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

Move & PLAY Study Team
December 2013

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.

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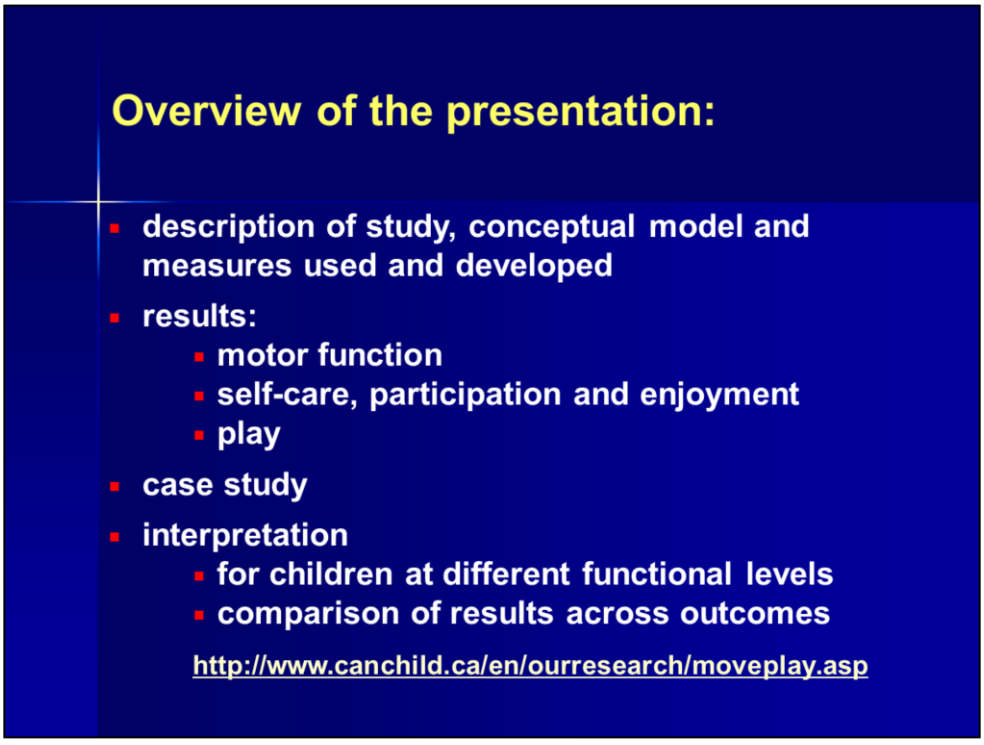
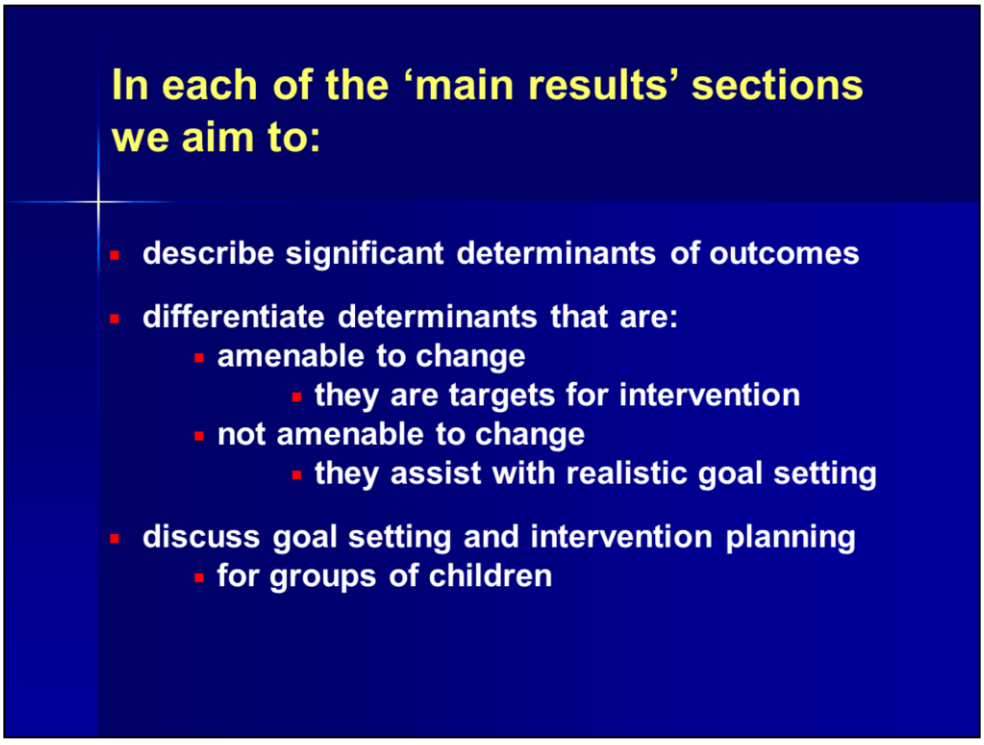
- Piotr Wilk, Statistician, Western University
- Therapist Assessors; Interviewers; and participating Parents and Children

Overall Study Coordination was provided through *CanChild*



The goal of this presentation is to provide you with a high-level overview of this study and its results. In the first part, we provide a description of the study and the conceptual model we developed, a brief overview of the outcomes we measured; determinants will be reviewed as we move through the presentation. We present our main findings with respect to outcomes of motor function, self-care, participation, enjoyment and play. After presenting a case study, we summarize the findings for children at different functional levels and compare results across outcomes.

A lot of information will be presented; please rest assured that everything is available on this website for your perusal at any time.



Details on how to administer and score many of the measures we used are contained in a complementary presentation about "Brief, reliable and valid instruments to obtain a holistic picture of children with cerebral palsy: Products of the Move & PLAY Study". It would be best to be familiar with this presentation before reviewing the Main Results presented here.

We conclude with:

- A Case Study of a child in the Move & PLAY study to illustrate how group results can be applied to an individual child
- A summary of the group results across the multiple outcomes and functional groups in the context of the *International Classification of Functioning, Disability and Health*, highlighting interesting findings

Why did we do the Move & PLAY study?

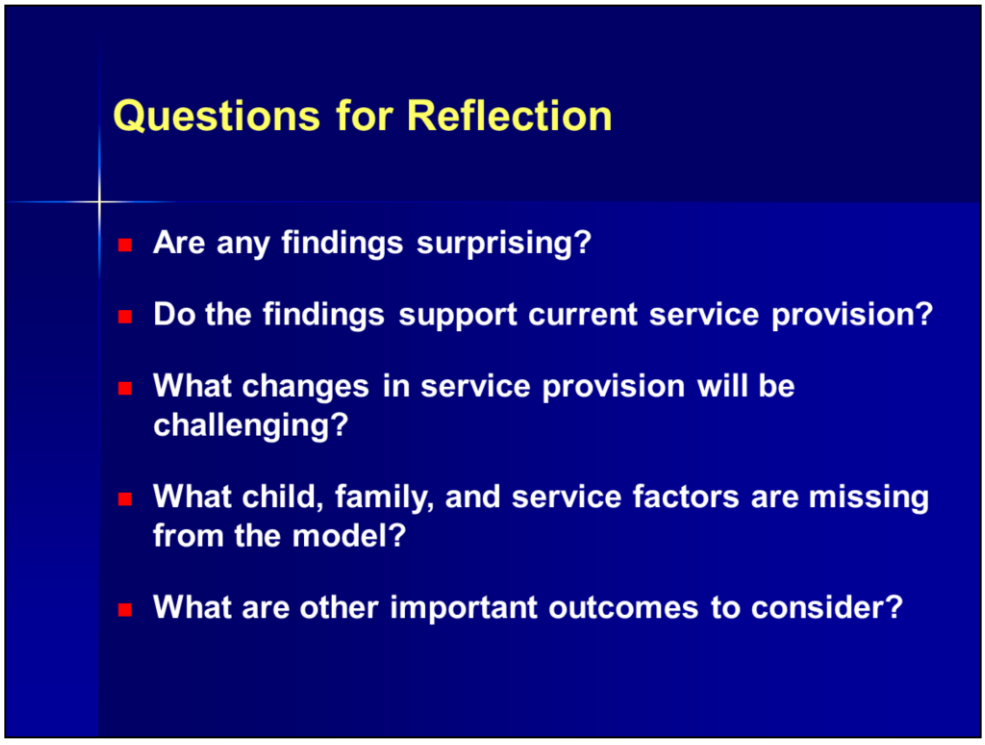
We wanted to better understand what helps young children who have cerebral palsy to:

- move around
- take care of themselves (self-care)
- participate in daily activities and play

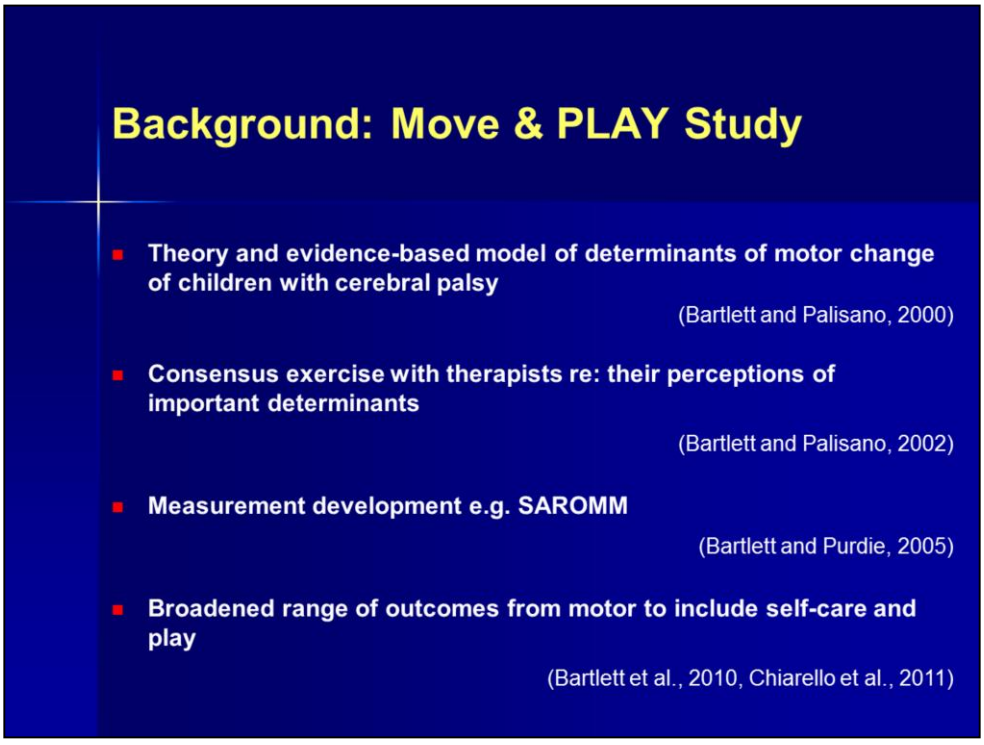
Questions asked

What combination of child, family and service factors explain the change in motor abilities of young children with CP?

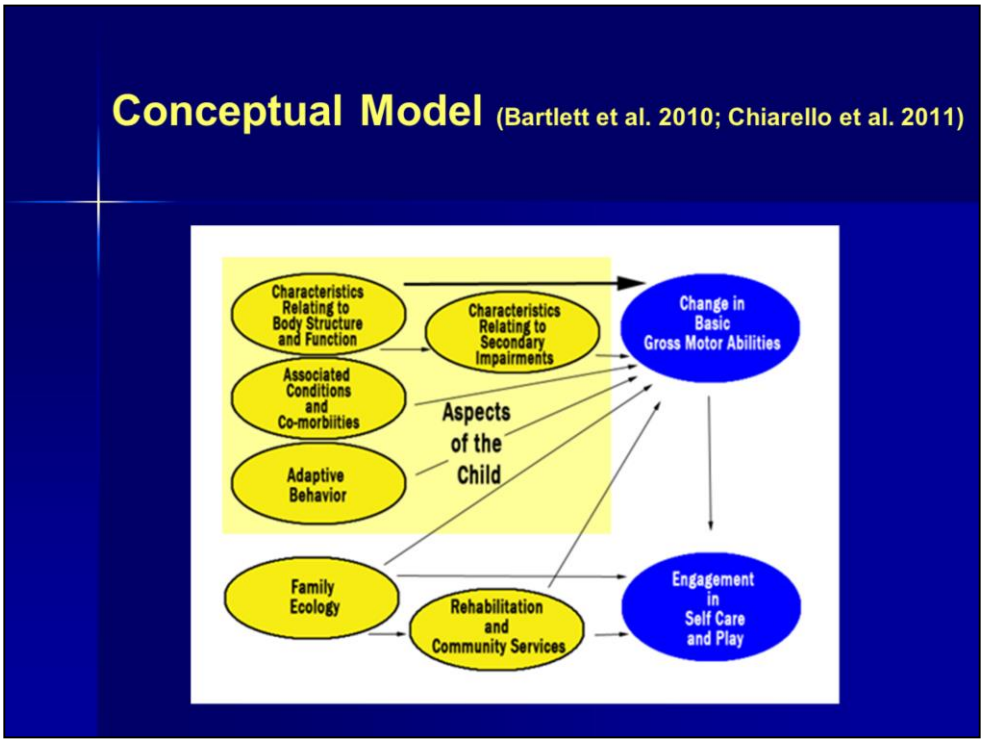
What combination of child, family and service factors explain participation in self-care, family and recreational activities and play of young children with CP?



As you go through this presentation, we ask that you reflect on the questions noted on the slide.



In the Move & PLAY study, we started with the development of a theory and evidence-based model of determinants of motor change of children with cerebral palsy, and followed it up with a consensus exercise with therapists that confirmed much of the existing literature and sharpened and refined the focus. During this time, measurement development was also occurring, and with the addition of Team Members in addition to Bartlett and Palisano, we broadened the outcomes to include self-care and play (including participation in family and recreation activities).



