

**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  
December 2013**

The focus of this presentation is on introducing brief, reliable and valid instruments to obtain a holistic picture of children with cerebral palsy. The measures presented were developed in the context of the Move & PLAY Study.



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

**Funded by**

**Canadian Institutes of Health Research**



**National Institute of Disability and Rehabilitation Research**

Move & PLAY stands for “Movement and Participation In Life Activities of Young Children with Cerebral Palsy”. This study was jointly funded by the Canadian Institutes of Health Research and the National Institute of Disability and Rehabilitation Research.

## Investigators



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The Investigators of this study include Doreen Bartlett from Western University, Lisa Chiarello and Bob Palisano from Drexel University, Peter Rosenbaum from McMaster University, Sally Westcott McCoy from the University of Washington, Lynn Jeffries from the University of Oklahoma Health Sciences Centre and Alyssa LaForme Fiss from Mercer University.

Investigators from CanChild include Cofounder and Scientist, Peter Rosenbaum, and Scientists Doreen Bartlett and Bob Palisano.

## COLLABORATORS

- Barbara Stoskopf, RN, MHSc, McMaster, CanChild, Project Coordinator
- Audrey Wood, PT, MS, Drexel University, Regional Coordinator
- Allison Yocum, PT, DSc, PCS, University of Washington, Regional Coordinator
- Tina Hjørngaard, Canadian Parent Consultant
- Barbara Sieck Taylor, American Parent Consultant
- Piotr Wilk, Statistician, Western University
- Therapist Assessors; Interviewers; and participating Parents and Children

Overall Study Coordination was provided through *CanChild*



Barb Stoskopf was the overall study coordinator at CanChild; regional coordinators included Audrey Wood at Drexel University and Allison Yocum at the University of Washington.

We had two parent consultants who informed all aspects of this study: Tina Hjørngaard in Canada and Barb Sieck Taylor in the US.

Piotr Wilk, from Western University was our statistician.

We'd also like to acknowledge the collaboration of 62 therapist assessors, 17 interviewers and last, but not least, participating parents and children without whom this study would not have been possible.

The overall study coordination was provided through CanChild.

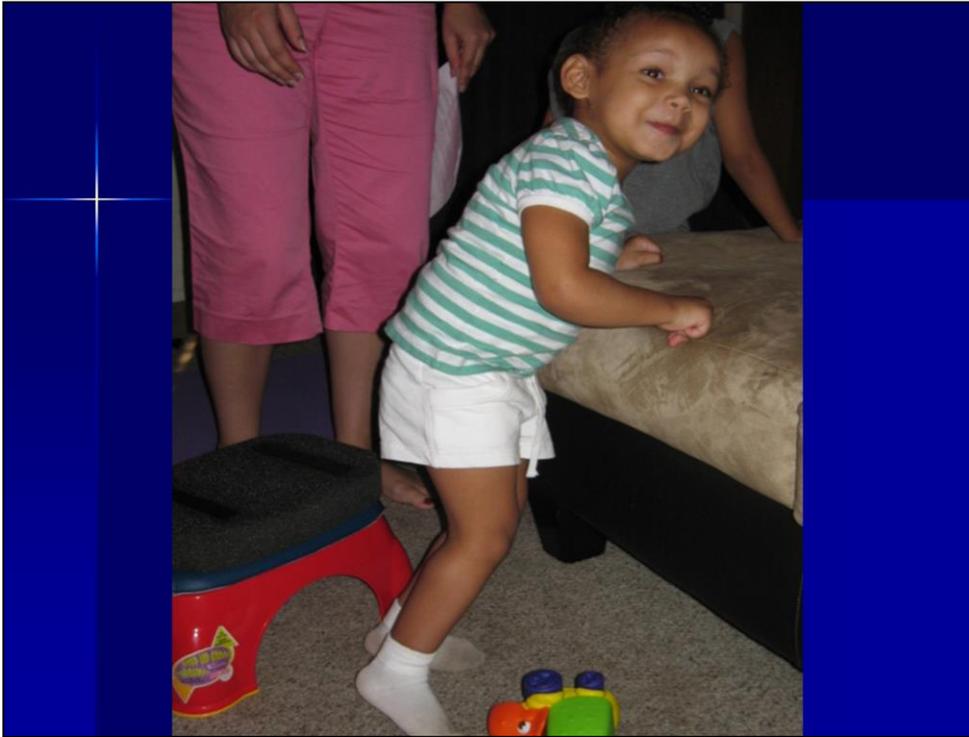
## Population of Interest: Cerebral Palsy

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)

The population of interest in the Move & PLAY Study is cerebral palsy (or CP), a diagnosis that “describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributable to non-progressive disturbances that occurred in the developing 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.”

This international consensus definition highlights the multiple aspects of cerebral palsy that ought to be considered when planning rehabilitation services for individual children and their families.



Here is a participant of the Move & PLAY study, just to provide an image of the focus of the work.

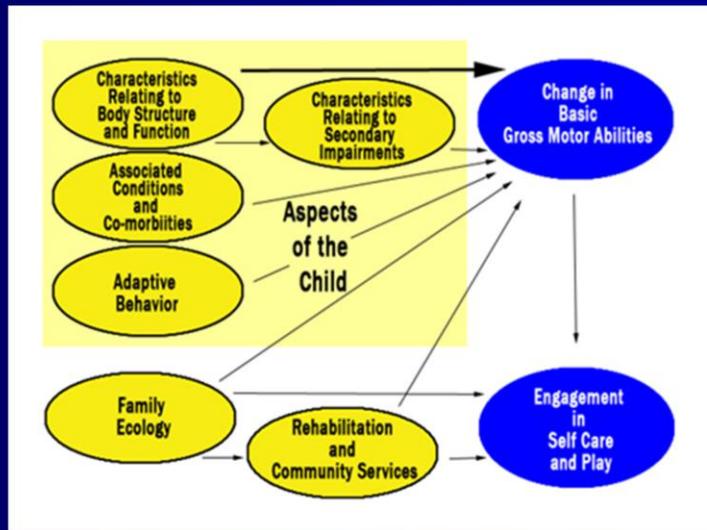
## **Complexity Requires a Holistic View**

- ❖ **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**

As is readily depicted by the definition of CP, the condition is complex and requires a holistic view. Children with CP can have a range of complex and unique challenges that impact motor function and participation in daily life.

