THE EFFECTS OF HEARING LOSS ON LANGUAGE AND LITERACY SKILLS IN DOWN SYNDROME: ASSESSING PARENTS' KNOWLEDGE

by
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ACKNOWLEDGEMENTS

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ABSTRACT

ANNALISE CLAIRE VALLE: The Effect of Hearing Loss on Language and Literacy Skills in Down Syndrome: An Assessment of Parents’ Knowledge (Under the direction of Dr. Susan Loveall and Dr. Rebecca Lowe)

Purpose: Although hearing loss (HL) is prevalent in individuals with Down syndrome (DS), there has been little research investigating the effects of HL on language and literacy skills in this population. The purpose of this study is to document the frequency of HL in DS, as well as language and literacy outcomes, and to determine if there is a difference in language and literacy outcomes for children with DS with HL and those without HL. Parental knowledge of HL and language development was also measured.

Method: A five-part survey was distributed to 77 members of DS-Connect, a National Institute of Health registry of parents and families with an individual with DS, targeting those with a child with DS between the ages of 5 and 10. The survey measured participants’ demographics, experience with ENTs and audiologists, experience with Speech-Language Pathologists (SLPs), knowledge on HL and hearing health, and child’s language and literacy skills.

Results: Results indicated a high prevalence (48%) of HL in DS. However, the data indicated no difference in language and literacy outcomes for individuals with DS with HL and those without HL. Further, parents were generally knowledgeable regarding the signs of HL and items that can cause harm to the hearing system.

Discussion: Our results are consistent with previous research suggesting high rates of HL in DS, indicating early assessment and intervention is important for this population. However, the lack of differences in language and literacy outcomes between those with and without HL paired with the reported regular audiology checkups suggests that not only are individuals with DS with HL being identified and treated early, HL is not negatively impacting their communication outcomes. However, these results should be interpreted with some caution as we do not have a measure of the severity of HL, which could compact the results. Finally, parent knowledge of HL appears sufficient and may be tied to their experiences with ENTs and audiologists.

Keywords: Down syndrome; literacy; hearing loss
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The Effects of Hearing Loss on Literacy Skills in Down Syndrome: Assessing Parents’ Knowledge

Down syndrome (DS) is the most common genetically caused intellectual disability (Brown & Percy, 2007; Centers for Disease Control and Prevention, 2016), and individuals with DS often demonstrate delays and difficulties with language (Abbeduto, Warren, & Conners, 2007). One possible cause of this language impairment is the high rate of hearing loss (HL) common in DS (Brown & Percy, 2007). While the effects of conductive, sensorineural, and mixed HL on language and literacy development are well documented in typically developing children (Partington & Galloway, 2005; Williams, 2010), there is a gap in the literature on the effects of HL on language and literacy skills in DS. However, because HL is prevalent in DS, more research is needed to document the effects of HL on literacy skills. This knowledge could, in turn, be used to promote prevention and early intervention of HL.

DS Phenotype

DS is associated with a phenotypic profile, or pattern of observable characteristics, that have resulted from the interaction of the DS genotype with environmental factors (Fidler, Most, & Philofsky, 2009). It appears, then, that extra 21st chromosome material, the cause of DS, predisposes individuals with DS to certain physical and cognitive outcomes (Abbeduto et. al., 2007; Brown & Percy, 2007; Fidler, 2005), though not all individuals with DS will exhibit each characteristic.
Cognitively, DS is associated with intellectual disability, which can range from mild to severe (Abbeduto et al., 2007; Laws & Hall, 2014), and significant delays in verbal short-term and working memory (Jarrold, Baddeley, & Phillips, 1999; Vicari, Carlesimo, & Caltagirone, 1995; Vicari, 2006) There is also a predisposition to early onset Alzheimer’s disease in DS (Abbeduto et. al., 2007). DS is also associated with linguistic delays, especially in expressive and syntactic domains (Brown & Percy, 2007; Fidler, 2005). Physically, individuals with DS often have hypotonia, congenital heart disease, middle ear disease, distinctive craniofacial structures, small oral cavities and enlarged tongues, and poor motor functioning (Brown & Percy, 2007; Fidler, 2005).

**HL in DS**

DS is also associated with high rates of HL (Abbeduto et al., 2007; Laws & Hall, 2014; Mazzoni, Ackley, & Nash, 1994). The three types of HL are conductive HL, sensorineural HL, and mixed HL. Conductive HL indicates an attenuation in the outer or middle ear and can include otitis media (middle ear infection), occluding wax (the large buildup of wax in the ear), or effusion (sticky fluid buildup in the middle ear; Martin, 2014). Approximately 80% of all children, including those who are typical development (TD), experience an episode of otitis media once in childhood, but there are minimal lasting effects (Klausen, Moller, Holmefjord, Reisaeter, & Asbjornsen, 2000). The type of HL can fluctuate, remain stable, or alternate with normal hearing over a period of time (Klausen et al., 2000). Treatment and prevention of conductive HL are possible and includes tympanostomy tubes or pressure equalization tubes, antibiotics, wax removal, and hearing aids (Brown & Percy 2007; Snashall, 2016). Bone-Anchored Hearing Aids (BAHA) are also a treatment option for conductive HL (Centers for Disease Control and
Prevention, 2015). Sensorineural HL, in contrast, indicates an attenuation in the cochlea or auditory nerve. This type of HL is often permanent but can be treated with hearing aids or cochlear implants (Martin, 2014). Mixed HL is characterized by an attenuation in the middle or outer ear, as well as damage to the cochlea or auditory nerve (Martin, 2014).

Two-thirds of toddlers with DS will experience either mild or moderate conductive or sensorineural HL (Abbeduto et al., 2007; Klausen et al., 2000; Laws & Hall, 2014; Mazzoni et al., 1994). Conductive HL is the most frequent type of HL in DS (Abbedutto et al., 2007; Laws & Hall, 2014; Mazzoni et al. 1994) because of the physical characteristics associated with DS. This includes large adenoids, a small nasopharynx, impaired swallowing, narrow and horizontal Eustachian tube, narrow ear canal, malformations of the middle ear bones, malformation of the pinna, and immune abnormalities, which can lead to otitis media, Eustachian tube dysfunction, or occlusion of wax (Abbeduto et al., 2007; Brown & Percy, 2007; Fidler, 2005; Laws & Hall, 2014; Mazzoni et al. 1994; Snashall, 2016). Laws and Hall (2014) reported a prevalence rate of 93% for conductive HL due to otitis media at age one in DS. However, despite the high levels of otitis media, only a small percentage of participants were reported to have been treated with hearing aids or tubes (Laws & Hall, 2014).

While not as common as conductive HL, sensorineural HL is still more prevalent in DS than in the typically developing population. In a study conducted by Mazzoni et al. (1994), 10% of individuals with DS had sensorineural HL; in TD, sensorineural HL affects only two to three infants per 1,000 births (Paludetti, et al. 2012). By the age of 40, many adults with DS also experience degenerative cochlear changes which can cause
sensorineural HL (Snashall, 2016). Because of the high rates of conductive HL, individuals with sensorineural HL are often diagnosed with mixed HL.

