Collaborative Developmental Monitoring to Provide Optimal Individualized Services for Children with Cerebral Palsy

Disclosure Information
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Speaker Names:
Doreen Bartlett, Sarah Westcott McCoy, Lisa Chiarello, Barb Galuppi

Disclosure of Relevant Financial Relationships
We have the following financial relationships to disclose:
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Disclosure of Off-Label and/or investigative uses:
We will not discuss off label use and/or investigational use in this presentation

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Barbara Sieck Taylor
Lisa Diller
Paula Drew
Nancy Ford
Marquitha Gilbert
Kimberly Rayfield

Setting the Stage

Checking up and Checking In: Partnering with Families of Children with Cerebral Palsy

Link to Video: canchild.ca/checkingin

Plan for the Afternoon

- Situating our research, overview of Move & PLAY products (Doreen)
- Overview of the On Track Study (Sally)
- Compatibility of our approach with current perspectives in pediatric rehabilitation (Lisa)
- Lessons learned from youth and families about how they prefer to receive developmental monitoring information (Doreen)
- Walking through a case study using products from Move & PLAY and On Track (Barb)
- Break out groups – three additional case studies; large group discussion (all)
- Wrapping up: questions and relevance (Barb)
Who is participating today?

- Parents of children or youth with CP
- Physical therapists
- Occupational therapists
- Developmental pediatricians or physiatrists
- Nurses
- Recreation therapists
- Other front line service providers?
- Service managers
- Educators
- Researchers
- Who are we missing?

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, pg 9)

Functional Classifications

- Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997; 2008)
- Manual Ability Classification System (MACS) (Eliasson et al. 2006)
- Communication Function Classification System (CFCS) (Hidecker et al. 2011)
Functional Classifications

- Gross Motor Function Classification System (GMFCS)  
  Enhanced communication among team members
- Manual Ability Classification System (MACS)  
  Sharper focus on function
- Communication Function Classification System (CFCS)  
  Assistance with realistic goal setting and intervention planning

Functional Profiles

In an extension of the work conducted by Hidecker et al. (2012), from a sample of 671 children with CP, we confirmed that the most prevalent profile was:
- GMFCS-I, MACS-I, CFCS-I (11%)
- GMFCS-I, MACS-II, CFCS-I (10%)
- GMFCS-II, MACS-II, CFCS-I (6%)

[Bartlett et al. under review]

... comprising 27% of the sample

The remaining 73% of the children were scattered in 69 of the possible 125 cells, with less than 5% in each

[Bartlett et al. under review]
Dilemma of Heterogeneity

- Traditionally we have looked to evidence from randomized controlled trials and systematic reviews to provide evidence of effectiveness of interventions
- Problem: these designs work best with homogeneous conditions
- Prospective cohort studies provide an alternative to understand the variability inherent in heterogeneous populations

Background: Move & PLAY Conceptual Model

<table>
<thead>
<tr>
<th>Construct</th>
<th>Measure</th>
<th>Reference</th>
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</thead>
<tbody>
<tr>
<td>Balance</td>
<td>Early Clinical Assessment of Balance (ECAB)</td>
<td>McCoy et al. 2014</td>
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<tr>
<td>Strength</td>
<td>Functional Strength Assessment (FSA)</td>
<td>Jeffries et al. 2016</td>
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<td>Range of Motion</td>
<td>Spinal Alignment and Range of Motion Measure (SAROMM)</td>
<td>Bartlett and Purdie, 2005</td>
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<td>Endurance</td>
<td>Early Activity Scale for Endurance (EASE)</td>
<td>McCoy et al. 2012</td>
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<td>Health</td>
<td>CHILD Health Conditions Questionnaire</td>
<td>Veling et al. 2011</td>
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<tr>
<td>Participation in Recreation and Leisure</td>
<td>Child Engagement in Daily Life Measure – Participation in Recreation (CEDL-RM)</td>
<td>McCrae et al. 2014</td>
</tr>
</tbody>
</table>
Measures: Primary Body Structure/Function Impairments

Early Clinical Assessment of Balance (ECAB)
- Pediatric Berg Balance Scale (Franjoine et al., 1999)
- Modified Movement Assessment of Infants (Chandler et al., 1980)
  - Measured for head & trunk equilibrium, protective extension, sitting, standing & movement balance (McCoy et al. 2014)
  - 10-15 minutes to complete
  - Scored out of 100

