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Parenting attitudes and stress levels among parents of children who are deaf

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Parenting attitudes and stress levels among parents of children who are deaf

Thesis Proposal

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Abstract

The purpose of this study is to determine the attitudes and stressors of parents of children who are deaf. Parents of children with differing levels of hearing loss and communication modalities participated in this study. An electronic questionnaire assessed parents' attitudes and stress levels that are involved in the Northwest Arkansas Hands and Voices program. The parents received a qualitative survey generated from Survey Monkey examining how their attitudes and stress are affected by their child's hearing loss and if the Hands and Voices program alleviates some of the stress they may experience. Descriptive analyses were used to examine the results.

Children with hearing loss often display language delays and have difficulty acquiring normal oral language skills (Quittner, Barker, Cruz, Snell, Grimley, Botteri, 2010). Hearing parents of these children may display higher stress and negative attitudes toward their child's hearing loss. The resulting stress and negative attitudes can cause a communication barrier between the parent and child, which in turn can negatively affect a child's development (Quittner, et al, 2010). These negative attitudes may correlate between hearing parent's misconception of the capabilities for communication and day-to-day living of individuals, especially their children who are deaf (Cooper, Rose, Mason, 2004). However, it is unclear how the attitudes of caregivers might be addressed via parent support networks in a therapeutic context due to paucity in research.

Choosing Communication Modalities

With the wide array of children having differing types of hearing loss, parents and caregivers must choose a type of modality in which to communicate with their child (Crowe, 2014). These different types of modalities range from verbal only with the help of auditory-verbal therapy, cued speech, which uses a combination of visual and auditory cues, to manual communication, such as American Sign Language. Hearing loss may vary in need of accommodation as well, for example the use of hearing aids, FM systems, and cochlear implants (Decker, 2012). However, there is no definitive and objective communication modality that has been proven to improve a child's developmental outcomes (Crowe, 2014). Because of this, deciding on which mode of communication is best for each individual child becomes difficult (Crowe, 2014). Some of the options parents may choose include the use of speech and lip-reading, the use of sign language, a combination of modalities or, if the family is multilingual, spoken multilingualism (Crowe, 2014).

Ranging from mild to profound, the degree of hearing loss may limit the choices a parent and child have when choosing a communication mode (Crowe, 2014). Consequently, decisions on communication modality may also be effected by the degree and type of hearing loss and use of assistive devices the child may use, like hearing aids and cochlear implants (Crowe, 2014).

The decision on what modality to choose becomes stressful because effective communication is imperative for a child's cognitive and social development (Decker, 2012). The majority of children with a hearing loss have parents with normal hearing, thus requiring many parents to research and learn what communication methods are available to them (Decker, 2012). Choosing a method of communication for hearing parents may become overwhelming and controversial to those who have little experience with hearing loss (Decker, 2012).

Parental Stressors with Deafness

Parents of children who have a hearing loss tend to develop more context-specific stressors that may include communication barriers, management of hearing aids and cochlear implants, and financial needs related to their child's hearing loss (Quittner, et al, 2010). Parenting becomes increasingly difficult when faced with these added needs as well as choosing appropriate therapy and school programs

(Prakash, S., Prakash , S.G.R, Ravichandran, Susan, & Alex, 2013). Deciding on different management options of amplification, accommodations, and other needs for a parent's specific child is difficult and creates stress among caregivers (Prakash et al, 2013).

In a recent study, Prakash and collegues (2013) surveyed 50 mothers of children using hearing aids and cochlear implants. Mothers have revealed to have the higher levels of stress and even depression compared to fathers when their child has a hearing loss. Using the Parental Stress Index and Centre for Epidemiologic Studies Depression Scale, the study found that mothers of children who only needed hearing aids had significantly less stress than compared to the mothers of children with cochlear implants. The researchers also found the strong need for family-based intervention and support systems for children and their parents (Prakash et al, 2013).

Parental Stressors with Communication Barriers

Oral language delays and communication difficulties co-occur with deafness and as a result may cause behavioral problems in children with hearing loss (Quittner et al, 2010). Observable behavior problems can include aggression, disobedience, and inattention due to a child's frustration with communication (Quittner et al, 2010). A recent study suggests that there is a higher rate of behavioral problems in deaf children than their hearing peers (Quittner et al, 2010). Since behavior is a form of communication, these increased behavioral problems are the child's attempt to communicate wants and needs to parents and caregivers in the absence of adequate language skills.

