Brief, Reliable and Valid Instruments to Obtain a Holistic Picture of Children with Cerebral Palsy: Products of the Move & PLAY Study

Move & PLAY Study Team

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Move & Play

Movement and Participation in Life Activities of Young Children with Cerebral Palsy

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Overall Study Coordination was provided through *CanChild*

CanChild
Centre for Childhood Disability Research

Population of Interest: Cerebral Palsy

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.

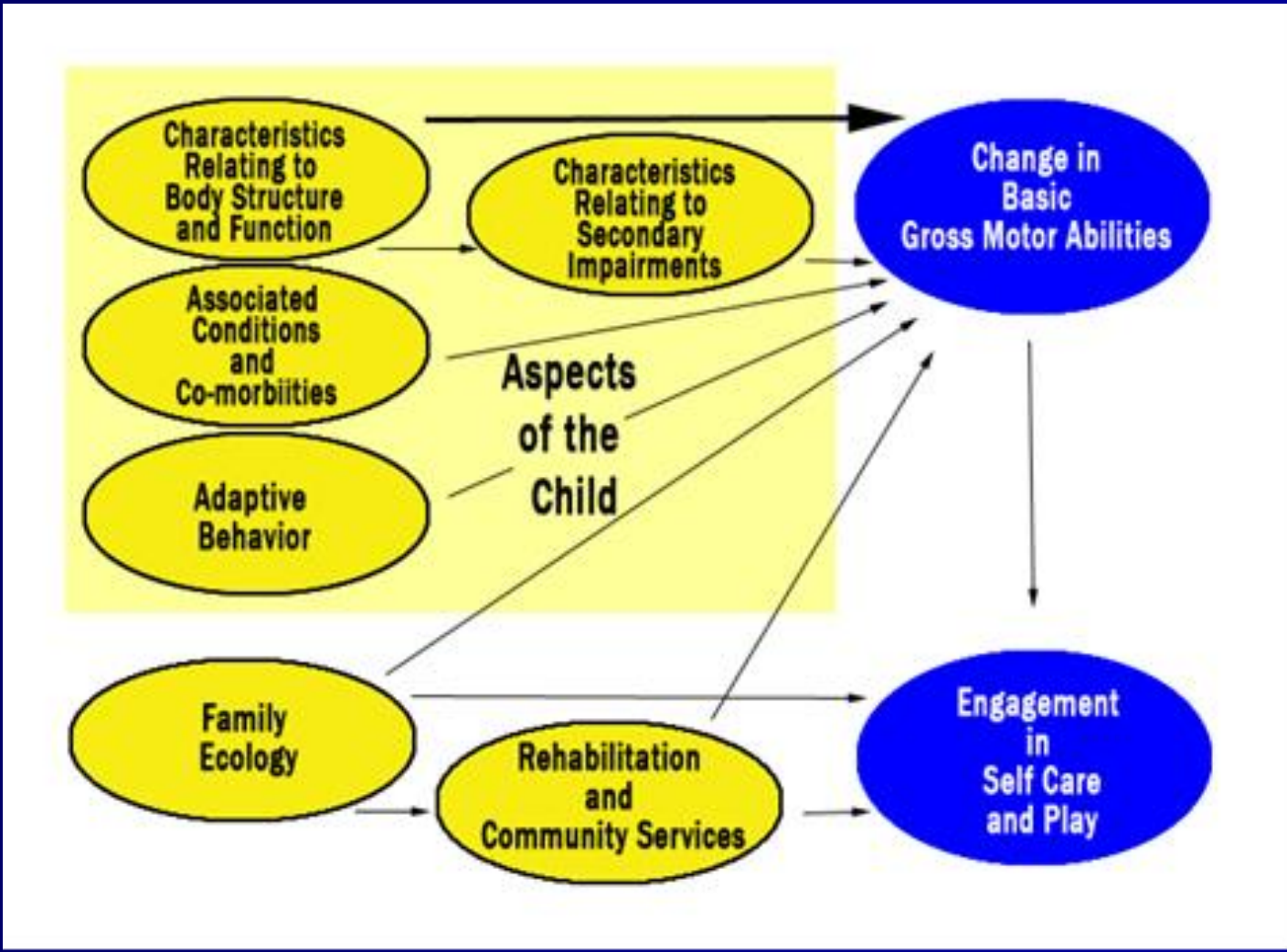
(Rosenbaum et al. 2007, page 9)

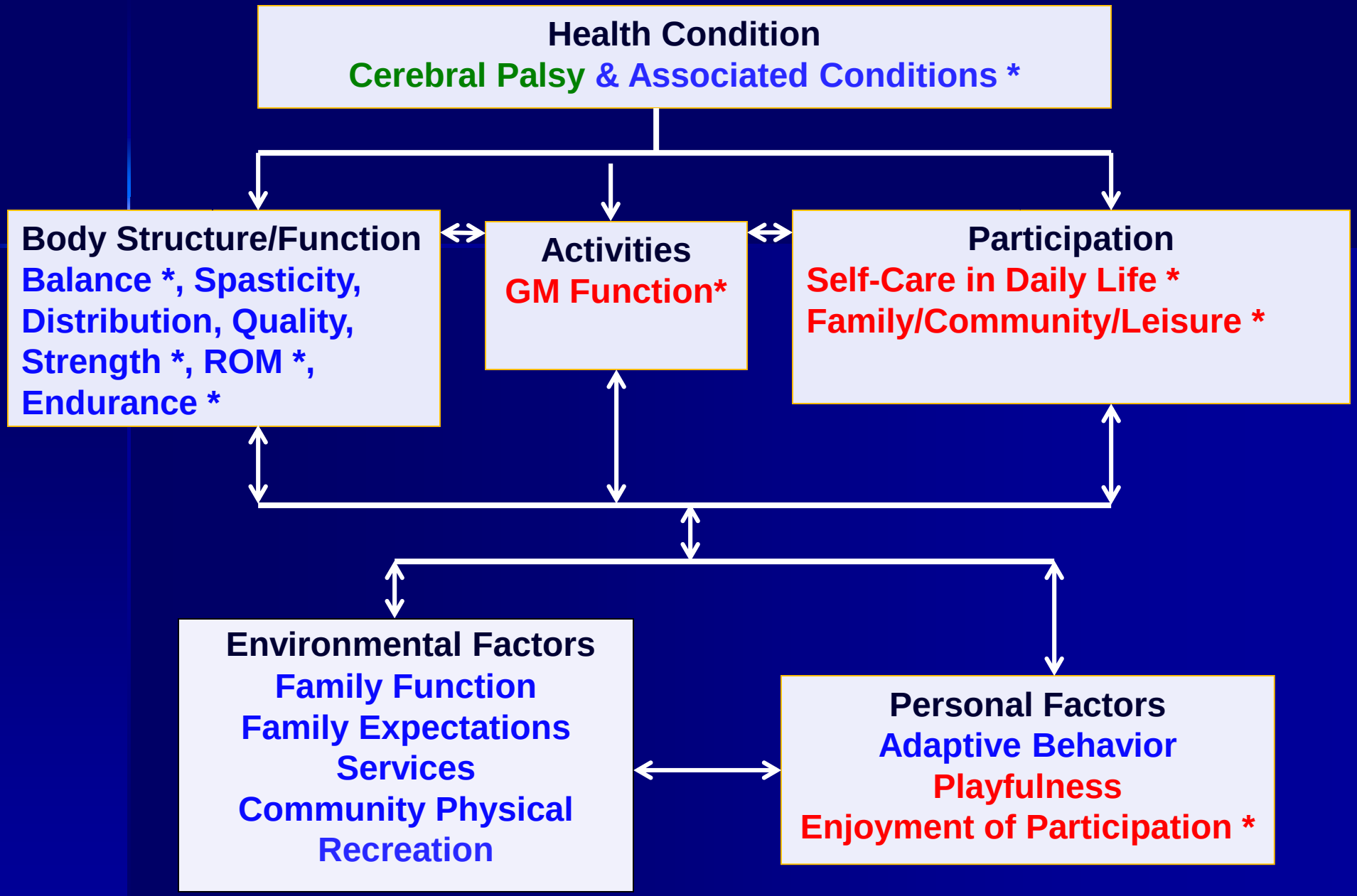
Complexity Requires a Holistic View

- **Children with cerebral palsy have complex and unique challenges that impact motor function and participation in daily life**
- **Conceptual Model: Move & PLAY study available at:**

  http://www.canchild.ca/en/ourresearch/moveplay.asp
- **Clinicians should be using several (brief) assessment tools for different aspects of the condition to provide a holistic view of each individual client**

