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

Move & PLAY Study Team

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Move & Play

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

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Overall Study Coordination was provided through *CanChild*

CanChild
Centre for Childhood Disability Research

Overview of the presentation:

- description of study, conceptual model and measures used and developed
- results:
  - motor function
  - self-care, participation and enjoyment
  - play
- case study
- interpretation
  - for children at different functional levels
  - comparison of results across outcomes

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

In each of the ‘main results’ sections we aim to:

- describe significant determinants of outcomes
- differentiate determinants that are:
  - amenable to change
    - they are targets for intervention
  - not amenable to change
    - they assist with realistic goal setting
- discuss goal setting and intervention planning
  - for groups of children

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?

Questions for Reflection

- Are any findings surprising?
- Do the findings support current service provision?
- What changes in service provision will be challenging?
- What child, family, and service factors are missing from the model?
- What are other important outcomes to consider?

Background: Move & PLAY Study

- **Theory and evidence-based model of determinants of motor change of children with cerebral palsy**

  (Bartlett and Palisano, 2000)

- **Consensus exercise with therapists re: their perceptions of important determinants**

  (Bartlett and Palisano, 2002)

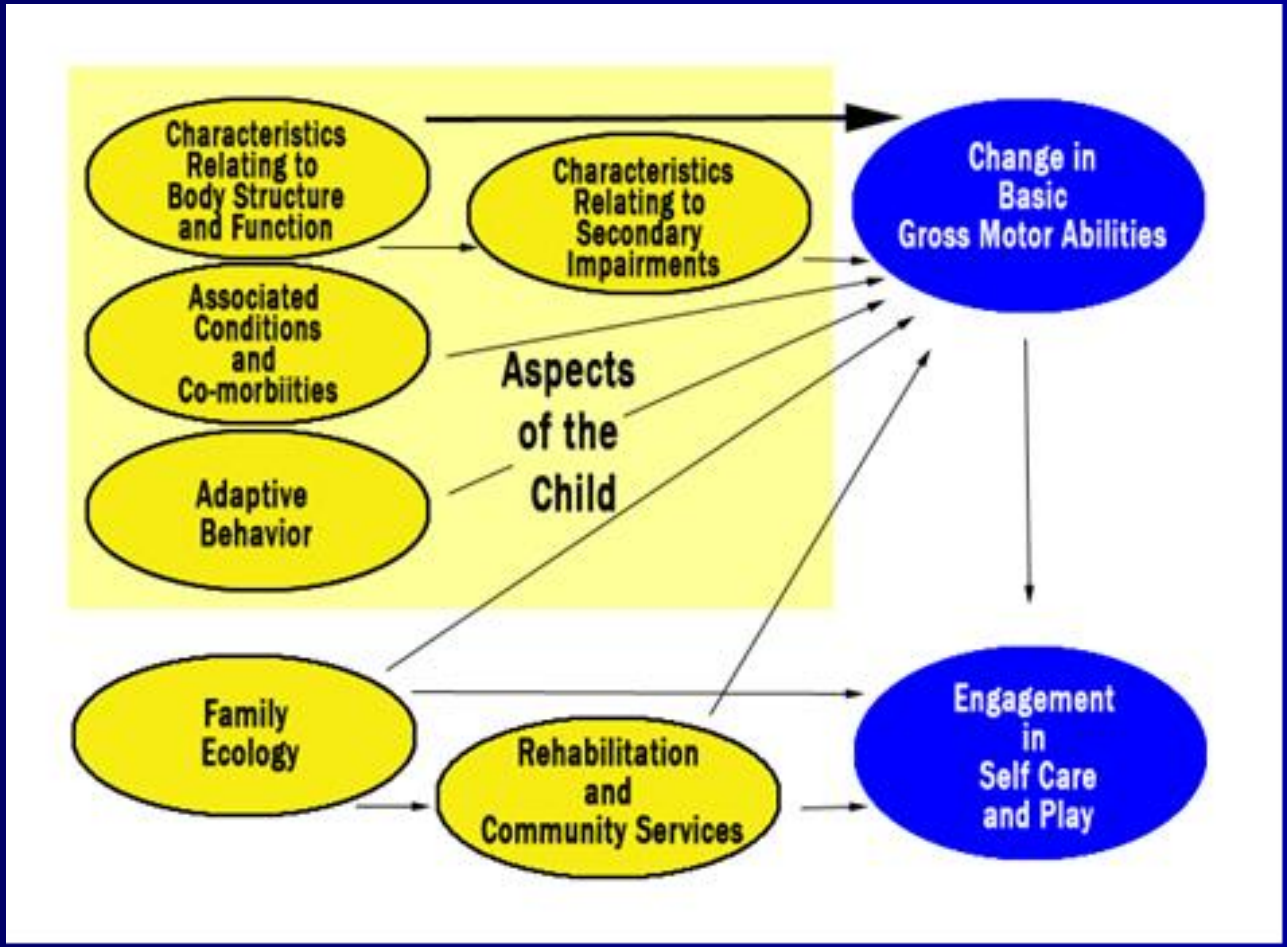
- **Measurement development e.g. SAROMM**

  (Bartlett and Purdie, 2005)

- **Broadened range of outcomes from motor to include self-care and play**

  (Bartlett et al., 2010, Chiarello et al., 2011)

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



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

Measures

Time 1

- Early Coping Inventory
- Early Activity Scale for Endurance
- Health Conditions
- Family Demographics

Time 2

- Family Environment Scale, Family's Expectation of Child and Service Questionnaire

Time 1 and 3

- Child Engagement in Daily Life Measure

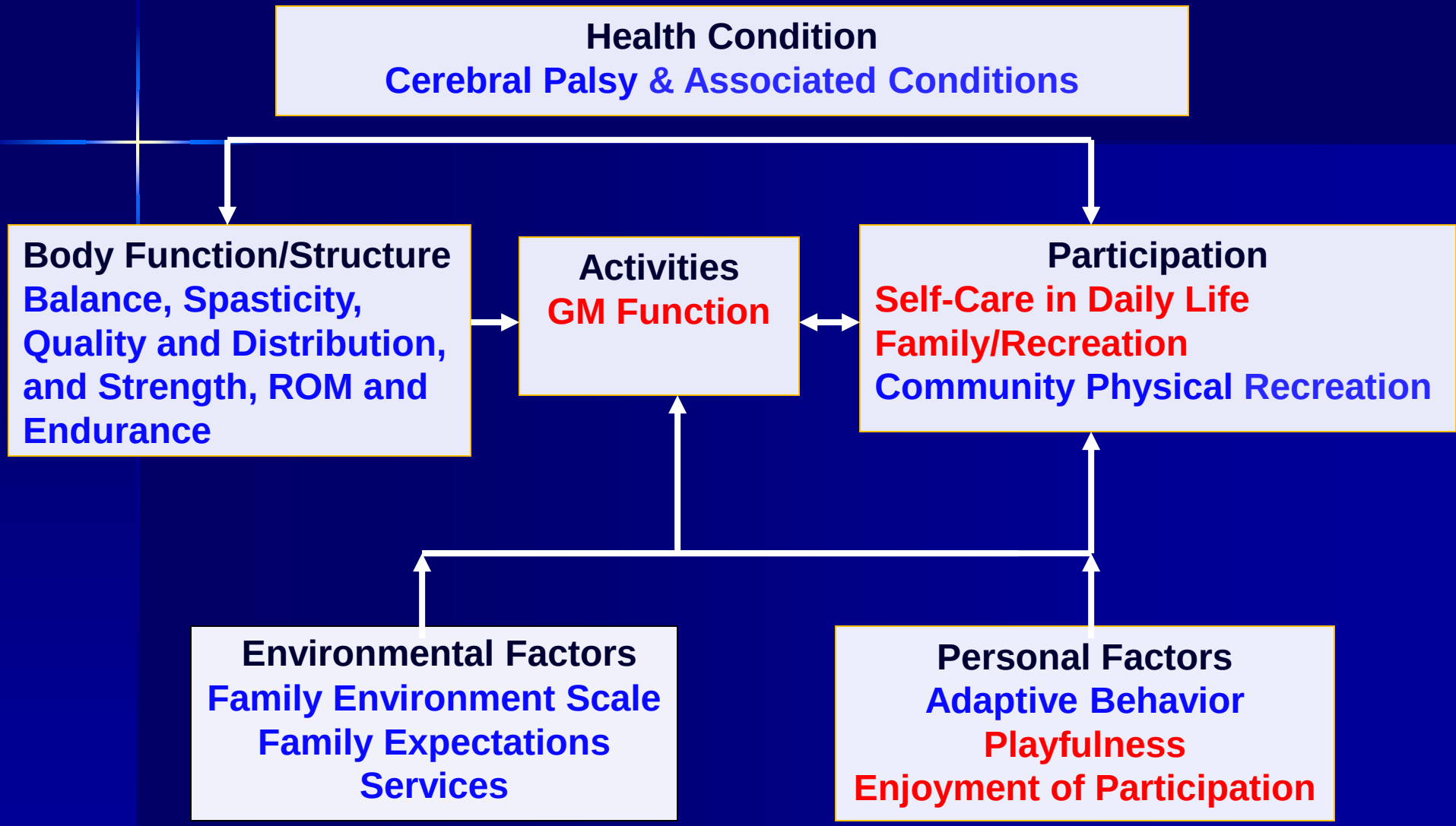
- Modified Ashworth Scale
- Gross Motor Performance Measure
- Early Clinical Assessment of Balance
- Functional Strength Assessment
- Spinal Alignment and Range of Motion Measure
- Distribution and GMFCS

- Gross Motor Function **(GMFM-66-B&C)**
- Test of Playfulness

Measuring Outcomes: Time 1 & 3

- **Motor Function**
  - GMFM Basal & Ceiling (Brunton & Bartlett, 2011)
- **Self-care**
  - Child Engagement in Daily Life (Chiarello et al., in press)
- **Amount and Enjoyment of Participation**
  - Child Engagement in Daily Life
- **Playfulness**
  - Test of Playfulness (Bundy, 2005)

Components of ICF - Move & PLAY Models



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

MOVING

Revisiting Question Asked

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

Although we set out to investigate the determinants of CHANGE in motor abilities, the model explained only

- **9% of the variance of change in motor function for children in GMFCS levels I & II**
- **13% of the variance of change in motor function for children in GMFCS levels III, IV & V**

To assist with interpretation and understanding, we present the results in the context of determinants of motor function at Time 3 (and remain humbled by the complexities associated with predicting / explaining change in function)

What did we learn about Motor Function?

