

Daily Living Transactions: Understanding how children and carers work together to complete daily living tasks and routines when the child has cerebral palsy.

Robyn Heesh

Bachelor of Occupational Therapy

Master of Health Science Research (Occupational Therapy)

School of Allied Health,  
Australian Catholic University  
Melbourne, Victoria  
Australia

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## STATEMENT OF SOURCES

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the Human Research Ethics Committee (HREC), at Australian Catholic University (HREC registration number 2016- 112H).

Robyn Heesh

23/07/2018

Date

## STATEMENT OF APPRECIATION

This thesis is based on working as an occupational therapist with children with cerebral palsy, and their families over the past 20 years. These experiences have led me to the realisation that all children have the capability to learn and be active in their lives. To assist me to launch from this clinical understating and translate it to research, I was very fortunate to have the A team. I was privileged to have Christine Imms as a supervisor. I would like to thank Christine for sharing her vast expertise and wisdom, her respect and faith in the project and her endless patience. Sue Greaves was instrumental in helping me to move into the world of research, and I thank her for encouraging me to “stop talking about it and just get on with it”. Thank you to Sue for her open and welcoming door, frank words of advice and practical clinical insights. A heartfelt thanks to Loretta Sheppard for her unfailing good will, faith in the project, and ongoing support.

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## LIST OF ABBREVIATIONS

AAC	Augmentative and alternative communication
ADL	Activities of daily living
CFCS	Communication Functional Classification System
CPCHILD	Caregiver Priority and Child Health Index of Life with Disability
EDACS	Eating and Drinking Classification System
GMFCS	Gross Motor Functional Classification System
HRQOL	Health related quality of life
MACS	Manual Ability Classification System
<i>M</i>	Mean
PEDI	Pediatric Evaluation of Disability Inventory
PODD	Pragmatically organised dynamic display (communication book)
<i>SD</i>	Standard deviation
SEIFA	Socio-economic index for areas
TD	Typically developing
VCPR	Victorian Cerebral Palsy Register

## ABSTRACT

*Objective:* This research explored how children with cerebral palsy (CP) functioning at Gross Motor Function Classification System (GMFCS) levels IV and V work together with their carers to complete daily routines. It aimed to investigate the activities and skills that are important and may inform goal setting and intervention planning for children and carers.

*Design:* An explanatory sequential mixed methods study.

*Method:* Non-ambulant children (GMFCS IV and V) aged 5-18 years and their carers were recruited from the Victorian Cerebral Palsy Register. A study specific survey and the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD), were used to describe the children, carers, and their daily routines. Descriptive statistics were used to rank routines according to importance, level of assistance and difficulty. Data collected from video elicited interviews in the homes of five child/carer pairs was then analysed using qualitative methodology. The thematic analysis of the interviews examined what happened and the transactions between child and carer that occur during daily routines.

*Results:* Survey data were obtained from 78 carers of children with CP (child mean age 12.3 years, *SD* 3.7 years; female *n*=39; GMFCS IV, *n*=23). Nine young people also completed the youth version of the CPCHILD. All routines were rated as important. Some were completed with greater ease and higher rates of independence, with some children able to contribute to easier routines such as sitting in a wheelchair, eating, and moving indoors/outdoors. Findings from the five child/carer interviews highlighted how carers and children work together during routines. Themes were derived describing how families negotiate a busy life, and the child, carer and contextual factors that influence routines and that change on a daily basis. Children

used a range of small but important skills that contributed to the completion of daily routines, such as closing their hands for upper limb dressing, leaning forward for hygiene routines, and relaxing their body to be hoisted safely.

*Conclusion:* Children with CP functioning at GMFCS levels IV and V will always need assistance, but there are small skills and actions that they can learn and use to positively influence daily routines. In-depth examination of five child/carer pairs provided rich information about how they work together to complete routines, even on ‘difficult’ days. This new and important knowledge may inform therapy interventions that addresses and value the skills of both the child and their carer that are useful during daily routines.

## **CHAPTER 1: INTRODUCTION AND OVERVIEW OF THE THESIS**

The overall focus of this research was to further understand the daily routines of children with cerebral palsy who were non-ambulant and required assistance from a carer, and to explore how children and carers worked together in daily life to complete important routines. This chapter provides an overview of background literature to support the overall purpose, the significance of the research and includes a summary of the structure of the thesis.

### **Background**

Cerebral palsy is an umbrella term for a group of disorders that are permanent, but not unchanging, and involve a disorder of posture and movement due to a non-progressive lesion to the developing brain. Cerebral palsy may also be accompanied by secondary effects such as disturbances in cognition, sensory perception, communication, and the presence of epilepsy or musculoskeletal issues (Rosenbaum et al., 2007). The prevalence of cerebral palsy as reported by the Australian Cerebral Palsy Register (ACPR) is 2.1 per 1000 live births (ACPR, 2016). Associated conditions are common in children with cerebral palsy and along with motor type and distribution of cerebral palsy, can affect learning and capabilities in daily life. The ACPR reported the prevalence of associated conditions at age five years as: intellectual impairment (48%), epilepsy (28%), speech (61%), visual (34.4%) and hearing (11.5%) impairment.

Functional outcomes for children with cerebral palsy vary considerably and can be described using classification systems in the domains of mobility, hand use, communication and eating. The Gross Motor Functional Classification System (GMFCS) (see Appendix A) has five scales describing the daily mobility of children with cerebral palsy (Palisano et al., 2000). The Manual Ability Classification System (MACS) (see Appendix B) classifies the

ability of children to handle age appropriate objects during daily activities (Eliasson et al., 2006). The Communication Function Classification System (CFCS) (see Appendix C) describes the effectiveness of communication performance as a sender and receiver of information (Hidecker et al., 2011) and the Eating and Drinking Ability Classification System (EDACS) (see Appendix D) describes the eating and drinking ability of children with cerebral palsy (Sellers, Mandy, Pennington, Hankins, & Morris, 2014). Each classification system has a scale with five levels ranging from I to V, where level V describes children with poorer abilities and level I, children with better abilities. For ease of reading the phrase “children at GMFCS IV and V” will be used in this thesis instead of “children with cerebral palsy functioning at GMFCS level IV and V.”

