

IRG: Smart and Connected Family Engagement for Equitable Early Intervention Service Design



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Project Challenge

- Practitioner and family experiences of pediatric re/habilitation can be inequitable.¹⁻²
- The Young Children’s Participation and Environment Measure (YC-PEM) is an evidence-based and promising electronic patient-reported outcome measure that was designed with and for caregivers for research and practice.³⁻⁵
- This project examined historically minoritized caregivers’ responses to improve YC-PEM and Participation and Environment Measure (PEM) reach for equitable service design.⁶

Intellectual Merit

- Our project advances a smart and connected approach to family-centered early intervention (EI) service design by 1) upgrading the Participation and Environment Measure Plus (PEM+) prototype and 2) evaluating the upgraded PEM+ version within EI.
- The second year focused on PEM upgrades, including the development of new PEM content about the impact of racial inequity on children’s participation and conducting cognitive testing of new PEM content. This information was used to develop a virtual conversational agent (VCA) to help caregivers navigate PEM+.

Supplemental Materials and References



Major Outcomes/Progress

- We completed 8 semi-structured cognitive interviews (55-90 minutes each) using videoconferencing to gather caregiver feedback (see Figure 1). Interviews were transcribed verbatim, cross-checked for accuracy, and deductively and inductively content analyzed by multiple staff in three rounds.
- We examined caregiver experience with dialogue agents to define functional requirements needed to pursue user-centered design of an intelligent VCA for supporting PEM user navigation (see Figure 2).
- We examined caregiver perspectives of the clarity and relevance of proposed YC-PEM content modifications (see Table 1).

Figure 1. Child and Caregiver Characteristics

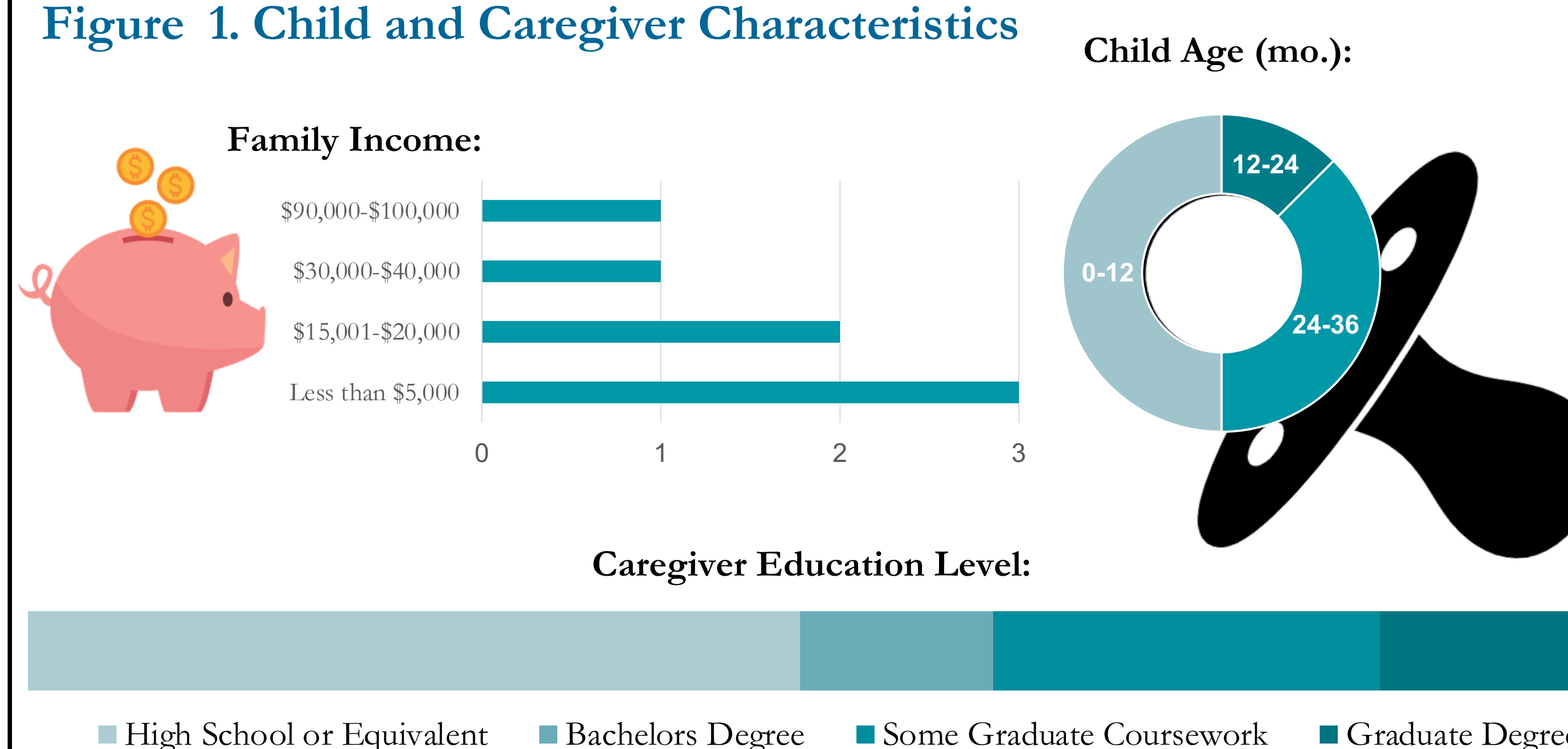
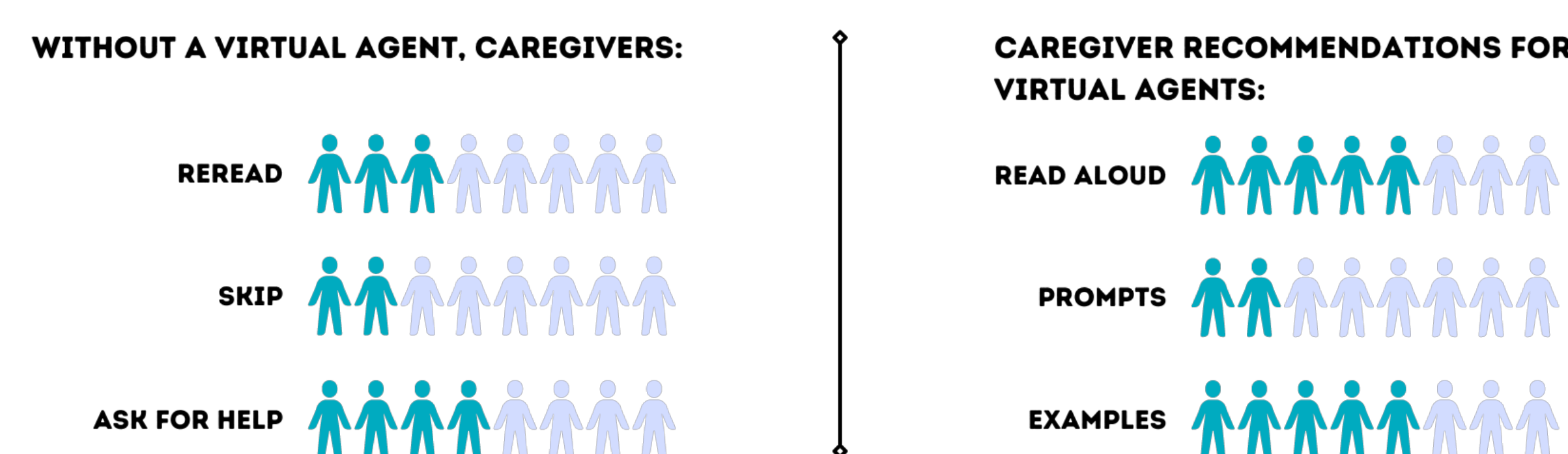