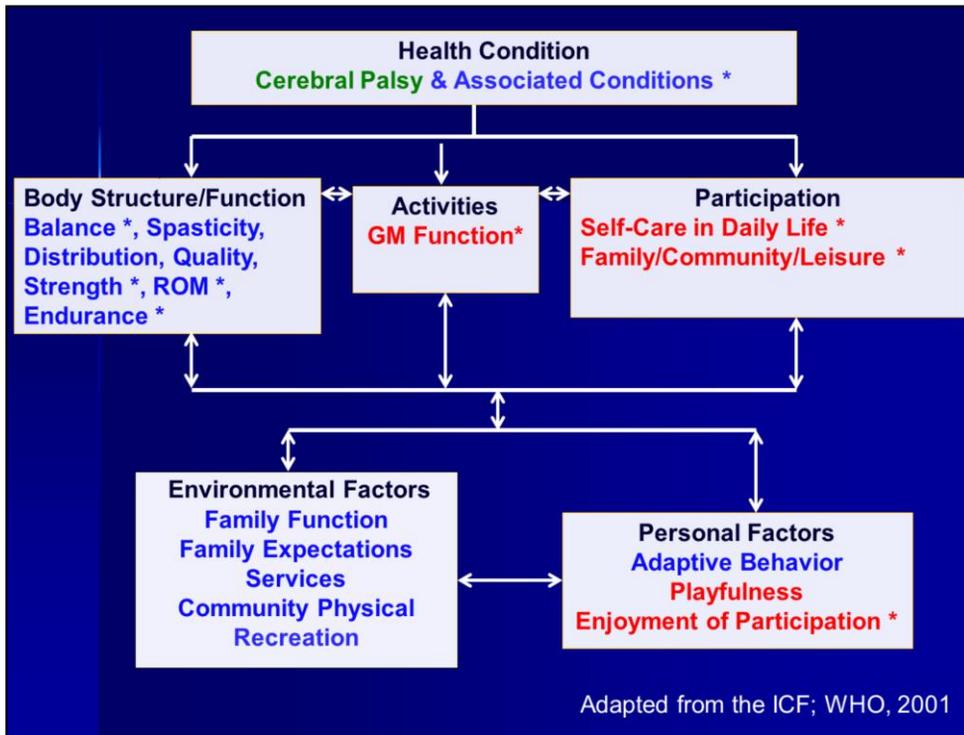
To understand this complexity, we have developed a conceptual model, a description of which is provided in a summary on our study's website. We have also developed a range of assessment tools to enable clinicians to obtain a holistic view of each individual child. Importantly, we have aimed to develop BRIEF tools to enhance feasibility of implementation.

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



The conceptual model describes multiple aspects of the child, including characteristics relating to body structure and function that ‘come with’ a diagnosis of CP. These include variations in balance or postural control, distribution of involvement, spasticity and quality of movement. Characteristics of secondary conditions associated with CP include impairments of range of motion, strength and endurance. As seen in the definition of CP, it is associated with other conditions, such as epilepsy and many possible co-existing health conditions. A final child construct that we consider in the model is ‘adaptive behaviour’ – this represents the extent of resiliency each child brings to the holistic picture. This construct is a personal child factor, unrelated to a diagnosis of cerebral palsy.

We also consider environmental contexts in which children develop, notably family ecology and rehabilitation and community services. All of these constructs are considered as determinants to the outcomes of interest in Move & PLAY: motor function, self-care, participation, and playfulness.



The conceptual model was informed by the World Health Organization’s International Classification of Functioning, Disability and Health. Here is an adaptation of the ICF model, illustrating where aspects of the Move & PLAY study fit. The health condition is CP; we have included the associated conditions along with the health condition. Body structure and function includes the primary impairments associated with variations in balance, spasticity, distribution of involvement, and quality of movement, as well as secondary conditions involving impairments of strength, range of motion and endurance. The activity-level variable in our study is gross motor function. Two aspects of participation include self-care and involvement in recreation and leisure activities. Environmental factors include aspects of families and the rehabilitation and community services that children and families make use of. Finally, personal factors include aspects of the child including adaptive behaviour, playfulness and enjoyment.

In this figure, determinants of our selected outcomes are in blue; the outcomes are in red. The factors with an asterisk are measures that we developed in the context of the Move & PLAY study, which is the focus of this presentation.

**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**

By the end of this presentation, you will ...

In this presentation, we focus on the interpretation of individual measures. In the next [accompanying] presentation, we investigate these (and other) factors as determinants of outcomes of motor function, self-care, participation, enjoyment and play. Think of the focus of this presentation as 'building blocks' for a more holistic picture, which is the focus of the next presentation.

## **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)**

Starting with the Gross Motor Function Measure...

## 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)**

The Gross Motor Function Measure is a standardized observational instrument designed to measure change in motor function over time in children with CP – either in response to intervention or in the normal clinical course.

The GMFM initially comprised 88 items, reflecting motor abilities of very young children through to 5-year-old children developing typically.

The items on the measure comprise activities from five dimensions (*list*).

The current gold standard is now the GMFM-66 which was created through a process called Rasch Analysis that facilitated the removal of 22 items from the original measure and provided information about the difficulty of performing each of the remaining 66 items.

The GMFM-66 can take between 45-60 minutes to administer depending on the child and the therapist and their interactions.

Therapists can enter the scores from the 66 items into a computerized scoring program, the Gross Motor Ability Estimator (GMAE) to calculate a GMFM-66

score.

## 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*

The scoring manual should be used to ensure adherence to administration guidelines for each item and to ascertain specific criteria for each level of the items. Items are scaled as *noted on the slide*.

## **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**

45-60 minutes is a long assessment– for both therapists and children and their families. Therefore, two shortened versions of the GMFM were created that used information obtained from the Rasch analysis of the GMFM-66. Here we present the GMFM-66-Basal and Ceiling approach, which was developed for use in the Move & PLAY Study. There is also the GMFM-66-Item Set approach, developed by Dianne Russell; however, it was not available at the time our study started.

The Basal and Ceiling version of the GMFM-66 required the development of a new score sheet that lists all of the GMFM-66 items in their difficulty order, from easiest to hardest. The number and wording of all of the items remains the same. The score sheet, which is posted on the Move & PLAY website, contains suggested starting points based on a child's age and Gross Motor Function Classification System (GMFCS) level. For those who are unfamiliar with the GMFCS, an expanded and revised version going up to 18 years of age is available on the CanChild website ([www.canchild.ca](http://www.canchild.ca); search GMFCS).

As for the full GMFM, each item describes the starting position in CAPS and then the maximum function for a score of 3 is included after the colon. New to this score sheet are columns on the left hand side that indicate which of the five dimensions the item was part of in the original measure.

Once a starting point has been located (again, based on the child's GMFCS level and age) items are administered and scored from easiest to most difficult, first aiming to get three consecutive 3s (that is, full task completion) as a basal score. More difficult items are sequentially administered until three consecutive 0s (i.e. tasks that the child does not initiate) are obtained; this is the ceiling score. Check to make sure that a minimum of 15 items have been administered (including basal and ceiling scores, but not items that are 'not tested'). If 15 or more items have been administered, then the test is complete. If there are fewer than 15 items, continue to administer items by alternating between scores lower than the basal and higher than the ceiling until you have 15 items tested.