Children at GMFCS IV and V are the focus of this research. They tend to perform more poorly than other children in functional assessments, have increased frequency of associated conditions and therefore require more support and resources in daily life (Ward et al., 2014). There are many studies that compare children at GMFCS IV and V to children with milder forms of cerebral palsy or typically developing children, and subsequently these poorer outcomes for children at GMFCS IV and V are well established in the literature (Phipps & Roberts, 2012). The focus of research involving children at GMFCS IV and V is often on medical or surgical intervention, with little information about what is useful for children to learn to support their participation in daily life (Novak et al., 2013). This current research aimed to provide insights that focus on the strengths and explore the narratives of this group of children to highlight and describe what they can do in daily life with assistance from their carers.

Daily routines are made up of simple or complex actions and tasks that meet the requirements of usual day-to-day procedures such as getting dressed, attending to personal hygiene and getting to school (World Health Organization, 2007). The completion of tasks during a daily routine for a young child and carer can be viewed as a transaction. This transaction comprises of the actions of the child, actions of the carer and the context within which the routine occurs. Change within the system of child, carer and context is a dynamic process, where change in one part of the system drives and effects change in other parts of the system (Sameroff & Mackenzie, 2003). This can be part of learning for all children. As a typically developing child gains skills, the carer responds by providing less assistance and therefore contributing to the development of further independence. Children without impairments will usually be independent in many aspects of daily routines by five years, becoming gradually less physically reliant on their carers as they grow (Bundy & Lane, 2012). For consistency of language, persons aged between 5 and 18 years will be subsequently referred to as “children” for the purposes of this thesis.

Children with cerebral palsy develop and learn skills in daily life in a way that is likely to be different and take more time than other children. Children with milder forms of cerebral palsy (GMFCS I-III) may take longer to become independent and may still require assistance from a carer for some difficult daily tasks but are likely to develop independence. However, children at GMFCS IV and V are likely to require ongoing frequent assistance through childhood, adolescence and adulthood. The assistance the child at GMFCS IV and V needs in daily life is likely to require a physical closeness with the carer, which could be similar to the transactions that occur in daily life of young typically developing children and their carer. Although the health and well-being of carers is a critical part of how children complete daily routines, the impact on the carer of having a child with disability has already

been widely discussed in the literature. An in-depth analysis of the broader health needs of carers was therefore beyond the scope of this project. For the purpose of this research, the carer was defined as a person who takes primary responsibility for attending to practical aspects of caring for the child within daily routines and could include the mother or father, grandparent, adoptive or foster parent, other family member, or could include a long term paid carer who knows the child well.

As well as requiring extra assistance, the actions and sequence of tasks that make up a daily routine for a child at GMFCS IV or V aged 5 to 18 years is different to that of a typically developing child or a child with milder forms of cerebral palsy. The child is likely to require specialised equipment, such as an adapted shower chair or hoist. Dependence on equipment alters routines, making the child more reliant on the supportiveness of the context. The amount of equipment, the contextual set up, the variability of the skills of the child and carer and the inconsistency of performance of children with a complex movement difficulty makes daily routines different to other children.

Further understanding of the practical ways that children at GMFCS IV and V can contribute to daily life may provide information that could make tasks easier for the carer and support children to be actively engaged and influence what happens to them in their personal care routines. Currently there is a lack of evidence about the skill development of children at GMFCS IV and V and the way they interact with their carer and their context to contribute to completion of daily routines to guide our understanding of this important developmental trajectory.



### **Significance**

Knowledge gained from this study aimed to explore how skill development for children at GMFCS IV and V is likely to occur over time, is dependent on the relationship with the carer and occurs in the changing complexities of everyday life. There are areas of daily life where children can contribute more, and some areas where they may require more assistance, exploration of this was one goal of this work.

Knowledge gained from this study may benefit society by highlighting how people with significant disability are able to be more active participants in life. The research outcomes aimed to provide practical information for clinicians and carers when setting goals for therapy for children at GMFCS IV and V. As this research aimed to focus on goals in those areas of the children's function that appeared to make the most difference to families and children on a daily basis, findings may be useful in guiding intervention. What was learned may also assist carers and children to ease the effort of caregiving and contribute to the health and well-being of both carers and their children. Ultimately, these research outcomes may inform provision of therapy to specifically address important skills and actions of children, practiced within the context of carer-child transactions which occur during daily routines.

### Structure of the thesis

The thesis is presented in seven chapters as follows:

- |            |  |
|------------|--|
| Chapter 1  | Introduction   |
| Chapter 2  | Background and a structured review of the literature   |
| Chapter 3  | Outline of the extended methods for the thesis. Detailed methods of Study 1, the quantitative phase                        |
| Chapter 4a | A manuscript reporting the findings of Study 1 prepared for submission to the journal <i>Disability and Rehabilitation</i> |
| Chapter 4b | Extended discussion about the results of Study 1   |
| Chapter 5  | Detailed methodology of Study 2, the qualitative phase   |
| Chapter 6  | The findings of Study 2  |
| Chapter 7  | The overall discussion of the research findings and conclusions  |

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## CHAPTER 2: BACKGROUND

### Introduction

In this chapter, literature that focuses on the skills and development of children with cerebral palsy at Gross Motor Functional Classification System (GMFCS) IV and V, and their carers was reviewed. The use of the cerebral palsy classification systems to describe children is explored, and evidence-based interventions for children at GMFCS IV and V is outlined. Learning about these children's skills cannot be viewed in isolation. Therefore, the background to the review includes information that frames how the attainment of skills for children at GMFCS IV and V interacts with the carer and the context. In particular, a broader understanding of the health, care needs, learning and therapy needs of these children was sought to inform the overall research questions. A search of the literature was then conducted to identify research specifically about how children at GMFCS IV and V actively interacted with their carer and engaged in daily routines.

