10-1-2018

A Collaborative Approach to Decision Making Through Developmental Monitoring to Provide Individualized Services for Children With Cerebral Palsy.

Doreen J Bartlett

Sarah W McCoy

Lisa A Chiarello

Lisa Avery

Barbara Galuppi

See next page for additional authors

Citation of this paper:

"This is a pre-copyedited, author-produced version of an article accepted for publication in Physical Therapy following peer review. The version of record Bartlett DJ, Westcott-McCoy S, Chiarello L, Avery L, Galuppi B, and the On Track Study Team (2018). A collaborative approach to decision-making through developmental monitoring to provide individualized services for children with cerebral palsy, 98(10), 865-875 is available online at: https://academic.oup.com/ptj/article/98/10/865/5049484".

The On Track Study was funded by: The Canadian Institutes of Health Research, MOP-119276 and The Patient-Centered Outcomes Research Institute, CE-12-11-5321.

The On Track Study Team includes Dr. Doreen Bartlett, Faculty of Health Sciences, Western University.

Authors
Doreen J Bartlett, Sarah W McCoy, Lisa A Chiarello, Lisa Avery, Barbara Galuppi, and On Track Study Team

OXFORD UNIVERSITY PRESS | Physical Therapy
Journal of the American Physical Therapy Association

A collaborative approach to decision making through developmental monitoring to provide individualized services for children with cerebral palsy

Journal:	*Physical Therapy*
Manuscript ID	PTJ-2017-0510.R1
Manuscript Category:	Perspective
Section:	Pediatrics
Keywords:	Cerebral Palsy, developmental monitoring, individualized care, collaboration

A collaborative approach to decision-making through developmental monitoring to provide individualized services for children with cerebral palsy

Doreen J. Bartlett, BSc (PT) PhD, Professor Emerita, School of Physical Therapy,

Western University, 1588 Elborn College, London, Ontario, Canada N6G 1H1.

Address all correspondence to Dr. Bartlett at djbartle@uwo.ca

Sarah Westcott McCoy, PT PhD, Department of Rehabilitation Medicine,

University of Washington, Seattle, Washington

Lisa A. Chiarello, PT PhD, Department of Physical Therapy and Rehabilitation Sciences,

Drexel University, Philadelphia, Pennsylvania

Lisa Avery, Msc, Statistical Consultant, Orillia, Ontario, Canada

Barbara Galuppi, BA, Project Coordinator, CanChild Centre for Childhood Disability Research,

McMaster University, Hamilton, Ontario, Canada

And the On Track Study Team

Abstract

Currently 199 words

In this perspective paper, we suggest a process to improve **physical and occupational** therapists' and families' collaboration to provide appropriate, efficient, and effective evidence-based services to improve motor function, self-care performance and participation in family and recreation activities for children with cerebral palsy (CP)**. This process** is informed by two multi-site prospective cohort studies (Move & PLAY and On Track). The heterogeneity of children with CP is described, limiting the utility of evidence from randomized controlled trials and systematic reviews to inform service planning for children with CP. An evidence-based alternative using prospective cohort studies that produce knowledge of determinants of outcomes important to children and families and methods for developmental monitoring using longitudinal developmental and reference percentile curves to inform individualized care is suggested. Guiding questions are provided to explore how knowledge of determinants and developmental monitoring can inform family-centered, collaborative, strengths-based and focused service programs to support early development and function. Although this perspective paper is focused on children with CP, the research approach described for collection of useful information and the clinical method of data use may be helpful for people with other heterogeneous chronic health conditions in which **physical and occupational** therapists face similar challenges.

Manuscript word count: 4791

In this perspective **paper**, we explore the challenge that **physical and occupational** therapists face when attempting to use evidence of effectiveness of interventions to support people with heterogeneous health conditions, such as cerebral palsy (CP). We define CP and describe how variable children with this diagnosis are. We then selectively review published literature that highlights difficulties in using information from randomized controlled trials (RCTs) and systematic reviews to inform service planning for children with CP. We propose an evidence-based alternative using prospective cohort studies that produce knowledge of determinants of outcomes important to children and families and methods for developmental monitoring using longitudinal and reference percentile curves to inform individualized care. We provide guidelines to explore how this evidence can be used to plan family-centred, collaborative, strengths-based services to support development and function.

Cerebral Palsy and Heterogeneity

> *Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture ….. often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.*[1, pg9]

Traditionally, children with CP have been described by type of motor disorder or distribution of involvement. Recently, functional classification systems have been identified to be more useful and reliable than systems based on impairments.[2] The Gross Motor Function Classification System (GMFCS),[3,4] the Manual Ability Classification System (MACS),[5] and the Communication Function Classification System (CFCS)[6] are 5-level ordinal classification systems to categorize usual performance in gross motor, hand, and communication function in every-day life **with evidence supporting their reliability and validity**. In all systems, level I represents the highest function and level V the lowest. Together, these systems contribute significantly in understanding the variable manifestation of CP**. They** also provide enhanced

communication among team members (including families), a sharper focus on function, and assistance with both realistic goal setting and intervention planning.

Hidecker et al.[7] were the first to describe the relationships among these three systems. The most common profile among 222 children was all being in level I, representing ten percent of the sample. They also found GMFCS-II, MACS-II, and CFCS-I to represent five percent of their sample. Our group[8] recently replicated this study with 671 children and confirmed that GMFCS-I, MACS-I and CFCS-I was the most common profile (eleven percent), with ten percent occurring in GMFCS-I, MACS-II, and CFCS-I, and six percent in GMFCS-II, MACS-II, and CFCS-I. The remaining 73 percent of the children were scattered in 69 additional cells, each with a frequency of under five percent, highlighting the heterogeneity of gross motor, hand, and communication functions.

Although CP is primarily a motor disorder, individual children also experience a range of associated impairments in body functions and health conditions. In addition to investigating the inter-relationships among the three systems, we also determined the number and impact of associated health conditions of selected profiles[8] using the Health Conditions Questionnaire.[9] Although both the average number and impact of health conditions increased as function was more limited, the range of both indices varied considerably, further highlighting the relative uniqueness of individual children.

In additional efforts to categorize children with CP more comprehensively **than is possible using the GMFCS, MACS, and CFCS alone, we investigated use of other key features of CP. These features included** measures of spasticity, balance, distribution of involvement, strength, range of motion, endurance, and impact of health conditions**. W**e establish**ed** five levels of functioning **using two techniques:** a summative, quintile approach and cluster analysis.[10] **In the quintile approach, we simply summed the total scores of all measures, divided the ranked grand total scores into five groups of children with successively lower scores, and described the central tendency and variability of each**

of the five groups. Using cluster analysis, children were organized into five groups based on commonly occurring clusters of levels of the additional key features. These two **techniques** yielded similar groups of children, both ranked by functional ability. The ranked solution was expected in the summative, quintile approach as it is inherent in the method used. A ranked solution was not expected when using cluster analysis**. Our results** differ**ed** from results in other groups of children (e.g. developmental coordination disorder, in which distinct subgroups of children with different constellations of strengths and relative limitations were identified).[11] Although average function decreased from the most to least functional groups, there was significant variability in scores on individual measures within each of the five groups, with considerable overlap among groups**. This** finding, **specifically the variability in scores within each group studied, as well as overlap among groups,** has been observed by others investigating scores across GMFCS levels.[12] These results again highlight the heterogeneity of children with CP. **As a result of this preparatory work, w**e concluded that although it is possible to develop a more comprehensive classification, it was not clinically useful. Instead, we believe that routine comprehensive assessments are essential with each measure interpreted separately to understand individual children's relative strengths and limitations.

Difficulties in applying knowledge from intervention studies to inform decision making about interventions for people with cerebral palsy

Traditionally, therapists look to evidence from RCTs and systematic reviews as evidence of effectiveness of interventions. Novak and colleagues[13] conducted a systematic review of systematic reviews of a wide variety of interventions for children with CP. Although they acknowledged CP as a complex and heterogeneous condition, they included any motor subtype, topography, or functional ability level in their analyses. Furthermore, they did not acknowledge the limitations of RCTs for providing useful evidence of effectiveness of interventions for this heterogeneous group of children.

Responses to this review were many. **Critiques** highlight**ed** the heterogeneity of CP, the necessity to include the specific clinical features of the sub-population studied, and the importance of these aspects to clinical decision-making about interventions to meet the needs of individual children.[14-17] The goal of establishing evidence of treatment efficacy for the whole population of children with CP was viewed as an over-simplification of a very complex health condition.[15] **Several authors suggested that this complexity requires consideration of details** on a case-by-case basis before appropriate interventions could be planned for individual children.[18] Similar to our view, several groups indicated their preference for prospective cohort studies to understand factors associated with children's outcomes.[16,18,19] Our research has used comprehensive rehabilitation outcomes research[20] which is structured around the World Health Organization's International Classification of Functioning, Disability and Health.[21] Comprehensive rehabilitation outcomes research is useful when one has a less uniform group of people (such as CP), when interventions are multi-dimensional and individualized, and when there are significant personal and environmental influences on outcomes.