GMFCS Levels I & II

- Model explained 58% of the variability in children's motor abilities

GMFCS Levels III, IV, V

- Model explained 75% of the variability in children's motor abilities

Higher motor abilities were related to:

- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Higher strength, fewer ROM limitations and better endurance
- Greater participation in community recreation programs

- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Higher strength, fewer ROM limitations and better endurance
- More effective adaptive behavior

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

Taking Care of Yourself

What did we learn about Self-Care?

GMFCS Levels I & II

- Model explained 65% of the variability in children's self-care abilities

GMFCS Levels III, IV, V

- Model explained 75% of the variability in children's self-care abilities

Higher participation in self-care was related to:

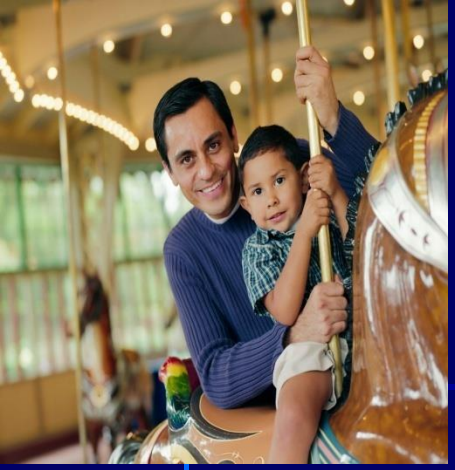
- Higher motor abilities
- Better health
- More effective adaptive behavior
- Greater extent services met needs

- Higher motor abilities
- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Better health
- More effective adaptive behavior
- Stronger attributes of families
- Parent's weaker perceptions of family-centeredness of services

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

Participation



What did we learn about Participation in Family and Recreational Activities?

GMFCS Levels I & II

- Model explained 35% of the variability in children's participation abilities

GMFCS Levels III, IV, V

- Model explained 40% of the variability in children's participation abilities

More participation in family & recreation activities was related to:

- More effective adaptive behavior
- Stronger attributes of families
- Greater involvement in community programs

- More effective adaptive behavior
- Stronger attributes of families
- Greater involvement in community programs
- Higher gross motor abilities

How can practitioners and families support children's Participation?

- Recommended focus of services includes:
  - 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
  - assist families in accessing and collaborate with community programs for their children
  - optimize gross motor abilities
    - enhance balance
    - prevent secondary impairments

What did we learn about Enjoyment of participation?

GMFCS Levels I & II

- Model explained 28% of the variability in children's enjoyment abilities

GMFCS Levels III, IV, V

- Model explained 38% of the variability in children's enjoyment abilities

More enjoyment in family & recreation activities was related to:

- More effective adaptive behavior
- Greater extent services met needs

- More effective adaptive behavior
- Stronger attributes of families

How can practitioners and families support children's Enjoyment of Participation?

- Recommended focus of services includes:
  - 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

Playfulness

What did we learn about Playfulness?

GMFCS Levels I & II

- Model explained 22% of the variability in children's playfulness abilities

GMFCS Levels III, IV, V

- Model explained 44% of the variability in children's playfulness abilities

Higher Playfulness was related to:

- Better health
- Higher gross motor abilities

- Higher gross motor abilities
- More effective adaptive behavior
- Parent's weaker perceptions of family-centeredness of services

How can practitioners and families support children's Playfulness?

- 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

Summary & Considerations for Practice

Summary:

- Structural equation modeling: associations between determinants and outcomes; not cause-effect
- Explained variance higher for models of determinants of gross motor function & self-care
- Body functions & structures and secondary impairments are primary determinants of gross motor function

Summary:

- Explained variance lower for models of determinants of participation, enjoyment of participation, and playfulness

- Contextual personal and environmental factors are primary determinants of participation and play:

  - Notably, adaptive behavior is a determinant of self-care, participation and enjoyment for all children and for motor function and playfulness in children in levels III, IV and V

Limitations:

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

Considerations for Decision Making

- What child, family, environment, service factors are associated with gross motor function, self-care, participation, and playfulness?

- What determinants are amendable to change?

- When potential for change in body functions & structures and activity is limited, what are considerations for realistic goal setting, task accommodation, assistive technology, or environmental modifications?

Considerations for Decision Making

- **Model provides framework for decision making but determinants and strength of associations vary among individual children and families**

Thoughts and Discussion

- Are any findings surprising?
- Do the findings support current service provision?
- What changes in service provision will be challenging?
- What child, family, and service factors are missing from the model?
- What are other important outcomes to consider?

Case Study: “Juan”

40-month-old boy who was a participant in the Move & PLAY study with a history of prematurity, spastic diplegia, GMFCS level III, uses orthoses and a walker

Lives with two adults and one sibling

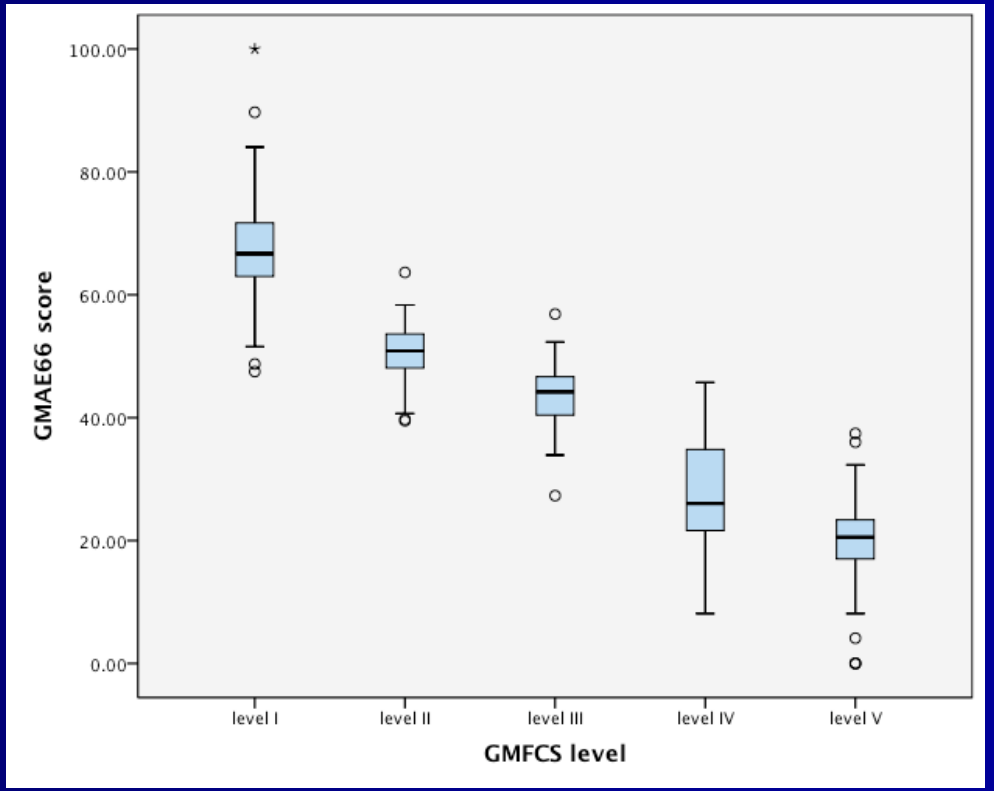
Annual household income: $15,000 – 29,000 (USD)

