



# Parent-to-Parent Support Survey – A Pilot Study of The CARE Family Retreat

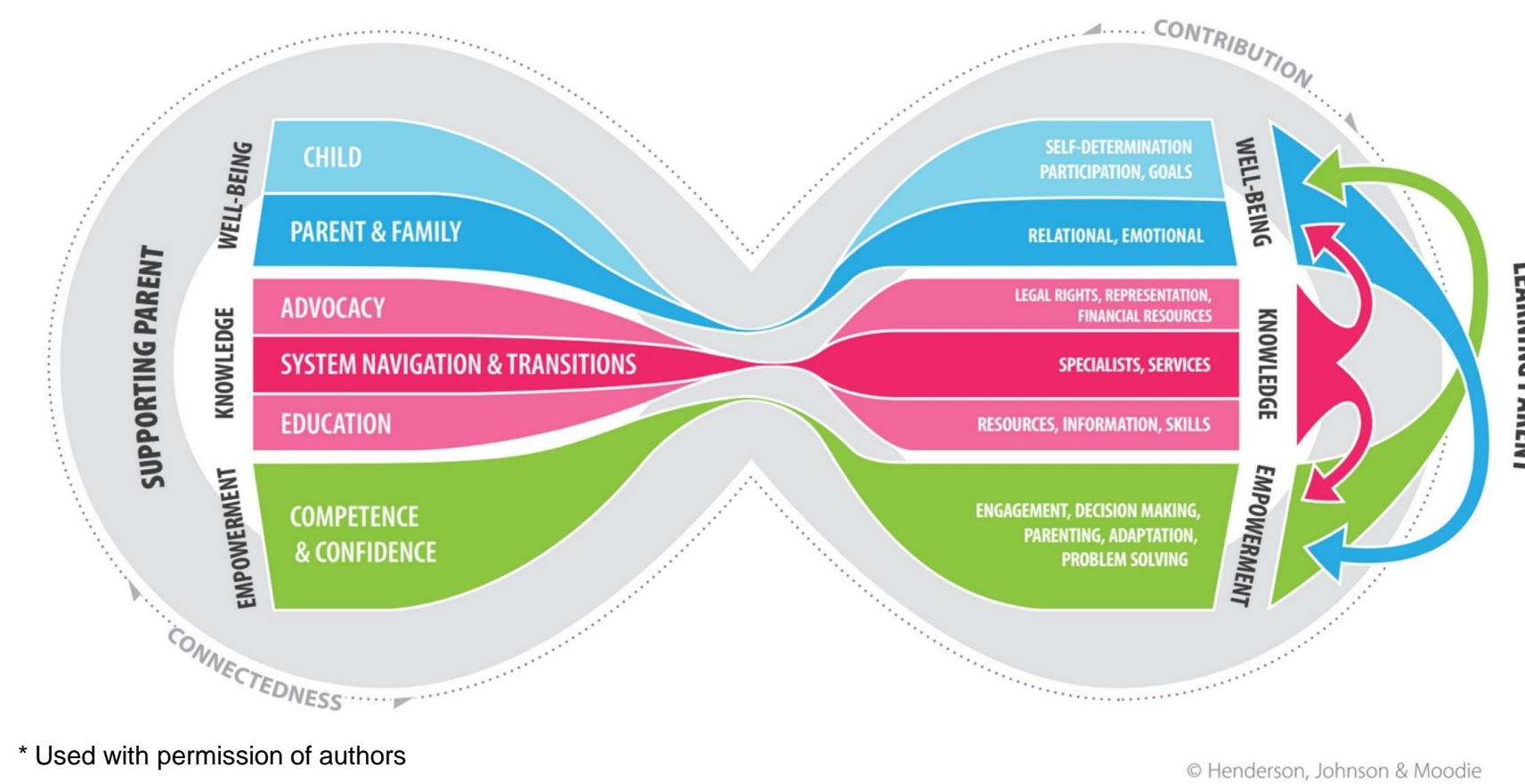
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## Abstract

