study were teenagers or young adults, however they were not educated in a school for the Deaf or even in a classroom exclusively for students with hearing loss due to their being educated in the inclusive general education setting in their neighborhood schools. Thus, a student's educational placement may affect which identity type he or she selects for self.

Differences in identity are likely to be rooted in whether or not an individual's developed identity included a central view of self as a person with hearing loss or a view of self without hearing loss (K. Anderson & Arnoldi, 2012). These authors posit that if "the person I am" is the only child with hearing loss in the grade and/or school, then "the person society expects me to become" is likely to be a person who views self as fitting in with others who do not have hearing loss by association. This appears to be the case with the student participants in the present study in that their inclusive settings, they are one student of a few, if not the only student with hearing loss, in their schools.

**deaf (medical).** One student participant (Danny) selected the deaf identity type and stated that he only uses that term when he does not wear his hearing aids. Another student participant (Barry) explained that although he does not view himself as a member of the deaf identity type, he does use the label when explaining his hearing loss and communication needs to others because it is easier for others to understand information about his hearing loss when they use deafness as a reference point. This example of using a different identity type to describe himself from what he would personally select, illustrates that regardless of what has occurred in the past, human action cannot be

understood without the subjective interpretations given to situations (Thomas & Thomas, 1928). This inability to separate human action from situations in which they occur is termed the Thomas Theorem or Axiom; if people define situations as real, they are real in their consequences. Individuals determine how they will behave or act in a situation depending on how they perceive the environment (J. M. White & Klein, 2008). Barry perceives others will not understand if he tries to explain he views himself as a person with hearing loss or even a hearing identity so he therefore chooses to describe himself by using the deaf identity type even though he does not view himself in that way by sharing, “I don’t say deaf because that’s the word I’m using to describe the hearing loss. When I describe myself as a person I don’t use deaf because I describe myself as hearing but my friends call me whatever they want such as half deaf kid or saying I’m deaf” even though he does not view himself as having that identity type. This example from Barry illustrates the use of the term, deaf, to describe the hearing loss rather than describing himself as an individual. No caregivers/parents selected the deaf identity type for their sons. When discussing traits or characteristics that are present in individuals they would classify as the deaf identity type, the defining characteristics included having to use sign language to communicate with others and the physical lack of access to sound.

According to Melick (1999), and many other researchers within the literature on Deaf Studies/Deafness, individuals with mild to profound hearing loss may categorize themselves as hard of hearing. Yet, three of the student participants in the present study were not familiar with the hard of hearing identity type. All four of the students were diagnosed with moderate to severe sensorineural hearing loss and communicated with

others using spoken language and listening. Melick posits individuals with severe to profound hearing loss would identify themselves as late deafened, oral deaf, or culturally Deaf. However, two of the four students primarily identified themselves as a person with hearing loss while two participants selected the hearing identity type when they wore their hearing aids. These findings appear to contradict prior research that defines individuals with hearing loss as being members of the deaf or Deaf identity types. The findings in the present study agree with those of Melick (1999) in that Melick posited members of the hard of hearing, late deafened, and oral deaf groups prefer to associate with the hearing community whereas members of the culturally Deaf group are more comfortable associating with the Deaf community. All ten participants in the present study used the hearing identity type or hearing group as their reference point for normality which points to the preferred community of association as being similar in the present study. Therefore, results of this study were consistent yet varied with findings in prior research as they serve to extend the research related to perceptions of identity and hearing loss in students with hearing loss who use spoken language and listening to communicate and who are educated in the general education setting.

### **Essence 2: Fluidity**

A second essence revealed in the findings is the notion that identity is not static even though the hearing loss is a permanent condition of the students. This notion of identity type shifting based on the context/environment, interactions with others, and previous experiences fostered students' ability to identify themselves in more than one way. The essence of fluidity is based on the idea of the individual having some control

over what happens in his or her environment and how he or she is able to interact within changing social situations. This aspect of fluidity resonates with tenets of Symbolic Interaction Theory and the Multidimensional Identity Model (Mcilroy & Storbeck, 2011; Mead, 1934; Reynolds & Pope, 1991).

Researchers have posited students with severe to profound hearing loss, who utilize sign language to communicate with others and who are educated in residential school settings, will identify as culturally Deaf and might choose to demonstrate fluidity by identifying as the hearing identity type when interacting in other situations in which they can communicate using spoken language. Individuals who demonstrate this type of fluidity are said to be members of the DeaF identity type a proposed by Mcilroy and Storbeck (2011). Mcilroy and Storbeck define DeaF identity as the cultural space from which individuals with hearing loss transition within and between both the Deaf community and the hearing community thereby encompassing a fluid view of identity in that individuals can move from one identity type to another as they choose depending on the roles, interactions, and contexts or settings in which the individual engages. The capital F highlights the individual's fluid interactions with his or her typically hearing family members; whereas, during social interactions with peers who have hearing loss who use American Sign Language, the individual is able to fluidly connect and identify with members of the Deaf community/culture which results in a cross-cultural bicultural dialogue between sign language and a spoken or written language (Mcilroy, 2010). One student participant, Devin, who categorized himself as a member of the hard of hearing

identity type, could be classified as a member of the DeaF category as outlined by Mcilroy and Storbeck's research due to his knowledge of American Sign Language.

For all the participants in the present study, perceptions of identity fluctuated because the identity types they chose for the students depended greatly on the situational context and interactions with others. Students tended to select multiple identity types, based on flexible views of themselves in varying situations and particular social contexts. For example, a student participant described himself as being hearing in a quiet setting, as hard of hearing in a noisy environment, and as deaf when his hearing aids malfunctioned. In contrast, the caregivers/parents viewed their children's identity types from a binary perspective by selecting either the hearing or person with hearing loss identity type for their children. The impact of the perception of hearing loss shifted depending upon whether or not communication was able to occur which further contributed to the fluidity nature of perceptions of identity as related to hearing loss. For instance, if a child were able to communicate using spoken language and listening in spite of the challenges associated with hearing loss, he was able to be viewed as hearing by self and others. Yet if a child were able to communicate via sign language, he also demonstrated fluidity by being able to communicate with others who sign (Mcilroy & Storbeck, 2011).

Even with recognizing that fluidity occurs, caregivers/parents also spoke of the static nature of hearing loss and the influence hearing loss has on perceptions of identity within their families. One way this may occur is through caregivers' or parental feelings about the hearing loss being an influential factor in the development of the students' perceptions of identity and self awareness. If caregivers/parents are conflicted about the

student's hearing loss, the student can absorb his or her caregivers'/parents' feelings and internalize that something is wrong with him or her (K. Anderson & Arnoldi, 2012).

However, if the student feels he or she is perfect just the way he or she is, the student will be better able to internalize these feelings and formulate a sense of identity, even if it changes depending upon interactions with others, the context/environment/setting, and life experiences. Therefore, even if the students' identity types fluctuate, they are able to communicate that identity type to others due to having a core sense of who they are.

The participants' theoretical frames of selecting identity type were most evident when discussing the concept of fluidity and how, with use of accommodations, the students were able to identify as members of the hearing identity type within some social situations, contexts/environments, and interactions with others. Participants who selected the hearing identity type, were rooted in the "normal" paradigm in contrast with students with hearing loss being viewed as disabled in spite of the presence of a moderate to severe sensorineural hearing loss. In the present study, those who viewed the students as being hearing impaired tended to place a higher emphasis on the hearing loss by explaining the hearing loss had a greater influence on the students' lives. Conversely, the participants expressed that the hearing loss was well managed through accommodations and by making adaptations in daily lives (e.g., appointments with ear doctor or audiologist, buying hearing aid batteries, use of compensatory listening skills).

This essence of fluidity will help explain the variability in perceptions of identity as related to hearing loss as evidenced by this conceptualization of self determined identity types. Findings from the present study indicate this fluctuating view of identity

depends on the situation. Perceptions of identity as related to hearing loss can change daily depending on interactions with others, the context/environment/setting, and life experiences. This notion of fluidity is similar to the concept of “inbetweenity” or living “between spaces” which thus becomes an individual’s way of navigating the boundaries of identity and feelings of belonging to specific groups in certain situations and not in others (Brueggeman, 2009). Further, personality attributes are also a factor when considering perceptions of identity (e.g., being a leader vs. struggling with self-esteem). The student participants tended to select multiple identity types depending on specific scenarios for themselves while the caregiver/parent participants selected primarily one or a possible two identity types for their children in thinking of the big picture or the majority of scenarios their sons may face in life. Moreover, the perception of the impact of hearing loss shifts depending on whether or not communication is able to occur which contributes to the fluidity of identity types related to hearing loss. Even with subscribing to the person-first ideology and recognizing fluidity occurs, caregivers/parents also spoke of the permanency or static nature of the hearing loss and the impact this has on perceptions of identity within their children since the hearing loss will always be a factor and impact the family’s lives.