Conceptual Model (Bartlett et al. 2010; Chiarello et al. 2011)





Adapted from the ICF; WHO, 2001

Objectives: **to understand how to administer, score and interpret:**

- an abbreviated version of the **Gross Motor Function Measure** using a basal and ceiling approach (**GMFM-66-B&C**)
- **Early Clinical Assessment of Balance**
- **Functional Strength Assessment**
- **Spinal Alignment and Range of Motion Measure**

Parent report measures:

- **Family Expectations of Child**
- **Early Activity Scale for Endurance**
- **Health Conditions Questionnaire**
- **Child Engagement in Daily Life Measure**

Measures not included in this presentation:

- **Physical measures not perceived to be amenable to change with therapy**
  - Spasticity
  - Quality of movement
- **Test of Playfulness**
- **Adaptive Behaviour**
- **Family Function**
- **Medical, therapy and community services**

Gross Motor Function Measure (GMFM)

The Gross Motor Function Measure (GMFM)

(Russell et al. 2002)

- **Standardized observational instrument to measure change over time in children with CP**
- **Reflect the ability level of typical 5-year-old children**
- **Activities from 5 dimensions:**
  - lying and rolling, crawling and kneeling, sitting, standing and walking, running, jumping
- **Originally 88 items; reduced to 66**
- **Computerized scoring program (GMAE)**

Item Scaling:

- 0 child does not initiate
- 1 initiates (less than 10%)
- 2 partially completes (10 - < 100%)
- 3 completes (100% task completion)
- NT not tested

Refer to detailed item descriptions in manual

GMFM-66-Basal & Ceiling (GMFM-66-B&C)

(Brunton & Bartlett, 2011)

- **Developed a modified score sheet with the items in difficulty order: easiest to hardest**
  http://www.canchild.ca/en/ourresearch/moveplay.asp
  - Entry points suggested for GMFCS and age
  - Each item: CAPS – start position, after colon – maximum function for score of 3
  - Columns on left indicate dimension
- **Basal = 3 consecutive 3s**
- **Ceiling = 3 consecutive 0s**
- **Minimum of 15 items need to be scored**

Validation of the GMFM-66-B&C

(Brunton & Bartlett, 2011)

- **Concurrent Validity with the GMFM-66**
  - ICC = 0.987 (95% CI = 0.972-0.994)
- **Inter-rater Reliability**
  - ICC = 0.970 (95% CI = 0.932 – 0.986)
- **Test-retest Reliability (over 2 week period)**
  - GMFM-66-B&C = 0.994 (95% CI = 0.987-0.997)
- **Average Time to Completion** (in minutes)
  - Time 1 = 26.0 (SD = 9.3)
  - Time 2 = 21.1 (SD = 7.8)

Equipment: Assemble Prior to Testing

(Russell et al. 2002)

- **Stop watch**
- **Mat**
- **Measuring tape**
- **Flagging tape / masking tape** (arrange two parallel lines 8” apart and 20’ long)
- **Circle**
- **Ruler**
- **Large Ball**
- **24” long stick**
- **Small toy**
- **Bench for sitting feet on floor**

Guidelines for Administration

(Russell et al. 2002)

- Sufficient space, warmth, comfort
- Shorts and t-shirt ideal; bare feet
- Maximum of 3 trials each item (score BEST)
- Spontaneous performance OK
- Can place child in start position, but no other facilitation
- Use toys / incentives / creativity

GMFM-66-B&C

Scoring using the GMAE2

Download available from:

http://canchild.ca

Search GMAE-2

Case Illustration

- **Katie, age 3 ½ years, spastic diplegia, level III**

- **Enter data into the GMAE**

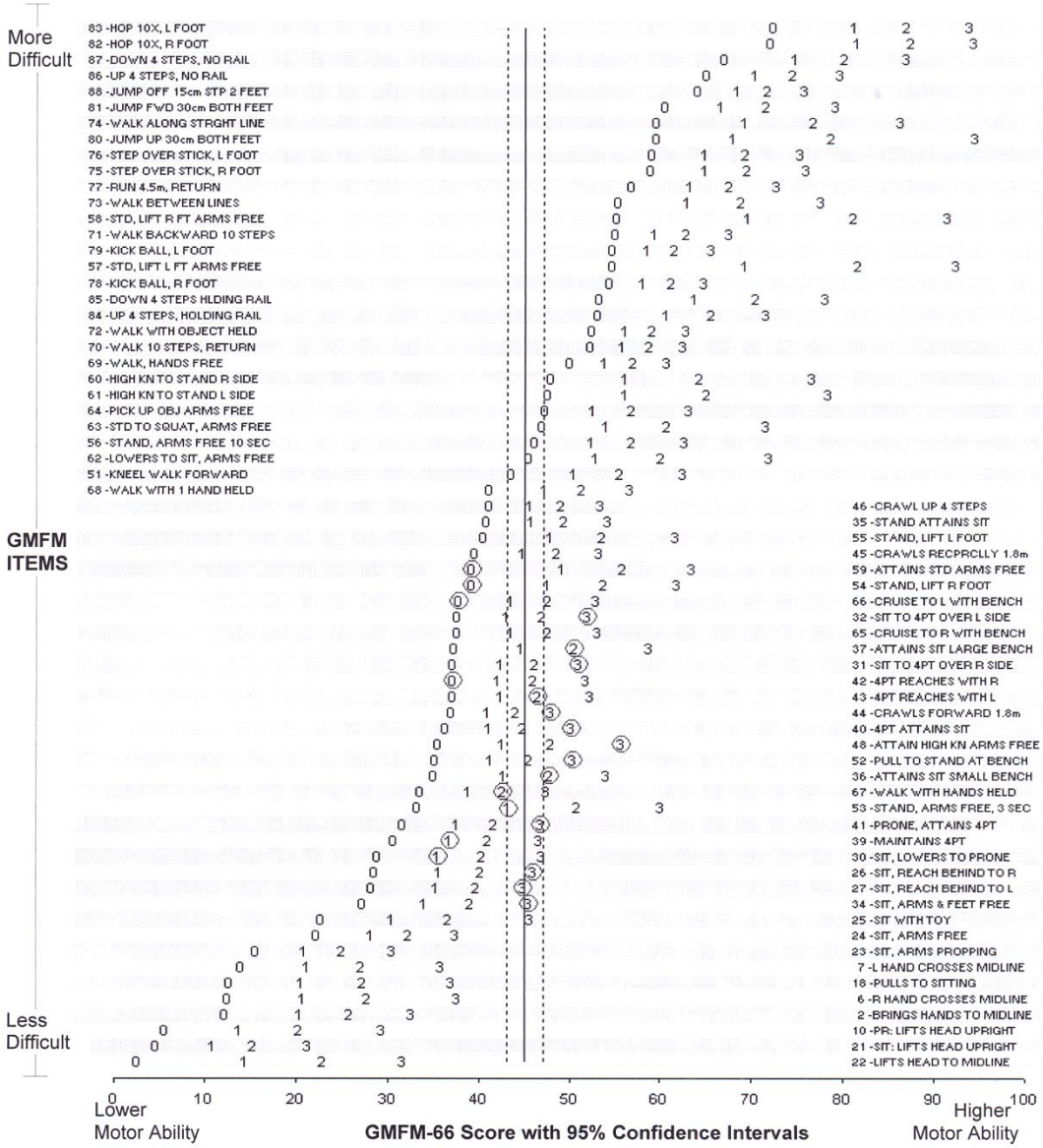
  - **GMFM-66 = 45.1 (95% CI = 43.1 to 47.2)**
  - ***pattern of scoring on item map can assist with***
    - ***realistic goal setting for motor function***
    - ***timing of successful goal attainment***