The overall goal of the CARE Project Family Retreat endeavor was to develop a replicable model demonstrating how EHDH programs can engage families, focusing on early involvement and education of parents as a critical “next step” in providing a comprehensive, seamless system of service delivery to families of children birth to three. The CARE Project Family Retreat was developed and implemented as a weekend workshop for families of children recently identified as deaf or hard of hearing in two states as a pilot project. A program evaluation based on the conceptual model of parent-to-parent support described by Henderson et al., (2016) was used as a framework. The aim of this program evaluation is to assess the impact of The CARE Project family retreat on family and child well-being, knowledge, and empowerment with families of children who have been recently diagnosed as deaf or hard of hearing. The program evaluation tool was designed as a pre-post questionnaire with a satisfaction survey included on the post-retreat form. Data analysis consisted of the comparison of pre-retreat responses and the post-retreat satisfaction responses. Data is presented in the aggregate for two states and include summary statistics (e.g., means, variability, proportions). Next steps for project development are detailed. Implications for interventions and activities designed to provide parent-to-parent support are detailed.

Figure 1. A revised conceptual framework of parent to parent support for parents of children who are deaf or hard of hearing.



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## Method

This study was approved by the Internal Review Board (IRB) at the University of Arkansas for Medical Sciences (UAMS) protocol # 207213.

### Materials

The program evaluation tool used in this study was developed by the authors based on the conceptual model shown in Figure 1 (Henderson et al., 2016). The questionnaire and survey were designed to assess the impact of the CARE Project Family Retreats. For the pilot study, the questionnaire was designed for the learning parent. Development of the questionnaire for the supporting parent is in progress.

The CARE Project Family Retreat Program Evaluation included (a) demographic information, (b) pre-retreat survey and (c) post-retreat questionnaire with satisfaction survey (Figure 2).

### Participants

A total of 109 individuals participated in the two family retreats held as part of the Care Project Family Retreat National Initiative. Family retreat participants included 36 parents, 26 newly identified children, 19 siblings, and 28 professionals.

## Results

Results presented are preliminary and represent average scores by Region for 29 participants (Region I = 17; Region IV = 12). The average increase in parental perception across categories for all 17 items was about 2 points (see Figure 3).

Figure 2. Demographic data collection tool, learning parent pre/post questionnaire for parent-to-parent support and satisfaction survey.

**THE CARE PROJECT FAMILY RETREAT DEMOGRAPHIC INFORMATION**

MCHB AREA \_\_\_\_\_  
Location \_\_\_\_\_  
Date \_\_\_\_\_  
Participant Number \_\_\_\_\_

Circle the answer that best describes you and your child's race, gender, ethnicity, and other basic demographic information.

Parent/Guardian Information					
Age in Years	Under 25	26-35	36-45	46-55	55+
Gender	Male	Female	-----	-----	-----
Race	White	Black	Hispanic or Latino	Native American	Asian
	Pacific Islander	Mixed	If Other, Please Specify: _____		
Marital Status	Single, Never Married	Single, Previously Married	Married	Widowed	Divorced
Education	No Degree	High School	Some College	Undergraduate Degree	Graduate Degree
Relationship to Child	Biological Parent	Foster Parent	Step Parent	Adoptive Parent	Grand Parent
	Other, Please Specify: _____				
Child Information					
Child Age in Years	Under 3	3-5	6-10	11-15	16+
Gender	Male	Female	-----	-----	-----
Race	White	Black	Hispanic or Latino	Native American	Asian
	Pacific Islander	Mixed	If Other, Please Specify: _____		
Childcare Setting	Home	Daycare	If Other, Please Specify: _____		
Education Setting	Home School	Preschool	Elementary School	High School	College
Technology Use	None	Hearing Aid	Cochlear Implant	Bone Anchored Implant	-----

**THE CARE PROJECT FAMILY RETREAT PRE-RETREAT SURVEY**

MCHB AREA \_\_\_\_\_  
Location \_\_\_\_\_  
Date \_\_\_\_\_  
Participant Number \_\_\_\_\_

Please complete this program evaluation survey before the retreat and return it to one of the CARE Project Volunteers.

