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Relationship of physical, occupational, and speech services to developmental outcomes of children with cerebral palsy

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Rehabilitation services to developmental outcomes

Relationship of physical, occupational, and speech services to developmental outcomes of children with cerebral palsy

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Rehabilitation services to developmental outcomes

Abstract (219 words)

Aim: Determination of rehabilitation services is complex and not fully understood. We explored relationships of rehabilitation services to development of children with cerebral palsy (CP).

Method: A prospective longitudinal study with 656 children with CP, 1.5-11.9 years-old, and their parents from the US and Canada was conducted. Children were assessed 2-5 times over two years by therapists using standardized measures of balance and walking endurance. **Parents completed questionnaires on demographics, rehabilitation services, and their children's performance in self-care and participation in recreation. Therapists and parents collaboratively classified children's Gross Motor Function Classification System (GMFCS) levels. Longitudinal graphs for each GMFCS level, depicting change across time by percentiles, were created. Relationships between services (amount, focus, family-centeredness, and the extent services met children's needs) and whether change in balance, walking endurance, and participation was "more than" and "less than" to the reference of "as expected" were analyzed using multinomial models.**

Results: Children were more likely to progress "more than expected" in participation in recreation when services were family-centered, met children's needs, and focused on structured play/recreation. A focus on health and well-being was positively associated with participation and self-care. Amount of services did not predict outcomes.

Interpretation: Services that are family-centered, consider the needs of the child, focus on structured play/recreational activities and health/well-being may enhance development of children with CP.

What this paper adds:

- **Family-centeredness of rehabilitation services was positively associated with a greater frequency of children's participation in family/recreation activities and walking endurance.**
- **The extent that parents perceived that rehabilitation services met their children's needs was associated with a greater frequency of participation in family/recreation activities.**
- **Structured play and recreational activities and health/well-being are important considerations when planning rehabilitation services for self-care and participation.**
- **Amount of rehabilitation services was not related to developmental outcomes.**

Shortened form of title: Rehabilitation services to developmental outcomes

Rehabilitation services to developmental outcomes

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4 Decision-making regarding the most effective and efficient amount of therapy
5 services for children with cerebral palsy (CP), focus of services, and manner in
6 which services are provided is complex.^{1,2} Decisions not only rely on goals and
7 evidence of the effectiveness of interventions but also on the family's
8 preferences, therapist availability and expertise, the setting where services are
9 provided, and health care and insurance policies.³⁻⁵ As a consequence,
10 knowledge of the amount of services needed to optimize outcomes for children
11 with CP is unclear. Additionally, when interventions are designed to improve
12 gross motor function, studies do not consistently show that more therapy
13 sessions produce better outcomes.^{6,7}
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17 Bailes et al.⁴ recommend a frequency of 1 to 2 therapy sessions a week or every-
18 other-week for children who demonstrate continuous progress toward goals. This
19 recommendation corresponds to the average frequency of physical therapy (PT)
20 and occupational therapy (OT) that the majority of children in the United
21 States/Canada were receiving in our previous study of 399 children with CP, 2-6
22 years of age.³ The small percentage of children receiving more than 12 sessions
23 of therapy per month in this study indicates that intensive therapy, as defined in
24 research, was not common in practice. This most likely reflects the **availability**
25 **of services**, financial cost, and family time commitment associated with a high
26 intensity of therapy, coupled with a lack of research evidence to substantiate a
27 positive effect of additional therapy for general outcomes.⁶ Parent and
28 professional advocacy are also likely to influence decisions on amount of
29 therapy.²
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33 Previous research examining the relationship between amount of rehabilitation
34 services in combination with attributes of the child and family, and outcomes of
35 gross motor, self-care, and participation in family/recreational activities only,
36 revealed that children who participated in more recreation/leisure programs had
37 better gross motor function.⁸⁻¹⁰ This relationship may reflect that children with
38 higher functional abilities participate in more community programs. Further
39 analysis of the amount of OT, PT, and speech therapy (ST) revealed a primary
40 relationship to the functional ability of the children; i.e., the lower the functional
41 ability of the children, the greater the amount of therapy services provided.^{3,11}
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45 A systematic review of interventions for children with CP concluded that infants
46 with CP respond best to interventions that include task-specific practice of child-
47 initiated movements, environmental modifications, and parent education.¹²
48 Another systematic review concluded that constraint-induced movement therapy,
49 goal-directed training, bi-manual training, home programs, and context-focused
50 therapy have evidence of effectiveness to improve motor activities, function, and
51 self-care.¹³ Previous research suggested that changes in body structures or
52 function do not predict change in activity^{13,14} or participation.¹³ Interestingly, while
53 parent report of the focus of intervention suggested that therapists are
54 addressing all three domains of the International Classification of Function,
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Rehabilitation services to developmental outcomes