In their response to the letters to the editor, Novak and colleagues[22] acknowledged the limitations of RCTs and supported the use of alternative research designs. Furthermore, they strongly agreed with others[17] that "the essential next step for the field is to prioritize the development of in-depth, subgroup-specific, valid and patient-oriented, internationally endorsed clinical guidelines, using rigorous, accepted methodologies and involving appropriate consultation."[22,p. 405] We believe that our work is situated to contribute to this next step. Our 'consultation' has included assembling a skilled and knowledgeable research team, as well as working closely with both front-line **physical** therapists[23] and parents of children with CP.[24]

An evidence-based alternative: Prospective cohort studies

As is the case for many chronic health conditions,[25] knowledge of prognosis is essential for intervention planning for children with CP. Although CP is a non-progressive condition, functional decline by adulthood has been well reported.[26-29] Research has also suggested **that** a decline in motor function may begin earlier in life. Average developmental patterns of motor function for children have been graphed for all five levels of the GMFCS.[30] Highest levels of functioning were shown to peak when children are 7 or 8 years old, followed by a decline in motor abilities for children and youth in GMFCS levels III, IV, and V.[31] Three goals for early rehabilitation consistently identified by children with CP and their families[32,33] are to optimize motor function, prevent the development of secondary conditions or impairments that impact life-long health, and promote children's participation in their daily lives.[20,34] In our approach, we focus on children with CP from the time of diagnosis through elementary school age**. Furthermore, we** value family-centred care and a collaborative approach focusing on children's developmental strengths and environmental supports through a strengths-based perspective. We perceive prospective cohort studies to provide an alternative to RCTs in providing an evidence base for realistic goal setting and intervention planning for this heterogeneous group of children. Figure 1 contains an overview of the processes and products of our research, described in more detail next.

Knowledge of determinants of outcomes

Consistent with a focus on understanding prognostic factors to inform intervention decisions, the Move & PLAY Study (**Move**ment and **P**articipation in **L**ife **A**ctivities for **Y**oung Children with CP) was designed to test a model of determinants of gross motor function, performance in self-care, and participation in family and recreation activities.[20,34] Four hundred twenty-nine children with CP aged 18 months to 5 years of age were followed over three time points in one year. Ethical approvals were obtained by many academic and clinical institutions in this multisite study. **S**igned informed consent was obtained from all parent participants on behalf of their children.[35-37] Measures of child, family, and service factors that

are comprehensive and brief to administer, **with evidence supporting reliability and validity**, were completed by trained **physical and occupational** therapist assessors and parents. Data were analysed separately for children who were able to walk without a gait aide (i.e. GMFCS levels I&II) and for children who used either a gait aide or wheelchair for mobility (i.e .GMFCS levels III,IV&V). Resulting determinants of the three primary outcomes by functional groups are summarized in Table 1.

We believe it is useful to differentiate determinants that are modifiable from those that are not. **Stable** factors assist with realistic goal setting, while modifiable factors are potential foci for intervention. For example, if a goal is improving motor function, it is reasonable to focus interventions on improving balance and preventing secondary impairments for both groups of children using activity-focused interventions.[38] For children in GMFCS levels III,IV&V, it is also prudent to focus on fostering adaptive behaviours by encouraging and supporting children's self-awareness, motivation, and persistence.[39] Conversely, we perceive that knowledge of children's quality of movement, spasticity, and distribution of involvement are less amenable to physical **or occupational** therapy intervention and therefore assist with realistic goal setting. If a goal is enhancing self-care performance, then optimizing gross motor abilities - within a child's prognostic potential[30] – is a reasonable goal of intervention, as are promoting health and adaptive behaviour for all children and supporting a family's role in nurturing their children for those in levels III,IV,&V. Clearly, not all health conditions are modifiable. **T**hose that are **stable** assist with realistic goal setting. If a goal is enhancing participation in recreation activities, intervention should focus primarily on fostering adaptive behaviour and supporting families in nurturing their children.

An important output of the Move & PLAY Study was the development of brief, psychometrically sound measures, enabling efficient data collection of the many features of CP, an essential component of comprehensive developmental monitoring. Appendix 1 contains a description of these measures and their psychometric properties. These measures, as well as instructional videos for the Early Clinical Assessment

of Balance, the Functional Strength Assessment, and the Spinal Alignment and Range of Motion Measure are available on the Move & PLAY study website (https://canchild.ca). Appendix 2 summarizes a list of equipment recommended to complete the therapist administered assessments.

Knowledge to assist with interpretation of change over time

The Move & PLAY Study revealed *which* attributes determine motor function, performance in self-care, and participation in family and recreation activities. Next we needed to learn *how* these measures change over time and vary within groups. This issue lead to the development of the On Track Study (Developmental Trajectories of Impairments, Associated Health Conditions and Participation of Children with Cerebral Palsy), another multisite, prospective cohort study designed to develop both longitudinal and reference percentile curves. In this study, we followed 708 children with CP 18 months to 12 years of age across 1 to 5 study visits. Again, we obtained approval from multiple academic and clinical research ethics boards prior to data collection. **S**igned informed consent was obtained by parent participants. **C**hild assent was obtained from children as required by each IRB. Six hundred fifty-eight families completed two visits over one year; 424 families completed five visits over two years. At each visit, data on balance, range of motion, strength, endurance, health conditions, performance of self-care in daily life, and participation in family and recreation activities (i.e. measures described in Appendix 1, aside from the Gross Motor Function Measure (GMFM)) were collected from trained therapist assessors **(again, both physical and occupational therapists participated)** and parent respondents. For children older than 3 years of age in GMFCS levels I,II&III, data were also collected on the Six-minute Walk Test, using guidelines specifically developed for children with CP.[40] **Research evidence supports the reliability and validity of t**he Six-minute Walk Test in children with typical development[41] and children with CP 4 to 18 years-old classified as GMFCS levels I, II, or III (ICC = 0.91-0.98).[42] More information about the protocol of the On Track Study is available in a related manuscript.[43] We also obtained consensus classifications of the GMFCS, MACS and

CFCS.[44] We plotted all measures over time for each of these three classification systems and observed that for every measure, the GMFCS was the best measure for discriminating distinct functional groups. Having collected longitudinal data across all functional levels for our measures of interest we were ready to examine how children's abilities develop over time and how those abilities are distributed within functional levels.

Knowledge of average developmental trajectories of functionally distinct groups of children

Previous work resulted in the Ontario Motor Growth (OMG) Curves,[30] a set of GMFCS-specific longitudinal curves describing the change in GMFM scores[45] from 18 months to adolescence (Figure 2). Information from the OMG curves is useful to understand the prognosis for motor function for children in each of the five GMFCS levels as they develop over time, in broad brush-strokes, particularly for children older than 2 years of age for whom the GMFCS is more reliable.[3] Appropriate interventions can then be planned for children in different GMFCS levels, based on their prognosis. By focusing on prognosis, knowledge of longitudinal trajectories increases efficiency of service delivery. For example, for most older children at GMFCS level III, community ambulation is not a realistic goal. Whereas household ambulation is possible and encouraged, community mobility is generally more effective and efficient using some form of **wheeled or** powered mobility.

In the **O**n Track study, a similar process was used to create longitudinal trajectories for children grouped by GMFCS level for each of the measures described in Appendix 1, as well as the Six Minute Walk Test. Hierarchical models were used to predict the average change in the measures over time using longitudinal data. All measures were described by either a simple linear function or by an asymptotic function in which scores approach a stable limit over time. These analyses allow prediction of the developmental course according to functional level, with scores being expected to improve, decrease or remain stable as children age. **T**hese expectations can vary by functional level. Once available in the public

domain, new knowledge from the On Track Study will provide guidance for average development for children with CP aged 18 months to 12 years of age for balance, range of motion, muscle strength, endurance, impact of health conditions, performance in self-care, and participation in family and recreation activities.

Knowledge of reference percentiles of functionally distinct groups of children

Although knowledge of average development of children in each GMFCS levels is useful, there is significant within-level variability[30] (i.e. the heterogeneity issue previously described), as well as limited information to assist with interpreting both status at one point in time and change over time. As a result, reference percentile curves for motor function were developed and published.[46] Figure 3 provides an example of percentiles for GMFM data for children in GMFCS level I. The GMFM centiles were constructed using Cole and Green's LMS method.[47] In the On Track study, quantile regression was used for the same purpose. Quantile regression allows cross-sectional estimation of scores at a given age for any quantile of the sample. Quantile regression was employed because it requires no distributional assumptions and is effective in the presence of floor and ceiling effects.

To interpret the meaning of a child's score at one point in time relative to other children of the same GMFCS level and age, one can use the percentile graph of the relevant GMFCS level and identify the percentile located at the intersection of the child's GMFM score and age. For example, using Figure 3, one can readily determine that 'Gail', a five-year old child in GMFCS level I with a GMFM-66 score of 77 will be at the 50th percentile. That is, 50% of children at the same age and GMFCS level would score higher and 50% would score lower. This child is functioning in the middle of the range of motor abilities for children in GMFCS level I at this time. Families might or might not be interested in how their child compares with other children of the same GMFCS level and age. Nonetheless, this baseline value helps with understanding a

child's relative strengths and limitations across a range of measures, as well as interpretation of change over time, described next.

