Considerations for Pediatric Physical Therapy Curriculum Based on the Findings of the On Track Study

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For more information on the On Track Developmental Monitoring System (DMS), including PowerPoint presentations of the measures, main study results, and additional references, please refer to the On Track website.[a]

This document may be useful to faculty in framing collaborative pediatric physical therapy (PT) clinical decision making for children with cerebral palsy (CP). We understand the complexity of management of children with CP, and recognize this document is not all encompassing. Principles of management may change as children age or new research becomes available. Key constructs for curriculum are presented followed by description of the comprehensive system of assessment tools, longitudinal developmental trajectories, and reference percentiles created for the On Track DMS.

Key Constructs for Curriculum

1. CP is complex and development is variable.
2. The neurologic lesion that results in cerebral palsy is static, but the physical condition and function of children with cerebral palsy may change over time with the development of secondary impairments.
3. There is a need for systematic methods for developmental monitoring of children with CP to identify change over time, through the use of efficient and clinically feasible measures in clinical practice.
4. Developmental monitoring should be based on comparisons of children's body function/structure health, gross motor, self-care, and participation outcomes to other children with CP with similar functional abilities (Gross Motor Function Classification System [GMFCS] levels)
5. Outcomes are complex and should be framed based on the context of the individual child and family, therefore monitoring should be tracked on percentile development graphs.
6. Collaboration with the family and the child is essential to determining children's progress, needs, and effective plans for service delivery.
7. Curriculum should aim to teach clinical reasoning and evidence-based frameworks to help guide practice.

Overview of On Track[1]: On Track was a large, multi-site research study across Canada and the United States. On Track created longitudinal developmental trajectories and to describe changes in balance (primary impairment), range of motion limitations, strength, and endurance (secondary impairments), impact of health conditions, and participation in self-care, recreation, and leisure activities over one-year in children with CP aged 18 months through 11 years. 708 children with CP and their families in each of the 5 levels of the Gross Motor Function Classification System (GMFCS)[b] participated. Trained therapist assessors measured primary and secondary impairments, and parents completed questionnaires about the child's endurance, health conditions, and participation on 2-5 occasions over 2 years (6-months apart). Following the methods of the Ontario Motor Growth Curves study,[2,3] longitudinal developmental curves and reference percentiles graphs were then developed for use in the On Track Developmental Monitoring System (On Track DMS).

International Classification of Functioning, Disability, and Health (ICF)[4]**:** Measurement across the ICF is important for children with CP. There is a need for assessment tools that are clinically feasible, brief, psychometrically sound, and efficient to provide a comprehensive examination of children with CP and to allow documentation of change over time. Below are measures used in the On Track DMS designed and/or selected to meet these needs.

On Track DMS Measures: The measures and associated training materials are available on the On Track study website.[c]

- Associated Health Conditions
  - Health Conditions Questionnaire[5,6]
- Body Function & Structure: Primary and Secondary Impairments
  - Balance: Early Clinical Assessment of Balance[7,8]
  - Strength: Functional Strength Assessment[9,10]
  - Range of Motion: Spinal Alignment and Range of Motion Measure[9,10]
  - Endurance: Early Activity Scale for Endurance (parent report)[9–11]
  - Functional Walking Capacity: Six-Minute Walk Test[11,12]
  - Walking Performance: Step Watch Monitoring[13]

    - Activity Performance: Actigraph Monitoring[13]
- Activity
    - Performance of Self-Care: Child Engagement in Daily Life Measure[14,15]
    - Gross Motor Function Measure-66-Basal & Ceiling (GMFM-66-B&C)[2,3,16] (note these data are shared from the previous Ontario Motor Growth Curve study)[2,3]
- Participation
    - Participation in Recreation and Leisure Activities: Child Engagement in Daily Life Measure[17]

Longitudinal Developmental Trajectories: Longitudinal trajectories provide easily understood and useful tools for families and PTs to discuss how well their children are doing in relationship to other children with CP of similar functional ability levels. By plotting a child's score on the longitudinal developmental trajectory, the PT can determine where the child's current score on a measure compares to the average score of all children within that GMFCS level. Due to variability in development of children with CP, even within a particular GMFCS level, longitudinal developmental trajectories should be used as an estimate of the child's current development and to discuss with families the expected change in relation to other children within the same GMFCS level, but should not be used to evaluate an individual child's progress over time.

