

# On the Move: Feasibility and Acceptability of an In-Home Body Weight Supported Harness System for Infants with Down Syndrome

Jana M. Iverson<sup>1</sup>, Marie Canty<sup>2</sup>, Izza Choudhry<sup>1</sup>, Ashley N. Collimore<sup>1</sup>, Anna Donato<sup>1</sup>, Erica Friedman<sup>1</sup>, Marc Maffei<sup>1</sup>, Katherine Pawlowski<sup>2</sup>, Sydney Reynders<sup>2</sup>, and Nicole Baumer<sup>2</sup>

<sup>1</sup>Sargent College of Health and Rehabilitation Sciences, Boston University, <sup>2</sup>Down Syndrome Program, Boston Children's Hospital

## Background:

- Early mobility drives exploration, communication, and interactions with caregivers
- Infants with Down syndrome (DS) have substantial delays in onset of independent mobility
- Cost-effective, caregiver-implemented interventions that support mobility may have a powerful effect on development and foundational learning skills in infants with DS

## Research Aims:

In order to support clinical trial readiness of the PUMA body-weight support harness system as a home-based mobility intervention, for infants with DS, we aimed to:

1. Identify home-based observational and standardized developmental assessment measures that are best suited to serve as primary outcome measures during a clinical trial
2. Examine the feasibility and acceptability of the PUMA system for infants with DS and their families

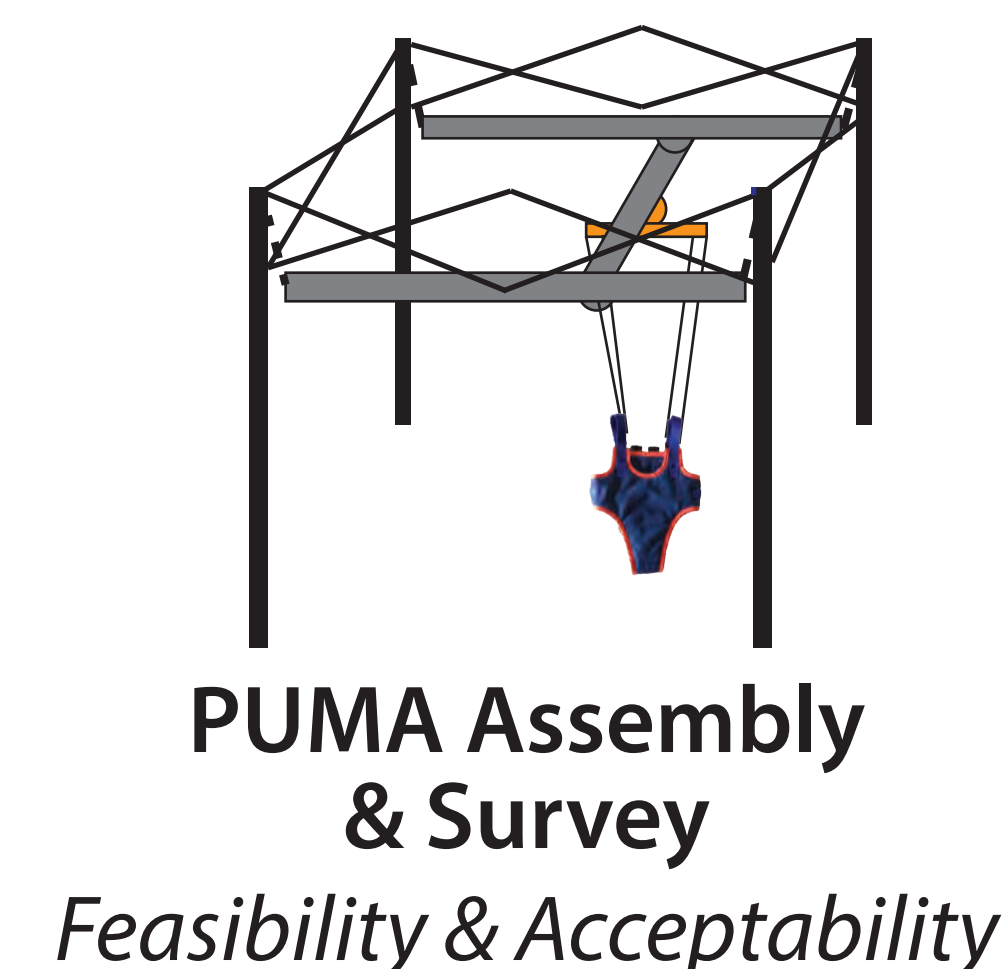
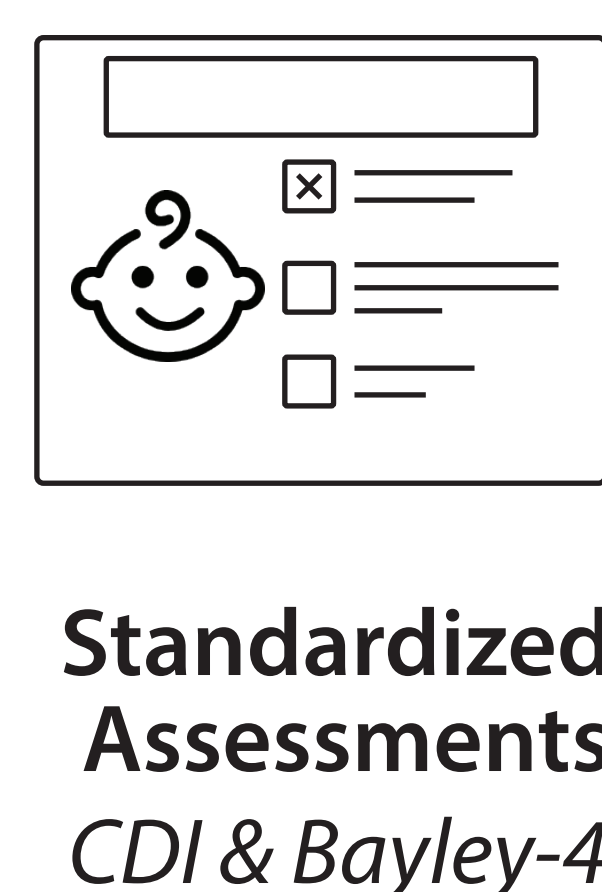
## Methods:

### Aim 1

- 7 infants with DS able to sit independently
  - Age 14 ± 4 mo. at 1<sup>st</sup> visit, 4 males
  - Home-based observations
  - Communication development measured monthly
  - Cognition and Gross Motor measured at 1, 3, & 6 mo.
- 7 age- and sex-matched typically developing (TD) infants
  - 5 walkers, 2 pre-walkers, single home-based observation

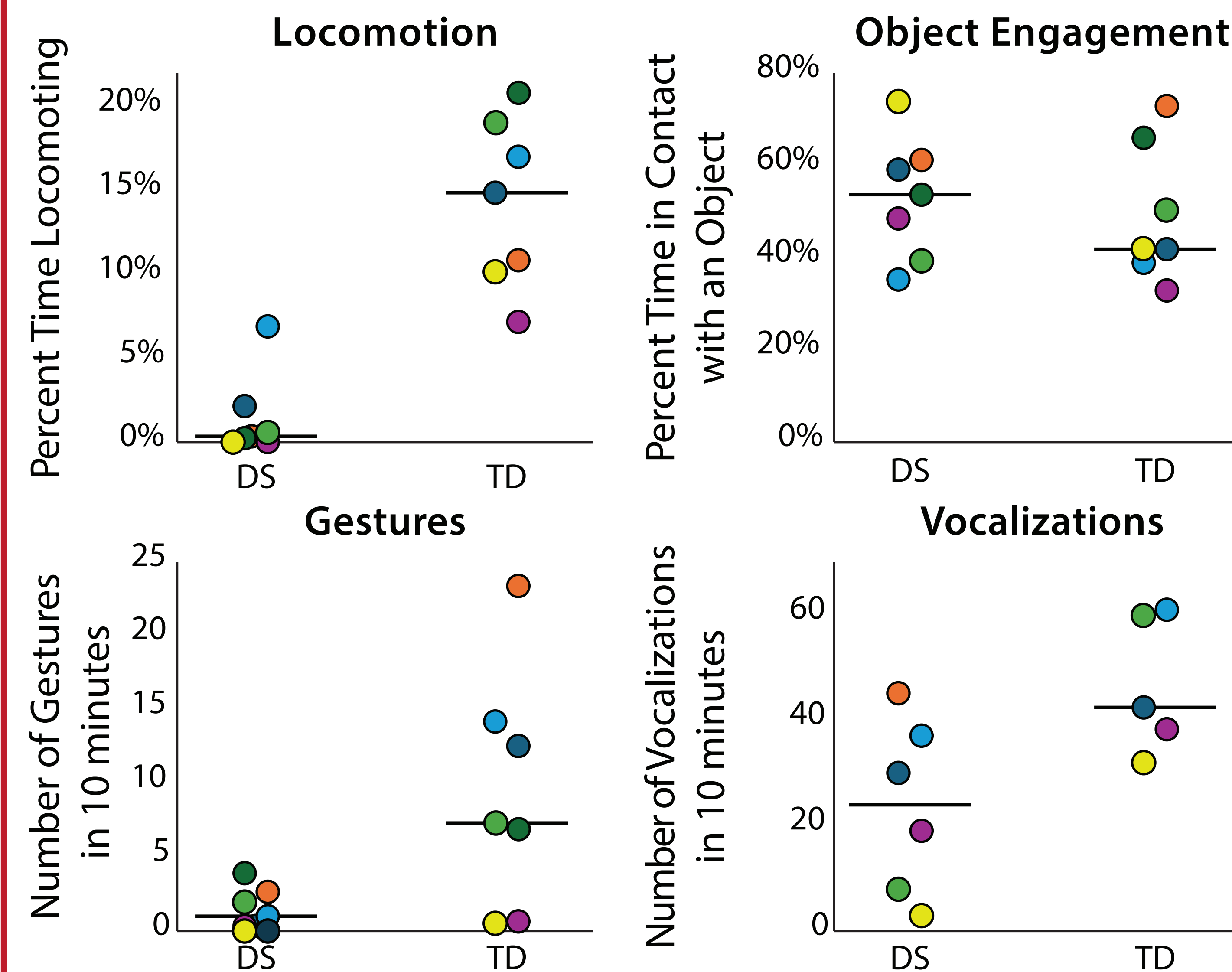
### Aim 2

- 8 caregivers of infants with DS completed one PUMA assembly session



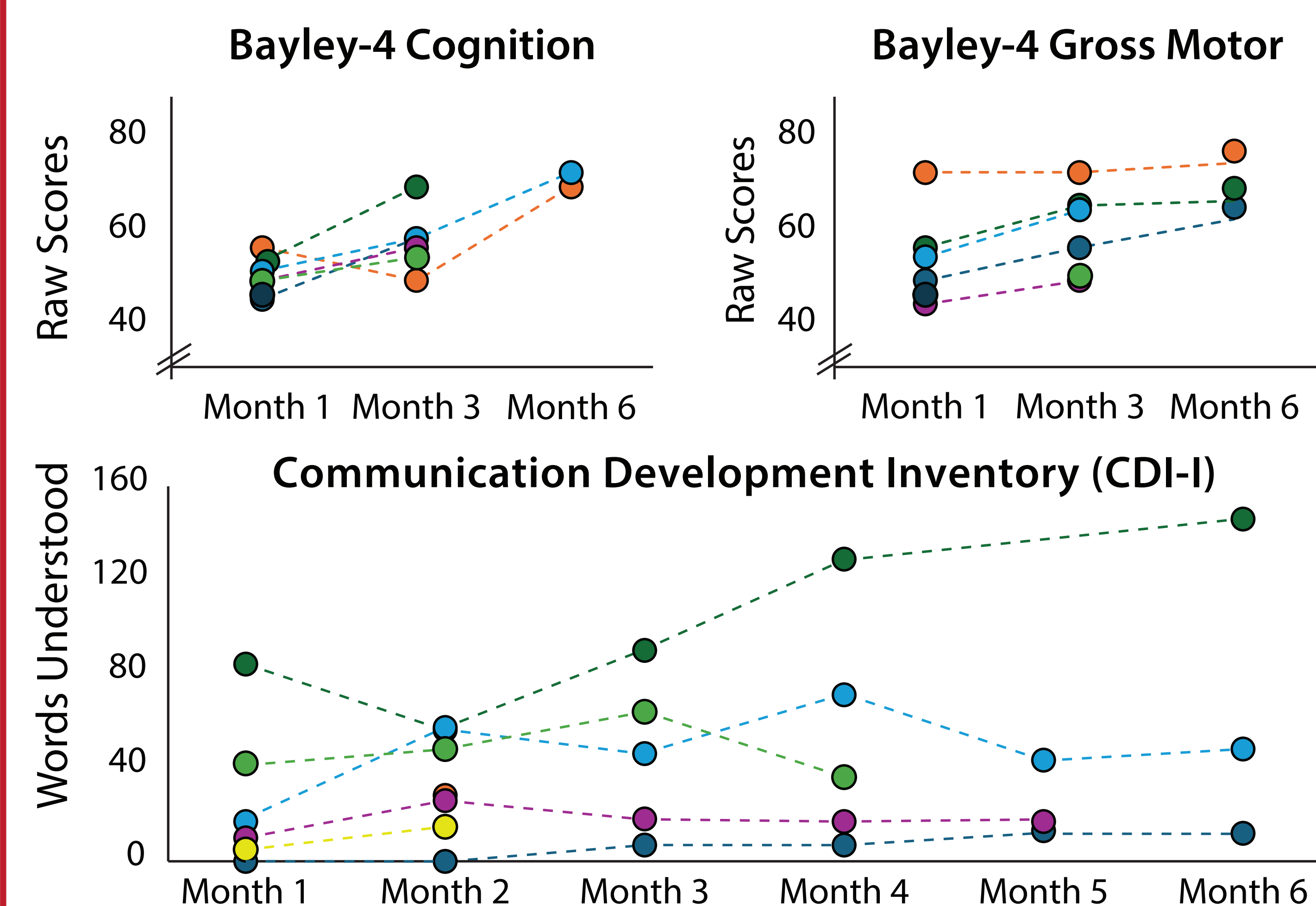
## Aim 1: Observational Outcomes

Infants with DS spend less time moving and communicate less frequently than TD infants.