Disability, and Health¹⁵ (ICF), parents and professionals have different perspectives.¹⁶ Parent ratings were significantly higher than therapist ratings for the focus of all interventions, and parent and therapist ratings were not related.¹⁶ Parents perceived that therapists were providing family-centered services and embedding activities into daily routines. Therapists considered the environment and task as modifiable factors that might enable activity and participation of children with limitations in motor ability.¹⁶

The aim of this study was to describe the relationship between the amount, focus, and family-centeredness of therapy services, **extent children's needs were met by services**, and developmental outcomes, expressed as clinically significant changes in percentile rank of balance and walking endurance and frequency of participation in family/recreational activities over one year. We expected that children with the most optimal change would have services with more focus on practice of specific tasks, environmental modifications, and family-centeredness and that parents would report that their children's needs were being met to a greater extent by their rehabilitation services.

Method:

Participants:

Participants were 656 children with CP, age 1.5-11.9 years at the time of recruitment. Their families enrolled in the On Track study (2012-2017), an international (Canada and US), multi-site prospective cohort design (ClinicalTrials.gov identifier: NCT02391948). **The On Track study's primary aim was to create longitudinal developmental trajectories and percentile graphs of children's developmental changes across time in several body functions, self-care performance, and participation.** Children were eligible if they had a diagnosis of CP or were suspected to have a diagnosis of CP (i.e., exhibited delayed motor development, muscle stiffness, and difficulties with balance and moving). Eligibility was monitored throughout the study; the final dataset represents children confirmed to have CP. Institutional Review Board (IRB) approvals were maintained at each University as well as at required clinical sites. All families and children of appropriate age signed approved consent and assent forms, according to IRB regulations. For this analysis, participants with both baseline and 12-month assessments from the larger On Track sample (power analysis available in protocol document: <https://www.canchild.ca/en/research-in-practice/current-studies/on-track>) were included. **Participant characteristics are in Table I. Comparisons between the Canadian and USA participants showed that there were no significant differences between the two groups related to the children's age, GMFCS level, and gender.**

Measurements:

Rehabilitation services to developmental outcomes

The *Gross Motor Function Classification System* (GMFCS)¹⁷ was used to classify the children into functional ability levels. Details on the GMFCS and the supported psychometric properties are included in Table II.

Children's Developmental Outcomes

Outcomes that were measured by therapist assessors included balance (*Early Clinical Assessment of Balance* [ECAB]¹⁸) and walking endurance (*Six-Minute Walk test*, [6MWT]¹⁹). Outcomes measured by parent questionnaires included children's participation frequency in family/recreational activities and performance within self-care activities (*Child Engagement in Daily Life* measure [CEDL]²⁰). A short description of each measure and psychometric support are included in Table II. The outcome of balance was chosen because it has a strong correlation to gross motor development.²¹ Walking distance using the 6MWT was selected to represent functional mobility. Participation frequency in family/recreational activities and performance in self-care activities were selected because these outcomes represent the broadest and most important outcome of effective therapy intervention.¹⁰

Services Questionnaire

The services questionnaire was developed for the Move & PLAY study³; then it was modified to reduce the length. All sections are noted in Table II, and the questionnaire can be found on the study website. For this study, the amount, focus, family-centeredness, and extent parents reported their children's needs were met by services were used. The selection of these services variables represents the amount of service and encompasses our hypotheses on service issues that would have positive relationships with the outcomes.⁸⁻¹⁰ Service variables from the 12-month assessments were utilized in the analyses.

The amount of PT, OT, and ST services was reported by parents as the estimated number of sessions/year and subsequently was categorized as follows: 0-1 (none or once/year); 2-30 (few to every other week); 31-52 (every other week to weekly); 53-155 (weekly to 2-3 times per week), and ≥ 156 (>3 times per week). These categories were chosen based on the data distributions and the researchers' knowledge of typical therapy services in North America. Table II details the variables and measurement scales for focus of therapy, family-centeredness, and rating of extent that all services received met children's needs.

Procedures:

Ninety physical and occupational therapists completed standardized workshops to understand the study, the measures and equipment for data collection, and additional information relating to safety, privacy, confidentiality, and administration. Assessments were completed in families' homes or the clinics where children received services. The ECAB was completed for all children; the 6MWT was performed by children in GMFCS levels I, II, and III. Parents

Rehabilitation services to developmental outcomes

completed the services and CEDL questionnaires through paper booklets or online, based on parents' preference.