### **Essence 3: Management and Resiliency**

The third essence is one of management and resiliency. Particularly within the caregiver/parent participants, the theme of adjustment emerged. Four of the six caregivers/parents (Eileen, Mark, Jessica, Scott) spoke of hearing aid maintenance, the scheduling of otolaryngology and audiology appointments, purchasing of hearing aid

batteries, ensuring accommodations are in place at school, dealing with insurance and medical companies, informing others of their sons' needs, and the family routinely adjusting to the students' hearing abilities within the home, school, and community environments.

Both father participants (Scott, Mark) spoke of how well their sons managed the hearing loss which led to the hearing loss having less of an impact on the family unit. However, these same two father participants revealed concern over possible teasing and bullying of their sons due to their wearing hearing aids. This worry was not present for only the father participants; two mother participants (Eileen, Kate) also expressed anxiety over these social situations. In a similar fashion, two of the mother caregiver/parent participants (Shannon, Eileen) felt that the hearing loss had a major presence in their sons' lives in spite of successful management or adjustment to the hearing loss.

Perseverance or a sense of resiliency, emerged as themes within the data sets in the present study. Participants spoke of a sense of persevering or not giving up when working to ensure accommodations are in place and are being followed. For two caregivers/parents (Jessica, Shannon), a sense of resiliency emerged in that in spite of challenges and difficult circumstances, they strive to deal with adversity and do the best they can in raising their sons.

**Role as informational source.** Both the students and the caregivers/parents expressed that there are times they serve as informational sources to others about hearing loss and the communication needs. Whether they are informing others of what hearing aids do, which seat is optimal in terms of preferential seating, or why information may be

misheard or misunderstood, student and caregiver/parent participants shared stories of how they fulfill their roles dispensing information. Participants also spoke of how they continually explain to others about the hearing loss even if others do not understand. A sense of resiliency and remaining true to how you define self was apparent when participants described others selecting an identity type they themselves do not necessarily agree with or when the participants chose to select a specific identity type as a reference point for the sake of helping others to understand hearing loss.

**Advocacy.** The theme of advocacy was prevalent among all ten participants' comments. The term self-advocacy has been used interchangeably with the term self-determination. These two terms are related, they are not entirely identical. According to Test, Fowler, Wood, Brewer, and Eddy (2005), self-advocacy pertains to four domains: (a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. Prior to developing self-determination and utilizing self-advocacy skills in their lives, students must first know how they define and identify themselves as related to hearing loss (Jackson et al., 2008). All of the students in the present study expressed they utilized self-advocacy skills which portrayed their awareness of self identity. However, discrepancies among the perceptions of advocacy demonstrated by the students by the caregivers/parents existed. For example, according to Larry, he can hear everything that is said in class and does not ask his teacher for specific accommodations. However, his mother, Eileen, reported that he would benefit from advocating for himself more often in the school setting.

A recurring theme surfaced in caregivers/parents' descriptions of their roles in serving as unremitting advocates for their children. Advocacy occurred more often when children were younger which infers that as students aged, they began to advocate for themselves. The caregiver/parent participants placed value on the self-advocacy through asking for repetition, changing hearing aid batteries, and putting themselves into locations better hear when interacting in varying contexts and with different people.

The third essence of maintenance and resiliency indicates that the centrality of how identity influences one's self-advocacy efforts. If a caregiver/parent perceives he or she cannot rise to the challenge and serve as an advocate then his or her child may absorb that sense of not being able to change the circumstances and a sense of learned helplessness may permeate the environment when it comes to living with the hearing loss. However, if a caregiver/parent demonstrates advocacy, then his or her child is more likely to gain the skills he or she needs to advocate for his or her hearing loss (K. Anderson & Arnoldi, 2012; Mcilroy & Storbeck, 2011).

### **Limitations**

The present study, similar to other research, had a number of limitations. First, due to the chosen method of analysis, the focus of this study was not on finding a consensus across the participants. Rather, the purpose was to explore the richness of the phenomenon of perceptions of identity related to hearing loss through interviews to gather information on the participants' perspective by probing phenomena that cannot be directly observed such as feelings, thoughts, intentions, past experiences, decisions, and

the meanings individuals attach to events (Merriam, 1998). Thus, the findings included universal ideas as well as some that are specific to individual participants.

A second limitation of the study is that saturation was not achieved due to the small sample size of ten participants choosing to participate within the present study. Also relating to the sample size, a third limitation of the present study is only two of the possible four father participants within the four participating families or clusters were involved as participants. The remaining two father participants opted to not participate in the interviews with the researcher while all four of the mother participants did choose to participate. A fourth limitation, as with any qualitative study, is that this research is interpretive in nature. Other researchers analyzing the same data set may provide differing, though equally valid, findings (Glesne, 2011).

### **Implications of the Findings**

The presence of diversity in perceptions of identity as related to hearing loss emerged from this study. First, in considering the students' perceptions of identity, the findings indicate that the identity the participants selected at the time of the present study may differ from the identity they would choose at another point in time due to identity not being static and constantly evolving.

### **Symbolic Interaction Theory**

The four mutually related concepts of the Symbolic Interaction Theory: (a) identities, (b) roles, (c) interactions, and (d) contexts (Mead, 1934) were evident for synthesis of the data from the study.

**Identities.** The findings of this study conceptually extend the literature on symbolic interaction as related to perceptions of identity and hearing loss. All of the participants in this study looked to the hearing identity type as the reference point for normality and health in spite of viewing the student participants as not being out of the norm due to having hearing loss, especially in cases where the hearing loss was well managed. This view reflects the aspect of the Symbolic Interaction Theory that designates an individual constructs the meaning of symbols from interactions even if that meaning differs from the meanings others have constructed of the same phenomenon (Mead, 1934). So, even if the participants did not view the student with hearing loss as being deaf, others in that student's life may perceive him as being a member of the deaf identity type.

One caregiver/parent participant, Eileen, spoke at length about the role advocacy plays in selecting an identity type for her son. Eileen explained that for her, a person with hearing loss identity type advocates for him or herself by being upfront about what he or she does not hear and shares ways of accommodating for the hearing loss. However, a person who would be categorized as hard of hearing, according to Eileen, does not advocate for him or herself. Taken together, the findings of this study related to the differing perceptions of not only the student participants' identities as related to hearing loss but to also what each identity type actually means or what characteristics go with each identity type as presented by Glickman and colleagues suggest that there is a multitude of ways in which constructions of identity can be developed. Consequently,

the definition of the identity types by each individual is unique to the individual and others should be aware of these differences.

**Roles.** According to the experts shared norms are applied to the occupants of social positions in establishing roles (Heiss, 1981) and are group-held beliefs about how members of a society should behave in a given context. For some caregivers/parents, when the student with hearing loss is present, the caregivers/parents may have to adjust their beliefs about how people should behave. The caregiver/parent, or even the student, may now have to fulfill a role of informant in explaining to others about the hearing loss and the accommodations needed for successful communication to occur.

Past experiences and events may shape roles in the present (Maines et al., 1983; Wheaton, 1990); whereas, current roles may shape experiences. Strains of this were observed in the present study in that participants based their decisions or perceptions on prior and current experiences. All of the caregiver/parent participants spoke of acting as advocates for their sons in regards to requesting accommodations at the schools, sharing specifics of hearing loss with teachers and coaches, and explaining to others in the community about their sons' needs. However, two of the caregivers/parents spoke of their role as advocate only occurring as the need arose. Jessica spoke of several examples in which coaches or teachers were not informed of her son's hearing loss at the start of the interaction in an effort to respect her son and his abilities rather than focusing on a weakness he might have. Moreover, within roles, behavior once considered as normal is redefined as abnormal in certain roles. For example, caregivers/parents who manage the hearing loss through use of listening technology such as hearing aids view the child's use

and wearing of hearing aids as normal due to the family adjusting and accommodating for the hearing loss.

In Symbolic Interaction Theory, child socialization is viewed as a complex process by which children memorize roles, actively learn various roles, and participate in the formation of their identities (LaRossa & Reitzes, 1993). For the student participants in the present study, they are currently and have been educated in the general education setting with hearing peers. They have not had to learn sign language to communicate with others due to utilizing spoken English although one student participant did know sign language. These factors most likely contributed to the roles the students have assumed in their daily lives and therefore impacted identity development as related to their hearing loss. Devin spoke of hardships his friends with more severe hearing loss have faced and expressed gratitude at not being in the deaf identity type he placed them into due to his role as being able to act as a liaison or bridge between the two worlds. Since Devin has knowledge of American Sign Language, he can fulfill the role of interpreter and communicate with members of the hearing identity type and the deaf identity type.