### Background

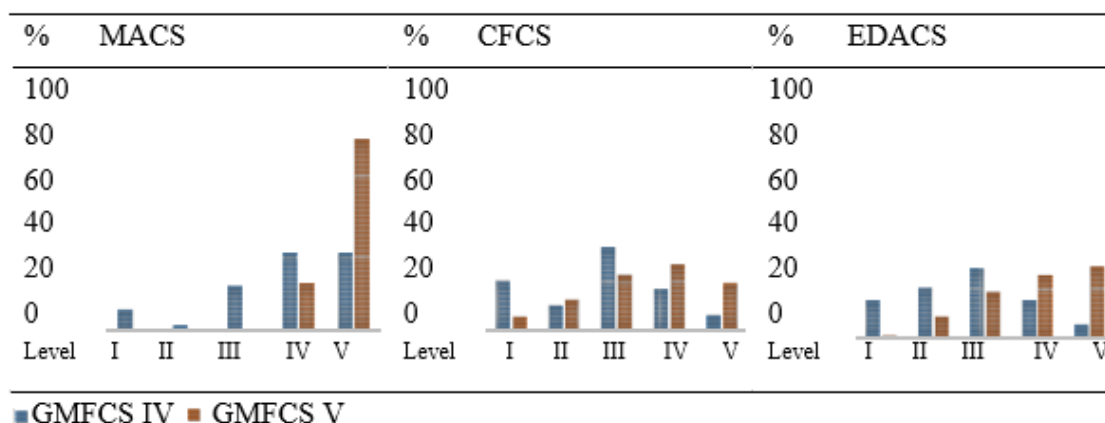
This thesis aimed to expand the understanding of how best to support children with cerebral palsy who function at GMFCS level IV or V. The latest report from the Australian Cerebral Palsy Register (ACPR) indicate that there were 7241 children, birth years 1996 and 2009, born with cerebral palsy in Australia, 2048 of them in Victoria (ACPR, 2016). Of these children, 72.4% were classified at GMFCS I to III, 12.5% at GMFCS IV and 15.1% at GMFCS V. Therefore, about 27.6% (approximately  $n = 511$ ) of children with cerebral palsy in Victoria were classified at GMFCS IV and V at that point in time. A Swedish study in 2006 reported similar proportions: 69% of children at GMFCS I to III, 15% at GMFCS IV and at 16% at GMFCS V (Himmelman, Beckung, Hagberg, & Uvebrant, 2006). European studies reported that 10% to 36% of children with cerebral palsy are in the subtype of

quadriplegic cerebral palsy (Cans, 2000), suggesting that this prevalence is consistent in Western countries. This is important as the information gathered about children in Australia in this study may be of interest to similar populations in other countries.

### **Cerebral palsy classification systems**

The cerebral palsy classification systems provide information that describes the functional abilities of children in four domains. Four systems were described in the introductory chapter of this thesis and include the GMFCS, the Manual Ability Classification System (MACS), the Communication Functional Classification System (CFCS) and the Eating and Drinking Classification System (EDACS) (see Appendices A to D). The classifications by themselves do not describe everything that is important about a child's functioning, however for the purpose of this study reviewing the patterns of how children at GMFCS IV and V were reported to perform on other classification systems was useful as it highlights the complexity and variability of this group of children.

A child's rating on the MACS provides information about how they use their hands to complete age appropriate activities in daily life (Eliasson et al., 2006). There was evidence in the literature that the manual abilities of children at GMFCS IV, as reflected by their MACS level were varied (see Figure 2.1). Children at GMFCS V were less varied, with 20% of children classified as MACS I to IV, and 80% of children with very low abilities classified at MACS V (Carnahan, Arner, & Hagglund, 2007). Only about 50% of children tended to be classified at the same MACS and GMFCS levels (Carnahan et al., 2007). It is therefore important to consider both GMFCS and MACS classifications for children as they measure different abilities.



*Figure 2.1.* The percentage of children at GMFCS IV and V at each level of the Manual Ability Classification System (MACS); Communication Function Classification System (CFCS) and the Eating and Drinking Classification System (EDACS). (Eliasson et al., 2006; Hidecker et al., 2012; Sellers, Mandy, Pennington, Hankins, & Morris, 2014)

The CFCS provides information about children's communication abilities (Hidecker et al., 2011). Data about how children at GMFCS IV and V were reported to function across the levels of the CFCS are included in Figure 2.1. In one study, children at GMFCS IV showed a wide spread of communication abilities with a higher proportion of children having better abilities. Children at GMFCS V showed a higher representation at the end of the CFCS scale that represented poorer abilities, indicating that many children functioning at GMFCS V also have significant difficulties with communication skills (Hidecker et al., 2012).

The EDACS provides data on the eating and drinking abilities of children with cerebral palsy with preliminary evidence that demonstrated a significant but moderate positive association (*Kendall's tau*=0.5,  $p<0.01$ ) between GMFCS and the EDACS (Sellers, Mandy, Pennington, Hankins, & Morris, 2014). A significant but moderate association between the EDACS and the other classification systems was also reported, with recent evidence also suggesting the EDACS is valid and reliable for use with children with cerebral palsy (Tschirren et al., 2018). Children at GMFCS IV had a spread of reported EDACS classification levels, with about 75% of children having better eating and drinking abilities,

rated at EDACS I, II or III (see Figure 2.1). Children at GMFCS V showed a slightly different trend with many more children rated as having poorer eating and drinking abilities (Sellers et al., 2014). This pattern was also evident in a more recent study that also suggested that the EDACS was a useful adjunct to describe children for research and clinical practice (Benfer et al., 2017). Although there are trends demonstrating a positive relationship between GMFCS and EDACS levels, they do measure different abilities.

Children at GMFCS IV and V have varied abilities in the different domains of function as rated by the cerebral palsy classification systems. Assumptions about how a child at GMFCS IV and V might be classified on the MACS, CFCS and EDACS cannot be made as they measure different abilities, and children will present with varying abilities across the functional domains. The cerebral palsy classification tools are important for clinicians and families to use and understand and can guide selection of treatment and intervention that best suits their children.

### **Evidence based approaches to therapy**

Evidence based practice involves consideration of individual clinical expertise, best research evidence and patients' values and expectations (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). Clinicians and funding services need to ensure the services they provide are based on the best available evidence (Sackett et al., 1996). Finding suitable evidence to guide practice can be challenging for clinicians who support children at GMFCS IV and V because these children are complex, few in number and thus less well known, and can vary in their functional skills. Novak et al. (2013) conducted a comprehensive review of systematic reviews which summarised the best available evidence for intervention for children with cerebral palsy at all levels. This review identified that most research that



included children at GMFCS IV and V focused on medical and surgical, rather than allied health interventions. In the few studies about interventions to support skill development that were available, there was some support for the use of goal directed training and home programs for children at GMFCS IV and V, if the proposed outcomes of interventions were related to function and self-care (Novak et al., 2013).

