



# Caregiver Contributions to Development and Trial Implementation of a Relationship-Based Early Intervention for Young Children With or at Risk for FASD

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We have no conflicts of interest to disclose.

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An Early Intervention Enhancement for Infants and Toddlers with Prenatal Alcohol Exposure with or at-risk for Fetal Alcohol Spectrum Disorders

# Presentation Objectives

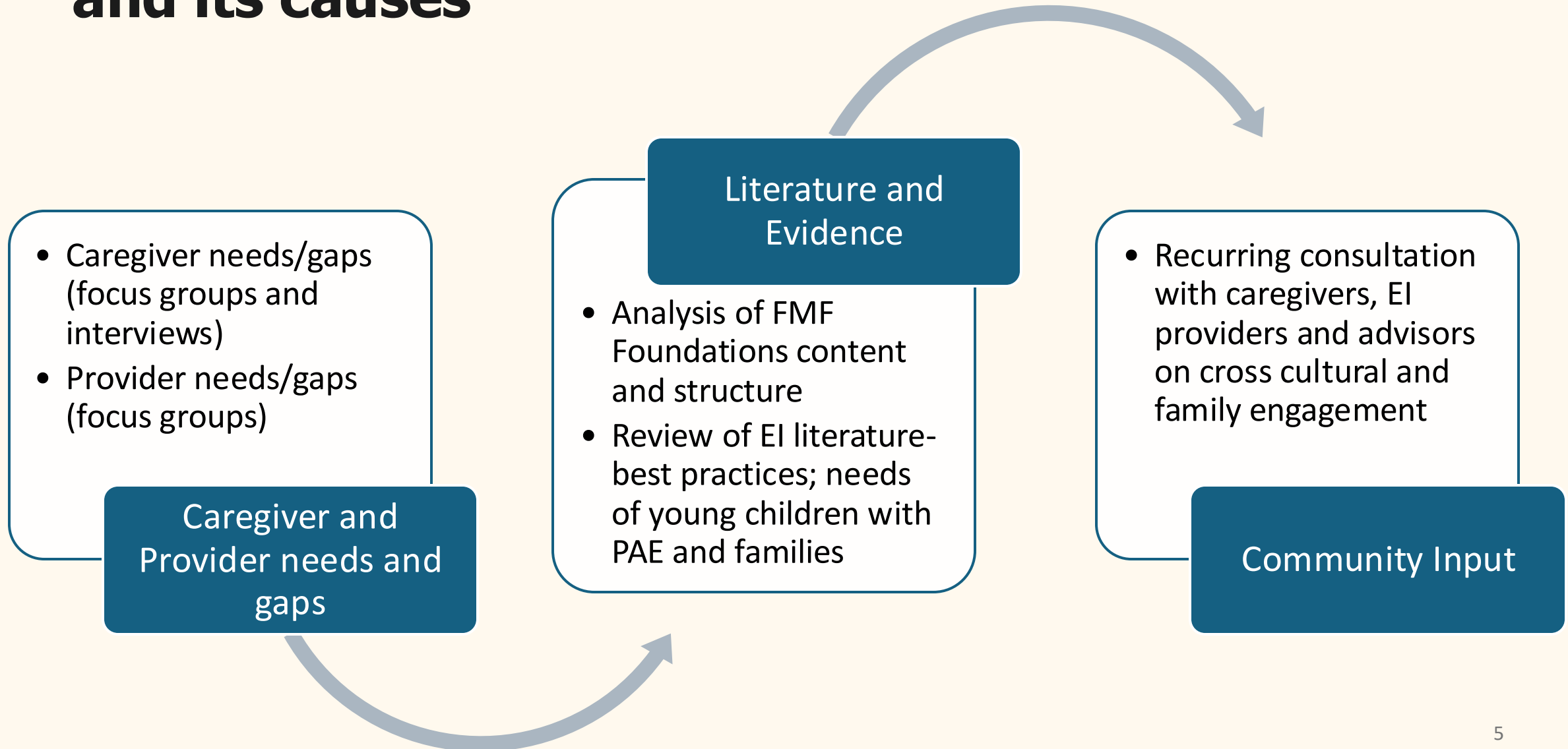
1. Understand how caregiver experiences and input shaped the systematic development process of FMF Bridges using the 6 SQuID Framework.
2. Identify unique intervention components that, among other elements, provide “care for the caregiver”.
3. Learn about preliminary experiences of caregivers involved in a small-scale feasibility trial.