Assessors reviewed the parents' questionnaire responses for completeness. If items were not answered, parents were queried as to whether they had missed or chosen not to answer the question. The GMFCS was independently completed by both the assessor and the parent, with subsequent discussion to reach consensus, if needed. Consensus was reached 97.8% of the time, and all disagreements were within one level.²² Based on study protocol, final classifications of children were the parent rating, unless the assessor reported specific information (e.g., parent unready to choose a classification level or definitive information in support of a particular classification level). All data were entered into an online database (EmPOWER Health Research Inc.). Specific procedures for handling missing data were followed (see study website).

Data Analysis

Children's progress on the ECAB, 6MWT, CEDL participation in family/recreational (CEDL-Participation), and CEDL performance of self-care (CEDL-Self-Care) percentile graphs was evaluated using the age and GMFCS-specific percentile scores on each measure. Reference percentile graphs can be found on the study website. Using all available data, the baseline percentile score was subtracted from the 12-month score to determine the one-year change in percentile score. Development was then classified into three categories. Children whose change in percentiles was in the lowest 10% of the sample were considered to be developing "less than expected." Those whose changes were in the central 80% of changes (from the 10th to 90th percentile) were considered "as expected," and those with the 10% largest changes as "more than expected." **Because typical variability in percentile scores is large, "as expected" changes may include increases or decreases in both absolute score and rank.** The smallest 10% of changes are necessarily decreases in rank, some of which may be large decreases, and the 10% highest changes in rank will always be improvements in rank.

These development classifications (with possible values of "less than," "as," or "more than expected") for each of the four outcome measures (participation, self-care, balance, and walking endurance) were used as dependent variables. Multinomial regression models were fit to examine the impact on each of these dependent variables of the following four service categories: the amount (PT, OT, ST service sessions), focus (eight focus variables), family-centeredness, and extent children's needs were met by services on children's progress. Thus, for each of the four outcomes, 13 separate univariate models were fit to independently examine the effect of each of the services variables (three for amount, eight for focus, and one each for family-centeredness and extent needs met). Country of residence was included as a covariate and fit for all models as therapy services are different within Canada and the USA. (In Canada, a

Rehabilitation services to developmental outcomes

single-payer system exists; whereas in the USA, children can receive services through private insurance, private pay, and/or federal- and state-funded programs. Previously we reported that children 2-5 years of age with CP living in the USA received a greater amount of therapy services and more often received services in two or more settings, as compared to children living in Canada.³⁾

The reference level for the models was developing “as expected.” A likelihood ratio test (LRT) was used to determine if each **service variable** was associated with development on the four outcomes. If the LRT was statistically significant ($p < 0.05$) then the odds ratios (OR) were calculated, which corresponded to the increased (or decreased) odds for each unit change in **the service variable**. To facilitate interpretation, we also calculated the relative risk (RR) of developing more or less than expected for the highest versus the lowest level of the **service variable**. **Note that a relative risk of 1 indicates no differences between groups. For comparisons between the “more than expected” and “as expected” groups, values greater than 1 indicate those receiving the highest level of services are more likely to be progressing “more than expected.” For comparisons between “less than expected” and “as expected” values, less than 1 indicated that those receiving the highest level of services are more likely to develop “as expected” than “less than expected.”**

Results:

Detailed descriptive data on the ECAB,²³ 6MWT,²⁴ and CEDL-Participation²⁵ and CEDL-Self-Care percentile graphs²⁶ can be found in other publications and on **the On Track study website (<https://www.canchild.ca/en/research-in-practice/current-studies/on-track>)**. Services variables reported by families are detailed by GMFCS Level for the 12-month assessment sessions in Table III. Amount of PT services increased as functional limitations increased, ranging from therapy sessions 2-30 times/year for children at GMFCS Level I to therapy sessions from 31-52 times/year for children at GMFCS Level V. The lowest focus of therapy was reported to be on self-care activities, with ratings corresponding to a “small extent” (mean=2.1-2.9). The highest focus of therapy ratings was for the secondary body structure/function domain (stretching tight muscles, strengthening muscles, and/or activities to increase fitness) (mean=3.8-4.0). Family-centeredness was rated in a similar manner among children within each GMFCS level and clustered around the moderate level (mean=3.4-3.5). Ratings of the extent that parents perceived that children’s needs were met were at a moderate to great extent for children at GMFCS Level I (mean=3.8) as compared to closer to a moderate extent for children at GMFCS Level V (mean=3.3).

Relationship to developmental percentiles

Results of the LRT from multinomial models for each service variable of interest, controlling for country, are presented in Table IV. **While we expected that**

Rehabilitation services to developmental outcomes

country would be a significant predictor due to the differences in Canadian and USA health care services, this was not the case, and removing country from the models produced nearly identical results. The amount of PT, OT, and ST services did not significantly influence change in any outcomes. A service focus on environmental modifications was not significantly related to any outcomes. There were no significant relationships of the service variables to the balance (ECAB) outcome. There were several exploratory results for the other three outcomes as follows.