Although it is not the focus of this research, there are many studies in the literature that highlight the decline with age, and limitations in function of children at GMFCS IV and V. One study assessed the relationship between functional levels using the GMFCS and MACS and activities of daily living measures. It identified that children at GMFCS IV and V aged between 3 and 15 years demonstrated little improvement in functional skills with increasing age compared the children GMFCS I and II (Ohrvall, Eliasson, Lowing, Odman, & Krumlinde-Sundholm, 2010). Other studies have indicated that children at GMFCS IV may decline in motor function as they reach their teens (Palisano, Hanna, Rosenbaum, & Tieman, 2010), and are reported to become more dependent and less able to complete motor skills such as a standing transfer, stepping and using a walking device over time (Blumetti et al., 2012). Attainment of self-care and mobility skills were best predicted by GMFCS level and intellectual capacity, indicating poorer outcome with increased GMFCS level and lower intellectual functioning (Kruijsen-Terpstra et al., 2015). These studies that highlight a decline in function for children at GMFCS IV and V provide guidance about what may need to be addressed for children, however little information is provided about possible interventions to support capacity and performance.

There is emerging research focusing on what children at GMFCS IV and V can do. A recent study by Mensch, Echteld, Evenhuis, and Rameckers (2016) identified the subtle

motor skills that children with severe and multiple disabilities were able to achieve, although their research did not specifically link skills to daily routines. Overall, more evidence is required to support intervention selection for children at GMFCS IV and V. What is known provides very little guidance about how to promote positive outcomes for the development of skills for use in the complex daily lives of children and their carers.

### **Therapy goals as a part of everyday life**

When children require a large amount of assistance in daily routines, their skills cannot be seen in isolation, but need to be viewed in the context of the interactions or transactions that occur between the child and carer when daily routines are undertaken. This is important for both the child and the carer. Although the needs of carers are varied, the potential impact of caring for a child with cerebral palsy on the well-being of the carer suggests that intervention to support ease of care routines is likely to be an important goal of therapy (Bundy & Lane, 2012). Self-care has been identified as a priority goal of intervention children at GMFCS IV and V and their families (Gimeno, Gordon, Tustin, & Lin, 2013) and children at all GMFCS levels (Brandão, Oliveira, & Mancini, 2014). Carers of children at GMFCS IV and V, as well as their children, therefore require interventions that are relevant and meaningful to their daily life (Cronin & Mandich, 2016).

Providing opportunities and support for children to learn skills so that they actively engage in their daily life may also be important for the child's well-being. In a study of young people with cerebral palsy at MACS level I and II, it was found that by doing daily activities, a sense of self-identity was built (Bergqvist, Ohrvall, Himmelmann, & Peny-Dahlstrand, 2017). The participants interviewed in the study indicated that 'doing' sometimes resulted in pain and fatigue. It was still, however, important for the children and adolescents with

cerebral palsy to perform activities of daily living independently as this formed part of their self-worth (Bergqvist et al., 2017). Although there was no literature identified that explored this sense of self-worth in children at GMFCS IV and V, it is possible that children with cerebral palsy with more severe mobility impairment may have a similar experience.

### **Impact on carers**

Providing care to children at GMFCS IV and V can impact on the carer, as these children can require extra time and support to lead healthy and meaningful lives and participate in their communities. Higher MACS and GMFCS levels and lower intellectual capacity have been shown to be predictive of self-care abilities suggesting that children at GMFCS IV and V have poorer abilities and therefore need more assistance (Ohrvall et al., 2010; Smits et al., 2011). Carers of children at GMFCS IV and V are likely to have less time for themselves and other family members, as the daily care needs of children who use wheelchairs for mobility have been shown to take longer than more mobile children with cerebral palsy (Sawyer et al., 2011). Planning and coordinating the extra services and support children need may also require time and effort from the carer. Parents of children at GMFCS IV and V, as compared with parents of children with cerebral palsy with better abilities, are more likely to request financial assistance to access equipment, home modification and toys, information about services, and community activities (Palisano, Almarsi, et al., 2010). Children with complex and severe disabilities have also been shown to require more support, out of pocket expenses from their families and assistance from carers and families to participate in daily life (Bourke-Taylor, Cotter, & Stephan, 2014).

Caring for children at GMFCS IV and V can impact on the mental health and quality of life of the carers (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013). Parents are at

greater risk of experiencing lower quality of life and increased caring burden as the GMFCS level of their child increases (Ward et al., 2014). Increased carer burden and lower quality of life has been reported in mothers of children with cerebral palsy who have more severe motor impairment compared to mothers of children with milder impairments (Ozkan, 2018). Caring for a child with a disability can also have a negative impact on the mental health of the mother (Bourke-Taylor, Howie, Law, & Pallant, 2012). The health and wellbeing of the carer, and the family, is therefore an important consideration of those providing health services to children at GMFCS IV and V.

### **Transactions between children and carers**

The transactions that occur during daily routines are of interest to this research as a potentially important point of intervention to support positive outcomes for both the child at GMFCS IV and V and their carer. The interactions between a child and their carers over time in a variety of situations, can be described as a transactional process where there is potential for child learning and development. These transaction can occur for a young child and a carer during completion of tasks during a daily routines. Transactions are driven by the dynamic interaction between the child and the child's context, which is made up of the child, carer and objects within their immediate experience (Batorowicz, King, Mishra, & Missiuna, 2015). The child is changed by contextual experiences, with the experience then being shaped by the child's changing responses and development (Sameroff & MacKenzie, 2003). The process of transactions highlights the complexity of the carer-child dyad, where the interactions that affect the child's ability to learn and achieve skills are bidirectional and dynamic.

Transactions between carers and children continue to influence child behaviour from early childhood into adolescence (Sameroff & MacKenzie, 2003). As children at GMFCS IV

and V are likely to require more assistance in daily life, the transactions with their carer are likely to include more practical and physical elements than a typically developing older child and adolescent who are likely to be independent in self-care routines. The transactions may also be complicated by the variability of abilities in the subgroup of children and the variability in carers' abilities to respond.

How children and carers work together to achieve daily routines requires some consideration of the three parts of a transaction; the child, the carer and the context. The location where the transactions happen, such as the family home, can be described as the child's social context, where the immediate experience of the interactions of child, carer, activity, place, time and objects, occurs on a daily basis. This is distinct from the social environment which encompasses the broader aspects of the child's socio-physical structures involving institutions and wider cultural influences (Batorowicz et al., 2015). Developing an understanding of the context of daily routines is therefore integral to investigating the learning and actions of the people involved.