**The Effect of HL on Language and Literacy Skills**

In TD, HL, especially during ages of language acquisition, can negatively impact language and literacy skills (Klausen et al., 2000; Mazzoni et al., 1994; Pardington & Galloway, 2005). Conductive HL, for example, can be recurrent and fluctuate, exposing children to an inconsistent language model. Recurrent conductive HL can then lead to difficulties receiving and organizing auditory information and has been linked to delays in literacy and numeracy skills (Pardington & Galloway, 2005). More specifically, conductive HL can lead to poor development of auditory discrimination, phonological awareness, short-term memory skills, and auditory sequential memory skills (Brown & Percy, 2007; Laws & Hall, 2014; Pardington & Galloway, 2005). Conductive HL may also lead to difficulty forming linguistic categories, such as tenses or plurals and articulation (Williams, 2010), and may result in lower IQ test scores, poor reading and spelling skills, and lower social maturity (Pardington & Galloway, 2005; Williams, 2010).

Sensorineural HL is characterized by difficulty with auditory discrimination and tasks involving language concepts, auditory memory, syntax, semantics, and vocabulary skills (Williams, 2010). Sensorineural HL has also been linked to deficits in reading and spelling (Williams, 2010). Finally, mixed HL will contain some or all of the effects of both conductive and sensorineural HL (Williams, 2010).

Despite limited research on the effects of HL on language and literacy outcomes in DS, initial evidence suggests that cognitive, speech, language, and literacy skills are
also impacted by HL in this population. For example, Libb, Dahle, Smith, McCollister, and McLain (1985) examined children with DS with HL compared to those without HL and found that participants with abnormal tympanograms had much lower IQs than those who had normal tympanograms. Tympanograms measure the compliance, air pressure, and volume of the middle ear and, if normal, can indicate normal middle ear function (Martin, 2014). Similarly, Mazzoni et al. (1994) reported that children with DS with HL showed greater deficits in language acquisition and auditory processing (Mazzoni et al., 1994). Finally, Laws and Hall (2014) investigated the effect of early HL on language outcomes in DS and found a significant, negative impact on language expression, receptive vocabulary, narrative abilities, and speech accuracy. While the impact of HL on language abilities has been scarcely investigated, no research to date has examined the impact of HL on literacy outcomes in DS.

**Developmental Milestones and Early Language**

To understand the impact of HL on language, it is important to first understand the language milestones seen in typically developing children. These developmental milestones outline the typical developmental trajectory and time points at which a child should perform or demonstrate specific behaviors, including speech and language behaviors. Developmental milestones are a useful reference to compare a child’s performance against to determine if the child is progressing typically towards cognitive, speech/language, and physical/motor goals.

Within the first two months of age, a child should be able to move their eyes or head in the direction of sound and begin to vocalize (e.g. cooing). By four months, a child should begin to babble and cry to show needs or emotion. By six months, a child should
begin to respond to sounds by making sounds and responding to their own name (Centers for Disease Control and Prevention, 2017). The onset of symbolic intentional communication usually occurs around 9 months of age and includes canonical babbling (e.g. “baba,” “baka”) (Abbeduto et. al., 2007, Centers for Disease Control and Prevention, 2017). By 9 months, a child should also begin pointing at things and copying gestures. Around the age of one year, a child should begin to use simple gestures for words such as “no” or “bye-bye,” say simple words like “mama” and “dada,” and understand words for common items like “cup” or “juice” (Centers for Disease Control and Prevention, 2017; American Speech and Hearing Association).

TD children usually produce their first words around 12 months of age, though there is variability in this (Abbeduto et. al., 2007). By 18 months, a child should be able to say several single words and point to something he or she wants. By two years, a child should begin to point to things or pictures when named and follow simple instructions. By three years, a child should begin to understand simple prepositions, follow two or three step instructions, carry on a conversation using two or three sentences, and understand “why” questions. By four years, a child should be able to tell stories, say their first and last name, name some letters and numbers, understand “when” and “how” questions, and use conjunctions “when,” “so,” and “if.” By five years, a child should be able to speak clearly, tell a simple story in full sentences, use the future tense, say name and address, and speak with 100% intelligibility (American Speech and Hearing Association; Centers for Disease Control and Prevention, 2017; Paul & Norbury, 2012).

Unfortunately, while early development in DS has been well researched, specific milestones have not been documented as thoroughly as in TD. According to Fidler
(2005), understanding the early development trajectory in DS can be important in formulating intervention.

What research is available on developmental milestones in DS suggests the same progression of milestones, but at a delayed rate and with an increasing gap between individuals with DS and the age at which they reach more advanced milestones (Abbedutto et al. 2007). The first stage of language development is vocalization (e.g. cooing); this prelinguistic stage is atypical, but not delayed. Infants with DS produce more non-speech like sounds than speech-like sounds. Also, the onset and frequency of using gestures in DS seem to match TD (Fidler, 2005). However, intentional symbolic communication or canonical babbling may not develop until 24 to 36 months of age in DS. The average milestone for production of first words is 21 months, although many do not produce first words until much later (Abbeduto et. al., 2007).

**Language and Reading Skills in DS**

HL has been linked to later emerging language and literacy skills, including vocabulary, syntax, phonological processing, and word reading, all important subskills of reading comprehension (Conners, Loveall, Moore, Hume, & Maddox, 2011; Gough & Tunmer, 1986; Vellutino, Tunmer, Jaccard, & Chen, 2007). Individuals with DS demonstrate a unique pattern of reading skills when compared to typically developing peers (Bochner, Outhred, & Pierterse, 2001; Loveall & Conners, 2016), and HL may negatively impact the development of these abilities in a large portion of the population. Understanding the patterns of strength and weakness across language and literacy within individuals with DS is important when documenting the impact of HL on these outcomes.
**Vocabulary.** Vocabulary is tied to reading success (Hart and Risley, 2003), and though vocabulary is typically reported to be an area of relative strength in DS, it develops at a much slower rate than in typically developing children (Abbeduto et al., 2007). A variety of factors are related to vocabulary growth, including chronological age, cognitive ability, hearing status, and exposure to vocabulary (Abbeduto et al., 2007; Lund, Werfel, & Schuele, 2015). Cunningham and Stanovich (2001) found that vocabulary growth in children with TD is tied to exposure to language more so than direct teaching. HL, then, can negatively impact vocabulary development by inhibiting a child’s exposure to language. HL can also lead to impaired speech perception abilities, which in turn have also been linked to smaller spoken vocabularies (Lund et al., 2015). In DS, maternal education has also been found to predict children’s vocabulary scores (Abbeduto et al., 2007). Due to their high rates of HL, children with DS are at risk for slower vocabulary development.