Attends preschool; receives PT & OT 4x / month

Case study: Juan
Gross Motor Function

Juan had a GMFM score of 49.0

40th percentile for a child in GMFCS level III



Case study: Juan
Gross Motor Function

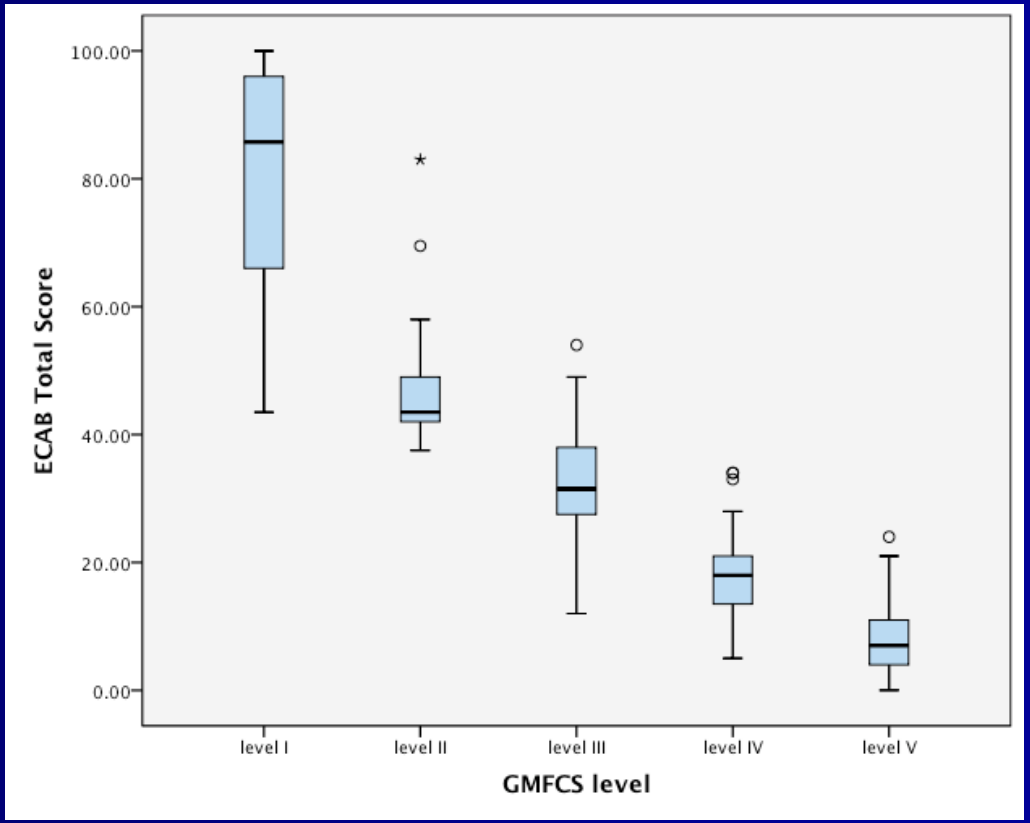
Juan is a child in GMFCS level III

Significant determinants of motor function for children at Level III-V:

- **primary impairments**
- **secondary impairments**
- **adaptive behavior**

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

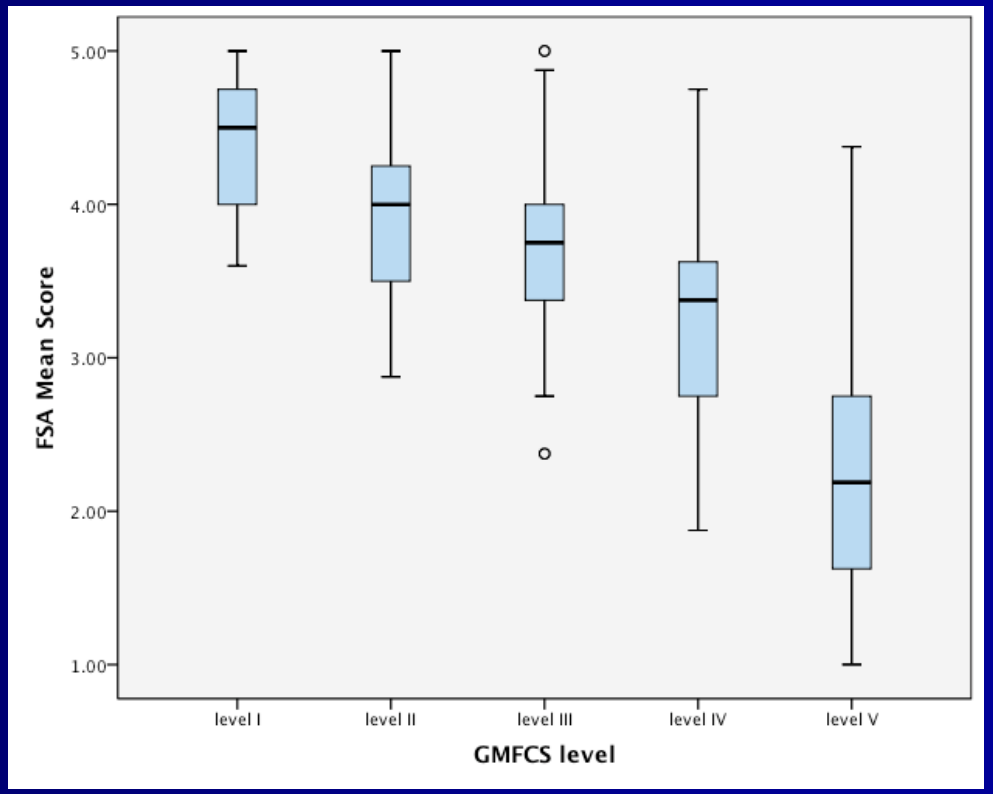
Early Clinical Assessment of Balance (ECAB) score = 41.5/100 is > the 75th percentile for GMFCS level III



