

# Facts To Go ...

## Parents' Experiences of Classifying their Children with Cerebral Palsy & Recommendations for Family-Centered Care

### Introduction

Three classification systems are routinely used to provide a functional profile of children with cerebral palsy (CP). The **Gross Motor Function Classification System**<sup>1</sup> (GMFCS) classifies gross motor performance, the **Manual Ability Classification System**<sup>2</sup> (MACS) classifies hand use and object manipulation, and the **Communication Function Classification System**<sup>3</sup> (CFCS) classifies the receiving and sending of information. Each system has five levels of function, with level I being the highest level of function and level V being the lowest level of function. The GMFCS<sup>4</sup> and MACS<sup>5</sup> also have evidence of stability, as the classification level of most children do not change over time.

The **On Track** study is a multi-site collaboration across Canada and the United States that aims to create developmental trajectories of children with CP. These trajectories can be used by service providers and families to discuss the child's areas of strength and areas for improvement, to set goals, and to plan for the future.

One of the methods for the On Track study is a **consensus classification**,<sup>6</sup> where a parent classifies their child's levels of function using the GMFCS, MACS, and CFCS and then discusses the classifications with the therapist assessor to reach consensus on the child's levels of function. The consensus classification method has a number of benefits for both parents and therapists. A fuller picture of the child's function throughout the day can be

obtained by involving parents in the classification process, as parents are most familiar with their child's usual performance as opposed to their optimal capability.<sup>7</sup> Additionally, parents can speak to the child's motor function in a variety of environmental settings.<sup>8</sup> Involvement in the classification process allows information to be more accessible and may address family needs.

However, a gap in knowledge exists with respect to how parents respond to classifying their children's levels of function and how they understand and utilize this information. Further, no studies to date have examined parents' perspectives about having prognostic discussions with therapists, and how they experience receiving this type of information.

### Purpose of this Summary

This summary outlines the findings of a published manuscript entitled *Parents' experiences and perceptions when classifying their children with cerebral palsy: Recommendations for service providers*.<sup>9</sup> The objectives for the qualitative research study described in this paper were to: a) understand parents' experiences of classifying their children using the GMFCS, MACS, and CFCS, b) understand parents' perceptions regarding the usefulness of these systems relating to current and future function, and c) collate parents' recommendations for service providers on how to facilitate a family-centered approach when communicating information.

## What was Done

**Semi-structured interviews** were conducted with seven mothers who participated with their children in the On Track study. Parents were intentionally selected to represent a range of children's ages, functional abilities, and level of consensus with therapists (i.e., agreed on classification levels, disagreed on classification levels, or agreed on classification levels after discussion and revision).

Each interview lasted between 30 to 60 minutes and followed an interview guide of 8 to 12 questions focusing on parents' prior exposure to classification systems, experience using the systems, perceptions of system utility, and advice for service providers. Parent responses were audiotaped, transcribed, and analyzed by the researchers to develop meaningful themes and conclusions.

## Study Findings & Discussion

Participants expressed a **range of experiences and perceptions** when describing their experiences with the classification systems. The functional abilities of their children seem to have influenced parents' experiences, similar to previous research findings.<sup>10</sup> For example, a participant whose child's gross motor function was classified as level V (limited self-mobility) talked about her experience being negative, overwhelming, and frustrating. To this participant, the systems seemed to have a disability focus and did not capture everything. In contrast, two participants whose children's gross motor function was classified as level I (walk in all settings) talked about how the criteria were appropriate, easy to understand, and perceived as a checklist of abilities.

Most participants viewed discussion of the classification systems positively and as a means of facilitating further understanding of these systems. Therapists often clarified and explained distinctions between levels of function so that parents could better

understand why and how they are used. This suggests that an **honest and direct conversation** between parents and service providers about the use of the classification systems is beneficial to parents and can help address their desire for information.<sup>11,12</sup>

Most parents had a general idea that their children were most likely to develop within the same level of function over time, and seemed to respond well to having a conversation with the interviewer about prognosis. This positive response suggests that parents were **open to discussions about future function** and found this type of information useful in terms of practical planning for the future and developing realistic expectations.

Some participants said that they did not see the use for these classification systems in day-to-day life, but did see them as useful in terms of securing services, advocating for their children, and communicating about their children with others. Most participants also acknowledged the clinical usefulness of the classification systems. All of the participants used the classification systems and discussion with therapist assessors as a means to reflect on how far the child has developed, set achievement goals, and track progress.

Given these various perceptions of usefulness cited by parents, there appears to be a **personal and holistic benefit** to using the classification systems in practice as well as involving parents in this process.

**Six recommendations** for service providers emerged from this study:

1. Acknowledge individual parent reactions;
2. Make the child a priority;
3. Use an individualized, holistic approach;
4. Facilitate a positive, open dialogue;
5. Foster connections;
6. Be a dependable resource.

These recommendations are elaborated on in detail in the “Tip Sheet” provided within the original manuscript.

Lastly, the formation of **strong partnerships with children and families** is very influential in determining how parents interact with service providers and how supported and satisfied they feel. This concept has been highlighted in other studies,<sup>12-14</sup> further emphasizing its importance in influencing parents’ experiences with clinical services and staff.

### Conclusion and Implications

Knowledge of parents’ experiences when using the GMFCS, MACS, and CFCS can provide useful insight for service providers collaborating with parents to classify function of children with CP. Using parents’ recommendations can facilitate family-centered care and meaningful collaboration for goal setting and rehabilitation planning.

### Acknowledgements

Thanks to Barb Galuppi, project coordinator at *CanChild*, and Liz Lusk, physical therapist at TVCC, for assisting with participant recruitment. We would like to thank the parent participants for sharing their experiences and perspectives so openly. This project was funded by a Canadian Institutes of Health Research Operating Grant (MOP #119276) as part of the On Track study.

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