**Syntax.** Syntax is the way in which words are combined into sentences to express meaning. Syntax, especially expressive syntax, is considered to be an area of especial difficulty in DS (Laws & Hall, 2014) and in individuals with sensorineural HL more broadly (Williams, 2010). Cognitive ability, including auditory short-term memory and visual short-term memory, and hearing status contribute to syntactic abilities (Abbedutto et al., 2007). Abbedutto et al. (2007) reported that in 31 participants with DS, syntax comprehension decreased with increasing age; syntax develops at younger ages, plateaus in adolescence, and decreases around age 17 (Abbeduto et al., 2007).
**Phonological skills and word recognition.** Phonological processing skills, including phonological awareness, phonological memory, and phonological access to lexical store, and word recognition are two components of reading comprehension (Lonigan et al., 2009). Phonological awareness, the awareness of the sound structure of words, may be impacted by HL (Abbedutto et al., 2007). For example, previous research by Lund et al. (2015) found evidence that children with HL develop phonological awareness differently than children without HL and that this was tied to different literacy outcomes. Phonological processing skills, including phonological awareness and phonological memory, are well-documented difficulties for many individuals with DS (Hulme et al., 2012; Kay-Raining Bird, Cleave, & McConnell, 2000). Phonological decoding has also been noted to be difficult for individuals with DS. Interestingly, despite difficulties with phonological processing, word recognition is a relative strength, matching developmental expectations in DS (Hulme et al., 2012; Kay-Raining Bird et al., 2000; Loveall & Conners, 2016).

**Impact of Parents on Hearing, Speech, Language, and Literacy Outcomes**

**Impact of parent prevention.** Parents play an important role in implementing prevention and treatment of HL for their children (Centers for Disease Control and Prevention, 2015). If parents are well informed about HL at the time of diagnosis, the intervention and treatment process is easier to initiate. The earlier a child starts receiving intervention services, the less likely their language and speech skills will be negatively impacted by HL (Centers for Disease Control and Prevention, 2015). Parents need the following components to sufficiently address their child’s HL: basic information on HL and hearing devices, information on the early stages of auditory development in TD,
insight into language development in children with varying degrees of HL, and guidance and support as they cope with their child’s HL (Reichmuth, Embacher, Matulat, Zehnhoff-Dinnesen, & Glanemann, 2013).

**Parent role in language and literacy development.** The role parents play in the early development of their child’s language development and literacy skills is immense. For example, in the language domain, Hart and Risley (2003) documented that almost everything a child learns, including language, interaction styles, and vocabulary, comes from their families and that 86-98% of the words in a child’s vocabulary can also be found in their parents’ vocabulary. In the literacy domain, a meta-analysis by Bus, Ijzendoorn, and Pellegrini (1995) found that parent-child book reading is a strong predictor of written language acquisition, which provides a foundation for reading comprehension and reading achievement, independent of family socioeconomic status. However, despite the overwhelming amount of research tying parent knowledge and practices to children’s language and literacy outcomes in TD, this has not been well-documented in DS.

**Purpose of the Present Study**

While the effects of HL on reading skills have been documented in TD children, there is a paucity of research on this topic in DS. Understanding the relationship between HL and language and literacy skills in DS is crucial to successful prevention and intervention. Parents play a large role in the identification and treatment of HL, which could be important in limiting the negative effects of HL on language and literacy skills in children DS. The purpose of this study is to examine parental knowledge of HL in DS.
and to examine links between HL and language and literacy outcomes. We specifically addressed the following research aims:

1. Document parent knowledge and attitudes regarding language, literacy, and HL.
   a. We hypothesized that parents will have insufficient knowledge, but will have positive attitudes regarding HL, language, and literacy.

2. Document HL frequency in DS.
   a. We hypothesized that parents will report a high prevalence of conductive HL and occurrences of otitis media for their child, consistent with previous literature (Laws & Hall, 2014).

3. Document language and literacy outcomes in DS.
   a. We hypothesized that language and literacy outcomes will be delayed.

4. Determine if there is a difference in language and literacy outcomes for children with DS with HL vs. those without HL.
   a. We hypothesized that parents would report stronger language and literacy skills in children reported to not have HL vs. those with HL.
Methods

Design

The present study was a within-subjects, descriptive study. The survey measured several dependent variables, including parents’ experience with, knowledge of, and attitudes toward HL and language and literacy skills, the child’s HL and the child’s language and literacy skills.

Participants

A total of 77 parents of children with DS participated in the present study. Participants of this project were recruited through the National Institute of Health’s DS-Connect portal, which is a registry for families, researchers, and clinicians in support of studies to benefit the DS community. All participants were parents of a child with DS between the ages of 5-10 years. Participants had to be over the age of 18 to complete the survey. A history of HL was not required to participate in the survey.

Child demographics. The ages of the child represented by their parent in this study were estimated from child’s birth month and year. Ages ranged from 5.17 to 10 years, with their birth years ranging from 2008 to 2013. There were 35 (46%) males, 41 (53%) females, and one “other” represented in this survey. Child race was primarily white, and child’s ethnicity was primarily non-Hispanic or Latino. Child demographics are presented in Table 1.
Table 1

**Child Demographics**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (n=77)</td>
<td>7.41 (1.30)</td>
<td>5.17-10.0</td>
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</table>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Sex (n=77)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>46</td>
</tr>
<tr>
<td>Female</td>
<td>41</td>
<td>53</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Child’s Race (n=77)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Black or African American</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>White</td>
<td>71</td>
<td>92</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Preferred not to answer</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Child’s Ethnicity (n=77)</strong></td>
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<tr>
<td>Hispanic or Latino</td>
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<td>12</td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>66</td>
<td>86</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Child’s current or highest level of education (n=77)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Intervention/ Headstart program or similar</td>
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<td>1</td>
</tr>
<tr>
<td>Preschool</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Kindergarten</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>1st grade</td>
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<td>32</td>
</tr>
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<td>2nd grade</td>
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<td>18</td>
</tr>
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<td>3rd grade</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
<td>4th grade</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Parent demographics.** The age of parents who participated in this survey was estimated from birth year and ranged from approximately 35 to 57 years. Parent’s race was primarily white, and ethnicity was primarily non-Hispanic or Latino. Included in the survey were 67 (87%) biological mothers, 7 (9%) biological fathers, and 3 (4%) adoptive mothers. Of the parents who participated, 70 (91%) had additional children, and two (3%) had other children with DS. Parents’ current or highest level of education included 37 (48%) who graduated with a graduate/professional degree and 22 (29%) who graduated with a B.A./B.S. degree. Parent participant demographics are presented in Table 2.
## Materials

A recruitment email was distributed to DS-Connect members who met the inclusion criteria, which included a link to the cover letter. The cover letter included a link to an informed consent form and then the five-part survey (Appendix A). The survey was distributed, completed, and submitted online.

Part 1 of the survey contained background questions about the participant and their child with DS. These questions included information on their age, gender, ethnicity, and level of education.

Part 2 of the survey included questions on hearing history and experience with an Audiologist or ENT. The participants were asked to indicate if their child has a history of HL, their knowledge of the type of HL their child experienced, and the developmental
goals and milestones in DS. The purpose of this section was to obtain information on the
history of the child and their experience with hearing services, as well as to collect
information on how well-informed parents feel regarding HL and development goals.