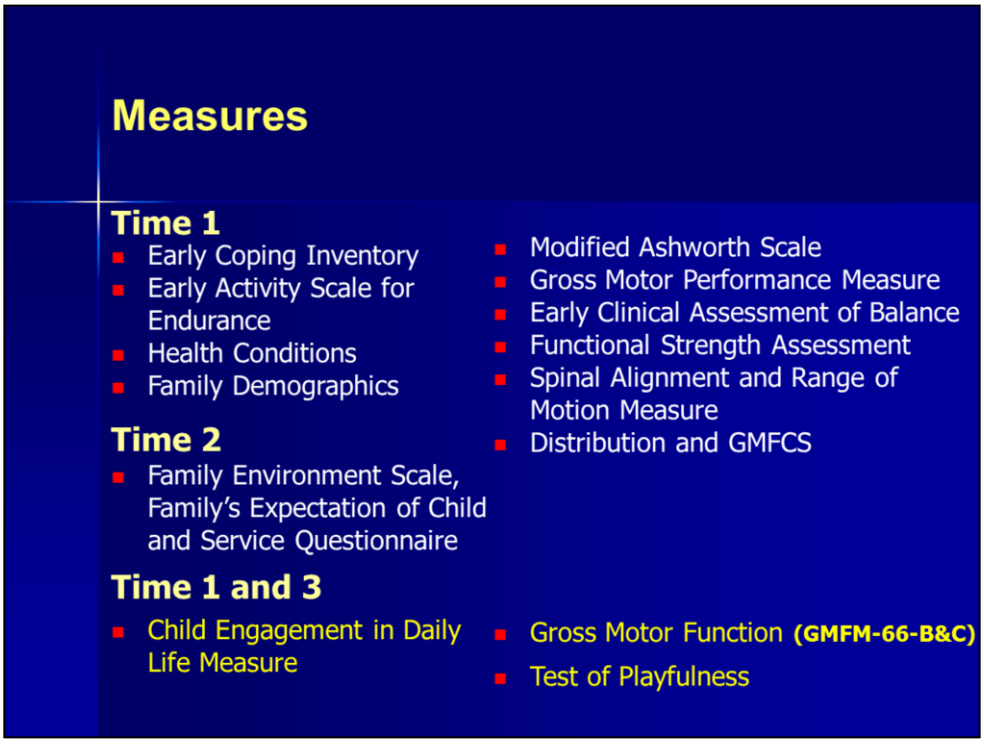
Here is our final model for the Move & PLAY Study. You can see that it is informed by the World Health Organization's International Classification of Functioning Disability and Health. Aspects of the child include characteristics relating to Body Structure and Function (and here we refer to primary impairments of deficits in balance and quality of movement, spasticity and distribution of involvement), Secondary Impairments (i.e. deficits in strength, range of motion and endurance – impairments that arise over time in children with CP), associated conditions and comorbidities that often occur, as well as adaptive behaviour, which is a 'personal factor' that is about individual children – aspects of them that are not related to the diagnosis of cerebral palsy. We are also interested in the contribution of 'environmental factors' impacting a range of outcomes – specifically the role of families and services. Again, our range of outcomes of interest included motor function, self-care, participation, and play.

Setting and Participants

- 6 Canadian provinces; 4 regions in the US
- Convenience sample of 429 children with CP and parents
  - 242 boys, 187 girls
  - 18-60 months of age
  - Varied gross motor abilities across all GMFCS levels
  - Parents
    - 92% mothers
  - 90% retention rate over one year

Methods

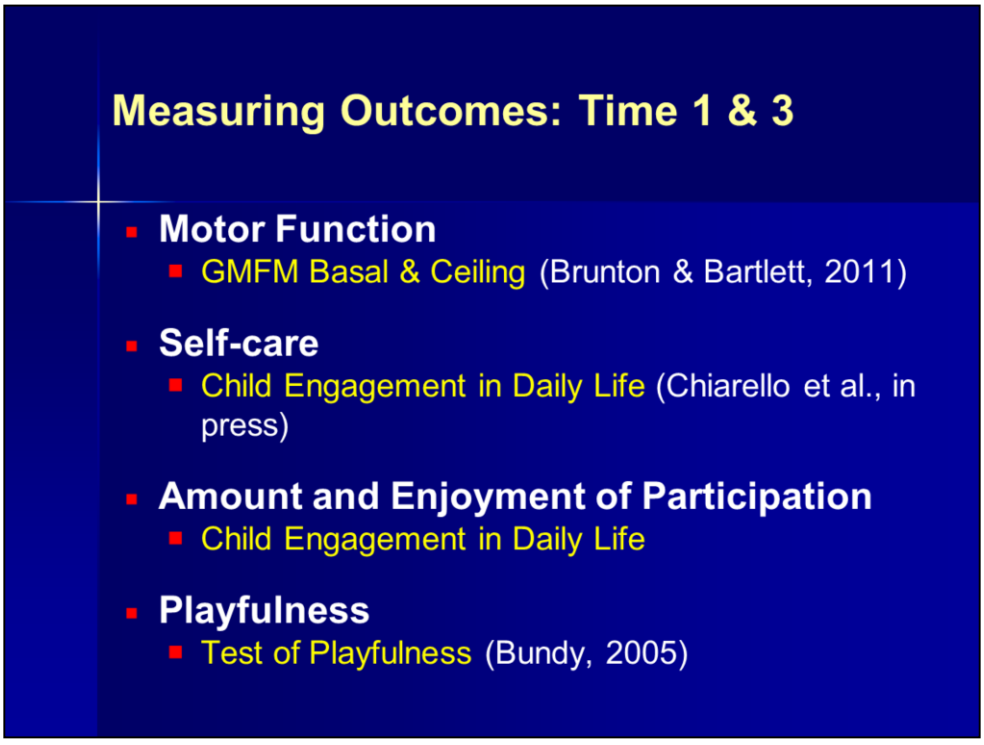
- Prospective cohort study
- Data collected in children's homes or therapy clinics
- 3 data collection sessions over a one year period
- Data analysis: Structure Equation Modeling



At the beginning of the one-year period for each child, parents completed the Early Coping Inventory, the Early Activity Scale for Endurance, the Health Conditions Questionnaire and a demographic questionnaire, as well as the Child Engagement in Daily Life Measure. At the same visit, therapists collected data using the modified Ashworth Scale, the Gross Motor Performance Measure, the Early Clinical Assessment of Balance, the Functional Strength Assessment, the Spinal Alignment and Range of Motion Measure, distribution of involvement and the Gross Motor Function Classification System, as well as the Gross Motor Function Measure and the Test of Playfulness.

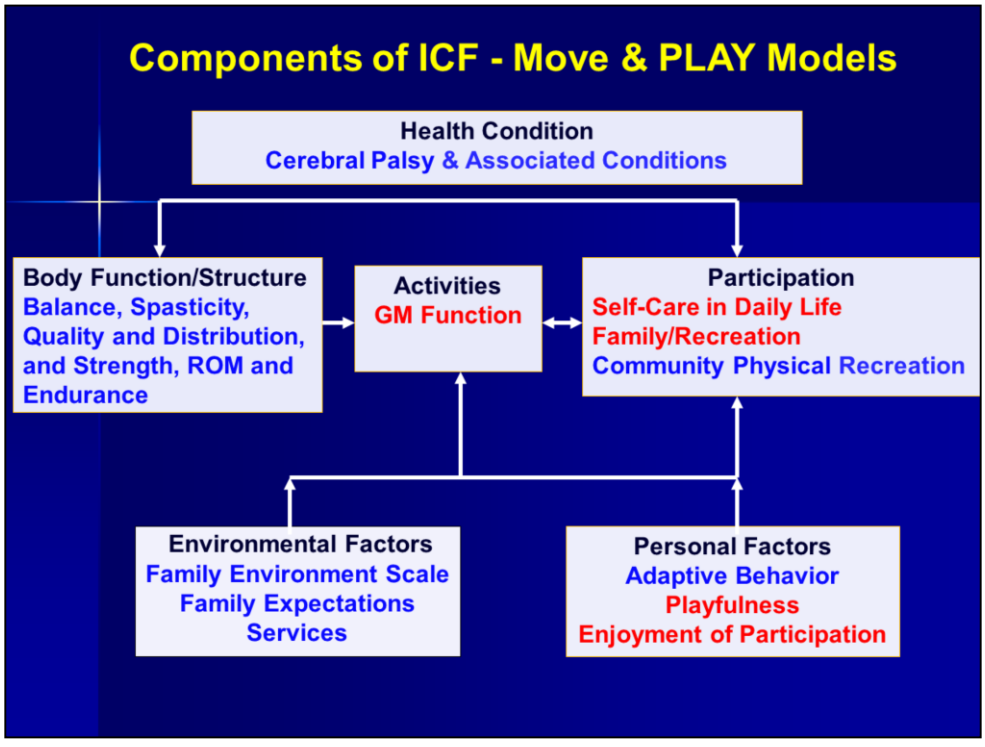
Six months later, interviewers collected data using the Family Environment Scale, a measure of Family's Expectations of their children and a services questionnaire.

One year after the first data collection point, parents again completed the Child Engagement in Daily Life Measure and therapists repeated the GMFM and the Test of Playfulness.



These four outcomes were measured at both Time 1 and 3; details of the basal and ceiling approach of the GMFM and the Child Engagement in Daily Life Measure are provided in the complementary presentation.

The Test of Playfulness measures how a child approaches play. Administration involves observing 10 minutes of a play situation; scoring is completed in 10 minutes using a standardized data collection form. There are four dimensions to this measure: intrinsic motivation (i.e. the drive to be involved with the activity comes from within), internal locus of control (i.e. child takes charge of his or her situation), freedom to suspend reality (i.e. the child is not bound by constraints of reality) and framing (i.e the child is able to give and read social cues). Each of 31 items is scored on a 4-point ordinal scale measuring the extent, intensity and / or the skill of the behaviour. A ToP score is obtained through Rasch Analysis. Therapists require extensive training and testing prior to being able to score this measure.



We can easily map the factors in our Move & PLAY Models to the ICF. Cerebral palsy and the associated health conditions map onto the element of 'health condition'. Body function and structure factors included primary impairments of balance, spasticity, quality of movement and distribution of involvement, as well as secondary impairments of reduced strength, range of motion and endurance. The sole activity-level variable in this study was gross motor function. Participation included both participation in self-care in daily life and in family and recreational activities. Participation in community physical recreation was measured using the Services Questionnaire. Our study also included environmental contextual factors of family ecology and rehabilitation services and personal contextual factors relating to adaptive behaviour, playfulness and enjoyment of participation. The blue font represents factors considered to be 'determinants' and the red font represents outcomes in the models tested.

As indicated previously, most of these measures have been described in a complementary presentation. A few that have not been described before are mentioned here:

1) The Family Environment Scale – this is a 90-item questionnaire that measures three dimensions of family functioning: i) relationships (cohesion, expressiveness and conflict), ii) personal growth (independence,

achievement orientation, intellectual-cultural orientation, active-recreational orientation and moral-religious orientation) and iii) system maintenance (organization and control). Parents respond 'true and false' for each item, indicating their perception of their family's environment

2) Services – many aspects of services were measured, but these are the only ones that were significantly related to some of the outcomes:
    i) Participation in community physical recreation – we asked parents if their children participated in the following community programs: horseback riding, aquatics, gym programs, dance / movement programs, and or sports programs
    ii) Family-centredness of services – we asked parents to respond to 13 questions about their perceptions of various aspects of family-centred services, providing response options from 1 (not at all) to 5 (completely)
    iii) Services meeting needs – we asked parents to respond to 3 questions relating to their perceptions of the extent to which all of the services they and they child received supported the outcomes of i) motor abilities, ii) participation in self-care, and iii) participation in play, with response options from 1 (not at all) to 5 (completely).
3) Adaptive Behaviour – we used the Early Coping Inventory to measure adaptive behaviour. Parents completed 48 items covering 3 domains: i) sensorimotor organization (which refers to self regulation and adaptive responses to sensory stimuli), ii) reactive behaviours (responses to the social and physical environments, and iii) self-initiated behaviours (self-directed actions to meet personal needs and interact with objects and people). Each item scored on a 5-point ordinal scale from 1 (behaviour is not effective) to 5 (behaviour is consistently effective across situations)

Details of how all of the measures were scored and how the data were used in analyses are contained in the following manuscript:

Bartlett D, Chiarello L, McCoy S, Palisano R, Jeffries L, Fiss A, Rosenbaum P, Wilk P. Determinants of Gross Motor Function of Young Children with Cerebral Palsy: A Prospective Cohort Study. *Developmental Medicine and Child Neurology,* Early OnLine – October 2013 – DOI: 10.1111/dmcn.12317.

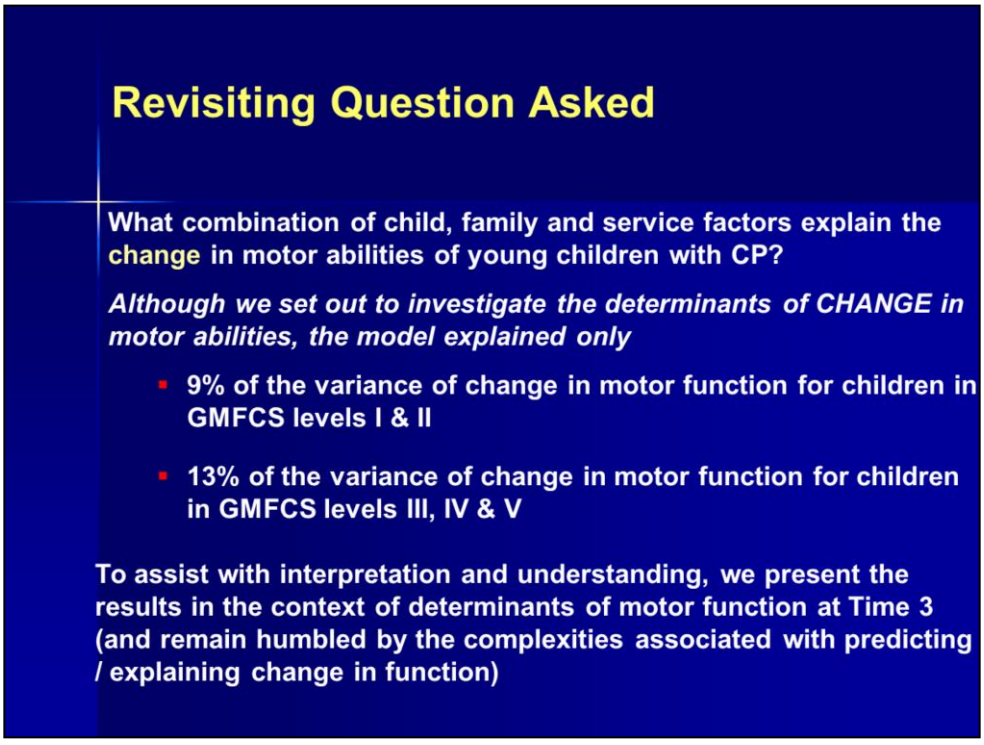
Analysis

- Examined Time 1 determinant data to see if differences between:
  - GMFCS levels
  - Sex
  - Age groups (18-30, 31-42, 43-60 months)
- Many GMFCS level differences
- No sex differences
- A few age differences
  - GMFM, Self-care, Balance

