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THE ROLE OF SIBLINGS IN THE HABILITATION OF FAMILES WITH CHIDLREN WHO ARE DEAF OR HARD-OF-HEARING

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An Independent Study
submitted in partial fulfillment of the requirements for
the degree of:

Master of Science in Deaf Education

Washington University School of Medicine
Program in Audiology and Communication Sciences

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Abstract:
Siblings play a vital role in the health of a family as they adjust to having a child who is deaf or hard-of-hearing. In this project, a series of workshops has been designed for the siblings of children with a hearing loss to help better understand hearing loss and foster healthy sibling relationships.

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Epigraph

"Whether one celebrates or denies the sibling bond – as long as one has a brother or sister alive, there is always another human being who has known one as a child, who has experienced one in a unique and intimate way over which one has had little control, who has been a mirror, however distorted, of one's childhood and youth – someone, in short who has been a child of, and has shared the same parents."

(Bank and Kahn, 1982)

"Siblings have a powerful influence on the lives of their brothers and sisters through having longitudinal, physical, and emotional contact at critical stages throughout their lives."

(Gallagher and Powell, 1993)

Siblings have long been a population with whom little research has been done. The introduction of a disability into a family can touch the lives of everyone involved. With a hearing loss, a child can have delayed development in the areas of language and communication. Those factors coupled with minimal interaction may have detrimental affects on sibling relationships. Based on a need for family based intervention involving siblings, this project developed a fun, child-friendly workshop for siblings of children who are deaf or hard of hearing. *The Shared Experience* was developed to educate non-disabled siblings on the hearing loss of their brother or sister in the hopes of fostering healthy sibling relationships. The workshop series gives siblings the tools needed to play a role in the life of their brother or sister with hearing loss. It is also the hope of the workshop for parents to gain tools to foster those relationships within the household. Overall, *The Shared Experience* will help families to strategically overcome the stress on personal relationships that can be caused by the hearing loss.

The Roles Siblings and Families Play

In order to affectively examine the role siblings play in families with children who are deaf or hard of hearing, the family structure must be understood. Carpenter (1998) discussed "The stereotyped notion of 'the family' – two married parents of the opposite sex, with two children, who rely on only the father's income – is the reality for an ever decreasing number of families." In this statement, the typical family structure in the United States is appraised. Historically, the concept of family fit the mold as described by Carpenter. The author's most accurate assessment is that this model is dwindling in the current age. The dynamic of the family structure is changing at its very core. Roles are being reassigned and family members are taking on very untraditional roles. The model of the family takes another shift when a child with a

disability enters the picture. According to Carpenter (1998), when a child with any disability or special need comes into a family, the need of a healthy and effective family becomes vital. In the traditional model of a family, the children are nurtured and play a role in the family unit. Yet when a child with a disability is introduced to a family, those roles will then shift in order to nurture the children and address the disability. When a family member has a disability, certain factors aren't present that can be present in the typical family unit. The lines of communication, which are vital to a healthy relationship, may be severely impaired due to added stress and confusion. Lack of financial resources can also be a factor due to the increase in medical needs that may come with a disability. In 1996, Carpenter introduced a very interesting model of how families change when a disability invades.

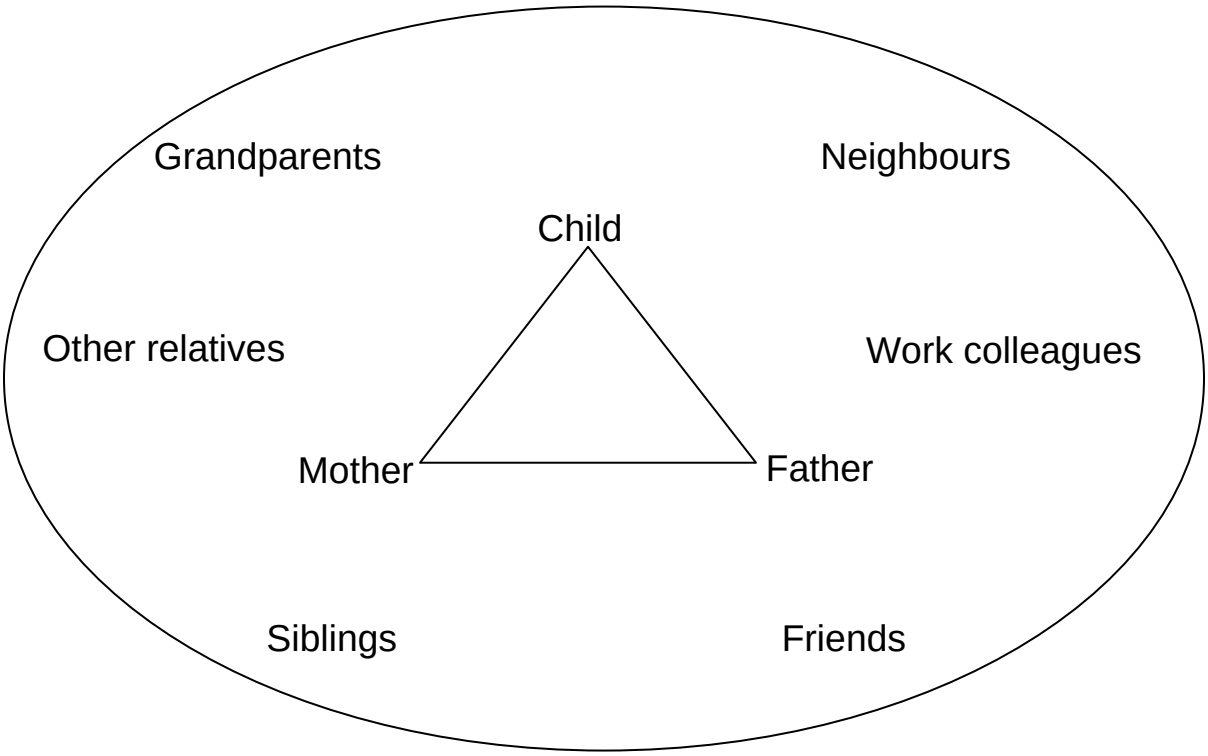

Table 1. The family infrastructure. (Carpenter, 1998)

The previous graph developed by Carpenter (1998), examines the structure of extended family and how it applies to a family with a child with a disability. At the core of the structure are the child and her parents. They are then encompassed by all the people in their lives that may also influence the family. Traditionally these people may play a small role but that role can be amplified by the effects of the disability. The pyramid in the middle can be representative of the disability in that it connects the child and parents, but there is also a network of people that can also be in the realm of the disability. The siblings of these children are affected by the disability. "The adjustment of siblings who have a brother or sister with a severe disability is therefore important in optimizing family interactions" (Opperman, 2003). Opperman and Alant offered insight into the adjustment of siblings and how important it is for all the parts of a family to be functional in order to support the child and her disability. The purpose of this project is to examine the role siblings play and find ways to better foster healthy relationships despite the disability.