Measures: Secondary Body Structure/Function Impairments

Functional Strength Assessment (FSA)
- Modeled from manual muscle testing (Jeffries et al. 2016)
- 10 minutes to complete
- Average score of items (max 5)

Measures: Secondary Body Structure/Function Impairments

Spinal Alignment & Range of Motion Measure (SAROMM) (Bartlett & Purdie, 2005)
- Method of spinal alignment & ROM measurement based on observation of neck, back, extremities
- 15 minutes to administer
- Average score of items (of 26 items)
**Measures: Secondary Body Structure/Function Impairments**

Early Activities Scale for Endurance (EASE)
- Parent rates child’s endurance, movement inside/outside, whether movement increases heart rate, etc.
- 4-item Questionnaire available: [https://canchild.ca/en/research-in-practice/current-studies/on-track](https://canchild.ca/en/research-in-practice/current-studies/on-track)
- 10-item in publication [McCoy SW, et al. 2012]
- 10 minutes to complete 10-items, 5 for 4 items
- Average score of items (max 5)

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**Measures: Health**

Child Health Conditions Questionnaire
- Presence of impairments of body functions and health conditions related to international consensus definition of CP and the ICF
- Questions where parent indicates if a health problem exists and how much it impacts the child’s daily life [Wong et al. 2011]
- 5 minutes to complete; average impact

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**Measures: Outcomes**

Activity: Basic Motor Abilities
GMFM-66 – B&C (Brunton & Bartlett 2011)
- GMFM66 Items in difficulty order
- Suggestions for start points using age, GMFCS
- Test a minimum of 15 items
- Establish Basal = 3 scores of “3” – Completes the item
- Establish Ceiling = 3 scores of “0” – Does not initiate
- 15 – 20 minutes to complete
- Scored out of 100
Measures: Outcomes

Participation: Participation in Self-care & Recreation and Leisure

Child Engagement in Daily Life Measure (CEDL)

Part 1. Participation in family & recreational activities

Part 2. Participation in Self-care - 10 minutes to complete; Parts 1 and 2 scored out of 100

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Determinants</th>
<th>Level 1 and II</th>
<th>Level III, IV, and V</th>
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<td>Motor Function Impairments</td>
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<td>NS</td>
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<td>0.24</td>
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<td>Community Programs</td>
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<td>Family Attributes</td>
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<td>NS</td>
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<tr>
<td>Services met needs</td>
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<td>Family Attributes</td>
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<tr>
<td>Services met needs</td>
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<td>0.09</td>
<td>NS</td>
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Limitation of Move & PLAY

- Interpretation of the meaning of scores was limited to cross-sectional data of preschool children
On Track Study Primary Aims

To establish longitudinal and reference percentile curves for:
- primary & secondary impairments & health conditions by GMFCS levels
- participation in family & recreational activities & self-care by meaningful classifications (including gross motor, hand & communication functions)

Methods

Design: prospective cohort study
Targeted Sample: 875 children with CP
18 months to 10 years at study outset
Data collection:
- 5 data collection points on 600 children (initial, 6, 12, 18 and 24 months) 424 completed
- 2 data collection points on 875 children (initial and 12 months) 656 completed

Expected Outcomes

- To anticipate current and future strengths and needs of children with CP
- To understand whether individual children are changing ‘as expected’, ‘more than expected’ or ‘less than expected’
- With evidence from both the Move & PLAY and On Track Studies, we will be able to:
  - proactively plan efficient services and supports to optimize outcomes
  - better direct future classification of children with CP
  - better direct future research on the relationship of services to outcomes
Identify important outcomes

Determine determinants of outcomes

Assess knowledge about the progress of outcomes and participation

Acquire knowledge about the distribution across age

Acquire knowledge of impact of changes in time, set goals, and make decisions about interventions

= Powerful evidence for evaluating the progression of children over time

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Drawing the curves: Developmental Trajectories and Centile Curves