Oral language delays can have an impact on families in more ways than just behavior. Stress levels specific to parents with a child with hearing loss may be related to other issues including: (1) discrepancy with the caregivers' expectations of their hearing impaired child's language ability and the child's actual language skill and; (2) learning new communicative strategies such as Auditory Verbal Therapy (AVT), cued speech, or American Sign Language to effectively communicate with their child (Quittner, et al, 2010). As the family recognizes the need for communication and attempt to address that need with a communicative method, learning new techniques to communicate with a child can be a source of family stress.

The oral language delays in children who are deaf can cause parental stress due to the consequent communication barrier between parent and child. This may alter parent attitudes toward deafness in general. According to Hadadian and Rose (1991), any obstacle that negatively affects the primary caregiver and child relationship can alter a child's development. A hearing impaired child's psychosocial difficulties may have a direct correlation to the negative parental attitudes and interactions with the child in their early formative years (Hadadian & Rose, 1991). Because of the difficulty communicating with a child who is deaf, caregivers often report frustration and decreased responsiveness to their child's communication cues (Hadadian & Rose, 1991).

Parental Support Groups

There is evidence to suggest that programs providing, a support system for parents with children with hearing loss can alleviate stress and improve attitudes in the hearing parent and hearing impaired child relationship (Hadadian & Rose, 1991). Parent-to-parent peer support groups provide assistance, perspectives, and experience to parents who have children with hearing loss (Henderson, Johnson, & Moodie, 2014). Parents of children with a hearing loss have reported benefits from this type of peer support (ASHA Leader, 2015). In order for the most benefit from support programs to occur, there must be encouragement between parents in order to inform others about the health care system, advocacy, and the best resources available to them and their children (ASHA Leader, 2015). Family based interventions and support systems may alleviate or help to mitigate these specific stressors on parents (Nann, 2007).

Family-based interventions along with support from peers and professionals may be imperative for parents and caregivers who have children with deafness to alleviate stress (Prakash et al, 2013). Not only does early intervention with such a program help the parent, but is important to the language development of the child with a hearing loss (Owens, 2010). Parents' participation in rehabilitation programs for their children's language and hearing is important for the overall communication development of the child.

In the current study, hearing parents will be asked to respond to questions regarding deafness stress levels and their participation in parental support groups such as the Hands and Voices organization. The already established Hands and

Voices program is a national organization dedicated to supporting families of children who have a hearing loss (H&V Blog, 2014). It is a parent-led organization that provides a non-biased environment for families that choose different modes of communication for their child and provides access to information and support (H&V Blog, 2014). Hands and Voices provides local chapters for families in almost every state (H&V Blog, 2014).

Summary and Questions of the Study

A review of the literature displays how parents may experience increased context-specific stressors when they have a child with a hearing loss. However, it is not clear how it may affect the parental attitudes toward deafness itself and the parent stress level of those families involved with support groups such as Hands and Voices. Therefore, the goal of this study is to investigate the attitudes and stress levels of parents involved in parent, peer support groups. The specific questions of the study are the following:

1. What attitudes do parents display toward deafness in general and what may affect those attitudes?
2. Do stressors arise from communication between the parent and child with deafness or from other stressors such as appointments, accommodations, or learning new communication modalities?
3. Do support groups such as Hands and Voices add to parental stress or alleviate some stressors faced?

Methodology

Participants

Participants included fifteen hearing caregivers participating in the local Arkansas Hands and Voices program and who have children with hearing loss. Each child relies on varying modalities of communication including oral speech, lip reading, and American Sign Language (ASL).

Materials

An electronic survey adapted from the Attitudes to Deafness Scale (Hadadian & Rose, 1991) was administered to the parents participating in the Hands and Voices program. This qualitative survey was generated using Survey Monkey, an online survey generator. The survey was completed by the parents to assess the parental attitudes toward deafness, observe the context specific stressors that the parents may face on a day-to-day basis, and evaluate the effectiveness of the Hands and Voices program.

Procedures

The participants met once for the annual Arkansas Hands and Voices chapter meeting in Little Rock, Arkansas. Once the meeting was complete, participants were asked to complete the qualitative survey via Survey Monkey online or manually filling out the hardcopy of the survey provided to them. Participants then completed the qualitative survey individually and returned it to the researcher.