Rosenberg (1979) revealed that school-aged children's self-esteem was dependent upon the caregivers'/parents' views of the children. Furthermore, the desire to think well of oneself and to protect one's self-concept against change are powerful motivators of behavior. Roles provide rules or expectations of behaviors (J. M. White & Klein, 2008). Without clear expectations shared by both the individual and others, it is impossible for individuals to perform the role or for others to know how their behavior influences the

individual (J. M. White & Klein, 2008). Thus, the student participants in the study may have based their perceptions of their identity based on what they have learned over the years from their caregivers/parents. This was evident by Barry's comment that he selected the person with hearing loss identity type since that was what he had grown up with; his caregivers/parents also selected that identity type for their son. Similarly, Shannon acknowledged she at first selected the hard of hearing identity type for her son because the term is what has been used on the paperwork at her son's school (i.e., Individualized Education Plan). Jessica, on the other hand, chose a different identity type from what the school paperwork uses. She explained she would only use the hearing impaired identity type when working in her role as an educational professional but would never select that identity type in her role as mother to a child with hearing loss due to her feeling that the hearing impaired identity type has a negative connotation associated with it.

**Interactions.** It is through social interaction that individuals apply broad shared symbols and actively create specific meanings of self, others, and situations (LaRossa & Reitzes, 1993). The actions, responses, and subjective meanings of other people are another feature of social interaction. Some individuals have more impact on an individual's identity than do other individuals (Hoelter, 1985; Hughes, 1962) such as siblings, peers, caregivers/parents, teachers, and counselors. The participants in the present study used hearing individuals as their normality and reference point. In a way, the participants measured identity as the extent to which student participants were able to interact as a hearing person might through managing their hearing loss. Interactions in

which successful communication occurred helped to view the students as fitting into the hearing identity type whereas interactions in which communication was a struggle led to viewing the students as being members of the person with hearing loss, hard of hearing, or hearing impaired identity types.

**Contexts.** The connections that are made between the individual and society are referred to as contexts in Symbolic Interaction Theory (LaRossa & Reitzes, 1993; Strauss, 1987). How an individual negotiates his or her identity is influenced by the contexts of the immediate factors that influence the individual's relationships with others (e.g., involvement with baseball team, performance in classroom). Structural contexts represent the interactive environment in which the relationships take place, such as within the community or school. All of the participants spoke about how the impact of hearing loss on the students' lives can fluctuate depending upon the contexts and settings as well as the technology that is used and the people with whom interactions are occurring. In some contexts, one identity type may have been applicable but then in another context, a differing identity type would be selected by the participants (e.g., hearing identity type in a quiet classroom setting versus a person with hearing loss identity type in a noisy restaurant).

This notion of identity shifting based on the contexts as well as the identities, roles, and interactions bears witness to the concept of Stryker's (1980) "identity theory." Stryker suggests individuals actively infuse roles with identities, commitment, and salience. Rosenberg (1979, 1981) elaborates Stryker's "identity theory" by defining four sets of self-processes: (a) reflected appraisals in which individuals are influenced by the

attitudes of others toward self; (b) social comparisons in which individuals evaluate themselves by comparing themselves to certain individuals, groups, or social categories; (c) self-attributions in which individuals use their own behaviors as a basis for making inferences about self-descriptions or competencies; and (d) psychological centrality, in which self-concept is an organization of components, some of which are the foci of attention and thus are given greater import. These four sets of self-processes were evident in the essence of participants choosing their own identities or self determined identity types.

Within the psychology literature, two models of ethnic and cultural identity are of relevance to the findings of the present study. A well-known model that relates to the development of ethnic identity is Phinney's (1992) Model of Ethnic Identity Development. This model is composed of three elements. The first is the affective component or the measure of how strongly an individual feels a sense of belonging and commitment to his or her ethnic community. The second element of Phinney's model constitutes the cognitive component or the extent to which individuals adopt or are interested in their ethnicity in terms of its history, traditions, and values. The third element of Phinney's model is the behavioral component that accounts for the level of the individual's involvement in activities related to his or her ethnicity (Phinney, 1992). Thus, Phinney's Model of Ethnic Identity Development allows an individual to feel and demonstrate a strong sense of belonging and pride in one's ethnicity through participating in events or activities that revolve around the person's ethnic identity. For many of the caregiver/parent participants in the study, they or the students, were able to achieve a

strong sense of belonging and pride in fitting in with the hearing world through use of technology and accommodations. Many of the caregivers/parents spoke of instances in which their sons assimilated with their hearing peers in educational and social settings.

For the four participants who identified themselves or their sons as the hearing identity type (Barry, Larry, Jessica, Eileen), these participants felt a sense of belonging or commitment to the hearing society. The second element of Phinney's model constitutes the cognitive component or the extent to which individuals adopt or are interested in their ethnicity in terms of its history, traditions, and values while the third element of Phinney's model is the behavioral component that accounts for the level of the individual's involvement in activities related to his or her ethnicity (Phinney, 1992). Therefore, the participants who selected the hearing identity type feel that the individuals are able to successfully communicate and live as a hearing identity type or hearing person in everyday situations. Thus, Phinney's Model of Ethnic Identity Development allows an individual to feel and demonstrate a strong sense of belonging and pride in one's ethnicity through participating in events or activities that revolve around the person's ethnic identity (e.g., hearing society).

A second model of identity development of particular relevance to the present study is Berry's Model of Identity in which culture is highlighted. Proponents of Berry's Model of Identity consider the value of maintaining one's cultural heritage in juxtaposition with the value that is placed by the individual on developing relationships with the larger society (Berry, 1997). Thus, an individual's identity with a cultural heritage may or may not conflict with the values that culture places on membership of the

individual in the larger society. None of the participants discussed culture within their interviews. Researchers within Deaf Studies/Deafness have long touted culture as being a hallmark or standard of the culturally Deaf identity type. Within the present study, the culturally Deaf identity type did not surface and the medical view of deaf identity type was used to describe the hearing loss or the ear rather than describe the individual. Therefore, in view of Berry's Model of Identity, the participants in the present study viewed the hearing culture or world as being their reference point when discussing themselves or the students with hearing loss.

### **Social Identity Model**

In addition to Symbolic Interaction Theory, Social Identity Theory delineates the relationship between the individual and society and the development of an individual's personal and social identities (C. A. Baker, 2012; Mead, 1934; Tajfel & Turner, 1986). Social identity is defined as the "aspects of an individual's self-image that derive from the social categories to which he perceives himself as 'belonging'" (Tajfel & Turner, 1986). Therefore, an individual's social identity refers to that part of one's sense of identity that emerges from his or her belonging to a particular group and thus, acts as a locus of interaction between personal and group identity. One cluster, the Color family, (Devin, Shannon) especially focused on the aspect of "fitting in" or a sense of belonging. Devin, the student, spoke of his being able to be versatile and float between the deaf identity type and the hearing identity type due to his knowledge of sign language and being able to serve in the role of interpreter. However, he, himself did not feel a sense of belonging in either group as he felt a sense of isolation and categorized himself into a

separate category comprised of the hard of hearing identity type. Devin's caregiver/parent, Shannon, discussed her son's lack of friendships with his hearing peers, citing an example of having never been invited to a birthday party of a hearing peer as he wrapped up his ninth grade year.

Another caregiver/parent, Eileen, spoke of her son's struggles to fit in and form friendships as well. She described how her son will go through various phases and fads rather than being himself in his efforts to be as normal as possible and to fit in with peers. The other two clusters (i.e., Sand and White families) of caregivers/parents described their sons as being popular and friends with a variety of peers. Tajfel (1982) further states that an individual's identity derives from his or her knowledge of membership in a group combined with the value and emotional significance attached to that membership. This extension of Mead's original definition of social identity includes three facets of social identity: (a) cognitive which is the recognition of belonging to the group, (b) evaluative refers to the recognition of the value attached to the group, and (c) emotional notes the attitudes of the group members (Tajfel, 1982; Tajfel & Turner, 1986). In spite of Eileen speaking about her son's struggles to fit in with his peers' social group, she classified him as the hearing identity type which aligned with Larry's perception of himself as a hearing identity type. Likewise, both of Barry's caregivers/parents' perceptions of him as a hearing identity type matched with Barry's perception of self identity as a hearing identity type.

