



# The Participation and Environment Measure for Children and Youth (PEM-CY)

**Gary Bedell, Ph.D., OTR/L, FAOTA**

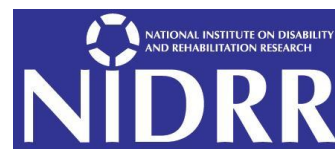
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# Research Team & Sponsors

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- 
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# Presentation Objectives

1. To describe the development of the Participation and Environment Measure for Children and Youth (PEM-CY)
2. To describe the psychometric properties (reliability and validity) of the PEM-CY
3. To show how scores obtained from the PEM-CY provide profiles of children's participation in home, school, and community settings
4. To discuss implications and future directions

# **OBJECTIVE 1: DEVELOPMENT OF THE PEM-CY**

*To develop a population-based measurement tool with information being gathered via parent-report.*

# Phase 1: Parent Perspectives to inform content, format and approach

1. What do parents perceive to be the **important types of activities** in which children and youth with disabilities participate?
2. What do parents identify as the **types of environmental factors** that support or hinder a child's participation in important life situations?
3. **How do parents appraise** their children's participation and the environmental supports and barriers to participation?

(Bedell, Khetani, Cousins, Coster, & Law, M., 2011).

# Phase 1: Parent Sample (*n*=41)

Variable		Disability Sample (n = 24)		No Disability Sample (n = 17)
		BU	McMaster	Tufts
<b>Respondent Mother</b>	<b>(<i>n</i>=38)</b>	14	9	15
<b>Race/Ethnicity</b>				
Caucasian	( <i>n</i> =36)	11	9	16
Black	( <i>n</i> =2)	2	0	0
Hispanic	( <i>n</i> =2)	1	0	1
Other	( <i>n</i> =1)	0	1	0
<b>Respondent Education</b>				
Graduate Degree	( <i>n</i> =15)	8	0	7
College Degree	( <i>n</i> =15)	4	3	8
Some College	( <i>n</i> =8)	1	5	2
High School / Less	( <i>n</i> =3)	1	2	0

# Phase 1: Child/Youth sample

Variable	Disability Sample (n = 24)		No Disability Sample (n = 17)
	BU	McMaster	Tufts
<b>Child's Age</b>			
5-12 (n=22)	8	8	6
13-17 (n= 19)	7	1	11
>18 (n=3)	0	3	0
<b>Child's Gender</b>			
Male (n=26)	10	7	9
Female (n=18)	5	5	8
<b>Primary Diagnostic Condition</b>			
Down Syndrome (n=5)	2	3	
Autism Spectrum, Asperger's (n=9)	7	2	
Dyslexia, Learning Disability (n=3)	2	1	
ADD/ADHD (n=5)	1	4	
Acquired Brain Injury (n=1)	0	1	
Other (n=4)	3	1	

# Phase 1: Key findings:

- **Important Activities:**

- Identified *home, school, and community* activities
- Consistency in responses *regardless of* whether child had disability or not

- **Environmental Factors:**

- Identified a *broader* range of environmental factors than what is reported in the International Classification of Functioning, Disability and Health (ICF)
- Identified factors specific to *the home, school, and community* settings

- **Ways of appraising children's participation:**

- Participation is a *multidimensional* construct
- Experience of participation is *inextricably* linked with environment
- Appraising participation and environment naturally leads to a conversation about *parents' strategies to promote participation*



# Implications of Phase 1 Findings that informed PEM-CY Design

- Incorporate parents' descriptions of relevant activities and factors in home, school, and community settings
  - Include items **not** in the ICF: **child factors, activity demands, safety, available and adequate resources**
- Capture ways that parents understand and judge participation
  - Participation is about **frequency** and **engagement/involvement**
  - Whether a parent **desires change** in their child's participation matters (*more is not always better, different expectations in different situations*)
- **Explicitly link** participation and environment in the **same** measure
- Ask about how parents promote participation in home, school, & community settings (i.e., their **strategies**)

# PEM-CY

- Parent-report - takes about 30 minutes
- 3 sections: Home (10 items), School (5 items), and Community (10 items)
- Each section asks about participation and environment
- **Participation Questions:**
  - **How often:** 8-point scale, from never (0) to daily (7)
  - **How involved:** 5-point scale, from minimally involved (1) to very involved (5)
  - **Desire for change:** Yes or No, along with 5 options to clarify the type(s) of change desired (*increase/decrease frequency, involvement, variety*)
- **Environment Questions:**
  - **Environmental factors and activity demands:** four options including, not an issue, usually helps, sometimes helps/sometimes makes harder, usually makes harder
  - **Resources:** four options including, not needed, usually yes, sometimes yes/sometimes no, usually no)
- ***Parent strategies to promote participation for each setting***

HOME Participation

A) Typically, how often does your child participate in 1 or more activities of this type?

B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities?

C) Would you like your child's participation to change in this type of activity?

CHECK ONE RESPONSE

CHECK ONE RESPONSE

IF YES, CHECK ALL THAT APPLY

- Daily
- Few times a week
- Once a week
- Few times a month
- Once a month
- Few times in last four months
- Once in last four months
- Never (skip to Question C)
- 5 Very involved
- 4
- 3 Somewhat involved
- 2
- 1 Minimally involved
- No change desired
- Yes, do more often
- Yes, do less often
- Yes, be more involved
- Yes, be less involved
- Yes, be involved in a broader variety of activities

	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
<b>1) Computer and video games</b>																			
<b>2) Indoor play and games</b> (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)																			
<b>3) Arts, crafts, music, and hobbies</b> (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)																			
<b>4) Watching TV, videos, and DVDs</b>																			
<b>5) Getting together with other people</b> (e.g., interacting with peers, family, other houseguests)																			
<b>6) Socializing using technology</b> (e.g., telephone, computer)																			
<b>7) Household chores</b> (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet)																			
<b>8) Personal care management</b> (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup)																			
<b>9) School preparation (not homework)</b> (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule)																			
<b>10) Homework</b> (e.g., daily reading, homework assignments, school projects)																			

## **1) Computer and video games**

## **2) Indoor play and games**

(e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up)

## **3) Arts, crafts, music, and hobbies**

(e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun)

HOME Participation

**A) Typically, how often does your child participate in 1 or more activities of this type?**

**B) Think about 1 or 2 activities of this type that your child participates in most often. Typically, how involved is your child when doing these activities?**

**C) Would you like your child's participation to change in this type of activity?**

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	Daily	Few times a week	Once a week	Few times a month	Once a month	Few times in last four months	Once in last four months	Never (skip to Question C)	5 Very involved	4	3 Somewhat involved	2	1 Minimally involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more involved	Yes, be less involved	Yes, be involved in a broader variety of activities
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CHECK ONE RESPONSE

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CHECK ONE RESPONSE

C) Would you like your child's participation to change in this type of activity?