Case Study: Juan
Strength

Juan's average score for Strength = 3.25

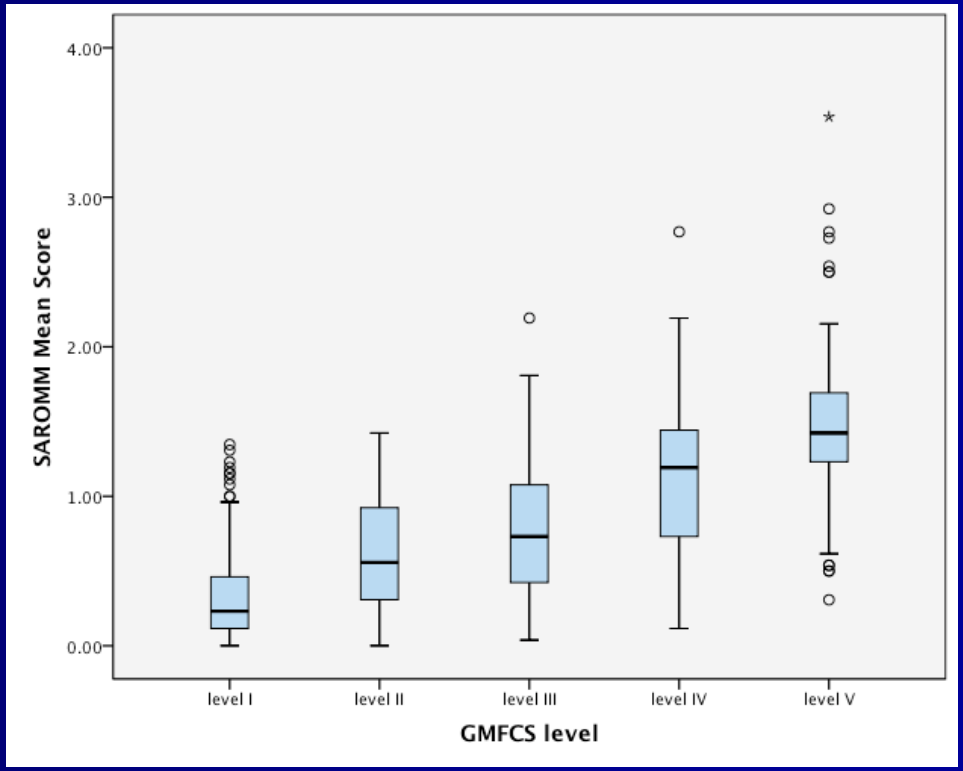
< 25th percentile for GMFCS level III



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

Juan has an average SAROMM score of 0.85

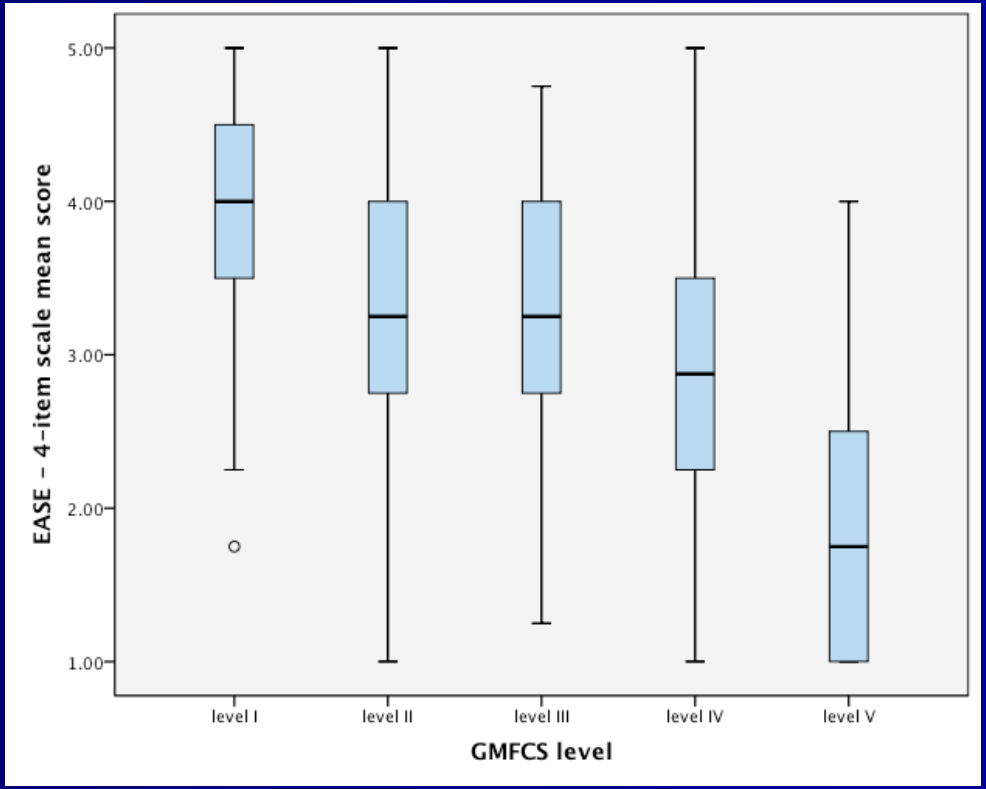
~ median value for GMFCS level III



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

Juan had an EASE score of 2.5

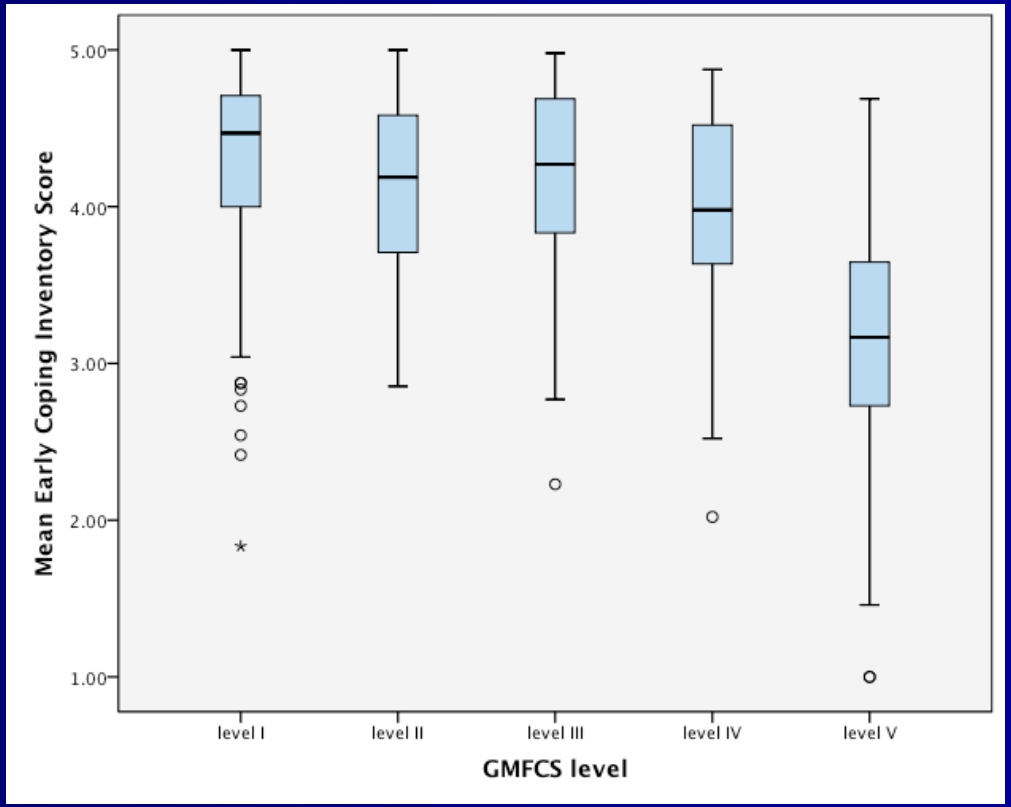
Endurance < 25th percentile for GMFCS level III



Case study: Juan
Adaptive Behavior (Zeitlin et al. 1988)

Juan had an adaptive behavior score of 3.2

Adaptive behavior < 25th percentile for GMFCS level III



Case Study: Decision making supporting Juan's Motor Function

Determinants

- Primary Body S/F Impairments
  - Balance > 75th
  - Strength < 25th
  - ROM 50th
  - Endurance < 25th
- Adaptive behavior < 25th

Outcome

Juan had a GMFM-66 score at the 40th percentile for children at level III

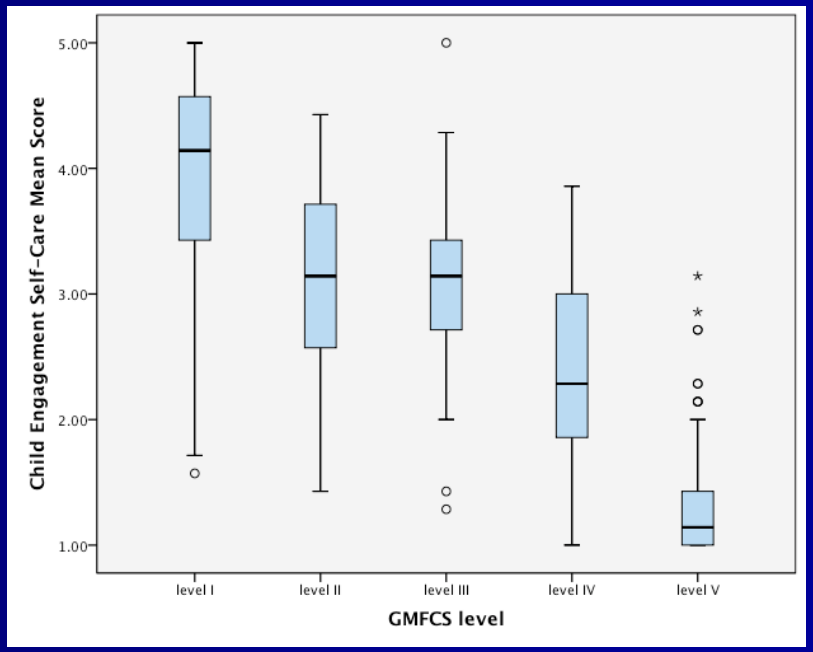
What is a logical plan of care for Juan?

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)



Case study: Juan
Self-Care

Significant Determinants of Self-Care for children at Level III-V

- Higher motor abilities
- Better balance, better quality of movement, lower spasticity, and fewer limbs and parts of the body involved
- Better health
- More effective adaptive behavior
- Stronger attributes of families
- Parent's weaker perceptions of family-centeredness of services

Juan's reported Health Conditions

(Wong et al. 2011)

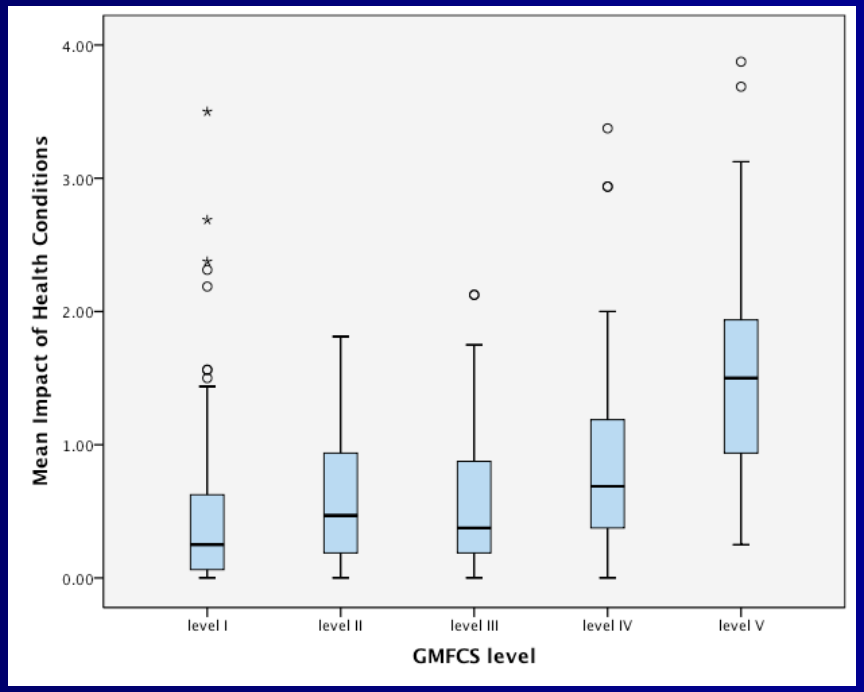
8 health conditions:

Seeing	small extent
Learning and Understanding	very small extent
Speaking / communicating	moderate extent
Emotions / behaviour	moderate extent
Digestion	small extent
Sleeping	very great extent
Heart problems (prior patent ductus)	not at all
Pain	moderate extent

Case Study: Juan Health

Juan's parents reported a health conditions score of 1.25

> 75th percentile for GMFCS level III

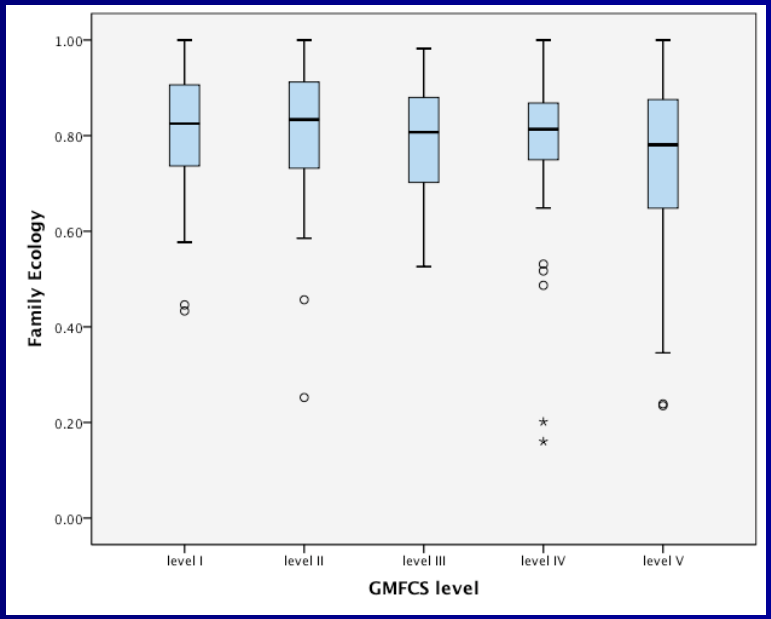


Case Study: Juan
Family Ecology (Moos and Moos, 2002, and our measure)

Juan's family ecology score was 0.60.

