


# Single-centre parental survey of paediatric rehabilitation services for children with cerebral palsy

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## ABSTRACT

Cerebral palsy (CP) is the most common childhood motor disability. The dose of usual care for rehabilitation therapies is unknown. The purpose of this study was to describe current dosage of rehabilitation services for children with CP recruited from a paediatric hospital system in the USA. 96 children with CP were included in this cross-sectional survey. Parents reported frequency, intensity, time and type of therapy services. Weekly frequency was the most common. Children with CP received 0.9–1.2 hours/month of each discipline in the educational setting and 1.5–2.0 hours/month in the clinical setting, lower than the recommendations for improvements in motor skills.

## INTRODUCTION

Cerebral palsy (CP) is the most common motor disability for children.<sup>1</sup> Many children with CP demonstrate motor and speech impairments, warranting referrals to rehabilitation services (physical therapy (PT), occupational therapy (OT), speech and language pathology (SL/P)) to maximise independence.<sup>1,2</sup> Services are provided in educational (school) and/or clinical (outpatient) settings. The dosage of health service models for rehabilitation can be operationally defined by frequency (how often), intensity (repetitions or child effort), time (how long) and type (discipline and/or treatment) of intervention.<sup>3</sup> The purpose of this study is to describe usual care for rehabilitation disciplines, PT, OT and SL/P recruited from a single centre in the USA.

## METHODS

For this cross-sectional survey, 96 children with CP of all severity levels aged 2–8 years (4.9±2.1 years) were recruited to participate. Most of the children in the study participated in a larger pragmatic clinical trial (NCT02897024) comparing the effectiveness of two intensities of PT in an outpatient setting. All data described here are prior to initiation of the clinical trial. Usual care for

rehabilitation services the child received in the prior 6 months was gathered via parent report (see online supplemental file 1).

## Patient and public involvement

Patients/parents were not involved in the study design.

## RESULTS

**Table 1** summarises all rehabilitation services. About half to most children received PT, OT and SL/P in educational and clinical settings. For those receiving therapy, the most common frequency was weekly, regardless of setting or discipline. Children with CP received between 0.9 and 1.2 hours of therapy for each discipline (PT, OT and SL/P) per month in the educational setting for a mean combined total of PT, OT and SL/P services for 1.0 hours/month. They receive between 1.5 and 2.0 hours of therapy for each discipline per month in the clinical setting for a mean combined total of 1.8 hours/month.

## DISCUSSION

The results of this study indicate weekly frequency of rehabilitation services was most common, regardless of discipline or where the services were delivered. This work joins others that reported weekly frequency as the most common in 2012, where the authors suggested this frequency was based on convention (such as scheduling).<sup>4</sup> The results from this study may suggest that children with CP receive low total hours of PT, OT and SL/P per month in educational and clinical settings. A recent review found that 14–25 hours of goal-directed rehabilitation is needed to achieve an individual goal, and 30–40 hours of rehabilitation is needed for a change in motor ability for children with CP.<sup>5</sup> This is important because if children are receiving 1–2 hours of a specific discipline per month, they are (1) being ‘under-dosed’ for change in motor/

**Table 1** Summary of all rehabilitation services: number of participants enrolled, frequency and hours/month

| Educational setting |           |               |                  |
|---------------------|-----------|---------------|------------------|
|                     | n (%)     | Frequency (%) | Mean hours/month |
| PT                  | 52 (61.2) | Weekly (47.1) | 1.2              |
| OT                  | 51 (60.7) | Weekly (45.2) | 1.0              |
| SL/P                | 44 (51.7) | Weekly (41.2) | 0.9              |
| Clinical setting    |           |               |                  |
| PT                  | 54 (61.4) | Weekly (43.2) | 2.0              |
| OT                  | 45 (51.7) | Weekly (31.0) | 1.5              |
| SL/P                | 40 (45.5) | Weekly (34.1) | 2.0              |

OT, occupational therapy; PT, physical therapy; SL/P, speech and language pathology.

speech skills, (2) the intervention may be primarily delivered by the family outside of a clinical or educational setting, or (3) a combination of these scenarios.<sup>5</sup> If children are being underdosed, this suggests there may be an inadequate amount of rehabilitation treatment delivered in usual care. Home programmes delivered by the family can be effective if feedback, repetition and self-initiated movement of the child are considered.<sup>5</sup> If families are providing treatment via a home programme then information about efficacy, caregiver burden and quantification of the dose at home is needed.<sup>6</sup> It is unlikely that the dosages of rehabilitation services reported by parents are improving motor skills to the best extent possible based on the currently available evidence. While assuring efficacy of treatment, future work could consider implementation strategies to promote evidence-based doses that consider frequency, intensity, time and type in the plan of care. Limitations include: (1) participants were recruited from a single hospital system, and (2) survey data relied on parent report with potential for recall bias.

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**Contributors** SH, RF and JCH developed the parent questionnaire to record medical history and neurorehabilitation dose. RB and JCH collected the data.

RB, SH, RF and JCH were involved in writing, editing and revising sections of the manuscript. JCH serves as the primary guarantor.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The procedures described in this manuscript were approved by the Institutional Review Board (Buck-IRB) at The Ohio State University (2016N0031).

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**ACHIEVE Therapy Record Form**

Study ID: \_\_\_\_\_

Caregiver: \_\_\_\_\_

Timepoint: Baseline

Date: \_\_\_\_\_

As part of the ACHIEVE program, we would like to keep track of your child's past, present and future participation in therapy services and recreational physical activities. Please indicate whether your child has participated in the following therapies or physical activities and answer the associated questions. Each box does not need to be filled out if it is not applicable to your child. Please carefully look at each column heading in order to choose the correct frequency of therapy.

**Past Therapy Services and Physical Activities** (prior to starting the ACHIEVE program)

|  | <b>Weekly</b>                                    | <b>Every Other Week</b>                          | <b>Once a Month</b>                              | <b>Intensive Program</b>  | <b>Other: _____</b>                              |
|--|--|--|--|---|--|
| <b>Outpatient Physical Therapy</b>       | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |
| <b>Outpatient Occupational Therapy</b>   | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |
| <b>Outpatient Speech Therapy</b>         | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |
| <b>School-based Physical Therapy</b>     | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |
| <b>School-based Occupational Therapy</b> | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |
| <b>School-based Speech Therapy</b>       | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date: | Minutes per session:<br>Start date:<br>End date:<br>Number of sessions: | Minutes per session:<br>Start date:<br>End date: |