Part 3 of the survey contained questions concerning the language and literacy
skills of the child with DS. The questions asked about the child’s experience with SLPs
and asked the parent to provide information about their child’s reading skills. The
purpose of this section was to determine parents’ attitudes toward literacy skills and to
document their child’s literacy skills.

Part 4 of the survey contained a series of hearing and language developmental
milestones, and parents were asked to indicate the age at which their child reached each
milestone. The milestones were taken from the DS-Connect Developmental
Questionnaire and Paul and Norbury (2012). The milestones included the age the child
began responding to sound, babbling, understanding words for common items, pointing
to pictures when named, understanding questions, naming some letters and numbers, and
using conjunctions. The purpose of this section was to determine the age at which
children with DS reach each milestone.

Part 5 of the survey included questions testing the parents’ knowledge of HL. For
example, one question asked participants to select any items from a provided list that can
harm the hearing system and/or weaken hearing. The list included items adapted from
Lass, Woodford, and Everly-Myers (1990), Williams (2010), and Cone et al. (2015). The
final question asked participants to select the items from a provided list that can indicate
HL. The list included items adapted from Williams (2010), Hearing Loss Association of
America (2017), and Fishers Auditory Checklist (Fisher, 1976). The purpose of this section was to assess the parents’ knowledge of hearing health and signs of HL.

Procedure

The 35-question survey was created and administered via Qualtrics and was distributed to participants in February 2018. Permission for the survey procedures and documents was received from the University of Mississippi Institutional Review Board. A recruitment email was distributed and presented to the participant with a brief survey description including a link to the cover letter. The estimated testing time for the survey was 10-15 minutes. As an incentive to participate, at the end of the survey, participants could submit their email address to enter a drawing for one of three $25 gift cards.
Results

Parent’s Knowledge and Attitudes Regarding Language, Literacy, and Hearing

When asked to rank their own knowledge, a majority of participants indicated “average” knowledge on HL in general, “good” knowledge of their child’s HL, “good” knowledge of speech and language developmental goals and milestones in TD, and “good” knowledge of speech and language developmental goals and milestones in DS (see Table 3).

Table 3

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Average</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>HL in general</td>
<td>4 (5%)</td>
<td>25 (32%)</td>
<td>46 (60%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Your child's HL</td>
<td>14 (19%)</td>
<td>37 (49%)</td>
<td>21 (28%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Speech and language</td>
<td>15 (19%)</td>
<td>50 (65%)</td>
<td>10 (13%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>developmental goals and</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>milestones in TD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech and language</td>
<td>18 (23%)</td>
<td>45 (58%)</td>
<td>13 (16%)</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>developmental goals and</td>
<td></td>
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<td></td>
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<tr>
<td>milestones in DS</td>
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</table>

Of the 77 participants, 76 children had received a speech and/or language development assessment and all 77 had seen an SLP for speech or language therapy. A majority of children were also reported to use speech as their primary mode of communication (see Table 4).
Table 4
*Child’s Language and Literacy Skills and Parent Attitudes*

<table>
<thead>
<tr>
<th>Child’s primary mode of communication (n=77)</th>
<th>n%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>57 (74%)</td>
</tr>
<tr>
<td>Sign Language</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>Augmentative and alternative communication (AAC)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Primarily nonverbal</td>
<td>8 (10%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (6%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Importance of reading to/with young children (n=77)</th>
<th>n%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely important</td>
<td>64 (83%)</td>
</tr>
<tr>
<td>Very important</td>
<td>10 (13%)</td>
</tr>
<tr>
<td>Moderately important</td>
<td>3 (4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How often do you/did you read to your child while they were ages 0-5? (n=76)</th>
<th>n%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a month or less</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Less often than once a week</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Once a week</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>2 to 5 times a week</td>
<td>13 (17%)</td>
</tr>
<tr>
<td>More than 5 times a week</td>
<td>56 (73%)</td>
</tr>
</tbody>
</table>

In questions 28 and 29, parents were asked to report on the importance of reading to children (*not at all important* = 0 to *extremely important* =4) as well as the frequency of reading to their own child from ages 0-5 years (*once a month or less* = 0 to *more than 5 times a week* = 4). The importance of reading to/with young children was rated as “extremely important” by 64 (83%) participants. A majority of parents also indicated that they read to their child more than 5 times a week between the ages of 0 and 5 years (see Tables 4 and 5). In question 24, parents were also asked to self-report on their knowledge of HL in general, their child’s HL specifically, goals and milestones in TD, and goals and milestones in DS (*poor* = 0 to *excellent* = 3). Finally, parents were asked if they had received information on signs of HL (*no* = 0, *yes* = 1) (see Table 5).
Table 5
Descriptive Statistics for Self-Reported Parent Knowledge and Attitudes

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of reading to child</td>
<td>77</td>
<td>3.79</td>
<td>0.496</td>
</tr>
<tr>
<td>Frequency reading to child while</td>
<td>76</td>
<td>3.55</td>
<td>0.929</td>
</tr>
<tr>
<td>0-5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent knowledge on HL in general</td>
<td>77</td>
<td>1.40</td>
<td>0.634</td>
</tr>
<tr>
<td>Parent knowledge of child's HL</td>
<td>75</td>
<td>1.83</td>
<td>0.778</td>
</tr>
<tr>
<td>Parent knowledge of goals and</td>
<td>77</td>
<td>2.01</td>
<td>0.659</td>
</tr>
<tr>
<td>milestones in TD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent knowledge of goals and</td>
<td>77</td>
<td>2.03</td>
<td>0.707</td>
</tr>
<tr>
<td>milestones in DS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received info on signs of HL</td>
<td>76</td>
<td>0.87</td>
<td>0.596</td>
</tr>
</tbody>
</table>

When tested on items that can harm hearing, only 20 participants (26%) correctly identified every item in the list. However, all participants selected at least one correct item and selected correct items more often than distractors. Almost all participants (95%) correctly identified that large amounts of ear wax (95%) and malformations of the ear can harm hearing (90%), and 63% correctly identified that cotton swabs can harm the hearing system. Surprisingly, only 36% of participants were able to identify that certain antibiotics can harm hearing. Further, participants largely did not select incorrect distractor items, including aspirin in small doses (1%), ibuprofen or naproxen (1%), and having some earwax (16%). Finally, only 3% of participants indicated that antihistamines can harm hearing, which was also an incorrect item (see Figure 1).
Figure 1

Percentage of Participants That Correctly Identified Items That Can or Cannot Harm Hearing

Of the 77 participants that responded to the HL signs question, only 9 (12%) participants correctly identified every item in the list that can indicate HL. However, all participants were able to identify at least one correct item, and participants as a whole selected correct items more often than distractors. A majority of parents were able to indicate that louder speech, articulation difficulty and disorders, and displaying slow or delayed responses to verbal stimuli can indicate HL. Surprisingly, only 40% of participants were able to identify that tugging on the ears can indicate HL. Only 26% of participants were able to indicate that softer speech can indicate HL. Only 16% incorrectly identified that low energy can indicate HL and only 6% incorrectly identified that watching television at a low volume can indicate HL (see Figure 2). Descriptive statistics were calculated for parents’ overall score for items that can harm hearing and signs of HL. Questions 34 and 35 presented participants with a list of 8 items to identify that could harm hearing or indicate a HL. They could earn up to 8 points for question 34.
and 8 points for question 35, 8 being excellent and 0 being poor. Mean score for items that can harm hearing was 5.6 and standard deviation was .98. Mean score for signs of HL was 5.84 and standard deviation was 1.08 (see Table 6).