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

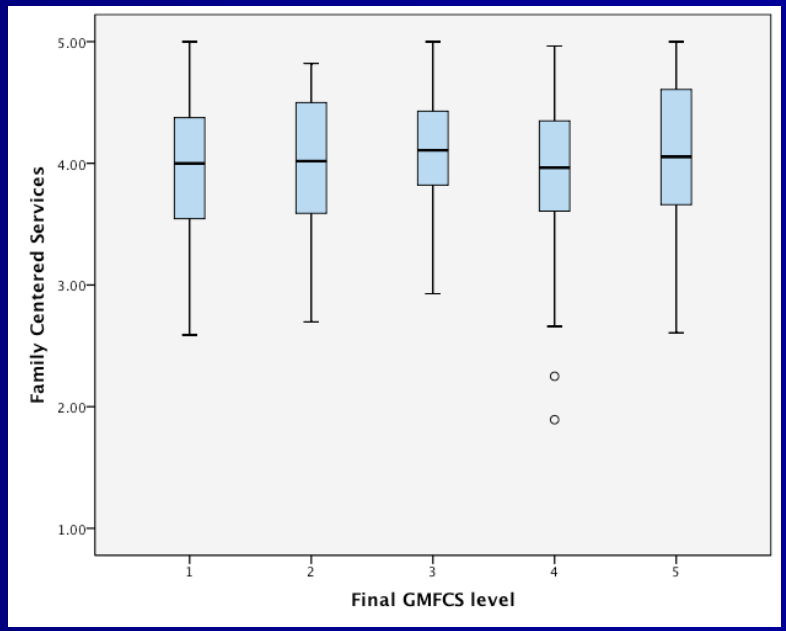
Note, however, that median family ecology scores are ~0.80 out of a top score of 1.0.



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).



Case Study: Decision making supporting Juan's Self-Care

Determinants

- **Motor abilities: 40th percentile**
- **Body S/F Impairments**
  - **Balance > 75th**
  - **Endurance < 25th**
  - **Strength < 25th**
  - **ROM 50th**
- **Adaptive behavior < 25th**
- **Health problems > 75th**
- **Family ecology < 25th**
- **Family centered services 25th - 50th**

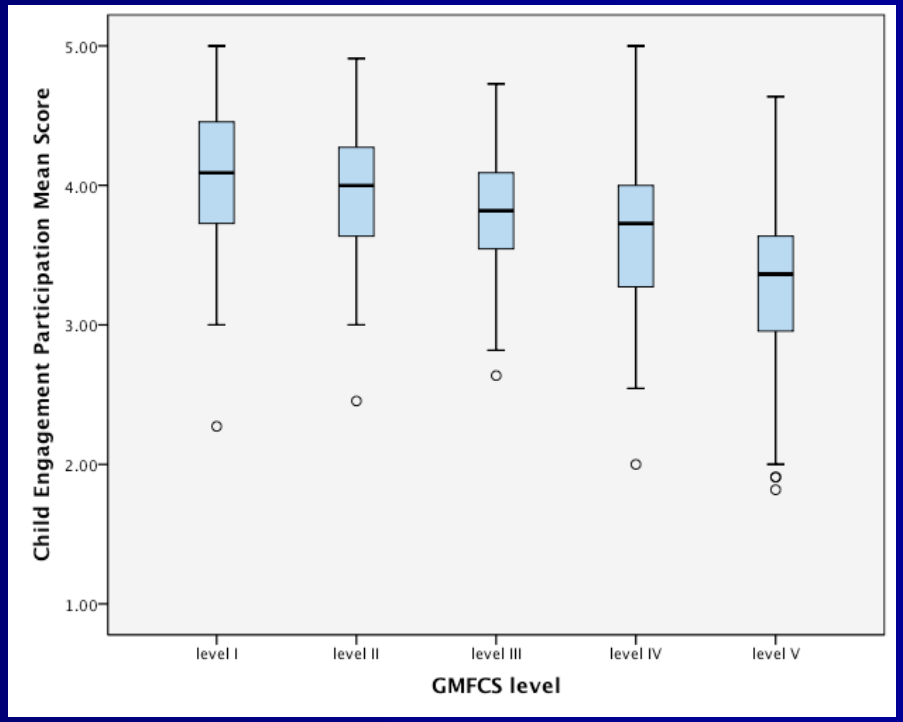
Outcome

- Juan had an average Self-Care score of 3.3, right around the 50th percentile for children at level III

What is a logical plan of care for Juan?

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



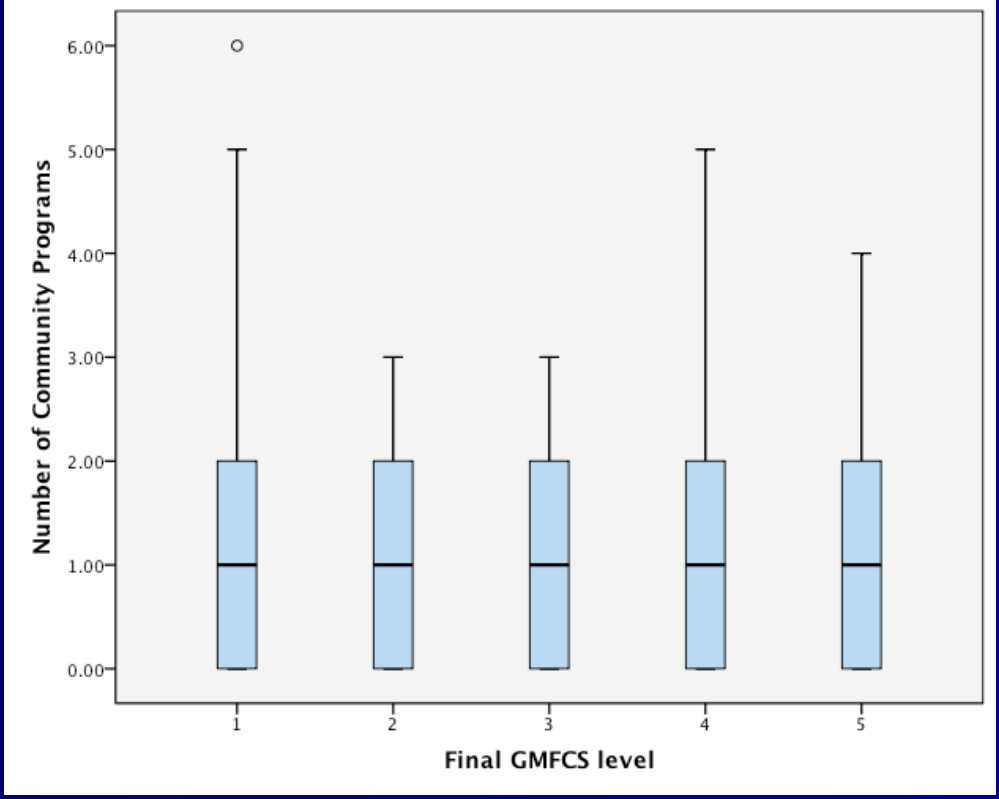
Case Study: Juan
Amount of Participation

- 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



Case Study: Decision making supporting Juan's Participation

Determinants

- Adaptive behavior < 25th percentile
- Attributes of family < 25th percentile
- Motor abilities: 40th percentile
- Community programs: 25th percentile