Item Map by Difficulty Order

Gross Motor Function Measure
GMFM-66

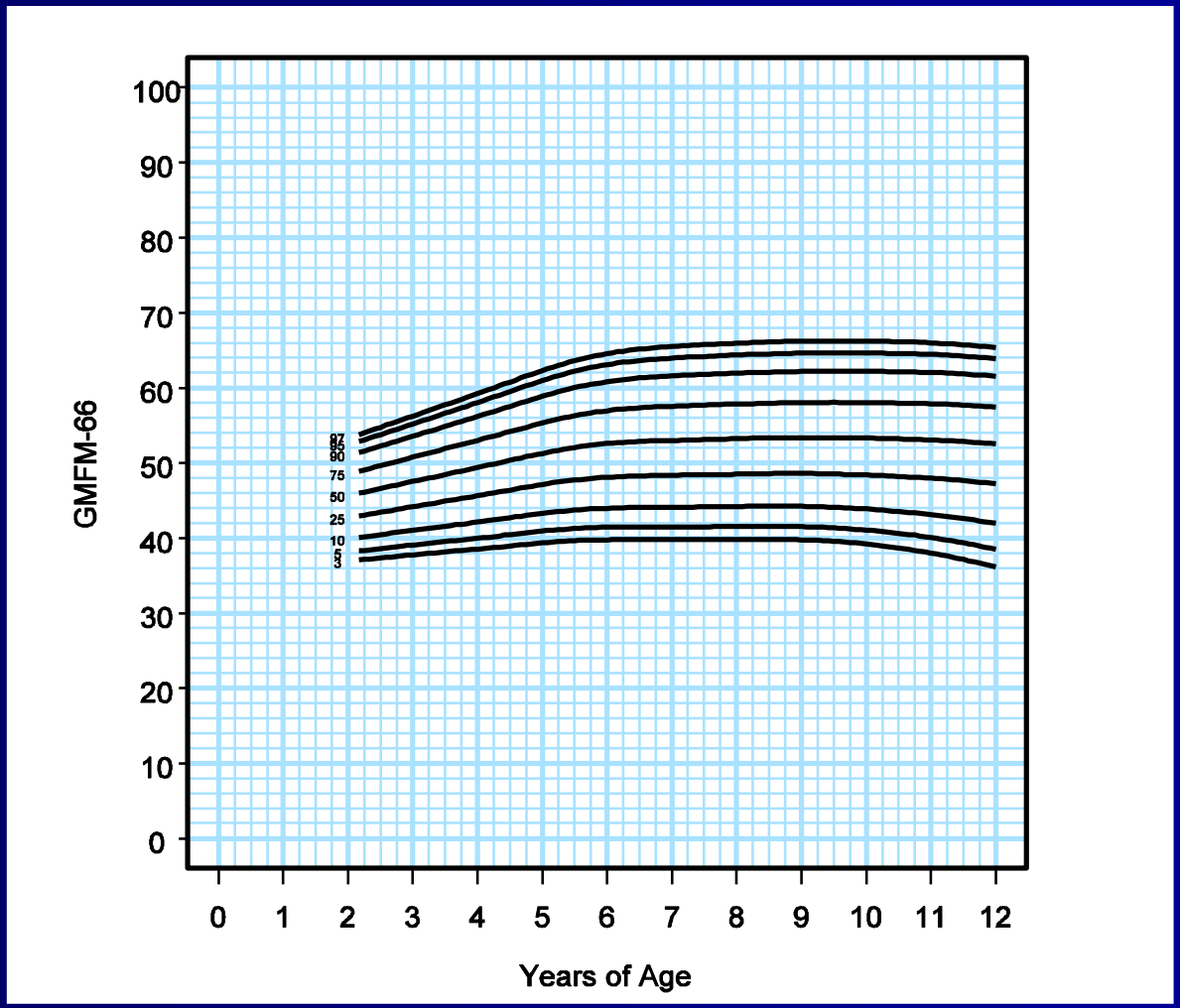
Client ID:	01
Name:	Katie
Assessment Date:	08 December 2008
Date of Birth:	08 June 2005
Age:	3y 6m

GMFM-66 Score:	45.14
Standard Error:	1.05
95% Confidence Interval:	43.08 to 47.20



Interpreting the GMFM-66-B&C

(Hanna et al. 2008)



Variability by GMFCS Level

Tables on CanChild Website (Hanna et al. 2008)

http://motorgrowth.canchild.ca/en/MotorGrowthCurves/overview.asp

	I	II	III	IV	V
N	147	78	107	121	117
mean change	3.0	–0.8	3.3	2.5	3.6
sd change	15.6	15.5	12.4	11.8	13.2
probability	interval of change in percentiles				
50%	± 10.5	± 10.5	± 8.4	± 8.0	± 8.9
80%	± 20.0	± 19.9	±15.9	± 15.1	± 16.9

Katie – as expected

	Time 1	Time 2
GMFM-66	45.1	48.1
Percentile	25th	35th

- change in GMFM score of 3 points
- the GMFM-66 scores translate to percentile ranks of 25th and 35th, a difference of 10
- this amount of change means that Katie is developing as *might be expected* (within ± 16)

Katie – better than expected

	Time 1	Time 2
GMFM-66	45.1	54.2
Percentile	25th	75th

- change in GMFM score of 9 points
- the GMFM-66 scores translate to percentile ranks of 25th and 75th, a difference of 50
- this amount of change means that Katie is developing *better than expected* (outside ± 16)

Katie – more poorly than expected

	Time 1	Time 2
GMFM-66	45.1	40.4
Percentile	25th	5th

- Decline in GMFM score of almost 5 points
- the GMFM-66 scores translate to percentile ranks of 25th and the 5th, a difference of 20
- this amount of change means that Katie is developing *more poorly than expected* (outside $\pm$ 16)

Summary: Utility of the GMFM-66-B&C

(Brunton & Bartlett, 2011)

- **Fewer items to be administered/scored**
- **Decreased time to administer, leaving time to assess other aspects of the child and family**
- **Provides an accurate estimate of the motor abilities of the child – GMFM-66 Score; details are available:**

  http://www.canchild.ca/en/ourresearch/moveplay.asp
- **Use of the GMAE software allows for interpretation of scores over time and the use of item maps**

Early Clinical Assessment of Balance (ECAB)

Early Clinical Assessment of Balance (ECAB)

(McCoy et al. 2013)

- **A new measure of balance that was developed in the Move & PLAY Study; available at:**

  http://www.canchild.ca/en/ourresearch/moveplay.asp

- **Accommodates children across all GMFCS levels**

- **An integration of two existing balance measures:**
  - Movement Assessment of Infants (MAI)
  - Pediatric Balance Scale (PBS)

Items from the Movement Assessment of Infants (MAI)

(Chandler, Andrew & Swanson, 1980)

- **PART I : 7 items (some bilateral) from the Automatic Reactions section of the MAI:**
  - Lateral head righting (R/L)
  - Head righting in flexion and extension
  - Rotation in the trunk (R/L)
  - Equilibrium reactions in sitting (R/L)
  - Protective extension to the side and backwards (R/L)

Items from the Pediatric Balance Scale (PBS)

(Franjoine, Gunther, and Taylor, 2003)

- **PART II : 6 items from the PBS**
  - Sitting with back unsupported but feet supported
  - Moving from sitting to standing
  - Standing unsupported with eyes closed
  - Standing unsupported with feet together
  - Turning 360 degrees
  - Placing alternative feet on a step while standing unsupported