People categorize themselves into groups in an attempt to establish a positive sense of value (C. A. Baker, 2012; Tajfel & Turner, 1986). One way of doing this is to

distinguish their membership in a group compared to that of other groups of which they are not members. These distinctions favor the group to which they belong (Mullen et al., 1992; Tajfel & Turner, 1986). In the present study, all of the student and caregiver/parent participants, with the exception of Danny, a student participant, chose to not identify the students as members of the Deaf or deaf identity types. In exploring their attitudes toward others in and outside of the Deaf or deaf group, participants expressed the students were more like the hearing group than the Deaf or deaf group based upon the two theories from the discipline of psychology of relevance to this study: Symbolic Interaction Theory and Social Identity Theory. Thus, special attention needs to be given when making inferences about identity type as related to perceptions of self-identities of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting as well as the perceptions of the caregivers/parents of the students. The purpose of phenomenological analysis is to arrive at the essence of a phenomenon, not at a construct with which all involved agree. Thus, in this section, the researcher discussed the essential components of self determined identity types as it emerged across the data of all interviews.

**Right to choose one's identity.** Irrespective of level of hearing loss, the presence of listening technology, or mode of communication, individuals have the right to select their own identity and define their own identity type. A diagnosis of moderate to severe sensorineural hearing loss does not necessarily guarantee an individual will categorize someone with that type of hearing loss as being deaf or hard of hearing. The participants selected for the present study are growing up in hearing-oriented environments where

spoken language and listening is their primary mode of communication. This environment and communication mode influences the findings of the present study in that the participants only know of one identity type (i.e., hearing identity type). By using the hearing identity type as their primary reference point for their identity, some participants established the hearing identity type as being the dominant or preferred identity. When one social identity (i.e., hearing identity type) takes precedence over all others, the individual classifies other people in terms of their membership in that one category. Those who share the dominant category membership (i.e., hearing identity type) are treated as ingroup members whereas those who are not in the category are outgroupers (Roccas & Brewer, 2002).

In choosing the hearing identity type, the participants minimized the hearing loss by not recognizing that aspect or trait of self (e.g., multicultural competence) or by compartmentalizing themselves by multiple identities being activated and expressed through a process of differentiation and isolation since social identities are context or situation specific (Roccas & Brewer, 2002). Therefore, in certain contexts, one group membership (e.g., hearing identity type) becomes the primary basis of social identity, whereas other group identities (e.g., student, son, person with hearing loss identity type, baseball player) become primary in different contexts. For example, one of the caregiver/parent participants spoke of being proud of his son for overcoming obstacles and limitations. Conversely, he spoke of his son's hearing loss as not being a major factor in describing his son by stating that his son was just like others ("normal/regular"). Thus, self determined identity types are acceptable even if they differ from the meaning

someone else has attributed to that same identity type. Similarly, identity types may differ in regards to the same individual (e.g., student's perceived identity type may differ from the caregiver/parent perception of his or her identity). To bridge any potential gaps communication is critical in trying to understand the perspectives of others.

Utilizing tenets of the Social Identity Theory, through focusing on personality attributes, students with hearing loss who use spoken language and listening and their caregivers/parents may perceive a sense of "belonging" based upon the personality attributes. Defining the students by focusing on the "aspects of an individual's self-image that derive from the social categories enables one to perceive self as 'belonging'" (Tajfel & Turner, 1986). Therefore, for these nine participants (i.e., four students and five caregivers/parents), the student's sense of identity may emerge from his belonging to a particular group and thus, acts as a locus of interaction between personal and group identity. For example, Scott, a caregiver/parent participant, perceived his son with hearing loss as a person with hearing loss identity type although his son selected the deaf identity type for himself which indicates he viewed himself as belonging to a separate group of individuals similar to him (e.g., deaf versus hearing group). However, the father participant selected a different social group by identifying his child as being a member of the person with hearing loss identity type and not "fitting in" with peers who he would classify as being deaf.

This perception of social identity and hearing loss was also evident in the identity terms participants chose to describe themselves and/or the students. Tajfel (1982) reiterates that an individual's identity derives from his or her knowledge of membership

in a group combined with the value and emotional significance attached to that membership. This is especially important to note due to others having a tendency to label the individual with hearing loss by the hearing loss which was incongruent with the individuals' perception of themselves in multiple flexible ways as can be seen in the findings of this study.

### **Multidimensional Identity Model**

Social theorists have noted that as society becomes increasingly fragmented, identities become more multidimensional, more complex, less static, and less anchored in social places. Countless social networks, significant others, and generalized others influence self-identities and lead to a self that is pulled in multiple directions leading to no anchored or core self according to Gergen (1991). As a result, some individuals may attempt to bracket these multiple affiliations by shifting from identity to identity and living double or even multiple lives while other individuals may try to bridge affiliations to form one multiply influenced and socially networked self (Brekhus, 2008).

A person's identity can encompass more than one culture, and as a result, these individuals, as adolescents, may exhibit more flexible behaviors and are open to more possibilities of defining themselves (Leigh et al., 1998; Leigh & Stinson, 1991). Within the present study, the participants demonstrated some aspects of multidimensional identity through their responses to the card sort activity in determining which identity type best fit the students. Two of the student participants chose two separate identity types (Barry, Danny) while four of the six caregiver/parent participants selected two separate identity types (Mark, Jessica, Shannon, Eileen) for their sons. A student

participant, Barry, shared that his hearing loss is a part of what makes him who he is but that it does not make up all of him. One caregiver/parent (Eileen) admitted that while the hearing loss made up a large portion of the pie of traits that described her son, she also recognizes other attributes that make up her son and she sees him for more than just his hearing loss. She expressed the hearing loss is just one of the many attributes that comprise her son. This mother's view is congruent with a study that analyzed identity and school placement of students with hearing loss. Almost 10% of caregivers/parents who had a child defined as deaf or hard of hearing by the school district where the student was enrolled did not provide a similar report of their children. Instead, these caregivers/parents considered other issues to be more relevant to their children's identity and health (Shaver et al., 2013). Conversely, another caregiver/parent (Shannon) identified her son's hearing loss as making up the majority of the pie of attributes to describe her son due to the hearing loss having such a huge impact on her son's daily living.

**Interactions with others.** Participants in both data sets spoke of fluidity occurring among differing contexts and interactions with others (i.e., caregivers/parents, siblings, family members, teachers, coaches, peers, members within the community). Jessica and Kate spoke of the fluctuating levels of impact of the hearing loss on their sons and the family in everyday life depending upon the identities, roles, contexts, and interactions with others. All four student participants echoed this belief that the level of hearing loss on their lives fluctuated from day to day even for the students who selected the hearing identity type as the category for themselves. One student participant (Larry)

explained how he may identify himself as a deaf person in a restaurant but with his family he identifies himself as a hearing person when discussing how when interacting with a waitress in a restaurant, he identifies as deaf or as a person with hearing loss but when interacting with his family, he is treated as hearing rather than a person with hearing loss. This examples sheds light on how differing identity types may exist for the same person based on interactions with others, the setting, and contexts which meshes with the Symbolic Interaction Theory.

All of the participants shared stories that revealed extended family members may not realize the impact of hearing loss and periodically may need reminding of the importance of providing accommodations at family functions and gatherings. The participants also reported siblings do not seem to treat the students with hearing loss any differently from other siblings and/or family members (i.e., rough and tumble play, repeating themselves so student can hear).

In discussing interactions with others, a caregiver/parent participant (Mark) discussed his perception of a stigma associated with hearing loss in his experiences raising his son with hearing loss. Often when a child has any special need or disability, people around him/her lower their expectations for normal social interactions that are suitable for their ages and stage of development (Bat-Chava & Martin, 2003). Some of the caregivers/parents (Mark, Jessica, Shannon) explained their hypersensitivity to hearing loss with one cluster, the White family (Mark, Jessica) raising the assumption their son copes better than they at times when it comes to dealing with the hearing loss through his actually living with it. Mark also was cognizant of the fact that most others

accept his son for who he is and his son's peers provide accommodations (when needed). His wife, Jessica, explained that within interactions with other, a lack of exposure or knowledge regarding hearing loss might lead to disconnects and not a true understanding of what it is like to live with a hearing loss. Several of the participants, in both data sets, commented on their friends being able to better handle the hearing loss when compared to strangers. Perhaps this is due to the fact that usually a significant amount of effort must be made for hearing individuals and individuals with hearing loss to understand one another.

According to Glickman (1986), the interactions of individuals with hearing loss with peers who are hearing is often strained and frustrating, as adolescents with hearing loss often struggle for communication, understanding, and solid relationships. This interaction with others influencing how students with hearing loss view themselves is similar to the concept of interactions within the Social Identity Theory. A student participant (Barry) made an interesting point that he is more comfortable discussing his hearing loss with close friends rather than discussing his hearing loss with strangers. As an outsider looking in, one must recognize individuals with hearing loss may not be comfortable discussing hearing loss with him or her. Another student participant (Danny) emphasized the importance of an individual with hearing loss needing to accept self as is before then moving on and working to accomplish goals. A support network (e.g., audiologists, coaches, preschool teachers and teaching assistants) was cited by all participants in the present study as invaluable in achieving educational and social goals as

they work through the emotions and experiences of living with or raising a child with hearing loss.