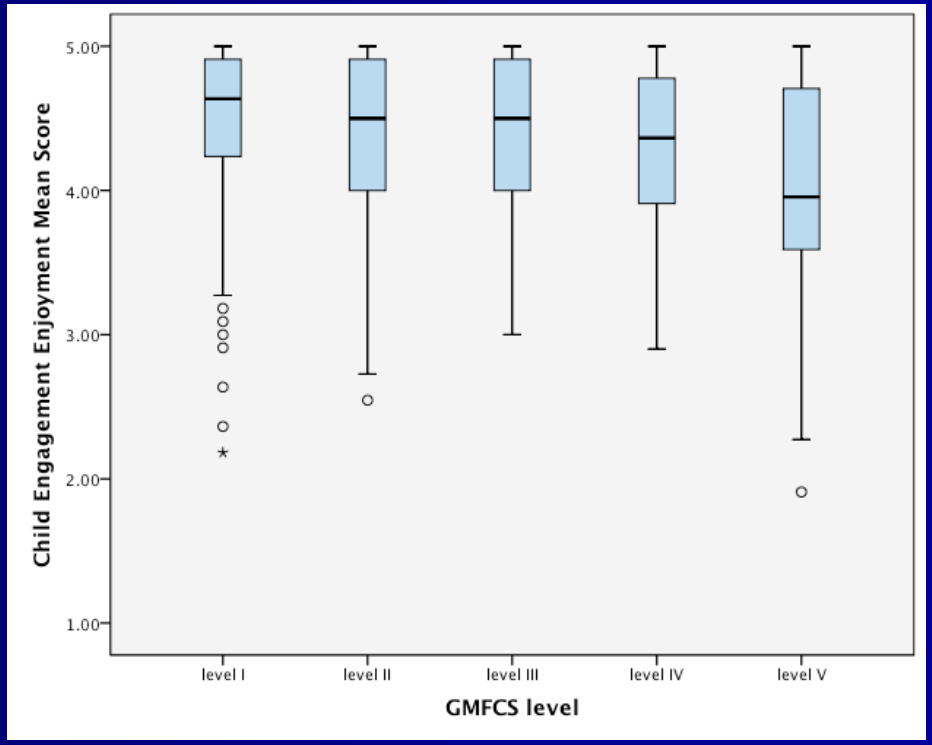
Outcome

- **Juan had an average participation score of 3 (once in awhile), well below the 25th percentile for children at level III**

What is a logical plan of care for Juan?

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



Case Study: Decision making supporting Juan's Enjoyment of Participation

Determinants

- Adaptive behavior < 25th percentile
- Attributes of family < 25th percentile

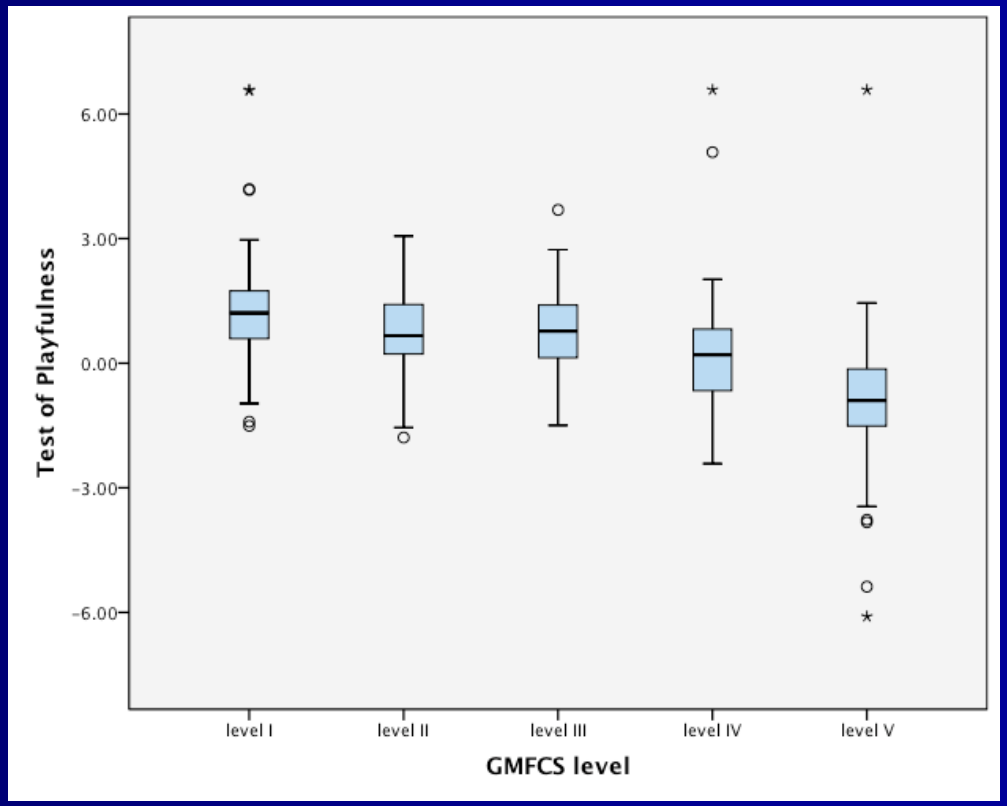
Outcome

- Juan had an average enjoyment score of 4 (very much) – at the 25th percentile for children at level III

What is a logical plan of care for Juan?

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



Case Study: Decision making supporting Juan's Playfulness

Determinants

- Motor abilities: 40th percentile
- Adaptive behavior < 25th percentile
- Family-centeredness of services: 25th - 50th percentile

Outcome

- Juan had an average playfulness score of 0.08, right around the 50th percentile for children at level III

What is a logical plan of care for Juan?

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?

Limitations in applying the group results to individual children

- Current interpretation of measures only from a cross sectional perspective
- Focus of On Track study (currently in progress) is to develop reference curves of both determinants and outcomes to better monitor children with CP across a range of abilities

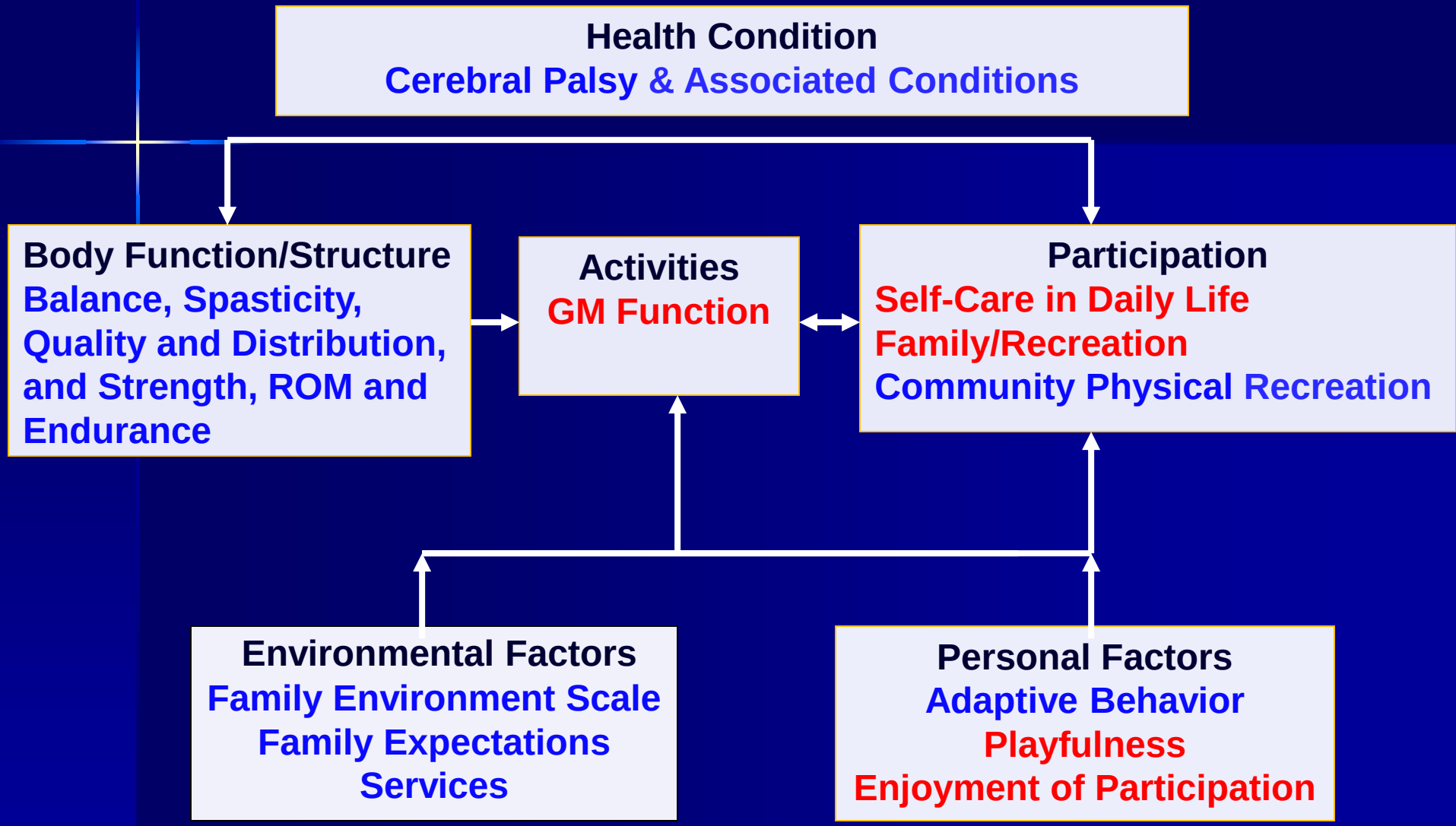
Despite the current limitations of applying the results of the Move & PLAY study to individual children, we encourage you to consider how the results can assist with clinical decision making.

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.