### **Learning in children at GMFCS IV and V**

Supporting children with cerebral palsy to develop new skills is likely to involve consideration of the child, the carer and context. Learning and teaching for children at GMFCS IV and V may be complex and time consuming for a variety of reasons. Approximately half of all children with cerebral palsy have some degree of intellectual impairment (Reid et al., 2016). It is possible that many children with cerebral palsy may not learn in the same way or as quickly as other children and may need additional interventions to accommodate their learning needs (Dunst, Trivette, Raab, & Masiello, 2008). Better performance on a cognitive assessment is linked to better performance on assessments of skill

performance and acquisition, and studies have shown that children at higher GMFCS levels tend to have a higher rate of difficulty with intellectual function (Dalvand, Dehghan, Hadian, Feizy, & Hosseini, 2012; Smits et al., 2011). However, performance on assessment of intellectual capacity of children may be affected by the child's motor skills, sensory deficits in vision and hearing, as well as difficulties in communication, hand function and attention (Turkoglu, Turkoglu, Celik, & Ucan, 2017). It is therefore likely that the cognitive abilities of children with more severe impairment are underestimated because of the lack of psychometrically sound cognitive assessments for children with cerebral palsy, that include appropriate adaptations to accommodate sensory and motor impairments (Yin Foo, Guppy, & Johnston, 2013). Formal assessment of a child's intellectual function can provide useful information about a child's function but may only provide a part of the picture. Level of cognitive ability is a factor that may need to be considered when developing goals for children at GMFCS IV and V, however assumptions about a child's potential to learn based on their motor abilities should be avoided.

Providing learning opportunities in contingency rich contexts has been found to be effective for very young children and children with significant developmental issues (Dunst et al., 2008) and is likely to be of benefit for children at GMFCS IV and V. Dunst, et al., (2008) describe them as follows.

Contingency rich environments are made up of everyday activities that are the contexts for children to learn expectancies and how to use behavior to produce environmental consequences. Everyday activities that are best suited for contingency detection and awareness are ones that include objects and materials, events and experiences, and opportunities to interact with others that have a high probability of being responsive if acted upon. (Dunst et, al., 2008, p12)

It is therefore proposed that learning occurs when the carer's responsiveness sustains the child's interactions with people and objects in their immediate context. Due to the complexity of children at GMFCS IV and V, the ability to learn is likely to be related to many transactional experiences over their lifespan. Learning in everyday contexts where the child is supported by the carer's responsiveness to the child's efforts may be a critical point of learning for children.

### **Useful skills for children**

How children at GMFCS IV and V learn may be different to other children and what they need to learn may also be different. The skills which are used by, and are useful for, a child at GMFCS IV and V during tasks that make up daily routines are likely to be different to the repertoire of skills of typically developing children. Because of this, norm referenced assessments that describe whether a child at GMFCS IV or V has attained skills in daily living routines at a similar rate to their typically developing peers, are not generally useful for families, clinicians or researchers for guiding intervention and assessing outcomes (O'Connor, Kerr, Shields, & Imms, 2015).

Measures of independence in attaining daily living skills currently in general use may not be sufficiently sensitive to detect the small observable changes in children at GMFCS IV and V. Mensch, Rameckers, Echteld, and Evenhuis (2015) in their systematic review of motor assessments for children with severe multiple disabilities, including those at GMFCS IV and V, reported a lack of validated tools. This review also highlighted the importance of identifying motor skills that children with severe multiple disabilities can use in their daily lives and a need for tools that measure subtle changes in performance. While exploration of measurement error and consideration of minimal important change and smallest detectable

changes in assessments of performance of daily living skills of children is important, exploration of these issues is beyond the scope of this thesis. The review also emphasised that the acquisition of subtle motor skills is possible for children with severe multiple disabilities and using these skills during their daily lives can have a positive impact on children's quality of life.

It is therefore likely that there is a set of unique and specific actions that children functioning at GMFCS IV and V may need to learn to enable them to be more easily cared for and to enable them to contribute to their own care needs. Changes in functional performance may involve learning simple actions to assist in completing a task, rather than an ability to complete the entire task independently (Ohrvall et al., 2010). To support children and carer learning and development, it is important to identify and define the skills or actions that could be useful during the series of tasks that make up functional routines. In this thesis, 'useful' was defined as a subjective measure of whether a skill assists a carer and a child at GMFCS IV or V to complete a task during a daily routine. Deciding what skills might be useful in daily life could require consideration of the child and carer's capacity (what they may be able to achieve given the opportunity), capability (what a child can do in a controlled context) and performance (what a child actually does on a daily basis) (Tieman, Palisano, Gracely, & Rosenbaum, 2004). The child needs to know what useful actions to attempt, but just as importantly, the carer needs to know what actions are useful so that they can be responsive to the child's effort to attempt the action, reinforce them on a daily basis and therefore drive learning and competence (Dunst et al., 2008). In everyday life, contributing to task completion might therefore require the skills of knowing what to do and when, communicating readiness to act, as well as performing some components of the task sequence.



### **Seeking the views of children**

Children with cerebral palsy have been shown to be capable of reporting on their own health related quality of life (Varni et al., 2005). Children at GMFCS IV and V, however, have high rates of comorbidities such as communication difficulties, learning and intellectual impairment (Delacy, Reid, & Australian Cerebral Palsy Register Group, 2016) which may impact their ability to participate in research. Children with communication impairment may rely on assistive technology such as augmentative and alternative communication (AAC) and therefore require more support and time to express their views. Including the views of children at GMFCS IV and V can be challenging for researchers. For example, researchers who designed health related quality of life surveys were not able to collect the views of children and had to rely on proxy report from carers (Elema et al., 2016; Narayanan et al., 2006). Where the views of children have been able to be captured, there is evidence of differences between child self-report and proxy report (Eiser & Varni, 2013). The documentation of self-reporting children at GMFCS IV and V is extremely limited in the literature. The internal experience of the child was seen to be integral to the transactions that occur in daily routines and children's views may differ from their carers. The views of children were deemed to be important for this research and therefore children were included in the study.