Lisa Avery & Steve Hanna

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Purpose

- Create Development Trajectories for each area of function to show expected change over time
- Create Centile Curves to measure function relative to peers and to determine if children are developing ‘onTrack’
Children were classified based on GMFCS level
For balance, strength, endurance, participation, range of motion separate curves were developed for each GMFCS level
Found the curve to best describe development over time

Raw Balance Data (ECAB)
GMFCS Level I

Developmental Trajectory
For Balance
GMFCS Level I
Raw Range of Motion Data (SAROMM)
GMFCS Level V

Development Trajectory
For Range of Motion
GMFCS Level V

Methods: Centile Curves
- Children were classified by GMFCS
- Examined distribution of scores at each age
- Scores are transformed to percentiles to express function relative to other children
- We treated the data cross-sectionally using measurements 1 year apart
Raw Balance (ECAB) Data
GMFCS Level I
for Centile Curves

Centile Curves for Balance
GMFCS Level I

Raw Range of Motion Data
(SAROMM) GMFCS Level V
For Centile Curves
Centile Curves for Range of Motion  
GMFCS Level V

Methods: On Track Change

- Calculated centile scores at baseline and 12 months.
- Examined how much change in centiles is typical.
- Children are changing as ‘expected’ if only 20% of children change more or less.

Results

- Development Trajectories:
  - 8 main outcomes per GMFCS level
  - 4 active physical outcomes on smaller sub-group
- Centile curves for 8 main outcomes per GMFCS level
- Estimated ‘usual’ amount of change over a one-year period.
Developmental Trajectories

Longitudinal Data
3-5 assessments/person
These curves have a functional form that describes the development of a typical child over time.
Inform us how development progresses with age

Centile Curves

Data are treated as cross-sectional.
There is no functional form to the curves, they are based on the distribution of the data.
The goal here is to describe how a child is performing relative to peers

1 year Centile Change

Looks at the range of change in centile score over a one year period.
Average change over one year is small – but there is a lot of variation.

<table>
<thead>
<tr>
<th>I-CAST Level</th>
<th>Level I</th>
<th>Level II</th>
<th>Level III</th>
<th>Level IV</th>
<th>Level V</th>
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<tr>
<td>N</td>
<td>217</td>
<td>147</td>
<td>73</td>
<td>116</td>
<td>103</td>
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<tr>
<td>mean</td>
<td>3.2</td>
<td>-0.4</td>
<td>3.2</td>
<td>5.1</td>
<td>3.7</td>
</tr>
<tr>
<td>sd</td>
<td>16.6</td>
<td>17.1</td>
<td>16.3</td>
<td>17</td>
<td>18.5</td>
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<td>25-75%</td>
<td>-2, +12</td>
<td>-10, +9</td>
<td>-4, +9</td>
<td>-7, +14</td>
<td>-7, +13</td>
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<tr>
<td>10-90%</td>
<td>-18, +25</td>
<td>-23, +19</td>
<td>-14, +22</td>
<td>-14, +29</td>
<td>-15, +29</td>
</tr>
</tbody>
</table>
Background:

Measure of Gross Motor Function
Classification of Gross Motor Function

Gross Motor Function Measure: GMFM-66
(Russell et al. 2002)
Measures change in motor function of children CP

Gross Motor Function Classification System
(GMFCS) and GMFCS E&R
(Palisano et al. 1997; 2008)
Classifies children with CP into one of five levels

Background:

Longitudinal Growth Curves

Background:

Reference Percentile Curves and Interpretive System
Collaborative Developmental Monitoring
Optimal Individualized Services

Child & Family Engagement

- A right
- Actively invested and involved in the client role in an intervention process
  - Being ready (receptive and hopeful), willing (committed), and able to participate in the intervention (confident)
- Optimizes outcomes

Motivational Theories and Frameworks

Self-determination Theory (Deci & Ryan, 2008)
Attend to basic psychological needs [autonomy (control & choice), relatedness (connected & supported), competence] > fosters motivation, engagement, and effectiveness of intervention
**Family Preferences and Priorities**

- **Process**
  - How do the families want to be involved?
  - How do the families want to receive information?
- **Outcomes**
  - What goals are meaningful and important to the family?