Figure 2
*Percentage of Participants That Correctly Identified Signs of HL*

Table 6
*Descriptive Statistics for Parents’ Knowledge of Items That Can Harm Hearing and Signs of HL*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Knowledge of Hearing Harm</td>
<td>77</td>
<td>5.6104</td>
<td>0.97543</td>
</tr>
<tr>
<td>Parent Knowledge of HL Signs</td>
<td>77</td>
<td>5.8442</td>
<td>1.07685</td>
</tr>
<tr>
<td>Total Parent Knowledge</td>
<td>77</td>
<td>11.4545</td>
<td>1.6347</td>
</tr>
</tbody>
</table>

**HL History**

Of the 77 children with DS represented in the present study, 33 (43%) were reported to have conductive HL, and 34 (44%) were reported to have no HL. A small number were reported to have sensorineural (1%) or mixed (4%) HL. For those with HL,
most were diagnosed at birth. The number of diagnoses then decreased with age. Additionally, a majority of parents (61%) reported that their child had a history of otitis media (middle ear infection), regardless of whether or not they reported HL. Of those with a history of otitis media, 26 (50%) reported that their child experienced more than 2 per year from ages 0-5 years.

Regarding experience with an ENT and audiologist, 66 (86%) participants reported that their child has his or her hearing tested at least once a year, while only 11 (14%) reported that their child has their hearing tested less often than once a year. No parents reported that their child had never had a hearing test. Of the participants that had access to ENTs and/or audiologists, 48 (63%) indicated that they were given information on signs that may indicate HL (see Table 7).
Table 7  
*HL History Questions*  

<table>
<thead>
<tr>
<th>HL History/Type ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conductive</td>
<td>33 (43%)</td>
</tr>
<tr>
<td>Sensorineural</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Mixed</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>6 (8%)</td>
</tr>
<tr>
<td>No HL</td>
<td>34 (44%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Diagnosed with HL ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No HL</td>
<td>34 (44%)</td>
</tr>
<tr>
<td>Birth</td>
<td>13 (17%)</td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>7 (9%)</td>
</tr>
<tr>
<td>1-2 years</td>
<td>8 (10%)</td>
</tr>
<tr>
<td>3-4 years</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>5-6 years</td>
<td>6 (8%)</td>
</tr>
<tr>
<td>7-8 years</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>No response</td>
<td>4 (5%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>History of Otitis Media ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>47 (61%)</td>
</tr>
<tr>
<td>No</td>
<td>29 (38%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Otitis Media occurrences from ages 0-5 ($n=52$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fewer than 2 per year</td>
<td>16 (31%)</td>
</tr>
<tr>
<td>2 per year</td>
<td>8 (15%)</td>
</tr>
<tr>
<td>More than 2 per year</td>
<td>26 (50%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>2 (4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hearing Testing Frequency ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing tests less often than once a year</td>
<td>11 (14%)</td>
</tr>
<tr>
<td>Hearing tests at least once a year</td>
<td>66 (86%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HL Treatment History ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No treatment needed</td>
<td>26 (34%)</td>
</tr>
<tr>
<td>Tympanostomy tubes</td>
<td>46 (60%)</td>
</tr>
<tr>
<td>Hearing Aid</td>
<td>9 (12%)</td>
</tr>
<tr>
<td>FM system</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>BAHA</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Audiology clinic or ENT Preference ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audiology Clinic</td>
<td>11 (14%)</td>
</tr>
<tr>
<td>ENT Office</td>
<td>20 (26%)</td>
</tr>
<tr>
<td>Both</td>
<td>31 (40%)</td>
</tr>
<tr>
<td>Neither</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>No Preference</td>
<td>13 (17%)</td>
</tr>
<tr>
<td>No access to Audiology or ENT</td>
<td>1 (1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Received information from Audiologist or ENT ($n=77$)</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>48 (63%)</td>
</tr>
<tr>
<td>No</td>
<td>19 (25%)</td>
</tr>
<tr>
<td>Unsure</td>
<td>9 (12%)</td>
</tr>
</tbody>
</table>
Language and Literacy Skills and Developmental Milestones

Of the 77 participants, 29 (38%) reported that their child’s overall language ability is average compared to other children their age with DS, and 28 (36%) reported that their child’s overall language ability is strong compared to other children their age with DS. When asked about reading skills, thirty-one parents (40%) indicated that their child’s reading skills are poor compared to TD individuals of the same age (see Table 8).

Table 8
Ranking of Child’s Reading and Language Skills

<table>
<thead>
<tr>
<th></th>
<th>Strong</th>
<th>Average</th>
<th>Poor</th>
<th>No language skills</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s reading skills compared to</td>
<td>8 (10%)</td>
<td>25 (33%)</td>
<td>31 (40%)</td>
<td>12 (16%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>other typically developing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>individuals of the same age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child’s overall language ability</td>
<td>28 (36%)</td>
<td>29 (38%)</td>
<td>14 (18%)</td>
<td>2 (3%)</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>compared to that of other children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>their age with DS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sixty-nine parents that indicated their child uses speech, sign language, augmentative and alternative communication, or “other” as their primary mode of communication were asked to indicate their child’s reading and language skills. A majority (75%) indicated that their child can recite the alphabet very well, 86% indicated that their child can identify single, written letters very well, and 71% indicated that their child knows the sounds of letters. A large percentage of parents (46%) also reported that their child reads basic picture books or simple stories. However, only 6 (9%) participants indicated that their child can read new or unfamiliar words very well. There was approximately an equal number of participants that indicated that they would describe their child as a reader, somewhat of a reader, and not at all as a reader (see Table 9).
Table 9
Child’s Receptive/Comprehension and Expressive/Production Skills

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, Very Well</th>
<th>Somewhat</th>
<th>No, not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can your child recite the alphabet?</td>
<td>52 (75%)</td>
<td>10 (15%)</td>
<td>7 (10%)</td>
</tr>
<tr>
<td>Can your child identify single, written letters?</td>
<td>59 (86%)</td>
<td>10 (14%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Does your child know sounds of letters?</td>
<td>49 (71%)</td>
<td>19 (28%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Can your child read single, written words?</td>
<td>35 (51%)</td>
<td>21 (30%)</td>
<td>13 (19%)</td>
</tr>
<tr>
<td>Can your child read new/unfamiliar words?</td>
<td>6 (9%)</td>
<td>31 (45%)</td>
<td>32 (46%)</td>
</tr>
<tr>
<td>Does your child read basic picture books or simple stories?</td>
<td>31 (46%)</td>
<td>18 (26%)</td>
<td>19 (28%)</td>
</tr>
<tr>
<td>Would you describe your child as a reader?</td>
<td>23 (33%)</td>
<td>22 (32%)</td>
<td>24 (35%)</td>
</tr>
</tbody>
</table>