Analysis

- Formulated variables for Structural Equation Modeling (SEM)
- Ran SEM for 2 groups, GMFCS levels I & II and GMFCS levels III-V, on 5 outcomes
  - Gross motor ability
  - Participation in self-care
  - Participation in family and recreational activities
  - Enjoyment of participation
  - Playfulness
- Produces group results

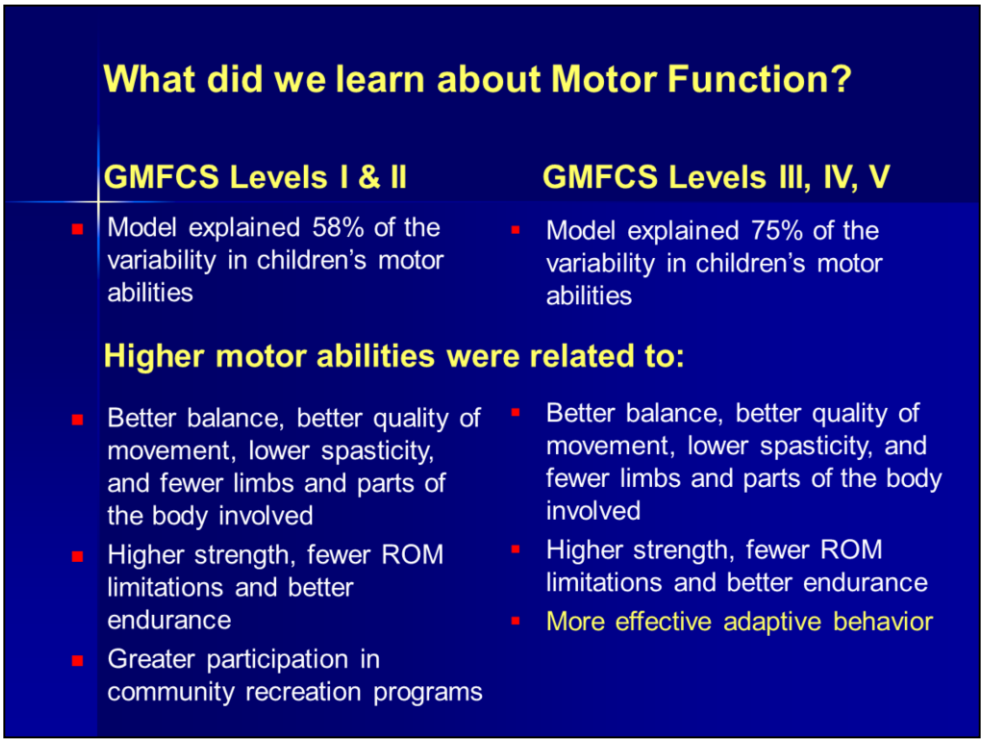
So, what did we learn about motor function?



We'll start by revisiting the first question we asked, which is noted on the top of this slide.

For levels I & II: Parents' stronger perception of family-centredness of services was associated with change in motor function.

For levels III, IV and V: better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved were associated with change in motor function.



For each of our 'main results' slides, we first present the proportion of variance the model explained for the outcomes in the two groups of children. We then highlight what was related to various outcomes.

So, what did we learn about Motor Function?

The model explained a greater proportion of variance in motor function at Time 3 for children in GMFCS levels III, IV and V than for children in levels I and II – ¾ versus just less than 2/3.

Primary impairments had a strong relationship in both groups, with…*[read from slide]..*Balance contributed most to the primary impairments (0.95) and it is amenable to physical therapy intervention. In contrast, quality of movement, spasticity and distribution of involvement can assist with realistic goal setting.

Secondary impairments had a modest relationship in both groups *[with .. Read from slide]*. All of the secondary impairments are amenable to intervention.

Participation in recreation programs had a small relationship to motor function

for children in levels I and II, and although participating in recreation programs could support motor function, the opposite causal relationship is also possible.

The only significant difference between the two groups was for adaptive behaviour, with this having a modest relationship for children in GMFCS levels III, IV and V. We believe that this personal determinant is amenable to intervention.

How can practitioners and families support children's Motor Function?

- Recommended focus of services includes:
  - optimizing 'body structures and function'
    - improve balance
    - prevent secondary impairments
  - fostering adaptive behavior (for children in GMFCS levels III, IV and V)
    - encourage and support the child's self-awareness, adaptability, motivation, persistence, and interactions with people in real-life situations

Moving on to self-care…..

We see a pattern similar to motor function, with a higher proportion of variance of self-care being explained by the conceptual model for children in GMFCS levels III, IV and V than for children in levels I and II.

In both groups of children, higher motor abilities, better health and more effective adaptive behaviours were associated with higher self-care abilities.

Primary impairments were only significant as a direct effect in children with more mobility limitations, with better balance, better quality of movement, lower spasticity and fewer limbs and parts of the body involved being associated with higher self-care abilities. In this group, stronger attributes of families and – paradoxically- parent's weaker perceptions of family-centred services were associated with higher abilities.

For children in levels I and II, the greater extent that services met the child's needs, the higher the self-care scores.

Although 'health' was significant in both groups, the impact was greater for children in levels I and II.

How can practitioners and families support children's Self-Care?

- Recommended focus of services includes:
  - optimize gross motor abilities
    - enhance balance
    - prevent secondary impairments
  - promote health
  - foster adaptive behavior
    - self-awareness, adaptability, motivation, persistence, problem-solving, and interactions with people in real-life situations
  - support family's role in nurturing their children
  - address family priorities and needs for their child

Moving on to participation….

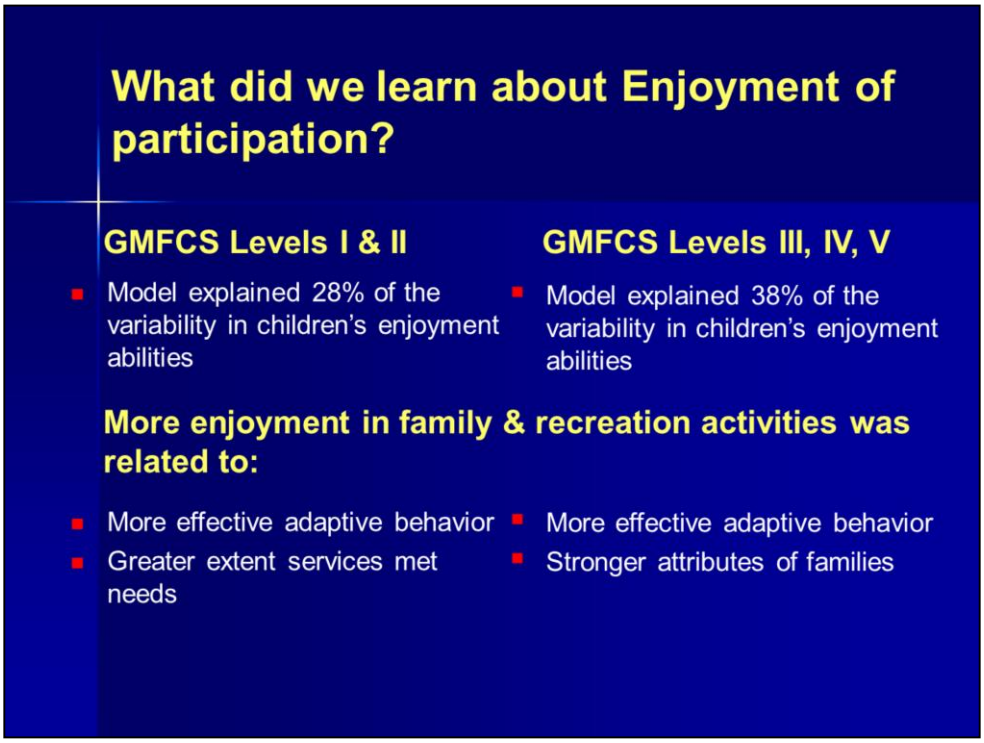
For this outcome, you can see that the pattern of proportion of variance explained by the model is the same, with a higher value for children in levels III, IV and V than for children in levels I and II, but the magnitude is much lower at 40 and 35%, respectively.

For both groups, more effective adaptive behaviour and stronger attributes of families were moderately related to participation.

For both groups, not surprisingly, greater involvement in community programs were related to participation, but the effect was only small for children in levels I and II and moderate for children in levels III, IV and V.

Finally, higher motor abilities was significant only for children in levels III, IV and V, and the relationship was 'small'.

For groups of children the model suggests that a focus of services to enhance participation should include: *[to read],* with the last recommendation referring only to children in GMFCS levels III, IV and V.



The results with respect to enjoyment follow the pattern of participation – the model continues to explain a greater proportion of variance for children in GMFCS levels III, IV and V, but – again, the magnitude of the proportions are more modest at 38% and 28%.

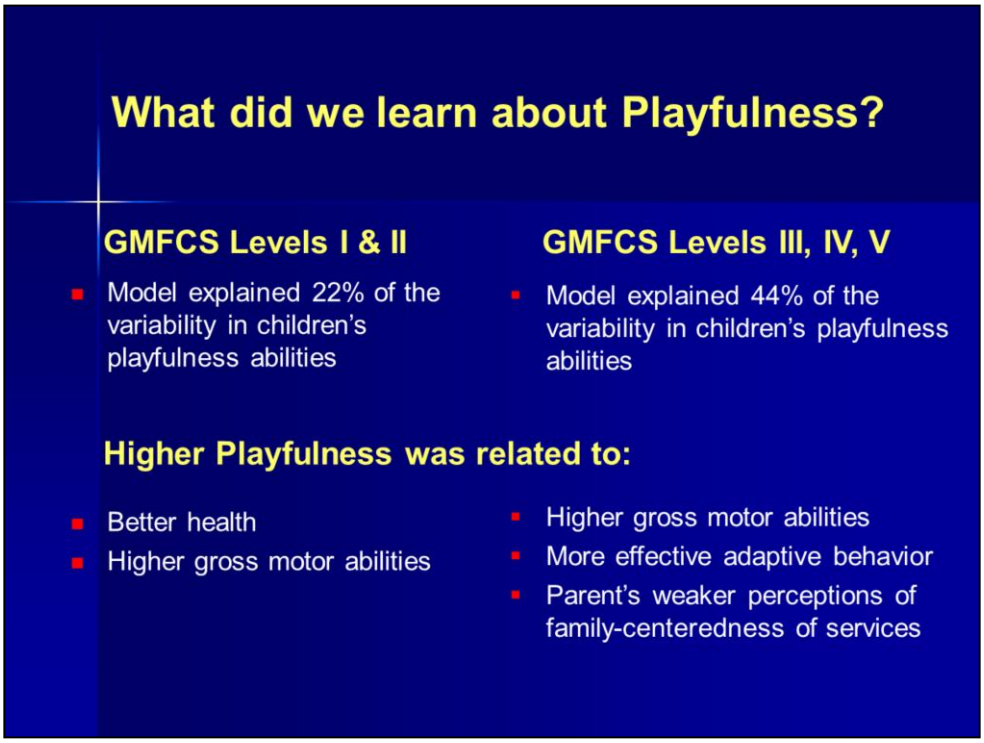
For both groups of children, greater enjoyment is associated with more effective adaptive behaviour.

For children in levels I and II, parents' stronger perceptions of services meeting needs was associated with higher enjoyment, and for children in levels III, IV and V, stronger attributes of families was associated with higher enjoyment.

In terms of supporting children's enjoyment of participation, the model testing suggests that a recommended focus of services includes *what is listed on this slide.*

The final outcome for consideration is ‘playfulness’. For this measure, we used the Test of Playfulness, which was briefly described earlier. Scoring is based on observation of a play session in which parents were instructed: “*I will watch you play with your child for 10 minutes. Please play with your child in whatever manner you typically play together. You can select to use toys and play materials or not. It is your decision. We are interested in understanding how young children play. I will be observing from the background so I won’t interfere with how you play together. If you move by playing, I will follow you as needed so I can still observe you.”*

Prior to being able to administer the ToP for this study, assessors were required to go through a calibration process with the original developer of this measure. Although the measure might not be widely used, we encourage therapists to consider this important outcome, at least from a conceptual basis.

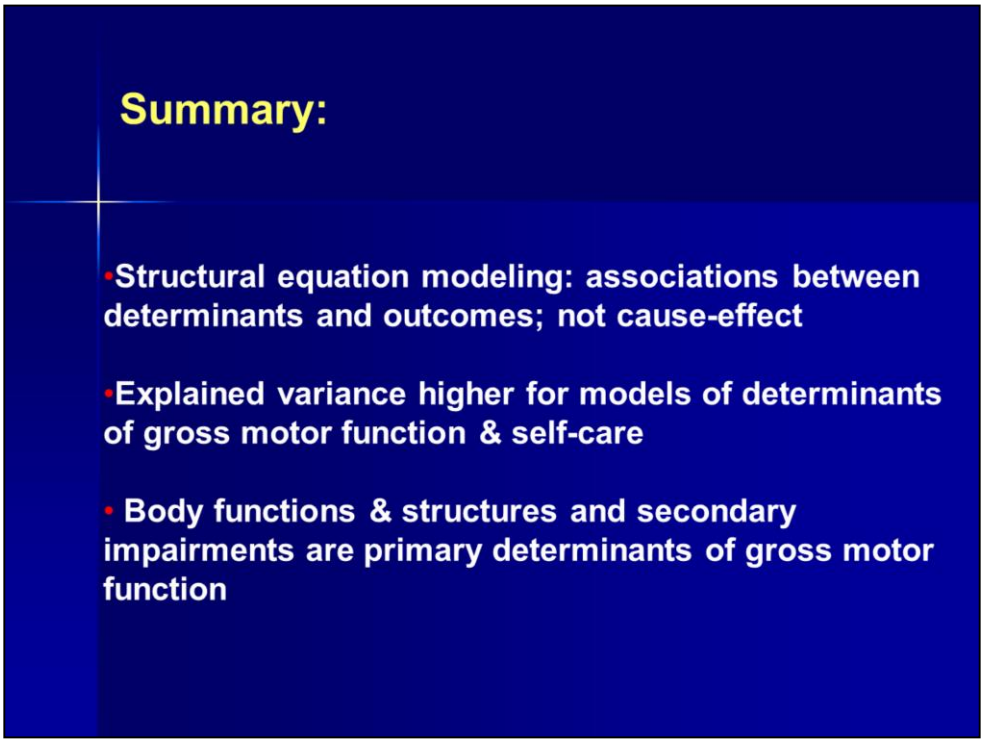


We found a similar pattern here with greater proportion of variance in playfulness explained for children in GMFCS levels III, IV and V, and interestingly, the magnitude was twice that of children in GMFCS levels I and II.