Perhaps more useful than interpreting a score at one point in time is a system developed to understand the meaning of change in GMFM scores over time. Previously, we published a table describing the mean changes in percentiles over two assessments, one year apart, along with the range of change scores observed in the middle 50% and 80% of the sample (Table 2). Using the same example provided in the previous paragraph, this table helps to interpret the magnitude of change over time. If at six years of age, 'Gail' attained a GMFM score of 86, she would now be at the 75th percentile: a gain of 25 percentiles. From Table 2 we can see that most children (80%) changed between -20 and +20 percentiles; 'Gail' changed more than this so we can interpret this as 'progressing better than expected'. However, if 'Gail's' score at age six dropped to 74, she would be in the 25th percentile at age six, a full 25 percentiles lower than the year before. This would be interpreted as 'progressing less than expected'. Referring to how much change is experienced by the central 80% of the sample helps to identify potential strengths and areas of concern while recognising the large variation in centiles over a one-year period. Finally, GMFM scores at six years between 76 and 84 are associated with roughly the 30th and 70th percentiles, representing change within $\pm$ 20 percentiles of the previous year's scores, indicating that she is 'progressing as expected'. Clearly, intervention planning to support motor function would be different in each of these scenarios.

As a result of the On Track Study, as for motor function,[46] we now have a system to understand children's change over time in balance, range of motion, strength, endurance, impact of health conditions, performance in self-care, and participation in family and recreation activities. We believe that this approach goes a long way to understanding each child's uniqueness (i.e. their relative strengths and limitations across developmental domains), both in the context of determinants as well as outcomes, which in turn assists with intervention planning.

Utility of the Results from the Move & PLAY and On Track Studies

We encourage therapists to have collaborative discussions with children, youth, and family members to ascertain what scores obtained at one point in time and change in scores over time mean to them. **These discussions should be grounded by the child and family goals** related to motor function, performance in self-care, and participation in family and recreation activities. **It is important for therapists and families to consider aspects of the child, family, and services that may have contributed to the changes. Table 3 contains a list of questions and topic areas to guide collaborative discussions. We suggest that all therapists who provide services to children with CP should consider whether and how they can use these measures and systems of interpretation to plan services in collaboration with families and other team members. Roles may differ across countries, and geographic regions within countries, as well as contexts of service delivery (e.g. early intervention, clinic, out-patient, or school settings).**

As a basis for collaborative discussions, we are currently exploring templates for reporting the results of this system of developmental monitoring to children and families (and others).[48] We envision recommending reports that vary in complexity to match the information needs of different groups. A simple pictorial format illustrating the constructs measured and the 'bottom line' result (i.e. progressing 'as', 'more', or 'less' than expected through the use of emojis) is perceived to be most suitable for young children and those with cognitive limitations. A mid-level format with the names of the measures, the raw scores, and their interpretations of change over time might be useful to older children who are likely candidates to assume their own health monitoring as they transition into the teenage years and adulthood. This mid-level format might also be useful for some families who prefer brief reports. Parents have suggested to us that they might also prefer to share this level of detail with other family members (e.g. grandparents) and with staff in their children's schools. The highest level of detail includes a multipage report with plotted

percentiles and transparency around changes in percentiles over time, before providing the 'bottom line'. Some parents have suggested that they want 'all possible information'.[48] Regardless of the format of presentation of the scores, discussion is encouraged.

Consistency with Current Approaches to Pediatric Rehabilitation

The approach described in this manuscript should be implemented in a family-centered manner to ensure that it matches family preferences and priorities.[49] Therapists are encouraged to be strength-based and individualize the process for each family context.[50] As part of the developmental monitoring and intervention planning process, it is important for therapists to engage families in a conversation to learn about their family context and collaborate with them to identify individualized goals. Based on these goals and consideration for prevention of secondary impairments and health promotion, the therapist and family can decide together what measures need to be administered, how the family wants to be involved in the monitoring, how frequently the monitoring needs to be done, and how the family wants to receive the findings.

Family engagement, active investment, and involvement in the intervention process is a family's right and we believe essential to optimizing outcomes.[51] Engaging families in the examination, evaluation, and progress monitoring process builds a relationship; authenticates the data; and provides an opportunity for therapists to explain concepts, discuss with families what a child is ready to learn next, and enhance family capacity to support their child's development. Therapists provide information in a manner that is understandable and useful for families.

We present several recommendations to honour a family-centered approach to assessment process. Monitoring standardized outcomes does not take the place of tracking progress on individualized goals of meaningful activities within the context of the child's daily life. For the standardized measures completed by parent report, (Health Conditions Questionnaire, Child Engagement in Daily Life, and the

Early Activity Scale for Endurance), we encourage therapists to discuss the items with the family to obtain additional qualitative information to guide intervention planning. As an example, understanding parent perspective on why their child plays infrequently with other children (whether it is secondary to limited time for playdates, unavailability of playmates, or child's hesitation to join friends on the playground due to mobility issues) will have direct implications on deciding if the intervention focus is on fostering the child's abilities or on modifying the environment. For the measures administered to the child, some families may want to assist with the items, serve as the recorder, or provide relevant information regarding how the child performs in other contexts. Engaging families in the assessment and monitoring process enriches the meaningfulness of the experience and optimizes the usefulness of the information for effective and efficient intervention planning.

Limitations and Future Research

Several limitations are evident in our research to date. First, the model of determinants of motor function, performance in self-care, and participation in family and recreation activities was tested only on children with CP between the ages of 18 months and 5 years of age. Measures developed in the context of the Move & PLAY study were initially validated for use only with younger children. In the On Track Study, we tested the psychometric properties for children as old as 12 years. **Additional items were added to the** Child Engagement in Daily Life Measure **and it** was **subsequently** re-Rasched **(i.e. the item difficulty order was re-evaluated;** manuscript in preparation). The Health Conditions Questionnaire, the Early Activity Scale for Endurance, the Early Clinical Assessment of Balance and the Functional Strength Assessment have only been validated for use with younger children with CP. Several measures from Move & PLAY that were not included in the On Track Study were those that have not yet been abbreviated and revised to be clinically feasible.

Future research should focus on development of brief and psychometrically sound measures of both children's adaptive behaviour and attributes of families, as well as testing both the psychometric properties of the measures described above and the model of determinants of gross motor function, performance in self-care, and participation in family and recreation activities among children with CP 6 to 12 years of age. We also believe that an important area for future inquiry is evaluation of strategies to promote adaptive behaviour. Qualitative research, as well as detailed case studies, are recommended to enrich our understanding of how to individualize developmental monitoring based on the context of the family and the goals that are meaningful to the child. Finally, knowledge from prospective cohort studies can inform future RCTs by clarifying the natural progression of various aspects of function and determining reasonable outcomes, allowing homogeneous subgroups to be identified.

Conclusions and Relevance

A collaborative approach to decision-making through developmental monitoring using results from two prospective cohort studies provides a structured, evidence-based method to monitor change over time of children with the heterogeneous health condition of CP. This method enables ascertainment of relative strengths and limitations in key developmental domains as a means to plan appropriate individualized care. Using such an approach is anticipated to enhance both efficiency and effectiveness of rehabilitation services. This approach is consistent with the American Physical Therapy Association's notion of an 'annual check-up' (http://www.apta.org/AnnualCheckup/), extending the practice of broad health screening and health promotion to comprehensive monitoring to enhance function and prevent secondary impairments. The parent research team members of the On Track Study created a pair of videos related to collaborative check-ups and conversations with health care providers to help focus rehabilitation and health care services ('Checking in and Checking up' available at (https://www.canchild.ca). As have others,[52] we advocate for the practice of periodic assessment, also described as "routine clinical assessment'.

Implementation of routine assessments is facilitated by 1) motivation from care providers and management to adopt the practice, 2) appropriate training, supervision, and support from clinical experts, 3) effective, ongoing, tailored, and timely communication among stakeholders (including families), 4) appropriate clinical space, assessments kits, and time, and 5) alignment of assessments with families' priorities.[52]

We also advocate for use of this structured approach to educating physical therapy students and novice therapists to support children with CP and their families comprehensively and appropriately. Comprehensive developmental monitoring encourages therapists to engage in deliberate practice enabling planning and implementation of relevant, individualized intervention.[50] Recent graduates can be further supported in providing appropriate services to this complex and heterogeneous population through the use of ongoing discussion of cases with coaching and mentoring from acknowledged clinical experts.[53]

This approach to serving children with CP is consistent with a 'health equity' perspective of health care in which appropriate individualized care is a key component. Health equity allows individuals to reach their full health potential and receive high quality care that is fair and appropriate to them and their needs, no matter where they live, what they have, or who they are.[54] Although our interest is in developing an evidence-based approach to supporting individualized care for children with CP, we believe that this approach using prospective cohort studies may be of use to researchers and therapists serving people with other complex, chronic, and heterogeneous health conditions.