# Steps for Quality Intervention Development (6SQuID) Framework

1. Defining and understanding the problem and its causes
2. Identifying which causal or contextual factors are modifiable
3. Deciding on the mechanisms of change
4. Clarifying how these will be delivered
5. Testing and adapting the intervention
6. Collect sufficient evidence of effectiveness to support rigorous evaluation

(Wight et al 2015; 2016)

# Step 1: Defining and understanding the problem and its causes



# Descriptive Research to Lay the Groundwork



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## Research in Developmental Disabilities

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Research  
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Developmental  
Disabilities

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The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders




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# Descriptive Research to Lay the Groundwork

*Article*

## Concerns and Strengths: Caregiver Perceptions of Their Infant/Toddler with Prenatal Alcohol Exposure <sup>†</sup>

Misty Pruner <sup>1,\*</sup> , Tracy Jirikowic <sup>2</sup>, Carolyn Baylor <sup>2</sup> and Susan Astley Hemingway <sup>3</sup>

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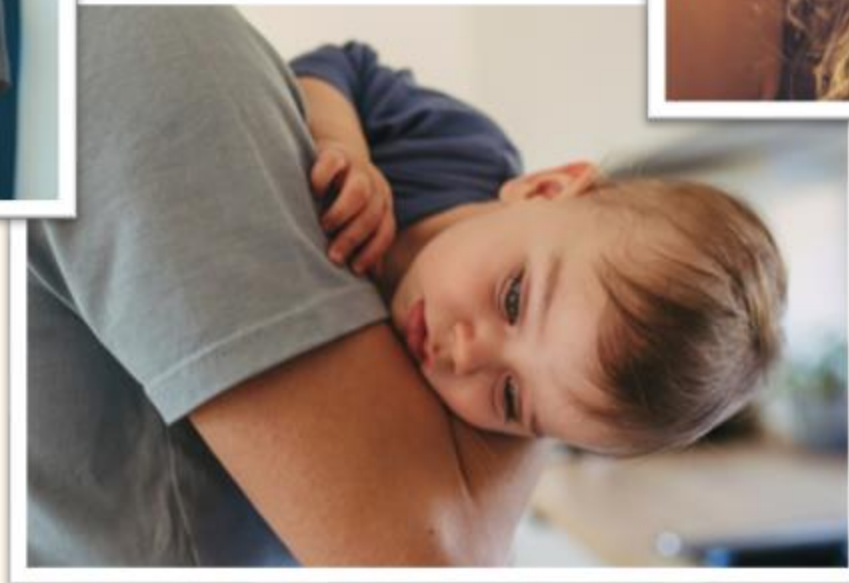
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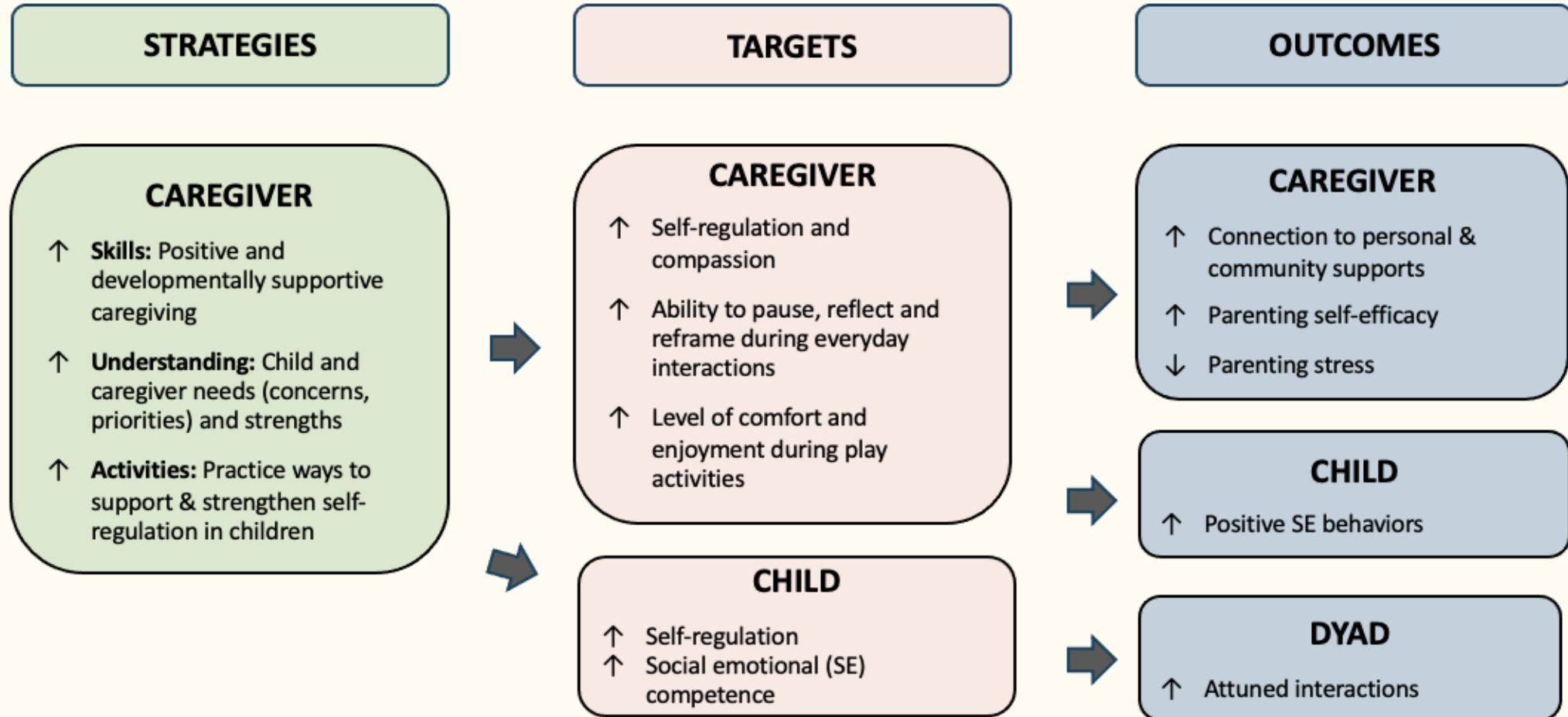
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† This is a part of a Ph.D. Thesis by Misty Pruner in the University of Washington.