The milestones presented in the survey are reached at ages varying from birth to 5 years in TD. For the milestone of moving the eyes or head in direction of sound, 54 (73%) participants indicated that their child reached this milestone from ages 0-5 months, and 13 (18%) indicated that their child reached this milestone from ages 6-12 months. The milestone of babbling using speech like sounds was reached by a majority of child participants from the ages 6-12 months. Understanding words for common items like “cup” and “juice” was reached by 24 (33%) participants by 2-12 months, and by 25 (34%) participants by 13-17 months. Pointing to pictures in a book when named was reached by 19 (26%) participants by 13-17 months and 21 (29%) participants by 18-23 months. The ability to name some letters and numbers was not reached by most participants by 2-3 years (39%) or by 4-5 years (33%). The milestone of understanding “why” questions was not reached yet in 25 (34%) children; however, it was reached from ages 4-5 years by 19 (26%) children and was reached from ages 6-8 years by 23 (32%) children. Understanding “when” and “how” questions was not yet reached by 33 (45%).
children and was reached by 25 (34%) children by the age of 6-8 years. The use of conjunctions was not yet reached by 46 (62%) children and was only reached by 15 (20%) children by the age of 6-8 years (see Figure 3).

Correlations between parent reports of knowledge and attitudes and children’s language (i.e. the age at which they reached each developmental milestone) and literacy skills are presented in Table 10. To determine the correlations between age at which a child met each developmental milestone, ages were reverse-coded so that higher scores indicate the participants reached the milestone at earlier ages. The scores from each milestone question (see Figure 3) were then added together for each participant. To compute literacy outcomes, scores on relating to the child’s literacy skills on the survey were added together (see Table 9), with higher scores indicating stronger literacy skills. There were significant positive correlations between child reading score and age (.32), milestones (.29), parents’ belief of the importance of reading to child (.27), and parents' reports of frequency of reading to child (.24). Child's milestones were also significantly and positively correlated with parents’ report of frequency of reading to child (.27) and child's frequency of otitis media (.30).
Figure 3

Age of Speech and Language Milestones
Table 10
Correlations of Parent and Child Variables

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Reading Skills</th>
<th>Milestones</th>
<th>Parent Knowledge Score</th>
<th>Importance of Reading to Child</th>
<th>Frequency of Reading to Child</th>
<th>Parent Knowledge of HL</th>
<th>Parent Knowledge of Child HL</th>
<th>Parent Knowledge of Milestones in TD</th>
<th>Parent Knowledge of Milestones in DS</th>
<th>Frequency of OM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Reading Skills</td>
<td>.32*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Milestones</td>
<td>.10</td>
<td>.29*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Parent Knowledge Score</td>
<td>.08</td>
<td>.01</td>
<td>.03</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Importance of Reading to Child</td>
<td>-.07</td>
<td>.27*</td>
<td>.18</td>
<td>.00</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Frequency of Reading to Child</td>
<td>-.13</td>
<td>.24*</td>
<td>.27*</td>
<td>.06</td>
<td>.50*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Parent Knowledge of HL in General</td>
<td>.01</td>
<td>.09</td>
<td>.00</td>
<td>.25*</td>
<td>.10</td>
<td>.18</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Parent Knowledge of Child's HL</td>
<td>.01</td>
<td>.08</td>
<td>-.09</td>
<td>.27*</td>
<td>.27*</td>
<td>.12</td>
<td>.53*</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Parent Knowledge of Milestones in TD</td>
<td>-.22+</td>
<td>.10</td>
<td>.18</td>
<td>.03</td>
<td>.21+</td>
<td>.38*</td>
<td>.40*</td>
<td>.40*</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Parent Knowledge of Milestones in DS</td>
<td>-.12</td>
<td>.06</td>
<td>.00</td>
<td>.09</td>
<td>.28*</td>
<td>.21+</td>
<td>.39*</td>
<td>.49*</td>
<td>.79*</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Frequency of OM</td>
<td>.27*</td>
<td>.18</td>
<td>.30*</td>
<td>.02</td>
<td>.17</td>
<td>-.01</td>
<td>.10</td>
<td>.05</td>
<td>-.06</td>
<td>-.05</td>
<td>--</td>
</tr>
</tbody>
</table>

* Correlation is significant at p < .05
+ Correlation is significant at p < .1
Comparing Children with DS with HL to Those Without HL on Language and Literacy Outcomes

An independent samples t-test was used to compare children with HL versus those without HL on the age in which they reached various speech and language related milestones. Ages were reverse-coded so that higher scores indicate the participants reached the milestone at earlier ages. These scores were then added together for each participant. Results indicated no significant difference between the group with HL (M = 32.39; SD = 7.00) and the group without HL (M = 33.03; SD = 6.10), \( t (69) = .40, p = .69 \).

An independent samples t-test was also used to compare groups on literacy skills. To compute literacy outcomes scores on questions 30-32 on the survey were added together, with higher scores indicating stronger literacy skills. Results again indicated no significant differences between the group with HL (M = 9.28; SD = 3.82) and the group without HL (M = 9.41; SD = 3.27), \( t (66) = .15, p = .8 \).
**Discussion**

The purpose of this study was to examine HL, language, and literacy in DS via parent reports. Specifically, we examined the following aims: documenting parents’ knowledge and attitudes regarding HL, language, and literacy, documenting the frequency of HL in DS, documenting language and literacy outcomes in DS, and determining if there is a difference in language and literacy outcomes for children with DS with HL vs. those without HL. Overall, we found a high percentage of HL in DS. However, there were no statistically significant differences in language and literacy outcomes between children with HL and those without. Parents were largely knowledgeable about HL and felt that reading to children was important.

This study indicated that parents have a good understanding of HL, including signs of HL and items that can harm hearing. The parent participants in this study reported high education levels, which may have contributed to their high level of understanding of HL. However, since the study was conducted online, it is possible that some participants looked up answers to questions with a right or wrong answer.

Parents reported a high prevalence of conductive HL (43%) and otitis media (61%) in their children with DS. This finding is somewhat consistent with research by Laws and Hall (2014), who reported a higher prevalence of 93% for otitis media by age one in DS. However, parents in this study indicated a greater percentage of HL treatment with tympanostomy tubes than reported in the study by Laws and Hall (2014). While approximately 80% of all children, including TD, experience an episode of otitis media
once in childhood, episodes do not typically reoccur (Klausen, 2000). The prevalence of recurrent otitis media is higher in DS than in TD. For sensorineural HL, the prevalence reported in this study was only 1%, which is lower than previous research conducted by Mazzoni et. al (1994). There were 4% that reported mixed HL, which also includes a component of sensorineural HL. Overall, 48% of participants indicated that their child has some type of HL.