IF YES, CHECK ALL THAT APPLY

HOME Environment

Do the following things help or make it harder for your child to participate in activities at home?

CHECK ONE RESPONSE

Not an issue	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder

1. The physical layout or amount of space and furniture in your home
2. The sensory qualities of the home environment (e.g., amount and/or type of sound, light, temperature, textures of objects)
3. The physical demands of typical activities in the home (e.g., strength, endurance, coordination)
4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)
5. The social demands of typical activities in the home (e.g., communication, interacting with others)
6. Your child's relationships with family members in the home (e.g., siblings, parent, grandparent)
7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home

Do the following things help or make it harder for your child to participate in activities at home?

CHECK ONE RESPONSE

1. The physical layout or amount of space and furniture in your home

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4. The cognitive demands of typical activities in the home (e.g., concentration, attention, problem-solving)

5. The social demands of typical activities in the home (e.g., communication, interacting with others)

6. Your child's relationships with family members in the home (e.g., siblings, parent, grandparent)

7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home



8. Services in the home (e.g., therapists, tutors, etc.)

9. Supplies in the home (e.g., sports equipment, crafts supplies, reading materials, assistive devices or technology, picture or word schedules)

10. Information (e.g., about activities, services, programs)

11. Do you (and your family) have enough time to support your child's participation at home?

12. Do you (and your family) have enough money to support your child's participation at home?

What are some things that you or other family members do that help your child participate successfully in activities at home?

PLEASE LIST UP TO 3 STRATEGIES

1.

2.

3.

# **PEM-CY On-Line Version**

***(Participation and Environment Hub at  
CanChild Centre, McMaster University)***

- [http://participation-environment.canchild.ca/en/participation\\_environment\\_measure\\_children\\_youth.asp](http://participation-environment.canchild.ca/en/participation_environment_measure_children_youth.asp)



## **Objective 2: Psychometric Properties of the PEM-CY**

**Coster, Bedell, Law, Khetani, Teplicky, Liljenquist, Gleason & Kao, 2011**



# From May – October 2010

## Date Collection:

- A web-based version of PEM-CY was developed, and hosted on a secure website
- Eligibility Criteria:
  - Self-identify as a parent or legal guardian of the child
  - Able to read English
  - Child was between 5 and 17 years of age at the time of enrolment
- Every 5<sup>th</sup> (later 3<sup>rd</sup>) participant was invited to participate in the test-retest component

## Data Analysis:

- Internal consistency of the Participation Frequency, Involvement, Change, and Environment Scales was examined using Cronbach's alpha
- Intraclass correlations were computed to examine consistency and agreement of scores across the retest periods.
- Correlations were conducted to examine the association between extent of desire for change and perceived supportiveness of the environment

# Sample Characteristics: Parents (n=576)

Variable	N (%)
<b>Respondent</b>	
Mother	519 (90)
Father	44 (8)
Guardian	9 (2)
<b>Annual Household Income</b>	
<40,000	65 (11)
40,000 – 80,000	137 (24)
>80,000	354 (62)
<b>Nationality</b>	
USA	213 (37)
Canadian	363 (63)
<b>Child Age (mean)</b>	11.2
<b>Child's Gender</b>	
Male	311 (54)

# Sample Characteristics: Children

Variable	N (%)
<b>Child Race / Ethnicity</b>	
Caucasian (Not Hispanic)	466 (81)
African-American	19 (3)
Latin-American or Hispanic	10 (2)
South Asian	15 (2)
Other / Missing	49 (8)
<b>Disability Status</b>	
Disability	282 (49)
No Disability	294 (51)
<b><i>Top 5 Parent-Reported 1<sup>st</sup> Diagnosis in <u>Disability Sample</u></i></b>	
Developmental Delay	71 (25.6)
Orthopaedic Impairment	53 (19.1)
Emotional Impairment	24 (8.7)
Speech/Language Impairment	23 (8.3)
Intellectual Delay	22 (7.9)

# How Summary Scores were Obtained

For each setting (home, school, community):

- **Participation Frequency** (% maximum possible or % never)
  - Sum of all ratings except “never” responses, divided by number of ratings
  - % never responses on frequency scale
- **Participation Involvement** (average of items – range = 0-5)
  - Average of all items in which child participated
- **Participation Desire for Change** (% yes responses)
  - Number of ‘yes, change’ responses, divided by total number of responses
- **Environmental Supportiveness** (% maximum possible)
  - Sum of all ratings divided by number of items rated



# How does the PEM-CY Perform?

- **Internal consistency: moderate to very good**
  - Participation Frequency: 0.59 to 0.70
  - Participation Involvement: 0.72 to 0.83
  - Environmental Supportiveness: 0.67 to 0.91
- **Test-retest reliability: moderate to very good**
  - Participation Frequency: 0.58 to 0.84
  - Participation Involvement: 0.69 to 0.76
  - Desires Change: 0.76 to 0.89
  - Environmental Supportiveness: 0.85 to 0.95
- **Negative association between desire for change and environmental supportiveness (-0.42 to -0.59)**



**OBJECTIVE 3:  
HOW SCORES FROM THE PEM-CY  
PROVIDE PARTICIPATION PROFILES**



# Ways of Analyzing Data from PEM-CY

- Descriptive analyses of responses **across settings**:
  - E.g., Participation patterns of children with and without disabilities in home vs. school vs. community settings
- Descriptive analyses of responses **within a setting**:
  - E.g., Home participation patterns
  - E.g., Impact of home environment on participation
  - E.g., Strategies used to promote participation at home

