



Family-Researcher Collaboration: Bringing the Family's Voice to Research

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NANCY FORD

Presenters



Alyssa LaForme Fiss, PT, PhD, PCS
Associate Professor, Mercer University, Atlanta, Georgia



Lynn Jeffries, PT, DPT, PhD, PCS
Associate Professor, University of Oklahoma, Oklahoma City, Oklahoma



Nancy Ford, Parent
Coca-Cola, Atlanta, Georgia

Objectives

At the conclusion of this session, participants will be able to:

- ❖ Discuss current evidence for inclusion of families of children with disabilities in research activities;
- ❖ Discuss parent perspectives on participation in research activities;
- ❖ Describe potential benefits and perceived barriers to family participation in research;
- ❖ Provide recommendations for inclusion of families on research teams;
- ❖ Implement strategies for collaboration and continued engagement of family members throughout the research process;
- ❖ Suggest research questions for family-centered outcomes research.



Background - Move & PLAY

Purpose: to understand the child, family and service determinants of change in motor function, self-care, participation and play of young children with cerebral palsy (CP) over one year.

Recruited 430 children in selected sites in both Canada and the United States, and maintained 90% of the sample over the year.

Children & their families participated in 3 assessment sessions, each 6 months apart.



Background – Who We Are

Move & PLAY Research Study Team

- Doreen Bartlett, PT, PhD, University of Western Ontario
- Lisa Chiarello, PT, PhD, PCS, Drexel University
- Robert Palisano, PT, PhD, Drexel University
- Peter Rosenbaum, MD,FRCP(C), McMaster University, *CanChild* Centre for Childhood Disability Research
- Sally Westcott McCoy, PT, PhD, University of Washington
- Lynn Jeffries, PT, PhD, PCS, University of Oklahoma
- Alyssa LaForme Fiss, PT, PhD, PCS, Mercer University
- Barbara Stoskopf, RN, MHSc, McMaster University, *CanChild* Centre for Childhood Disability Research
- Audrey Wood, PT, MS, Drexel University
- Allison Yocum, PT, DSc, PCS, University of Washington
- Barbara Sieck Taylor, USA, Parent consultant
- Tina Hjørngaard, Canada, Parent consultant



Background – On Track

- ❖ Large multi-site study
- ❖ Aims:
 - ❖ describe changes in primary & secondary impairments, health conditions, & participation in self-care, recreation, & leisure activities over one-year
 - ❖ create longitudinal developmental curves to provide easily understood & useful tools for families & service providers to discuss questions about how well their children are doing in relationship to other children with CP of similar functional ability levels
- ❖ Currently following 711 young children with CP aged 18 months through 11 years

Background – Who We Are



On Track Research Team – RESEARCHERS

[Doreen Bartlett](#), PT, PhD, Western University

[Sarah \(Sally\) Westcott McCoy](#), PT, PhD, FAPTA, University of Washington

[Lisa Chiarello](#), PT, PhD, PCS, Drexel University

[Bob Palisano](#), PT, ScD, FAPTA, Drexel University

[Lynn Jeffries](#), PT, DPT, PhD, PCS, University of Oklahoma

[Alyssa LaForme Fiss](#), PT, PhD, PCS, Mercer University

[Jan Willem Gorter](#), MD, PhD, FRCP(C), McMaster

[Steve Hanna](#), PhD, McMaster University, Hamilton

[Kristie Bjornson](#), PhD, PT, PCS, University of Washington

[Cheryl Kerfeld](#), PhD, PT, University of Washington

Background – Who We Are



On Track Research Team – Parents

Parent Investigators - CIHR & PCORI

Barbara Sieck Taylor (Pennsylvania USA)

Tina Hjorngaard (Ontario Canada)

Parent Investigators - PCORI

Lisa Diller (Washington USA)

Paula Drew (Oklahoma USA)

Nancy Ford (Georgia USA)

Marquitha Gilbert (Pennsylvania USA)

Kimberly Rayfield (Pennsylvania USA)

Background on Family-Researcher Collaborations

- Family-centered services are recognized as best practice in early childhood
- In family-centered outcomes research, perspectives, interests & values of families inform the research process
- Advocacy for family-centered outcomes research is still emerging
- Role of families in the research process ranges from passive to active participant

Family Participation

Turnbull, et al, 1998 identified a continuum of family participation:

- Level 1: Families as Research Participants
- Level 2: Families as Advisory Board Members
- Level 3: Families as Occasional Reviewers & Consultants
- Level 4: Researchers as Leaders & Families as Ongoing Advisors
- Level 5: Researchers & Families as Co-researchers
- Level 6: Families as Research Leaders & Researchers as Ongoing Advisors

Intent is to:

- address questions that matter to families
- disseminate findings in ways that enable families to make informed decisions about their children's care

Involving Families

Current best practices for involving families not known

Family involvement at all phases of research project

- Provide insight into formulating relevant research questions
- Provide direction & feedback on research methods
- Assist with recruitment & retention efforts
- Assist with data interpretation & analysis
- Assist with dissemination of results

(Boote, Telford, Cooper, 2002; Domecq, et al, 2014; White, Suchowierska, Campbell, 2004)

Steps to Involving Families (White et al, 2004)

1. Participant selection & recruitment
2. Roles and relationship clarification
3. Research team education
4. Management & support

Family Participation in Research

Benefits:

- Improved credibility of results
- Direct applicability & relevance to children and their families
- Improvement to the research process (better questionnaires/ methods; identification of problems earlier)
- Improved translation of research findings into clinical practice
- Improved meaningfulness & understandability of dissemination
- May lead to increased recruitment & retention of research participants
- Enhance empowerment of family participants

(Boote, et al, 2002; Domecq, Prutsky, Elraiyah, Wang, Nabhan et al, 2014; Tate & Pledger, 2003; Turnbull, Friesen & Ramirez, 1998; White, et al, 2004)

Family Participation in Research

Barriers

- Increased time
- Scheduling challenges
- Increased funding needs
- Researchers feeling criticized by parents
- Families understanding of research methods
- Lack of family homogeneity
- Identification of the “consumer”
- Geography

(Boote, et al, 2002, Domecq, et al, 2014; Perry, Slasberg, Macaulay, 2006; Turnbill et al, 1998)



Consultant to Collaborator



Our Journey at this point



Consultant

In the Move & PLAY study, parents

- Reviewed grant applications, provided feedback prior to revision & resubmission
- Reviewed all training materials & data collection forms with a view to being sensitive to potential issues with respect to reception by children & families
- Participated in interviewer training sessions
- Facilitated 'short titles' for 'Move & PLAY'
- Reviewed & refined recruitment brochures & posters
- Reviewed & refined feedback forms & newsletters for families



Family Newsletter

Family Newsletters included

- Resources
- Tips for promoting child development
- Common themes parents were reporting
- Parent consultant thoughts about participating in research
- Parent participant thoughts about participating in the Move & PLAY study

"I believe that inclusion of parent consultants adds depth & meaning to this research. Some research is full of jargon, & I think that by involving parents, the research will be more readable & accessible."

"By including parents, the results may be more meaningful to other parents - there is a peer connection. I hope that our involvement in this study will do this."



Family Newsletter

"When you have a child that has a diagnosis, it is nice to be involved, especially when she is young. It is important to get all the information you can possibly gather. I think it is important to educate people.... & to give me ideas of things that I can do.

***I also like to give back to the people who give to me (and my daughter).** It was great to have you guys on the home front for the first session. Emily is more comfortable & outgoing & confident in her own environment. I really liked how Barb (our PT) worked with her.*

*The biggest thing I remember about that first visit was when Barb sat Emily on that special stool... & I wasn't sure that she could do it... & I was nervous! **BUT SHE DID IT!** And now she is getting up on her knees. I'm so proud.*



Consultant

In the Move & PLAY study, parents:

- Provided feedback on initial descriptive analyses
- Reviewed & refined all knowledge translation summaries
- Provided permission to acknowledge contributions to study implementation

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Description

Understanding Determinants of Motor Abilities, Self-Care, and Play of Young Children with Cerebral Palsy (Move & PLAY Study) 2006-2009 -

Summary

Funders

Research Team

Main Study Results

Measures and Summaries for Practitioners and Families

Implications of Findings for Pediatric Physical Therapy Education

Articles

Presentations



Research Summaries

<http://www.canchild.ca/en/ourresearch/moveplay.asp>

- Conceptual model of the Move and PLAY Study
- Health Conditions of Children with Cerebral Palsy (CP)
- Gross Motor Function Measure (GMFM), New Shortened Versions
- Recreation and Rehabilitation Services
- Family Life
- Motor and Self-Care Abilities (English)/ Motor and Self-Care Abilities (French)



Health Conditions of Children With Cerebral Palsy (CP)

Movement and Participation in Life Activities of Young Children

Information for Families and Service Providers

The Move & PLAY study.....in brief:

Who participated? 430 preschool (18 months to 5 years) children with [Cerebral Palsy](#) (CP) and their families were recruited from many regions of Canada and the USA; all children had CP or problems with motor activities, [muscle tone](#) and [balance](#).