Please rate your experience for each of the following statements from 1 (extremely poor or negative) to 10 (extremely good or positive).

Family Well-Being	negative	positive
I feel connected with others who understand my questions and concerns.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I have meaningful interactions with parents who can share their experience.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I adapt easily to my child's changing needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I am confident in my ability to cope.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Child Well-Being		
I have the knowledge and skills to speak up for my child's needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I feel confident about supporting my child's development needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I helped develop short-term and long-term goals for my child.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
My child has opportunities to meet other children who are deaf or hard of hearing.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Knowledge		
I feel confident about sharing information with my extended family members.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I know where to go and how to get accurate information when I need it.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I am a confident decision-maker regarding my child's needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I have opportunities to learn from other parents, role models and mentors.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Empowerment		
I am confident in my ability to support language development and to communicate with my child.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I bounce back easily when I am faced with challenges.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I feel empowered to support my child's healthcare and educational needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I am confident about making the right choice based on my personal and family values.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I have the knowledge and skills I need to play an active role in my child's daily life.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Comments:		

**THE CARE PROJECT FAMILY RETREAT POST-RETREAT SURVEY**

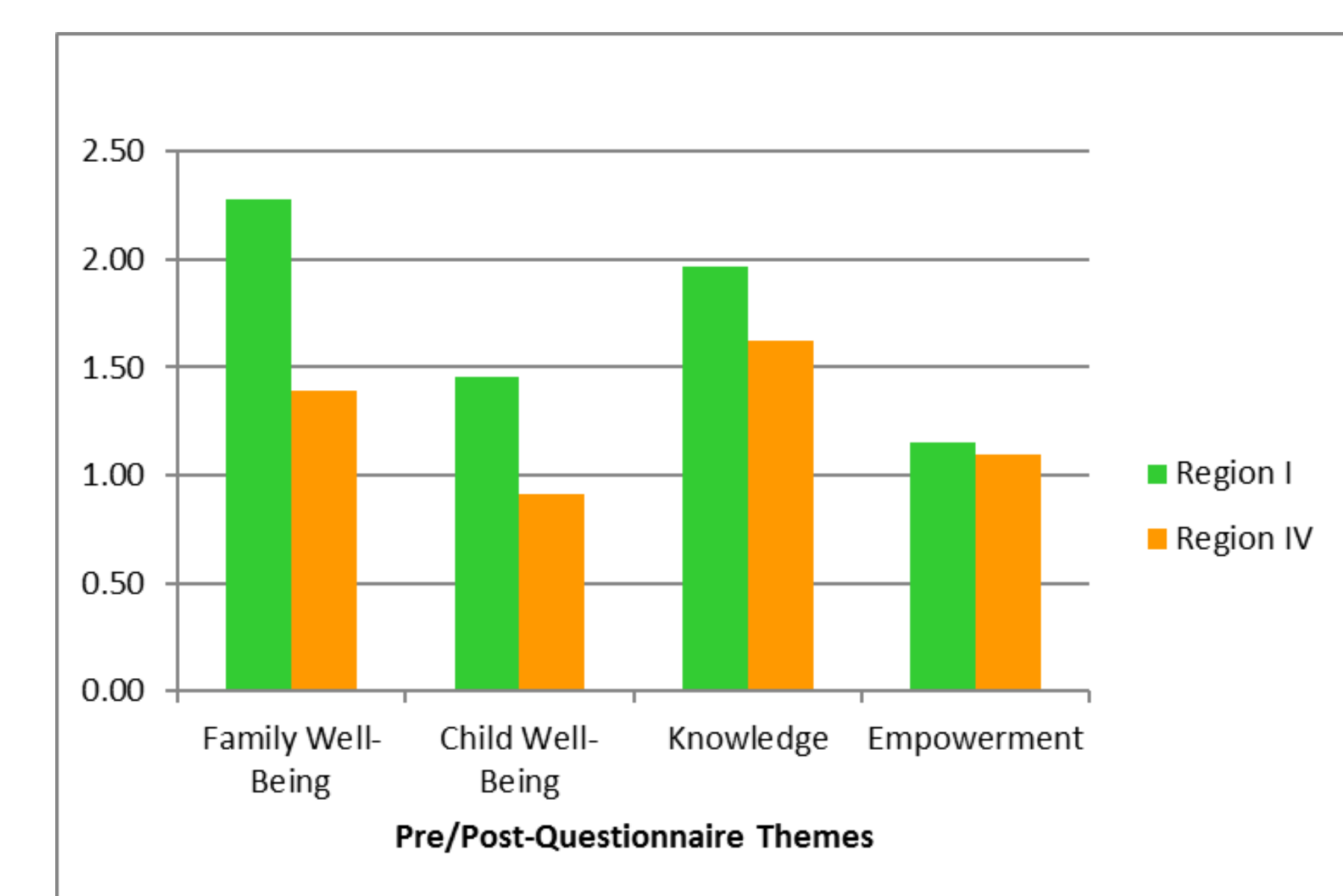
MCHB AREA \_\_\_\_\_  
Location \_\_\_\_\_  
Date \_\_\_\_\_  
Participant Number \_\_\_\_\_