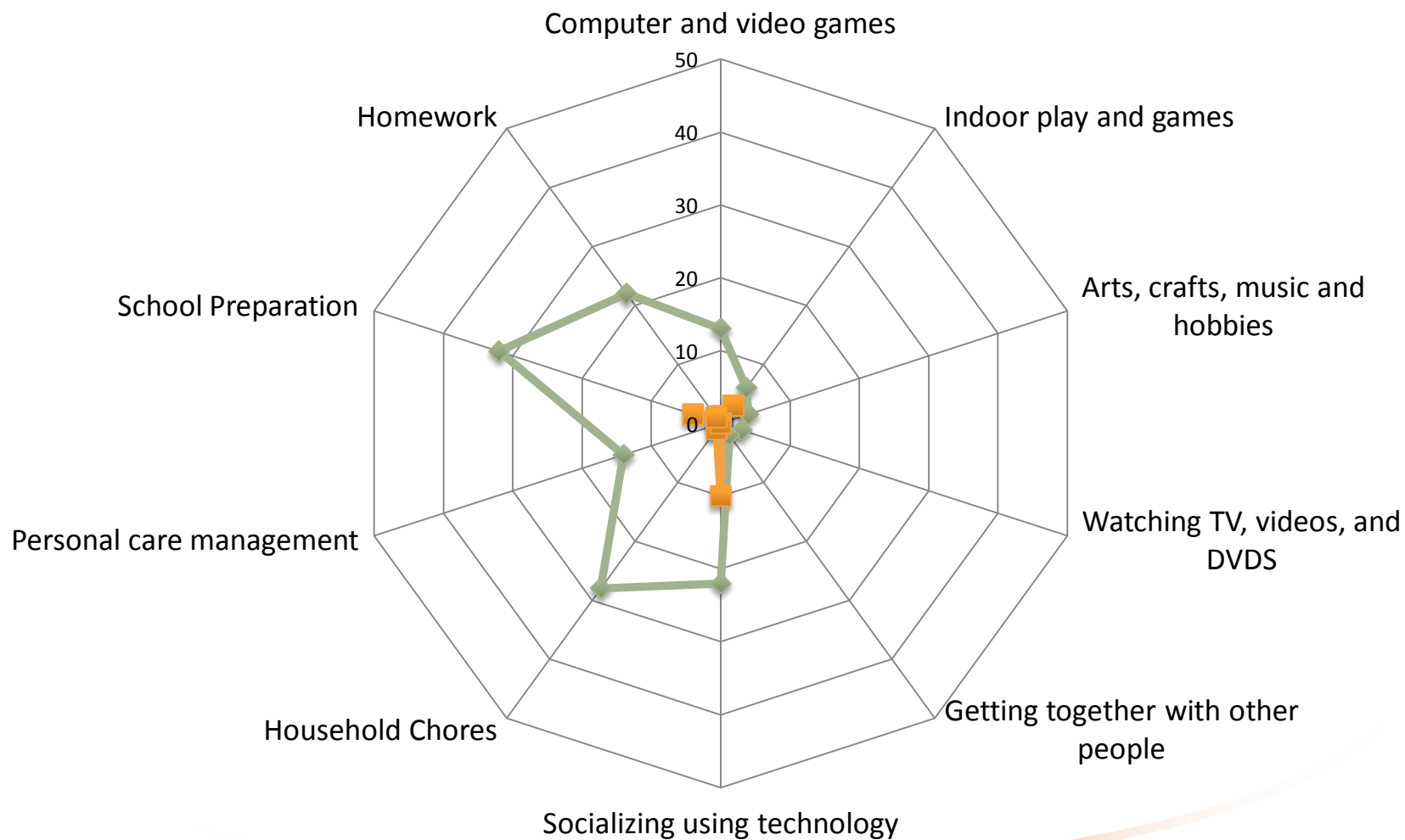
# PEM-CY Summary Scores – Home Setting

PEM-CY Scores	HOME		
	Disability Mean (SD)		
	Yes	No	ES
<b>Never Participates</b>	14.0 (20.1)	1.8 (4.3)	<b>1.0</b>
<b>Participation Frequency</b>	83.0 (11.6)	88.0 (7.2)	<b>0.5</b>
<b>Participation Involvement</b>	3.4 (0.8)	3.8 (0.5)	<b>0.7</b>
<b>Desires for Change</b>	67.1 (26.5)	53.5 (25.9)	<b>0.5</b>
<b>Environmental Supportiveness</b>	70.1 (14.9)	86.4 (11.5)	<b>1.2</b>

- Significant differences between children and youth with and without disabilities for all scores ( $p < 0.01$ )
- ES = Effect Size: Small = .20 to .49; Moderate = .50 to .79; Large  $\geq$  .80

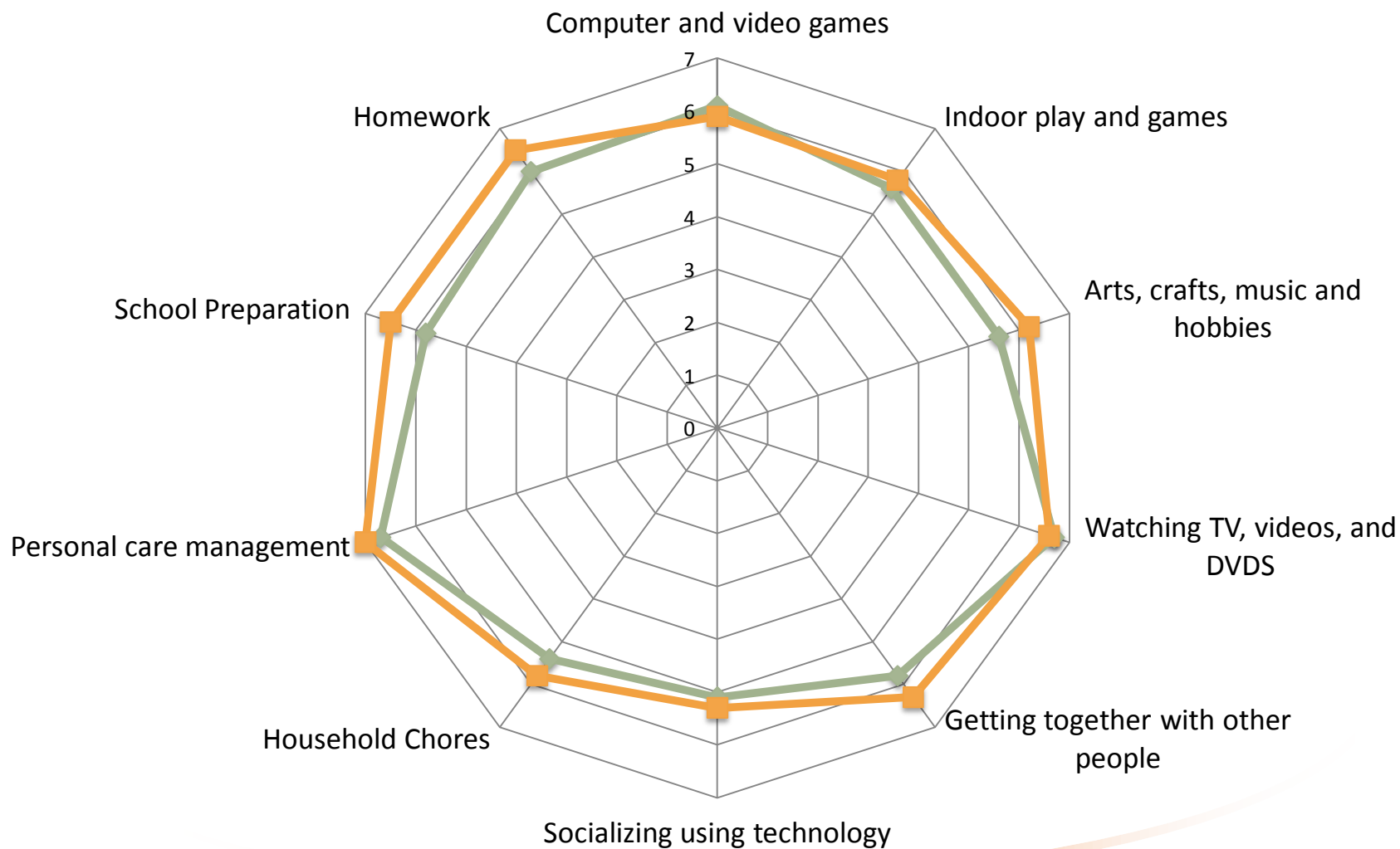
# Percentage of children who never participate in home-based activities