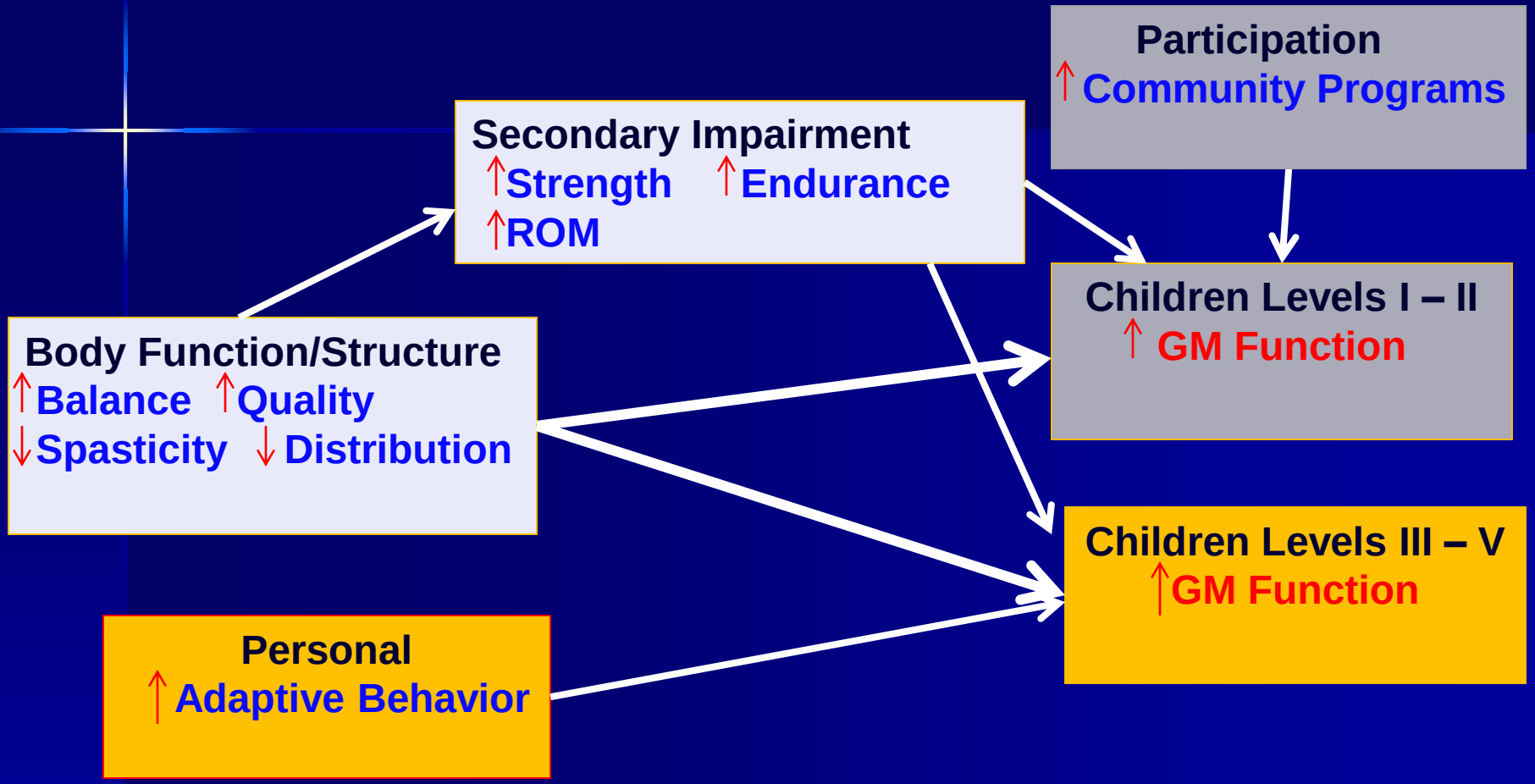
Summary of the group results

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

Components of ICF - Move & PLAY Models



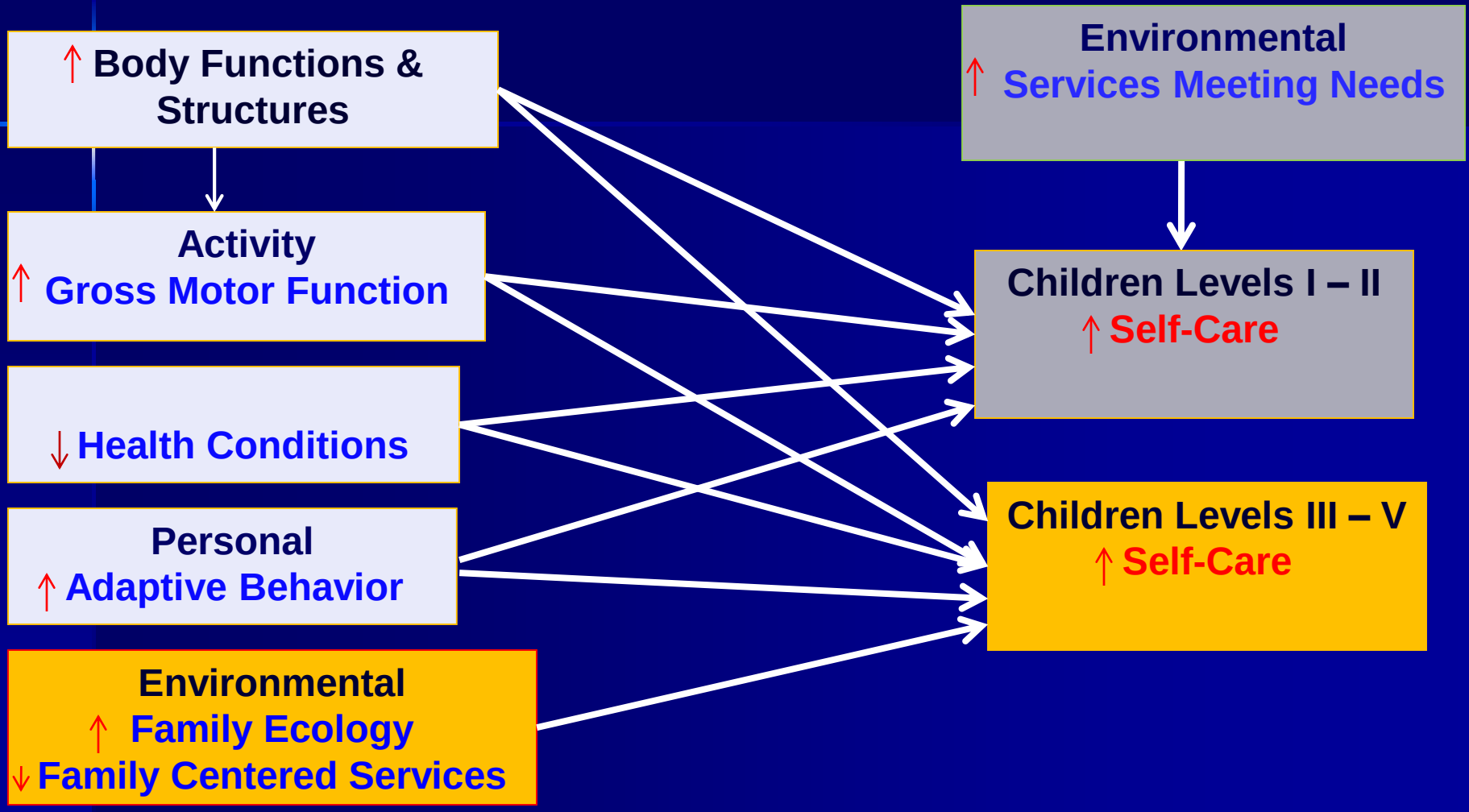
Determinants of Gross Motor Function



Determinants: Primarily Body Functions & Structures, Personal (children in levels III-V)

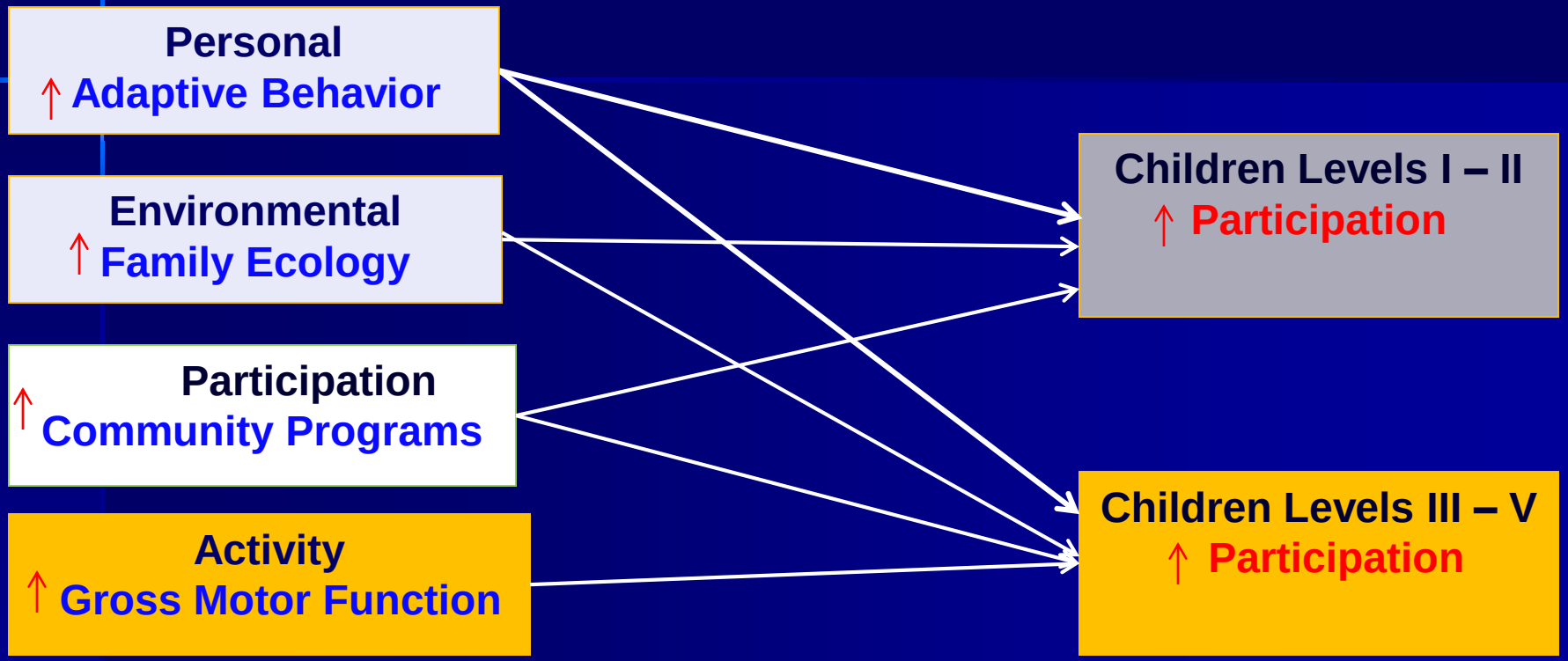
Issue – What impairments are amendable to change?

