

# Diversifying caregiver input to upgrade the Young Children's Participation and Environment Measure



for equitable pediatric re/habilitation practice



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## Purpose

- To examine caregiver experience with dialogue agents to define functional requirements needed to pursue user-centered design of an intelligent virtual agent for supporting Participation and Environment Measure (PEM) user navigation.
- To examine caregiver perspectives of the clarity and relevance of proposed Young Children's Participation and Environment Measure (YC-PEM) content modifications.

## Premise

- Practitioner and family experiences of pediatric re/habilitation can be inequitable.<sup>1-2</sup>
- The YC-PEM is an evidence-based and promising electronic patient-reported outcome measure that was designed with and for caregivers for research and practice.<sup>3-5</sup>
- This study examined historically minoritized caregivers' responses to improve YC-PEM and PEM reach for equitable service design.

## Methods

**Study Design:** Established Cultural Adaptation Methods<sup>6</sup>

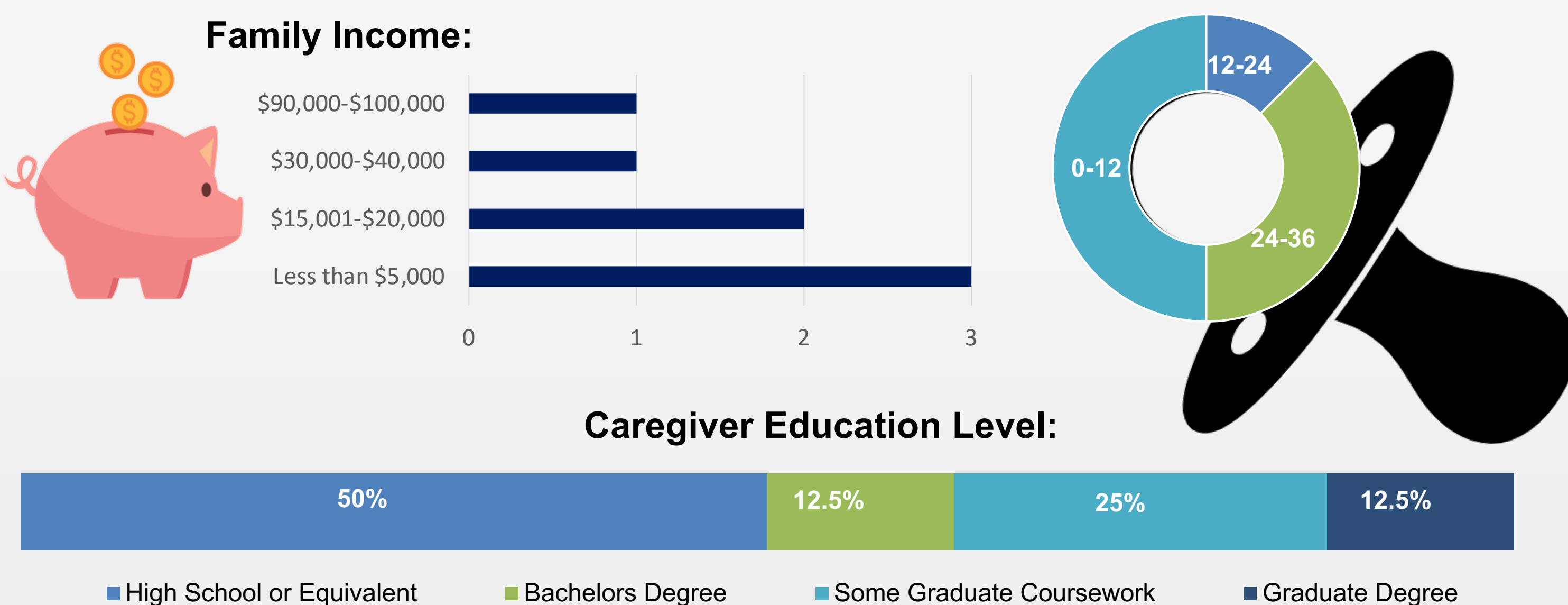
**Sample:** Eight Black, non-Hispanic or publicly insured caregivers were enrolled, with children 0-3 years old (M = 21.2 months) enrolled in early intervention.

**Data Collection:** Semi-structured cognitive interviews (55-90 minutes each) used videoconferencing to gather caregiver feedback on their responses to select content modifications while completing YC-PEM, and their ideas for core intelligent virtual agent functionality.

**Data Analysis:** Interviews were transcribed verbatim, cross-checked for accuracy, and deductively and inductively content analyzed by multiple staff in three rounds.

## Results

**Figure 1. Child and Caregiver Characteristics**



**Figure 2. Caregiver Feedback to Improve User Navigation**

**WITHOUT A VIRTUAL AGENT, CAREGIVERS:**



**CAREGIVER RECOMMENDATIONS FOR VIRTUAL AGENTS:**



## Results

**Table 1. Caregiver Feedback on YC-PEM Environmental Assessment**

Requested Edit	Environment	Exemplar Quote
Clarify Items 	Home	<b>CG4:</b> "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	<b>CG1:</b> "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	<b>CG3:</b> "Just a simple, negative or positive behaviors ... I think simple words to make it clear what you're looking for"
	Community	<b>CG5:</b> "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	<b>CG3:</b> "We know that that person (babysitter) is an ally, not just to his development, but to help us as well"
	Community	<b>CG7:</b> "Children saying "he can't play over here" or "we own this""
Understanding Environmental Content Modifications 	Home	<b>CG4:</b> "I don't do bad energy. You ain't even gonna step in my house"
	Community	<b>CG6:</b> "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"

## Conclusion

- Caregivers gave concrete suggestions to simplify the language used for anti-racist items, modify questions by breaking down its component parts, and provide more definitions/examples.
- Content upgrades can improve the validity of the tool in capturing systemic inequalities that can impact children's participation in their home, daycare/preschool, and community environments.
- Caregiver feedback can define framework for evaluating virtual agent functionality for PEM.

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