Acknowledgements

We acknowledge additional On Track Study Team members including academic researchers: Robert J. Palisano, Lynn M. Jeffries, Alyssa LaForme Fiss, Steven Hanna, and Jan Willem Gorter; US project coordinator Monica Smersh; and parent researchers: Lisa Diller, Paula Drew, Nancy Ford, Marquitha Gilbert, tina hjorngaard, Kimberly Rayfield, and Barbara Sieck Taylor. The Move & PLAY Study was funded by the Canadian Institutes of Health Research (CIHR; MOP 81107) and the US Department of

Education, National Institute for Disability and Rehabilitation Research (H133G060254). The On Track Study was funded by CIHR (MOP # 119276) and the Patient Centred Outcomes Research Institute (Grant # 5321). The statements presented in this work are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Conflict of Interest: Both Lisa Avery and Barb Galuppi received salary support from CIHR and PCORI for their work related to the On Track Study.

References

1. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol.* 2007; 49 (Suppl. 109):8-14.

2. Cans C. Description of children with cerebral palsy. Steps for the future. *Dev Med Child Neurol.* 2012; 54:679.

3. Palisano R, Rosenbaum P, Walter S, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*. 1997;39:214-23.

4. Palisano RJ, Rosenbaum P, Bartlett D, Livingston MH. Content validity of the Expanded and Revised Gross Motor Function Classification System. *Dev Med Child Neurol.* 2008:50:744-50.

5. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy. Scale development and evidence of validity and reliability. *Dev Med Child Neurol.* 2006;48:549-54.

6. Hidecker MJC, Paneth N, Rosenbaum PL, et al. Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy. *Dev Med Child Neurol.* 2011; 53:704-10.

7. Hidecker M, Ho N, Dodge N, et al. Inter-relationships of functional status in cerebral palsy: Analyzing gross motor function, manual ability, and communication function classification systems in children. *Dev Med Child Neurol.* 2012; 54:737-42.

8. Bartlett D, Dyszuk E, Galuppi B, Gorter JW. Inter-relationships of functional status and health conditions in children with cerebral palsy: A descriptive study. *Pediatr Phys Ther.* In Press.

9. Wong C, Bartlett DJ, Chiarello LA, *Chang HJ*, Stoskopf B. Comparison of the prevalence and impact of health problems of preschool children with or without cerebral palsy. *Child Care Health Dev,* 2011; 38:128-38.

10. Jeevanantham D, Bartlett D. Subgrouping children with cerebral palsy from a broader perspective using two methods. *Physiotherapy Theory and Practice.* In Press.

11. Jeevanantham D, Bartlett D. Perspectives on classification of selected childhood neurodisabilities. *Dev Neurorehabil,* 2017;20:194-206.

12. Oeffinger D, Gorton G, Bagley A, et al. Outcome assessments in children with cerebral palsy, part 1: Descriptive characteristics of GMFCS levels I to III. *Dev Med Child Neurol.* 2007;49:172-80.

13. Novak I, McIntyre S, Morgan C, et al. A systematic review of interventions for children with cerebral palsy: State of the evidence. *Dev Med Child Neurol.* 2013; 55:885-910.

14. Love S, Blair E. The right interventions of each child with cerebral palsy. Letter to the Editor. *Dev Med Child Neurol.* 2014;56:392.

15. Theologis T. Comments on a systematic review of interventions for children with cerebral palsy. Letter to the Editor. *Dev Med Child Neurol.* 2014;56:393-4.

16. Rutz E, Döderlein L, Svehlik M, Vavken P, Gaston MS. Critical considerations regarding 'the state of the evidence' for interventions in children with cerebral palsy. Letter to the Editor. *Dev Med Child Neurol.* 2014;56:397-8.

17. Autti-Rämö I, Eliasson AC, Forssberg H. How to bridge the gap between systematic reviews and clinical guidelines? Letter to the Editor. *Dev Med Child Neurol.* 2014;56:398-400.

18. Firth GB. Danger of limiting interventions for children with cerebral palsy to level one evidence. Letter to the Editor. *Dev Med Child Neurol.* 2014;56:393.

19. Thomason P, Graham HK. A systematic review of interventions for children with cerebral palsy: State of the evidence. Letter to the Editor. *Dev Med Child Neurol.* 2014;56:390-1.

20. Bartlett DJ, Chiarello LA, McCoy SW, et al. The Move & PLAY study: An example of Comprehensive Rehabilitation Outcomes Research. *Phys Ther*, 2010; 90:1660-72.

21. World Health Organization. *International Classification of Functioning, Disability, and Health.* Geneva: author; 2001.

22. Novak I, McIntyre S, Morgan C, et al. Novak et al. reply. *Dev Med Child Neurol.* 2014; 56:403-6.

23. Bartlett DJ, Palisano RJ. Physical therapists' perceptions of factors influencing the acquisition of motor abilities of children with cerebral palsy: Implications for clinical reasoning. *Phys Ther.* 2002;82:237-48.

24. Bartlett DJ, Chiarello LA, Hjorngaard T, Sieck Taylor B. Moving from 'parent consultant' to 'parent collaborator': One pediatric research team's experience. *Disabil Rehabil.* 2017;39:2228-35.

25. Fletcher RH, Fletcher SW *Clinical Epidemiology. The Essentials*. 5th Edition. Philadelphia PA: Wolters Kluwer Health / Lippincott, Williams and Wilkins; 2014.

26. Murphy KP, Molnar GE, Lankasky K. Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol.* 1995;37:1075-84.

27. Ando N, Ueda S. Functional deterioration in adults with cerebral palsy. *Clin Rehabil.* 2000; 14:300-6.

28. Andersson C, Mattsson, E. Adults with cerebral palsy: A survey describing problems, needs and resources, with special emphasis on locomotion. *Dev Med Child Neurol.* 2001;43:76-82.

29. Bottos M, Feliciangeli A, Sciuto L, Gericke C, Vianello A. Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol.* 2001;43:516-28.

30. Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *JAMA.* 2002;288:1357-63.

31. Hanna SE, Rosenbaum PR, Bartlett DJ, et al. Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. *Dev Med Child Neurol,* 2009, 51:295-302.

32. Øien I, Fallang B, Østensjo S. Goal-setting in paediatric rehabilitation: Perceptions of parents and professionals. *Child Care Health Dev.* 2009; 36:558-65.

33. Vargus-Adams JN, Martin LK. Domains of importance for parents, medical professionals and youth with cerebral palsy considering treatment outcomes. *Child Care Health Dev.* 2010; 37:276-81.

34. Chiarello LA, Palisano RJ, Bartlett DJ, McCoy SW. A multivariate model of determinants of changes in motor abilities and engagement in self-care and play of young children with cerebral palsy. *Phys Occup Ther Pediatr.* 2011;31:150-68.

35. Bartlett D, Chiarello L, McCoy S, et al. Determinants of gross motor function of young children with cerebral palsy: A prospective cohort study. *Dev Med Child Neurol,* 2014a;56:275-82.

36. Bartlett D, Chiarello L, McCoy S, et al. Determinants of self-care participation of young children with cerebral palsy. *Dev Neurorehabil.* 2014b;17:403-13.

37. Chiarello LA, Bartlett DJ, Westcott McCoy S, et al. Determinants of participation in family and recreational activities of young children with cerebral palsy. *Disabil Rehabil,* 2016;38:2455-68.

38. Valvano J. Activity-focused interventions for children with neurological conditions. *Phys Occup Ther Pediatr.* 2004; 24:79-107.

39. King G, Imms C, Stewart D, Freeman M, Nguyen T. A transactional framework for pediatric rehabilitation: Shifting the focus to situated contexts, transactional processes, and adaptive developmental outcomes. *Disabil Rehabil*. 2017; DOI: 10.1080/09638288.2017.1309583

40. Maher CA, Williams MT, Olds TS. The six-minute walk test for children with cerebral palsy. *Int J Rehabil Res.* 2008; 31:185-8.

41. Li AM, Yin J, Yu CCW, et al. The six-minute walk test in healthy children: reliability and validity. *Eur Resp J.* 2005;25:1057-60.

42. Thompson P, Beath T, Bell J, Jacobson G, Phair T, Salbach NM, Wright FV. Test-retest reliability of the 10-metre fast walk test and 6-minutes walk test in ambulatory school-aged children with cerebral palsy. *Dev Med Child Neurol.* 2008;50:370-6.

43. McCoy SW, Bartlett D, Smersh M, Galuppi B, Hanna S. Monitoring development of children with cerebral palsy: the On Track Study. Protocol of a longitudinal study of development and services. Under review.

44. Bartlett DJ, Galuppi B, Palisano RJ, Westcott McCoy S. Consensus classifications of gross motor, manual ability, and communication function classification systems between therapists and parents of children with cerebral palsy. Letter to the Editor. *Dev Med Child Neurol.* 2016; 58:98-9.

45. Russell DJ, Rosenbaum PL, Wright M, Avery LM. *Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual.* 2nd Edition. Clinics in Developmental Medicine. Mac Keith Press: London; 2013.