What did we do? We focused on learning what helps children with CP progress in their ability to move around, take care of themselves ([self-care](#): feeding, dressing, bathing) and [play](#).

What was our goal? We wanted to find out what we can change about the way we help young children who need rehabilitation services, so we can focus on providing the services that are most beneficial.

How did we do this? We collected information about many characteristics of the child, the family, and the recreation and rehabilitation services they receive, during 3 sessions over a one-year period.

Looking at health conditions:

This report focuses on what parents told us about the health conditions their children have, and how these conditions affected their daily lives. When we say "[health](#)", we mean **all the different functions of the whole body**.

- A parent survey asked if their children had problems with any of these 16 health conditions: seeing, hearing, learning, communicating, controlling emotions, seizures, the mouth, teeth and gums, digestion, growth, sleeping, repeated infections, breathing, the skin, the heart, and pain ([link to measure](#))
- Parents also rated how much each condition affected their children's daily activities - from "not at all " to "a very great extent". We call this "impact" of health conditions in this report

Comparisons between children with and without CP

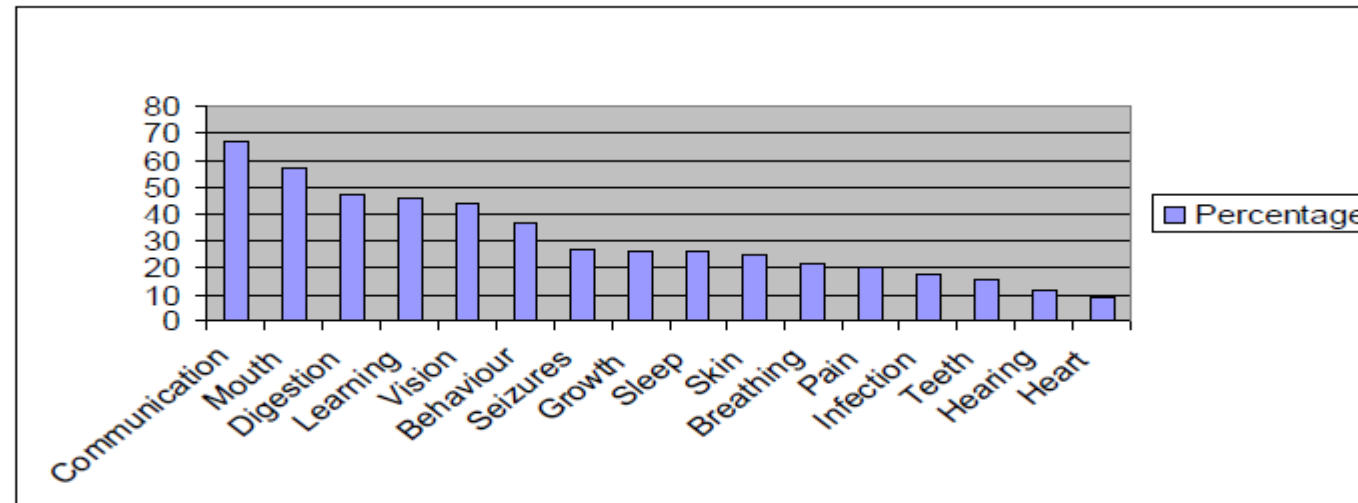
- Small substudy with 107 families with preschool children who did not have CP or problems with movement
- We compared health conditions and their impact, between the 2 groups (430 children with CP and 107 without CP)

What did we learn?