Luterman (1991) compared the family structure to a fine tuned network in saying "One part of the system cannot be altered without every other part being affected". This sentiment is vital to understanding how a disability, such as hearing loss, impacts to a family. Hearing loss has the ability to severely disjoin the family network. Families and the family structures discussed previously can be compromised by hearing loss. Opperman and Alant (2003) best describe that raising a child with a disability places challenges on the whole family. The disability can affect more than just the child and her parents; the extended family network can also be affected. The whole family must be willing to cope and adjust before the situation can be deemed healthy. A family must have the ability to work through their stages of grief to give the child the support needed. Hearing loss affects a family on many levels. Parents are often on the

front line of their battle in coping with the hearing loss. Luterman (1991) suggests that hearing loss can even affect the parenting process, “The deafness forces you to be more aware of the parenting process and the ramifications of each decision you make”. With this statement, Luterman exemplifies the weight put on the shoulders of parents when their child has a disability. They must go beyond the natural parenting process and bear more responsibility than they are often prepared for. The stress and emotions that can be felt by parents in their stage of grief can trickle down to the other parts of the network, similar to a chain reaction. Parents want to develop a certain locus of control over their lives and their family situation. However, the disability can unravel that plan and leave families trying to pick up the pieces of their lives. On the contrary, there can be immense hope in having a child with a disability because it can allow one the opportunity to celebrate the small victories that can be traditionally taken for granted. Another interesting area that has been considered in previous research is the socioeconomic status of families and how that may play a role in the family’s adaptation to the disability. Opperman and Alant (2003) found that families from a higher socioeconomic status have better access to health care and services to help the family to adjust to problems as they emerge. It was also found that socioeconomic status can affect the siblings as well. The siblings from the lower socioeconomic group can feel overloaded in taking on more care-giving responsibilities. That overextension of responsibility can lead to further emotional ramifications.

Beyond the adaptations that families have to make physically and financially, the emotional aspects of hearing loss can be the toughest hurdle for a family to overcome. The need for more doctor visits can immediately affect a family financially, yet the emotional burden of a family can have long ranged implications for the emotional health of the family. Ray (2002) stated, “Across studies, parents have demonstrated consistent concerns that siblings are ‘lost in

the shuffle". With this parents are addressing the concerns they have for the "healthy" children in their family. When a child identified with a hearing loss comes into the picture, initial audiologic appointments can be followed by a constant stream of other medical and specialist appointments. With that busy shuffle, the other children in the family can be left feeling vulnerable and alone. It can be hypothesized that medical professionals are only concerned with the patient and do not consider the greater impact of the disability on the family. Ray also found that siblings copy the emotions of the parent in worrying because it is the priority of the family. The health and well-being of the child with a hearing loss is at the forefront for the family, then siblings may emulate what they see in their parents. More often than not, the emotional impact associated with the hearing loss can carry more burden than the disability itself. All of the family's attention is on the child with hearing loss, so siblings can bear the burden in order to feel a part of the family. In some families, the parents choose to split themselves between the hearing child (or children) and the child with hearing loss. This is done with the premise that each part is receiving their due attention. Inversely, this can deepen the trench between the two parties. In the midst of trying to pull all the factors together, parents are also dealing with their own string of emotions. The stages of grief are individualized and progression is highly reliant on the reality the individual perceives. Adjustment to a hearing loss is not an easy road for all parties involved thus creating a need for intervention that is individualized based on the entire family unit.

"Family-centered approaches are widely recognized internationally as the most ecologically appropriate way of working with families of children with disabilities. Pivotal in this approach is its focus upon the needs of the whole family, rather than only the needs of the child (with a disability)" (Carpenter, 1998). This statement confirms the need for there to be a family based intervention system. Many departments of education across the country have

deemed family based intervention as best practice with regards to service delivery for families with children with disabilities. In family based intervention, the whole family plays a role. Giving each member of the family an even amount of responsibility can leverage the burden on any one person. Each person will have their part in the success of the child. By providing intervention services to the whole family, each member is more likely to maintain their personal dignity and feel a part of the family unit. Family-based intervention can create an open channel of communication that is vital to maintaining a healthy family network. Luterman (1991) states that for an optimally functioning family, "communication among family members is clear and direct". With this, Luterman defends the need for families to have clearly stated expectations and responsibilities. By doing this, each member is responsible and accountable for their own feelings. With direct communication, families are better able to communicate when a part of the network is awry. With a complete analysis of the family structure and of the role hearing loss plays, we will begin our examination of the importance of siblings.

The Need for Siblings Intervention

Siblings play a pivotal role in families with both hearing loss and normal hearing children. According to Lobato, Cao, and Plante (2006), children can often spend more time with their siblings in their lifetime than their parents. Additionally, the diagnosis of a disability can inversely affect the siblings as much as any other family member. These statements are justification of the need for there to be sibling intervention to help siblings cope and adapt to the changes that will happen in their lives. Many sources have stated the inattention to siblings of children, across all disabilities. Hearing loss greatly impacts the development of a child's communication and language skills. These skills are most critical when developing relationships and communicative interactions with loved ones.