In both groups, higher gross motor abilities were associated with a greater manifestation of playfulness. As for the findings for self-care, better health was associated with higher playfulness for children in levels I and II. Both more effective adaptive behaviour, and (again paradoxically) parents' weaker perceptions of family-centred services were associated with higher levels of playfulness for children with more limited mobility. All factors were moderately related to playfulness.

At a group level, the model testing results suggest that to enhance children's services, a focus should be as noted on this slide.

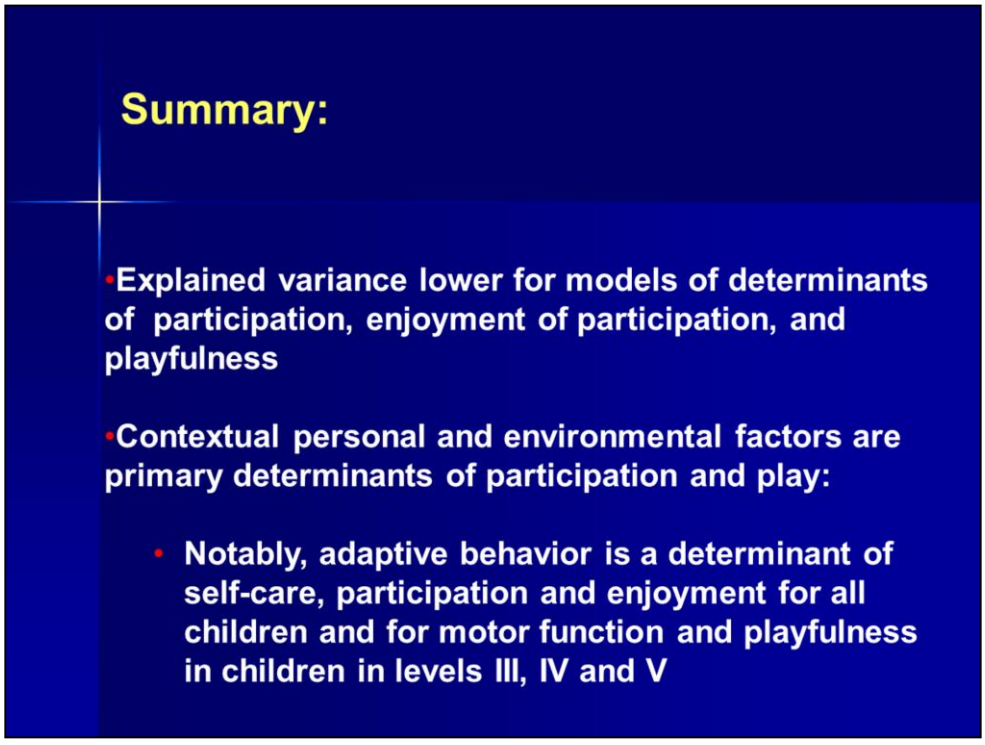
Summary & Considerations for Practice



In summary, it is first important to acknowledge that the use of SEM really tests for associations, and strictly speaking, it does not test for cause-and-effect relationships.

In terms of model testing, we established a stronger explanation of gross motor function and self-care than for participation in recreation and leisure activities, enjoyment of such participation and playfulness

Body functions and structures and secondary impairments were primary determinants of gross motor function.

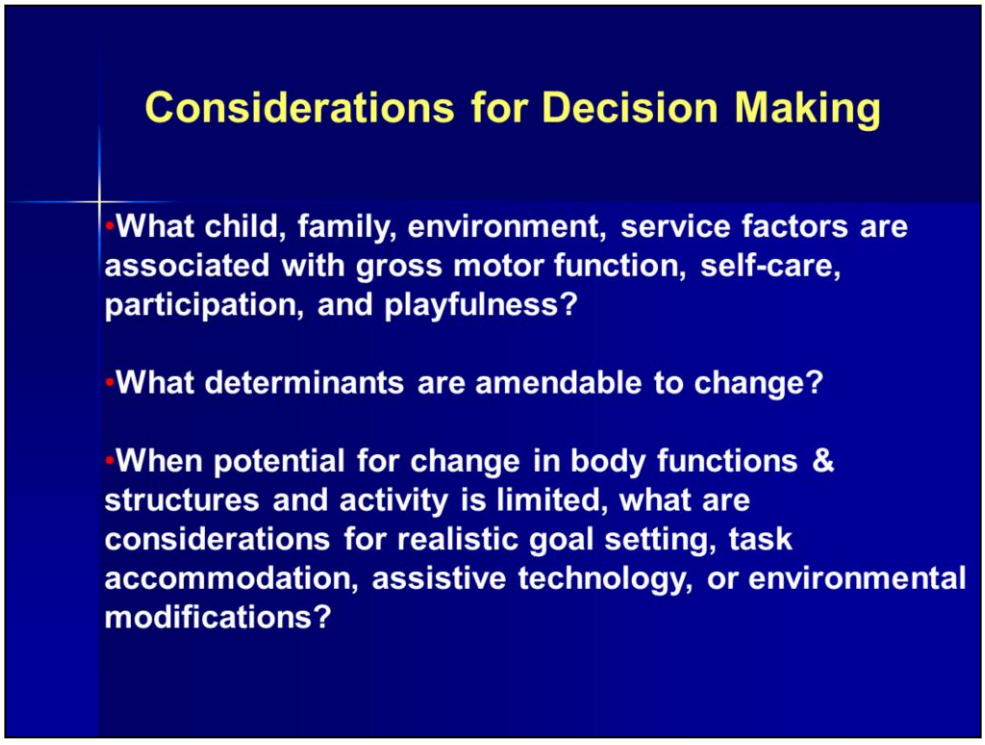


As described, the model explained less of the outcomes of participation, enjoyment of participation, and play – and adaptive behaviour and family involvement and community programs are associated with participation.

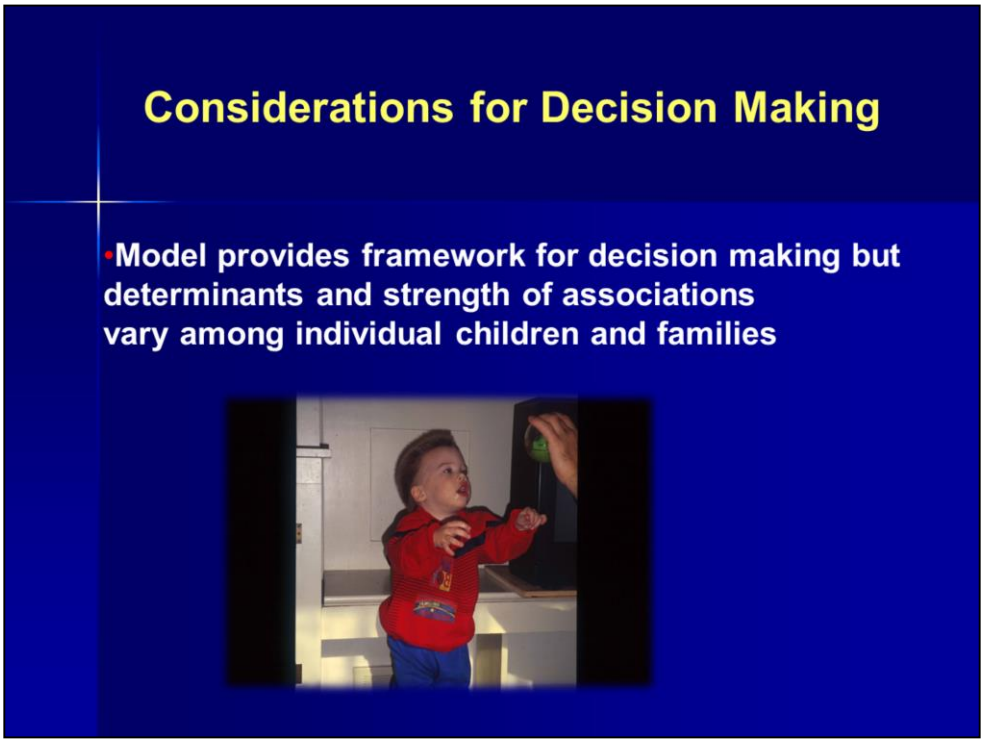
Adaptive behaviour stood out as a significant determinant of many outcomes for most children.

Limitations:

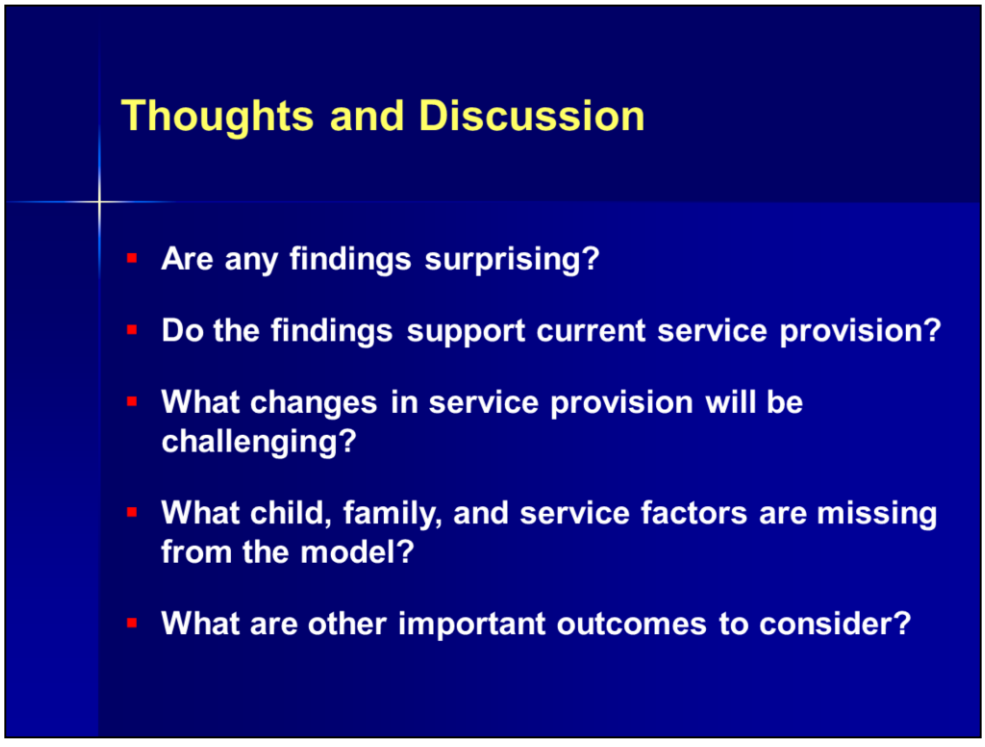
- No brief measure of adaptive behaviour available yet
- No brief measure of the attributes of families available



When thinking about clinical decision-making we encourage thinking about 'what child, family, environmental, and service factors are associated with gross motor function, self-care, participation and playfulness?'. Furthermore, we think it is useful to think about which determinants are amenable to change – these could be incorporated into intervention in efforts to enhance specific outcomes. In the situation of determinants not being amenable to change, one can think of the potential for change to be limited from physical or occupational therapy services – and in these conditions, examinations could assist with realistic goal setting, task accommodation, assistive technology or environmental modifications, and referral to other services.

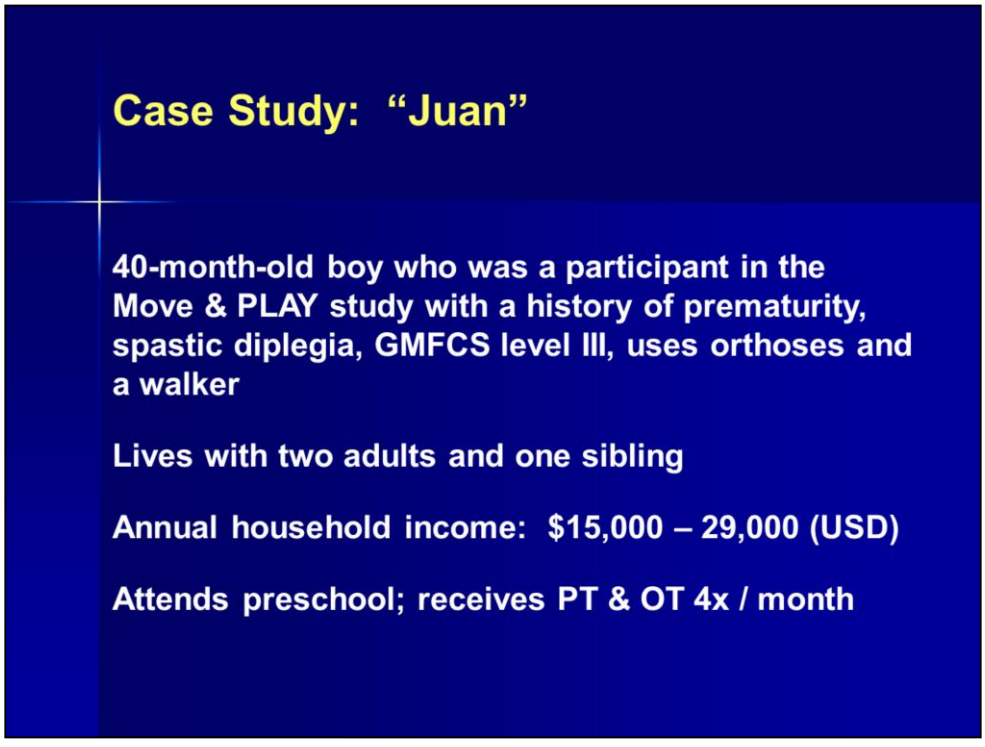


Finally, we believe the model provides a framework – a starting point – for decision-making, but determinants and strengths of associations vary among individual children and families, which need to be considered in setting goals and planning interventions, in the context of collaborative, family-centred practice.