46. Hanna SE, Bartlett DJ, Rivard LM, Russell DJ. Reference curves for the Gross Motor Function Measure (GMFM-66): Percentiles for clinical description and tracking over time among children with cerebral palsy. *Phys Ther.* 2008;88:596-607.

47. Cole T, Green P. Smoothing reference centiles curves: the LMS method and penalized likliehood. *Stat Med.* 1992;11:1305-19.

48. Deluzio TDB. How do individuals with cerebral palsy and their families prefer to receive and use evidence-based information to individualize services to optimize outcomes? *Electronic Thesis and Dissertation Repository*. 2017: 4627. Available at: http://ir.lib.uwo.ca/etd/4627. Accessed July 10, 2017.

49. King G, Chiarello L. Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. *J Child Neurol.* 2014;29:1046-54.

50. King G, Currie M, Bartlett D, et al. The development of expertise in pediatric rehabilitation therapists: Changes in approach, self-knowledge, and use of enabling and customizing strategies. *Dev Neurorehabil*. 2007; 10:223-40.

51. King G, Ziviani J. What does engagement look like? Goal-directed behavior in therapy. In: Poulsen A, Ziviani J, Cuskelly M, eds. Motivation and Goal Setting: Engaging Children and Parents in Therapy. London: Jessica Kingsley Publishers; 2015 pp 70-9.

52. Kerr C, Shields N, Quarmby L et al. Supports and barriers to implementation of routine clinical assessment for children with cerebral palsy: A mixed methods study. *Disabil Rehabil.* 2016; DOI: 10.1080/09638288.2016.1258736.

53. King G, Currie M, Bartlett DJ, et al. The development of expertise in pediatric rehabilitation therapists: The roles of motivation, openness to experience, and types of caseload experience. *Austral Occup Ther J.* 2008;55:108-22.

54. Health Equity Ontario. Income and Health: Opportunities to Achieve Health Equity in Ontario. Toronto: Queen's Printer for Ontario. 2016. Available at: http://www.hqontario.ca/System-Performance/Specialized -Reports/Health-Equity-Report; accessed December 20, 2016.

Tables

Table 1. Significant determinants of key outcomes in the Move & PLAY Study by functional groups.

Table 2. Change in Gross Motor Function Measure centile score by Gross Motor Function Classification System group. Adapted with permission from Hanna SE, Bartlett DJ, Rivard LM, Russell DJ. Reference curves for the Gross Motor Function Measure: Percentiles for clinical description and tracking over time among children with cerebral palsy. *Phys Ther.* 2008;88:596-607.

Table 3. Questions guiding discussions to explore the meaning of results with individual children and their families.

Figure Legends

Figure 1. Overview of processes and products of our work.

Figure 2. Gross motor development curves representing average development predicted by the Gross Motor Function Classification System. The diamonds on the vertical axis identify 4 items of the 66-item Gross Motor Function Measure (GMFM-66) that predict when children are expected to have a 50% chance of completing the item successfully. The GMFM-66 item 21 (diamond A) assesses whether a child can lift and maintain his oe her head in a vertical position with trunk support by a therapist while sitting, item 24 (diamond B) assesses whether a child can maintain a sitting position on a mat without support from his or

her armk for 3 seconds, item 69 (diamond C) measures a child's ability to walk forward 10 steps without support, and item 87 (diamond D) assesses the task of walking down 4 steps by alternating feet with arms free. Reprinted with permission from Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *JAMA.* 2002;288:1357-1363.

Figure 3. Gross Motor Function Classification System level I percentiles. Note: GMFM-66 = 66-item Gross Motor Function Measure. (we hold copyright to this figure at CanChild Centre for Childhood Disability Research)

Appendices

Appendix 1 (Supplementary File 1). Measures developed in the context of the Move & PLAY Study (either before or during – i.e. primarily for children aged 18 months to 5 years of age). All are available on the Move & PLAY study site at: https://canchild.ca/en/research-in-practice/current-studies/move-play-study-understanding-determinants-of-motor-abilities-self-care-and-play-of-young-children-with-cerebral-palsy

Appendix 2 (Supplementary File 2). Equipment needed for the therapist administered measures. All of the listed equipment can be stored in a rolling duffle bag for easy community transport.

Table 1. Significant determinants of key outcomes in the Move & PLAY Study by functional groups

Outcome		**Determinants***	**Functional Group**	
			Levels I & II	**Levels III, IV, & V**
Motor Function (Bartlett et al. 2014a)	**% variance explained⁺**		**58%**	**75%**
		Primary impairments	0.53	0.57
		Secondary impairments	0.25	0.26
		Adaptive behaviour	NS	0.20
		Participation in community programs	0.13	NS
Self-Care Participation§ (Bartlett et al. 2014b)	**% variance explained⁺**		**65%**	**75%**
		Motor abilities	0.41	0.44
		Primary impairments	NS	0.25
		Health	0.30	0.18
		Adaptive behaviour	0.20	0.12
		Attributes of family	NS	0.09
		Services met needs	0.19	NS
Participation in Recreation and Leisure (Chiarello et al. 2016)	**% variance explained⁺**		**35%**	**40%**
		Motor abilities	NS	0.18
		Adaptive behaviour	0.33	0.33
		Attributes of family	0.23	0.24
		Participation in community programs	0.17	0.24

⁺ proportion of variance of each outcome explained by significant determinants

* determinants are standardized beta weights from structural equation modelling: note that they are all presented 'positively' – i.e. primary impairments reflect better balance, better quality of movement, lower spasticity and fewer limbs and parts of the body involved; secondary impairments reflect higher strength, fewer range of motion limitations, and better endurance; adaptive behaviour is stronger adaptive tendencies; participation in community programs reflects a greater number; motor abilities reflect higher function; health reflects both a smaller number of conditions and lesser impact on daily life; attributes of family reflect more supportive tendencies; and services met needs reflects greater fit between needs and service delivery.

NS = non-significant

§ among children in GMFCS Levels III, IV and V, we also had the paradoxical finding of family-centred care being negatively associated with participation in self-care (- 0.13, $p < 0.01$)

Table 2: Change in Gross Motor Function Measure centile score by Gross Motor Function Classification System group.

	GMFCS Level				
	I	**II**	**III**	**IV**	**IV**
Sample Size	147	78	107	121	117
Mean change	3.0	-0.8	3.3	2.5	3.6
SD of change	15.6	15.5	12.4	11.8	13.2
Change in centile scores for the central 50% and 80% of the sample					
Central 50%	±10.5	±10.5	±8.4	±8.0	±8.9
Central 80%	±20.0	±19.9	±15.9	±15.1	±16.9

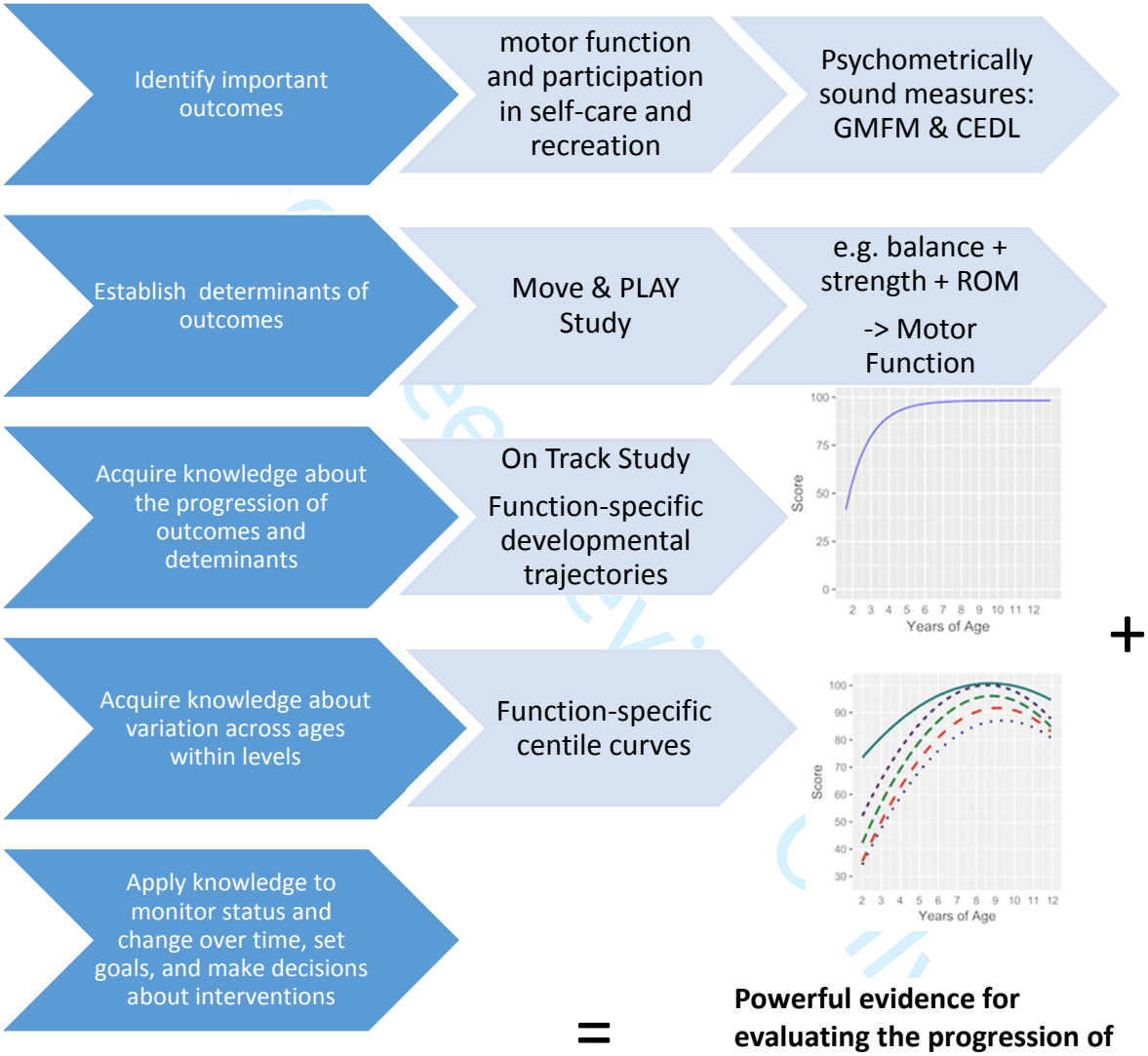
Notes: Gross Motor Function Classification System; SD – standard deviation