◆ Disability    ■ No Disability



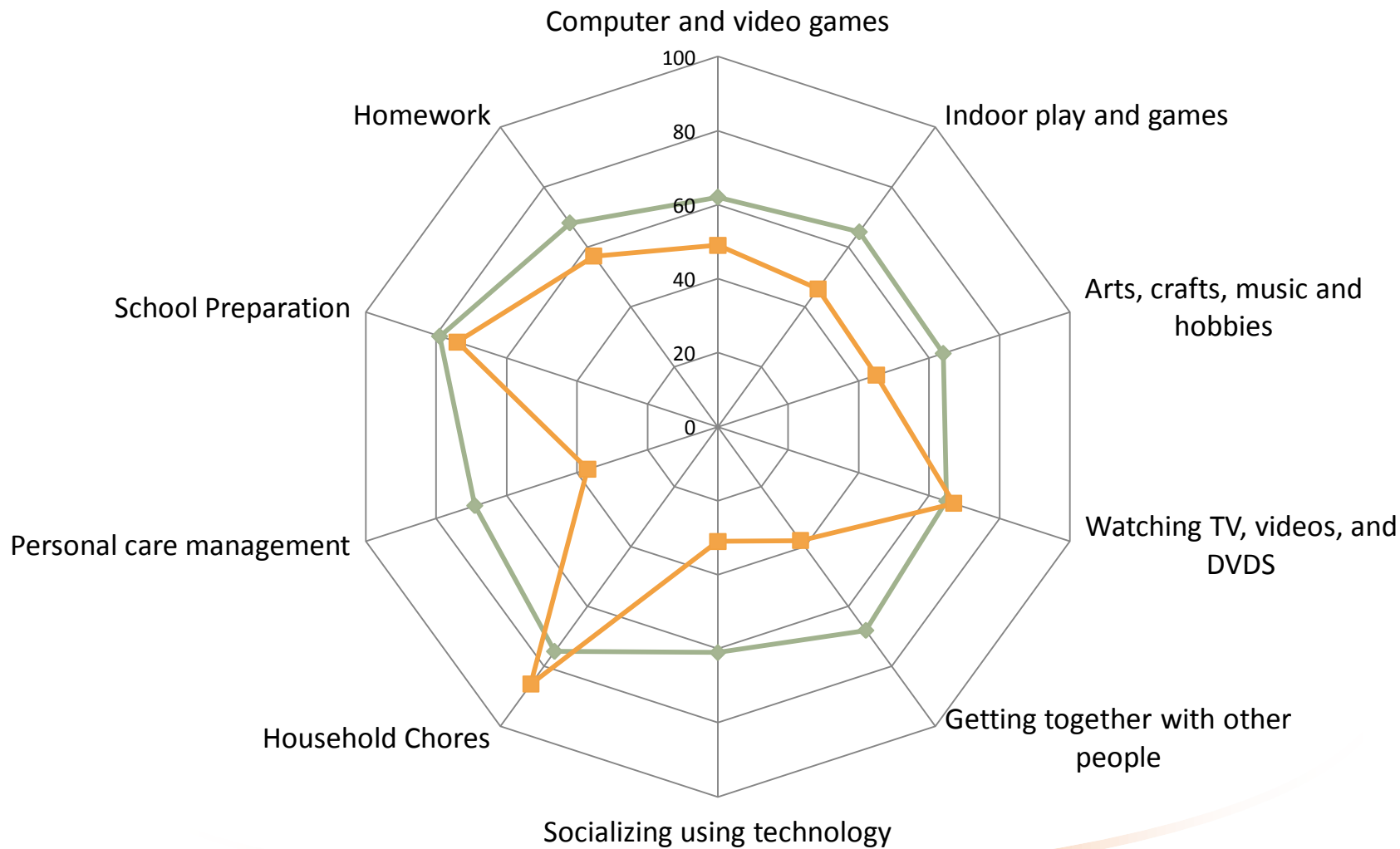
# Mean participation frequency in home-based activities

