Social Support Service Preferences of Parents and Caregivers of Children who are D/deaf or Hard of Hearing

Torri Ann Woodruff, M.S.^{1, 2}, Claire Marcus Bernstein Ph.D.¹, and Kathleen Cienkowski Ph.D.²

¹ Gallaudet University ² University of Connecticut

INTRODUCTION

"Support services" is a general term to describe informational and adjustment counseling that takes place between families and healthcare or educational providers. As shown in Figure 1, support services may provide parents and caregivers of a child with hearing loss information on a range of topics 1,2



Displayed in figure 2 are the various formats support services are often delivered through ³



Figure 2. Common group formats.

Support groups tend to be **technology** driven in audiology (e.g. cochlear implant groups focused on spoken language ⁴). However, this study is based on the hypothesis that the **educational philosophy** parents and caregivers have selected for their child may have a deeper connection to them personally and be a better predictor for needs and preferences.

PURPOSE

This study examines the relationship between the **educational approach** (**spoken language**, **visual language**, **tactile**, **written**, or **other**) utilized by a child who is D/deaf or Hard of Hearing, and the preferences of parents and caregivers for how support groups should be delivered.

METHODOLOGY

Phase 1. Semi-structured interviews with Audiologists

Audiologists were asked their opinions on support groups for parents and caregivers

 Questions were on topics such as who should lead a group, what topics should be covered, and how often they should occur

Responses were combined with information from the literature to build a survey for parents and caregivers about support group preferences

Additions to the survey based on audiologist input:

- Advocacy for the child and general information on parenting added as topics of discussion
- Social worker and service coordinator were added as options for who could lead the group

Phase 2. Online Survey to Parents and Caregivers

Parents and caregivers were asked their opinions on support groups. Participants were over the age of 18 and self-identified as a parent or caregiver to a child under the age of three who is D/deaf or Hard of Hearing.

Participants were recruited from schools for the deaf and resource centers.

Each participant was asked to anonymously complete the survey created in phase one about their child's communication and their preferences for support services. Participants were compensated \$10.00

RESULTS and CONCLUSIONS

Survey responses were received from 29 parents and caregivers. The results of the survey are shown below in Figures 3-8. It should be noted that because of the small sample sizes, groups comparisons could only be made for those families using spoken and visual languages.

Figure 3. Language modality/education approach used by child.

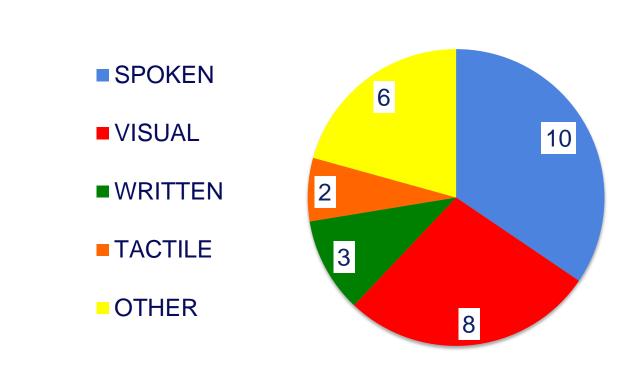


Figure 5. Topics that parents/caregivers would like covered.