### **Structured review of the literature**

#### **Aim of the literature review**

The purpose of this part of the literature review was to target more specifically research about what children at GMFCS IV and V can do during daily routines. Daily routines are a series of actions and tasks that are required to complete usual day-to-day procedures such as getting dressed and attending to personal hygiene (World Health

Organization, 2007). The specific question for the literature search was; *How do children with cerebral palsy functioning at GMFCS IV and V actively engage in daily routines?*

### Search strategy

Literature searches within four databases were conducted. The search terms used for Medline are outlined in Table 2.1. and variations to these were applied to Amed, CINAHL and Web of Science. The following limitations were applied: publication date between 2000 and 2018; English language; and peer reviewed.

Table 2.1.  
*Database search strategy for the literature review: Medline*

Concept	1 CP/Child	2 Severity	3 Daily Routine
Search terms	(MH "Cerebral Palsy") AB ("cerebral Palsy" OR "CP") OR TI ("cerebral Palsy" OR "CP")	AB ("severe" OR "GMFCS IV" OR "GMFCS V") OR TI ("severe" OR "GMFCS IV" OR "GMFCS V")	(MH "Activities of Daily Living") OR (MH "Self Care") TI OR AB ("activit* of daily living" OR "ADL*" OR "living Skills" OR "self care" OR "Self-care" OR "daily routines" OR "daily activ*" OR dress* OR Bath* OR Groom* OR meal* OR Cook* OR Eat* OR Feed* OR hygiene)

### Inclusion and exclusion criteria

Studies were included if they met the criteria outlined below:

- They contained information about children with cerebral palsy classified at GMFCS IV and V;
- The intervention evaluated was aimed at developing the skills and abilities of children in daily routines or the study described the skills and abilities of children related to daily routines;
- The outcomes included information about children's ability to learn or perform

aspects of a daily routine including interacting with a carer during a routine; and

- The research provided descriptive information relevant to the current research question.

It has been previously established that children at GMFCS IV and V tend to perform poorly on assessments that measure performance of activities of daily living compared to typically developing children, or children with cerebral palsy at GMFCS I, II and III. Studies that only reported on this comparison were not included, as they did not provide further information of what children can do in daily life. Studies were also excluded if they met any of the following criteria.

- Participants were under five years of age, as these children typically require assistance during daily routines regardless of GMFCS level;
- The study population included only children with milder forms of cerebral palsy (hemiplegia, GMFCS I, II, III);
- The interventions investigated were pharmaceutical, medical or surgical, or standing and exercise not related to daily routines, or if the study related to survival or validation of measures; or
- Outcomes that focused on comparing level of performance between children with cerebral palsy at GMFCS IV and V and typically developing children or children with cerebral palsy at GMFCS I, II and III.

### **Assessment of risk of bias**

Critical review of the internal validity of the included articles was undertaken using the Strengthening the Reporting of Observational studies in Epidemiology (STROBE)

checklist (Vandenbroucke et al., 2014) and the McMaster critical review form for qualitative studies (Letts et al., 2007).

### Synthesis of findings

A narrative synthesis was undertaken to compare and contrast the findings among the studies and to answer the specific literature research question. The flow of information through the search is described in Figure 2.2.

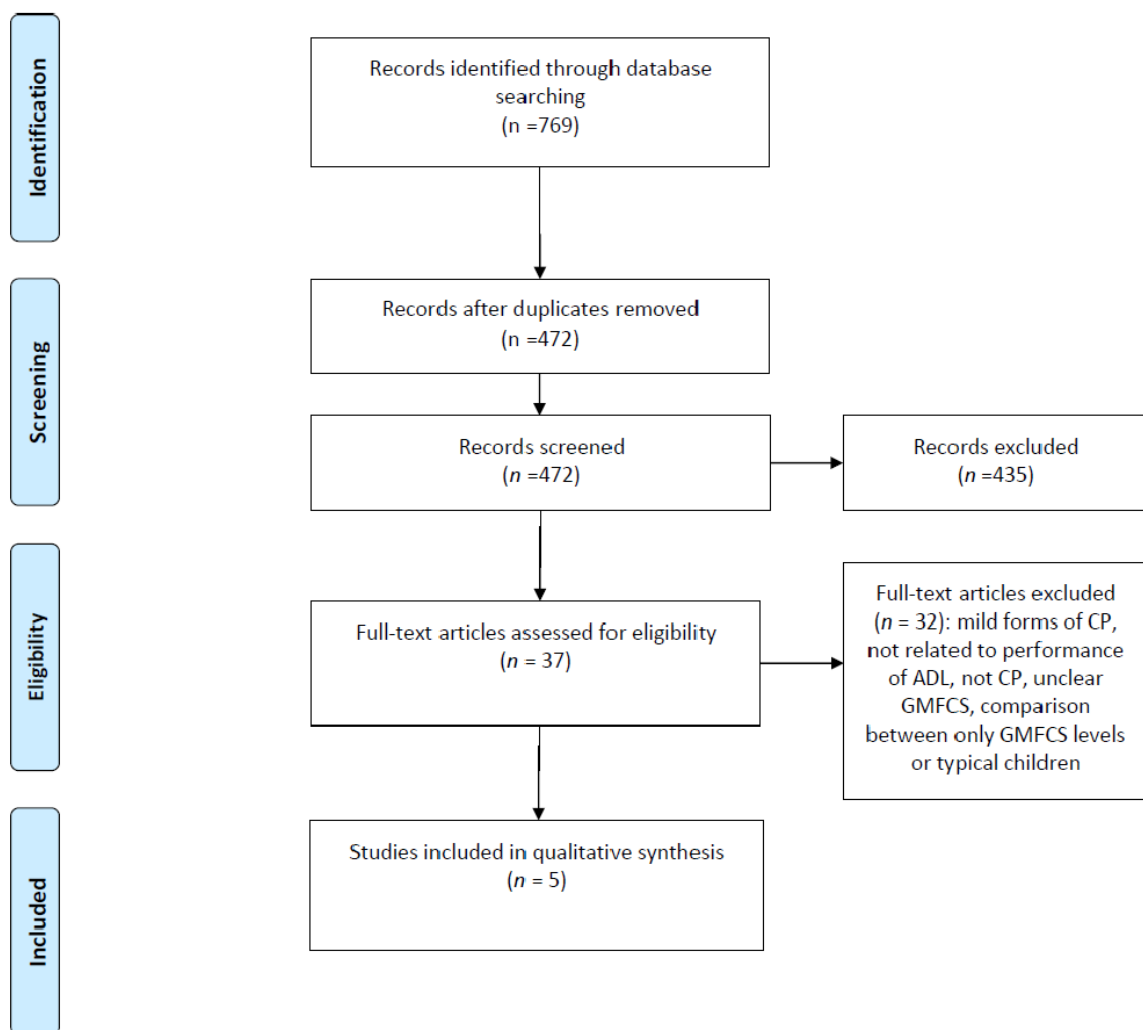


Figure 2.2. Flow diagram of search results of the literature review

Note. CP = cerebral palsy; ADL= activities of daily living; GMFCS = Gross Motor Functional Classification System.