## 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)

The validation of the GMFM-66-B&C was the focus of Laura Brunton's MSc work. She also looked at the item set approach; however, in the end, most therapists preferred the B&C approach and it is the abbreviated version that we advocate (and that we used in the Move & PLAY study).

The validity of the GMFM-66-B&C approach is supported by the strong relationship with the GMFM-66 (original version). An index of 1.00 would indicate a perfect relationship, and 0.987 is pretty close to this!

Also, scores between two raters (i.e. inter-rater reliability) were also pretty closely related with the value of 0.97 (again, with 1.00 meaning perfect agreement).

Finally, scores were stable over a two-week period (i.e. test-retest reliability was supported), as indicated by the ICC value of 0.994.

So, in summary, as can be seen from the values of the intra-class correlation coefficients (all above 0.97) (and the tight 95% confidence intervals, all between 0.93 and 0.99), the validity and reliability of this abbreviated version is

supported. Basically, this means that we are 95% confident that the indices for validity and reliability are all above 0.93, which could be considered 'excellent'.

On average, with some experience, it takes about 20 minutes to administer and about 5 minutes to score, once you have installed the software.

## 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**

The equipment needed to administer the B&C version is identical to that of the 66-item version of the GMFM, and is specified in the manual.

In addition, the modified score sheet is required, which can be accessed on the Move & PLAY website, as indicated earlier.

## 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**

The guidelines for administration are identical to that of the GMFM. The test should be conducted in an environment with sufficient space, warmth and comfort. Shorts and a t-shirt are ideal, and when administered in the standardized fashion for an activity-level variable, the child should be in bare feet.

As with the GMFM-66, you can administer each item up to 3 times and then you score the best performance of those three. If a child performs an item spontaneously – great - you can score that. A therapist can place the child in the starting position but are not allowed to facilitate the movement in any other way. As always being creative and using toys or other incentives is helpful.

## **GMFM-66-B&C**

### **Scoring using the GMAE2**

**Download available from:**

**<http://canchild.ca>**

**Search GMAE-2**

The second version of the Gross Motor Ability Estimator is freely available from the CanChild Website. It comes with a good tutorial to get you started on using it. When you get to the part in which item scores are entered, you will see that you have options to use any of the following options: the 88-item version, the full 66-item version, the Item Set approach or the Basal and Ceiling approach (the last option).

Once all available items are entered, a score and 95% CI are readily calculated. Percentile scores, item maps and other summary data are also available.

## Case Illustration

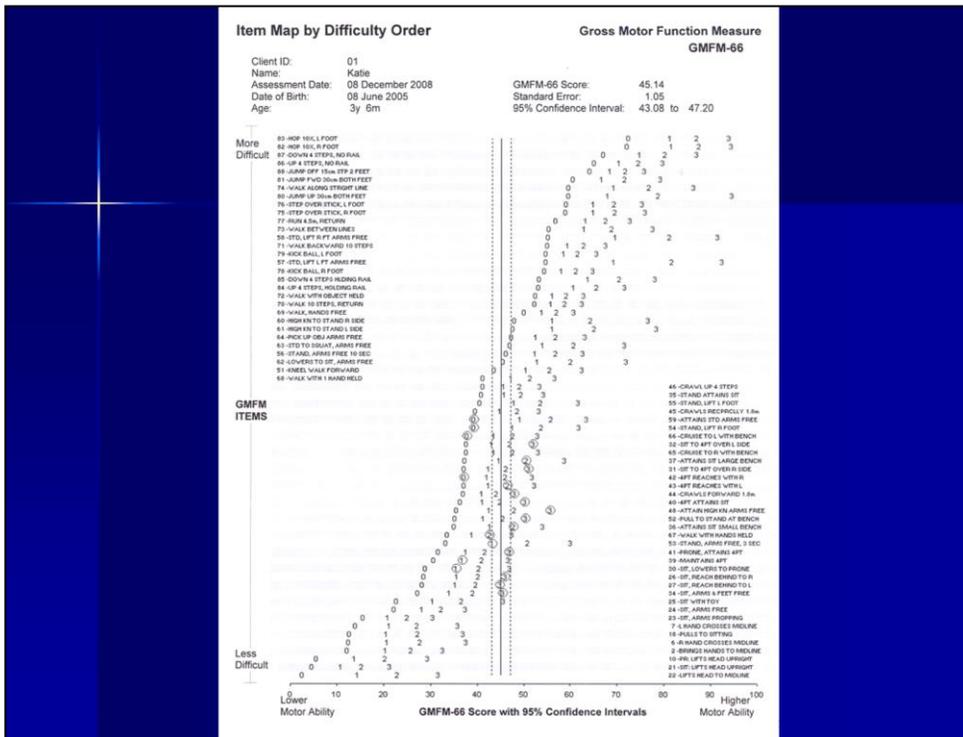
- **Katie, age 3 ½ years, spastic diplegia, level III**
- **Enter data into the GMAE**
  - **GMFM-66 = 45.1 (95% CI = 43.1 to 47.2)**
  - *pattern of scoring on item map can assist with*
    - *realistic goal setting for motor function*
    - *timing of successful goal attainment*

To illustrate the clinical utility and interpretation of the GMFM-66 scores, a case is used.

Katie is a 3 ½ year old with spastic bilateral CP at GMFCS level III.

Once her GMFM-66-B&C data have been entered into the GMAE, her full GMFM-66 score can be calculated – along with the 95% CI

An item map, placing the items in difficulty order, can also be generated, which can assist with realistic goal setting for motor function and timing of the duration of successful goal attainment, illustrated in the next slide.



Here is Katie’s item map for the GMFM-66-B&C scores. Along the ‘y axis’ the 66 GMFM items are ordered from the easiest (at the bottom) to the most difficult (at the top). In addition, placement of item scores of 0, 1, 2, and 3 are ordered along the ‘x axis’ according to their respective difficulties. When completing the B&C version with Katie, 21 items were administered, with three basal scores of 3 (starting at ‘sit, arms and feet free’), three ceiling scores of 0 (ending with ‘attains standing arms free’), and variation of scoring in between, with a ‘not tested item’ (cruise to right with bench) which is not scored. This item map can assist in the following ways:

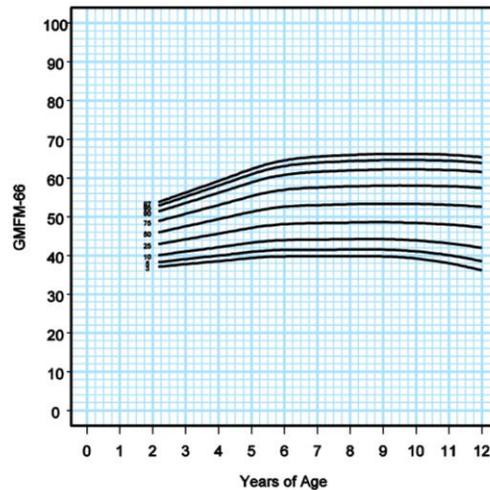
In terms of assisting with realistic goal setting for motor function, with her top completed item of moving from ‘sit 4 point over left side’, having a goal of ‘walking with 1 hand held’ (that is, 8 items more difficult along the continuum) is not likely a realistic goal at this time.