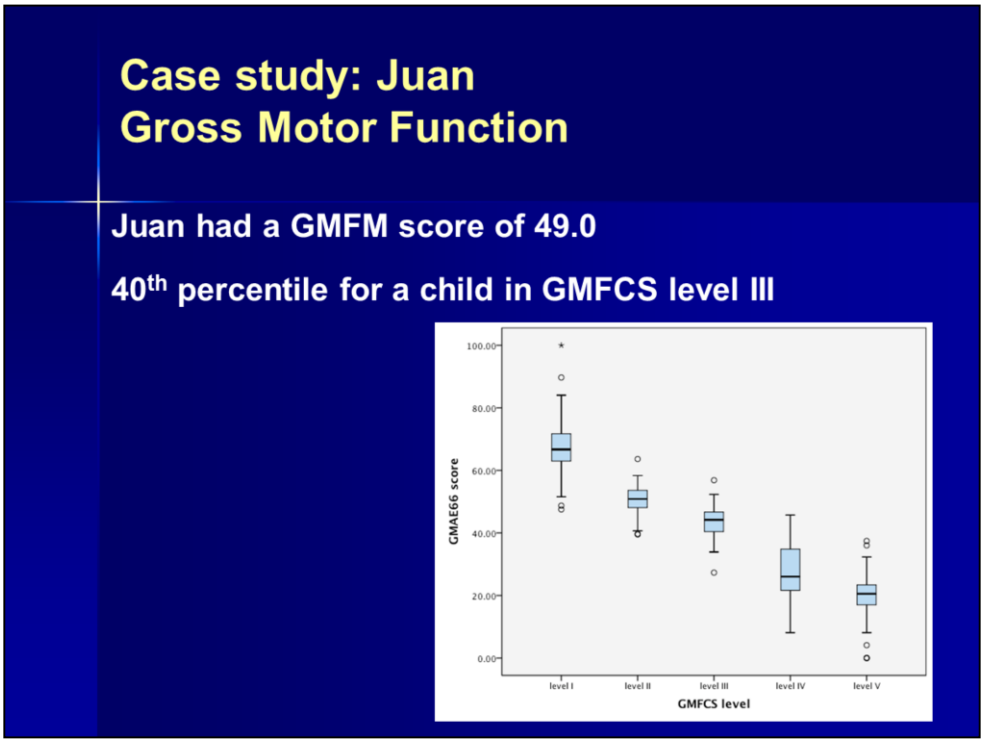


We urge you to consider the Move & PLAY study results in the context of the questions noted on this slide.

Taking some time in the form of group in-service discussion might lead to some innovations on how the results of the Move & PLAY Study can better inform practice. Please let us know about further insights you have by contacting CanChild (canchild@mcmaster.ca).



To assist with understanding how the group results can be used with individual children, we present a case. "Juan" was a 40-month old boy who was a participant of the Move & PLAY study. He had a history of prematurity, a diagnosis of spastic diplegia, was GMFCS level III, and at the time data were collected, used orthoses and a walker. He lives with two adults and a sibling. As can be seen, the household income is very modest. Juan attended preschool and received PT and OT 4 times per month.



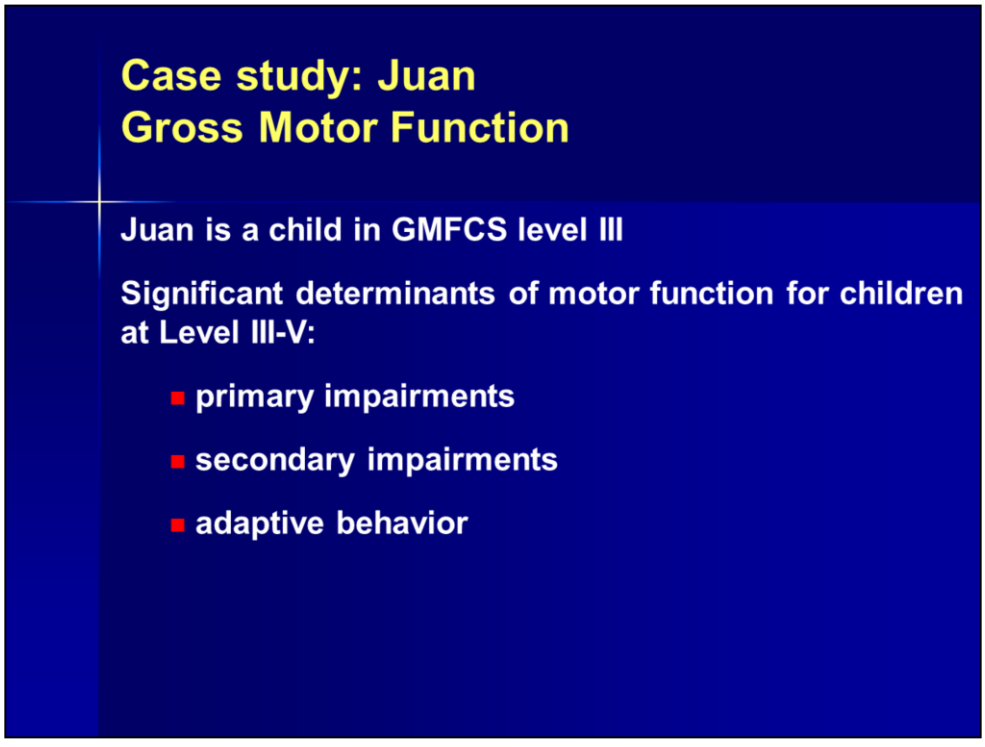
In looking at Juan's gross motor function, his GMFM score was 49 – Boxplots from the Move & PLAY Study help us understand his percentile score relative to other children in Level III (alternatively, and better, we can use the percentile curves for the GMFM presented in the complementary presentation and posted on the CanChild website – which put him at the 50th percentile).

Boxplots are the form of graph that we use in Move & PLAY to present the cross-sectional data obtained at Time 1. In each graph, the 5 GMFCS levels are placed along the x axis, and the scores of the measure occur along the y axis. In this case, the GMFM-66 scores range from a low of 0 to a high of 100.

Each of the 'boxes' have 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 75th percentile (i.e. 25% of participants score higher and 75% score lower). The bottom of the box corresponds to the 25th 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 25th percentile and the lower 25th 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 range (with the IQ range representing the difference between the scores of the 25th and 75th percentiles).

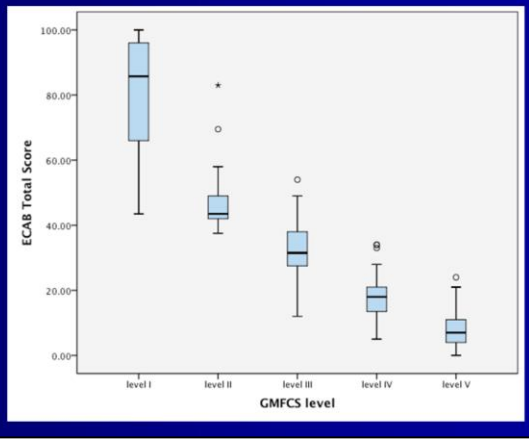
It is important to remember that these cross-sectional reference values were obtained from children aged 18 to 60 months. At 40 months of age, Juan is right in the middle of the age group, and so the reference values are relatively easy to understand. His GMFM score was 49, which corresponds to the 40th percentile for children in our study. Extrapolating by age, he is about where you might expect him to be.



Given that he is GMFCS level III, the significant determinants of motor function are primary and secondary impairments and adaptive behaviour. Of the primary impairments, balance is amenable to intervention – so this will be described. Secondary impairments include strength, range of motion and endurance. It is helpful to find out how Juan ranked across all of these determinants.

Case study: Juan
Balance (McCoy et al. 2013)

Early Clinical Assessment of Balance (ECAB) score = 41.5/100 is > the 75th percentile for GMFCS level III

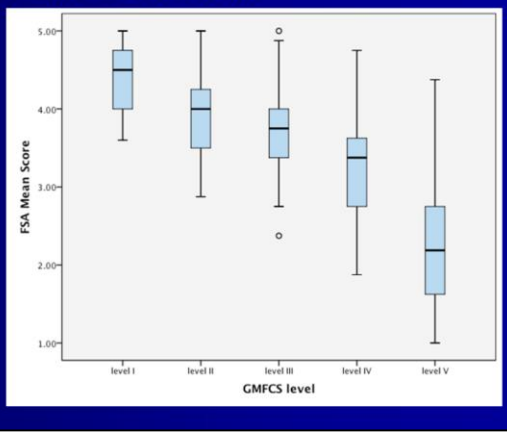


As described in the complementary presentation, the Early Clinical Assessment of Balance was developed in the Move & PLAY Study through a combination of selected items from the Automatic Reactions Section of the Movement Assessment of Infants and the Pediatric Balance Scale. As can be seen here, with a score of 41.5, representing higher than the 75th percentile, balance is a strength for Juan.

Case Study: Juan
Strength

Juan's average score for Strength = 3.25

< 25th percentile for GMFCS level III

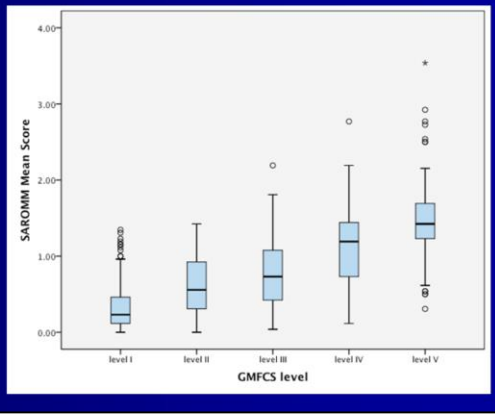


We obtained a composite measure to estimate muscle strength based on an average score of neck and trunk extensors, neck and trunk flexors, hip extensors, knee extensors, and shoulder flexors. With an average score of 3.25, representing below the 25th percentile, 'strength' – unlike balance - is clearly an area of concern for Juan.

Case Study: Juan
Range of Motion (SAROMM: Bartlett & Purdie, 2005)

Juan has an average SAROMM score of 0.85

~ median value for GMFCS level III



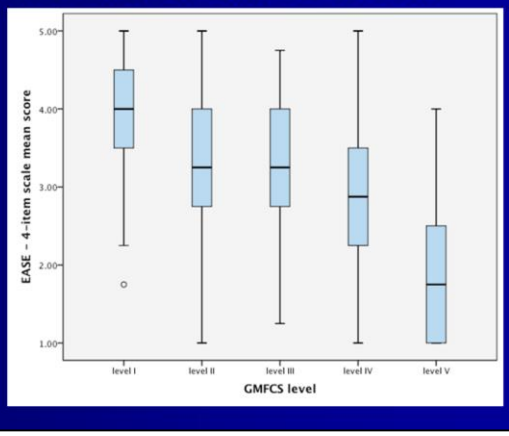
As for muscle strength, we obtained a composite score for range of motion using the Spinal Alignment and Range of Motion Measure (SAROMM). An average score is obtained across the 26 items, which are scaled from 0 to 4.

For this determinant, with a score of 0.85, Juan is around the median value, that is the 50th percentile, for children at level III.

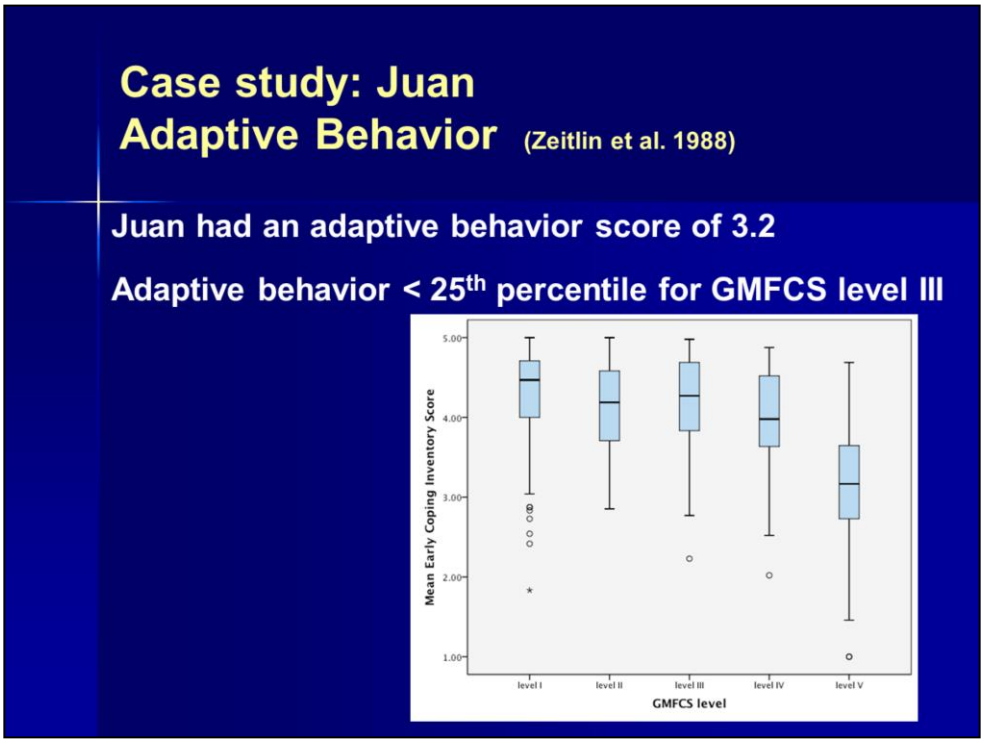
Case study: Juan
Endurance (McCoy et al. 2012)

Juan had an EASE score of 2.5

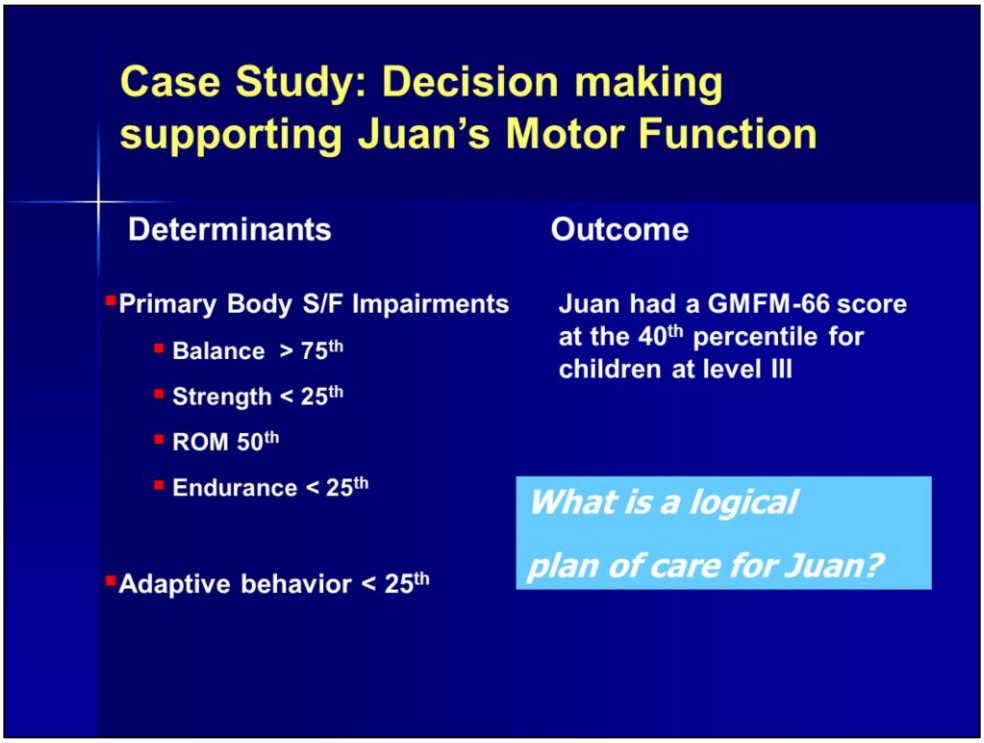
Endurance < 25th percentile for GMFCS level III



The Early Activity Scale for Endurance is a 4-item, parent-completed questionnaire. With a score of 2.5, representing below the 25th percentile, endurance – as for strength - is an additional area of concern for Juan.