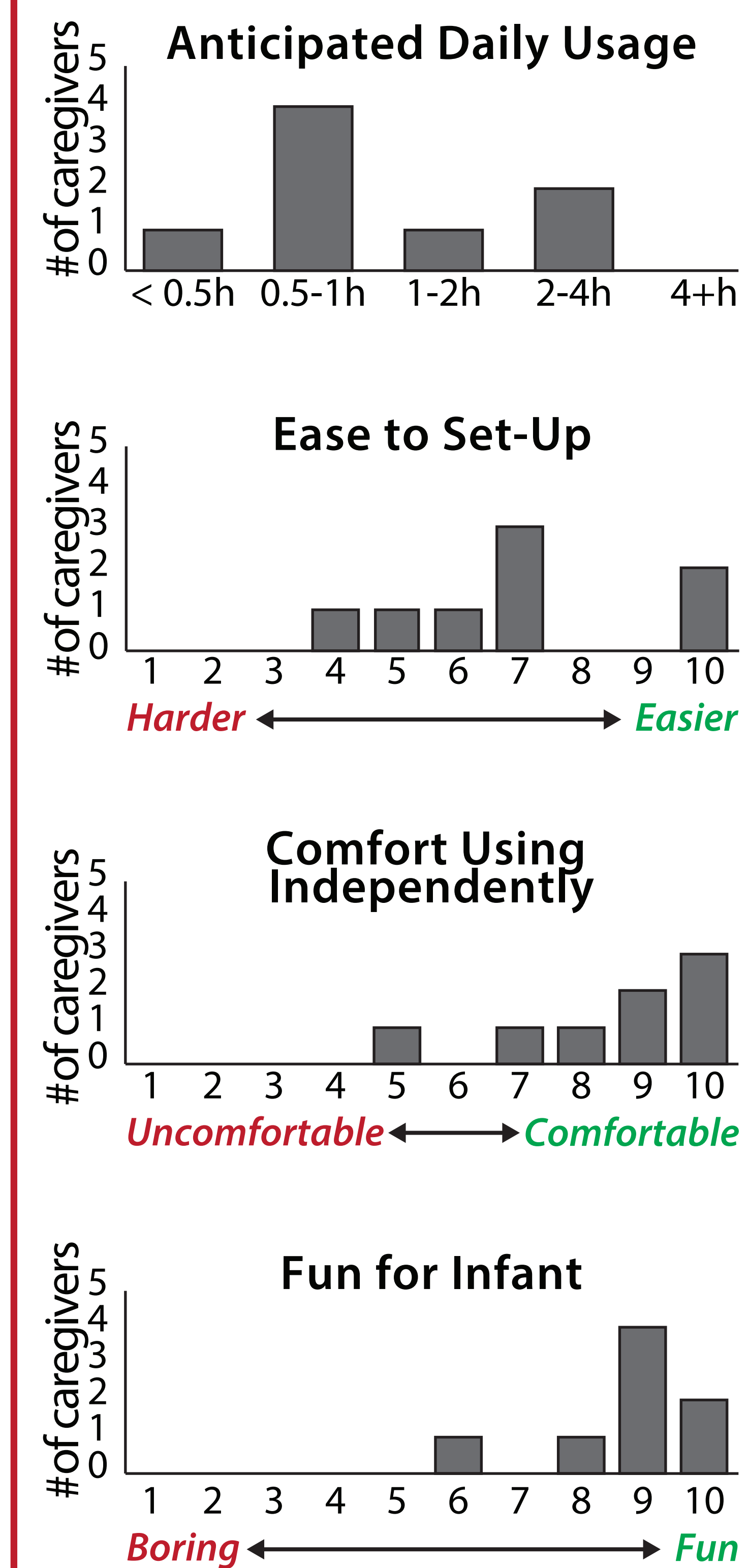
## Aim 1: Standardized Developmental Assessment Outcomes

Infants with DS showed wide variability in scores on standardized developmental assessments.



## Aim 2: PUMA Feasibility & Acceptability

Caregivers (n = 8) had positive reactions to the PUMA system.



PUMA Body-Weight Support Harness system

"I like that it would keep her upright and encourage her to move and strengthen her legs AND not take a toll on my back."

"The concept is great and I don't know of another product that's like it."

"[I like] That it's a different experience for my child."

"[I like] The ability for my daughter to work on weight bearing and standing. I feel she would engage better with play if she had more mobility."

## Conclusions

1. Observational and developmental measures collected at home are appropriate for infants with DS.
2. The PUMA system is acceptable to caregivers and feasible for use at home.

These results set the stage for the first clinical trial of a home-based mobility-supported intervention specifically tailored for infants with DS.

## Acknowledgments:

This project is supported by NIH-INCLUDE 1R21HD111945-01.  
Thank you to our participants for their time and support!