Walking endurance (6MWT): 6MWT progress was related to the degree of family-centeredness services, with a decreased likelihood of progressing “less than expected” for those reporting more family-centeredness (OR=0.57; 95% CI 0.38, 0.88). This corresponded to a RR of 0.16; children receiving family-centeredness services to the greatest extent are 16% more likely to progress “less than expected” than those receiving the family-centeredness to the least extent.

Frequency of participation (CEDL-Participation): Children were more likely to progress “more than expected” on participation in family/recreational activities when reporting increased family-centeredness service (OR=1.46; 95% CI 1.06, 2.02). This corresponds to a RR of 3.9; parents reporting the highest level of family-centeredness for their children are almost 4 times more likely to progress “more than expected” versus “as expected” with respect to participation than those reporting the lowest level of family-centeredness.

Children were more likely to progress “more than expected” than “as expected” when parents perceived their children’s needs were being met by services (OR=1.48; 95% CI 1.07, 2.03). The RR was 4.14; when parents perceived their children’s needs were being met by services, children were approximately 4 times more likely to progress “more than expected” than compared with children whose parents who reported needs met “as expected” or “less than expected.”

Children were more likely to progress “more than expected” when there was a focus on participation (structured play/recreation activities) (OR=1.30; 95% CI 1.07, 1.58). The RR was 2.55; children whose therapy had the greatest focus on structured play/recreation activities were approximately 2.5 times more likely to progress “more than expected” in frequency of participation in family/recreational activities than those with the least focus on structured play and recreation activities.

Progress on CEDL-participation was related to the degree of focus on health/well-being, with a decreased likelihood of progressing “less than expected” for those reporting more focus on health/well-being (OR=0.81; 95% CI 0.67, 0.99), corresponding to a RR of 0.61. Children with therapy having the greatest focus on health/well-being are only 60% as likely to progress “less than expected” relative to those with no, or very little, focus on health.

Rehabilitation services to developmental outcomes

Self-care performance (CEDL-self-care): Children were more likely to progress “more than expected” when there was a greater focus on health/well-being (OR=1.36 95% CI 1.11, 1.65), corresponding to a RR of 2.9. Children receiving services with the greatest focus on health/well-being are almost 3 times as likely to be progressing “more than expected” than those with no, or very little, focus on health.

Discussion:

Relationships of service variables to the percentile classification changes (progressing “more than” and “less than” to the reference of “as expected”) yielded interesting information. Collectively, in regards to the amount of therapy services, evidence suggests that there is not a simple cause-effect relationship between amount and intervention outcomes, especially when analyzed using observational designs.^{3, 8-10} Our findings suggest that the child’s gross motor function level, which has been shown to be relatively stable across time,³¹ how services are provided (family-centered, address parent perception of child needs), and the focus of services are important considerations that are not reflected in amount of service. We do not know what the relationship of service amount would be to individualized goal attainment or family outcomes. We also do not know if service amount was decreased, if progress of the outcomes measured would also decrease. Changes in movement ability are thought to relate to the amount of time individuals are able to practice throughout the day. This aspect of therapy intensity is difficult to capture and was not measured in our study.

Family-centeredness was associated with developing “more than expected” in family/recreational participation frequency, which agrees with previous research.¹⁰⁻¹³ This was also associated with the 6MWT distance, which suggests a relationship with activity outcomes. Parents’ rating of the extent they perceive services were meeting their children’s needs was associated with family/recreational participation frequency and is consistent with our earlier Move & PLAY study.⁸⁻¹⁰ It also resonates with comments from seven parents of children with CP (members of the On Track study research team), who indicated they understand their children and have knowledge about their children’s abilities and needs. These findings suggest positive outcomes when therapists discuss and collaborate with families as service decisions are made and value the families’ thoughts and desires.

Therapy focus on health/well-being and on structured play/recreation activities was related to family/recreational participation frequency, again supported by previous research.^{9,13} A focus on children’s health and well-being as a protective **intervention** to prevent “less than expected” development, and a focus on structured practice of play/recreation activities to promote “more than expected” participation, therefore, should be considered when providing rehabilitation services. Despite a general report by parents of a strong focus on primary and

Rehabilitation services to developmental outcomes

secondary body structure/function interventions during therapy, these focus variables did not predict the balance or walking endurance percentile classification changes. Given that both the ECAB and 6MWT measure functional ability, this provides some support to previous findings that therapy directed at the ICF body structure/function level may not transfer to the activity level.¹³⁻¹⁴ **We also did not find a relationship of environmental modifications to our outcomes. This may have been due to the larger number of children at GMFCS Level I and II.**

Limitations:

Services data were collected from parents rather than directly from therapists; therefore, they represent estimates from the parents' perspectives and may not reflect how therapists would report their services.¹⁶ **Parents were, however, asked to discuss/consult with their children's therapists when reporting the focus of services; 14.5% indicated that they did consult when answering the services questionnaire. Parent's rating of their perceptions that their children's needs were being met may represent psychological aspects, and parents' satisfaction with services could present a placebo-effect.** Services amount and focus were not manipulated within the study, so conclusions about the comparative effectiveness of services are not recommended. Nonetheless, the analytic approach is novel and sheds some light on the question.