Meyer (1997) listed common complaints of siblings when they have a brother or sister with a communication disorder. Siblings cite a lack of "information about their brother or sister's condition and that they experience extra child-care and household responsibilities, differential treatment, embarrassment, isolation from their peers, and disruptions in family activities due to their brother or sister's special needs". This is a small but concise list of the struggles that may arise when a communication disorder is present, similar to that of children with hearing loss. Siblings can feel left in the dark because they are never told the true problem of their brother or sister, thus not understanding the reaction of other family members. As previously stated, the emotions of other family members can be transferred to siblings, which can be intensified when the child is unaware of the cause of the stress. The additional responsibilities and differential treatment can be linked to the redirection of parents' attention. The hearing loss can become the core of the family's attention; consequently, the child with normal hearing can feel left out. All the attention is on their brother or sister and the sibling can feel as thought her needs aren't being met. The feelings of embarrassment and isolation were of particular concern for this project. Those emotions can come from feeling as though they were the only one with a sibling that is "different". A hearing loss can often manifest into a visible difference with hearing aids and cochlear implants. Hearing loss is a low incidence disability, so many children are unaware of its existence. Siblings can feel discomfort with the different appearance of their brother or sister but they can also feel as they are the only ones who have these feelings. Siblings' exploration of these feelings will be further discussed in the workshop design. Siblings may also feel frustrated when the typical family activities are interrupted by the management hearing loss. Those feelings can manifest into resentment and blame to the sibling for the disrupted family atmosphere.

Opperman and Alant (2003) did a study measuring the coping response of adolescent siblings of children with severe disabilities. The guiding objectives of the study were to determine the siblings understanding of the stressor of having a sibling with a disability and to identify the coping resources available to the siblings. The subjects included 19 siblings from South Africa who had a brother or sister with a disability. Both parents and the nondisabled siblings were interviewed. First the study examined the subjects' understanding of the repercussions of having a sibling with a disability. Overall feelings about the disability, the effects of the disability on family interactions, and the perception of other's understanding about the disability were examined. Regarding the overall feelings about the disability, there was an overwhelming (47%) response of ambivalence toward the disability. This doesn't necessarily mean that the respondents didn't care; this was considered "a mode of coping that adolescents use to work through their emotions regarding the issue". So becoming detached from the situation may be the best way for siblings to deal with the stress induced by the disability. These feelings of detachment also carried over into the siblings' feelings about family interactions. The table below displays the subjects' feeling about family interactions.

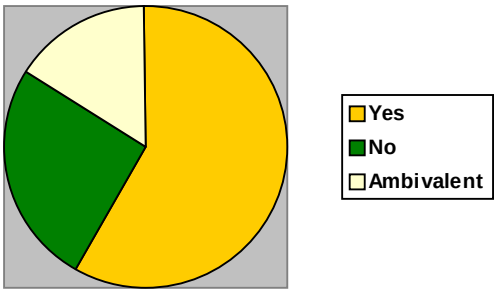

Table 2. The subject has unexpressed feelings with regard to have a sibling with a disability (Opperman & Alant, 2003)

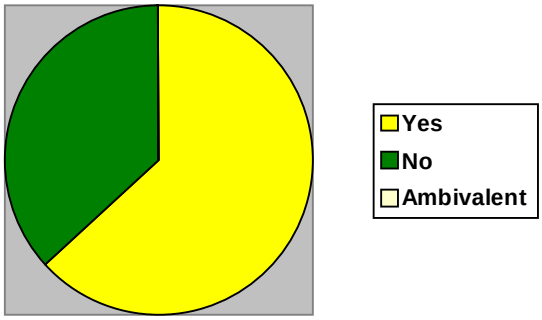

Table 3. The subject admits to not participating in family activities and preferring to do things of his/her own. (Opperman & Alant, 2003)

Subjects report the ability to interact with their disabled brother or sister in an unrestricted way. In comparison, the subjects also acknowledged a want to do activities independently instead of with the family. This can also be symptomatic of coping with the stress of having a sibling with a disability by becoming detached from family interactions.

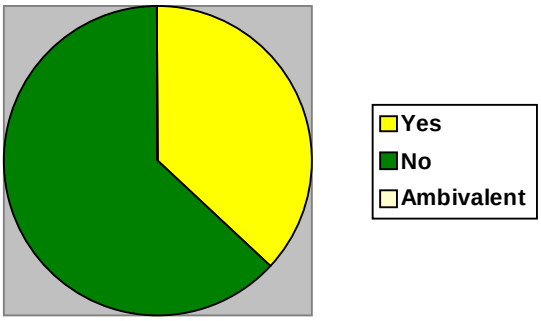

Table 4. The subject is dissatisfied with the amount of care-giving responsibilities he/she has, regarding the sibling with disability. (Opperman & Alant, 2003)

Overall, the subjects' feelings of accepted self-sacrifice in their responses to the additional responsibility required of the disability. That sentiment can be evidence of a bond between the siblings. Finally, the study examined how the subjects thought others reacted to their brother or sister. 84% of the subjects stated that they believe that others did not know how to act in the presence of their disabled sibling. With that, 89% admitted acceptance of their brother or sister without prejudice. This speaks highly on the sibling relationship that was built despite the stress. These findings indicate that relationships are built, but coping responses need further development in order to lessen the withdrawal factor previously described.

Sibling involvement in therapy is vital to developing pure and healthy relationships. Lobato, Kao, and Plante (2006) reflected on two scenarios of families and how siblings were treated during therapy in the home. One family allowed the siblings to join the therapy session and help the therapist. Meanwhile, the mother sat in a place to observe this in order to be able to recreate the activity. The authors regaled on the pride in the eyes of the siblings to show off the things they learned to help their brother. On the other hand, the authors also described the situation where the mother set up a therapy area in the living room. The mother closed the other siblings in another room and scolded them for peeking into the living room. Lobato determined that the mother's response was in denial that the disabled child is different. The siblings were only able to come out once the therapist was gone. This created a large divide within the family. In the first situation, the mother created an environment where all the members of the family played a role and then allowed the non-disabled siblings to be proud of a talent or skill. The second mother created a negative stigma toward the therapy by blocking the siblings out of the session. It was these scenarios that led the authors of the article to create a workshop to help siblings become more important in the lives of their brother or sister with a disability. The same sentiment was considered in the creation of this project.

***A Shared Experience*: The Workshop**

"A consistent theme in the literature is the importance of social supports for siblings. Social supports may be one of the most important factors in buffering the effects of potentially stressful situations… Therefore, it is expected that the role of support groups should be helpful to siblings in order to address their own needs." This statement by D'Arcy et. al. best illustrates the need for sibling support. As stated previously, it is not the disability that can create stress but the life and family alterations which lead to stress. The overall rationale of this project is to develop

a support program for siblings of children who are deaf or hard of hearing. It is the ambition of this project to give siblings the knowledge to understand hearing loss, coping strategies to assure them that they are not alone, motivation to know they can be a part of their brother or sister's life, and the encouragement to foster and build healthy sibling relationships.