We used the Early Coping Inventory, a standardized parent-completed tool, to measure Adaptive Behaviour – 48 items are scaled from 1 (not effective) to 5 (effective most of the time) and an average score was calculated. At this time, we do not have an abbreviated version of this measure. With a score of 3.2, this is well below the 25th percentile, representing an additional area of concern.



The interpretations of the meaning of Juan's scores, in the context of the results of testing the Move & PLAY model, can assist with clinical decision-making.

We encourage you to consider 'what is a logical plan of care for Juan' to support motor function? [pause]

As we discuss each outcome in our study we will be focusing on the determinants we studied in our model. Please keep in mind two points. First, we advocate that the plan of care include interventions with a direct focus on the outcome of interest. Second, there may be additional determinants that you will need to consider that we did not include in our model.

If improving motor function is a goal for Juan, a focus on improving strength and endurance (in the context of activity-based interventions), while considering ways to enhance adaptive behaviour, would be logical. Approaching intervention from a strengths-based perspective would suggest using his high postural control abilities to scaffold motor function. Valvano has written a very nice paper (citation in the reference list) on how to incorporate a focus on impairment-level factors through whole-body activities.

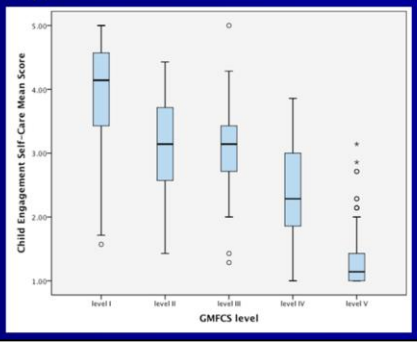
Alternatively, a percentile rank of 40 (relative to the boxplots) or 50 (relative to the reference percentile curves for the GMFM) is not out of the range of what you might expect, and if enhancing motor function is not a goal for his family, this aspect of his overall health condition could be monitored at this time.

Case study: Juan
Self-Care

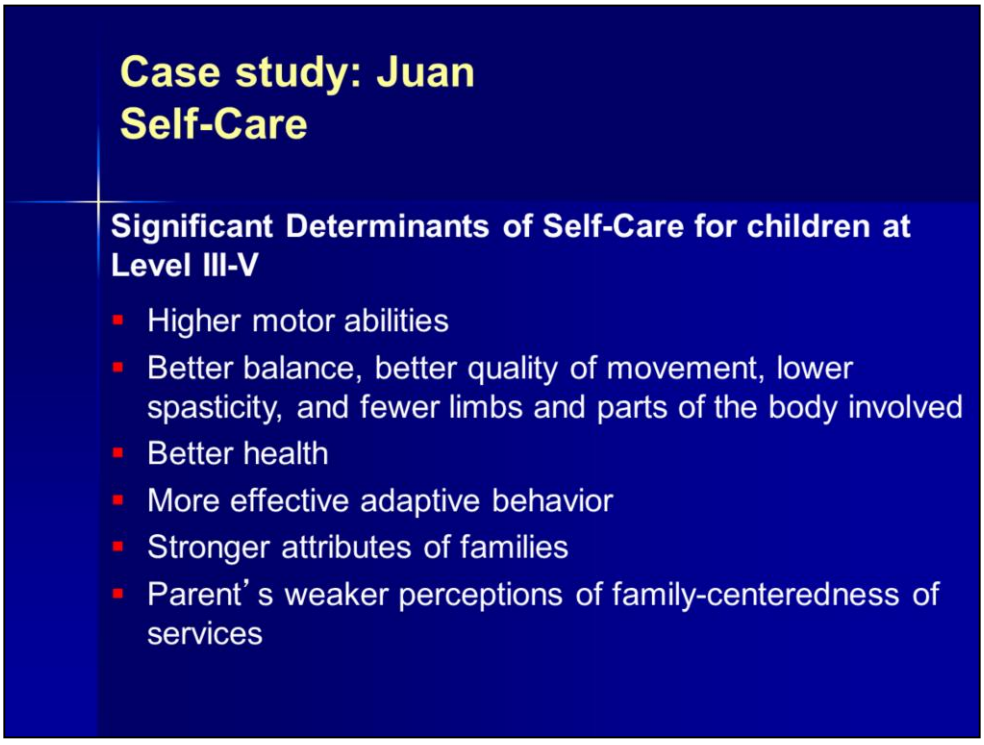
Juan had an average self-care score of 3.3

A 3 is at the median value for a child at GMFCS level III

(Score of 3: child completes part of the activity without help but requires help of adult to complete the activity)



For self-care, Juan's average score is at the median value, that is the 50th percentile, for a child GMFCS level III.



From group data, this is what is suggested as significant determinants of self-care for children in GMFCS levels III, IV and V: *[read]*

As we did for motor function, let's look at Juan's individual scores….. We've already described and interpreted Juan's scores for motor function, primary and secondary impairments, and adaptive behaviour, so let's look next at 'health'.

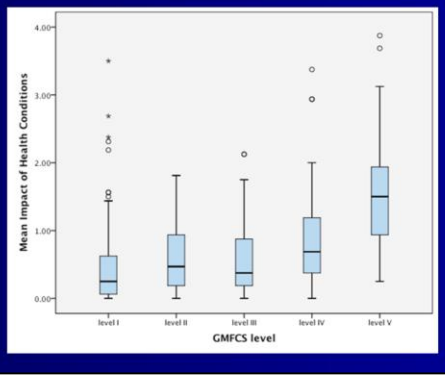
We developed the Health Conditions Questionnaire. Trained interviewers asked parents "Does your child have problems with seeing, hearing, etc." and if so, asked about the extent to which it affected their daily lives. The total score reflects a combination of the number and impact of health conditions, averaged across 16 conditions.

Juan's mother reported the following 8 health conditions: problems with seeing, learning and understanding, speaking and communicating, emotions and behaviour, digestion, sleeping, heart, and pain. The impact on his daily life ranged from 'not at all' for his prior patient ductus to a 'moderate extent' for speaking and communicating, emotions and behaviour, and pain, and to a 'very great extent' for sleeping.

Case Study: Juan Health

Juan's parents reported a health conditions score of 1.25

> 75th percentile for GMFCS level III



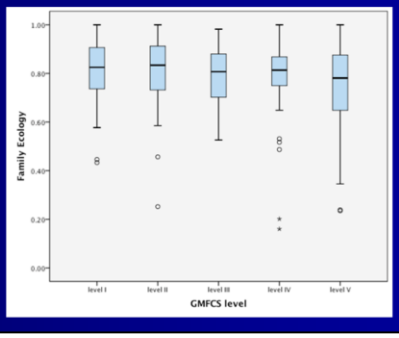
Juan's summary score of 1.25, was higher (i.e. worse) than more than 75% of children at level III, a finding that is consistent with children living in low socioeconomic conditions, as Juan is.

Case Study: Juan
Family Ecology (Moos and Moos, 2002, and our measure)

Juan's family ecology score was 0.60.

This is < 25th percentile for young children with CP in GMFCS level III

Note, however, that median family ecology scores are ~0.80 out of a top score of 1.0.



We used a combination of two parts of the **Family Environment Scale** (Moos and Moos, 2002): Family Relationships and the Family Degree of Social Integration, as well as the **Family's Expectation of Child** to measure family ecology. This second measure was developed through a consensus process by 9 parents whose young children with CP received services from Ontario Association for Children's Rehabilitation Services. It has 5 items: When helping your child to do things, the child is expected to: do best as can, take care of self, try things, do exercises, do family activities, with each item rated from 1 (not at all) To 7 (to a very great extent).

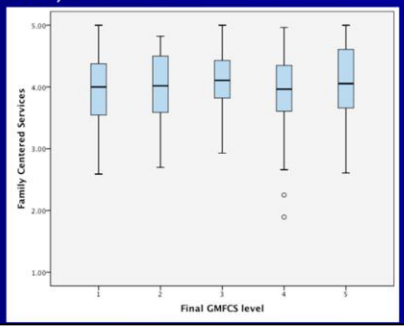
The **Final Family Ecology Score** is a combination of these two measures based on factor loadings as weights and then the final score was rescaled from 0-1.

Juan's family's score of 0.60 is well below the 25th percentile.

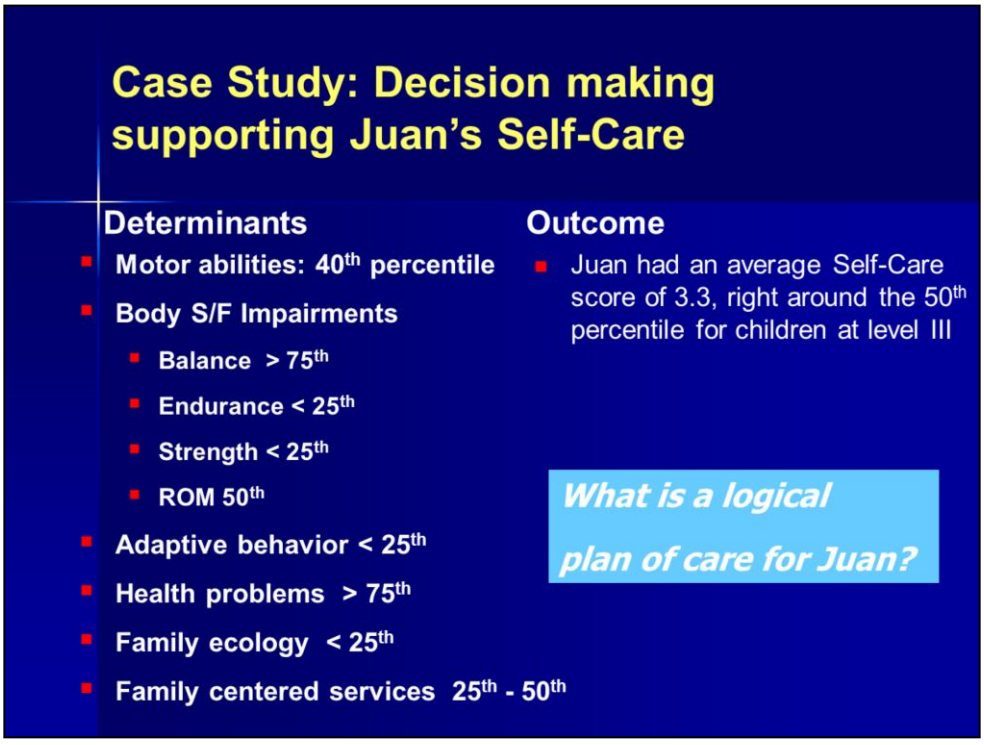
Case Study: Juan
Family-Centred Services

Juan has a Family Centred Services score of 3.91

Between the 25th and 50th value for child in GMFCS level III Note that median family centred services scores for children at all GMFCS levels are ~4.00 (to a great extent) out of a top score of 5.0 (to a very great extent).



Part of our services questionnaire measured family-centredness – on this value, Juan obtained a score of 3.91, which is between the 25th and 50th percentiles, but very near the median of 4 (to a great extent).



If improving self-care is a goal for Juan, what is a logical focus of intervention?

When looking at his rankings, remember that higher Health conditions are worse; for the rest, high scores are better.

Consider some of the following points:

- His motor score is relatively strong for his age at the 40th percentile (and therefore secondary impairments might not be a focus)
- Primary impairments (balance) have an additional direct relationship, but his balance score is very high at the 75th percentile, and also might not be a focus

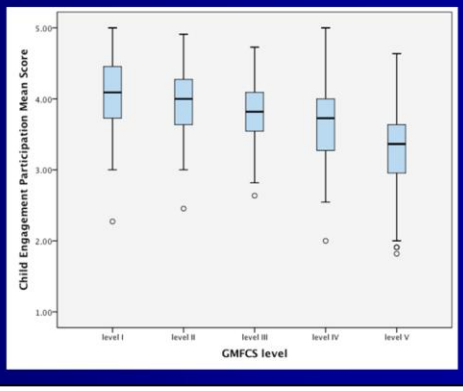
Conversely, what about the relationships between low adaptive behaviour, high impact of health conditions (especially emotions and behaviour, and pain), and low family scores with self care? What might be some implications for either direct services or referrals?

Alternately, again, because his percentile is around the 50th percentile for a child at level III who is in the middle of the age range of the sample of children aged 18 to 60 months, self-care might not be a priority focus in therapy, though

his plan of care may include evaluating and supporting his family's ability to provide caregiving.

Case Study: Juan
Amount of Participation

- Juan's average amount of participation score was 3, "once in awhile"
- 3 is well below 25th percentile for child at GMFCS III



When we turn to amount of participation, we can see that his average score of 3, representing participation 'once in a while' is well below the 25th percentile for children in level III. So, unlike the situation for motor function and self-care for Juan, you might advocate that enhancing participation in family and recreational activities might be a focus of therapy and services depending on the family's and child's interests and priorities.