*Please keep in mind that these results are based on averages for the total group.
Children are individuals and not all would fit the results described below.*

Health conditions in children with CP

- **16 health conditions:** this shows the percentage of children with each condition, starting with the most common one on the left- Communication (67% of children had difficulties with communication)



- **Average number of health conditions per child** increased as motor ability decreased; average number for children with greater motor abilities was 3 problems; average for those with the lowest motor abilities was 7 problems

Words highlighted in blue link to definitions in our glossary. The glossary and other summaries reporting the results of this study are available on the CanChild website : <http://www.canchild.ca/en/ourresearch/moveplay.asp>

What does this mean?

Thoughts for families

- ◇ Therapists need to know about the whole child, and all aspects of how the body functions; a problem with moving around is not the whole picture of your child's health
- ◇ Knowledge about your child's health issues, and about how these health conditions affect daily life, is important for everyone involved in their care
- ◇ Parents need to share information with their children's therapists about health conditions, hospitalizations, and surgeries, so that together, they can plan the best care
- ◇ Therapists are health care professionals, and a source of information regarding your child's health

Thoughts for service providers

- ◇ There is a lot of variation in children's health
- ◇ Service providers working with young children with CP need to regularly ask about health conditions, and consider their impact when planning care
- ◇ Children with CP are affected by more health conditions than children without CP, and the average impact of these conditions is also greater among all children with CP, regardless of motor ability
- ◇ The high occurrence of a variety of health conditions, and the extent to which they affect the children's daily activities, suggests that more attention be paid to this important aspect, particularly for children with lower motor abilities
- ◇ It is important for therapists to discuss with families how the children's health conditions impact the children's daily lives. Service providers have a role in health promotion and prevention. They can include strategies in care plans to reduce the impact of health conditions on daily life of children and families
- ◇ There is a need for coordinated care, including monitoring children's health, and providing information to families. Service providers should make referrals to other appropriate health professionals as indicated



Moving to Collaborators

In the On Tracks Study, parent collaborators have completed many of the same activities as consultants but have also moved into other areas.

- Participate in monthly meetings as a parent group & when available with the full research team
- Provide input into recruitment, data collection challenges, & ongoing input in to the project
- Provide oversight for the family newsletter
- Prepare short web-based communication “Parent to Parent”
- Collaborating in the development of video’s for parents related to research
- Collaborating in conference presentations
- Provide insight/editing on parent feedback forms



Moving to Collaborators

Future plans include:

- Participating in data interpretation
- Participating in the development of knowledge translation materials
- Participating in journal article preparation for both scientific journals & parent journals/resources

On Track

Description

Developmental Trajectories of Children with CP

The On Track Study is a large multi-site collaboration involving researchers, therapists, families, and children with cerebral palsy (CP) from across Canada and the United States. The aim of the CIHR funded study is to describe the changes in balance (a primary impairment), range of motion limitations, strength, and endurance (secondary impairments), number and impact of health conditions, and participation in self-care, recreation, and leisure activities over a one-year period in young children with CP aged 18 months through 11 years. We aim to recruit 175 children with CP, aged 18 months to 10 years, in each of the 5 levels of the [Gross Motor Function](#)

[Classification System \(GMFCS\)](#) for a total sample of 875 families. The On Track Study will recruit some families involved in our previous [Move & PLAY study](#), as well as welcoming some new children and their families to the project.

Trained therapist assessors will measure the primary and secondary impairments (i.e. balance, range of motion limitations, and strength) on 2 occasions (12-months apart). Parents will complete questionnaires to track changes in the child's endurance, health conditions, and participation in self-care and recreation activities, at the same data collection points. We will use these 2 data collection points to develop reference percentiles and we will present the data so that therapists can assist families to determine if children with CP are developing as expected, better than expected, or more poorly than expected, depending on their functional ability levels.

Parents will complete questionnaires to track changes in the child's endurance, health conditions, and participation in self-care and recreation activities, at the same data collection points. We will use these 2 data collection points to develop reference percentiles and we will present the data so that therapists can assist families to determine if children with CP are developing as expected, better than expected, or more poorly than expected, depending on their functional ability levels.

