

# "MY KID SAID WHAT?!" PARTICIPATION AND PROMIS SELF-REPORT IN CHILDREN WITH LONG-TERM PHYSICAL DISABILITIES

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## BACKGROUND

**Participation:** Attendance and/or involvement within an activity

Children with long-term physical disabilities are at greater risk for lack of participation in various environments

**Purpose:** Determine how the following are associated in kids with physical disabilities:

- Perceived life participation
- Physical abilities
- Social functioning

## METHODS

### Inclusion Criteria

- Age: 8-17 years of age
- Gross Motor Function Classification System (GMFCS)
  - Levels 1,2 or 3
- Long-term physical disability: Cerebral Palsy, Spina Bifida and more
- Able to complete the self-report measures with minimal cueing / clarification

### Protocol

- In-person or tele-interviews using survey-based outcome measures, such as PROMIS, CASP and PASS

## OBJECTIVE MEASURES

### PASS Question

Thinking about all the ways your disability affects you, are you okay with how things are going right now?

Yes or No

### Ability to Participate

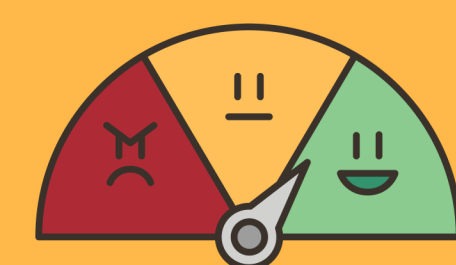
I participate in activities...

- Same as or more than others my age
- Somewhat less than others my age
- Much less than others my age
- Cannot participate like others my age

### PROMIS



Physical Mobility



Life Satisfaction



Peer Relationships

### CASP



Home Participation



Community Participation



School Participation

## RESULTS/FINDINGS

### Participants (n = 13)

- Age Mean: 13.2 years old
- Gender: F (54%)
- Location: Oregon (69%)
- Ethnicity: Caucasian (85%)
- Dx: Cerebral Palsy (77%)
- Average GMFCS Level: 1.9

### Statistical Results

- No statistically significant associations between measures

### Result 1

Higher self-scoring than anticipated, per caregivers + researchers

### Result 2

Only GMFCS Level 2 kids evaluated themselves as "Somewhat less than" for participation level

### Result 3

Only 23% of participants scored <40 in PROMIS Mobility

### Result 4

Majority scored ABOVE national average in Life Satisfaction (61%) + Peer Relationships (53%)

## DISCUSSION & IMPORTANCE

- Children with long-term physical disabilities might over-score themselves with PROs, suggesting that other factors besides disability (e.g. the child's self-efficacy) could impact self-rating.
- Occasionally missing out on a few activities or presenting with a more severe GMFCS level might not affect overall satisfaction negatively.
- Satisfaction with life participation in 8-17 year-olds w/ long-term physical disabilities might be similar to typically-developing kids in many cases.
- For children with long-term physical disabilities, physical therapists could focus more on assets and self-perceived capability.
- Future research should consider finding a participation PRO that is easier to understand for this population; also, consider how self-efficacy might affect self-perceived participation.

### REFERENCES

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