Analysis

Data collected from the participants was analyzed from the qualitative survey to determine the attitudes, stressors, and alleviation of such stress as a result from the Hands and Voices program. The raw data was collected and determined how parents cope with stressors from a child who is deaf.

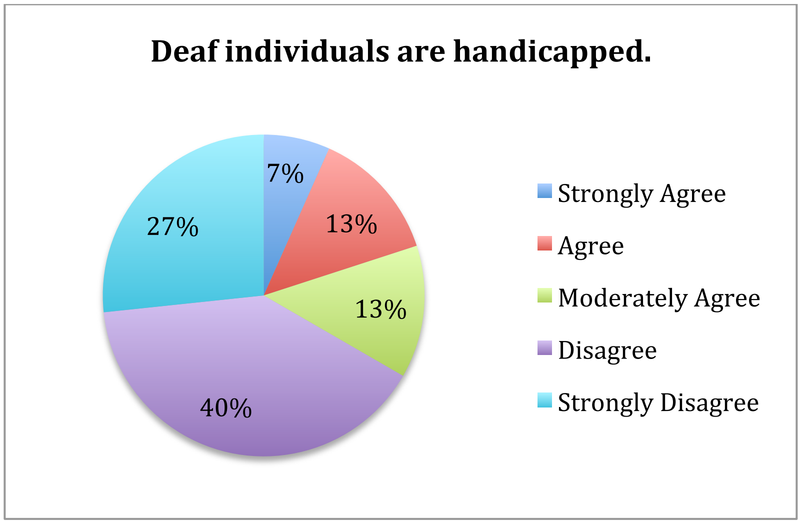
Results

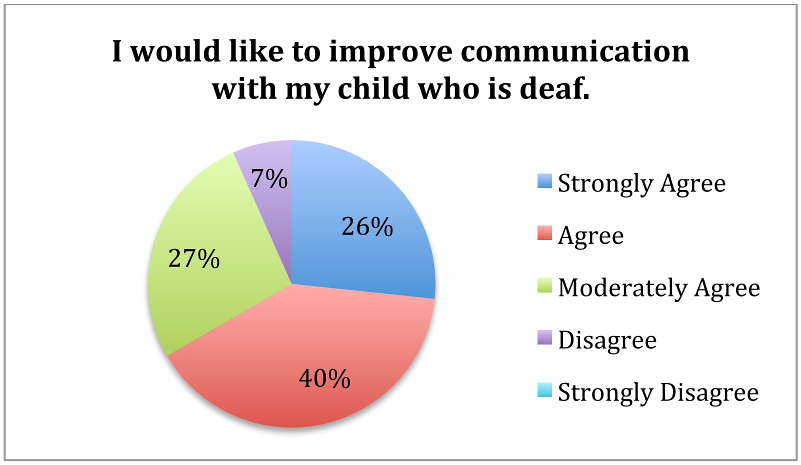
Demographics

A total of 15 parents of children who are deaf completed the qualitative survey. Every parent was a member of the Hands and Voices Arkansas chapter. An analysis of the responses demonstrated that 20% of the participating parents thought children who are deaf should learn to speak to communicate with their parents. A majority of the participants (67%) answered that deaf children are not handicapped and that more research should be done to find cures for deafness (60%). Every parent agreed that children with deafness may be at risk for developmental language delays.

Research Question One

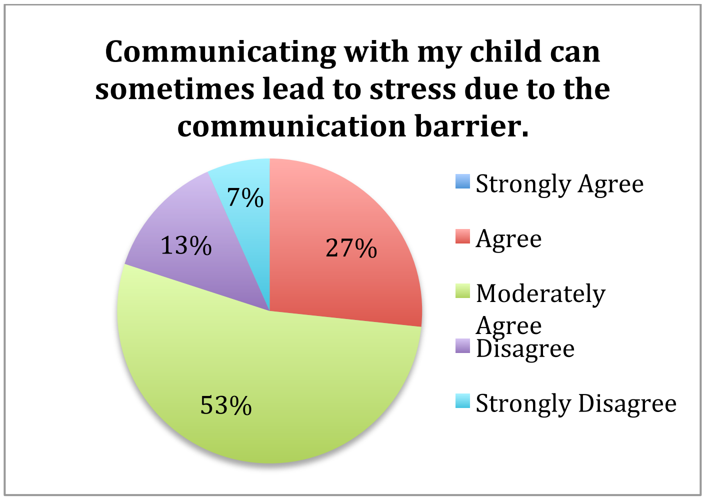
Research question one investigated the attitudes parents may display toward deafness in general and what may affect those attitudes. Only 20% of the participants believed that deafness is a handicap, while 27% answered that children who are deaf should be viewed as impaired. Every participant wanted to see more deaf individuals at events they attend and believed having a deaf friend would not be anymore difficult than a hearing friend. Every parent had a moderate to strong desire to learn American Sign Language, and 67% of the participants that wanted to improve their communication with their child who is deaf. Every parent moderately to strongly agreed that more research should be done to find a cure for deafness.