Future research to explore services relationship to outcomes should include studies of interventions to achieve certain goals versus global outcomes, interventions timed to readiness of the child for changes in motor behavior, and prospective studies of the manipulation of service amount and practice time to long-term outcomes.

Conclusion:

Our findings from a prospective cohort study of 656 participants indicate that the amount of therapy children with CP receive was most related to their functional ability level. Our hypotheses that children with the most optimal change would have services with more focus on practice of specific tasks (a focus on structured play/recreation activities), more family-centeredness, and parents would report that their children's needs were being met to a great extent by their rehabilitation services were modestly supported for our participation outcome. We also found clinically meaningful support for beneficial associations of a focus on health/well-being to higher development of participation in family/recreational activities and performance of self-care activities. Findings from services to outcomes analyses underscore the importance of emphasis on overall aspects of holistic care, as well as considering children's overall health/well-being and participation.

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Rehabilitation services to developmental outcomes

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Rehabilitation services to developmental outcomes

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Rehabilitation services to developmental outcomes

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Rehabilitation services to developmental outcomes

Table I: Child and Parent Respondent Demographics: Baseline and 12-month Assessments

		Participants	
		Baseline Completed n = 708 (%)	12-Month Completed n = 656 (%)
Child Age, years	Mean (SD)	6.01 (2.68)	7.07 (2.70)
	Minimum - Maximum	1.5 – 11.9	2.4 – 13.0
Child Gender	Male	396 (56)	369 (56)
	Female	312 (44)	287 (44)
Child GMFCS Level	I	227 (32)	217 (33)
	II	161 (23)	147 (22)
	III	80 (11)	73 (11)
	IV	129 (18)	116 (18)
	V	111 (16)	103 (16)
Child Distribution of Involvement*	Monoplegia	8 (1)	8 (1)
	Hemiplegia	198 (28)	184 (28)
	Diplegia	184 (26)	172 (26)
	Triplegia	39 (6)	38 (6)
	Quadriplegia	278 (39)	253 (39)
Child race*	American Indian/Alaska	15 (2)	11 (2)
	Asian	40 (6)	37 (6)
	Black/African American	60 (8)	56 (8)
	White	503 (72)	472 (73)
	Multi	81 (12)	73 (11)
Child ethnicity*	Hispanic	49 (7)	43 (7)
	Non-Hispanic	654 (93)	610 (93)
	Aboriginal	31 (4)	26 (4)
	Non-Aboriginal	672 (96)	627 (96)
Parent respondent race*	American Indian/Alaska	15 (2)	12 (2)
	Native		
	Asian	51 (7)	45 (7)
	Black/African American	56 (8)	52 (8)
	White	550 (79)	517 (80)
Parent respondent ethnicity*	Multi	26 (4)	22 (3)
	Hispanic	32 (5)	30 (5)
	Non-Hispanic	669 (95)	621 (95)
	Aboriginal	20 (3)	16 (3)
Parent respondent age, years*	Non-Aboriginal	681 (97)	635 (97)
	Mean (SD)	37.8 (7.9)	37.9 (8.0)
Parent respondent relationship to child* Baseline (n = 704)	Mother	628 (89)	578 (88)
	Father	51 (7)	51 (8)
	Other	25 (4)	25 (4)
Parent respondent education*	High School or less	160 (23)	147 (23)
	Community College / Associate's Degree	212 (30)	196 (30)
	University	328 (47)	307 (47)
Family Income*	≥\$75,000	306 (52)	293 (53)
	\$60,000 - \$74,999	78 (13)	72 (13)
	\$45,000 - \$59,999	50 (8)	47 (8)
	\$30,000 - \$44,999	58 (10)	49 (9)
	≤\$30,000	102 (17)	92 (17)
Family Composition	Adults (mean, SD)	2.1 (0.7)	2.1 (0.7)
	Children (mean, SD)	2.3 (1.1)	2.3 (1.1)
Country	Canada	347 (49)	330 (50)
	United States	361 (51)	326 (50)

Rehabilitation services to developmental outcomes

GMFCS = Gross Motor Function Classification System Level; CAD = Canadian Dollars; USD = United States Dollars

SD = standard deviation

* report based on the available information

Notes: "mother" includes mother, adoptive mother, foster mother, or custodial mother; "father" includes father, adoptive father, or stepfather; "other" includes grandparent, nursing supervisor, or aunt.