Also consistent with previous research, developmental milestones were delayed in our participants with DS when compared to typical ages of acquisition. Interestingly, the earlier milestones were reportedly achieved closer to the age of achievement in TD. However, as the milestones increased in age of expected achievement in TD, the achievement rate of the milestone in DS decreased. For example, the milestone of turning eyes or head in direction of sound was achieved by 73% of participants by 0-5 months of age, which is similar to the milestone of achieving that developmental skill in TD. However, the milestone of using conjunctions was not yet reached by 62% of participants but is reached by age 5 in TD. Thus, consistent with previous reports (Abbeduto et al., 2007), the gap in linguistic abilities appears to increase with age. These results are also consistent with the milestone results reported by DS-Connect.

There was a strong report of language and literacy skills for the easier skills, but as skills increased in difficulty, the reports were poor. For example, 86% of participants reported that their child can identify single letters, but only 33% would describe their child as a reader. There was a reported weakness in reading new or unfamiliar words, which is consistent with difficulties with phonological decoding. Also, there were strengths in word recognition, which is consistent with previous research.
There were significant positive correlations between child reading score and age milestones, parents’ belief of importance of reading to child, and parents' reports of frequency of reading to child. Child's milestones were also significantly and positively correlated with parents’ report of frequency of reading to child, and surprisingly, child's frequency of otitis media. The positive correlation between child’s milestones and frequency of otitis media may be influenced by a third variable; early treatment of otitis media and/or higher levels of parent involvement may be influencing child’s milestones.

Finally, there was no significant difference in reported language and literacy outcomes for children with DS with HL and those without HL. The implications of these results are positive for both the DS and audiology communities. It appears that parents are well informed of their child’s HL and more likely to seek assistance. Additionally, audiologists are aware of the ways in which to reduce the effect of HL. The results indicate that HL is not negatively impacting language and literacy in DS, which could be a result of early diagnostic testing paired with successful intervention. However, these results should be interpreted with some caution as the severity of HL was not reported on in this study and because language and literacy are still known to be areas of difficulty for individuals with DS. It is possible that the sample of participants with HL had only mild degrees of HL that would not impact these outcomes significantly. It is also possible that parents who elected to participate in the survey had children with high levels of language and reading skills.
Clinical Implications

Otitis media and conductive HL are well documented in DS, and therefore should be closely screened for and treated for children with DS. Audiologists and other primary care providers should be aware of the high prevalence of conductive HL and provide relevant diagnostic and preventative information to parents. Also, the positive correlations between parents reading to their child and outcomes in language and literacy skills indicate the importance of parents’ attitudes towards language and literacy.

Limitation and Future Direction

There are several limitations to note in the present study. The small sample size may have affected results; it would be beneficial to conduct a similar study with a larger sample size. Also, survey designs inherently have some potential pitfalls. First, participants may misinterpret the wording of items included in the survey. Also, since the survey was self-report, the results may have been affected by social desirably responding: participants’ responses may be different from what they actually know, understand, or do. Additionally, the survey was completed on a volunteer basis, and it is possible that only those participants interested in HL and literacy skills completed this survey. It is possible that those with a child with DS with HL were more likely to participate in this survey, inflating the reported percentage of HL in DS. It is also possible that parents who were concerned by their child’s delayed language and literacy skills were more likely to participate, negatively affecting the language and literacy skills results. Conversely, as noted above, it is possible that parents whose children have strong language and literacy skills were more interested in completing the study, inflating the language and literacy results. As a follow up to this study, it would be beneficial to compare standardized
assessment performance of language and literacy skills of individuals with DS and HL and DS with normal hearing.

It is also important to note that the participants were all members of DS-Connect. This may pose a threat to the internal validity of the results, as all members were part of a preexisting group. It is unknown how families in DS-Connect compare to families with DS not in DS-Connect. However, there may be differences in variables such as socioeconomic status, level of education, and interest in learning about topics relevant to DS such as HL.

Finally, in this study, parents did not report the degree of their child’s HL; consequently, we are not aware of the severity of their child’s HL or how that may have impacted the results regarding their language and literacy outcomes. As a follow up to this study, it would be helpful to document or measure the degree of HL in DS to further compare individuals with HL and without HL in DS. Also, while parents reported the type of HL their child experienced, the numbers were too low to compare outcomes in conductive vs. sensorineural vs. mixed. It would also be useful to measure parents’ role in outcomes for speech, language, and literacy in DS. Future studies may want to follow-up on this line of research.
LIST OF REFERENCES

American Speech and Hearing Association. How does your child hear and talk?


memory deficit. *Down Syndrome Research and Practice, 6*(3), 61-75. doi:10.3104/reviews.97


APPENDICES
Appendix A

Consent Form

Assessing Parents’ Knowledge of Signs of a Hearing Loss

**Investigators**
Annalise Valle, Student
Communication Sciences and Disorders
The University of Mississippi
(901) 219-4307

Susan Loveall, PhD
Communication Sciences and Disorders
The University of Mississippi
(662) 915-5126

**Description**
The purpose of this research project is to determine how informed parents are regarding signs of a hearing loss, including knowledge of developmental goals for children with Down syndrome. We would like to ask you some questions about your knowledge and experience.

**Cost and Payments**
It will take you approximately 10-15 minutes to complete this survey. After completing the survey, your email address will be entered into a drawing for a $25 Amazon gift card.

**Risks and Benefits**
It is possible that some of the questions will make you feel uncomfortable, particularly if you are not knowledgeable about a topic we ask about. We do not think that there are any other risks. Many people enjoy completing questionnaires.

**Confidentiality**
At the end of the survey, we will ask for your email address so that we can contact you if you are one of the raffle winners. Your email address will be stored separately from your survey responses at all times, so your data will be completely anonymous. Your data will also be kept confidential.

**Right to Withdraw**
You do not have to take part in this study and you may stop participation at any time. If you start the study and decide that you do not want to finish, you are free to exit the survey without completing it. You may skip a question if you prefer not to answer it.

**IRB Approval**
This study has been reviewed by The University of Mississippi’s Institutional Review Board.
Board (IRB). If you have any questions, concerns, or reports regarding your rights as a participant of research, please contact the IRB at (662) 915-7482 or irb@olemiss.edu.

Statement of Consent: By checking this box and completing the survey, I certify that I have read and understand the above information. I consent to participate in the study.

☒ Click to agree

By checking this box, I certify that I am at least 18 years old.