**Collaborative Practice**

- Goal-Setting
- Child Family Providers Together
- Intervention Planning
- Progress Monitoring
- Examination
- Evaluation

**Engaging Families**

- Builds a relationship
- Authenticates the data
- Provides opportunity to
  - Explain concepts
  - Discuss what child is ready to learn next
  - Enhance family’s capacity to support their child
  - Enhance child’s self-determination
Key Principles

- Relationship-based
- Understanding of the child and family
- Meaningful conversation
- Strength-based
- Individualized

Prevention and Health Promotion

- Share information with the child and family regarding
  - Body structures and functions
  - Healthy behaviors
  - Health management approach

Collaborative Decisions

- What measures to use
- How do child and family will be involved in the examinations and progress monitoring
- How frequently to administer measures
- How to document and share findings
  - Understandable and useful
**Additional Recommendations**

- Track progress on individualized goals of meaningful activities
- For Child Engagement in Daily Life Measure
  - Discuss items to understand context for child and family
- Consider other measures as indicated

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**How do individuals with cerebral palsy and their families prefer to receive and use evidence-based information?**

Tianna Deluzio, MSc

Funded through a research assistantship through the Canadian Institutes of Health Research Grant (MOP-119276)

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**Methods**

- Recruit participants
- Collect Data
  1. Demographic Q
  2. Pre-Interview Q
  3. Interviews
- Disseminate results to participants
- Memosing
- Thematic creation
- Initial coding
- Analyze data
- Focused coding
Participants

10 families – dyads or triads

<table>
<thead>
<tr>
<th>Children</th>
<th>Parents/Guardians</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ages 7-17</td>
<td>• Ages 32-64</td>
</tr>
<tr>
<td>• 5 females, 5 males</td>
<td>• 10 females, 3 males*</td>
</tr>
<tr>
<td>• 9/10 white*</td>
<td>• 8/10 white*</td>
</tr>
<tr>
<td>• GMFSC levels I-IV*</td>
<td>• Ranged income &amp; edu. levels</td>
</tr>
</tbody>
</table>

* = limitation

Results: Themes from Interviews

1. Child Preferences for Information Format
   - Visual information with colours, pictures and/or charts
   - Point form and straightforward

2. Parent Preferences for Information Format
   - Combination of text and visual information
   - One to two pages, point form where possible
   - Format that encourages two-way communication
Results

3. Type of Info Children Want to Receive

Interviewer: “So you’ve never gotten information just for you?”

Child: “No it’s always…it says my name on it, but it’s really just for mom and dad...It has my name on it, but then it’s not really for me.”

Parent: “[Laughs] That’s true, I’ve never thought about it ’til right this minute...there’s never been anything that’s for her.”

Results

4. Type of Info Parents Want to Receive

• Child’s “strengths and weaknesses”
• Child’s function in context of children with CP of “similar level”
• Child’s prognosis
• Community resources

Results

5. Other Families as an Information Sources

Parent 1: “So it’s not from doctors that we heard it, but through a friend whose boy had it done and it was that family’s story, meeting him, that said okay we want to do this.”

Parent 2: “Cause there’s a lot more to life than just sitting in a doctor’s office.”
Results

6. Not Receiving Enough Information

Parent: “If your child has autism…I feel like there’s more concrete information about what autism looks like and how that may impact [the child], but because [child] has multiple diagnoses and things happening, it’s hard to [understand]…is this related to the CP? Sensory issues? Cortical vision issues? It’s difficult to find information because she has those multiple diagnosis, it’s not just one.”

Results

7. Being Inclusive and Respectful

Parent: “Therapists need to be conscientious when they’re sharing info in front of the kids. Because sometimes the kids only hear certain pieces and they [get] overwhelmed.”

Child: “Tell the kids first, before you even tell the parents.”

Parent: “Tell it in a frame that the kids understand too. At times I would find that they would talk like he wasn’t even there. It’s like, well, just ask him.”

Report Card Mock-Ups

Supporting Your Child's Success

Your child’s success does not end with report cards. At [School Name], we offer a variety of resources to support your child’s academic and personal growth, including:

- **Parent-Teacher Conferences:** Regular opportunities for parents and teachers to discuss the child’s progress and any areas for improvement.
- **Individualized Education Plans (IEPs):** Tailored to each child’s unique needs and goals.
- **Behavioral Support Services:** Assistance in managing challenging behaviors and developing strategies for success.
- **Academic Support Services:** Extra help and resources to support learning.
- **Counseling Services:** Guidance and support for emotional and social development.