For Review Only

Rehabilitation services to developmental outcomes

Table II. Description of Measures and Their Psychometric Properties		
MEASURE	Description	PSYCHOMETRIC PROPERTIES
Gross Motor Function Classification System (GMFCS)¹⁷	Five-level classification system based on functional movement/mobility and independence of movement. Level I represents more functional mobility and Level V, the least independence of movement.	<u>Content validity</u> : confirmed via nominal group technique and Delphi survey. ²⁷ <u>Inter-rater reliability</u> : Kappa = 0.75 for children older than 2 years
Early Clinical Assessment of Balance (ECAB)¹⁸	The ECAB addresses postural control and balance across the developmental sequence. Part I has 7 items representing balance of the head and body in prone, supine, and floor sitting. The items are scored on a scale of 0=no response to 3=complete and consistent response. Part II has 6 items testing balance in sitting, standing, and moving in standing. Items are scored on a variable scale, which is weighted as the difficulty of the items increases. Both parts are summed for a total score between 0-100. A higher score represents better balance.	<u>Content validity</u> : (n = 410) ¹⁸ established through expertise on research team; <u>Internal consistency</u> : Cronbach's alpha = 0.92; <u>Construct validity</u> : known groups study: ECAB scores differed significantly among all GMFCS levels ($p < 0.001$); correlation with GMFM = 0.97 ($p < 0.001$); Children aged less than 31 months had significantly lower ECAB scores than children aged 31-42 or 43-60 months ($p < 0.01$); <u>Factor Loading</u> : ⁸ ECAB loaded most highly onto the Move & PLAY construct of "primary impairment" with a loading of 0.95 <u>Reliability</u> : ²⁸ (n = 28 children with CP, aged 2-7 years); <u>Inter-rater reliability</u> : ICC = 0.989 (95% CI = 0.976-0.995); <u>test-retest reliability</u> (same raters) ICC = 0.987 (95% CI = 0.971-0.994); <u>test-retest reliability</u> (different raters); ICC = 0.986 (95% CI = 0.971-0.994); <u>SEM</u> = 3.6; <u>MDC95</u> = 10
Six-Minute Walk Test (6MWT)¹⁹	The 6MWT is a submaximal clinical exercise test in which the distance walked under controlled conditions in 6 minutes is measured.	<u>Concurrent validity</u> : with VO2 max = 0.44 ($p < .001$) (typical children 12-16 years); ^{19,29} <u>Test-retest reliability</u> : ICC = 0.94 (95% CI 0.89-0.96) (typical children aged 12-16 years) ¹⁹
Child Engagement in Daily Life (CEDL) Measure²⁰	The CEDL is a 30-item questionnaire developed by the research team. Part one of the CEDL captures interaction with others and play; specifically, participation of the child in family/community life and leisure/recreational activities. This domain is scored on two 5-point Likert scales: how often a child participates (very often to never) and how much they enjoy their participation (very much to not at all). Part two measures self-care, defined as the degree that the child participates in his or her daily self-care activities (feeding, dressing, bathing, and toileting). The 5-point Likert ratings for daily self-care activities (from yes, initiates and performs consistently to no, unable) distinguish the need for physical assistance of an adult and, for children who do not require adult assistance, whether the child is able to perform the activity consistently.	<u>Construct validity</u> : (n = 429 in Move & PLAY and 110 children developing typically); <u>Internal consistency</u> : Cronbach's alpha Participation = 0.86 (frequency), 0.91 (enjoyment), Self-care = 0.90; <u>Known groups validity</u> : 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 2 older age groups ($p < 0.001$) in GMFCS levels I-III only. All motor ability groups performed significantly differently ($p < 0.001$). <u>Rasch analysis</u> : Participation performed well; self-care has been improved by adding items of intermediate difficulty for use in the On Track study <u>Test-retest reliability</u> : (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) <u>Analysis as an evaluative measure</u> : ³⁰ (n = 387): <u>Sensitivity to change over the period of 1 year</u> : participation and self-care had significantly higher scores at the end of 1 year for children in GMFCS Levels I and II and III ($p < 0.01$); effect sizes for