The median time between two assessments was 1 year. The average age was 7.5 (SD 2.6) at the first assessment point.

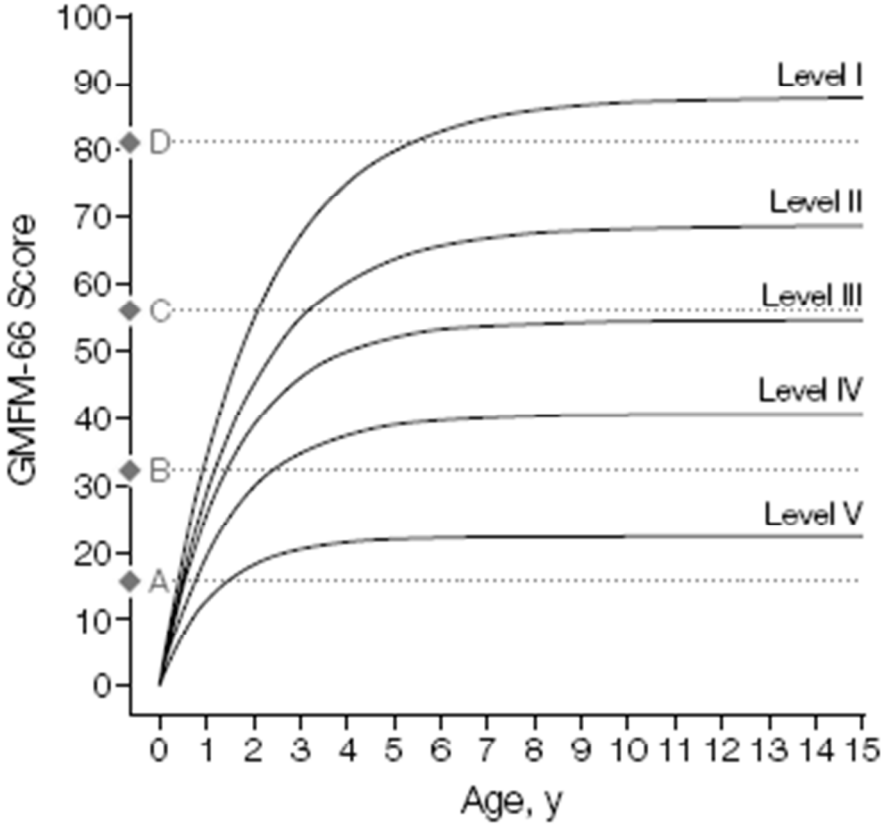
Table 3. Questions guiding discussions to explore the meaning of results with individual children and their families.

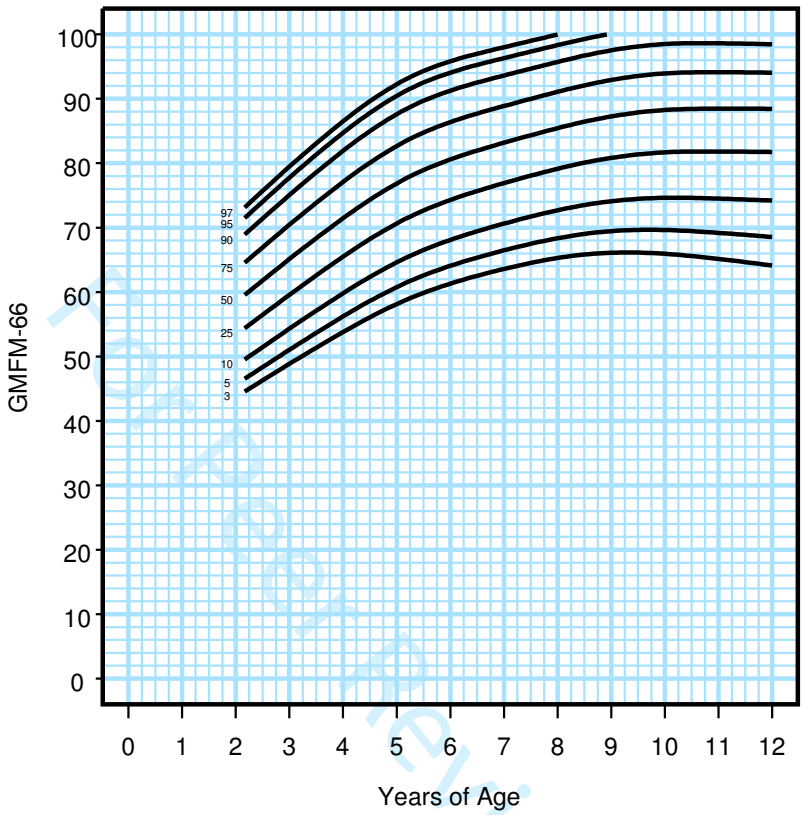
- How do the longitudinal trajectories assist with predicting future function, across different developmental domains, for you or your child? How is being able to predict future function useful to you or your child?
- How do the percentiles assist with understanding your child's current strengths and limitations, relative to other children of the same GMFCS level?
- Are the changes over time functionally or clinically significant? (note: it is important to look at the items within the measures that have actually changed, in addition to the total or average scores)
- Which measures do you believe are most useful to you and your child, and which measures are not useful at this time?
- How do the overall results of the Move & PLAY study, in combination with understanding change over time, assist with decision making about which services to pursue? Which outcomes are important to you (motor function, self-care performance, or participation in recreation and leisure activities)? Which developmental domains will assist with realistic goal setting? Which domain (i.e. child, family, or service variable) will you select as a focus of intervention?
- What logical possibilities exist for service planning and how do these fit with your family's goals and priorities?

Note: GMFCS = Gross Motor Function Classification System



Notes: GMFM = Gross Motor Function Measure; CEDL = Child Engagement in Daily Life Measure; ROM = Range of Motion





Appendix 1 (Supplementary File 1). Measures developed in the context of the Move & PLAY Study (either before or during – i.e. primarily for children aged 18 months to 5 years of age). All are available on the Move & PLAY study site at: https://canchild.ca/en/research-in-practice/current-studies/move-play-study-understanding-determinants-of-motor-abilities-self-care-and-play-of-young-children-with-cerebral-palsy

Measure	Description	Psychometric Properties
Parent Completed		
Health Conditions Questionnaire[1]	Developed for Move & PLAY for use with children with CP aged 18 months to 5 years - Items include problems with seeing, hearing, learning, communicating, controlling emotions, seizures, the mouth, teeth and gums, digestion, growth, sleeping, repeated infections, breathing, the skin, the heart, and pain (n = 16 plus two additional 'other' options) - if the parents report that the child has a problem, it is scored 'yes' (1) if not, it is scored 'no' (0) - if parents report 'yes' they are asked to rate the impact on daily life, from '1' (not at all) to '7' (to a very great extent) - scoring is based on number of health conditions and average impact - 5 minutes to complete	Developed from the international definition of CP[2] using the ICF[3] (content validity) Test-retest reliability for number of conditions: ICC = 0.80, 95% CI = 0.63 – 0.90 (n = 32) Test-retest reliability for average impact: ICC = 0.85, 95% CI = 0.72 – 0.93 (n = 32) Known groups validity: significant differences in both number and impact of health conditions among children developing typically and children in GMFCS groups (I, II&III, and IV&V) $p < 0.001$ (n = 537) - post hoc testing: all groups significantly different from each other for number ($p < 0.01$); for impact, all groups significantly different from each other ($p < 0.001$) except for GMFCS levels I and II&III SEM (95% CI) and MDC_{95} Number of health conditions 1.2 (95% CI ± 2.4); MDC_{95} = 3.4 Average impact of health conditions 0.3 (95% CI ± 0.6); MDC_{95} = 0.8
Early Activity Scale for Endurance (EASE)[4]	- 11 items initially generated for the Move & PLAY study for children with CP 18 months to 5 years: 10 items about frequency, intensity, duration and type of physical activity; 1 item (independent mobility or not) directing parent whether or not to complete the last 4 items - all items but 7 are scored on a 5-point ordinal scale of either frequency / intensity or duration - items 1-5 and 8-10 are scored from 1 (low value) to 5 (high value). Item scores (except for 7) are summed; details are described in the original manuscript[4] - 10 minutes to complete the 11-item version When evaluating the properties of the measures for the analysis of the model of gross motor function,[5] a 4-item version was developed (items 1, 2,3 and 5)	11-item version[4] Internal consistency: Cronbach's alpha = 0.93 Test-retest reliability: ICC = 0.95 (95% CI = 0.90-0.98) (n = 32 children with CP) Known groups validity – significant differences among children developing typically and children with CP in 5 levels of the GMFCS ($p < 0.001$); post hoc tests NS for levels II and III (n = 520) Convergent validity: Spearman's correlation with 6 minute walk test = 0.57 ($p = 0.001$) (n = 14 children with CP and 14 children developing typically) SEM = 2.9 MDC_{95} = 8.0 4-item version (tested in Move & PLAY (n = 429), unpublished) Good model fit: CFA – short version X^2 = 2.8 NS CFI = 0.998