☒ Click to certify age
Appendix B

Questionnaire

1. Statement of Consent: By checking this box and completing the survey, I certify that I have read and understand the above information. I consent to participate in the study.
   o Click to agree

2. By checking this box, I certify that I am at least 18 years old.
   o Click to certify age

3. Please indicate the birth month and year of your child with DS.
   __________ Month
   __________ Year

4. What is your child's sex?
   o Male
   o Female
   o Other

5. What is your child's race? (select all that apply)
   o American Indian or Alaska Native
   o Asian
   o Black or African American
   o Native Hawaiian or Pacific Islander
   o White
   o Other
   o Prefer not to answer

6. What is your child's ethnicity?
   o Hispanic or Latino
   o Not Hispanic or Latino
   o Prefer not to answer

7. What is your child's current or highest level of education?
   o No schooling completed
   o Early intervention/ Headstart program or similar
   o Preschool
   o Kindergarten
   o 1st grade
   o 2nd grade
   o 3rd grade
   o 4th grade
   o 5th grade or above
8. In what year were you born?  
__________________________

9. What is your sex?  
○ Male  
○ Female  
○ Other

10. What is your race? (select all that apply)  
○ American Indian or Alaska Native  
○ Asian  
○ Black or African American  
○ Native Hawaiian or Pacific Islander  
○ White  
○ Other  
○ Prefer not to answer

11. What is your ethnicity?  
○ Hispanic or Latino  
○ Not Hispanic or Latino  
○ Prefer not to answer

12. What is your relationship to the child?  
○ Biological Mother  
○ Biological Father  
○ Other biological caregiver (e.g. grandparent, aunt, or uncle)  
○ Adoptive Mother  
○ Adoptive Father  
○ Other adoptive caregiver  
○ Other (describe relationship) ___________________  
○ Prefer not to answer

13. Does your child have any siblings?  
○ Yes  
○ No

14. Do any of the child's siblings also have DS?  
○ Yes  
○ No
15. What is your current or highest level of education?
   - Completed 8th grade
   - Graduated high school/GED
   - Completed some college or technical school
   - Graduated with an associates/technical college degree
   - Graduated college with a B.A/B.S degree
   - Completed some graduate work
   - Graduated with a graduate/professional degree

16. Does your child have a history of a hearing loss? If so, please indicate type of hearing loss:
   - Conductive (problems with the ear canal, eardrum, or middle ear)
   - Sensorineural (permanent nerve hearing loss)
   - Mixed (both sensorineural and conductive hearing loss)
   - Unsure
   - No hearing loss

17. If you indicated that your child has a history of a hearing loss, at what age was he or she first diagnosed with a hearing loss?
   - No hearing loss
   - Birth
   - Less than 1 year
   - 1-2 years
   - 3-4 years
   - 5-6 years
   - 7-8 years
   - 9-10 years
   - Unsure

18. Does your child have a history of middle ear infection (Otitis Media)?
   - Yes
   - No
   - Unsure

19. If your child has/had a history of middle ear infection, how often do/did the infections occur from 0-5 years?
   - Fewer than 2 per year
   - 2 per year
   - More than 2 per year
   - Unsure
20. How often does your child have his or her hearing tested?
   o Never had a hearing test
   o Hearing tests less often than once a year
   o Hearing tests at least once a year
   o Unsure

21. What treatment(s) has your child had for hearing loss? (Select all that apply.)
   o No treatment needed (or no hearing loss)
   o Tympanostomy tubes (myringotomy tubes; PE or pressure equalization tubes) in eardrum to allow fluid to drain from middle ear
   o Hearing aid
   o FM amplification system
   o Cochlear implant
   o Unsure
   o Other _______________________

22. Do you prefer to visit an Audiology clinic or an ENT office?
   o Audiology Clinic
   o ENT office
   o Both
   o Neither
   o No Preference
   o I do not have access to Audiology or ENT services

23. Has an audiologist or ENT ever given you information on what signs to look for that may indicate hearing loss?
   o Yes
   o No
   o Unsure
24. Please indicate your level of knowledge on the following topics:

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Average</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing loss in general</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your child's hearing loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech and language developmental goals and milestones in typical development</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech and language developmental goals and milestones in Down syndrome</td>
<td></td>
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</tr>
</tbody>
</table>

25. Has your child ever received a speech and/or language development assessment?
   - Yes
   - No
   - Unsure

26. Has your child ever seen a Speech-Language Pathologist for speech or language therapy?
   - Yes
   - No
   - Unsure

27. What is your child's primary mode of communication?
   - Speech
   - Sign language
   - Augmentative and alternative communication (AAC)
   - Primarily nonverbal
   - Other: ________________________________

28. How important do you consider reading to/with young children to be?
   - Extremely important
   - Very important
   - Moderately important
   - Slightly important
   - Not at all important
29. How often do you/did you read to your child while they were ages 0-5?
   - Once a month or less
   - Less often than once a week
   - Once a week
   - 2 to 5 times a week
   - More than 5 times a week
   - Not applicable

30. How would you rate your child's reading skills compared to other typically developing individuals of the same age?
   - Strong
   - Average
   - Poor
   - No reading skills
   - Unsure

31. How would you rate your child’s overall language ability compared to that of other children their age with Down syndrome?
   - Strong
   - Average
   - Poor
   - No language skills
   - Unsure

32. Some of the following questions ask about receptive/comprehension skills, while others ask about expressive/production abilities. For questions that target expressive/production abilities, this can include speech, with sign language, or with an AAC. Please answer the following questions:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes, very well</th>
<th>Somewhat</th>
<th>No, not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can your child recite the alphabet?</td>
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<tr>
<td>Can your child identify single, written letters?</td>
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<td></td>
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<tr>
<td>Does your child know sounds of letters?</td>
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<tr>
<td>Can your child read single, written words?</td>
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<tr>
<td>Can your child read new/unfamiliar words?</td>
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<tr>
<td>Does your child read basic picture books or simple stories?</td>
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<tr>
<td>Would you describe your child as a reader?</td>
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<td></td>
</tr>
</tbody>
</table>
33. How old was your child when the following speech and language milestones were met?

<table>
<thead>
<tr>
<th>Does not have these skills</th>
<th>0-5 months</th>
<th>6-12 months</th>
<th>13-17 months</th>
<th>18-23 months</th>
<th>2-3 years</th>
<th>4-5 years</th>
<th>6-8 years</th>
<th>9-10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moves eyes or head in direction of sound</td>
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<tr>
<td>Babbles using speech like sounds</td>
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<tr>
<td>Understand words for common items like “cup” or “juice”</td>
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<td></td>
<td></td>
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<tr>
<td>Points to pictures in a book when named</td>
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<td></td>
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<tr>
<td>Names some letters and numbers</td>
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<tr>
<td>Understand “why” questions</td>
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<td></td>
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<td></td>
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<tr>
<td>Understand &quot;when&quot; and &quot;how&quot; questions</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Use of conjunctions &quot;when,&quot; &quot;so,&quot; &quot;because,&quot; and &quot;if&quot;</td>
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</tbody>
</table>
34. Without using an outside reference, please select the items from the following list that you believe can harm the hearing system and/or weaken hearing:
   o Large amounts of ear wax
   o Aspirin in small doses
   o Having no visible ear wax
   o Using cotton swabs
   o Certain antibiotics
   o Ibuprofen or naproxen
   o Having some ear wax
   o Malformation of the Ear
   o Antihistamines

35. Without using an outside reference, please select the items from the following list that you believe can indicate a hearing loss:
   o Tugging on the ears
   o Louder speech
   o Softer speech
   o Low energy
   o Having a history of ear infection(s)
   o Articulation difficulty and disorders (difficulty speaking as clearly as those of the same age)
   o Displaying slow or delayed responses to verbal stimuli
   o Watching television at a low volume