## Step 2: Identifying modifiable factors



# Step 3: Mechanisms of change



# Step 4: Clarifying how these will be delivered

- Intensity
  - Weekly/every other week, 1-hour sessions
- Duration
  - 10 home visits over 3-5 months
- Delivery
  - Trained community EI providers
  - Conducted in home with caregiver following current EI practices

Session 1	Introduction to FMF Bridges
Session 2	Knowing Your Child
Session 3	Knowing Yourself
Session 4	Self-Regulation and You
Session 5	1-2-3 Count on Me
Session 6	Seeing Things Differently
Session 7*	Sleep and Eating Problems
Session 8*	A Sensory Conversation
Session 9*	Advocacy and Resources
Session 10	OPEN/FLEX

## Step 4: Clarifying how these will be delivered

How this shows up in our work

- Provider is strengths-based, relationship-focused and culturally connected.
- Provider uses a parallel process with caregiver.
- Provider supports caregiver to:



# One example...

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Research in Developmental Disabilities

journal homepage: [www.elsevier.com/locate/redevdis](http://www.elsevier.com/locate/redevdis)



The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders



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**Session 1:**  
Introduction to  
FMF Bridges

*Example 1*

FMF Bridges 3 Aims:

1 Strengthen the relationship  
between you and your child

2 Reduce sources of stress  
for your family

3 Support self-regulation skills

## Session 3: Knowing Yourself

### Example 1

## UNDERSTANDING YOUR NEEDS

Every caregiver experiences stress of some kind. Some caregivers experience more stress than others. You may have many different thoughts and feelings in your mind all at once. They may be taking up a lot of space and energy. When this happens, it can be hard to attend to your child or connect with them in the way you normally do or want to do.

Below, caregivers of young children shared some of the everyday challenges they face. Some of these may be true for you or you may have different challenges.