## Results

Of the 472 publications initially retrieved, only five articles provided information pertinent to the research question. The included studies involved children with cerebral palsy who used wheelchairs for mobility with age ranges between 4 to 18 years. The studies were varied and included information about how children used assistive technology (AT) to express desires in daily routines (Borgestig, Rytterström, & Hemmingsson, 2017), how children communicated with a carer during a mealtime routine (Ferm, Ahlsén, & Björck-Åkesson, 2012), the achievement of continence (Singh, Masey, & Morton, 2006), the ability to retain the skill of sitting over time (Miyazaki et al., 2004) and the performance and development of eating skills (Pinnington & Hegarty, 2000). The outcomes of interest were varied and provided only limited information about the skills and abilities of children at GMFCS IV and V.

The skills of children during mealtimes were explored by three studies with outcomes suggesting that children may learn to use AT to express opinions during eating routines (Borgestig et al., 2017), that children could learn small oral motor and postural skills over time (Pinnington & Hegarty, 2000), and that participating in eating routines involved complex interactions with a known carer (Ferm et al., 2012). One study highlighted the possible importance of sitting skills in childhood and its impact of achievement of daily routines in later life (Miyazaki et al., 2004). A fifth study highlighted that some children with complex disabilities may have the ability to develop continence (Singh et al., 2006). Table 2.2 outlines the methodologies and a summary of the characteristics of the included studies.

Table 2.2

*Characteristics of included studies*

Author (year)	Study purpose	Research design	Participants			Measures	Daily Routine included	Transaction Included	Main findings
			Diagnosis	Age	Sample size				
Borgestig et al. (2017)	Gaze based AT during daily life	Longitudinal qualitative	CP (GMFCS IV&V)	<i>M</i> 9.5( <i>SD</i> 4.6) yrs	<i>n</i> =8	Two interviews one year apart	Daily routines	Yes-Express desires in daily routine	Children were able to learn to use AT to express needs in daily life
Ferm (2012)	Interaction between carers & child during mealtime	Two case comparison	FD- CP (GMFCS V) & carer	FD child-6.5 yrs	FD <i>n</i> =1	Video analysis of communication during feeding in home	Mealtime	Yes-Child/carer dyad	Achieving communication intent during daily routine relied on close interaction with a carer
			CD-TD child & carer	CD child-6.5 yrs	CD <i>n</i> =1				
Singh et al. (2006).	Determine levels of continence in relation to learning and mobility	Cohort - cross sectional data	CP (GMFCS I-V)	4-18 yrs	<i>n</i> =55 GMFCS IV&V <i>n</i> =24	Study specific continence measure, phone survey, review of medical records	Toileting	No	Most children with nil to moderate learning issues were able to achieve continence.

Miyazaki et al. (2004)	Investigate the progression of sitting skills	Longitudinal - predictive	CP (Spastic quadriplegic)	10 yrs (baseline) <i>M</i> 24 yrs ( <i>SD</i> 7.8) to <i>M</i> 33 yrs ( <i>SD</i> 7.8) at follow up	<i>n</i> =28 (Baseline and follow up)	Barthel Index	Sitting skills linked to ADL	No	Children with independent sitting skills at age 10 had better scores in independent in ADL as adults
Pinnington, (2000)	Children learning oral motor skills and postural control through training	ABA within subject design	Severe neurological disability (use of WC for mobility)	<i>M</i> 12 yrs Range 7-17 yrs	<i>n</i> =16	SOMA, video recording of oral motor/eating skills, use of RAE	Eating	No	Children demonstrated improvement in oral motor skills head and postural control following intervention

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*Note.* AT = assistive technology; CP = cerebral palsy; GMFCS = Gross Motor Functional Classification System; yrs = years; FD = focus dyad; CD = comparison dyad; TD = typically developing; ADL = activities of daily living; WC = wheelchair; SOMA = Schedule for Oral Motor Assessment; RAE = robotic aid to eating.

**Risk of Bias**

Limitations of the five studies included opportunistic sampling and small sample sizes. The population prevalence of children with cerebral palsy at GMFCS IV and V is relatively low, and this may explain why researchers tended to recruit from a convenience sample of readily available children based at schools or rehabilitation centres. Of the included studies, three studies used the GMFCS to classify the functional mobility of children (Borgestig et al., 2017; Ferm et al., 2012; Singh et al., 2006). Two studies that predated the development of the GMFCS didn't use this tool, however described the children adequately to make the classification level clear (Miyazaki et al., 2004; Pinnington & Hegarty, 2000).

No study included a standardised assessment specific to children with cerebral palsy at GMFCS IV and V. The five studies used descriptive statistics, observational assessments, and questionnaires devised by the authors with unknown psychometric properties. Several studies using the primary measure of this thesis, the Caregiver Priority and Child Health Index of Life with Disability (CPCHILD), were identified in the initial search but did not meet the inclusion criteria. These studies used the CPCHILD as a health-related quality of life outcome measure to assess the impact of medical and surgical interventions and reported changes in the overall scores on the CPCHILD but did not provide any detail about how the child's ability to participate in the daily routines had changed.

The two more recent studies (Ferm, 2012; Borgestig, 2017) were well conducted with clear aims, methods and outcomes. The research designs and analyses of the remaining studies were less clear and therefore provided questionable quality of evidence. As there was little literature available about how children at GMFCS IV and V engaged in daily routines, all five studies were included as they provided descriptions about children that posed



questions for further research. As the five studies provided quite different types of information, the reasons why they were included and their relevance to the researcher are outlined in separate paragraphs in the following section: Overview of findings.