The design for *A Shared Experience* was based on the SibShop program developed by Donald Meyer. The SibShop program was initially developed in 1985. According to the book, "***Sibshops: Workshops for Siblings of Children with Special Needs*"**,

> *"Sibshops are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so good thing, and for many somewhere in between. They reflect a belief that brothers and sisters have much to offer one another--if they are given a chance."*

SibShops provide siblings with a place to share their feelings and be surrounded by children with similar needs and feelings. Meyer designed SibShops on the premise of servicing an underserved population. First implemented in 1990, SibShops assisted siblings of children with varying disabilities. It was designed for siblings age eight to thirteen and was conducted as a two to three hour workshop. Meyer, Vadasy, and Fewell first developed the program based on five guiding goals. The goals include:

- Goal 1: Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.
- Goal 2: Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

- Goal 3: Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.
- Goal 4: Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.
- Goal 5: Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

With the first two goals, Meyer aimed to inform siblings they are not alone in their feelings, including fears of having a brother or sister with a disability. In SibShops, siblings are encouraged to become comfortable in the beginning with the hopes they will share their feelings with the group. Goal 3 was based on the first two. In interacting with their peers, the siblings will inevitably share how they cope with the stressors of having a sibling with a disability. This can give siblings new and fresh techniques to use when faced with challenges. The educational part of the workshop is encompassed in Goal 4. In order to better understand the life of their brother or sister, siblings must understand the disability. Knowledge of the disability may give the sibling a better understanding of what is happening in her brother or sister’s body or mind. Goal 5, on enriching family interactions, is the most important in the impact of SibShops. This is an outlet for siblings and an informational session for parents. Parents are allowed to see what affects the disability has had on the family, while receiving tips on how to improve the family environment.

The SibShop design was later implemented byD’Arcy et. al. in Cork, Ireland. The curriculum was evaluated to examine if the program was true to its guiding goals. The study also examined the effectiveness of the SibShops on sibling relationships. The participants were given

an initial survey to determine the baseline understanding of sibling relationships. Prior to the workshop, the participants were unsure about meeting other children with disabled siblings and uncomfortable talking about their siblings or disability. After the workshop was condcted, a second survey was sent to assess the effectiveness of the workshop. 56% of the siblings rated that they enjoyed meeting other children with siblings with disabilities (D'Arcy, 2005). This percentage is in comparison to the 43.8% of participants that were unsure of wanting to meet other siblings like themselves. The authors reported that participants began the workshop with sentiments of not wanting to play with their sibling because they did not know how to interact with them due to their disability. When asked again in the post-workshop interview, those same participants were excited to go home and become more active in their sibling's life. The participants also expressed a better understanding of the how the disability will affect the sibling's life. (ex. "It might take her longer to read and write.") 14 of the 16 participants reported that they enjoyed the SibShop and what they gained from it (D'Arcy 2005). In addition to the siblings' feedback, parent feedback was also considered. The parents served as a litmus test of whether or not attending SibShops improved interaction. Across all the participants' parents, they rated the effectiveness very high. Many of the parents believed the workshop heightened the personal interactions between their children.

Inspired by this evidence *A Shared Experience* was developed to directly address the needs of siblings of children with hearing loss. The target audience for this experience is children ages five to ten years old. Parents are very encouraged to stay with their child during each part of the workshop to gain insight as to the feelings of their children. In this way, the hearing siblings and parents will feel more confident in their ability to play and facilitate an active family life. In order to advertise the workshop, the *Informational Letter* can be sent home to the families (see

Appendix A). This form outlines the course of the workshop series, and facilitators of the workshop can insert their dates into the attached template. The *Shared Experience* is organized as follows: (To obtain an individual workshop schedule, see Appendix B)

Deaf?! Ear?!: How the ear works and things that can cause hearing loss

Deaf?! Ear?!: How the ear works and things that can cause hearing loss is the introductory workshop in the *Shared Experience* series. This workshop was designed to give the children a comprehensive look at the ear, hearing system, and how hearing loss impacts a normal hearing system. This workshop is vital to the hearing sibling's understanding of what is happening to her brother or sister with hearing loss. As stated previously, it is believed that with a clear understanding of hearing loss, the siblings will not be so hesitant to become active in their brother or sister's life. The workshop will begin with an ice breaker to get the group acquainted and to make the children comfortable. The ice breaker can be chosen from a list of ice breakers in Appendix I. Once rapport is built, the workshop will move onto explaining the parts of the ear. The recommended visual aid for this part of the workshop is "The Ear", a poster published by Super Duper Publications. The workshop facilitator will name all the parts of the ear illustrated on the poster. The facilitator will briefly talk about the function and purpose of each part of the ear. The facilitator will use the visual aid to assist in this explanation. After the facilitator completes her explanation, the participants will watch a video to further discuss the parts and functions of the ear. The video, on hearing, is produced in the Study Jams series from Scholastic. (See Appendix C for the link to the video.) The video was chosen because it explains all the parts and functions of the ear in a very practical way, while remaining child-friendly. The kinesthetic portion of this workshop will be acting out the parts and functions of the ear. For instructions on how to facilitate this activity, refer to Appendix C.

The first half of the workshop is dedicated to understanding the functions of a healthy ear so that the participants can understand "healthy hearing" and how one hears. The second half covers what happens to the healthy functioning ear when a child has a hearing loss. Then the facilitator will discuss that things can happen that may cause the ear not to function correctly. Potential ramifications, such as impact on listening and language, caused by a hearing loss will also be discussed. This is important for the participants to understand that a hearing loss can effect more than how a person hears. Hearing loss can effect speech, language, and balance as well. (See Appendix C for a complete list of discussion topics and assistive technologies.) The final portion of the first workshop will talk about the technologies used to help people with a hearing loss hear. Hearing aids, cochlear implants, bone conduction aids, and FM systems will be discussed. If available, the facilitator may bring in examples of the technologies discussed. Finally, the workshop will conclude with a review of all the topics discussed and time for any questions. A snack could be provided if available.