In terms of assisting with timing of the duration of successful goal attainment, it is useful to look at the spread of item scores. When scores are more closely spaced (as is the case for ‘sit, lowers to prone’), this item will likely be acquired over a shorter time than items which have scores more widely spaced (as is the case for ‘stand, arms free, 3 seconds’).

These two aspects of the item maps may be particularly useful for clinicians who are relatively new to working with children with CP.

## Interpreting the GMFM-66-B&C

(Hanna et al. 2008)



Same as the GMFM-66, reference percentile curves are available for each of the 5 GMFCS levels. These are available on the CanChild website, and more recently, have been included in the most recent version of the GMAE. Here is an example for children at Level III. A specific score at a given age yields a percentile – similar to the familiar weight, height and head circumference reference percentiles to monitor physical growth of infants and children. For Katie, at 3½ years of age, her score of 45 is around the 25<sup>th</sup> percentile. This is useful to understand where a child ranks relative to other children in the same GMFCS level.

More importantly, perhaps, is to understand how an individual child is doing over time.

## 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
<b>N</b>	147	78	107	121	117
<b>mean change</b>	3.0	-0.8	3.3	2.5	3.6
<b>sd change</b>	15.6	15.5	12.4	11.8	13.2
<b>probability</b>	<b>interval of change in percentiles</b>				
<b>50%</b>	± 10.5	± 10.5	± 8.4	± 8.0	± 8.9
<b>80%</b>	± 20.0	± 19.9	<b>± 15.9</b>	± 15.1	± 16.9

If you do serial assessments over a period of 9-12 months, you can determine if a child is developing “as expected”. The table shown here presents the interval of change in percentiles at both 50% and 80% probability levels. For this example, we have chosen the 80% probability values. If a child is developing ‘as expected’, the percentile for the second score would fall within the + or – range of 16 percentile points for a child at level III. If the percentile change over this interval is greater than 16 points, the child would be considered to be doing “better than expected” and conversely, if the percentile change was below the level of 16 points below the previous score, and the child would be determined to be doing “more poorly than expected”. An example follows.....

By tracking change over time, you could decide to “stay the course”, if the child was developing ‘as expected’ or you could search for explanations of either better or poorer capability than expected – and interventions would change accordingly.

### ***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  $\pm 16$ )

Here is a scenario in which the interpretation would be: “Katie is developing as expected”. Her change in GMFM-66 score over 9 to 12 months is 3 points, which translates to a difference (or ‘improvement’) of 10 percentile points. Because 10 is within  $\pm 16$ , she can be described as developing ‘as expected’. In this scenario, changing what is happening in rehabilitation might not be warranted, in the absence of other indicators.

## ***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  $\pm 16$ )

Here is an example of a change over a 9 to 12-month period in which change could be interpreted to be 'better than expected'. A change in GMFM score of 9 points translates to a change in percentile points of 50, which is well above the cut point of 16. In this situation, one might look to what has been different to explore potential contributors to the very good outcome. In addition to contributing to Katie's good outcome, it is possible that these factors might also be applicable to other children.

### ***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 5<sup>th</sup>, a difference of 20
- this amount of change means that Katie is developing *more poorly than expected* (outside  $\pm 16$ )

Conversely, a decline of almost 5 GMFM points is associated with a drop in percentile points of 20, which is outside the plus or minus 16 cut-points, so the interpretation would be that Katie is doing more poorly than expected. In this situation, it would be prudent to attempt to determine factors associated with this. Perhaps she has experienced a period of medical or functional instability, due to uncontrolled seizures or a recent surgery? It is also prudent to explore contextual factors. Is there a personal factor (such as anxiety) or an environmental factor (such as a difference in family functioning or a difference in service delivery) that might explain the relative decline? In this situation, intervention might be focused on aspects hypothesized to explain this less than optimal outcome.

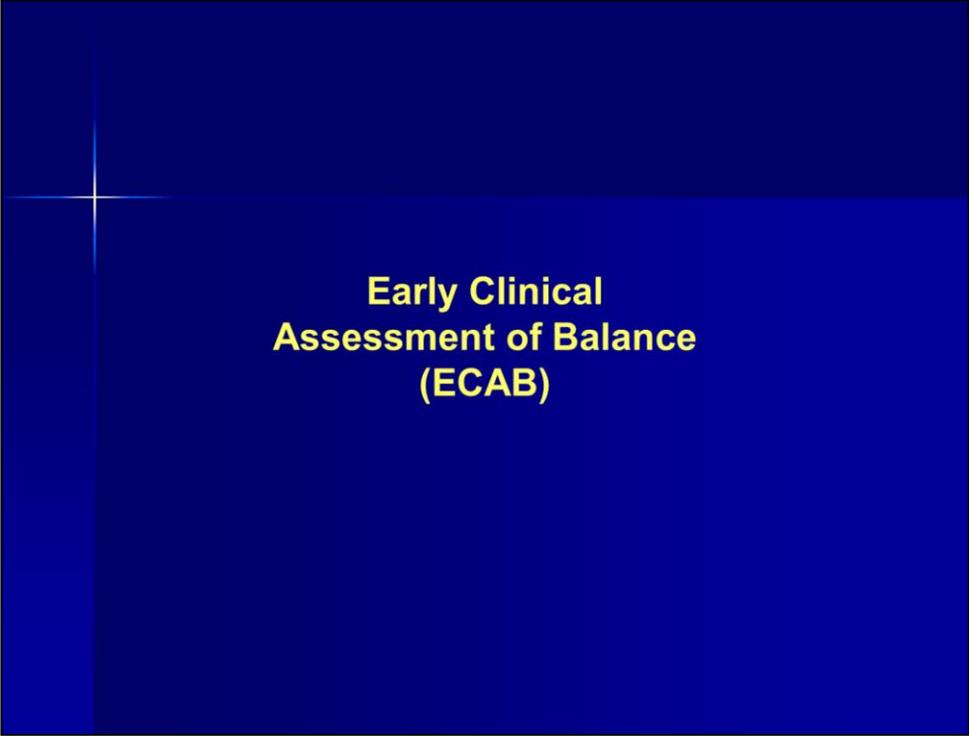
## Summary: Utility of the GMFM-66-B&C

(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

In summary for the GMFM-66-B&C, we recommend use of this abbreviated version because fewer items need to be administered and scored to obtain an accurate estimate of a child's motor function. Decreased time to administer leaves more time to assess other aspects of the child and family, such as those described outlined in our conceptual model. The score sheet is readily available on the CanChild website, as is the second version of the GMAE software. Using the percentile ranks, one can ascertain **if** a child is developing 'as expected' or 'not' and the item maps can help with realistic goal setting, and establishing the time period for successful goal attainment.