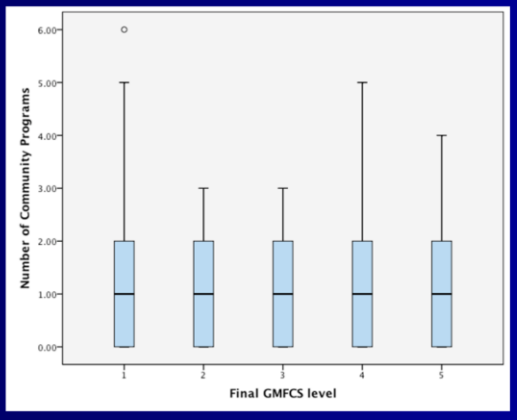
Case Study: Juan
Amount of Participation

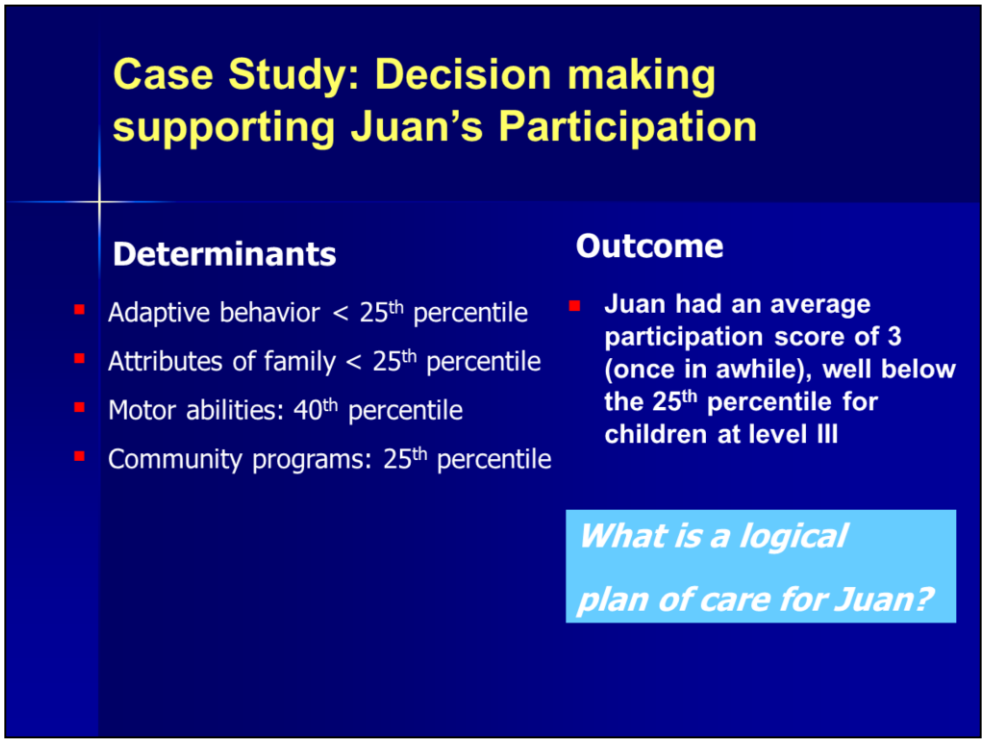
- Significant determinants of amount of participation for children at GMFCS levels III-V

- More effective adaptive behavior
- Stronger attributes of families
- Greater involvement in community programs
  - Involvement in community recreation programs: horseback riding, aquatics, gym programs, dance / movement programs, sports programs
- Higher gross motor abilities

Case Study: Juan
Community Participation

Juan did not participate in any community recreation programs

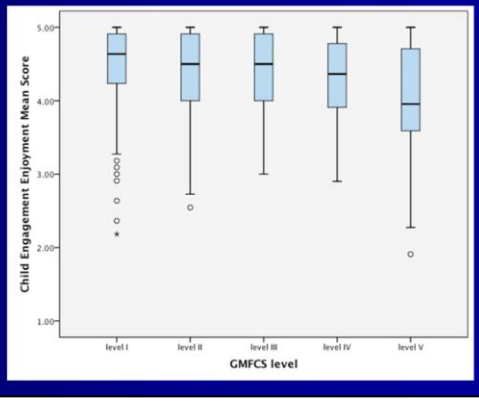




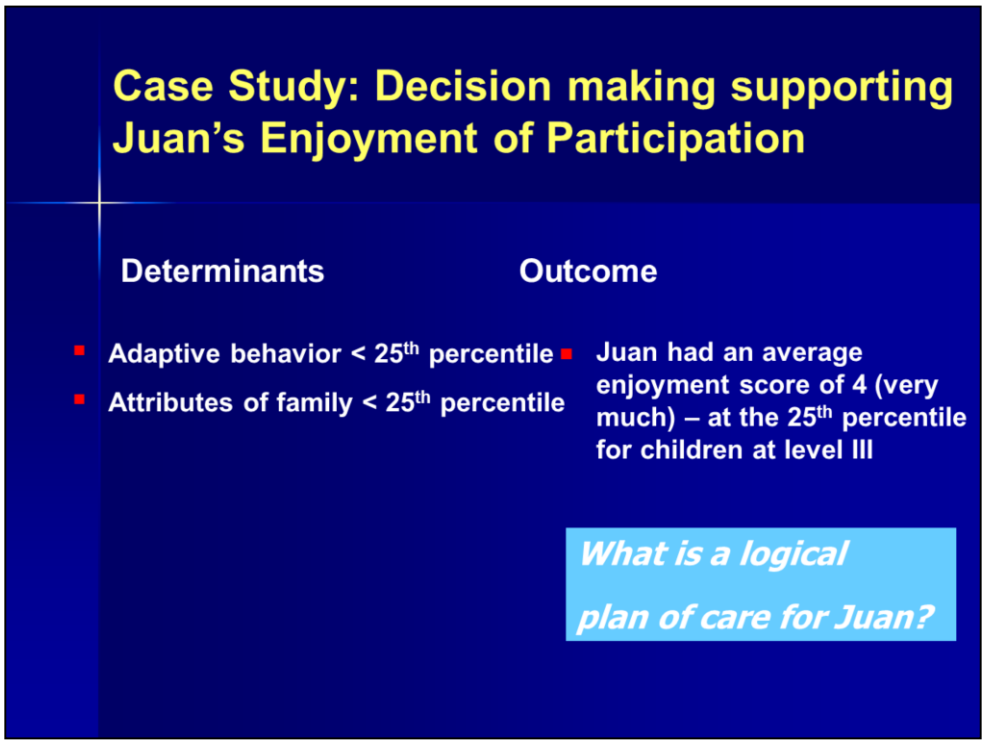
We've been through this a few times now, so it is your turn. What is a logical plan of care for Juan with respect to participation, in the context of the results of testing the Move & PLAY model?

Case Study: Juan
Enjoyment of Participation

- Juan's average enjoyment of participation score was 4, "very much"
- A score of 4 is at the 25th percentile for children at GMFCS level III



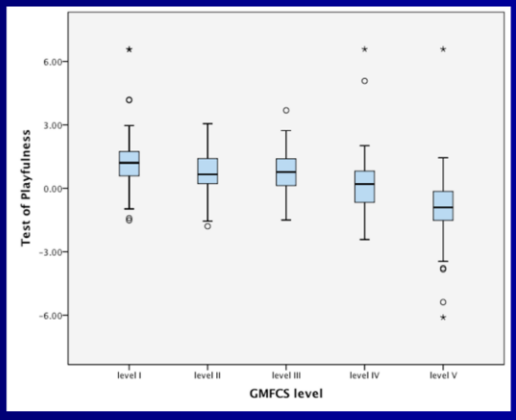
For enjoyment of participation, Juan scored an average for 4 – which is at the 25th percentile, but this score reflects the response option of 'very much' (level 5 would be 'a great deal, loves the activity')



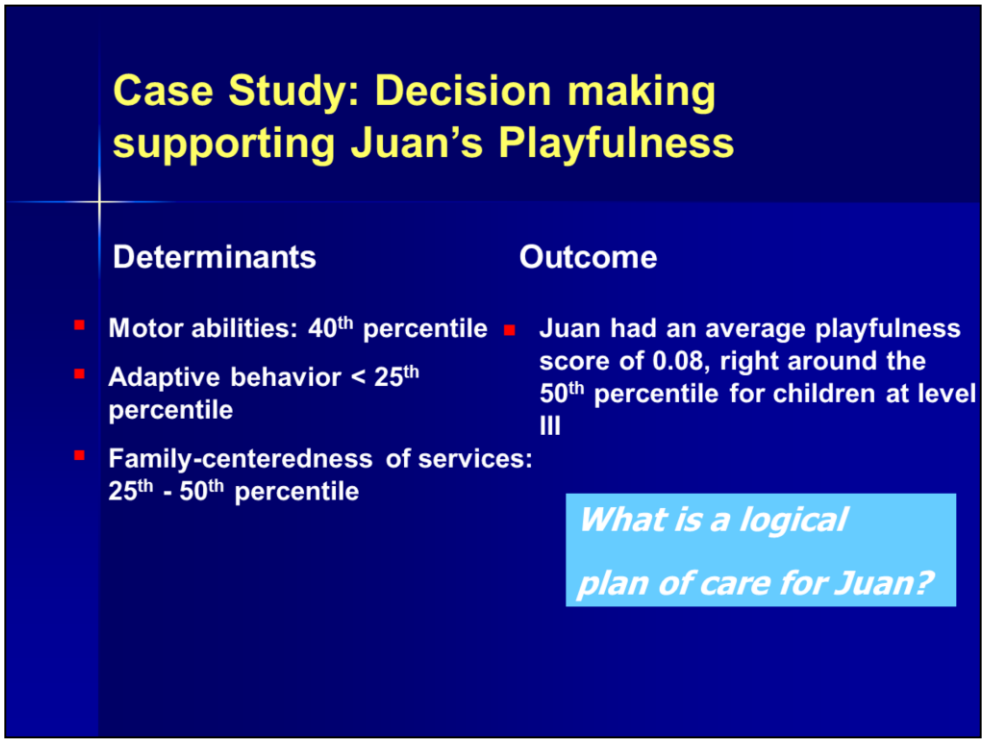
Although Juan's score is at around the 25th percentile, it still reflects a score of 'very much'. Nonetheless, his adaptive behaviour score and family ecology scores are also below the 25th percentile; however, these attributes are likely to be addressed in the 'participation' outcome goal, and so one might expect enjoyment to go up as well, as a result.

Case Study: Juan's Playfulness

- Juan's playfulness score was 0.08
- A score of 0.08 is ~50th percentile for children at GMFCS level III



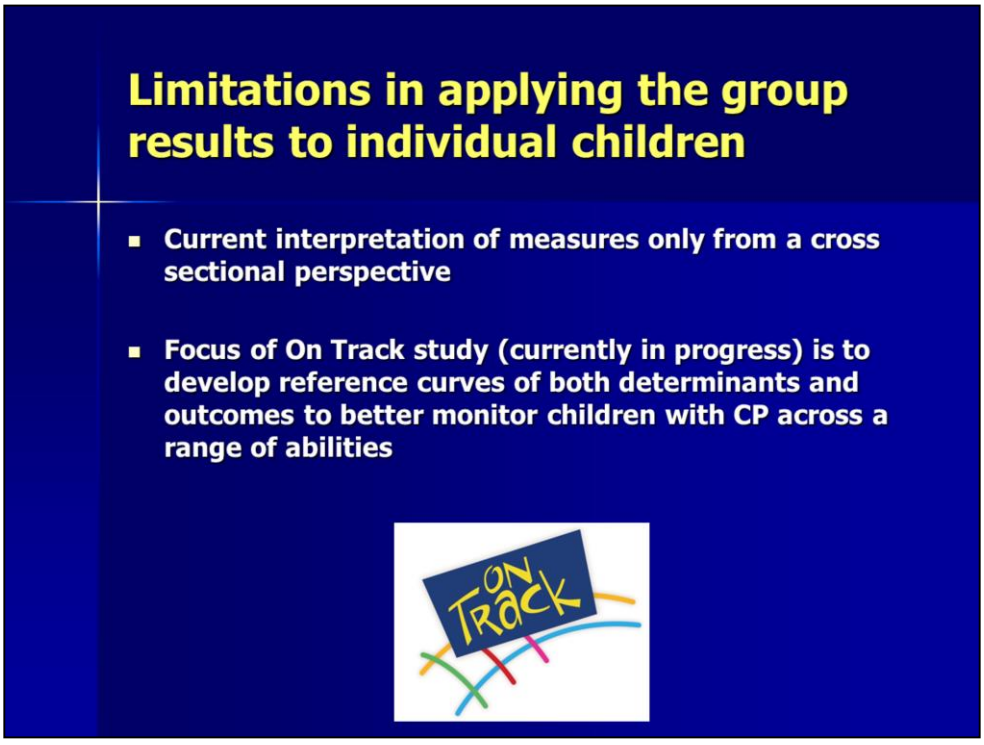
Juan's playfulness score was 0.08, which is right around the median value for children in level III. The playfulness score is obtained through Rasch analysis. The score in relation to 0 represents the relative playfulness of children. Higher scores indicate the child is more playful.



Again, for this outcome, a score around the median value might not suggest a need for intervention; however, if other goals recommend a focus on enhancing adaptive behaviour, a 'side effect' could be higher levels of playfulness.

Summary for Juan

- Which outcomes to work on?
  - Gross Motor
  - Participation in Self-Care
  - Participation in family and recreational activities
  - Playfulness
- What determinants to focus on?
  - Do specific determinants suggest type of intervention? Or more realistic goal-setting?



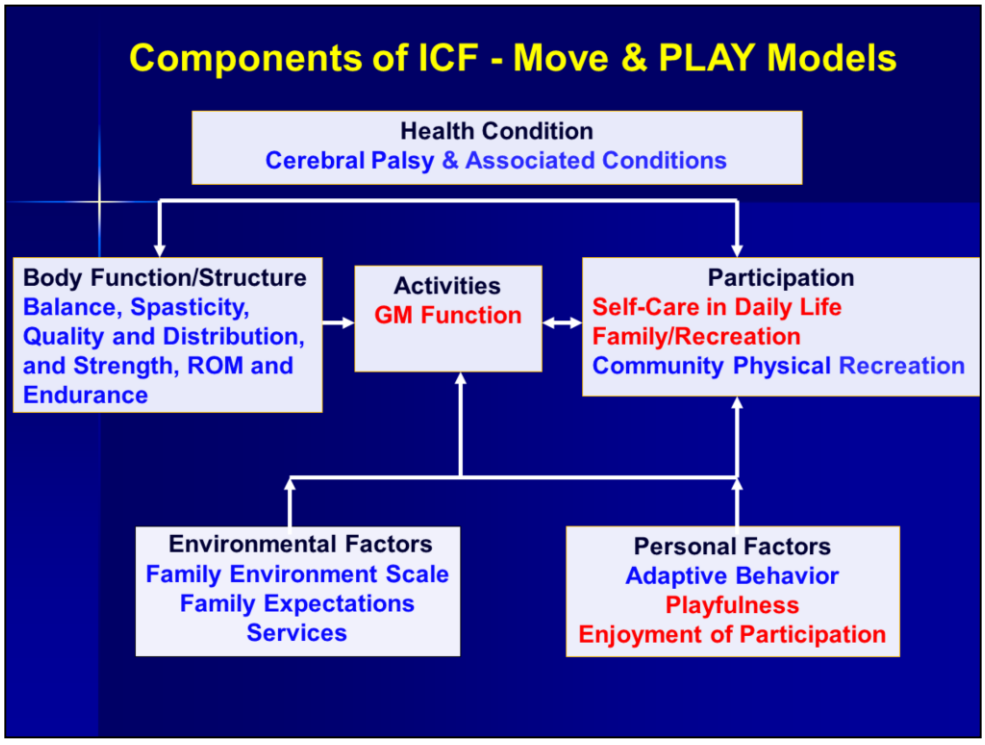
The primary limitation of application of the Move & PLAY Study results to individual children is that interpretation is currently limited to the cross-sectional reference data presented in the form of box-plots (described in the complementary measurement presentation). In the On Track Study, which is in progress, we intend to develop reference percentile curves for the measures described in the previous presentation.