What about me?!: What having a sibling with a hearing loss means to a child

The second workshop is designed to allow participants to highlight their talents and skills. This workshop focuses on self-discovery, allowing the participants to display their talents. The workshop will begin, as do all the sessions, with an ice breaker. Refer to Appendix I for a complete list of suggested ice breakers. Following the ice breaker, the group will play "The Web" game. This game is adapted from the SibShops manual by Don Meyer. The Web is a game where the participants will sit in a circle and build a web of yarn based on personal information. The facilitator starts with a ball of yarn. She will ask a question (ex. What is your favorite color?), she will answer the question and holding the beginning of the yarn, she will throw the ball to a person across the circle. The next person will answer the question, and holding onto the

next part of the yarn, will throw it to another person across the circle. This activity was chosen because it will be a visual representation of the many ways people can be connected. The next activity is called “Hog Call”. With this game, the participants will be given a name or an object. Every object will have one match amongst the group. The children will not know who their match is. The object of the game is to find their match blindfolded and by shouting out the object they were given (ex. peanut butter will be matched to jelly). This activity was chosen because it forces children to utilize different modes of communication to achieve the goal. At the next workshop, it will be used to show that different ways to communicate are important when they have a sibling with a hearing loss. The final activity of this workshop will be talking about strengths and weaknesses. Strengths and weaknesses activities are also adapted from the SibShop manual by Meyer. The focus of this activity for the participants is to reflect on the things that they do well and some things that challenge them. First, there will be a discussion of the definition of strengths and weaknesses. Then, the group will fill out the portion of the worksheet describing their weaknesses and strengths. The participants will have an opportunity to share their responses with each other. The portion about their sibling’s strengths and weaknesses will be saved for the next session. This workshop will conclude with a time for questions and a snack.

I can help!: What I can do for my brother/sister?

This third workshop in the series pulls together discussion topics from all the previous workshops. Siblings learn strategies to help them become more involved in the life of their brother or sister with hearing loss. Once again, the participants will begin with an ice breaker. The ice breakers are used to get the group comfortable with one another. The first discussion point will be on the importance of good communication. The group will review the effects that a hearing loss may have on communication. Strategies for good communication will be discussed

so that the siblings understand the communication needs of their brother or sister with hearing loss. The recommended visual aid is “Good Communication Skills”, published by Super Duper Publications. (For purchasing information, refer to Appendix E.) This aid is recommended because it explains the important characteristics of both an effective talker and listener. The workshop facilitator will connect the communication strategies on the poster to their importance when communicating with a child with hearing loss. The group will then play a game of “telephone” to further exemplify the importance of good communication. After a brief break, the group will return and read “*I Have a Sister--My Sister Is Deaf*” by Jeanne Whitehouse Peterson and Deborah Kogan Raya. This is the story of a young girl who has a sister with hearing loss. Following our story, the group will discuss what having a brother or sister with a hearing loss means to their family and how this can really become a special adventure. The strengths and weaknesses sheets, from the previous workshop, will be returned to the participants. The workshop facilitator will summarize the strengths and weakness that many people face. Participants will fill out the portion that discusses the perceived strengths and weaknesses of their sibling with hearing loss. Next, the facilitator will discuss how important it is for siblings to share their talents with their brother or sister. Becoming involved in language therapy sessions with the siblings is important and the sibling with normal hearing will be encouraged to do so. The final portion of the workshop will talk about what the sibling wants to share with her brother or sister with hearing loss. Craft supplies will be distributed to the group and the assignment will be to draw a picture of something that the participants want to share with their sibling. Once all the participants have completed their drawings, the group will come together to share. Before concluding the workshop, the facilitator will review the effects of hearing loss and how

important it is for the siblings to become active in the lives of the brothers and sister. Time for questions and a snack will conclude this final small group session.

Let's Celebrate!: A gathering of families with a shared experience

This is the final workshop in the series. *Let's Celebrate* is designed for all participating families to come together to have a picnic with the entire family. To begin the workshop, the families will be given art supplies. Each family will be instructed to make a poster, including the names of everyone in the family and special things that the family share (ex. family activities, pets, etc.). Once all the posters are completed, the families will take turns presenting their family poster to the group. All of the participants will be given certificates of participation for their work during the workshop series. A picnic lunch and time for the families to talk and network will follow. Workshop evaluations will also be distributed at that time.

Closing Thoughts

The purpose of this project was to develop a child-friendly workshop series to address the stressors and challenges that may arise in families having a child with hearing loss, including coping strategies to overcome such stress. There is little research related to needs and issues associated to the siblings of children with hearing loss. Research indicates the need for family-based intervention, including direct sibling intervention as well. Giving siblings appropriate avenues to discuss their feelings may prove to be quite valuable. A *Shared Experience* was carefully designed to educate siblings on hearing loss, motivate siblings to become active in communicating with their brother and sister, and foster healthy sibling relationships. The activities in the series are an effective blend of physical activities and group discussion. Recommendations for further study would be the implementation and evaluation of *A Shared Experience*. It would be interesting to examine the effectiveness of the workshops in the altering

of family interactions. Further research could also examine the comparative effectiveness of *A Shared Experience* and other sibling-based intervention programs for siblings of children with other low incidence disabilities. It is the final hope of this project to open the door for more research on important members of a family that have historically been overlooked.

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Appendix A:
Informational Letter

Dear Parents:

I will be hosting workshops for siblings of children with hearing loss. The workshops are geared toward siblings that are between 5-10 years of age. In the workshops, we will discuss topics related to hearing loss. The discussions are outlined below:

Part I: **Deaf?! Ear?!**: How the ear works and things that cause hearing loss.

As an introduction, we will talk about how the ear works. We will participate in child-friendly activities for siblings to better understand the many parts of the ear and how it functions. Finally, we will discuss the many causes of hearing loss as well as technologies that assist children with hearing loss.

Part II: **What about me?!**: What having a sibling with a hearing loss means to a child. What role do hearing siblings play in the life of a child with hearing loss?

In this portion, we will discuss common feelings that siblings may experience when their brother/sister is different from themselves and other children. Following our icebreakers and activities, we will discuss what having a brother/sister with a hearing loss means to a family and how this can really become a special adventure. Discussing strengths and weaknesses will also be a huge part of our workshop.