This abbreviated version of the GMFM-66 was the first product developed in the Move & PLAY study and – to date – has the most complete system for interpretation, based on previous CanChild research.



## **Early Clinical Assessment of Balance (ECAB)**

Given that the international consensus definition refers to aspects of 'movement and posture', a second measure that we sought to develop was a measure of balance or postural stability that would be applicable to children across all GMFCS levels – hence the Early Clinical Assessment of Balance (or ECAB), which is described next.

## 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)

The ECAB is a new measure designed to be used with children with CP across all GMFCS levels. It is an integration of two existing balance measures, a section from the Movement Assessment of Infants and items from the Pediatric Balance Scale.

## 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 MAI comprise Part I of the ECAB. 7 items, some of which are scored bilaterally, were adapted from the Automatic Reactions section of the scale, with permission from the original authors. These items include lateral head righting, head righting in flexion and extension, rotation in the trunk, equilibrium reactions in sitting, and protective extension to the side and backwards.

## 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

Part II of the ECAB comprises 6 items from the Pediatric Balance Scale. These items are 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, and 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

In selecting the items for the ECAB, one item was excluded from the automatic reactions section of the MAI. Specifically, protective extension forward was excluded, for the pragmatic reason that it is harder to test in older children than in infants.

From the PBS 6 items were selected: 2 from each of relatively easy, moderately difficult, and relatively difficult items. We also excluded items that were difficult to assess in young children (such as the forward reach test).

## 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)

As can be seen by the high values for the ICCs (as well as the tight 95% CIs), the ECAB has strong reliability. In addition, construct validity is supported by a high correlation with the GMFM. On average, the ECAB takes about 12 minutes to complete.

Finally, known groups validity of the ECAB is supported by statistically significantly different scores among all 5 GMFCS levels.

## 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

In addition to the score sheet, which contains all of the information needed to administer and score this measure, one needs an adjustable bench so that the child can sit with hips and knees at 90 degrees, a mat, a stopwatch and a 6-inch step stool. Optional equipment includes 2 child sized footprints (we've cut these from a carpet runner), a blindfold, flash cards to facilitate the timed items, and stickers, to be used creatively to enable testing of the items, particularly for younger children.

## 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*

When administering the ECAB, begin testing children in GMFCS levels I and II at the beginning of Part II (or item 8).

For children in levels III, IV or V, begin testing with the first item of Part I. Please note that for children in level III, both Parts I and II should be attempted.

For children with hemiplegia, begin testing the child at item 4.

In all cases, continue testing until the 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**

In terms of scoring Parts I and II are scored separately and then summed.

For Part I, responses are graded on a 4-point ordinal scale, from 0 to 3. Item scores are summed for a total possible Part I score of 36.

For Part II, the items are graded on a 5-point ordinal scale, which are re-weighted to account for the task's increased difficulty. Item scores are summed for a total possible Part II score of 64.

Parts I and II are summed for a maximal total ECAB score of 100, with higher scores representing better balance.

## Obtaining ECAB Scores for Children at Different GMFCS Levels

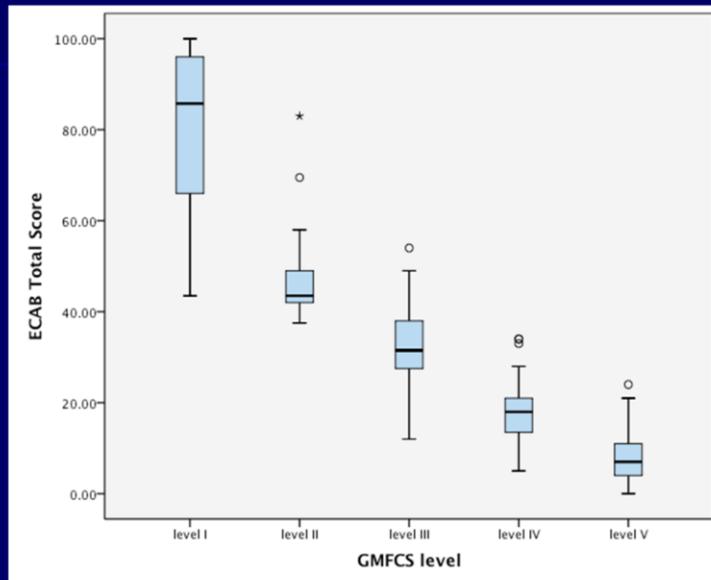
- ❖ **Children in GMFCS levels III, IV, V**
  - ❖ **For total score, sum all available items**
- ❖ **Children in GMFCS levels I & II:**
  - ❖ **For total score, sum 36 plus Part II score**
- ❖ **Children with hemiplegia**
  - ❖ **For total score, credit child with 12 for items 1-3, then sum rest of Parts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

Scoring varies a bit by GMFCS level of the child. For children in GMFCS levels III, IV and V, sum all available items for a total score.

For children in GMFCS levels I and II, assume that they obtain the maximum score of 36 for Part I and add this to the sum of scores for Part II.

For children with hemiplegia, credit the child with 12 for items 1 to 3 and then sum the rest of Parts I and II.

## Interpretation: ECAB



At this point we are limited to interpreting scores very crudely based on a cross-sectional sample of children from the Move & PLAY Study who were between 18 months and the 5<sup>th</sup> birthday at the time the data were collected.

This figure contains 5 'box plots', representing the scores (from 0 to 100) on the 'y axis' separately for children across the 5 GMFCS levels, along the 'x axis'.

Each of the 'boxes' has three important parts: the top, the bottom and a line somewhere in between. The line inside the box corresponds to the score representing the median value (i.e. the value obtained when the scores are rank ordered, explaining the value at which 50% of the participants score higher and 50% score lower). The top of the box corresponds to the 75<sup>th</sup> percentile (i.e. 25% of participants score higher and 75% score lower). The bottom of the box corresponds to the 25<sup>th</sup> percentile; in this case, 75% of the participants scored higher and 25% scored lower. In some cases, the lines extending above and below the boxes represent the upper 25<sup>th</sup> percentile and the lower 25<sup>th</sup> percentile, with the lines ending at the top and bottom scores, respectively. Occasionally there are 'outlying values' – depicted by dots - which represent scores outside the range of the lines extended to 1.5 times the interquartile (IQ) range (with the IQ range representing the difference between the scores of the 25<sup>th</sup> and 75<sup>th</sup> percentiles).