—◆— Disability    —■— No Disability



# Percentage of parents who desire change in home-based activities

—◆— Children with Disabilities    —■— Children without Disabilities



# PEM-CY Summary Scores – School Setting

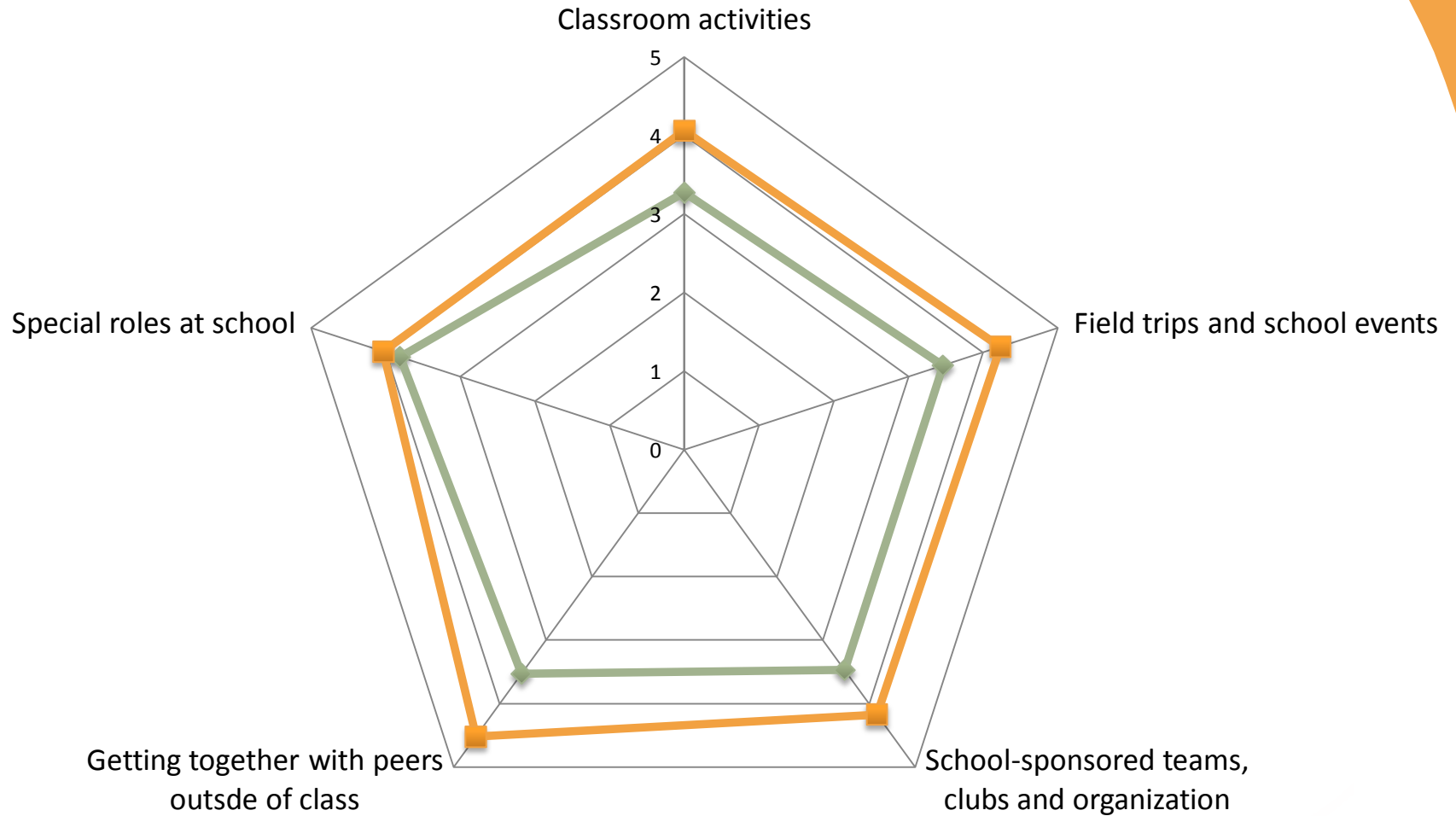
PEM-CY Scores	SCHOOL		
	Disability Mean (SD)		
	Yes	No	ES
<b>Never Participates</b>	33.6 (24.52)	16.3 (15.5)	<b>0.9</b>
<b>Participation Frequency</b>	65.3 (15.7)	72.1 (10.8)	<b>0.5</b>
<b>Participation Involvement</b>	3.4 (1.0)	4.2 (0.7)	<b>1.0</b>
<b>Desires for Change</b>	70.4 (29.8)	38.82 (31.9)	<b>1.0</b>
<b>Environmental Supportiveness</b>	72.9 (12.4)	87.6 (10.7)	<b>1.3</b>

- Significant differences between children and youth with and without disabilities for all scores ( $p < 0.01$ )
- ES = Effect Size: Small = .20 to .49; Moderate = .50 to .79; Large  $\geq$  .80