Part III: **I can help!**: What I can do for my brother/sister?

Research has shown that stronger sibling relationships are formed when siblings play an active role in the lives of children with disabilities. In this part of our program, we will talk about ways for siblings to become an active participant in helping their sibling learn to listen and communicate. Tips and strategies will be discussed for the siblings to implement in order to become more active in the life of their brother or sister.

Part IV: **Let's Celebrate!!**

In this final portion of our workshop series, we will have a picnic for all the families enrolled in the workshops. Families will have this time to interact and share similar experiences. This can serve as networking opportunity for both parents and children. This workshop will begin with all the families making a poster about the members of their family. Everyone will share their posters before our lunch begins. So bring your favorite picnic lunch and drink for your family.

Sincerely,

Lyndsey Jalvia

"A Shared Experience"
Saturday Workshops

☐ My family will participate in all four workshops. Please list the participants' names and ages below.

_____

_____

☐My family will only participate in some workshops. Please check those you will attend. Please list the participants' names and ages below.

____ Part I: **Deaf?! Ear?!**

____ Part II: **What about me?!**

____ Part III: **I can help!**

____ Part IV: **Let's Celebrate!!**

_____

_____

Parent or caregiver's name who will be accompanying the children to the workshop:

_____

We ask that no children with hearing loss be brought to the workshop.

Please return this sheet in your child's backpack to school. The teacher will then forward it to me. I look forward to spending time with your family.

Appendix B:
Workshop Schedules

Deaf?! Ear?!: How the ear works and things that can cause hearing loss

10:00- 10:15 Arrival and Registration

10:15- 10:30 Ice Breaker

10:30- 11:00 Parts of the Ear and Scholastic Video

11:00- 11:05 Break

11:05- 11:20 Act out the parts of the ear

11:20- 11:35 Affects of Hearing Loss

11:35- 11:50 Assistive Technologies

11:50- 12:00 Questions and Snack

What about me?!: What having a sibling who has a hearing loss means to a child

10:00- 10:15 Arrival and Registration

10:15- 10:30 Ice Breaker

10:30- 11:00 Web Game

11:00- 11:05 Break

11:05- 11:30 Hog Call

11:30- 11:50 Strengths and Weaknesses

11:50- 12:00 Questions and Snack

I Can Help!: What I can do for my brother/sister

10:00- 10:15 Arrival and Registration

10:15- 10:30 Ice Breaker

10:30- 11:00 Importance of good communication/ Good communication skills (telephone game)

11:00- 11:05 Break

11:05- 11:15 "*I have a sister, My sister is deaf*", read book and discussion

11:15- 11:35 Strengths and Weaknesses

11:35- 11:50 "What I want to share with my brother or sister."

11:50- 12:00 Questions and Snack

Let’s Celebrate!: A gathering of families with a shared experience

10:00- 10:15 Arrival and Registration

10:15- 10:45 Making the family posters

10:45- 11:00 Poster share

11:00- Picnic

Appendix C:
Lesson Plan and Supplemental Materials for Part I
Deaf?! Ear?!

This workshop is really an introduction to hearing loss and the ear. Begin with an icebreaker to get the group acquainted and comfortable. Choose an activity from the suggested list or incorporate your own. Next, the discussion of the parts of the ear will begin. There are many parts of this workshop that may be difficult for the participants so it may be easier to break them up into smaller groups. Use the talking points below to describe the parts of the ear as you point to the parts on the poster. The poster can be posted on the wall or held. Once the discussion has ended, ensure that there are no questions. If none, play the video on hearing. The link for the video can be found below.

After the break, the children will get the opportunity to act out the parts of the ear. Depending on the size of the group, it might be necessary to break into small groups so everyone has the chance to participate. See instructions below for each of the roles. Again, ask if there are any questions and explain this is how a healthy ear works. Next move onto the ways that a hearing loss can affect the functions of a healthy ear. See the talking points below for topics to lead the discussion. Always leave the floor open for questions and comments from the participants. Assistive technologies are the final part of this discussion. After talking about all this things that can happen to a healthy ear, it is important to also discuss what is available to help people with a hearing loss. It is very helpful to show each of these devices if examples are available to children with a hearing. The talking points below may help in describing all the available technologies. End the workshop with time for any questions that they parents or participants might have. If there are no questions, the snack can begin.

Parts of the Ear: These descriptions are to be used in conjunction with “The Ear” poster

-Sound travels like waves in the air.

- Auricle (ear lobe): collects and funnels sound into your canal
- Auditory (Ear canal) canal: carries the sound to your ear drum
- Ear drum: when the sound waves reach the ear drum, they lightly beat it like a real drum. When sounds hit the ear drum, it begins to move.
- Hammer, anvil, and stirrup: These are the three smallest bones in your body. They are all connected to each other. When the ear drum moves, the bones begin to move. When the bones move, they help to carry the sound closer to the brain.
- Oval window: a small hole that sends the sound waves into the inner parts of your ear.
- Cochlea: this looks like a snail. It is the organ that helps you to hear. Inside the cochlea are tiny hairs and some fluid. When the sound travels through the cochlea, all the tiny hairs begin to move. Those hairs figure out what sound you are hearing.

- Auditory nerve: This is the final step in the life of a sound wave. The auditory nerve takes the sound that began outside your ear, and brings it to the brain. The brain then knows what sound you just heard.

Scholastic Hearing Video

http://www.youtube.com/watch?v=CSO765hyxrc

Acting out the parts of the ear

-Sound travels in waves: One child will make a sound (an elephant, guitar, etc). The children will have a pool noodle as the sound wave.

- Auricle (ear lobe): This child will take the noodle and push it into the ear drum (child)

- Ear drum: this child will have a drum and bang it when he is hit by the sound wave.

- Hammer, anvil, and stirrup: These three children will move in a domino effect. The hammer will bump the anvil, and the anvil will bump the stirrup. Meanwhile, the children will be passing the noodle down the chain.

- Cochlea: this child will be curled up on the floor. Then will move his fingers when he is bumped by the stirrup, simulating the hairs moving.

- Auditory nerve: This is the final step in the life of a sound wave. This child will take the noodle and tell the brain (child) the sound is coming.