It is important to remember that these cross-sectional reference values were obtained from young children in the Move & PLAY study, which we think can be interpreted for children up to the 5<sup>th</sup> birthday (i.e. up to 60 months). Because Balance is a developmental function that improves with age, it is important to take age into account when interpreting the scores.



## **Functional Strength Assessment (FSA)**

The ECAB is the only measure of primary impairment we present, because it is the only factor amenable to physical therapy intervention. We move now to the measures of secondary impairments, all of which are potentially amenable to PT intervention. The first measure is the Functional Strength Assessment.

## **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**

For this instrument, we aimed to estimate force production in the following muscle groups: neck and trunk extensors, neck and trunk flexors, hip extensors, knee extensors and shoulder flexors. We initially also included ankle plantarflexors, but interestingly, it did not 'hold out' in the confirmatory factor analysis, and so we do not recommend testing them for this composite score.

## 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**

We developed this estimate because traditional manual muscle testing is time consuming, difficult to get full cooperation in young children (or with children with cognitive impairments) and there is no summary score. Accordingly, the Functional Strength Assessment emphasizes obtaining an estimate of major muscle groups only – not individual muscles, and a strategy to obtain a summary score.

Each muscle group can be rated on an ordinal scale from 1 to 5, allowing for limitations in available 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

Scaling will be familiar to rehabilitation therapists and is noted on the slide.

Few of us are able to contract strongly at the very end of range, so resistance is provided near end range – but not at the extreme.

Scoring can be done using a total of the ordinal scores or the average (when it comes to interpretation of the summary score we use the average score so that we can interpret relative to the scaling descriptions, with higher scores indicating better strength).

## 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**

No special equipment is required to administer the FSA.

## **Guidelines for Administration**

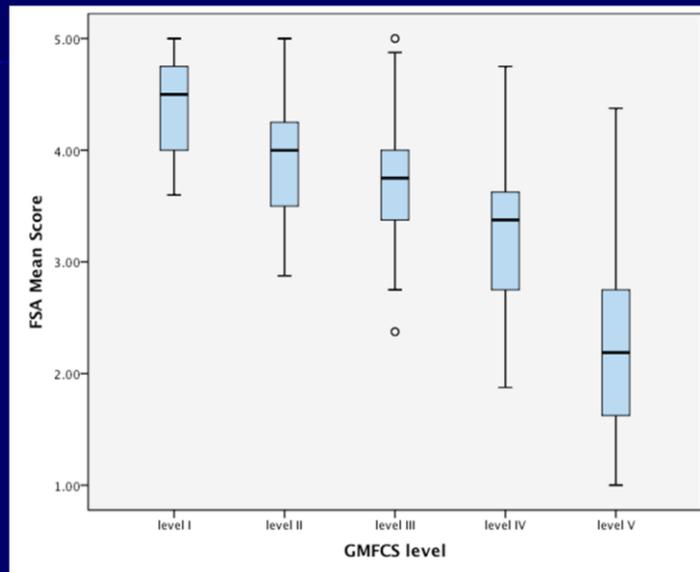
**Child should be alert and happy**

**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



Here are the cross-sectional reference box plots for children aged 18 to 60 months. Unlike the ECAB, we think that these boxplots do not need to take age into account. Recall that 'age appropriate resistance' is part of the criteria for scoring. As indicated earlier, children across GMFCS levels differed in strength scores, except for levels II and III.

For interpretation, at this point, children between the 25<sup>th</sup> and 75<sup>th</sup> percentiles might be developing 'as expected'. Strength scores above the 75<sup>th</sup> percentiles might indicate 'better than expected performance' and scores below the 25<sup>th</sup> percentile might indicate that functional strength training might be an appropriate target for intervention.

**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**

Both the score sheet and the manual needed to administer the SAROMM are posted on the CanChild webpage.

## 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

For interpretation, we are currently using the average score.

## 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

The most confusing aspect of the SAROMM is differentiating scores of 0 and 1 in a scenario such as this: consider a child with hemiplegia who typically postures the involved lower extremity in hip flexion, adduction, internal rotation, knee flexion and ankle plantar flexion, and also has full passive range of motion.

Take a moment to jot down scores for the items listed.

## 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

Here are the correct responses – please note that the scores of 1 for hip extension, hip abduction, hip external rotation, knee extension and ankle dorsiflexion indicate that this child is ‘at risk for’ future limitations in range, based on their posturing. Given their typical posturing, they are NOT at risk for future limitations of hip flexion, hip adduction, hip internal rotation or ankle plantar flexion range of motion, and thus score a 0.

The opposite would be true of a more involved child requiring a wheelchair for mobility who typically postures in hip extension, abduction and external rotation with ankle dorsiflexion (note that in this scenario, the knee(s) is typically flexed, as in the example of the child with hemiplegia).

## 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**

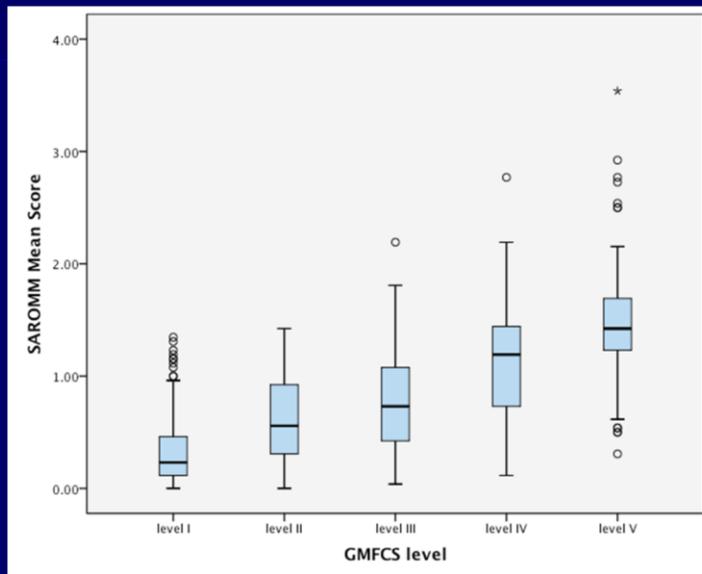
**Use standard PT techniques to administer items**