In 2013, our team was awarded additional funding (PCORI) to complement the original On Track Study by increasing data collection in a subsample of 600 children with cerebral palsy across all 5 GMFCS levels. Rather than having two observations across one year, this subsample will have five observations (6-months apart) across two years. With these data the first additional study aim is to create longitudinal developmental curves for impairments, health conditions, and participation variables by estimating the average pattern of change, important individual variations in the pattern of change between children, and the degree of consistency over time within children. Establishment of longitudinal developmental curves will provide easily understood and useful tools for families and service providers to discuss questions about how well their children are doing in relationship to other children with CP of similar functional ability levels. The second study aim is to utilize service data collected from parents and children's progress on the longitudinal developmental curves to develop recommendations for rehabilitation service provision for children with CP across functional ability levels. Having this information should assist with collaborative decision-making among family members and service providers that efficiently utilizes rehabilitation services to meet families' goals. To date this information does not exist, rather, many different types and intensities of services are recommended based primarily on convention, clinicians' past experiences, and education rather than on evidence of children's potentials to achieve goals. An additional sub-study under the PCORI funding is to collect direct physical activity measurements from a sub-set of the children in the larger study. These data will be examined in relationship to other measures of endurance and participation.

See [Chart of Recruitment and Assessment Sites Participating in the On Track Study](#)

See [Map of Sites Participating in the On Track Study](#)





Newsletters

[On Track Study Family Newsletter, First Edition, March 2014 \(English\) \(Spanish\)](#)
[On Track Study Family Newsletter, Second Edition, September 2014 \(English\) \(Spanish\)](#)
[On Track Study Family Newsletter, Third Edition, June 2015 \(English\) \(Spanish coming soon\)](#)

Reports

Family Feedback Forms

- [Family Feedback Form sample](#)

After each study visit, parents will receive individualized feedback with a summary of their child's scores in Balance, Strength, Range of Motion, Endurance, Overall health, Participation in Family and Recreational Activities and Self-Care Activities.

Parents are encouraged to share the feedback forms with the child's treating therapist(s) to help therapists consider how child, family, and service factors interact when planning interventions and evaluating outcomes. The intent is to facilitate this exchange between families and therapists to broaden the focus of rehabilitation services for young children with CP to include not only development of motor abilities but also comprehensive interventions and supports to enhance participation in daily activities and routines.

Parent to Parent Articles *written by parents for parents*

Parent to Parent articles are helpful resources written by the Parent Investigators in the On Track Study. New articles will be posted as they are available.

- Parent to Parent: Therapy in Natural Environments by Kimberly Rayfield [\(English\)](#) [\(French\)](#) [\(Spanish\)](#)
- Parent to Parent: Learning to Transition by Marquitha Gilbert [\(English\)](#) [\(French\)](#) [\(Spanish\)](#)
- Parent to Parent: Talking with Others about Your Child and CP by Barbara Sieck Taylor and Paula Drew [\(English\)](#) [\(French\)](#) [\(Spanish\)](#)

For more useful tips like these on the *CanChild* website, see [Tips FOR parents of children and youth cerebral palsy, FROM parents \(English\)](#)