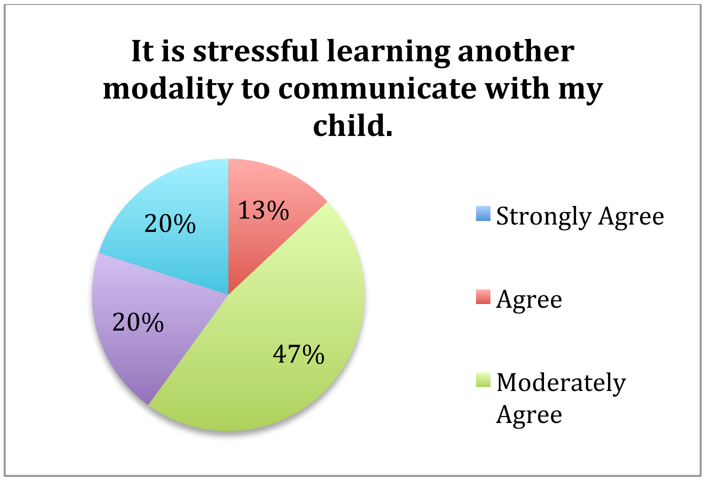




Research Question Two

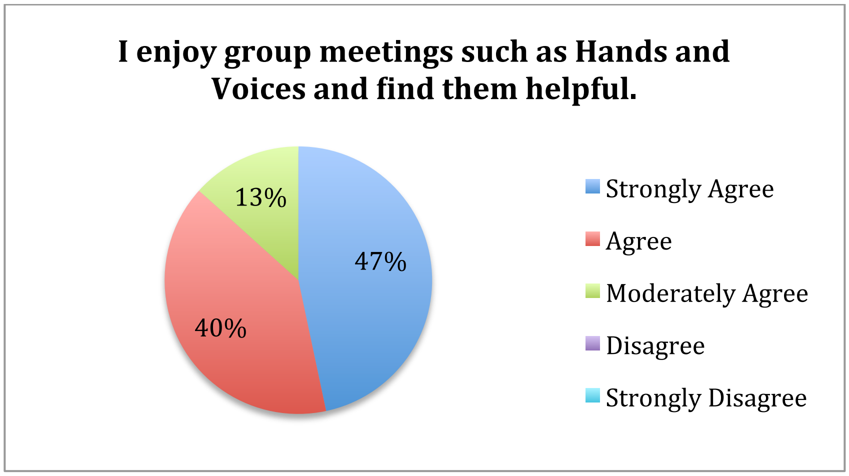
Research question two examined what stressors arise from communication between the parent and child with deafness whether it is from such stressors as appointments, accommodations, or learning new communication modalities. When asked if keeping up and going to appointments were stressful, 47% of parents moderately to completely agreed that it was stressful. 33% of the parents answered that their child with deafness always understood what they are communicating to them. However, 80% of the participants answered they only moderately agreed to completely agreed with having stress due to communication barriers with their child. Only one respondent found it stressful to communicate with their child in general and 5 were unsure. When asked if it was stressful learning a new modality to be able to communicate with their child, 60% of participants moderately to completely agreed that this leads to more stress in their routine.