Item Selection for the ECAB

- **Item 6 was removed from the MAI**
  - Protective extension forward was excluded because it is hard to test in older children

- **6 items were selected from the PBS to represent:**
  - 2 relatively easy items
  - 2 moderately difficult items
  - 2 relatively difficult items

Reliability and Validity of the ECAB

- **Inter-Rater Reliability: 0.989** (95% CI: 0.976 – 0.995)
- **Test-Retest Reliability: 0.986** (95% CI: 0.971 – 0.994)
- **Construct Validity with GMFM-66-B&C: 0.96** ($p<0.001$)
- **Time to complete: 11.6 minutes** (sd: 4.2)
  - (Randall et al. Under Review)
- **Known groups validity: ECAB scores are significantly different among all GMFCS levels**
  - (McCoy et al. 2013)

Equipment Required

- ✧ Adjustable height bench
- ✧ Mat
- ✧ Stopwatch
- ✧ A step stool 6-inches in height
- ✧ ECAB score sheet

Optional Equipment

- ✧ 2 child-size footprints
- ✧ Blindfold
- ✧ Flash cards
- ✧ Stickers

Administration

- Children in GMFCS levels I & II:
  - Begin testing the child at Part II (item 8)
- Children in GMFCS levels III, IV, V
  - Begin testing the child with Part I (item 1)
  - Children in level III attempt both Parts I and II
- Children with hemiplegia
  - Begin testing the child at item 4

In all cases: Continue testing until child can no longer do items

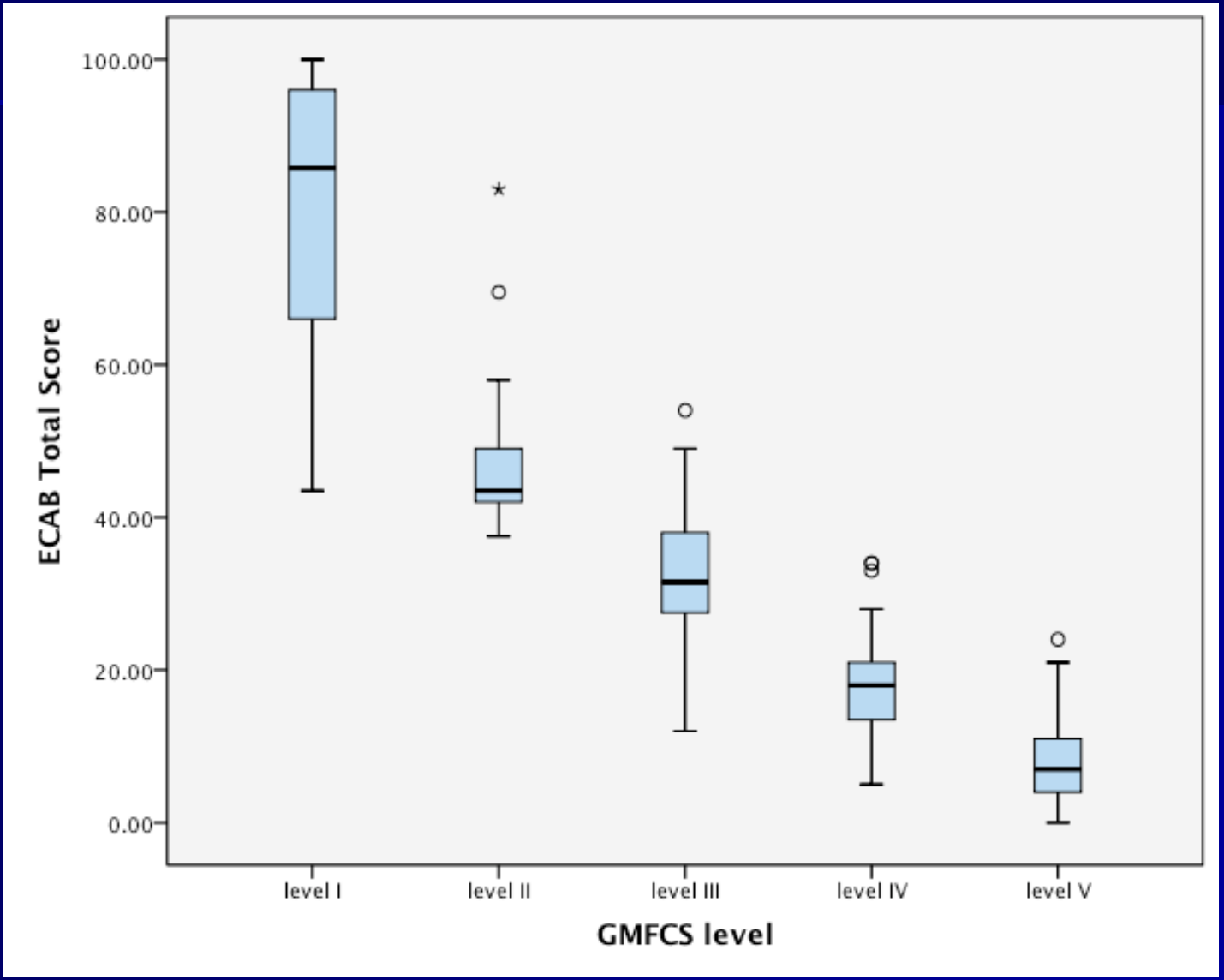
Scoring the ECAB

- **PART I**
  - Responses are graded on a 0–3 point ordinal scale
  - Maximum score Part I = 36
- **PART II**
  - Responses are graded on a 0–4 point ordinal scale
  - Scores are then re-weighted to account for the task's increased difficulty (details provided on the score-sheet)
  - Maximum score Part II = 64
- **MAXIMUM TOTAL SCORE = 100**

Obtaining ECAB Scores for Children at Different GMFCS Levels

- Children in GMFCS levels III, IV, V
  - For total score, sum all available items
- Children in GMFCS levels I & II:
  - For total score, sum 36 plus Part II score
- Children with hemiplegia
  - For total score, credit child with 12 for items 1-3, then sum rest of Parts I and II

Interpretation: ECAB



Functional Strength Assessment (FSA)

Functional Strength Assessment

(Jeffries et al, in preparation; measure pending posting)

Force production in selected muscle groups:

- **neck and trunk extensors**
- **neck and trunk flexors**
- **hip extensors**
- **knee extensors**
- **shoulder flexors**

Description of Measure

Traditional MMT is time consuming, difficult to get full cooperation of young children & no summary score

The system used in this study emphasizes obtaining an estimate of major muscle groups only, and strategy to obtain a summary score

Each muscle group can be rated on an ordinal scale 1-5 allowing for limitations in range of motion

Scaling

5	full available range against gravity and strong, age appropriate resistance
4	full available range against gravity and some resistance
3	full available range against gravity, but no resistance
2	unable to move completely against gravity
1	only flicker of contraction or just initiates movement against gravity

Scoring

Total or average score

Reliability and Validity of the FSA

(Jeffries et al, in preparation)

- **Test-Retest Reliability: 0.97** (95% CI: 0.95 – 0.99)
- **Internal consistency: Cronbach's Alpha = 0.93**
- **Discriminant Validity: differentiates across all GMFCS levels except for II and III**