Potential Research Directions

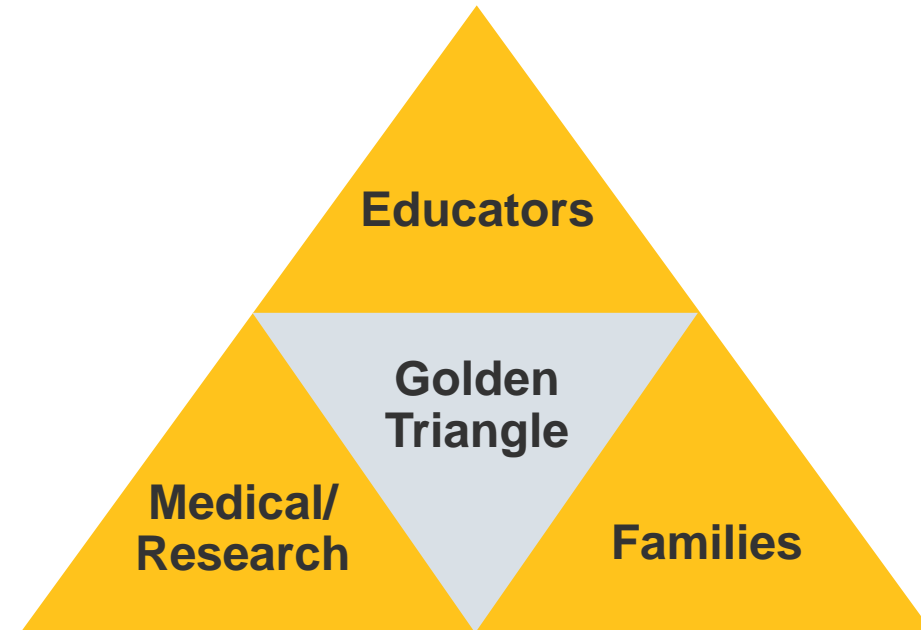
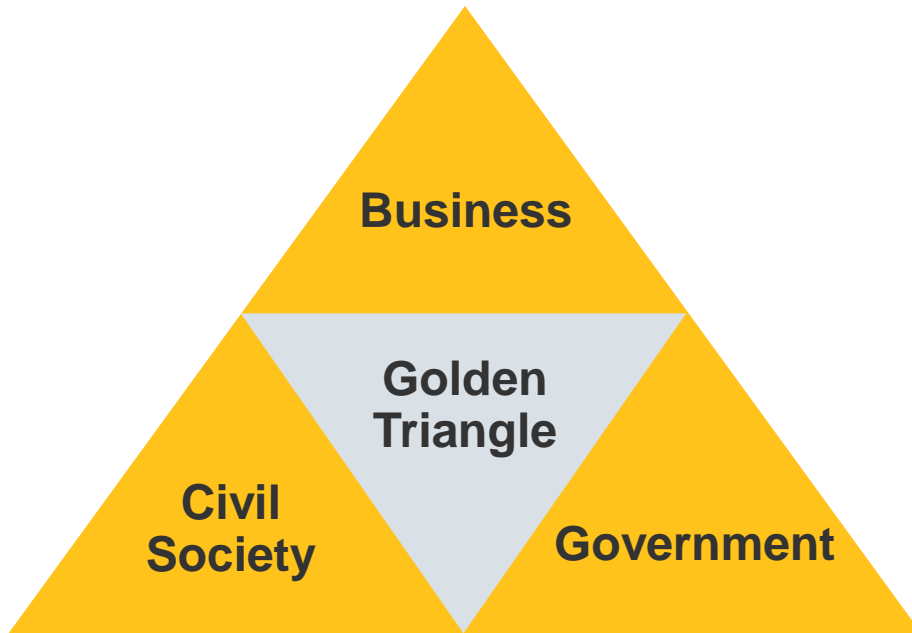
- Exploration of the impact of collaborative work between consumer & researcher
- Investigating benefits, barriers, challenges of moving into the other levels of collaboration based on Turnbull, et al, 1998 identified a continuum of family participation
- In-depth exploration of what parents want to know related to their children
- In-depth exploration of what children want to know

Many granting agencies are requiring consumer/family involvement to avoid research that is not meaningful & helpful to families.



The Parent Perspective

Family Perspectives



Parent Participation to Date

- Started in mid 2013
- Team meetings via conference call once a month for 60-90 minutes
- Prep time for team meetings 60-90 minutes per month
- 1-2 Focus group conference calls per year
- Develop parent to parent topics for newsletters
 - Therapy in Natural Environments
 - Talking with Others about Your Child and Cerebral Palsy
- Developing short video productions
 - Standardized measures - “One Size Does Not Fit Everyone”
 - Understanding children and youth perspectives and preferences
- Prepared exit survey to understand participants’ experiences in the study
- Optional Study investigator teleconferences for 2 ½ hours once a month

Example: Parent Focus Group Questions

1. What do families want to know about the development of their children with cerebral palsy?
2. What do school age children and youth with cerebral palsy want to know about their motor development?
3. How do families use the results of physical therapy assessments?
4. How are goals for physical therapy determined?
5. What role do parents have in the physical therapy assessment of their child?

Family Perspectives: Benefits

- Provides greater credibility to research process
- Encourages higher participation of families in research study
- Researchers better understand family challenges
 - PT, OT, Speech, Neurologist, Neurosurgeon, Special Educator
- Stronger dialogue among clinicians and families
- Questions & results are in “family friendly” language
 - Gross Motor Function Measure (GMFM)
 - How child is progressing vs. comparison to other children
- Creates network of parents to share learnings & experiences
- Provides HOPE to parents, families & children

Family Perspectives: Barriers

- Time for preparation and participation
- Right parents & families
 - Varying ages of children & experiences is beneficial
 - Willing to share feedback & experiences
 - Strong listening skills
 - Respectful and supportive, not critical
- Comfortable collaborating in a “virtual” environment
- Committed to helping other families

Your Questions or Experiences?