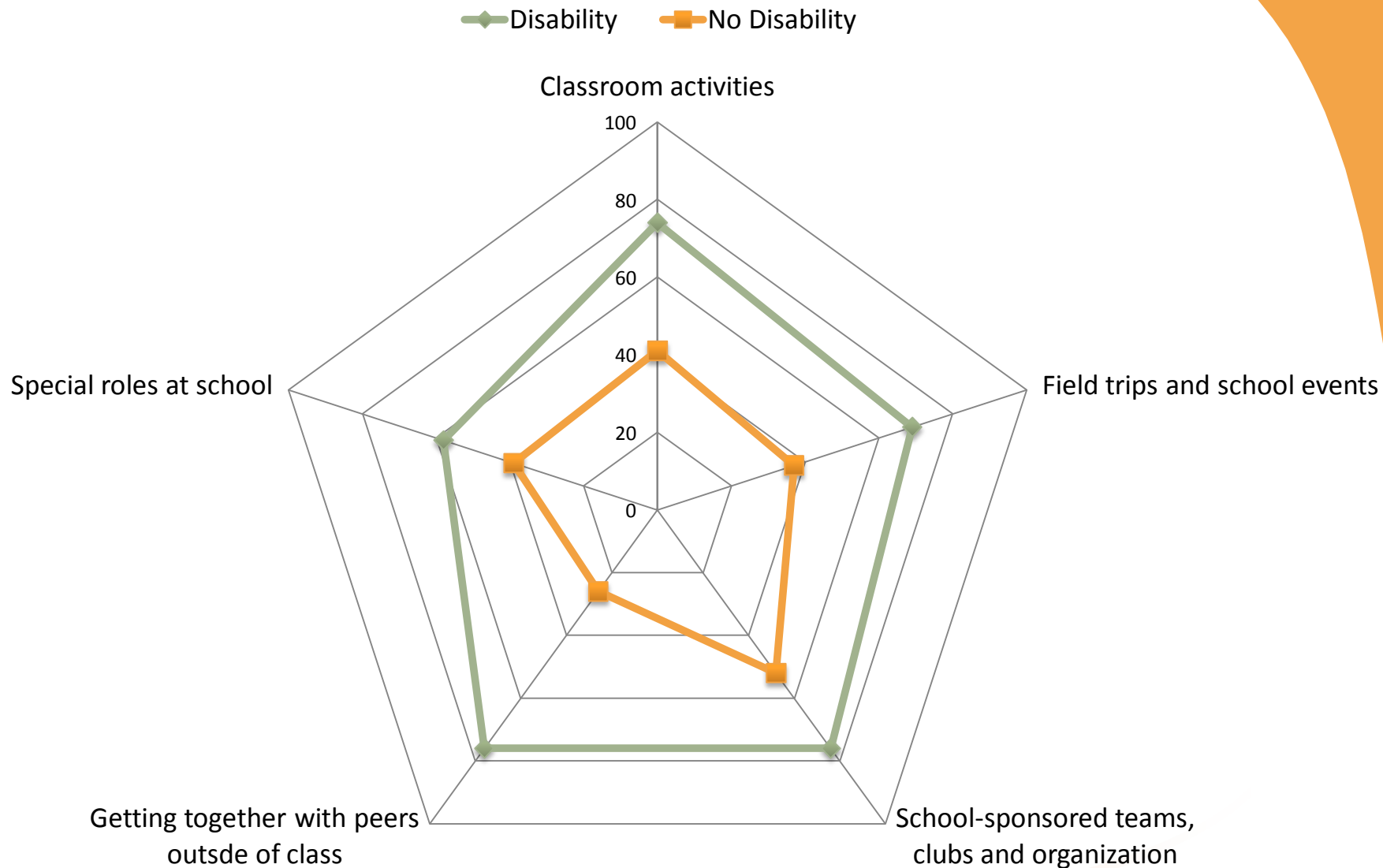


# Mean involvement in school-based activities

◆ Disability    ■ No Disability

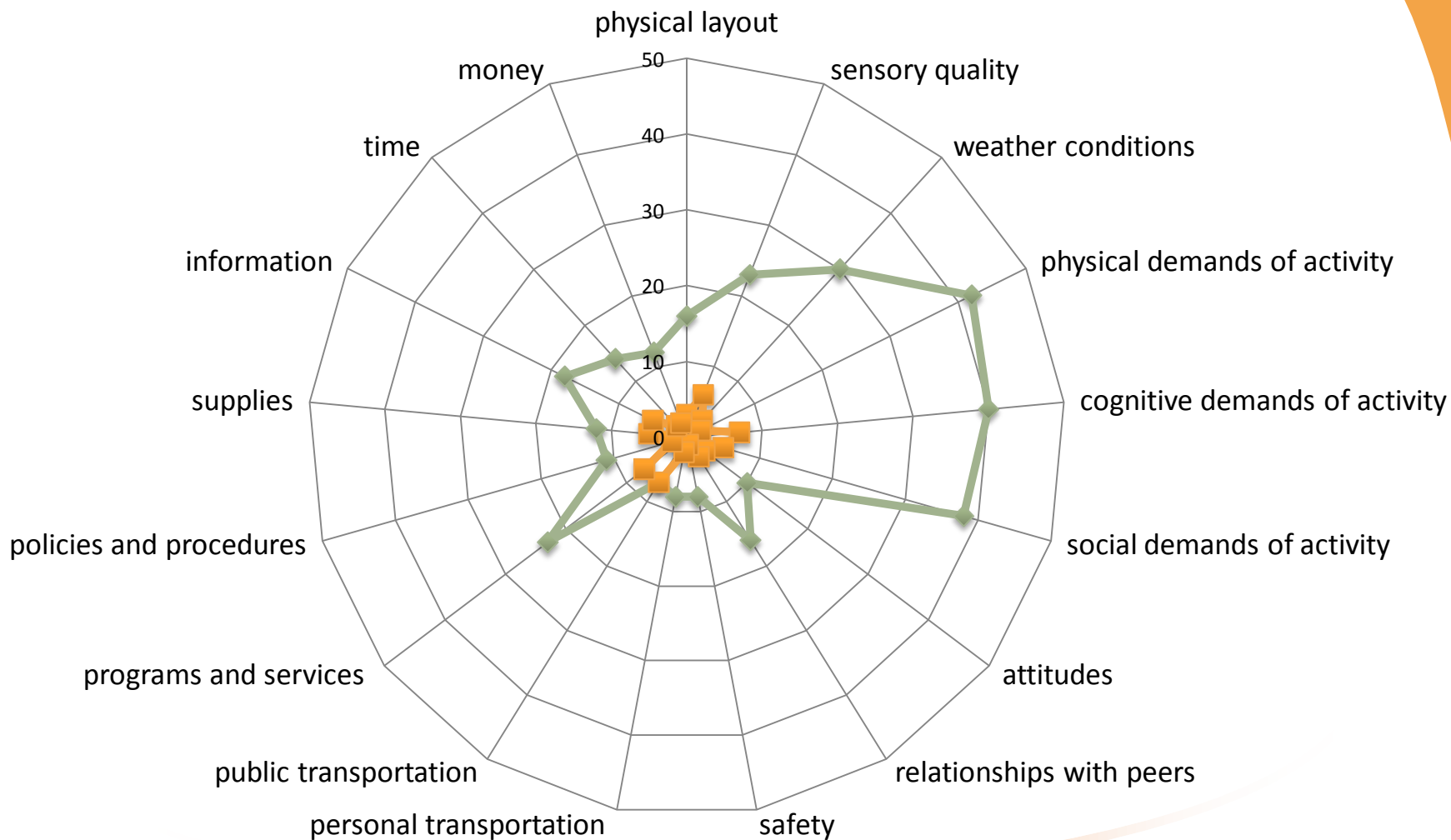


# Percentage of parents who desire change in school-based activities



# Percentage of parents who perceived the item as a barrier to school-based participation

◆ Disability    ■ No Disability



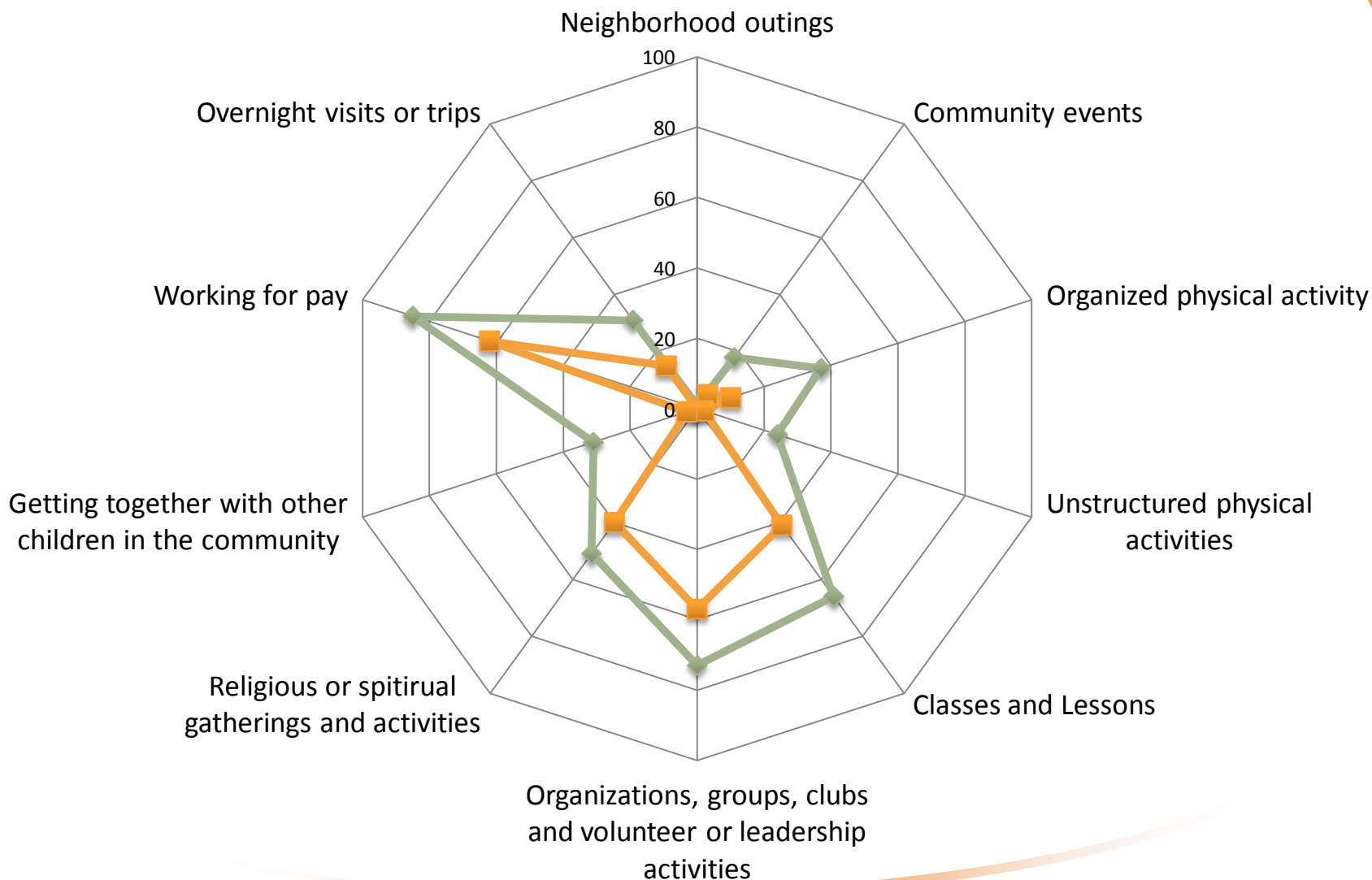
# PEM-CY Summary Scores – Community Setting

PEM-CY Scores	COMMUNITY		
	Disability Mean (SD)		
	Yes	No	ES
Never Participates	41.4 (20.1)	23.4 (14.8)	1.0