A theme of acceptance as a person first was a recurring trend within the interviews. Jessica revealed she shares the fact that her son has hearing loss as the need arises as she feels it is disrespectful to humanity to focus on the weaknesses. She is showcasing the concept of fluidity in recognizing that her son has hearing loss but he has other features and attributes for which he can and should be recognized. Eileen also spoke of not starting off an interaction with an individual by focusing on her son's hearing loss but rather waiting until the need arises, if at all.

Rather than focusing on the hearing loss and defining his son by this attribute, Mark chose a more fluid view by choosing to focus on the other features that define his son and view him as a person first (e.g., baseball player, hard worker, friendly). This belief was evident when Mark described hearing individuals by referring to them as "individuals without hearing loss" and to say "individuals with hearing loss" instead of saying "deaf individuals" or "hearing impaired individuals." By positioning these words from a standpoint of person-first and using person-first language, BWD reiterated his preference for viewing and accepting a person by his overall self (e.g., the kind of person his son is) rather than focusing on individual singular attributes of identity (e.g., hearing loss).

Another caregiver/parent participant (Jessica) also chose to shift focus away from the hearing loss and define her son by this attribute and instead to focus on the other features that define her son and view him as a person first (e.g., baseball player, good

student, understanding). Similarly, Eileen focused on the notion of acceptance and seeing the person first before the need by emphasizing that in spite of her son having hearing loss, she views him first as a person. One student participant (Larry), with regard to hearing status, also described himself as a person first before discussing his hearing loss.

**Other personality attributes.** In conjunction with accepting others as people first, some of the participants in both data sets focused on other attributes of themselves or of the student participants more so than the hearing loss. In conversation, nine of the participants (i.e., four students and five caregivers/parents), when describing themselves or their children with hearing loss, chose to describe by personality attributes and as people first. Only one caregiver/parent participant (Shannon) described the hearing loss during the initial description of her child.

Personality attributes of focus, such as being a leader or struggling with self-esteem, were other factors that contributed to perceptions of identity. This was particularly true for the participants who selected a hearing identity type. When the student participants described themselves, attributes that were provided did not relate to hearing loss (e.g., good baseball player, poor Math student, nice to friends) with the exception of one student (Barry) who said he is not good at hearing things but he is an excellent listener. This example demonstrates that individuals with hearing loss may view themselves primarily by other personality attributes rather than focusing solely on their hearing loss to define themselves which is congruent with the aspects of the Multidimensional Identity Model. All of the student participants appeared to identify

with multiple aspects of self but chose to do so in a “segmented fashion” by frequently only identifying with one aspect of identity at a time. This one aspect was determined more passively by the context rather than by the individual’s own wishes (i.e., in one setting Barry identifies himself as a hearing identity type yet in another setting he calls himself deaf to help others understand his hearing loss; Reynolds & Pope, 1991). This aspect is reflected by the student participants selecting multiple identity types, based on flexible views of themselves in varying situations and particular social contexts. One could view this as an example of being able to shift among identity types or being fluid or one could hypothesize the students are identifying selves in a “segmented fashion.”

**Always in motion.** Identity is not a static concept even if the hearing loss is always present. Utilizing aspects from the Symbolic Interaction Theory, Social Identity Theory, and Mcilroy and Storbeck’s (2011) concept of fluidity, one can recognize that an individual may choose to identify as one identity type in one context and as a different identity type in another context or within differing interactions (Mead, 1934). One way an individual can achieve simultaneous recognition of more than one social identity (e.g., how the individual perceives him or herself in comparison to others within a group) and yet maintain a single ingroup representation is to define the ingroup as the intersection of multiple group memberships (Roccas & Brewer, 2002). For example, a student can define his primary social identity in terms of the compound combination of gender and having a hearing loss, an identity shared only with other males who have hearing loss making him distinct from males as well as females with hearing loss. This creation of a separate and unique group is similar to how Devin viewed himself as being a hard of

hearing individual in that he had some characteristics of members of the hearing identity type yet also related to members of the deaf identity type yet viewed himself as uniquely hard of hearing in a separate identity type.

Further, one of the implications of the present research is for caregivers/parents, teachers, and counselors to provide supports to students with hearing loss that foster independence, support self-determination skills, and embrace all students as independent individuals who have the rights to form their own identities. To foster understanding of differing perceptions of identity related to hearing loss, other implications of the present study are for caregivers/parents, teachers, and counselors to increase expectations for students with hearing loss and to promote respect and acceptance of all individuals as fully capable human beings, regardless of hearing status. This affirms that an individual who recognizes all aspects of him or herself is said to operate from a merged social identity standpoint in which identity is the sum of one's combined group identifications (e.g., view of self as identifying with others by gender, age, interests) due to all the characteristics of the individual being important and salient across situations making for a highly inclusive and diverse view of identity (Roccas & Brewer, 2002).

**Manage and persevere.** A primary factor disclosed in the present study related to living with hearing highlighted management of hearing loss and one's being able to persevere and "bounce back" from setbacks encountered. Through a sense of resiliency, participants were able to more closely align with the hearing identity type and overcome hearing challenges through use of technology, accommodations, and sharing of information pertaining to the specifics of hearing loss. This implication sheds light on

the importance of teaching self-advocacy skills to caregivers/parents and students alike. Through reciprocity and exchanging of information related to hearing loss and communication needs, others will gain a better understanding of how individuals with hearing loss perceive themselves and how hearing loss is but one factor of who they are. Each student with hearing loss should feel he or she is a valued member of his or her classroom group. Moreover, each student's self-determination and independence should be nurtured by caregivers/parents, teachers, and counselors. Thus, when facilitating and developing students' self-advocacy skills, caregivers/parents, teachers, and counselors should focus on designing meaningful, age-appropriate, and positive learning experiences.

#### **A Conceptual Model of Perceptions of Identity of Students with Hearing Loss, and Their Caregivers/Parents as Related to Hearing Loss**

The three essences that emerged in the present study are (a) self determined identity type, (b) fluidity, and (c) management and resiliency can be depicted in the following conceptual model. The model illustrates the intricate relationship between each of the essences and perceptions of identity and hearing loss among the student and caregiver/parent participants. The perceptions of both students and the caregivers/parents were analyzed because caregivers/parents have been found to be influential in the identity development of their children. The caregivers/parents appear at the base of the model because they are viewed as being critical to the formation and development of identity within the students.

As the model depicts by the dual faces (see Figure 4), each participant spoke of identity as being a fluid, not fixed, concept. Depending upon interactions with others, the context/ environment/setting, and life experiences (both those in the past and those they currently face), participants selected an identity type from a continuum. The continuum in the center of the model displays identity types previously established within the literature in psychology, counseling, and Deaf Studies/Deafness.