These strategies are designed to work in concert with your child’s report cards to ensure a comprehensive approach to their education and development. For more information, please contact your child’s teacher or the school’s administration.
Walking Through a Case Study: Naiwen

- At the first study visit, Naiwen was 10 years of age; 12 months later she was 11
- She is at GMFCS II, MACS II and CFCS I, with diplegia
- Scores on the 8 measures, and their percentiles for GMFCS level II are provided next

<table>
<thead>
<tr>
<th>Measure</th>
<th>Visit 1</th>
<th>Visit 2</th>
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<tr>
<td></td>
<td>Score</td>
<td>Percentile</td>
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<tr>
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<tr>
<td>FSA</td>
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<td>6-MWT</td>
<td>823</td>
<td>15</td>
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<td>EASE</td>
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<table>
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<tr>
<td></td>
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<td>%</td>
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<td>%</td>
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### Checking Up and Checking In to Keep on Track

This tool is used regularly to ensure the child is meeting potential goals set by parents and/or child. Regular check-ups and check-ins are important to keep the child's progress on track. The tool is designed to help parents understand their child's progress and work together to set new goals as necessary. The tool includes sections for notes and recommendations, as well as areas for tracking progress in different areas.

#### Notes and Recommendations

- Name: [Name]
- Age: [Age]
- Goals: [Goals]

**Note:** Parents can add notes and recommendations to track progress and set new goals.

#### Balance

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<th>Item</th>
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<th>2</th>
<th>3</th>
<th>4</th>
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| Recommendations
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<tbody>
<tr>
<td>Set new goals based on current progress.</td>
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#### Strength

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| Recommendations
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#### Range of Motion

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| Recommendations
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<tr>
<td>Improve flexibility and range of motion exercises.</td>
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#### Endurance

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| Recommendations
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<tr>
<td>Increase endurance through regular physical activity.</td>
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#### Overall Health

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<td>Maintain a healthy lifestyle.</td>
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#### Participation in Self-Care Activities

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| Recommendations
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<tr>
<td>Encourage self-care routines.</td>
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#### Participation in Family and Recreational Activities

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| Recommendations
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<td>Engage in family and recreational activities.</td>
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#### Other

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<td>Address any other concerns.</td>
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The tool is designed to be used regularly and adjusted as needed to ensure the child's progress is on track. Parents should discuss any concerns or changes with their child's healthcare provider. The tool includes sections for notes and recommendations to track progress and set new goals.

---

For more information, visit the Dr. Frank Study website: [website link].
Utility of results from Move & PLAY?

Outcome | Determinants | Levels I and II | Levels III, IV and V
--- | --- | --- | ---
Motor Function (Bartlett et al. 2014a) | | | |
1st Impairments | NS | 0.20 | 0.26
2nd Impairments | NS | 0.20 | 0.26
Adaptive Behaviour | NS | 0.20 | 0.26
Community Programs | 0.13 | NS | |
Self-Care (Bartlett et al. 2014a) | | | |
Physical Abilities | | | |
1st Impairments | NS | 0.25 | 0.26
Health | 0.30 | 0.18 | 0.57
Adaptive Behaviour | 0.30 | 0.18 | 0.57
Community Programs | NS | 0.09 | 0.09
Services and Needs | 0.20 | NS | |
Recreation and Leisure (Ehrwein et al. 2015) | | | |
Motor Abilities | | | |
1st Impairments | NS | 0.25 | 0.26
Health | 0.30 | 0.18 | 0.57
Adaptive Behaviour | 0.30 | 0.18 | 0.57
Community Programs | 0.13 | 0.09 | 0.09
Attributes of Caregivers | 0.25 | 0.24 | 0.24

Break-out Groups & Large Group Discussion

Relevance

Creating the Future: Engaging Children with Cerebral Palsy in the Circle of Care

canchild.ca/creatingthefuture
Large Group Reflections

What are your thoughts about the potential utility of this approach to developmental monitoring?

Suggestions for us as we engage in dissemination activities?
Key References


Key References


Key References