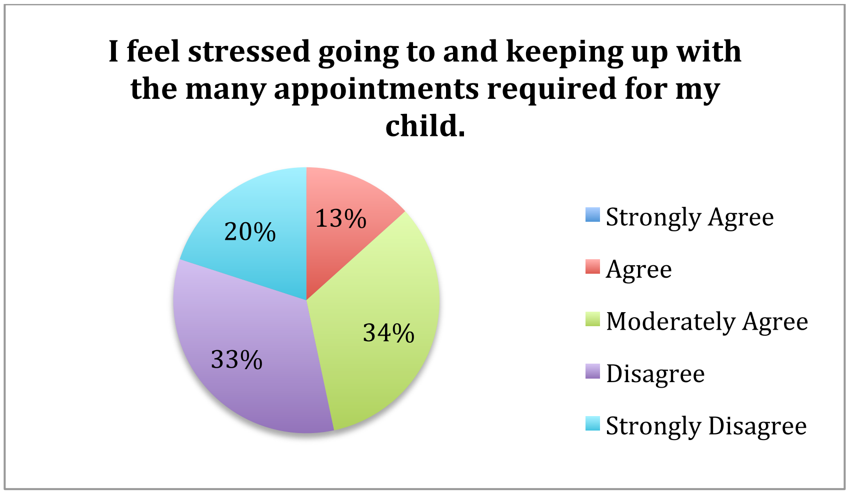




Research Question Three

Research question three looked at support groups such as Hands and Voices and whether they add to parental stress or alleviate some stressors faced. Every participant found group meetings such as Hands and Voices to be beneficial to them and worth their time. However, 47% found it moderately stressful going to and keeping up with the many appointments required for their child, even if they do enjoy the actual meetings. Every participant answered that they enjoy working with audiologists and speech language pathologists and only one parent answered that working with professionals can be stressful.


I enjoy group meetings such as Hands and Voices and find them helpful.


I feel stressed going to and keeping up with the many appointments required for my child.

Discussion

The purpose of this study was to find out the attitudes and stress levels of parents of children who are deaf. An electronic questionnaire was created to display the data of the significant attitudes and stresses the parents may have while also participating in support groups like Hands and Voices. The questions administered were directed at gaining the parents' opinions and investigating how peer support groups help alleviate parental stress.

After analyzing the results, it was surprising to find that few parents found that mode of communication was a not stressor, but that the actual communication barrier itself with their child was the main cause of stress. Participants recognized the importance of communication for their children and did not want any form of language or communication delay for their child. However, every parent understood the possible language delay that children with deafness will experience. Unsurprisingly, the parents had a nondiscriminatory attitude toward deafness in general. Most participants had strong opinions toward American Sign Language becoming more mainstream and learning more ASL and incorporating it with their personal communication with their child. Parents agreed that support groups, specifically Hands and Voices, was not stressful and worth their time. Support groups may not necessarily alleviate stress, but allow for parents to meet collectively with their peers.

The results also displayed that 67% of the participants answered that children who are deaf are not handicapped, and over 60% agreed that more research should be done to find cures for deafness. This indicates the parents' overall attitudes of deafness. The participants seemed to have a positive view of the communicative and developmental capabilities of their child who has hearing loss, but still wanted to find a cure for the deafness itself. Parents recognized the importance of hearing and listening for developing language. Participants also acknowledged the extra therapeutic involvement when a child has lost his or her hearing, but that does not make a child handicapped.

Many of the parents wanted to improve their communication with their child. However, 33% of the parents did not. This indicates that they have adequate communication abilities with their child who is deaf and are able to effectively communicate with their child.

Limitations did arise during the research process. Many parents involved with Hands and Voices elected not to take the survey, thus results do not represent the entire group. Only families involved in the Arkansas Hands and Voices program and have children who are deaf were asked to complete the questionnaire, so no comparisons to families that do not participate in other support groups or no supportive system can be made.

This research is strictly based on qualitative information. However, the results of the study are important and add to our understanding the needs of families with a child with a hearing loss. Results warrant incorporating peer support in therapy and intervention as an important component for parents with a child who is deaf or hard of hearing.

Future directions for this research could include comparing the attitudes and stressors of parents involved in support groups like Hands and Voices to parents who are not involved in any type of support group. Older children could also answer a questionnaire about their attitudes and stress levels in regards to their deafness. More parents of children with deafness who are involved in Hands and Voices chapters nationally could also participate in this survey. While all questions were on a Likert scale and designed to elicit a strong response, an option for parents to add comments should be considered. It is important for this information to be provided to professionals such as speech pathologists and audiologist that work with children with hearing loss and their families to encourage parents to attend support groups to reduce stress through active peer support.

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Appendix A-

1) Deaf children should learn to speak to communicate with hearing parents.

Strongly Agree Agree Moderate Disagree Strongly Disagree

2) I would like to have more deaf friends.