Reference Percentile Graphs: Reference percentiles provide additional and more detailed information than the longitudinal developmental trajectories and allow PTs to assist families in determining if children with CP are developing as expected. A single assessment allows for an understanding of a child's individual strengths and limitations related to a particular measure. By plotting the child's score on the reference percentile graphs, the PT can determine the percentile of the child's score compared to other children with CP of the same age and GMFCS level (e.g. the 5th percentile or the 65th percentile). Completing a second assessment approximately one year later (9-15 months later), provides an understanding of the child's individual change in abilities over time. Through calculation of the amount of change in percentiles over time, the PT and family can discuss if an individual child with CP is demonstrating scores that are progressing 'as expected,' (similar change in percentiles of middle 80% of children) 'more as expected,' (change in percentiles greater than the middle 80% of children representing the upper 10th percentile) or 'less than expected' (change in percentiles less than middle 80% of children representing the lower 10th percentile) over time, depending on their functional ability levels.

On Track Calculator: To facilitate efficient and accurate use of the On Track DMS in practice, an online calculator was created.[d] When the child's age and assessment scores are entered into the calculator, the child's scores are plotted onto the longitudinal developmental trajectories and reference percentiles. In addition, the child's percentiles, change in percentiles, and interpretation of the percentile change are determined. The calculator also produces printable reports that can be shared with families to facilitate prognostic service delivery discussions.

Collaboration with families: It is essential that collaborative developmental monitoring embrace the principles of family-centered care to promote optimal individualized services. PTs should discuss with families individual On Track DMS results to understand the context impacting the child's performance. In addition, children and their families should be actively involved in all aspects of the plan of care including:

- What measures to use and how frequently to administer measures
- How the child and family want to be involved in examinations and progress monitoring
- How to document and share findings
- What the plan of care for the child looks like

Consistency with essential competencies:

Components of the On Track DMS are consistent with the essential competencies of entry-level pediatric PT education.[18]

- *Human development*: Understanding the typical course of development of primary and secondary impairments, health conditions, and participation is essential to guide service delivery planning for children with CP as they grow and develop. The On Track longitudinal developmental trajectories provide evidence-based data to support prognostic discussions regarding a child's development.
- *Age appropriate patient/client management*: On Track DMS measures are clinically feasible and provide objective information to monitor development. The longitudinal developmental trajectories and reference

percentile graphs serve as valuable resources to monitor children with CP as they age and provide information to guide intervention planning. Together, these resources support age appropriate patient/client management.

- *Family-centered care*: Family-centered care and collaboration with children and their families is a hall-mark of the On Track DMS. The resources provided, such as printable family reports, facilitate collaborative discussion between families and PTs to improve the effectiveness and efficiency of services. Analysis of parent-reported services' relationships to developmental percentile outcomes supported that the extent of family-centeredness of the therapy intervention was associated with better participation and endurance outcomes.
- *Health promotion and safety*: The On Track DMS emphasizes the PTs' roles and responsibilities for health promotion and prevention of secondary health conditions. PTs share information with the child and family regarding the child's body structures and functions and health. Together they decide on strategies to optimize health management and healthy behaviors as children age. The On Track DMS is also consistent with the APTA's notion of an annual "Check up"[i] to enhance function and prevent secondary impairments.

Conclusions

- The On Track DMS provides a structured, evidence-based method as a basis for collaborative, individualized decision-making for intervention for individual children with CP.
- Longitudinal developmental trajectories compare a child's current scores on a particular measure to the average scores of other with CP of similar functional ability levels and help to predict expected change.
- Reference percentiles provide information to help determine if a child with CP is developing as expected.
- This data-driven approach to decision making is anticipated to enhance both the efficiency and effectiveness of interventions.
- Developmental monitoring must be an individualized collaborative process where the family perspective is used to provide important context to assessment results and to guide intervention planning.
- The On Track DMS can be used as an example of evidence-based, data driven decision making and is consistent with the essential competencies of entry-level pediatric PT education.

References

1. Bartlett DJ, McCoy SW, Chiarello LA, Avery L, Galuppi B, On Track Study Team. A Collaborative Approach to Decision Making Through Developmental Monitoring to Provide Individualized Services for Children With Cerebral Palsy. *Physical Therapy*. 2018;98(10):865-875. doi:10.1093/ptj/pzy081

2. Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: creation of motor development curves. *JAMA*. 2002;288(11):1357-1363.