Rehabilitation services to developmental outcomes

	<p>participation, were 0.22, 0.34, and 0.13 for children in GMFCS Levels I vs II and III vs IV and V, respectively; for self-care were 0.56, 0.58, and 0.08 for children in Levels I, II and III, and IV and V, respectively.</p> <p>Psychometric properties of the new 29-item version (expanded and revised to be appropriate for children up to 12 years of age) are being re-calculated within the On Track Study.</p>
<p>Services Questionnaire³</p> <p>The questionnaire includes: number of primary care visits, medical service visits, medical and surgical procedures, and community programs, coordination of care, and the variables used in this study:</p> <p>1) <u>Amount of physical, occupational, and speech and language therapy services, # of sessions and average time in sessions</u></p> <p>2) <u>Focus of Therapy:</u></p> <p>a) Primary impairments (relaxation of spastic muscles, physical guidance of movement, balance, etc.);</p> <p>b) Secondary impairments (stretching, strengthening, fitness);</p> <p>c) Activities to improve self-imitated abilities and use hands;</p> <p>d) Environment (assistive devices, equipment, home/school modifications);</p> <p>e) Self-care routines;</p> <p>f) Participation (play/recreational/leisure participation);</p> <p>g) Self-awareness and motivation (child's adaptive behavior);</p> <p>h) Health and well-being.</p> <p>Measurement scale: 0 = not sure 1 = not at all 2 = to a small extent 3 = to a moderate extent 4 = to a great extent 5 = to a very great extent</p> <p>3) <u>Family Centeredness:</u> Eleven items including areas such as: involvement of the child and family in the therapy program, facilitation of family routines, using the child's environments and toys, providing community resources, collaborative discussion/coordination of therapy plans.</p> <p>Measurement scale: 1 = not at all 2 = to a small extent 3 = to a moderate extent 4 = to a great extent 5 = to a very great extent</p> <p>4) <u>Extent services met their children's needs:</u> Motor abilities, self-care abilities, participation in play/recreation/leisure, and overall health.</p> <p>Measurement scale: 1 = not at all 2 = to a small extent 3 = to a moderate extent 4 = to a great extent 5 = to a very great extent</p>	<p><u>Content validity:</u> via experienced clinician review</p> <p><u>Test-retest reliability:</u> Amount of therapy visits ICC = 0.92; Focus of therapy services ICC = 0.55 – 0.95; Family-Centeredness ICC = 0.86; Number of Recreation and Leisure Programs ICC = 0.95; Coordination of Services ICC = 0.88; Perception that Services meeting needs ICC = 0.61</p>

Rehabilitation services to developmental outcomes

Table III: Descriptive Data on Services Received at the 12-month Assessment

Service	Gross Motor Function Classification System (GMFCS)				
	Level I n = 217	Level II n = 147	Level III n = 73	Level IV n = 116	Level V n = 103
Amount of Therapy	Median Number of Sessions Categories				
Occupational Therapy sessions	2-30	2-30	2-30	2-30	2-30
Physical Therapy sessions	2-30	2-30	31-52	31-52	31-52
Speech Therapy sessions	0-1	2-30	2-30	2-30	2-30
Focus of Therapy Visits:	Mean (SD)				
Primary Impairments (relaxation of spastic muscles, physical guidance of movement, etc.)	3.3 (1.4)	3.7 (1.3)	3.7 (1.2)	3.8 (1.2)	3.9 (1.1)
Secondary Impairments (stretching, strengthening, fitness)	3.8 (1.3)	4.0 (1.1)	4.0 (1.1)	4.0 (1.1)	3.9 (1.3)
Activities to improve self-initiated abilities	3.4 (1.5)	3.8 (1.4)	4.2 (1.0)	4.0 (1.0)	3.3 (1.4)
Environment (assistive devices, equipment, home/school modifications)	2.4 (1.5)	3.5 (1.4)	3.6 (1.2)	3.8 (1.1)	3.5 (1.3)
Self-care routines	2.2 (1.3)	2.6 (1.4)	2.9 (1.3)	2.4 (1.2)	2.1 (1.2)
Participation (structured play/recreational/leisure activities)	2.7 (1.5)	3.1 (1.5)	3.3 (1.2)	3.3 (1.1)	3.1 (1.2)
Self-awareness and motivation	3.0 (1.4)	3.3 (1.4)	3.3 (1.3)	3.2 (1.3)	2.8 (1.4)
Health and well-being	2.9 (1.4)	3.0 (1.4)	3.1 (1.3)	3.1 (1.3)	2.8 (1.3)
Family Centeredness	3.4 (0.9)	3.4 (0.9)	3.4 (0.8)	3.5 (0.8)	3.4 (0.8)
Needs met by services	3.8 (1.0)	3.6 (0.8)	3.5 (0.8)	3.5 (0.7)	3.3 (0.8)

SD = standard deviation

Note: Exact number of participants for each variable of interest is available on the study website.

Rehabilitation services to developmental outcomes

Table IV: Likelihood Ratio Tests Results for Service Variables Predictions of Outcomes.

Separate multinomial regression models were fit for each outcome and service variable, controlling for country.