Participation Frequency	54.5 (13.2)	63.3 (9.9)	0.8
Participation Involvement	3.5 (0.9)	4.2 (0.6)	0.8
Desires for Change	63.2 (26.0)	38.0 (26.2)	1.0
Environmental Supportiveness	66.4 (14.2)	88.1 (10.9)	1.7

- Significant differences between children and youth with and without disabilities for all scores ( $p < 0.01$ )
- ES = Effect Size: Small = .20 to .49; Moderate = .50 to .79; Large  $\geq$  .80

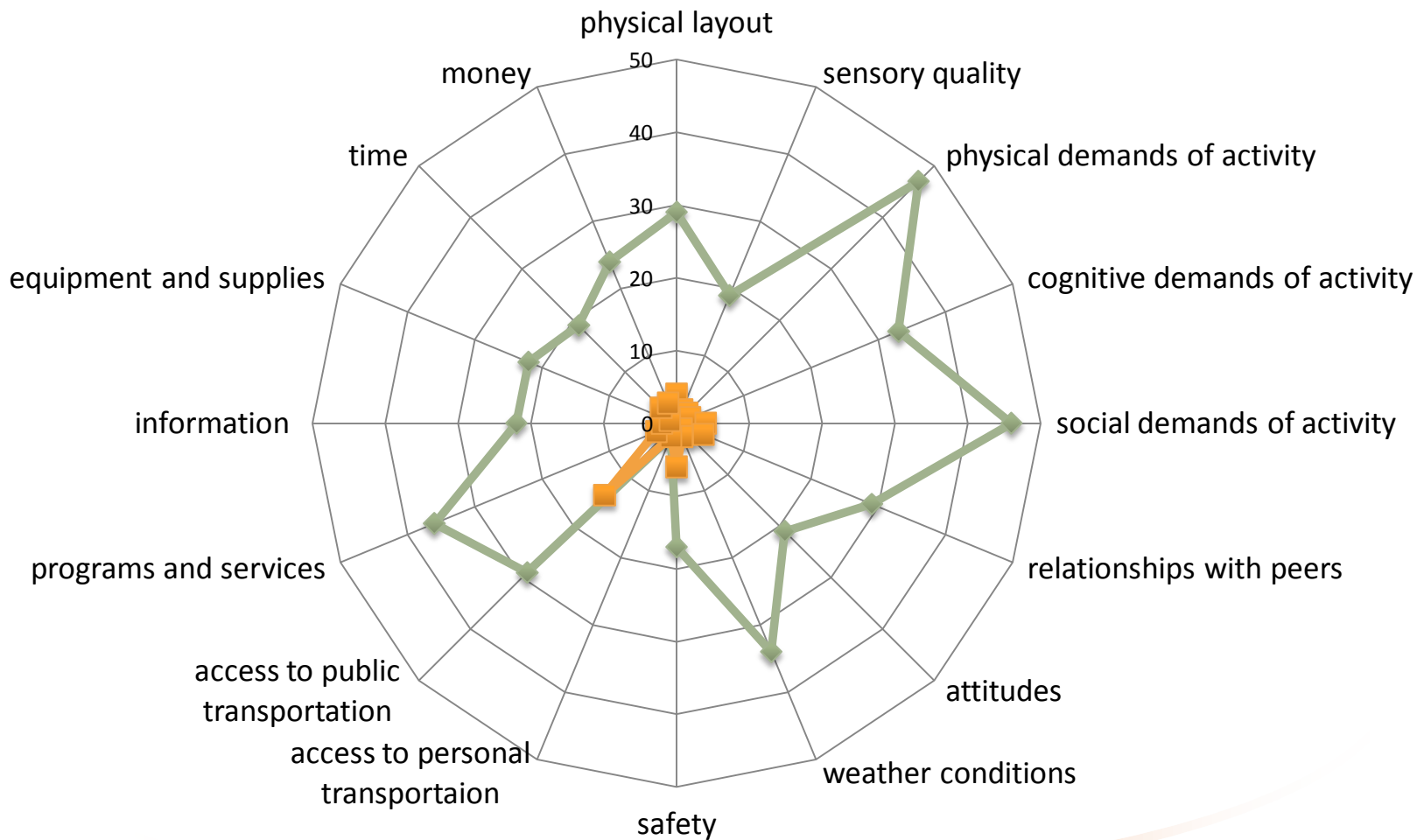
# Percentage of children who never participate in community-based activities