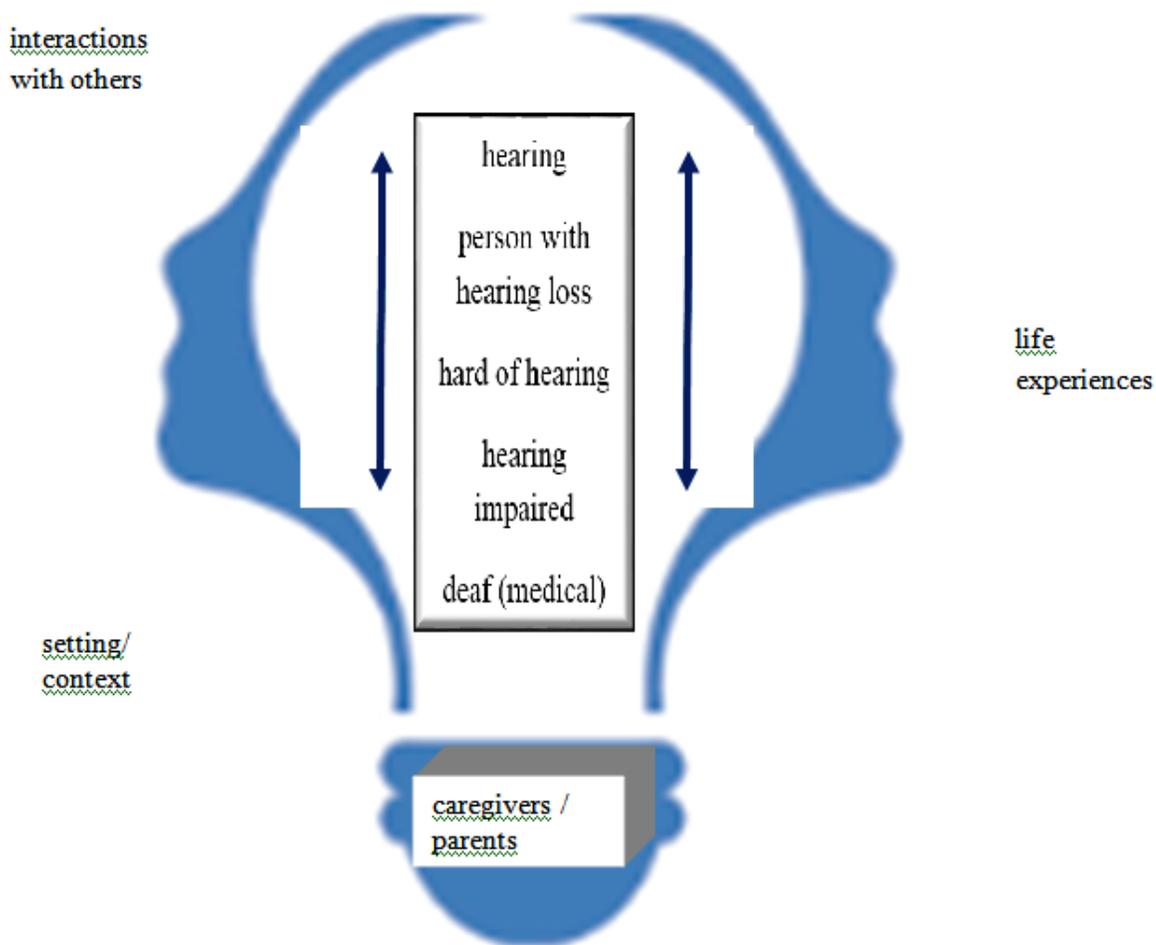


Figure 4. Conceptual Model of Perceptions of Identity of Students with Hearing Loss.

For example, within a quiet setting, such as in a classroom in which the student could readily access communication and comprehend what was being said, he might select a hearing identity type although he wears hearing aids and has a diagnosis of a moderate to severe sensorineural hearing loss in both ears. Yet, that same student, in a noisy setting, such as the gym or in a cafeteria during lunch, might select the person with hearing loss or deaf identity type due to the difficulty he experiences in communicating with others in this context/environment/setting. Therefore, identity is viewed as fluid or evolving depending on with whom the individuals interact, the context/environment/setting in which the interactions occur, and life experiences.

Life experiences, both those in the past and those occurring in the present, impact which identity type an individual chooses for him or herself or which “face” to show the world. These life experiences in explaining their hearing loss coupled with the perceptions of others regarding hearing loss bear an impact on if and how the participants manage the hearing loss and whether or not they persevere when faced with challenges. If an individual perceives others as not understanding or acknowledging him or herself as the identity type he or she self selects, the individual may refrain from authentically being him or herself and therefore defines self as the identity the other person perceives him or her to be. In doing so, the individual selects a different “face” of identity to display to the world.

### **Future Directions**

Future research should analyze perceptions of identity in a sample of younger students (e.g., lower elementary grades) as well as in more ethnically diverse students.

The age of identification of hearing loss may also be an interesting factor to examine in the future by working with participants who have been diagnosed with hearing loss at a later time than the student participants who participated in the present study. In the present study, the students' ages ranged from 12 to 17 years old with their caregivers/parents' ages being over 18. As the student sample in the present study was comprised of male students, future research is needed regarding self identities of female students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting as well as the perceptions of the caregivers/parents of the female students with hearing loss through qualitative research methodology.

Additional research on fathers' perceptions would be beneficial in order to gain more knowledge about how they perceive their children in terms of identity and hearing loss. A future researcher may also desire to analyze perceptions of identity in students with mild hearing loss compared to the students with moderate to severe sensorineural hearing loss (e.g., mild versus severe hearing loss) employed in the present study to examine the effect of a differing type or degree of hearing loss has on identity formation. Each of the participating families, or clusters, in the present study consisted of caregivers/parents who are still married to one another with the families living together in one household. Future research may want to analyze perceptions of identity related to hearing loss in families who are living in separate households due to separation or divorce. Moreover, perceptions of identity related to hearing loss held by teachers and counselors of students with hearing loss should be examined as the clusters expand from

being comprised solely of students and caregivers/parents. It would be interesting to compare differing perceptions of identity among general educators, teachers of Deaf/Hard of hearing students, speech language pathologists, other specialists, counselors, and various related school personnel.

A number of participants in the study spoke of multiple identity types being appropriate in describing the students with hearing loss due to the fluid nature of identity and the influence of interactions with others, the role the context or environment played, and the life experiences of the participants. These findings are similar to the outcomes from a previous study that highlighted adolescents' alignment with a specific group and proposed that ease or difficulties with communication, together with the participants' previous experiences of friendship and current preferences, combine in influencing their choices regarding group alignment in adolescents with hearing loss (Hardy, 2010). Thus, future research may want to examine the demands of competing identity types within an individual and how the individual copes and adopts differing forms of identity management (Roccas & Brewer, 2002). Another finding of the present study indicates identity is fluid and not a static concept. It would be of interest to interview the same participants who took part in this study at a later time, perhaps in ten years, to see if their perceptions of identity as related to hearing loss have evolved from or remained consistent with their present views.

Recommendations for future research also include the continuation and expansion of qualitative investigation for use with students with hearing loss on identity in order to illuminate more specific salient issues for this population. As a result, researchers may

attempt to reach students with hearing loss who may feel socially isolated in order to access specific needs and provide possible beneficial counseling interventions to address self-determination and advocacy skills and therefore reduce learned helplessness.

Based upon the findings of this study, future application of this research needs to explore practical definitions of identity type within the Deaf Studies/Deafness literature. By expanding on the binary conceptualization of what it means to be deaf, future researchers can highlight the divergent perceptions of identity that emerged in the present study. As the findings from the present study reveal, perceptions of deafness rely on more than just the hearing loss or culture due to the experience of living with hearing loss being a multidimensional and nuanced phenomenon. For example, there exists a disconnect among the labels or categories related to hearing loss used in school settings on legal paperwork and the labels or categories related to hearing loss used by caregivers/parents, students, and others. Through a better understanding of the differing perceptions of identity related to hearing loss, the discrepancies between the legal definitions of hearing loss and socially constructed definitions of hearing loss can be reconciled.

### **Conclusion**

The population of students with hearing loss, who use spoken language and listening as their primary mode of communication and who are educated in the general education setting, has not been the focus of research in terms of identity. Identity research within the Deaf Studies/Deafness literature has focused on students with more severe hearing loss who utilize American Sign Language and/or are educated in

residential school settings. Current literature within the constructs of identity and deafness has determined that students with hearing loss, who use sign language as the primary mode of communication and who are educated in residential schools or self-contained classrooms for the deaf, classify themselves as Deaf, deaf, bicultural/dual, or marginalized (Cornell & Lyness, 2004; Glickman & Carey, 1993; Melick, 1999; Most et al., 2007; Woodward, 1972). Analyzing how individuals with hearing loss identify themselves with how others (i.e., their caregivers/parents) perceive themselves is critical for understanding how perceptions of identity related to hearing loss can be viewed as social constructs. Others must not assume what is most central to individuals with hearing loss and they should be receptive to how the individual identifies him or herself (Cole & Edelman, 1991; Jackson et al., 2008; Schlesinger & Meadow, 1972).

The aim of this research, in agreement with Glickman (1986, 1996), McIlroy and Storbeck (2011), and Grushkin (2003) is to draw more attention to the individuals with hearing loss who create their own category or classification of identity or who seem to fit in more than one of the established categories (e.g., Deaf, deaf, DeaF, hard of hearing). This study provides an analysis of identity in students with hearing loss and of how their caregivers/parents identify the students as well as perceptions of hearing loss in both data sets of the students and the caregivers/parents. Findings of the study indicate some disconnects in perceptions of identity within individual clusters (i.e., each family was deemed a cluster in the present study) by caregivers/parents choosing a different identity type for the student than what the student selected for himself but the majority of the participants, across data sets, defined the hearing identity type as the strived for or sought

after identity type. To borrow from McIlroy and Storbeck's DeaF identity type (2011), one could even say that the identity type that was used as the reference point for these particular individuals was the HearinG identity type in that the participants perceived identity, as related to hearing loss, as that of being how well the students "fit in" to the hearing world. The capital G highlights the fluidity that exists when the students shift from one identity type to another depending upon interactions with others, the context/setting, and life experiences. Additionally, the person with hearing loss and hearing identity types were the two most common identity types selected by the participants in the present study.