- Brain: This child will shout out what the original sound was.

Affects of Hearing Loss Talking Points

- Hearing loss can affect more than just your ability to hear.
- Hearing loss can affect the way one speaks and communicates with the people around them.
- Hearing loss can make it really hard for the siblings to listen in noisy settings and crowded places.
- With a hearing loss, a child may have to go to the doctor more than the average child to make sure his ears are healthy and that he is hearing as well as he can with his device(s).
- Hearing loss can also have an impact on the balance of a child.
- Explain the ways the hearing loss can impact the natural interactions in a family.
    - Communication may be more strained and slower in order to make sure that the child with hearing loss understands the conversation.

- There will be times when your sibling has to have therapy that is one-on-one. Don't let those times discourage you from playing at other times.

Assistive Technologies Talking Points

- Hearing Aids- hearing aids amplify sounds. A hearing aid can make sounds louder for the listener.
- Cochlear Implants- This is a device implanted via surgery. It takes sound waves and changes them into electronic impulses that go directly to the brain. There is a part inside the head and a magnet on the outside of the head.
- Bone Conduction Aids- This aid is placed on the bone behind your ear. It uses sound waves to vibrate an external part and help children to hear. Put your fingers in your ears. Now let me hold this to your forehead. Listen!
- FM Systems- FM systems are used to help children hear in noisy settings. It helps to filter the sound you don't want to hear and amplify the sounds you do (i.e. the teacher's voice in a classroom).
- Explain the parts and what all these things do
    - for each device talk about the parts that are specific to them.
- If samples are available to you, they would be a good tangible example for the children.

Appendix D:
Lesson Plan and Supplemental Materials for Part II
What About Me?!

This second workshop was designed to be a time of self discovery and exploration for the participants. It is a workshop that really centers on just having fun. "What About Me?!" was sandwiched between the technical points in learning the ear and hearing loss and discussing ways to become involved so the participants are really able to learn things about themselves to better interact and help their siblings. Begin with an icebreaker to, again, get the group reacquainted and comfortable. Choose an activity from the suggested list or incorporate your own. After the break, the group will play "Hog Call". This game is a test of finding your match by only saying your person, place, or thing and listening for someone who might be your match. Due to the varying ages in the group, you might have to tell all the items and their matches before the game begins. This may ease game play. Once everyone has found their match, have each pair tell what they are. If there are mismatches, let the group try to sort it out on their own. The final discussion in this workshop is the most important in tying many points together. It is critical for the participants to understand their own strengths and weakness in order to relate to their sibling. Begin the discussion by talking about what strengths and weaknesses are. A graphic organizer can be used to better describe these two factors. The facilitator should use personal examples to demonstrate strengths and weaknesses. Next, have the participants come up with **ONE** of their own strengths and **ONE** weakness. This activity can be done and small groups and have them share their strengths and weaknesses with the members of their own group. At the end, have the children write their names and collect the papers for the next workshop. End the workshop with time for any questions that they parents or participants might have. If there are no questions, the snack can begin.

Web Game

This activity is meant to build relationships within the group. The group must sit on the floor in a circle. The facilitator starts with a ball of yarn. She will ask a question (ex. What is your favorite color?), she will answer the question and holding the beginning of the yarn, she will throw the ball to a person across the circle. The next person will answer the question, and holding onto the next part of the yarn, will throw it to another person across the circle. In all, the facilitator will ask 6 questions, thus, creating an intricate web with the yarn in the center of the circle. The facilitator will explain how the web, in the center of the circle, represents the many ways people can be connected. The web game should be done in the large group so the web can be large at the end. Web game was chosen to demonstrate that having a sibling with a hearing loss isn't the only thing that can connect the participants. Some may share the same favorite color or food as well. See the instructions below for further details. Begin with a simple question that everyone will be able to answer quickly. Then move onto a question that is a little more involved. Remind the participants to hold on tightly to the piece of yearn before throwing it to the next person. When there are no more questions or the yarn ends, discuss how everyone has something unique about themselves that can easily connect them to someone they didn't know before.

Hog Call

Clear the space to avoid any obstructions. The facilitator will write pairs on index cards (Batman and Robin, peanut butter and jelly, etc.). Each child will get one of each pair. The facilitator will give each child a bandana to cover his eyes. The objective of the game is for the child to yell out the word or person that they are in order to find their match. This game was chosen because it helps the children to realize how important their hearing is and how reliant they are on it.

Strengths and Weaknesses

See above for instructions and the next page for worksheet.

Strengths and Weaknesses

Everyone has strengths- these are things that we do well.

Everyone has weaknesses- these are things that we may have trouble doing.

One of my strengths:

_____

One of my weaknesses:

_____

One of my sibling's strengths:

_____

One of my sibling's weaknesses:

_____

Appendix E:
Lesson Plan and Supplemental Materials for Part III
I Can Help!

This is the final small group discussion workshop of the series. Begin with an icebreaker to, again, get the group reacquainted and comfortable. Choose an activity from the suggested list or incorporate your own. Knowing how to communicate with a person with hearing loss is the most important skill for the participants to gain. It is critical to stress the good communication skills. The visual aid can be posted or in the hands of the facilitator when it is being discussed. Use the talking points below as you point out the strategies on the poster. Once the good communication skills discussion is complete if there is extra time, a game of telephone can be played. Telephone can be substituted with role playing communication strategies. One child can be the talker and the other can be the listener. This will also be effective in communicating the strategies. If the group is large, they can be broken up into smaller groups. After the break, the book reading and discussion for "*I have a sister, My sister is deaf*". Read the book and emphasize the point where the hearing siblings is frustrated or expressing feelings about having a sister with a hearing loss. After reading the book, discuss what having a sibling with hearing loss can feel like. Assure the participants that their feelings are valid and expressing them can only help their interactions with their brother or sister. If it is helpful, you can write their responses on the board or on paper to help organize the discussion.