A word cloud of caregiver challenges. The words are arranged in a roughly circular shape, with varying font sizes and colors. The most prominent words are 'Mental Health', 'Family Conflict', 'Housing', 'Child Health', 'Exhaustion', 'Money', 'Childcare', and 'Job'. Other words include 'Safety in My Home', 'Transportation', 'Respite', 'Unpredictable Schedule', 'Nutrition', 'Safety in My Community', 'Finances', 'Exercise', 'Stigma', 'Discrimination', 'Quality friendships', 'Caregiver Health', 'Racism', 'Shame', 'Addiction', 'Access to Resources', 'Hospitalizations', and 'Setting Boundaries'.

Safety in My Home  
Transportation Respite Money  
Mental Health Unpredictable Schedule  
Nutrition  
Safety in My Community Family Conflict  
Childcare Finances Exercise Stigma Discrimination  
Quality friendships Housing Caregiver Health  
Exhaustion Racism Shame  
Addiction Access to Resources Child Health  
Job Setting Boundaries Hospitalizations

## How it's going...

**Themes** from  
implementation &  
provider fidelity data

### **Creates:**

- A dedicated space to reflect
- Opportunity to identify current stressors
- Awareness of existing family strengths

**Provider quote**  
from implementation  
& fidelity data

S3: Knowing  
Yourself session

*A dedicated time to look at their stressors...helped mom realize that she took the most difficult first step (asking for help) which resulted in all the support that followed... that was powerful to witness*

**Provider quote**  
from implementation  
& fidelity data


S3: Knowing  
Yourself session

*Identified her source of stress (e.g., guilt that she is not spending enough time with child, she is not providing enough for him) and lots of affirmation that she is doing an amazing job to truly know him and take care of him the best she can.*

# Another example...

*Article*

## **Concerns and Strengths: Caregiver Perceptions of Their Infant/Toddler with Prenatal Alcohol Exposure <sup>†</sup>**

Misty Pruner <sup>1,\*</sup> , Tracy Jirikowic <sup>2</sup>, Carolyn Baylor <sup>2</sup> and Susan Astley Hemingway <sup>3</sup>

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## **Session 1:** Introduction to FMF Bridges

*Example 3*

### **What does the research say about strengths?**

Research studying young children with prenatal alcohol exposure found that caregivers had many **strengths** to share about their child. Here are the top 5!

She is a  
happy baby

He is friendly  
& social

My child is  
so lovable

Curious &  
tries everything

Smart &  
bright

## **Session 6:** Seeing Things Differently

### *Example 3*

### **What does the research say about challenging behaviors?**

Caregivers of young children with prenatal alcohol exposure reported concerns about a wide range of behaviors. Here are some of their biggest concerns.

She screams  
loudly

He bangs his  
head when mad

She has a  
big temper

He has sudden  
mood changes

They can be  
fussy and whiny

## How it's going...

**Themes** from  
implementation &  
provider fidelity data

### **Helps to:**

- Recognize and celebrate child strengths
- Normalize experiences

## **Provider quotes**

from implementation  
& fidelity data

S1 and S6

*Child just had some leaps with his skills in a few areas, and it was delightful to celebrate his growth with mom*

*Learning that child is doing well in sensory processing is reassuring and relieving to mom...*

*Parent appreciated knowing that sleep is hard for a lot of families.*

# Step 5: Testing and Adapting the Intervention

Demographics	Enrolled (n=8)	Completed (n=4)
<b><u>Child</u></b>		
Age at baseline	M=28.7 mos ; 6-32 mos	M=24.0 mos; 23-32 mos
Sex at birth	Female:1; Male: 7	Male: 4
<b><u>Primary Caregiver</u></b>		
Biological parent	5	1
Foster parent	1	1
Adoptive parent	2	2
<b><u>Prenatal alcohol exposure</u></b>		
High risk	5	2
Some risk	3	2

# Step 5: Testing and Adapting the Intervention: Intervention Fidelity

## SESSION THREE: Knowing Yourself

YES	NO	Comments
<input type="checkbox"/> Beginning ARC	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Check in	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Share handout 3A	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Listen to meditation	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Share handout 3B	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Middle ARC	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Play Activity	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	
<input type="checkbox"/> Closing ARC	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5	

If an activity is done, place a checkmark in checkbox. If an activity is not done, check the following code above:

- 1 = No time or interrupted
- 2 = Infant/toddler state did not allow
- 3 = Caregiver did not want to do
- 4 = FMF Bridges Provider decided not appropriate
- 5 = Other (specify)

# Questions from our caregiver interview guide

1. Focusing on logistics, how well did the following work for you?
  - Session length and frequency
  - Handouts
  - Video/meditation
  - Play activities
  - Learning materials
2. What were your favorite parts or key takeaways?
3. If you're seeing value in the program, how can we make it more feasible to participate?
4. If you're not seeing a lot of value, how can we make it more feasible to participate?