Figure 2. Caregiver Feedback to Improve User Navigation



Major Outcomes/Progress (cont.)

Table 1. Caregiver Feedback on YC-PEM Environmental Assessment

Requested Edit	Environment	Exemplar Quote
Clarify Items 	Home	CG4: “I think you should put positive or negative behaviors when a professional who cares for your child comes into your home cause I’m not gonna lie I didn’t know what the microaggressive – I just saw aggressive and behavior. I was like, okay, it’s gotta be with the kid but it wasn’t”
	Community	CG1: “Working at a restaurant or a store ... Children are people, they are going to come in. But instructors and coaches and childcare providers ... that’s part of your job description”
Remove or Simplify Terms 	Home	CG3: “Just a simple, negative or positive behaviors ... I think simple words to make it clear what you’re looking for”
	Community	CG5: “Not every parent has the privilege of being in a higher education or getting the privilege of knowing in some ways saying they are synonyms. So it’s better to use a very simple word that everybody can understand it”
Add Item Examples 	Home	CG3: “We know that that person (babysitter) is an ally, not just to his development, but to help us as well”
	Community	CG7: “Children saying “he can’t play over here” or “we own this””
Understanding Environmental Content Modifications 	Home	CG4: “I don’t do bad energy. You ain’t even gonna step in my house”
	Community	CG6: “I mean, where we live, she goes and does activities but their attitudes are still OK. I mean, when we go do activities like her music and me class, I mean there’s no one that looks like her, but there’s still positive attitudes towards her”

Broader Impact

- Caregiver feedback will be mapped to framework evaluating VCA functionality for PEM.⁷
- Content upgrades can improve tool validity when capturing systemic inequalities impacting children’s participation in home, daycare/preschool, & community environments.

Future Goals

- Evaluate the upgraded PEM electronic option using a hybrid study design to identify supports and barriers to implementing it in EI practice.