The present study yielded three essences pertaining to the phenomenon of perceptions of identity as related to hearing loss. Self determined identity type, or the right to select one's own identity type, the notion of fluidity, or recognizing the identity type may change, and a sense of management and resiliency, or maintaining the identity type and overcoming adversity blend together to provide a rich and colorful experience of living with hearing loss. An individual can experience the phenomenon of perceiving identity as related to hearing loss through use of one or two of these three essences; however the experience would not be as rich. Therefore, if all three essences are present in an individual's life the individual will be able to define oneself in a variety of situations. Further, the individual will be able to maintain his or her established identity leading to a more vibrant experience of the phenomenon.

Knowing who we are and seeking self actualization or understanding of ourselves is at the heart of social life, combining the 'most mundane of things' with 'the most

extraordinary' (Jenkins, 1996). Identity marks the way in which individuals and collectives are distinguished in their social relationships from other individuals and collectives (Simmel, 1971). Identity also embraces 'being' and 'becoming'; thereby reflecting practice and process (Jenkins, 1996). One's identity is shaped by interactions with others and evolves over time. The researcher began the study by discussing the current identity types that exist in the Deaf Studies/Deafness literature as well as aspects of identity related to the psychology and counseling literature as they pertained to perceptions of identity and hearing loss. The researcher then analyzed the data of ten phenomenological interviews with four students with hearing loss and their six caregivers/parents in order to explore the essence of perceptions of identity as related to hearing loss.

The present study emphasized perceptions of identity in both students and caregivers/parents so that others could be encouraged to broaden their perceptions of identity from a strictly medical deaf diagnosis or culturally Deaf definition to incorporate the shades of gray or "inbetweenity" and recognize the diversity in multiple identity types (Brueggeman, 2009). Further, when perceiving others, regardless of disability, special need, hearing loss, or any other trait that distinguishes us, we must realize that our perceptions may differ from the perceptions of the individuals and be respectful of those differences. Irrespective of how the hearing loss was acquired or the age of onset of hearing loss, there is also the issue of whether one is viewed differently by family, friends, colleagues, and by people with whom one comes into contact in their lives. All

of these factors interact when analyzing how an individual is affected by and copes with hearing loss (Pray & Jordan, 2010).

The study contributes to the field of special education by providing the illustration of how students and their caregivers/parents perceive the phenomenon of identity as related to hearing loss. The study broadens the body of phenomenological research as well as the limited research involving the perceptions of self-identities of students with hearing loss who use spoken language and listening as their primary mode of communication and who are educated in the general education setting as well as the perceptions of the caregivers/parents of the students with hearing loss. Bearing in mind that identity is self determined, fluid, and maintained, we must remember self-determined people use a comprehensive, and reasonably accurate, knowledge of themselves and their strengths and limitations influenced by evaluations of significant others, reinforcement, and attributions of one's own behavior (Wehmeyer & Schalock, 2001). Students with strong self-advocacy skills are more likely to succeed in their pursuits as they will be able to request necessary accommodations for themselves in the future (West et al., 1999).

One must completely accept oneself for advocacy, growth, and change to occur for that individual (Landreth, 2002). It is imperative for one to truly know who he or she is and to establish identity before moving on to address aspects or areas he or she would like to change. Recognizing all he or she is or knowing how he or she identifies self, one is able to truly be the best version of him or herself as can be seen by this statement from a student participant, "My hearing loss is a part of me and contributes to my overall perception of myself. The whole conversation today, definitely, helped me in the fact

that I can appreciate and recognize everything that I am” in regards to hearing loss and identity by thinking about “the parts that make me me.” Thus, through better understanding self and how others perceive self, true understanding and affirmation of one another can occur. As the famed existentialist philosopher, Kierkegaard, stated, “If you label me, you negate me” so by being open to and respectful of differing perceptions of identity, more positivity can occur for students with hearing loss and for their caregivers/parents.

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## APPENDIX A

### CHARACTERISTICS OF GROUPS OF INDIVIDUALS WITH HEARING LOSS

Group	Level of Hearing Loss	Main Communication Method (U.S. & Canada)	Knowledge of a Sign Language	Community of Association	More Information
<b>Hard of Hearing</b>	Mild to profound	Spoken or written English	None or very little	Hearing	<p>Consider themselves as hearing people who have developed a hearing loss</p> <p>Make up vast majority of those with hearing loss</p> <p>Many do not take action to help with hearing loss</p>
<b>Late Deafened</b>	Severe to profound	Written English, speech reading, and/or a form of sign language	Varies—Learned as a second language	Hearing	<p>People who acquire hearing loss after acquiring spoken language</p> <p>Easily confused with the hard of hearing group (see above)</p> <p>More likely to seek help in dealing with hearing loss</p>
<b>Oral Deaf</b>	Severe to profound	Written English, speech reading, and/or a form of sign language	Varies—Learned as a second language	Hearing	<p>People who were born with hearing loss or acquire hearing loss at a young age</p> <p>Have sought help with hearing loss</p>
<b>Culturally Deaf</b>	Severe to profound	American Sign Language	Fluent—Learned as first language	Deaf	<p>People who were born with hearing loss or acquire hearing loss at a young age</p> <p>Do not consider themselves as disabled</p>

Source: Melick, A. M. (1999). Deaf identity development: A qualitative inquiry. *US, ProQuest Information & Learning*, 59.

## APPENDIX B

### DEFINITIONS OF TERMS

For the purpose of this study the following terms related to hearing loss are defined as follows:

**American Sign Language (ASL)** - a visual language of signs in which the brain processes linguistic information through the eyes and ASL is the signed language of individuals who identify themselves as members of the Deaf culture/community in the United States (Lane et al., 1996). ASL is a full-fledged language that is historically, grammatically, and structurally independent of spoken English (Hill, 2012). ASL arose from the mixture of French Sign Language, home signs, and an indigenous sign language that was in use by individuals with hearing loss in America prior to the founding of the first school for the deaf (Groce, 1985; Lane et al., 1996; Lane, Pillard, & French, 2007). ASL is the language of a sizable minority with estimates ranging from 500,000 to two million speakers in the United States alone; there are also many speakers in Canada (Lane et al., 1996). This large population of ASL speakers, and the several means for the transmission of ASL across the generations (residential schools, Deaf children of Deaf parents, the Deaf club), assure a rich culture for Deaf culture/community (Lane et al., 1996). The shape, placement, and movement of the hands, as well as facial expressions and body movements, all play important parts in conveying information (Liddell, 2003). ASL is expressed not only with manual signs but also with grammatically obligatory and optional nonmanual signals produced on the face and upper torso (Hill, 2012). In addition to grammatical structure, understanding ASL involves conceptual mappings between semantic representations and numerous types of both spatial and non-spatial conceptualizations (Liddell, 2003). The basic concepts of linguistics of phonology, morphology, syntax, semantics, and use of language apply to ASL structure (Valli, Lucas, Mulrooney, & Villanueva, 2011). ASL is both a stigmatized language in mainstream American society and the standard language in the American Deaf culture/community (Lane et al., 1996; Padden & Humphries, 2005). ASL has been recognized as an official and formal language.

**cochlear implant** – an electronic biomedical device that can be surgically implanted into a person's cochlea (a sense organ in the ear that translates sound into nerve impulses to be sent to the brain). The implant consists of a tiny receiver which is placed under the skin in the bony part of the skull behind the ear. The receiver has a probe with several electrodes (usually 22), that is surgically implanted into the cochlea. A cochlear implant can be beneficial if a severe to profound hearing loss is caused by problems with the cochlea (e.g., damaged hair cells) or if the hearing loss is caused by problems with the middle ear that cannot be surgically corrected. A person with a cochlear implant also wears a hearing aid like device that incorporates a microphone, a processor and a

transducer. The processor manipulates what the microphone receives and it sends a signal to the transducer, which is usually worn just behind the ear. The transducer changes the signal from an electrical signal to a magnetic signal that can be received through the skin by the implanted receiver. The receiver then stimulates the probe in the cochlea causing the person to hear. Cochlear implants are only used in cases of profound hearing loss, some implants are successful, and some types of hearing loss are not improvable with a cochlear implant.

**deaf** – refers to the audiological or medical condition of not hearing. Those who find themselves losing their hearing because of illness, trauma or age may also fit in this category. The term, deaf, can be interchangeable at times with the phrase, person with hearing loss, as it is a matter of personal preference.

**Deaf** – refers to a particular group of deaf people who share a language, American Sign Language (ASL), and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of knowledge, beliefs, and practices about themselves and their connection to the larger society (DeNaples, K., personal communication, April 2, 2013; Padden & Humphries, 1988).