Your feedback is important to us!  
Please complete this program evaluation survey after the retreat and return it to one of the CARE Project Volunteers.

Please rate your experience for each of the following statements from 1 (extremely poor or negative) to 10 (extremely good or positive).

Family Well-Being	negative	positive
I feel connected with others who understand my questions and concerns.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I have meaningful interactions with parents who can share their experience.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I adapt easily to my child's changing needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I am confident in my ability to cope.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Child Well-Being		
I have the knowledge and skills to speak up for my child's needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I feel confident about supporting my child's development needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I helped develop short-term and long-term goals for my child.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
My child has opportunities to meet other children who are deaf or hard of hearing.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Knowledge		
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I know where to go and how to get accurate information when I need it.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
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I feel empowered to support my child's healthcare and educational needs.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I am confident about making the right choice based on my personal and family values.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I have the knowledge and skills I need to play an active role in my child's daily life.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Overall Satisfaction		
I felt welcomed.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
My interactions with participants and volunteers were meaningful and authentic.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Sharing stories with others who understood my journey was validating and affirming.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
I was satisfied with the content of the workshop.	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10
Comments (Use the back if needed):		

Figure 3. Increase in parent-to-parent perception following Care Project Family Retreats.



### Family Well-Being

There was an average increase of 2 points for the four items. The first two items (connectedness and interaction) increased by 3 points and the second two items (adaptation and confidence) increased an average of about 1 point.

### Child Well-Being

There was an average increase of 1 point from pre- to post-retreat questionnaire results overall. The gain was evenly distributed across the four items (advocacy, confidence, goals, socialization).

### Knowledge

Sub-categories of knowledge included sharing information, finding accurate information, confidence in decision-making, and interaction with other parents. Results showed an average increase of about 1 point. The largest gain of about 3 points was shown for finding accurate information whereas the second largest increase was for sharing information.

### Empowerment

For empowerment, there was an average increase of about 1 point. The largest gain of about 1.5 points was observed for confidence in communication with the second and third largest gains of about 1.4 observed for adaptation and decision-making.

### Satisfaction Survey

The satisfaction survey assessed how welcomed participants felt, the meaningfulness and authenticity of interactions, feelings of affirmation and validation with story sharing, and level of satisfaction with workshop content. The average satisfaction score overall on a scale of 1 to 10 for all items was 9.5 or better for both workshops.

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## Introduction

A number of authors have reported on summer camps or family retreats as educational experiences offered to meet the needs of special interests or specific health populations (Heike, Leavitt, Aspinall, Andrews, Carey & Ose, 2010; Huelsing, Kanafani, Mao & White, 2010; Maslow & Lobato, 2009; Maslow & Lobato, 2010; O'Mahar, Holmbeck, Jandasek, & Zukerman, 2009; Seal & Seal, 2011; Sinh, Kable, Guerro, Sullivan & Elsas, 2000); however, there is a general lack of evidence based on a high quality conceptual framework designed specific to the population.