	measuring frequency / intensity all on an ordinal scale from 1 (never) to 5 (always) - scoring is based on the average value of the 4 items - five minutes to complete the 4-item version	TLI = 0.993 RMSE = 0.03 Internal consistency: Cronbach's alpha = 0.83 Test-retest reliability: ICC = 0.75 (95% CI 0.54-0.87) (n = 32) Factor Loading:[6] the EASE loaded significantly onto the Move & PLAY construct of 'secondary impairment' with a loading of 0.66 Convergent validity: (On Track, unpublished data), (n=376): GMFCS levels I-III, Pearson correlation of EASE to 6MWT = 0.30 ($p<0.001$); Construct validity: Significant differences between GMFCS levels I-III, Level I>II>III ($p<0.03$), between age groups, 1.5-3 years-olds > 6-9 and 9-12 year-olds ($p=0.006$, $p=0.001$) and 3-6 year-olds > 9-12 year-olds ($p=0.006$), between sex, boys > girls ($p=0.02$) SEM = 0.5 (95% CI $\pm$ 1.0); MDC_{95} = 1.4
Child Engagement in Daily Life Measure[7]	Initially developed for children with CP 18 months to 5 years of age - 18 item questionnaire with 2 domains: participation in family and recreational activities (11 items) and performance of self-care in daily life (7 items) - two dimensions of recreation participation are measured: frequency (from '5' very often to '1' never) and enjoyment (from '5' a great deal to '1'' not at all) - the ratings for the self-care domain reflect the degree the child participates in daily self-care activities (from '5' yes, initiates and performs consistently to '1' no, unable) - average item scores were used for reliability and validity - Rasch analysis was also conducted - the Rasched score is reported - 10 minutes to complete	(n = 429 in Move & PLAY and 110 children developing typically) Internal consistency: Cronbach's alpha Participation = 0.86 (frequency), 0.91 (enjoyment) Self-care = 0.90 Test-retest reliability: (n = 33) Participation frequency: ICC = 0.70 (95% CI = 0.47-0.84) Participation enjoyment: ICC = 0.70 (95% CI = 0.47-0.84) Self-care: ICC = 0.96 (95% CI = 0.91-0.98) Known groups validity: frequency in and enjoyment of participation in recreation and self-care varied by age and GMFCS level (i.e. children developing typically, GMFCS I, GMFCS II & III, GMFCS IV & V) ($p < 0.001$) - there was an age by motor ability interaction for self-care, with the youngest children performing less than the two older age groups ($p < 0.001$). All motor ability groups performed significantly differently ($p < 0.001$) Rasch analysis: Participation performed well; self-care has been improved by adding items of intermediate difficulty for use in the On Track study Analysis for the purposes of evaluation:[8] (n = 387) Sensitivity to change over the period of one year: Both participation and self-care had

		significantly higher scores at the end of one year for children in GMFCS levels I and II&III ($p < 0.01$) For participation, effect sizes were 0.22, 0.34 and 0.13 for children in GMFCS levels I vs II & III vs IV & V, respectively For self-care, effect sizes were 0.56, 0.58, and 0.08 for children in levels I, II&III, and IV & V, respectively Psychometric properties of the new 29-item version (expanded and revised to be appropriate for children up to 12 years of age – as yet unpublished) was re-evaluated in the On Track Study Test-retest reliability Self Care: (n = 41) ICC = 0.96 (95% CI 0.93-0.98) Participation Frequency: (n = 74) ICC = 0.76 (95% CI 0.64-0.84) Participation Enjoyment: (n = 72) ICC = 0.72 (95% CI 0.58-0.81) SEM (95% CI); MDC_{95} Self Care: 4.8 (95% CI $\pm$ 9.4); MDC_{95} = 13.3 Participation Frequency: 4.9 (95% CI $\pm$ 9.6) MDC_{95} = 13.6 Participation Enjoyment: 0.27 (95% CI $\pm$ 0.5) MDC_{95} = 0.7
Therapist Completed		
Gross Motor Function Measure (GMFM-66-B&C)[9]	Based on the 'gold standard' for measuring gross motor function of children with CP – the Gross Motor Function Measure for use with children having motor function abilities up to the level of a typically developing 5 year old (GMFM),[10] specifically the GMFM-66, the version reduced from 88 items via Rasch analysis - for the Basal and Ceiling approach (i.e. GMFM-66-B&C), the 66 items were first reordered based on difficulty level - guidelines extrapolated from Rosenbaum et al.[11] using age and GMFCS level are used to select the first item to be administered - each item is scored on a 4-point ordinal scale from '0' (does not initiate) to 3 (completes) - therapists score items relevant to a child's current ability level by completing a minimum of 15 items between a basal	(n = 26) Test-retest reliability – ICC = 0.994 (95% CI = 0.987 – 0.997) Concurrent validity with the GMFM-66 – ICC = 0.987 (95% CI = 0.972 – 0.994) SEM = 1.3 (95% CI $\pm$ 2.5); MDC_{95} = 3.5

	score of 3 consecutive '3s' and a ceiling score of 3 consecutive '0s' - GMFM-66 scores are calculated using the GMAE - 15 – 20 minutes to complete	
Spinal Alignment and Range of Motion Measure (SAROMM)[12]	- Developed as a discriminative tool for use with children and adolescents with CP - the SAROMM manual should be consulted prior to administering and scoring - 4 items in Spinal Alignment and 11 items in Range of Motion and Muscle Extensibility subscales (all tested bilaterally) for a total of 26 items - each item is scored from '0' (representing the ability to align normally with no passive limitations) to '4' (severe deviation in spinal alignment or limitations in joint range of motions or muscle extensibility) - average scores are used for analysis - 15 minutes to administer	Content validity established with consultation with experienced pediatric physical therapists through focus groups - administration details, testing protocol and scoring criteria refined through a Delphi process (n = 25; 5 in each GMFCS level) Inter-rater reliability – ICC = 0.89 (95% CI = 0.76 – 0.95) Test-retest reliability – ICC = 0.93 (95% CI = 0.86 – 0.97) Construct validity: age and GMFCS level contributed significantly to SAROMM score (r^2 = 0.44) SEM = 3.1 (95% CI $\pm$ 6); MDC_{95} = 8.5 Cronbach's alpha = 0.95 (Move & PLAY, unpublished) Known groups validity: scores differentiate children at all GMFCS levels, except II and III ($p < 0.006$)[6] Factor Loading:[6] the SAROMM loaded second most highly onto the Move & PLAY construct of 'secondary impairment' with a loading of 0.74
Early Clinical Assessment of Balance (ECAB)[13]	The ECAB is a 13-item test that estimates postural stability of children with CP aged 18 months to 5 years of age across all GMFCS levels - items were generated from the Automatic Reactions Section of the Movement Assessment of Infants (MAI)[14] and selected items from the Pediatric Balance Scale (PBS)[15] - 7 items selected from the MAI (5 bilaterally) were scaled as originally designed (from 0 - 3) – total possible subscore = 36 (early evidence of reliability among 16 children with CP: ICC = 0.96 (95% CI = 0.90 – 0.99) - 6 items were selected from the PBS (with variable scaling to reflect difficulty level)- total possible subscore = 64	(n = 410) - content validity – established through expertise on research team - internal consistency – Cronbach's alpha = 0.92 - known groups validity: - ECAB scores differed significantly among all GMFCS levels ($p < 0.001$) - Children aged less than 31 months had significantly lower ECAB scores than children aged 31-42 or 43-60 months ($p < 0.01$) - construct validity – correlation with GMFM was high at 0.97 ($p < 0.001$) Factor Loading:[6] the ECAB loaded most highly onto the Move & PLAY construct of 'primary impairment' with a loading of 0.95