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

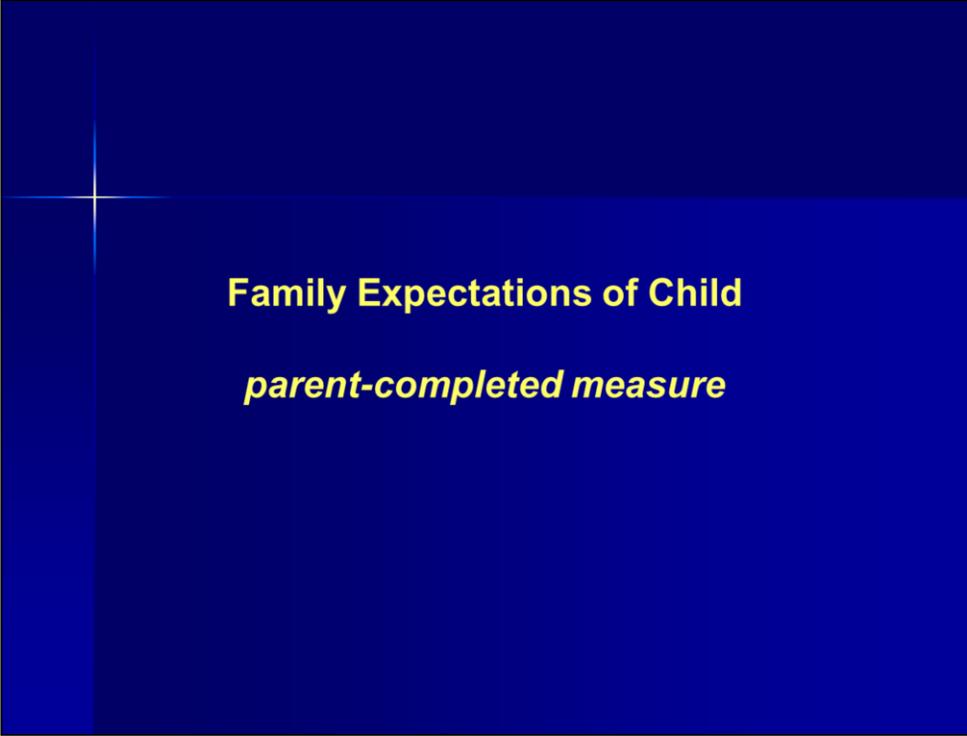
**If need to test passively, expect a “firm” end feel**

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

## Interpretation: SAROMM



As for the ECAB, these are scores that do change with age, with higher scores (or more restrictions) as children get older.



**Family Expectations of Child**  
*parent-completed measure*

Now moving on to the parent-completed measures.... The first is the Family Expectations of Child measure.

## Family Expectations of Child

(Bartlett et al. unpublished, 2011)

### Items

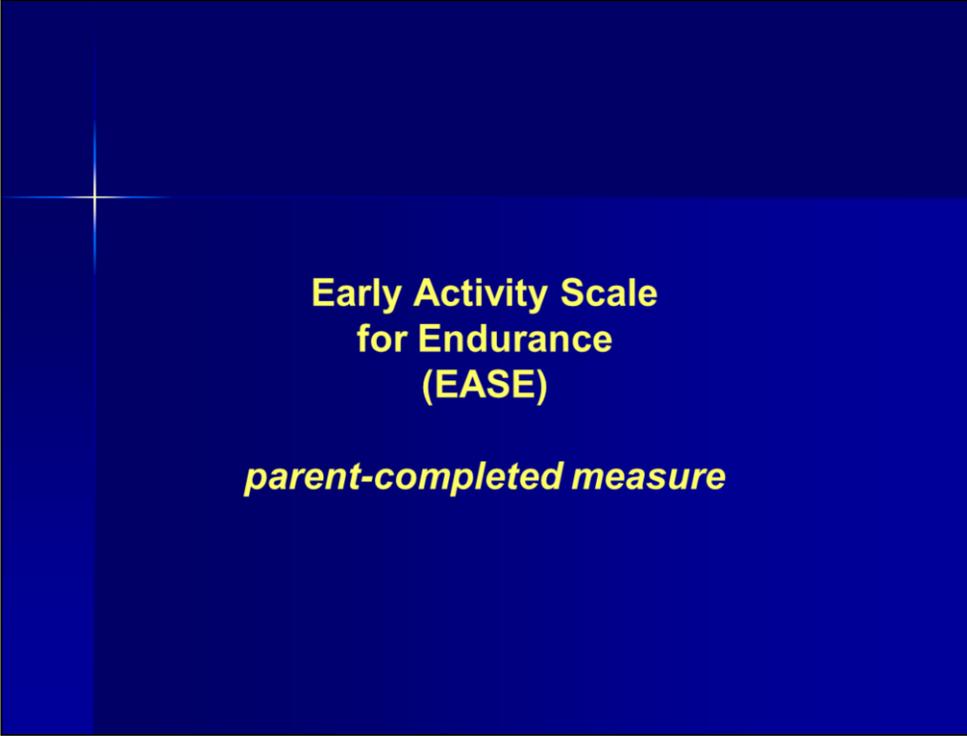
#### •5-items

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

- doing the best that he or she can
- assisting in self-care
- 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')

We don't have any guidelines for interpreting Family's Expectations, but this information can be useful for intervention planning. A score sheet is posted on the Move & PLAY study site.



**Early Activity Scale  
for Endurance  
(EASE)**

*parent-completed measure*

The next parent-completed measure is the Early Activity Scale for Endurance (or the EASE).

**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

We started with 10 items, but condensed them to 4 with the use of confirmatory factor analysis.

## EASE Scaling

### Responses to statements:

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

### Scoring

- ✧ Total or average score

So on the EASE, a high score represents better endurance.

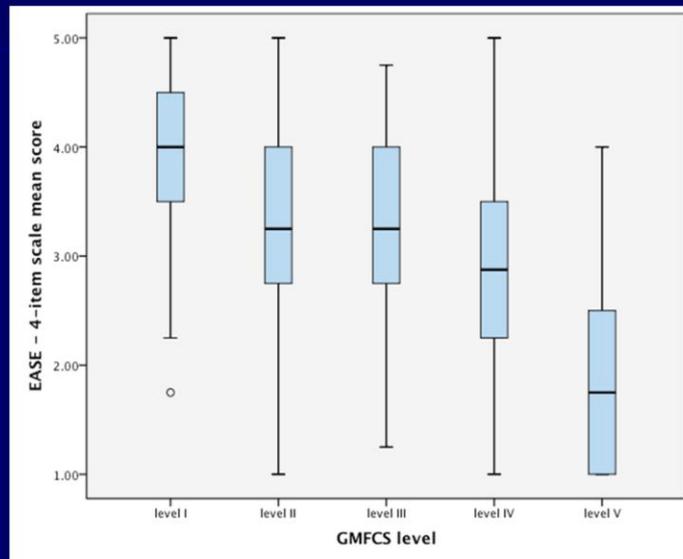
## Reliability and Validity of the EASE

(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



Like strength, we think that these boxplots do not need to take age into account. Here we use the average of 4 items.

For interpretation, at this point, children between the 25<sup>th</sup> and 75<sup>th</sup> percentiles might be developing 'as expected'. Endurance scores above the 75<sup>th</sup> percentiles might indicate 'better than expected' endurance and scores below the 25<sup>th</sup> percentile might indicate that endurance activities might be an appropriate target for intervention.