Paraphrased from  
**caregiver exit  
interview**

***Initial impression:***

*It was awesome.*

*Guidance was helpful. Liked the combination of just enough structure but also lots of "space" for conversations.*

Paraphrased from  
**caregiver exit  
interview**

***Regarding logistics:***

*I liked the consistency of every week for 10 weeks to just move through it at a steady pace and have the certainty of the schedule and move through it*

Paraphrased from  
**caregiver exit  
interview**

## ***Overall experience:***

*It was like....a therapy session but it's so necessary and then you loop it into a playtime with the children and you realize how it all fits and why it's important*

*...but led by a professional who's telling us, guiding us and ...giving us space for reflection is just as valuable and meaningful where I'm sure not a lot of families have time to reflect and talk through those things...the protected space.*

# Step 6: Collecting sufficient evidence of effectiveness to support rigorous evaluation

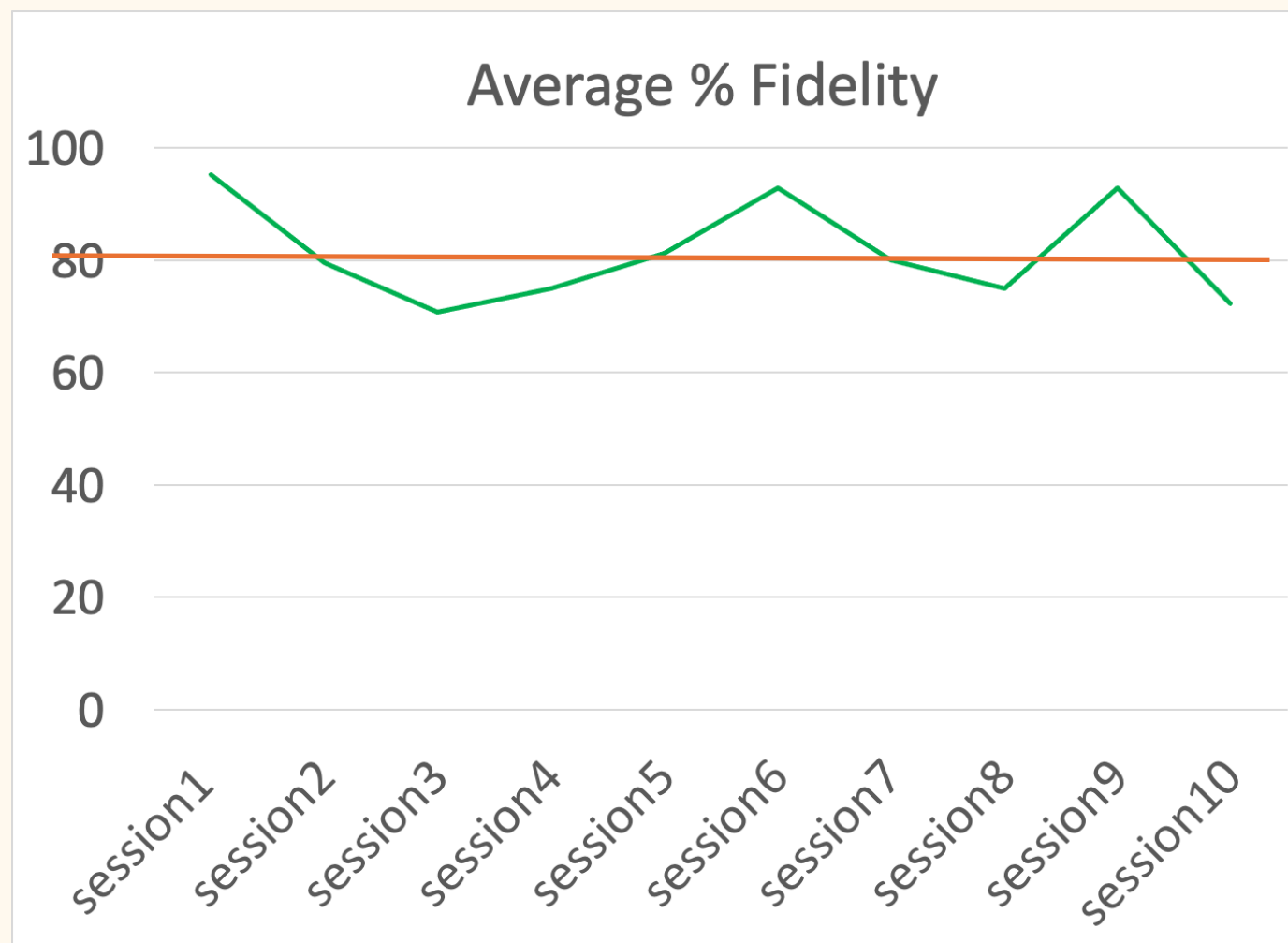
## 3 Key Milestones:

**1) Can FMF Bridges be implemented with fidelity?**

**2) Is FMF Bridges acceptable to providers?**

**3) Is FMF Bridges acceptable to caregivers?**

# 1) Can FMF Bridges be Implemented with Fidelity?

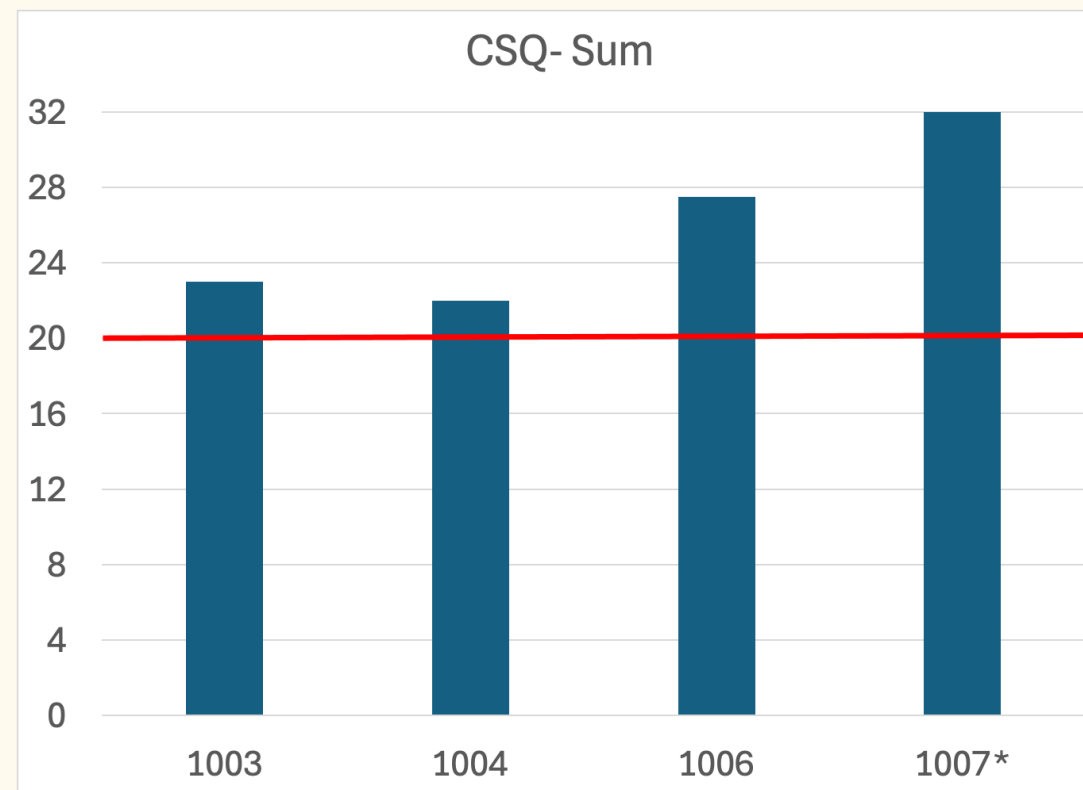


### 3) Is FMF Bridges Acceptable to Caregivers?

#### Client Satisfaction Questionnaire (CSQ-8)

- Self-report measure to assess satisfaction of a treatment or intervention program.
- 8 items
  - Each item scored 1-4
  - Total score range: 8-32