Determinants of Self-Care



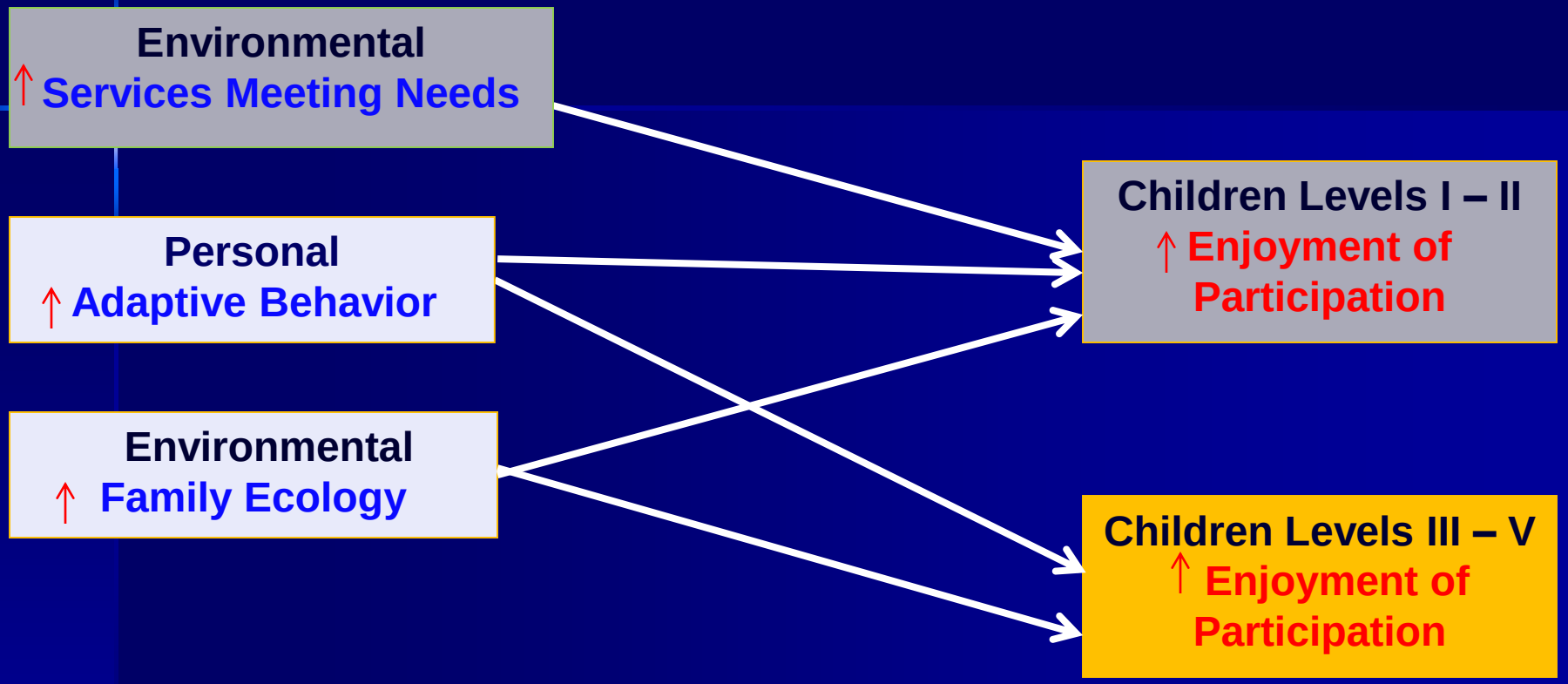
Determinants: Health Conditions, Body Functions & Structures, Activity, Personal, Environmental

Determinants of Amount of Participation



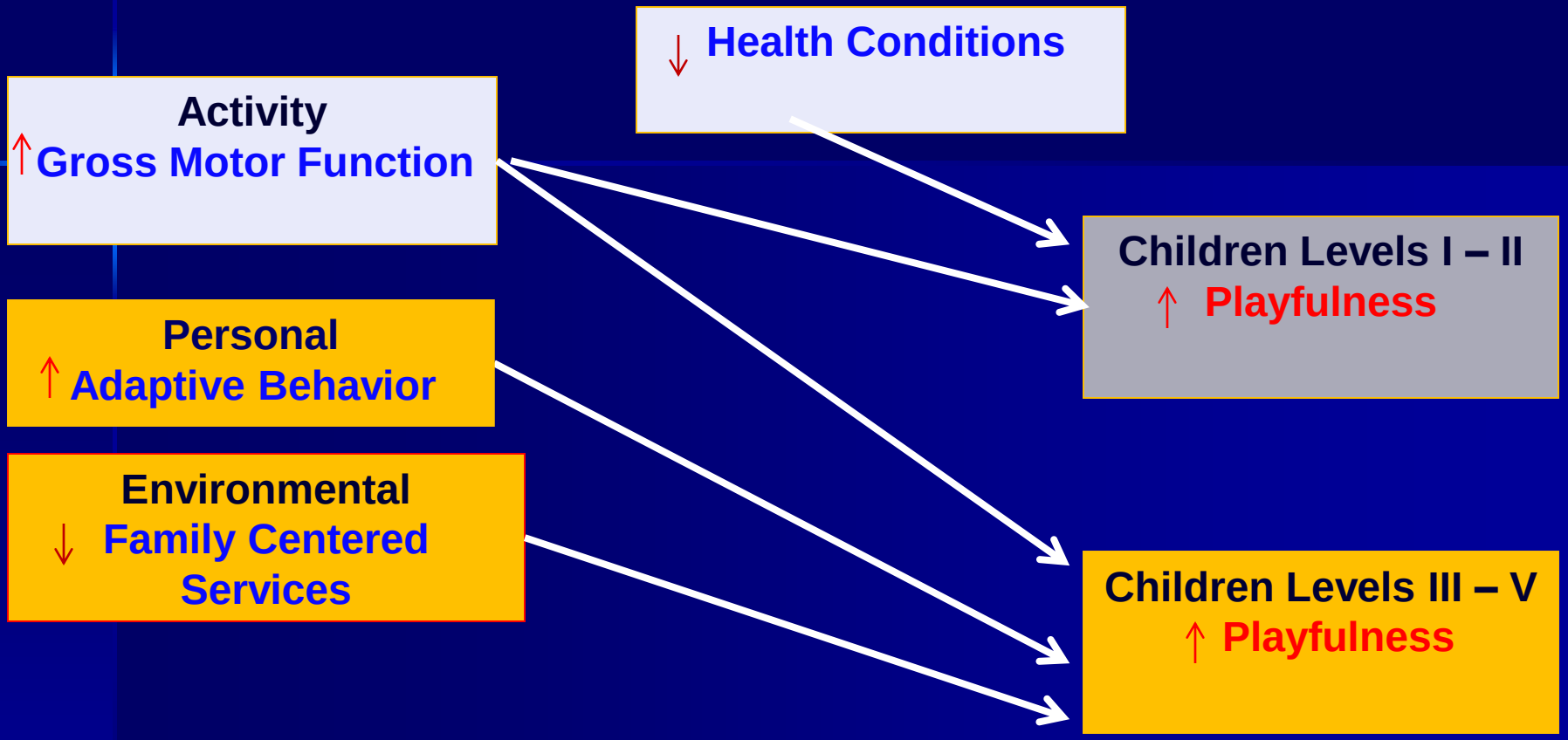
Determinants: Personal, Environmental, Participation
Activity (children in levels III-V)

Determinants of Enjoyment of Participation



Determinants: Personal, Environmental

Determinants of Playfulness



Determinants: Activity
Health Conditions (children in levels I & II)
Personal, Environmental (children in levels III, IV, & V)

For more information or to provide feedback, contact

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

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