**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

For scoring, we impute a 'zero' if the child does not have the health condition, and use the scoring of the Likert Scales to come up with a total sum, divided by 16. In short, as for the SAROMM, we are using the average score. The number in this case is not meaningful – but can be interpreted in the context of scores of children in the same GMFCS level.

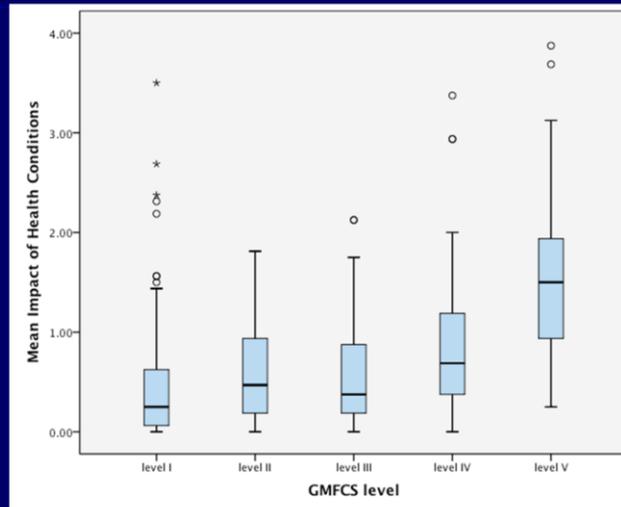
## Reliability and Validity

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



This graph represents the average impact of the 16 health conditions, again with 'zero' being imputed if the health condition is absent (note that higher scores reflect a greater cumulative impact of health conditions). We currently do not have evidence that these results are related to age, therefore, at the present time, we suggest using interpretations similar to the FSA and the EASE:

-children between the 25<sup>th</sup> and 75<sup>th</sup> percentiles might be experiencing associated health conditions in a pattern and extent that is 'as expected'. Scores below the 25<sup>th</sup> percentile might indicate 'better than expected health' and scores above the 75<sup>th</sup> percentile might indicate that further investigation and possible referral is necessary to optimize overall health and associated outcomes.

At this point, we do not have evidence that these summary scores would change for children between 18 and 60 months of age.

**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:

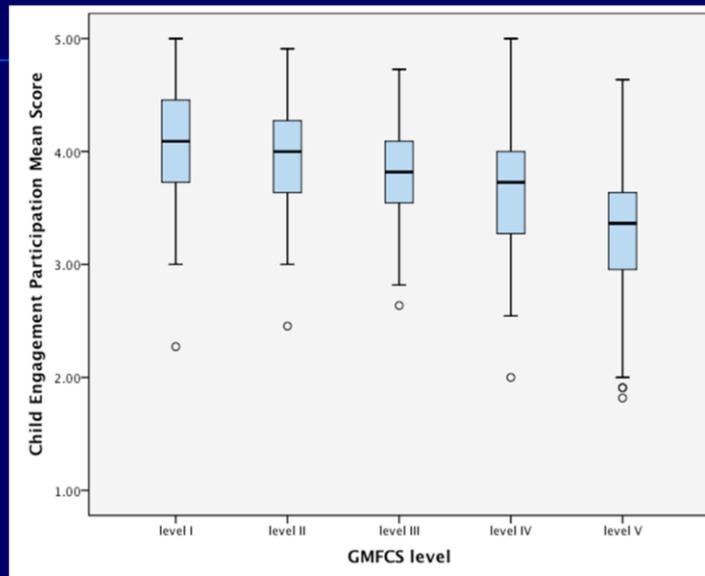
- Participation in family / recreational activities = 0.86
- Self-care = 0.90

### ✧ Test-retest reliability

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

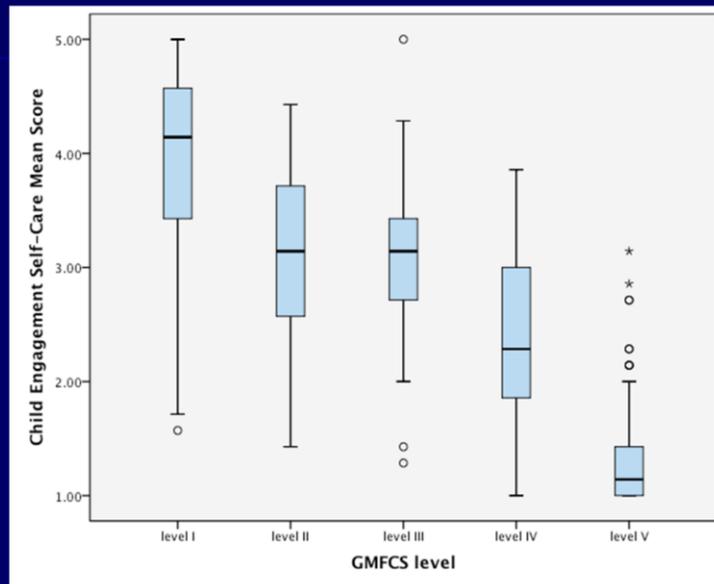
### ✧ Rasch analysis supported participation; refinements to self-care (preliminary results good)

## Interpretation: Participation



Given that participation is expected to increase with age; we do not yet have solid guidelines of interpretation here.

## Interpretation: Self-Care



The influence of age is expected to be greater for self-care, but firm guidelines for interpretation are not yet available. As can be readily seen, expectations for independence in self-care among children in GMFCS level V is relatively limited.

## Limitations

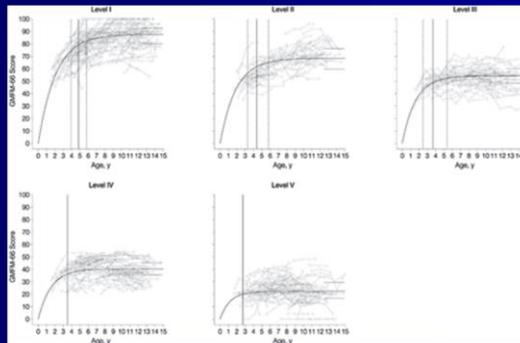
- ❖ Interpretation of all measures except the GMFM is currently limited to cross-sectional reference data for children 18 months up to the 5<sup>th</sup> birthday
- ❖ A brief measures of adaptive behaviour is not yet available publicly

Several limitations, as noted on the slide, should be kept in mind when applying these guidelines.

## 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 25<sup>th</sup> percentile in each level*



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

Just one cautionary note before closing: please recall the series of 'spaghetti plots' of GMFM scores for children in all GMFM levels – children are spread across all percentiles, and some children will score below the 25<sup>th</sup> percentile. As such, it is probably best to interpret percentiles based on relative strengths and weaknesses, rather than the 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**

We encourage you to use these measures with young children with CP on your caseloads.

## For More Information



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

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