To begin the discussion on strengths and weaknesses, have the participants tell you what they remember from the previous workshop. You can also write these responses down as well. Hand back their papers from the last week and talk about the strengths and weaknesses the participants found in themselves. These discussions can also happen in smaller groups if needed. After reviewing, instruct the participants to think of **ONE** strength and **ONE** weakness of their sibling with a hearing loss. In thinking of the weakness, discuss with the participants things they can do to help their sibling with that weakness. Then talk what they can learn from their sibling's strength. End the discussion on a positive note and not talking about weaknesses. The final activity in this workshop will revolve around what the participants want to teach their brother or sister. Encourage the importance of playing with and teaching things to the sibling with hearing loss. Have the participants draw a picture of one thing they want to do with their sibling after the workshop. Once the pictures are complete, encourage everyone to share their pictures and what they want to do with their brother or sister. End the workshop with time for any questions that they parents or participants might have. If there are no questions, the snack can begin.

Good Communication Talking Points

- When talking to someone with a hearing loss, it is very important to have good communication skills to make sure the listener fully understands the entire message.
- Good communication skills including being a good listener and talker.
- When listening, it is important to look at the speaker, listen carefully, and ask a question when you don't understand what is being said.
- Sometimes, it is hard to understand the speech of someone with a hearing loss. You really need to listen carefully. Don't be afraid to ask a question to clarify something that you didn't understand.
- Being a good talker is as vital as being a good listener.
- When talking to a person with a hearing loss, remember to always speak clearly.

- Even if the person has a listening device, they still need you to speak clearly to make sure they receive the entire message.
- With a listening device, a person with a hearing loss does not need the talker to shout or speak loudly. Change your voice, pace your speech and talk clearly.

Telephone

This classic game best exemplifies what happens to a message after going through many different people and the message each person perceives. The facilitator will begin a message with the person to her left. The message will be whispered from person to person until it gets back to the facilitator. The final person to get the message will say it out loud.

Strengths & Weakness

Revisit this topic and have the participants share about their strengths and weaknesses. Explain that the siblings with hearing loss can have strengths and weaknesses just like them. It is important to recognize these things, so we can better understand how to interact with the siblings. The participants will list some of the strengths and weaknesses they perceive in their sibling. This can really connect to the fact that all people have things that they can and cannot do well. Considering all those things, we love and accept them for who they are.

What I want share with my brother or sister

We end the small group discussion part of the workshop series by talking about interactions with siblings with a hearing loss. The best thing you can do with your sibling with hearing loss is to play or talk with your sibling. Share some of who you are with them. Teach them your favorite trick or play with them and strong relationships will be built. Give the participants paper and art materials; instruct them to draw a picture of what they will share with their brother or sister (it can be a skill or a toy, etc.). The group will come together and share their drawings.

Appendix F:
Lesson Plan and Supplemental Materials for Part IV
Let's Celebrate

This workshop is the culmination of the entire four week workshop series. The families should all arrive at the regular starting time. We will not begin with an icebreaker for this workshop. Instead, begin by talking about the purpose of the workshop series (to give normal hearing siblings the knowledge to understand hearing loss, coping strategies to assure them they are not alone, motivation to know they can be a part of their brother or sister's life, and the encouragement to build and foster healthy sibling relationships). The first activity is for the families to make their posters. Encourage the families to include the names of the members and family information (favorite things to do together, favorite place to eat, special talents in the family). The families will be supplied with all the art materials and have 30 minutes to complete their posters. When time expires, it will be time for the families to share their posters. It is very important to encourage all the family members to take part in the poster sharing. Following the poster share, the facilitator will give out the certificates of participation. The participants can be called up individually and recognized or the certificates can be handed to each participant during the picnic. See the next page for the Certificate of Participation. The facilitator will thank all the families for their participation and lead them to the picnic site.

Certificate of Participation

_____

has completed *A Shared Experience* workshop series on (insert date).

_____

(insert your name)
Workshop Facilitator

Appendix G:
List of Suggested Ice Breakers

(Adapted from *SibShops: Workshops for Siblings of Children with Special Needs* by Don Meyer)

- Facetags

Take regular sticky name tags. Draw the outline of a face on them. Give the children markers, crayons and other craft supplies. Have the children draw a self-portrait and write their name under their face.

- Go Stand in the Corner

This game is similar to voting but this voting is done on your feet. Have two assistants stand on each side of the room with signs for the voting options. The facilitator will have the children stand in the middle of the room. Give them two options (cereal or bacon and eggs). The children will have to choose which option they like better. They will separate to their corner. The facilitator will continue with a list of similar things and the children will move to the appropriate corner.

- The Name Game

This game tests the memory and listening skills of the children. The game will begin with the facilitator saying her name ("My name is Lyndsey.") The next person in the circle will say his name but repeating the previous person's name before his own. (ex "That is Lyndsey and I am Brad.") The rest of the circle will continue in the pattern, repeating the names of all the people previous before stating their own.

- Telephone

This classic game best exemplifies what happens to a message after going through many different people and the message each person perceives. The facilitator will begin a message with the person to her left. The message will be whispered from person to person until it gets back to the facilitator. The final person to get the message will say it out loud.

- M&M Game

Each child in the circle will get two M&M's candy. The facilitator will write the following legend on a poster board:
Red= Tell us your favorite tv show.
Green= Do you have a pet? If so, what its name?
Blue= Do you have a favorite book? Why do you like it the best?
Yellow= What is your favorite thing to do in school?
Brown= Tell us your favorite thing to eat.
Orange= What is your favorite color?
The group will go around the circle until all the participants have responded. The children will be able to eat their candy once they have answered the question.

- Charades

This is a classic mime game. The facilitator will write words or phrases on index cards and place them folded in a fish bowl. Each child will have a turn to come and pick an index card. The participant who correctly guesses the word being acted out will be the next person to mime.

- Who am I?

The facilitator will write the name of famous people (ex. Hanana Montana, Bugs Bunny, etc.) on index cards. Participants will come up one at a time and have an index card placed on their forehead (or taped to their back) so they don't see what it is. The group will have to describe things about the person to the participant. The participant will have to guess who they are.

- Musical Chairs

Musical chairs is a classic game for children. The game will start with chairs with one less than the number of players. The facilitator will play music. When the music stops, the children will have to find a chair. The person without a chair is out. Another chair will be removed and the game will continue until there is a winner.

- Parachute

The facilitator will get a brightly colored parachute. The children will play various games with the parachute. They can begin by making waves with the parachute then have one person pretend to be the shark under the waves. The group can also toss balls on the parachute.