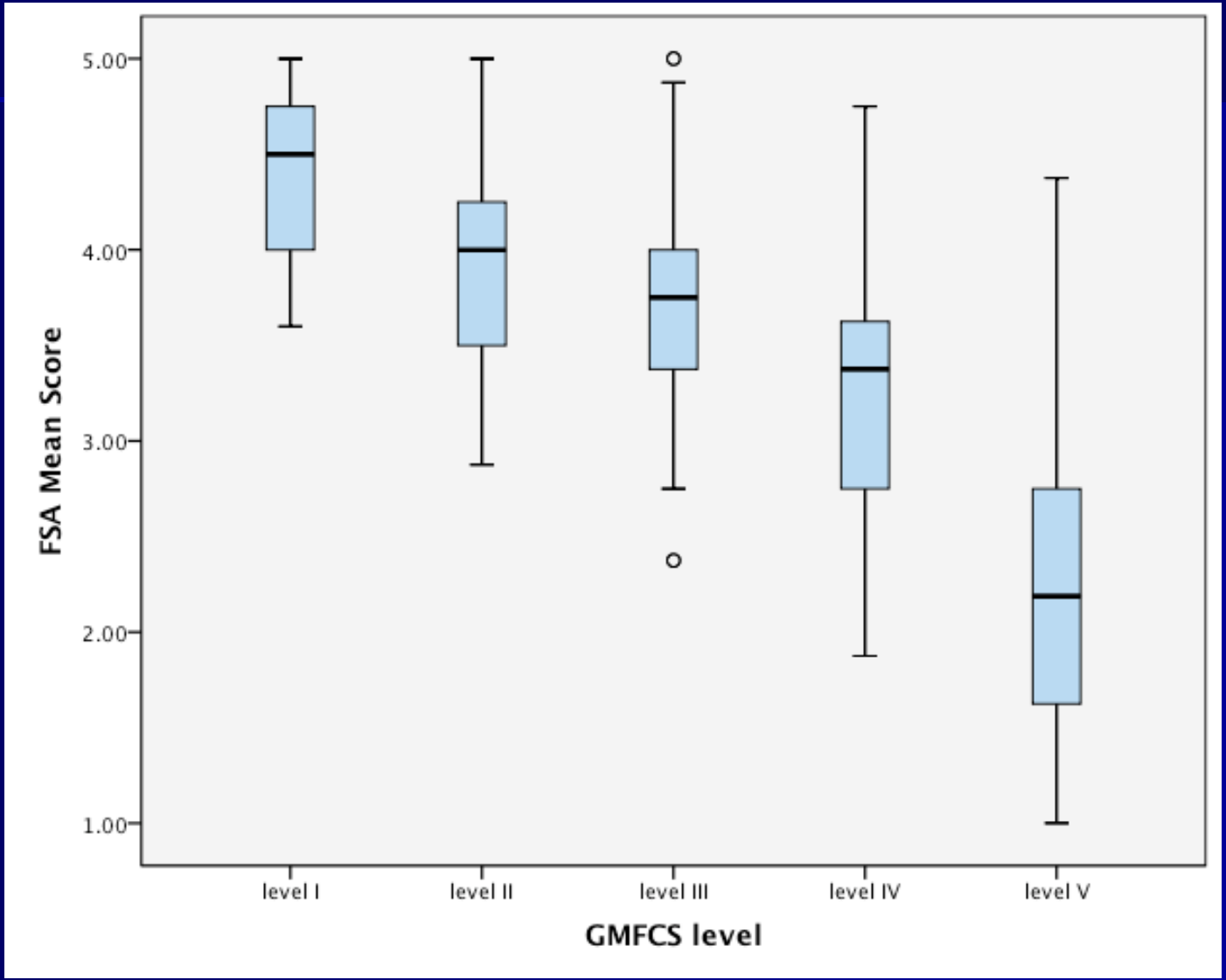
Equipment

- No special equipment
- Ideally the child will be dressed in shorts & t-shirt
- Useful to have:
  - A sturdy chair (or adjustable stool)
  - A mat
  - Stickers, Bubbles, Toys, etc to elicit movements

Guidelines for Administration

- Child should be alert and happy
- Use your knowledge, skills, and creativity!
- It may be useful to count to 5 to encourage the child to maintain the position during testing
- Use stickers, bubbles, toys, etc. to elicit anti-gravity movement

Interpretation: FSA



Spinal Alignment and Range of Motion Measure (SAROMM)

SAROMM (Bartlett and Purdie, 2005)

Aim is to obtain a full-body summary score of the extent of limitations in spinal alignment & range of motion / extensibility

4 items in spinal alignment subscale

22 items in the range of motion subscale, all but 2 in the lower extremity

Uses standard PT techniques, but uses ordinal scale, rather than goniometer, to estimate limitations

Scaling

0 normal alignment and range with active correction

(NO POSTURING of the limbs putting individual ‘at risk’ for contracture)

1 normal alignment and range with passive correction

2 “mild” fixed deformity

3 “moderate” fixed deformity

4 “severe” fixed deformity

Decisions about 2, 3, 4 based on photos for items 1-4 and 25-26 and on specified “cut-points” for the remaining

Details in the manual and score-sheet posted on the CanChild site

Total or average score used for analysis

Scaling: Differentiating 0 and 1

Situation: Child with hemiplegia postures lower extremity in hip flexion, adduction, internal rotation, knee flexion and ankle plantar flexion; full passive range

Scores for:

- **Hip flexion**
- **Hip extension**
- **Hip adduction**
- **Hip abduction**
- **Hip internal rotation**
- **Hip external rotation**
- **Knee extension**
- **Ankle plantar flexion**
- **Ankle dorsiflexion**

Scaling: Differentiating 0 and 1

Situation: Child with hemiplegia postures lower extremity in hip flexion, adduction, internal rotation, knee flexion and ankle plantar flexion; full passive range

Scores for:

Hip flexion	0
Hip extension	1
Hip adduction	0
Hip abduction	1
Hip internal rotation	0
Hip external rotation	1
Knee extension	1
Ankle plantar flexion	0
Ankle dorsiflexion	1

Reliability and Validity of the SAROMM

(Bartlett and Purdie, 2005)

- **Reliabilities (inter-rater and test-retest): ICCs > 0.80**
- **Internal consistency: Cronbach's Alpha = 0.95**
- **Known Groups Validity: differentiates across all GMFCS levels**

Equipment

Adjustable stool (hips and knees 90 degrees) for spinal alignment subscale

Floor mat for other items

Guidelines for Administration

Have child dressed appropriately so can palpate / visualize to score properly

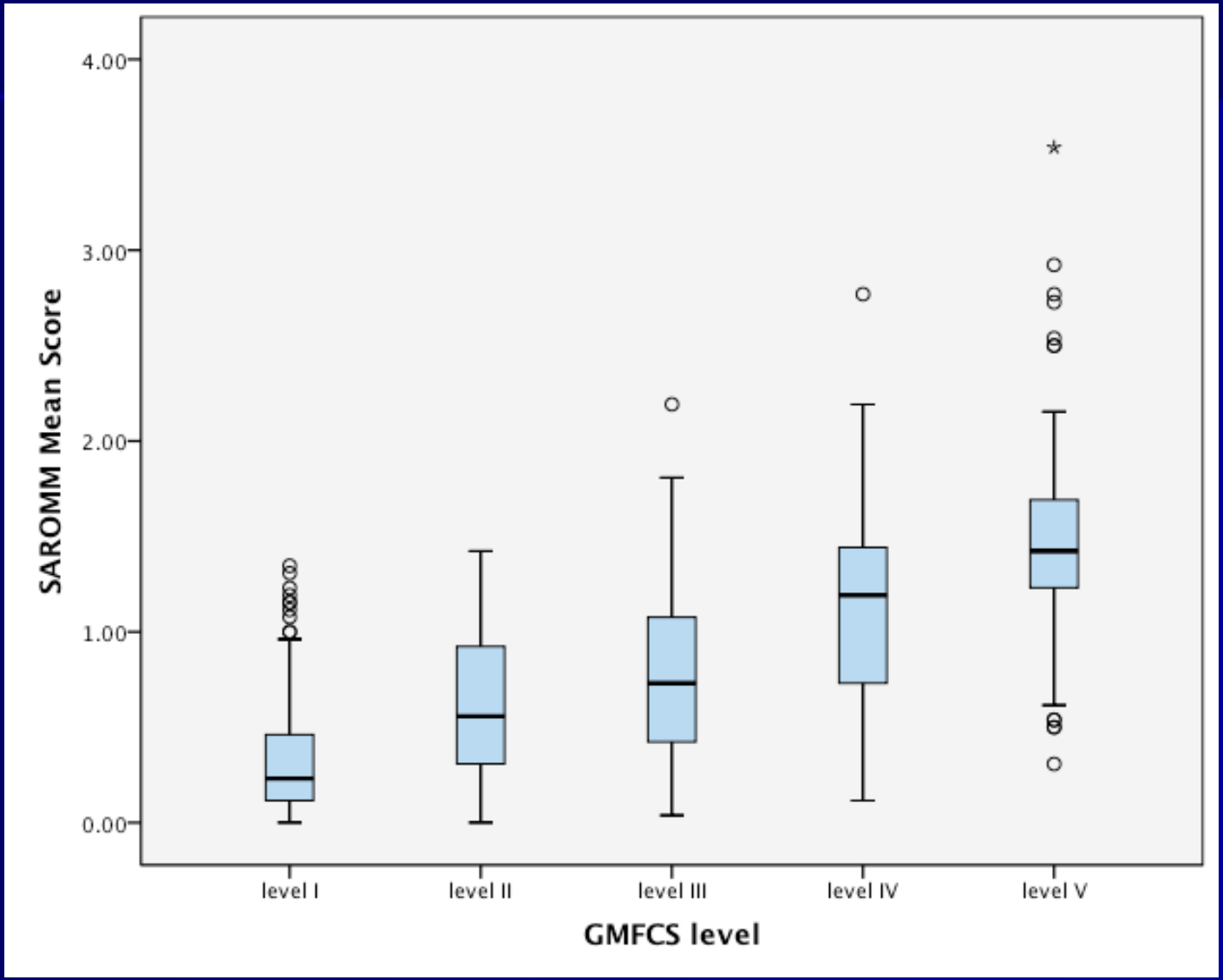
Use standard PT techniques to administer items