◆ Disability    ■ No Disability



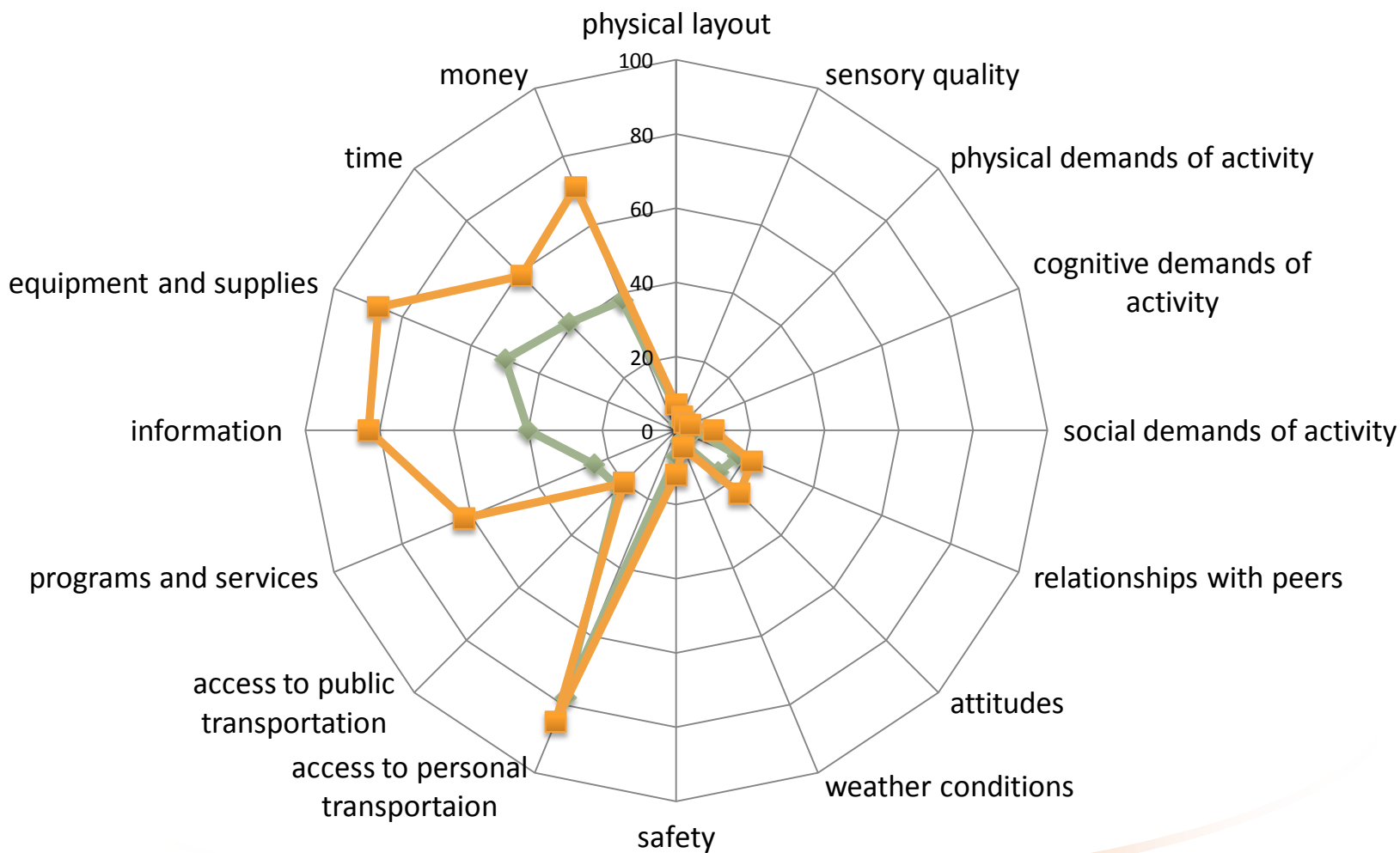
# Percentage of parents who perceived the item as a barrier to community-based participation

—◆— Disability —■— No Disability



# Percentage of parents who perceived the item as a support to community-based participation

Disability No Disability





# **OBJECTIVE 4: IMPLICATIONS & FUTURE DIRECTIONS**



# Implications & future directions

- **For parents & caregivers** to gain valuable information about child's participation and supports/barriers (*to share with others*)
- **For service providers** to describe child's strengths and limitations, define therapeutic goals, and identify strategies to promote participation (*in collaboration with family*)
- **For programs & services** to identify type of and prevalence of participation needs and environmental supports and barriers of children/youth in their program to help inform program improvement and resource allocation
- **For researchers & policy makers** to use in large-scale population-based research to examine similarities and differences in participation (& environmental supports / barriers) across groups (*e.g., diagnoses/health condition, sex, race/ethnicity, income*), and across settings (*that differ in geography, resources, organizational systems*) to inform policy & resource allocation decisions

# Contact Information

- Participation and Environment Hub web-pages at **CanChild Centre for Childhood Disability Research**, McMaster University:
  - <http://participation-environment.canchild.ca/en/index.asp>
  - <http://www.canchild.ca/en/ourresearch/pep.asp>
- For information about availability of the PEM-CY, please contact:
  - Rachel Teplicky, MSc., OT Reg. (Ont.) Research Coordinator
    - [teplicr@mcmaster.ca](mailto:teplicr@mcmaster.ca)
- For information about the **Young Children's Participation and Environment Measure (YC-PEM)**, please contact primary author: Mary Khetani, Sc.D., OTR/L ([mary.khetani@colostate.edu](mailto:mary.khetani@colostate.edu)):
  - <http://www.cperl.colostate.edu/>
  - [http://participation-environment.canchild.ca/en/young\\_children\\_participation\\_environment.asp](http://participation-environment.canchild.ca/en/young_children_participation_environment.asp)

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**Thank you!**

**Additional discussion &  
questions**