Despite the current limitations of applying the results of the Move & PLAY study to individual children, we encourage you to consider how the results can assist with clinical decision making.

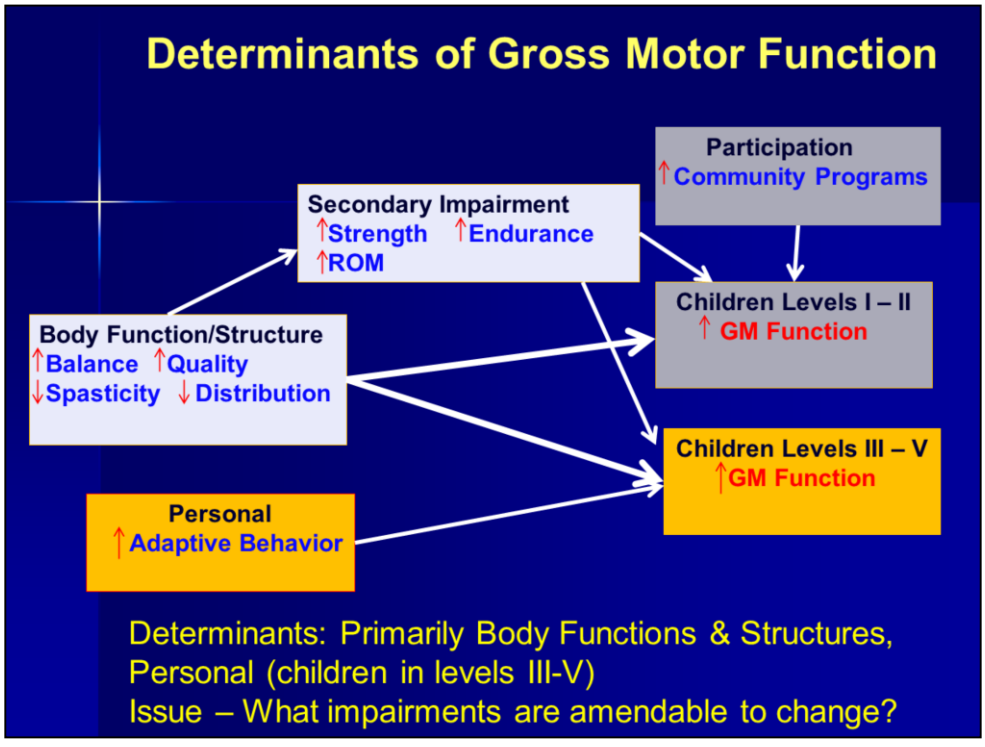
It will be interesting to learn about novel 'case studies' that lead to innovative approaches to optimizing outcomes of motor function, self-care, participation and playfulness of young children with CP across functional ability levels.

Summary of the group results

- Revisiting the ICF
- Determinants of the 4 outcomes in two groups of children
  - GMFCS I & II
  - GMFCS III, IV, & V



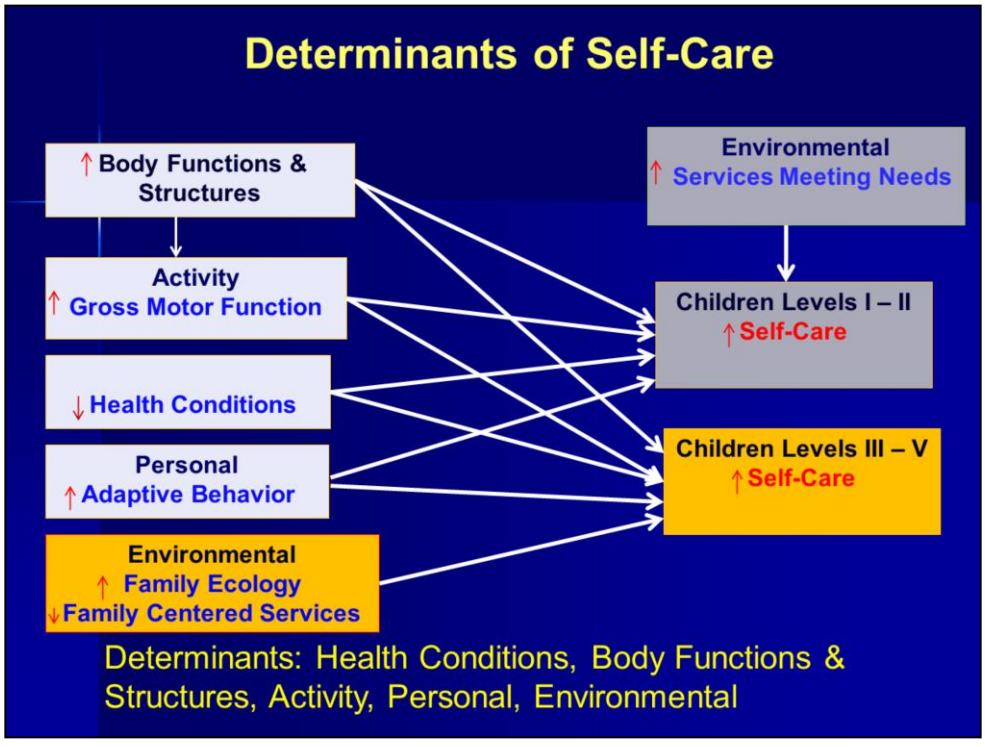
In review, the blue font represents factors considered to be ‘determinants’ and the red font represents outcomes in the models tested.



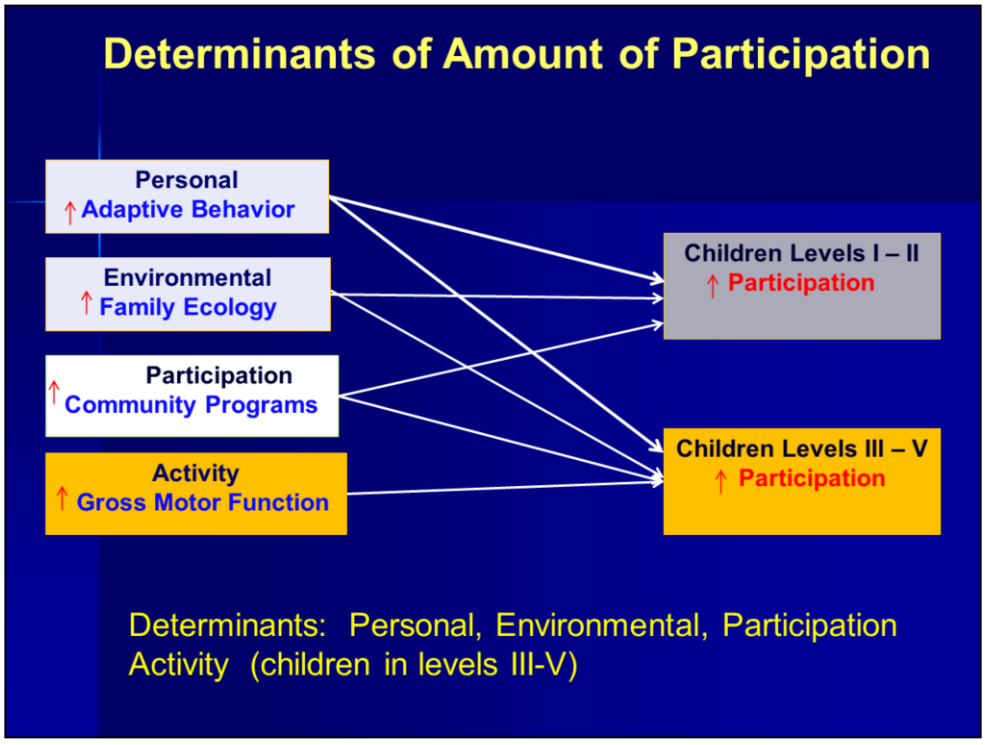
In these next few slides, we summarize the results in the context of the ICF for different outcomes. Grey boxes indicate factors associated only with outcomes for children in levels I and II. Yellow boxes indicate significant factors for children with GMFCS levels III, IV and V. The thickness of the arrows indicates the relative strength of association.

This slide focuses on motor function, and for both groups of children, body functions (both primary and secondary impairments) are associated with this outcome. The personal factor of adaptive behaviour is only associated with motor function for children in GMFCS levels III, IV and V.

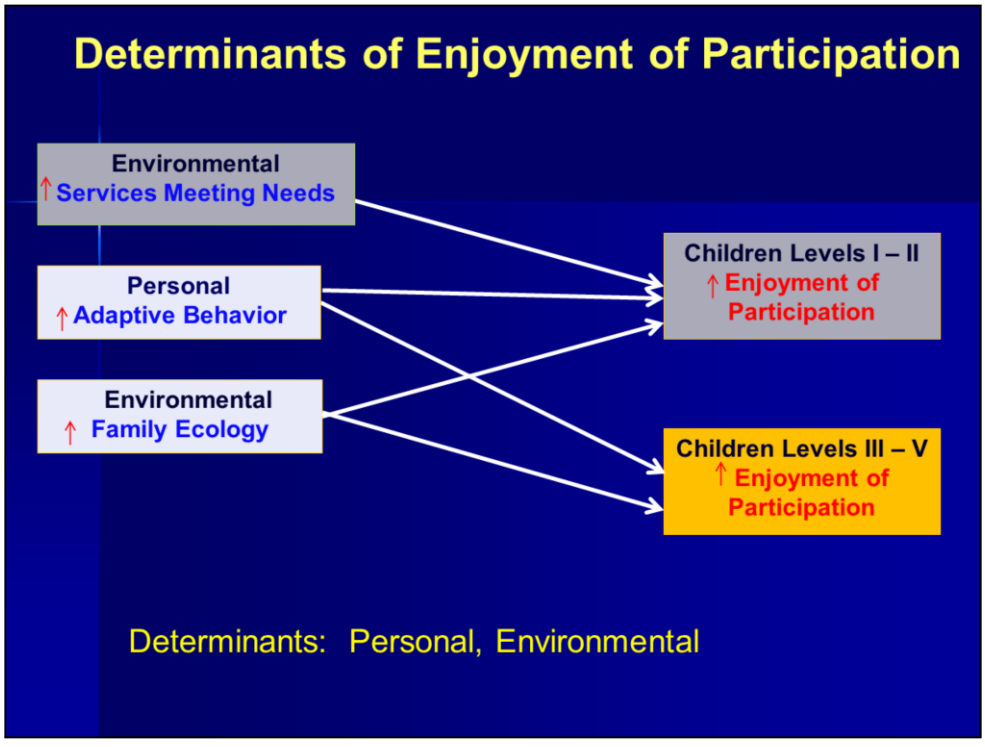
As you move through these summary slides, consider the impairments that are amenable to change versus those that are not.



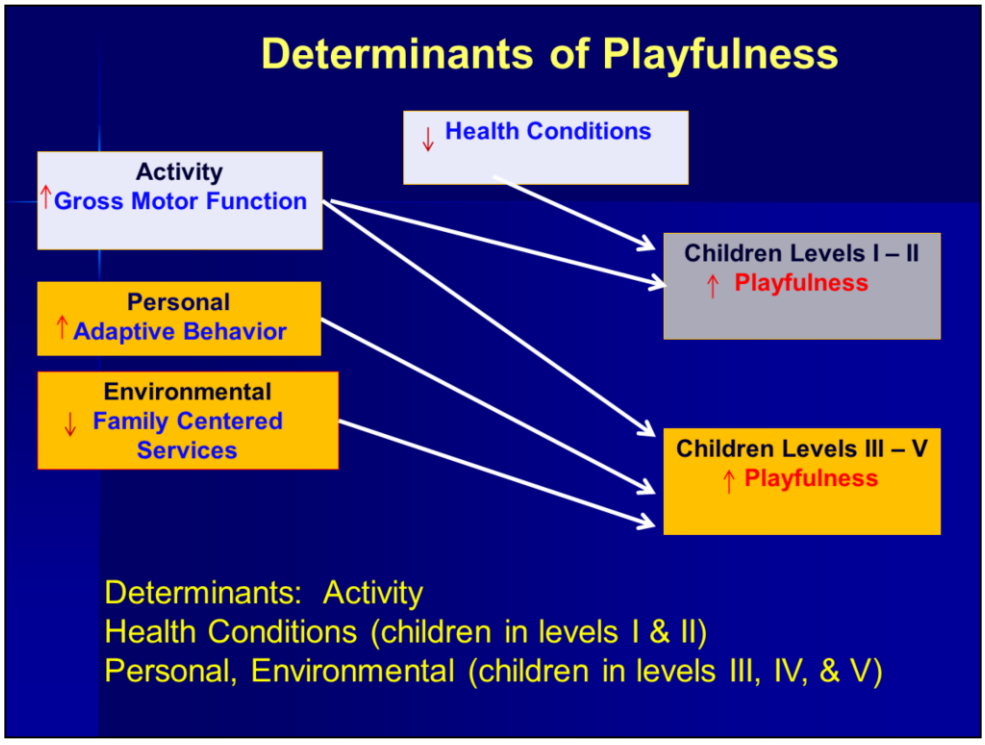
When looking at the outcome of self-care, multiple aspects of the ICF are associated: health conditions, body structures and function, activity, and the personal and environmental contextual factors. Self-care is clearly an outcome that has many potential influences.



In terms of participation in recreation and leisure, the determinants shift to personal and environmental contextual factors. For children in levels III, IV and V, the activity-level variable of gross motor function is also associated with participation.



When we look at enjoyment of participation in recreation and leisure, only the personal and environmental contextual factors are associated.



The outcome of playfulness is interesting. For both groups of children, activity is a significant determinant. Associated health conditions are only significant for children in levels I and II; and for children in levels III, IV and V – both personal and environmental aspects are associated with playfulness.

For more information or to provide feedback, contact

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

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