Ensure child is relaxed for passive testing; move the limbs slowly and firmly to minimize the effects of spasticity

If need to test passively, expect a “firm” end feel

Do not conduct passive testing if painful for the child; note “not tested”

Interpretation: SAROMM



Family Expectations of Child

parent-completed measure

Family Expectations of Child

(Bartlett et al. unpublished, 2011)

Items

•5-items

•parents rate their expectations of their child's regular performance in:

- doing the best that he or she can
- assisting in self-caare
- trying everything
- doing exercises / activities that therapists recommend
- doing all regular family activities

using a 7-point scale (1 'not at all'; 7 'to a very great extent')

Early Activity Scale for Endurance (EASE)

parent-completed measure

EASE (McCoy et al. 2012; abbreviated version pending publication)

Items

- 4-items
- parents rate the child's level of energy, fatigue with activity and overall ability to sustain active movement without getting tired

EASE Scaling

Responses to statements:

- **Never (1)**
- **Rarely (2)**
- **Sometimes (3)**
- **Often (4)**
- **Always (5)**

Scoring

✧ Total or average score

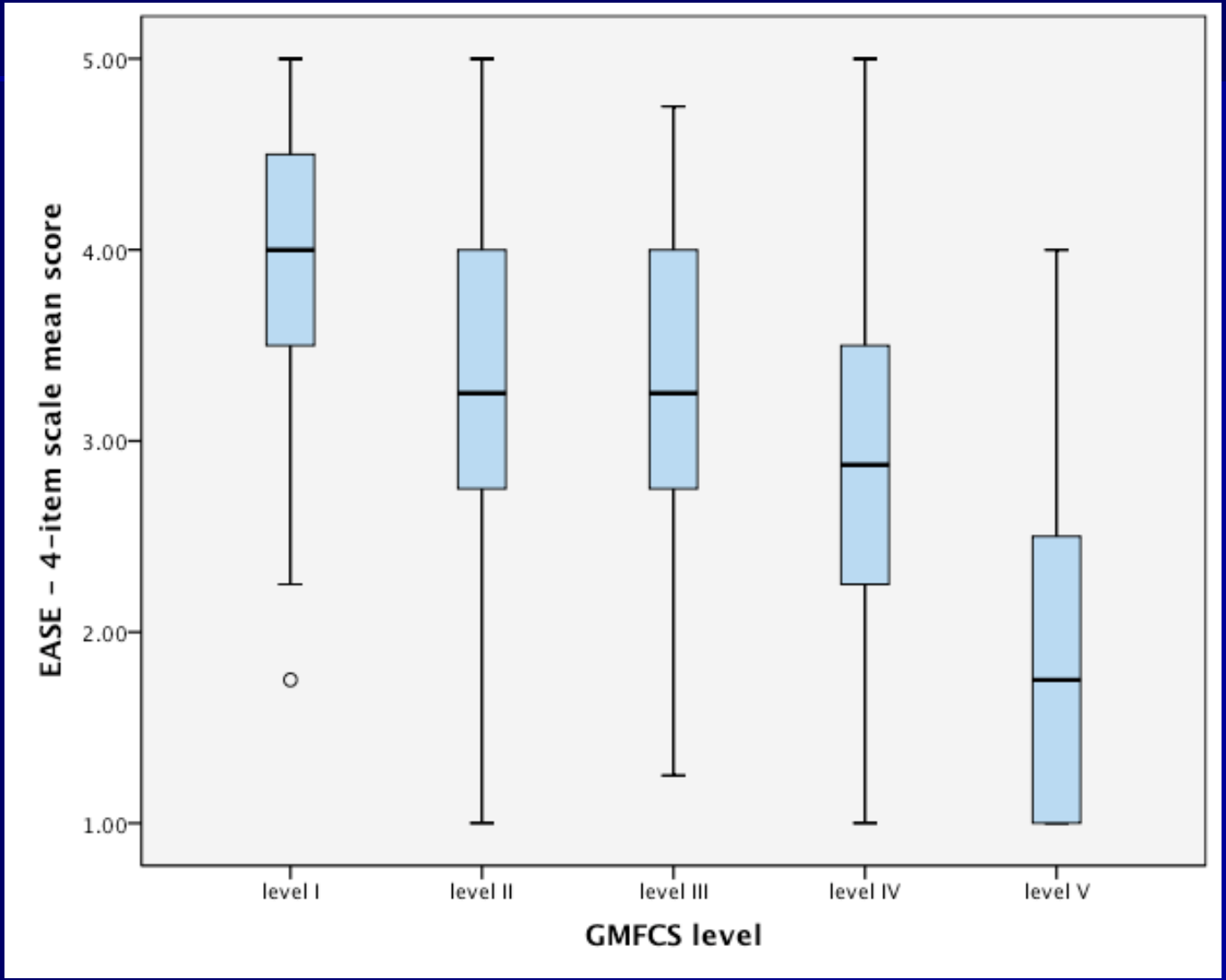
Reliability and Validity of the EASE

(McCoy et al. 2012)

Four items supported through confirmatory factor analysis

- ✧ Cronbach's alpha = 0.83
- ✧ test-retest reliability = 0.75 (95% CI 0.54 – 0.87)
- ✧ construct validity – r = 0.52 with 6 Minute Walk Test ($p < .05$)

Interpretation: EASE



Child Health Conditions Questionnaire

parent-completed measure

Child Health Conditions Questionnaire

(Wong et al. 2011)

Items

- **16-items (with an additional ‘other’)**

- **parents respond ‘yes’ or ‘no’ to “*does your child have problems _____?”***

- **if ‘yes’ – to what extent does it affect his or her daily life (7-point Likert scale; from ‘not at all’ to ‘a very great extent)**