(Attkisson & Zwick, 1982; Larsen et al., 1979)

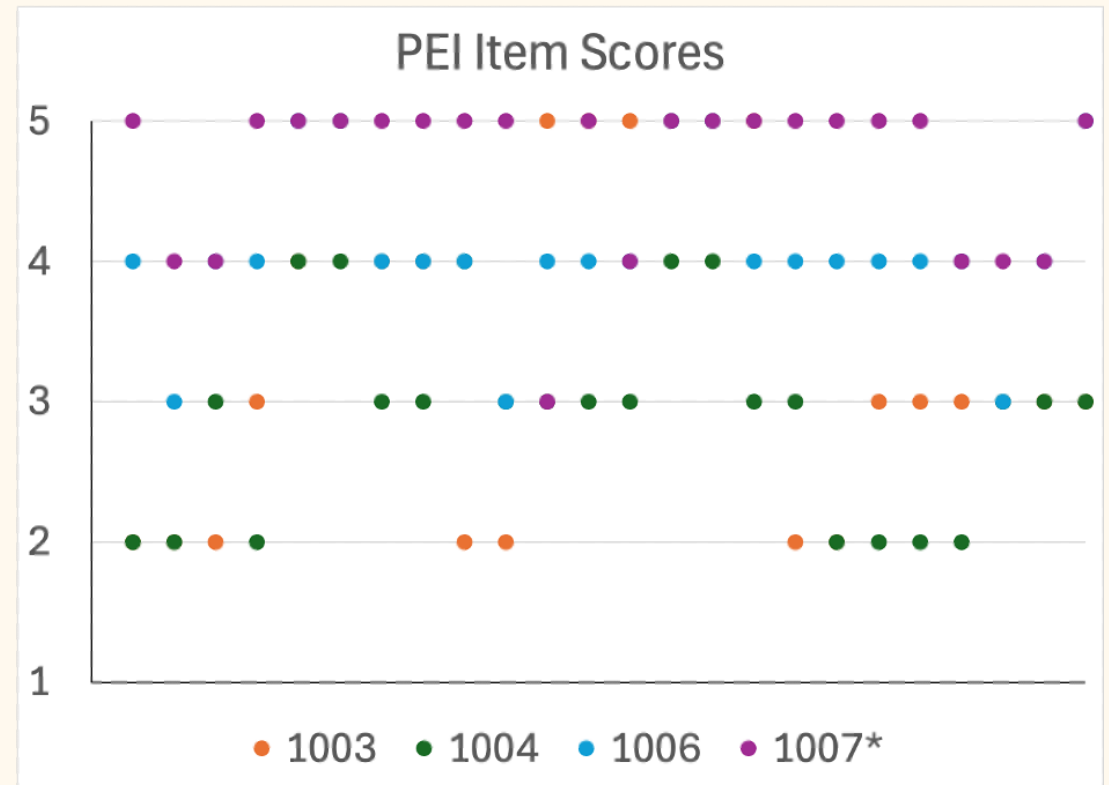


# 3) Is FMF Bridges Acceptable to Caregivers?

## Parent Evaluation Inventory (PEI)

- Self-report measure to assess parents' learning experience of an intervention
- 24 items
  - Each item scored 1–5
  - Total score range: 24–120

(Modified from Kazdin, 1987)



## Key messages and next steps:

- Caregiver contributions underpin FMF Bridges intervention development
- Provided examples of where caregiver input "shows up" in FMF Bridges
- Showing promising fidelity outcomes and providers are engaged and invested!
- Promising acceptability outcomes from a small number of caregivers who finished FMF Bridges

# Thank you to our team and questions

- Tracy Jirikowic, [tracyj@uw.edu](mailto:tracyj@uw.edu)
- Misty Pruner, [mpruner@uw.edu](mailto:mpruner@uw.edu)
- Heather Carmichael Olson
- Lin-Ya Hsu
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- Monica Smersh
- Suzie Kirschner
- Carolyn Baylor
- Andrew Humbert
- Advisory Panels