	- Total possible ECAB score = 100 - 10-15 minutes to complete	Evidence supporting reliability[16] (n = 28 children with CP, aged 2-7 years) - Inter-rater reliability ICC = 0.989 (95% CI = 0.976-0.995) - test-retest reliability (same raters) ICC = 0.987 (95% CI = 0.971-0.994) - test-retest reliability (different raters) ICC = 0.986 (95% CI = 0.971-0.994) SEM = 3.6 (95% CI ± 7); MDC_{95} = 10
Functional Strength Assessment (FSA)[6]	FSA developed for the Move & PLAY Study to assess muscle strength of children with CP 18 months to 5 years - estimates of strength are obtained for the following muscle groups: neck and trunk flexors and extensors, and hip extensors, knee extensors and shoulder flexors bilaterally - each muscle group is rated from '1' (only flicker of contraction of just initiates movement against gravity) to '5' (full available range against gravity and strong resistance) - best performance of multiple trials permitted - average score is used - 10 minutes to complete	Construct validity is supported by similarity to standard methods of manual muscle testing in children Jeffries et al.[6] (n = 429) - Known groups validity: significant difference among all GMFCS levels ($p < 0.001$), except for levels II & III - Factor Loading: the FSA loaded most highly onto the Move & PLAY construct of 'secondary impairment' with a loading of 0.95 Tested in Move & PLAY (n = 28 children with CP) Inter-rater reliability : ICC = 0.996 (95% CI = 0.991 – 0.998) Test-retest reliability: ICC = 0.97 (95% CI 0.95-0.99) Tested in Move & PLAY (n = 429) (unpublished) Cronbach's alpha = 0.93 SEM = 0.17 (95% CI ± 0.3); MDC_{95} = 0.4

CP = cerebral palsy; ICF = International Classification of Functioning, Disability and Health; WHO = World Health Organization; ICC = intra-class correlation coefficient; CI = confidence interval; GMFCS = Gross Motor Function Classification System; EASE = Early Activity Scale for Endurance; SEM = standard error of measurement; MDC_{95} = minimal detectable change (at the 95% CI); CFA = confirmatory factor analysis; X^2 = Chi Square analysis; NS = non-significant; CFI = comparative fit index; TLI = Tucker Lewis Index; RMSE = root mean square error of approximation; GMFM = Gross Motor Function Measure; GMFM-66-B&C = Basal and Ceiling Approach of the GMFM; GMAE = Gross Motor Ability Estimator; SAROMM = Spinal Alignment and Range of Motion Measure; ECAB = Early Clinical Assessment of Balance; MAI = Movement Assessment of Infants; PBS = Pediatric Balance Scale; FSA = Functional Strength Assessment

References

1. Wong C, Bartlett DJ, Chiarello LA, *Chang HJ*, Stoskopf B. Comparison of the prevalence and impact of health problems of preschool children with or without cerebral palsy. *Child Care Health Dev,* 2011; 38:128-38.
2. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol.* 2007; 49 (Suppl. 109):8-14.
3. World Health Organization. *International Classification of Functioning, Disability, and Health.* Geneva: author; 2001.
4. McCoy SW, Yocum A, Bartlett DJ, et al. Development of the Early Activity Scale for Endurance (EASE) for children with cerebral palsy. *Pediatr Phys Ther*; 2012; 24:232-40.
5. Bartlett D, Chiarello L, McCoy S, et al. Determinants of gross motor function of young children with cerebral palsy: A prospective cohort study. *Dev Med Child Neurol,* 2014;56:275-82.
6. Jeffries L, Fiss A, Westcott McCoy S, Bartlett DJ. Description of primary and secondary impairments in young children with cerebral palsy. *Pediatr Phys Ther.* 2016;28:7-14.
7. Chiarello L, Palisano R, McCoy SW, et al. Child Engagement in Daily Life: A measure of participation for young children with cerebral palsy. *Disabil Rehabil.* 2014;35:1804-16.
8. Palisano R, Chiarello L, McCoy SW, Bartlett D, An M. Use of the Child Engagement in Daily Life and Ease of Caregiving for children to measure change in young children with cerebral palsy. *Phys Occup Ther Pediatr.* 2015;35:280-95.
9. Brunton LK, Bartlett DJ. Validity and reliability of two abbreviated versions of the Gross Motor Function Measure. *Phys Ther.* 2011;91:577-88.
10. Russell DJ, Rosenbaum PL, Wright M, Avery LM. *Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual.* 2nd Edition. Clinics in Developmental Medicine. Mac Keith Press: London; 2013.
11. Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: Creation of motor development curves. *JAMA.* 2002;288:1357-63.
12. Bartlett DJ, Purdie B. Testing of the *Spinal Alignment and Range of Motion Measure:* A discriminative measure of posture and flexibility for children with cerebral palsy. *Dev Med Child Neurol.* 2005; 47:739-43.
13. McCoy SW, Bartlett DJ, Yocum A, et al. Development and validity of the Early Clinical Assessment of Balance for young children with cerebral palsy. *Dev Neurorehabil.* 2014;17:375-83.
14. Chandler L, Andrew M, Swanson M. Movement assessment of infants: A manual. Rolling Bay, WA; 1980.
15. Franjoine MR, Gunther JS, Taylor MJ. Pediatric Balance Scale: A modified version of the Berg Balance Scale for the school-aged child with mild to moderate motor impairment. *Pediatr Phys Ther.* 2003;15:114-28.
16. Randall KE, Bartlett DJ, McCoy S. Measuring postural stability in young children with cerebral palsy: Comparison of two instruments. *Pediatr Phys Ther,* 2014; 26:332-7.

Appendix 2 (Supplementary File 2). Equipment needed for the therapist administered measures. All of the listed equipment can be stored in a rolling duffle bag for easy community transport.

Measure	Equipment Needed
Gross Motor Function Measure (GMFM-66-B&C)[1]	- Stop watch - Mat * - Circle (24 inch) * note: *we purchased adult yoga mats and cut 24 inches off the end to make a non-slip circle; the remainder of the yoga mat was sufficient for the 'mat' above* - Measuring tape - Masking tape and flagging tape *(to make two straight lines 20 cm (8") apart and 6 m (20 ft) long)* - 12" ruler - Ball (soccer sized; item 72) - 30-60 cm (12-24") long sticks (items 75, 76) - Small interesting toy less than 10 cm (4") in height - Bench + for sitting with feet flat on the floor In addition to the equipment listed above, adapt the following from the setting in which the assessment is occurring: a large bench, coffee table, or table appropriate height for standing and cruising and stairs (5 steps, standard 7" rise). If any equipment is not available, choose equipment that is similar to the specifications. Note any substitutions in equipment on the scoresheet.
Spinal Alignment and Range of Motion Measure (SAROMM)[2]	- A firm sitting surface for the spinal alignment subscale and the upper extremity items, so that hips and knees are at 90 degrees in (supported sitting). This can be the wheelchair (if he or she uses one or the adjustable height bench + described below - A floor mat is needed to test other items
Early Clinical Assessment of Balance (ECAB)[3]	Required: - Adjustable height bench + - Mat - Stop watch - Step Stool 6" in height Optional, but helpful: - child sized foot prints (cut from non-slip carpet) - blind fold - flash cards (to keep child amused during static testing) - stickers *Note: the step stool is the base of the adjustable height bench +*
Functional Strength Assessment (FSA)[4]	No special equipment needed - For younger children, it is useful to have a sturdy bench or chair for the therapist to sit on while testing the child's neck, trunk, and hip extensors in prone suspension on the therapist's lap, and for testing the child' knee extensors and shoulder flexors in sitting. A mat is useful for testing neck and trunk flexors - for older children, a raised mat is useful (or other firm, flat surface)

GMFM-66-B&C = Basal and Ceiling Approach of the GMFM; cm = centimetre; m = metre; SAROMM = Spinal Alignment and Range of Motion Measure; ECAB = Early Clinical Assessment of Balance; FSA = Functional Strength Assessment

+ note: for the bench: we designed an easily fabricated, light-weight, portable, and adjustable bench described in the following article: Stoskopf B, Fedrock D, Bartlett D. Reinventing the adjustable bench for community-based research and practice. Suggestions from the Field. *Pediatric Physical Therapy.* 2014;26:274-276.

References

1. Brunton LK, Bartlett DJ. Validity and reliability of two abbreviated versions of the Gross Motor Function Measure. *Phys Ther.* 2011;91:577-88.
2. Bartlett DJ, Purdie B. Testing of the *Spinal Alignment and Range of Motion Measure:* A discriminative measure of posture and flexibility for children with cerebral palsy. *Dev Med Child Neurol.* 2005; 47:739-43.
3. McCoy SW, Bartlett DJ, Yocum A, et al. Development and validity of the Early Clinical Assessment of Balance for young children with cerebral palsy. *Dev Neurorehabil.* 2014;17:375-83.
4. Jeffries L, Fiss A, Westcott McCoy S, Bartlett DJ. Description of primary and secondary impairments in young children with cerebral palsy. *Pediatr Phys Ther.* 2016;28:7-14.