Strongly Agree Agree Moderate Disagree Strongly Disagree

3) Deaf people should learn speech rather than sign language.

Strongly Agree Agree Moderate Disagree Strongly Disagree

4) Deaf people are handicapped.

Strongly Agree Agree Moderate Disagree Strongly Disagree

5) More research should be done to find cures for deafness.

Strongly Agree Agree Moderate Disagree Strongly Disagree

6) Deaf children should be taught in sign language.

Strongly Agree Agree Moderate Disagree Strongly Disagree

7) Deaf children may be at risk for developmental language delays.

Strongly Agree Agree Moderate Disagree Strongly Disagree

8) I would like to have more deaf colleagues.

Strongly Agree Agree Moderate Disagree Strongly Disagree

9) Deaf people should learn to lip-read.

Strongly Agree Agree Moderate Disagree Strongly Disagree

10) Interpreters should be available for deaf people at work.

Strongly Agree Agree Moderate Disagree Strongly Disagree

11) Deaf people should automatically receive help in their home environment.

Strongly Agree Agree Moderate Disagree Strongly Disagree

12) All deaf people should be offered corrective surgery.

Strongly Agree Agree Moderate Disagree Strongly Disagree

13) Training more professionals to work with deaf clients would be a waste of time.

Strongly Agree Agree Moderate Disagree Strongly Disagree

14) Having a deaf colleague would cause problems in the workplace.

Strongly Agree Agree Moderate Disagree Strongly Disagree

15) Deaf people are physiologically impaired.

Strongly Agree Agree Moderate Disagree Strongly Disagree

16) Deaf people should not be viewed as “impaired.”

Strongly Agree Agree Moderate Disagree Strongly Disagree

17) I would like to see more deaf people at the clubs/societies I attend.

Strongly Agree Agree Moderate Disagree Strongly Disagree

18) Having a deaf friend would be difficult.

Strongly Agree Agree Moderate Disagree Strongly Disagree

19) Deaf people have their own culture.

Strongly Agree Agree Moderate Disagree Strongly Disagree

20) I think learning sign is important.

Strongly Agree Agree Moderate Disagree Strongly Disagree

21) I have a desire to learn ASL.

Strongly Agree Agree Moderate Disagree Strongly Disagree

22) I want to improve my communication with my child who is deaf.

Strongly Agree Agree Moderate Disagree Strongly Disagree

23) I am satisfied with the level of communication I have with my child who is deaf.

Strongly Agree Agree Moderate Disagree Strongly Disagree

24) I use more speech reading than sign with my child to communicate.

Strongly Agree Agree Moderate Disagree Strongly Disagree

25) I think my method of communication is best for my child to learn language.

Strongly Agree Agree Moderate Disagree Strongly Disagree

26) I think my child always understands what I am communicating to them.

Strongly Agree Agree Moderate Disagree Strongly Disagree

27) I think communicating with my child can sometimes lead to stress due to the communication barrier.

Strongly Agree Agree Moderate Disagree Strongly Disagree

28) I think communication at my child’s age is important.

Strongly Agree Agree Moderate Disagree Strongly Disagree

29) I find it stressful to communicate with my child.

Strongly Agree Agree Moderate Disagree Strongly Disagree

30) It is stressful learning another modality to communicate with my child.

Strongly Agree Agree Moderate Disagree Strongly Disagree

31) I think working with professionals such as audiologists and speech language pathologists stressful.

Strongly Agree Agree Moderate Disagree Strongly Disagree

32) I think working with professionals such as audiologists and speech language pathologists enjoyable.

Strongly Agree Agree Moderate Disagree Strongly Disagree

33) I enjoy group meetings such as Hands and Voices and find them helpful.

Strongly Agree Agree Moderate Disagree Strongly Disagree

34) I find group meetings such as Hands and Voices to be stressful.

Strongly Agree Agree Moderate Disagree Strongly Disagree

35) I find group meetings like Hands and Voices too time consuming.

Strongly Agree Agree Moderate Disagree Strongly Disagree

36) I think group meetings like Hands and Voices is worth my time.

Strongly Agree Agree Moderate Disagree Strongly Disagree

37) I feel stressed going to and keeping up with the many appointments required for my child.

Strongly Agree Agree Moderate Disagree Strongly Disagree

38) I enjoy going to and keeping up with the many appointments required for my child.

Strongly Agree Agree Moderate Disagree Strongly Disagree