Variables	Child Engagement in Daily Life—Participation		Child Engagement in Daily Life—Self Care		Early Clinical Assessment of Balance		Six-Minute Walk Test	
	χ^2	p	χ^2	p	χ^2	p	χ^2	p
PT sessions/year	0.65	0.72	0.90	0.64	1.83	0.40	0.17	0.92
OT sessions/year	1.18	0.55	0.45	0.80	1.19	0.55	1.97	0.37
ST sessions/year	4.06	0.13	0.11	0.95	0.75	0.69	3.43	0.18
Family-centeredness	8.41	0.02	4.00	0.14	0.94	0.62	7.13	0.028
Needs met by services	7.89	0.02	4.29	0.12	3.12	0.21	2.48	0.29
Focus on primary impairments	3.17	0.21	3.58	0.17	0.27	0.87	2.74	0.25
Focus on secondary impairments	1.24	0.54	4.21	0.12	4.04	0.13	0.74	0.69
Focus on activities to improve self-initiation	3.20	0.20	1.37	0.51	2.65	0.27	0.84	0.66
Focus on environment	2.39	0.30	0.72	0.70	1.68	0.43	0.99	0.61
Focus on self-care routines	4.09	0.13	0.23	0.89	2.98	0.23	3.37	0.19
Focus on participation	10.28	0.01	0.78	0.68	0.92	0.63	0.61	0.74
Focus on self-awareness and motivation	4.58	0.10	3.27	0.20	4.50	0.11	0.29	0.87
Focus on health/well-being	6.33	0.04	10.37	0.01	0.77	0.68	1.26	0.53

Bolded values correspond to the service variables with likelihood ratio test p -values of <0.05

Degrees of freedom = 2 for all analyses PT = Physical Therapy OT = Occupational Therapy ST = Speech Therapy

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Supplemental Table: Odds ratios of a one-unit level increase in services and relative risk of those receiving the highest level of service relative to the lowest level of service for 13 multinomial regression models examining the relationship between development and services, from Table 4.

	Child Engagement in Daily Life -Participation				Child Engagement in Daily Life -Self Care				Early Clinical Assessment of Balance				Six-Minute Walk Test			
	Better Than Expected		Less Than Expected		Better Than Expected		Less Than Expected		Better Than Expected		Less Than Expected		Better Than Expected		Less Than Expected	
	RR	OR	RR	OR	RR	OR	RR	OR	RR	OR	RR	OR	RR	OR	RR	OR
PT sessions/year	0.78	1.05	0.74	1.06	0.69	0.90	0.79	0.93	1.81	1.19	1.04	1.01	1.17	1.05	1.22	1.06
OT sessions/year	0.92	0.95	0.59	1.27	0.78	0.93	1.19	1.05	1.63	1.15	0.93	0.98	0.83	0.95	2.21	1.27
ST sessions/year	2.17	0.86	0.69	1.28	1.09	1.03	1.14	1.04	1.38	1.10	1.23	1.06	0.60	0.86	2.27	1.28
Family centeredness	3.95	0.83	0.48	0.57	3.05	1.37	1.28	1.07	1.22	1.06	1.64	1.15	0.52	0.83	0.16	0.57
Needs met by services	4.14	0.87	0.57	0.75	3.05	1.37	0.82	0.95	1.54	1.13	0.48	0.81	0.63	0.87	0.39	0.75
Focus on primary impairments	1.73	0.88	0.73	0.83	1.99	1.21	1.31	1.08	1.01	1.00	1.20	1.05	0.64	0.88	0.54	0.83
Focus on secondary impairments	1.21	1.13	0.70	0.96	2.33	1.27	1.38	1.09	1.71	1.16	1.96	1.21	1.53	1.13	0.87	0.96
Focus on activities to improve self-initiation	1.91	0.90	0.90	0.94	1.43	1.11	1.28	1.07	1.39	1.10	1.64	1.15	0.70	0.90	0.81	0.94
Focus on environment	1.66	0.89	1.09	1.03	1.31	1.08	1.06	1.02	1.09	1.02	1.48	1.12	0.67	0.89	1.09	1.03
Focus on self-care routines	2.00	0.90	1.06	1.22	1.00	1.00	1.18	1.05	0.89	0.97	1.71	1.17	0.70	0.90	1.95	1.22
Focus on participation	2.55	0.97	0.61	0.91	1.34	1.09	0.99	1.00	1.37	1.10	1.07	1.02	0.91	0.97	0.73	0.91
Focus on self-awareness and motivation	1.91	0.96	0.77	0.94	1.70	1.16	0.80	0.94	1.84	1.19	1.49	1.12	0.86	0.96	0.82	0.94
Focus on health/well-being	1.46	0.92	0.48	0.87	2.90	1.36	0.83	0.95	1.34	1.09	1.07	1.02	0.76	0.92	0.63	0.87