Scoring

✧**Total number of health conditions or average impact**

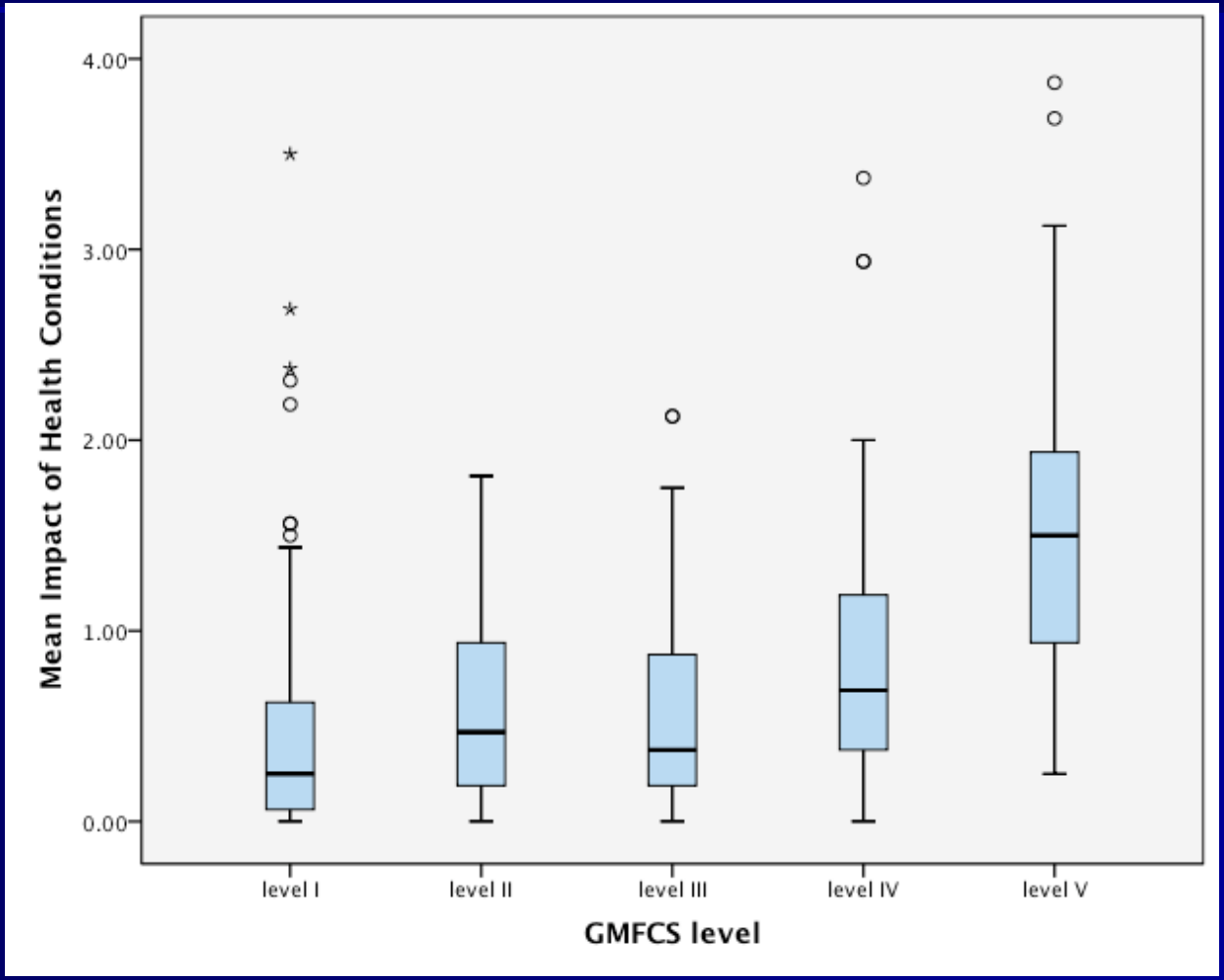
Reliability and Validity

Test-retest reliability – ICC = 0.85 (95% CI 0.72 – 0.93)

Content validity – international definition; ICF informed

Discriminant validity – differences among all GMFCS

Interpretation: Health Conditions



Child Engagement in Daily Life Measure

parent-completed measure

Child Engagement in Daily Life

(Chiarello et al. Under review; measure pending posting)

Items / Subscales

- **40-items (5-point Likert Scales)**
- **parents rate the child's:**
  - **1) frequency and degree of enjoyment in participating in family and community life & recreation and leisure activities**
  - **2) need for physical help and ability to consistently do ADLs (self-care)**

Scaling and Scoring

Scaling – from 1 to 5

- **Participation:** never, almost never, once in a while, often, very often
- **Enjoyment:** not at all, very little, somewhat, very much, a great deal
- **Self-Care:** does not do the activity; does assist but needs help for all; does part independently, but needs help for some; independently some of the time; independently most of the time

Scoring

- Average frequency of participation in family and recreational activities; enjoyment of participation; and participation in self-care

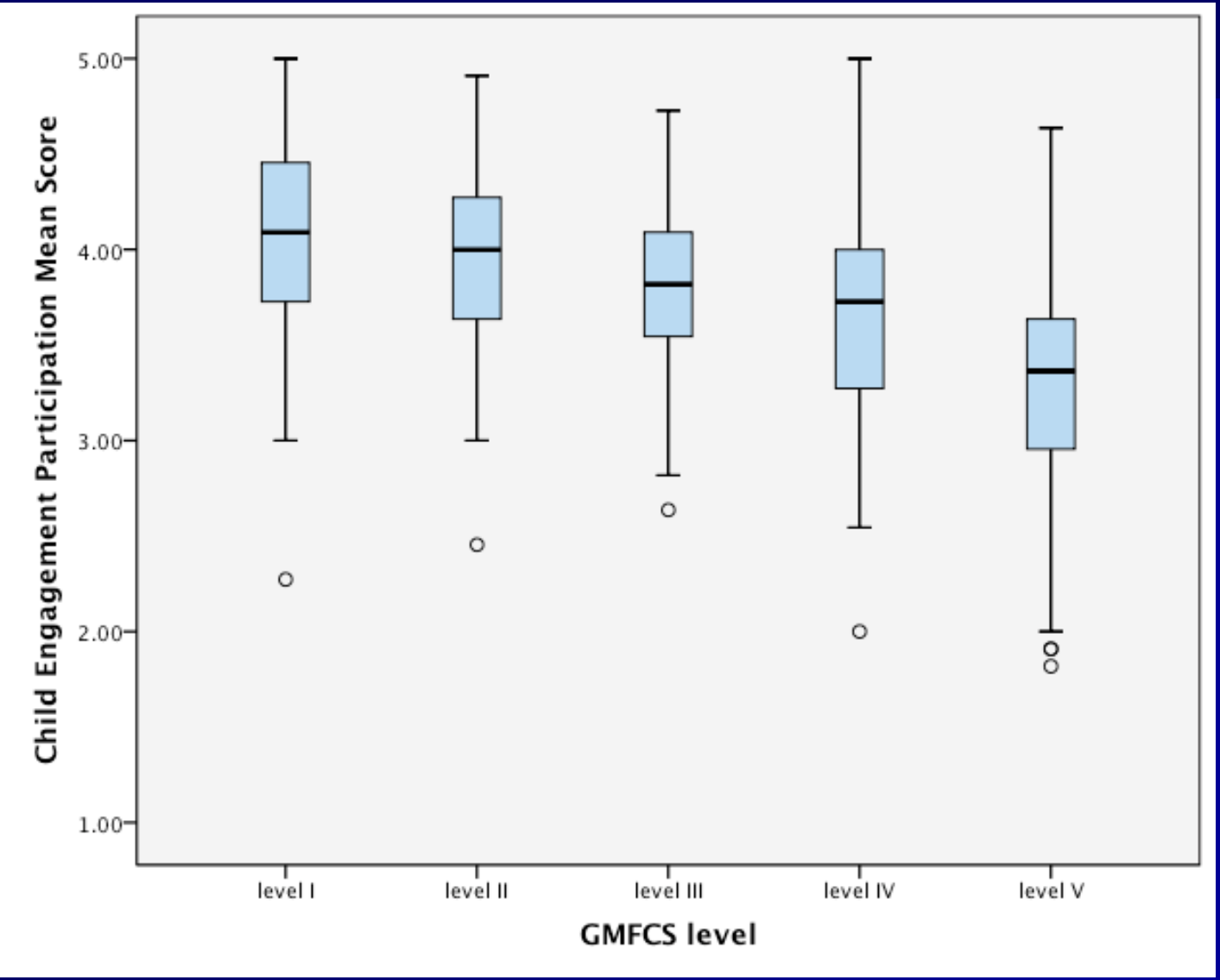
Reliability and Validity

- **Cronbach's alpha:**
  - **Participation in family / recreational activities = 0.86**
  - **Self-care = 0.90**