3. 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. *Physical Therapy*. 2008;88(5):596-607. doi:10.2522/ptj.20070314

4. World Health Organization. *How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF). Exposure Draft for Comment.* Geneva: WHO; 2013.

5. Wong C, Bartlett DJ, Chiarello LA, Chang H-J, Stoskopf B. Comparison of the prevalence and impact of health problems of pre-school children with and without cerebral palsy: Health problems of children with CP. *Child: Care, Health and Development*. 2012;38(1):128-138. doi:10.1111/j.1365-2214.2011.01233.x

6. Bartlett DJ, Gorter JW, Jeffries L, Avery LM, Hanna SE. Longitudinal trajectories and reference percentiles for the impact of associated health conditions of children with cerebral palsy. *Dev Med Child Neurol*. 2018;In press.

7. McCoy SW, Bartlett DJ, Yocum A, et al. Development and validity of the early clinical assessment of balance for young children with cerebral palsy. *Developmental Neurorehabilitation*. 2014;17(6):375-383. doi:10.3109/17518423.2013.827755

8. Fiss A, McCoy S, Bartlett DJ, Avery LM, Hanna SE. Developmental trajectories for the Early Clinical Assessment of Balance by Gross Motor Function Classification System level for children with cerebral palsy. *Phys Ther*. 2018;In press.

9. Jeffries L, Fiss A, McCoy SW, Bartlett DJ. Description of Primary and Secondary Impairments in Young Children With Cerebral Palsy: *Pediatric Physical Therapy*. 2016;28(1):7-14. doi:10.1097/PEP.0000000000000221

10. Jeffries L, Fiss A, McCoy S, Bartlett DJ, Avery LM, Hanna SE. Developmental trajectories and reference percentiles for range of motion, endurance, and muscle strength of children with cerebral palsy. *Phys Ther*. 2018;In press.

11. Fiss A, Jeffries L, Yocum A, McCoy S. Validity of the 4-Item Early Activity Scale for Endurance and the Six-Minute Walk Test. *Pediatr Phys Ther*. 2018;In Press.

12. Fiss A, Jeffries L, Bjornson K, Avery LM, Hanna SE, McCoy S. Developmental Trajectories and Reference Percentiles for the 6-Minute Walk Test for Children with Cerebral Palsy. *Pediatr Phys Ther*. 2018;In press.

13. Bjornson K, Fiss A, Avery LM, et al. Longitudinal trajectories of physical activity and walking performance by Gross Motor Function Classification System level for children with cerebral palsy. *Disabil Rehabil*. In press.

14. Bartlett DJ, Chiarello LA, McCoy SW, et al. Determinants of self-care participation of young children with cerebral palsy. *Developmental Neurorehabilitation*. 2014;17(6):403-413. doi:10.3109/17518423.2014.897398

15. Palisano R, Chiarello L, Avery L, Hanna S. Self-care trajectories and reference percentiles for children with cerebral palsy. *Phys Occupat Ther Pediatr*. 2020;40(1):62-78. doi:10.1080/01942638.

16. Brunton LK, Bartlett DJ. Validity and Reliability of Two Abbreviated Versions of the Gross Motor Function Measure. *Physical Therapy*. 2011;91(4):577-588. doi:10.2522/ptj.20100279

17. Chiarello L, Palisano R, Hanna S, Avery L. Longitudinal trajectories and reference percentiles for participation in family and recreational activities of children with cerebral palsy. 2019;Dev Neurorehabil(In review).

18. Rapport MJ, Furze J, Martin K, et al. Essential Competencies in Entry-Level Pediatric Physical Therapy Education: *Pediatric Physical Therapy*. 2014;26(1):7-18. doi:10.1097/PEP.0000000000000003

Links

a. https://www.canchild.ca/en/research-in-practice/current-studies/on-track
b. https://canchild.ca/en/resources/42-gross-motor-function-classification-system---e-&-r
c. https://www.canchild.ca/en/research-in-practice/current-studies/on-track/on-track-measures
d. https://www.canchild.ca/en/research-in-practice/current-studies/on-track/on-track-calculator