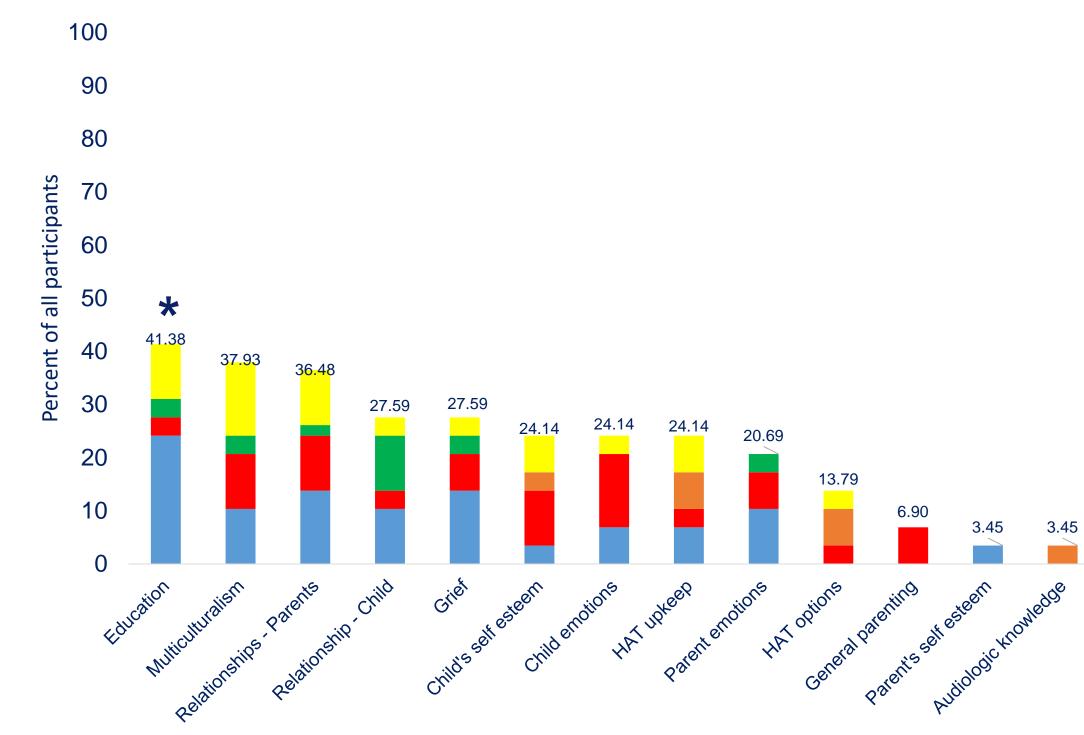


Figure 6. Frequency of responses for the logistical considerations.

How should the group be held?

In person, at [n=23]

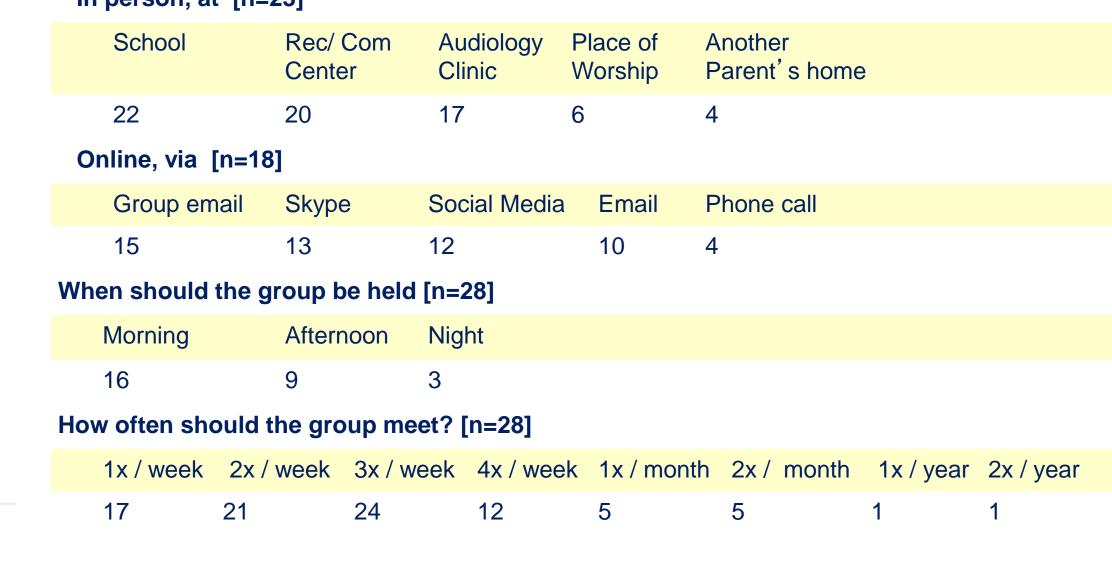


Figure 7. Frequency of response for group composition.

Who should be in the group? [n=28]									
	Age of diagnosi s	Age	Gender	Other Diagnoses	Other – Education				
	28	28	27	2	1				
Who should lead the group?									
	Teacher	Audiologist	Social Worker	Service Coordinator	Other Parent	Self	No one/ Self led		
	28	26	14	13	3	2	0		
Who should attend the group?									
	Child	Siblings	Extende d Family		Significant Others		Any caregiver	Most contact w/ child	No one
	20	16	15	13	11	6	5	1	0

Educational approach only had a significant impact on some preferences for the visual communication group. But, this was in line with the general trend for all groups surveyed.

Results suggest, factors other than modality impact preferences; thus, a **family-centered approach** should be implemented.

REFERENCES

¹Meadow-Orlans, K. P., Mertenn, D. M., Sass-Lehrer, M. A., & Scott-Olson, K. (1997). Support services for parents and their children who are deaf or hard of hearing: A national survey. American Annals of the deaf, 142(4), 278-292.

²Mikkelsen, U. J., Neilsen, P., & Rasmussen, S. (2001). Support services in Denmark for parents of children who are deaf or hard of hearing - a national survey. Scandinavian Audiology, 30(2), 116-119. doi: 10.1080/01050390175-166862

³Henderson, R. J., Jonson, A. M., & Moodie, S. T. (2016). Revised conceptual framework of parent-to-parent support for parents of children who are deaf or hard of hearing: A modified Delphi Study. American Journal of Audiology, 25, 110-125. doi: 10.1044/2016 AJA-15-0059

⁴Kelly, P. M. (2013). Parent perceptions of audiology and speech-language services and support for young children with cochlear implants (Doctoral dissertation). Retrieved from ProQuest. UMI 3609188

ACKNOWLEDGMENTS

This would not have been possible without the guidance of my thesis committee, Dr. Claire Marcus Bernstein, Dr. Kathleen Cienkowski, and Dr. Matthew Bakke. The idea from this project came from my clinical and educational experiences at Gallaudet University. Support for this project came from the American Speech- Language - Hearing Association's SPARC (Students Pursuing Academic Research Careers).