**DeaF** – a fluid cross-cultural identity construct that focuses on the bicultural individual who has moved from one category type to another, hence the capital letter, F, signifying the crossing of cultural lines (e.g., growing up as a Deaf individual and then as an adult, choosing a hearing identity type after receiving a cochlear implant or hearing aid).

**Deaf culture/community** – Deaf Culture consists of a set of learned behaviors of a group of people who share a language, beliefs, rules of behavior, values, traditions, experiences, and attitudes. People in the Deaf community consider themselves a linguistic minority, not a group of disabled people, and their language which is American Sign Language, has been recognized as a true language. They all share a common bond and develop strong life-long relationships (DeNaples, K., personal communication, April 2, 2013; Holcomb, 2013).

**deafness** - lacking or deficient in the sense of hearing.

**hard of hearing (HH)** - denotes a person with a mild-to-moderate hearing loss or a deaf person who does not have/want any cultural affiliation with the Deaf culture/community or can be used to describe both identity types. Current literature within deafness states that individuals who choose the HH identity type can participate in the social, cultural, political, and legal life of the Deaf culture/community or they can live their lives completely within the parameters of the “hearing world.” However, they may have a more difficult time establishing a satisfying cultural/social identity.

**hearing** – the hearing world is that which is of the dominant culture in that individuals who identify themselves as hearing are able to function in and interact with other individuals who have full hearing or normal hearing levels in both ears.

**hearing aid** - A hearing aid is a device that amplifies or helps an individual to hear better. Hearing aids are made up of three parts (a) a microphone, (b) an amplifier, and (c) a speaker. They come in many shapes, sizes, and utilize various technologies (e.g., analog, digital, programmable, telecoil). Hearing aids are unable to restore an individual's hearing to normal hearing levels.

**hearing loss** – less than full hearing in both ears or below normal hearing levels. The term, person with hearing loss, can be interchangeable at times with the word, deaf, as it is a matter of personal preference and up to the user as to how he or she identifies him or herself (Padden & Humphries, 1988). For example, one could define oneself as a person who is deaf, or a person who is hard of hearing, or a person with hearing loss (McIlroy & Storbeck, 2011).

**teacher of the Deaf/Hard of Hearing (TOD/HH)** – A teacher of students who are deaf or hard of hearing is an individual who holds at least a bachelor's degree and licensure to teach students with hearing loss. A TOD/HH has preparation in language and communication strategies to facilitate students' acquisition of language and academic content. An itinerant TOD/HH travels from one school to another, visiting multiple D/HH students in local neighborhood school programs. The itinerant teacher of D/HH students acts as a link between the school and family of the D/HH.

**APPENDIX C**

**PARTICIPANT DEMOGRAPHICS TABLE**

Family	Parents			Child				
	Name/ Age	Occupation	Number of Years Married	Name Age Grade	Diagnosis Age	Type/degree of hearing loss	Amplification used	Length of D/HH support services in the general education setting
Sand	Kate 45	Homemaker/ learning support teacher aide	23					
	Scott 46	Key account manager						
				Danny 12 Fifth	18 mos.	moderate to severe sensorineural hearing loss in both ears with a history of fluctuating hearing levels	hearing aids in both ears and FM system when needed	Since third grade (past two years)
White	Jessica 44	School psychologist	20					
	Mark 44	Hospital help desk manager						
				Barry 17 11th	4 years	moderate to severe sensorineural hearing loss in both ears	Hearing aids in both ears	Since Kindergarten (for the last 12 years)

**Participant Demographics Table (Cont.)**

Family	Parents			Child				
	Name/ Age	Occupation	Number of Years Married	Name Age Grade	Diagnosis Age	Type/degree of hearing loss	Amplification used	Length of D/HH support services in the general education setting
Day	Eileen 45	Business support manager	N/A					
				Larry 15 11th	4 years	moderate to severe sensorineural hearing loss in both ears	hearing aids in both ears	Since Kindergarten (for the past 10 years)
Coral	Shannon 44	Medical billing manager	17					
				Devin 16 Ninth	3 years	moderate to severe sensorineural hearing loss in both ears	Hearing aids in both ears	Since three years of age (for the last 13 years)

**APPENDIX D****DEMOGRAPHIC INFORMATION FORM**

Parent Name:

Mother's age:

Mother's occupation

Father's age:

Father's occupation

Number of years married:

Name of child:

Child's DOB:

Age of diagnosis of hearing loss:

Type/degree of hearing loss:

Other medical needs (if any):

How long has your child received hearing support services?

Are there any other family members who have hearing loss? If yes, what is relation to your child?

Other than your child, had you had any experiences with deaf people? If yes, please describe here.

## **APPENDIX E**

### **INTERVIEW PROTOCOL**

#### **Introduction of Interview:**

I am going to ask you some questions about how you describe yourself/your child and your experiences with hearing loss. There are no right answers—I am interested in all of your thoughts and experiences. Our conversation is confidential, which means that I will not share what we talk about with anyone in a way that would directly identify you.

Before we begin, do you have any questions for me?

#### **Child Interview Questions**

1. Tell me about yourself (i.e., what are some things you can do really well, what are some things that are hard for you to do).
2. Tell me about what hearing loss means for you based on the demographic form question that asks about prior experience (e.g., what happens as a result because of hearing loss? What does hearing loss mean to you?).
3. (If applicable and based on demographic form) When do you wear your hearing aids (e.g., why or why not)?
4. Are your friends more alike or more different from you? In what ways? (e.g., Tell me about your three closest friends. When you think about these friends how are you all alike and how are you all different?)
5. We're about halfway through the interview now and from my point of view, it's going very well. What are some things that have been hard for you when you are around kids in your class or are spending time with friends or other kids your age outside of school (e.g., challenges that you have come across in your school or in general)?
6. During these times, what has helped you hear better or what has made it worse?
7. Tell me one piece of advice you would share with another student (e.g., if another student were to come in here right now, who just found out he or she had hearing

loss, what is one thing you would share with him or her? What is one thing you wish someone would have told you at the start of the journey?).

8. Does it seem, at times, as if others just can't understand what it's like to have a hearing loss? If so, how (e.g., how have you explained to others about hearing loss)?
9. If you had to pick one or more of these cards that best describes or matches you, which would you pick (e.g., what made you choose this card and not that card? What would it take for you to choose this card?)?

Card sort activity with categories of D/deaf, hard of hearing, person with hearing loss, hearing, both, none, blank card.

10. We're getting close to the end of our conversation, but before we wrap up, I'd like to ask do you sometimes forget that you have hearing loss? If so, when (e.g., Describe the times you forget you have a hearing loss and the times when it is obvious you have a hearing loss)? Remember, there is no right answer—I'm interested in your thoughts, in your own words.
11. That covers the things I wanted to ask. Anything you care to add?

### **Caregiver/Parent Interview Questions**

1. Briefly tell me about your child (i.e., what are some things he or she can do really well, what are some things that are hard for him or her to do).
2. Tell me about what hearing loss means for you (e.g., what happens because of hearing loss).
3. (If applicable and based on demographic form) When does your child wear hearing aids (e.g., why or why not)?
4. Are your child's friends more alike or more different from him/her? In what ways? (e.g., Tell me about your child's three closest friends. When you think about these friends how they all alike and how are they all different?)

5. We're about halfway through the interview now and from my point of view, it's going very well. What are some challenges that you have come across in your home or in social situations?
6. During those challenges, what helps your child to hear better or makes it worse?
7. Tell me one piece of advice you would share with another parent (e.g., if another parent were to come in here right now, who just found out his or her child had hearing loss, what is one thing you would share with him or her? What is one thing you wish someone would have told you at the start of the journey?).
8. Does it seem, at times, as if others just can't understand what it's like to have a hearing loss? If so, how (e.g., how have you explained to others about hearing loss)?
9. If you had to pick one or more of these cards that best describes or matches your child, which would you pick (e.g., what made you choose this card and not that card? What would it take for you to choose this card?)?

Card sort activity with categories of D/deaf, hard of hearing, person with hearing loss, hearing, both, none, blank card.

10. We're getting close to the end of our conversation, but before we wrap up, I'd like to ask do you sometimes forget that your child has hearing loss? If so, when (e.g., Describe the times you forget your child has a hearing loss and the times when it is obvious your child has a hearing loss)? Remember, there is no right answer—I'm interested in your thoughts, in your own words.
11. That covers the things I wanted to ask. Anything you care to add?

### **Additional Probes**

Would you elaborate on that?

Can you tell me more?

Could you say some more about that?

How did that make you feel?

If so, how \_\_\_\_\_?

Oh yes, I see.

**Support and Recognition Responses**

- You've been telling me some really important things. How's it going for you?
- I appreciate your willingness to express your feelings about that. You're helping me understand—and that's exactly why I wanted to interview you.