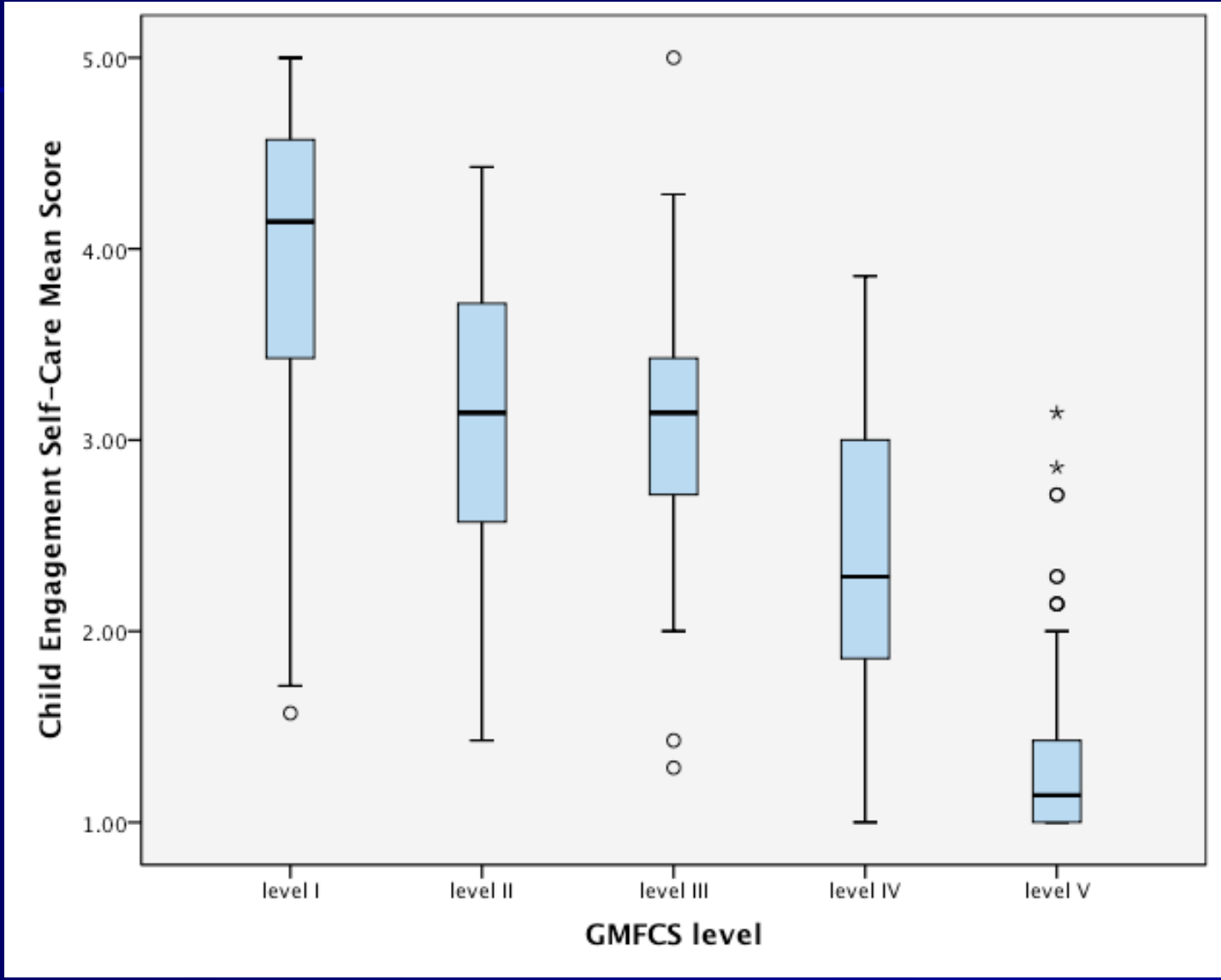
- **Test-retest reliability**
  - **Participation = 0.70** (95% CI 0.47 – 0.84)
  - **Self-care = 0.96** (95% CI 0.91 – 0.98)

- **Rasch analysis supported participation; refinements to self-care (preliminary results good)**

Interpretation: Participation



Interpretation: Self-Care



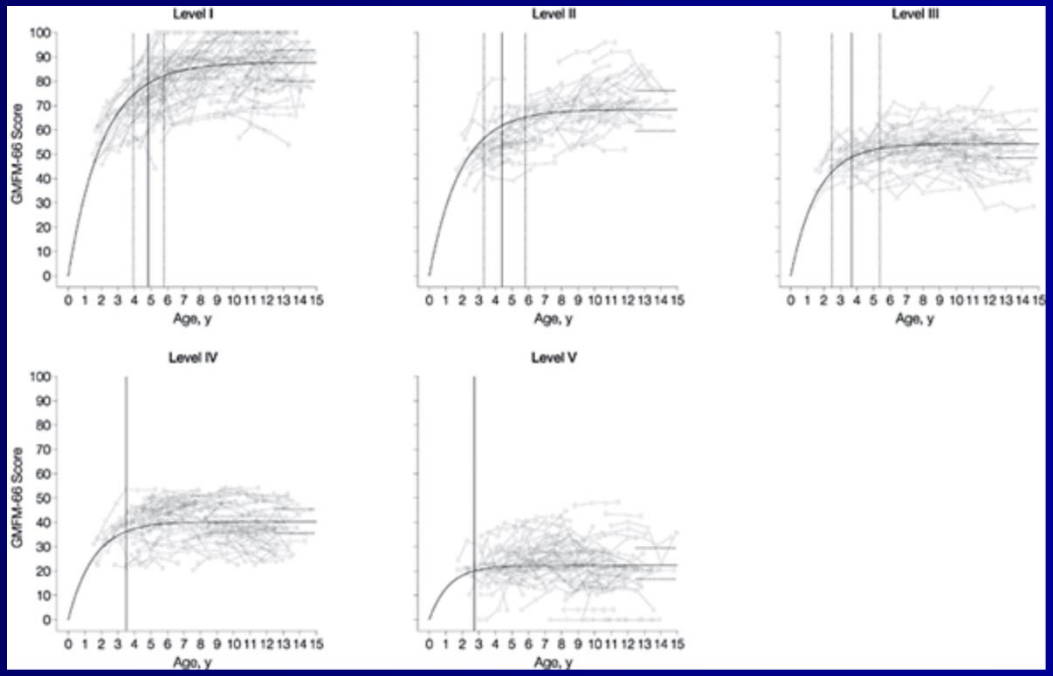
Limitations

- Interpretation of all measures except the GMFM is currently limited to cross-sectional reference data for children 18 months up to the 5th birthday
- A brief measures of adaptive behaviour is not yet available publicly

Limitations – Interpretations RELATIVE

- **Recall that children are spread across the full continuum of scores (e.g. GMFM;** Rosenbaum et al. 2002**)**

Some children will be below the 25th percentile in each level



- **probably better to interpret percentiles based on relative strengths and weaknesses, rather than absolute number**

To realize the clinical utility of these instruments, access the following complementary presentation:

Supporting Motor Function, Self-care, Participation and Playfulness of Young Children with Cerebral Palsy

For More Information

http://www.canchild.ca/en/ourresearch/moveplay.asp

Key References

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