### **Overview of findings**

Borgestig et al. (2017) interviewed carers of children with cerebral palsy at GMFCS IV and V from the perspective of the impact of an AT eye gaze system on the child and family. The results of the qualitative analysis indicated that children who were previously unable to communicate were able to learn to express daily needs, for example asking for a drink, using the AT eye gaze system. The study included a detailed audit of the methods involved in data analysis and the theoretical underpinning driving the research design. The study was limited by the convenience sampling of carers, and the lack of inclusion of the views of children. Outcomes highlighted an ability of children with complex and severe disability to learn in response to increased expectation and challenge, and children's reliance on the supportive context of a well-known carer. While methodological flaws make it difficult to generalise findings, this study provided useful information about how children with cerebral palsy with significant functional impairment may be slower to learn than other children, but they still have capacity for positive change.

Ferm et al. (2012) analysed the transactions between a child with cerebral palsy functioning at GMFCS V with no intellectual impairment, who used AAC and had complex communication needs and her carer during a mealtime routine. This focus dyad was compared to a typically developing child and her carer, which they termed the comparison dyad. The two dyads were matched for age (6 years 6 months), gender (female), carer relationship to child (primary female carer) and geographical area. The single case

comparison involved analysis of videos using activity-based communication analysis. The occurrence of variables and comparison of means using chi square tests were reported. Although the study included comparisons with a typical child (an exclusion criteria) it was included as the comparison highlighted differences, rather than only ratings of better or worse performance. The results of the analysis highlighted that the interactions between the focus dyad involved the discussion of the practical task at hand, as compared to the comparison dyad who engaged in a variety of social topics that were unrelated to the immediate context. There were pauses during communication in the focus dyad, which allowed time for the child to respond, clarification between the child and carer of intention and checking for communication accuracy. This was in contrast to the pauses from the comparison dyad, which usually coincided with time for the carer to address their own needs, e.g., thinking about what they were doing or eating their own meal, or with a change of subject. Of particular interest to this research was the intense social closeness of the focus dyad child and carer that relied on the carer noticing and responding to the child's communication efforts in relation to the performance of the daily routine. The communication efforts were individual to the child and included physical movement and action, facial expressions and speech. A strength of the study was that data collection involved filming in the natural home environment and included a rigorous analysis of discrete components of the communication interactions between the dyads. The analysis of the social interaction was undertaken by the researchers rather than giving the participants opportunity to interpret and code their own interactions, and this was highlighted by the authors as a limitation of the study. Additionally, in-depth analysis of only two dyads meant it was not possible to generalise findings to other children. The study provided a description of the abilities of the child and the transaction between a child with a severe disability and their carer during a daily routine that was particularly relevant and of interest.

Singh et al. (2006) described the achievement of continence in relation to GMFCS and learning disability. Although the study included children from all GMFCS levels, the findings described the abilities of children in each GMFCS level, rather than only making comparison between groups. This cross-sectional study used descriptive statistics to report information in one-time period and relied on parent report over the phone. The use of study-specific questionnaires was outlined and described, but the psychometric properties were not reported. Some of the children at GMFCS IV and V were reported to achieve continence, though at a later age than other children, including up to 12 years of age. There was some weak evidence that the achievement of continence correlated with learning disability, but this requires further research. Although the study did not explore the motor skills that children needed to develop continence, or whether children with cerebral palsy needed different motor skills to achieve continence than typically developing children, it did explore the topic with the expectation that children at GMFCS IV and V might have the potential to learn skills to develop continence over time. A limitation of the study was that the authors did not explore other possibilities for the variability of achieving continence such as MACS level, communication skills or carer assistance. Although the study had limitations in its design, it highlighted the variability of function that exist in children with cerebral palsy at GMFCS IV and V. Of interest to this current research was information about how learning the skills of continence may take longer for children at GMFCS IV and V, and the importance of providing more time and opportunity for children to learn skills to contribute to their ease of care and quality of life.

The Miyazaki et al. (2004) longitudinal retrospective study examined the retention of independent sitting ability of adults with cerebral palsy over a 23-year period. They attempted to correlate the presence or absence of sitting at age ten years to outcomes for independence

in activities of daily living (ADL), and locomotion in adulthood. This was a descriptive study with no inferential analysis because of the small sample size ( $n=28$ ). The study specific measures utilised were not standardised but were well explained and simple enough to provide a descriptive overview of the function of the included participants. This article was included as it aimed to investigate childhood functional ability, the progression of motor abilities and how this could link to participation in daily routines in adulthood. The study concluded that achieving sitting was important to work towards before of ten years of age as it was less likely to be achieved as the children aged. It also concluded that the ability to sit was likely to indicate better participation in ADL, although it did not outline the causation of abilities. Additionally, a number of issues that were raised by this study made it of interest to this current research. The proposal that the development of sitting skills might be important for children who are not anticipated to progress to standing and walking and that development of this skill could have an impact on participation in ADL activities was of interest. The importance of considering the functional needs across the lifespan when focusing on motor goals of children, and whether attainment of motor skills in childhood could impact on function in adulthood were also of interest.

An ABA within subject study design was used by (Pinnington & Hegarty, 2000) to investigate whether using a robotic device that provided consistent food presentation to a child during mealtimes could improve postural control and oral motor skills. The study was of interest as it did not aim to compare skills of children with significant disability to other children, but to record the ability of the children to learn functional skills given the time and opportunity to practice. The children were adequately described to make assumptions about their GMFCS level. Non-parametric analysis was used to record and compare significant differences in oral motor behaviour using video analysis of children over several time

periods. A major limitation was the impracticality of the main intervention, that is, the use of a robotic device during mealtimes for children with severe impairment. The study did however, present some useful information about how children with severe functional difficulties improved in a range of oral motor and postural skills when provided with increasing challenge in a structured way. The study premise, that higher expectations of the child's ability allowed previously redundant or unchallenged motor skills to emerge, was also important. The study concluded that the ongoing viability of a robotic device for feeding was not well established. However, children with poorer skills were found to respond to the opportunity to learn subtle, small skills that were graded, based on individual's performance, within the context of a daily routine. The study highlighted the potential benefit of providing intervention during daily routines due to the increased opportunity for practice, and that small and structured modifications to the context of a daily routine had potential to drive change in skill performance of children with severe and complex movement difficulties.

### **Discussion**

There were few studies available that highlighted the skills, abilities and achievements of children at GMFCS IV and V. The included studies in this review provided a small amount of information about skills that children at GMFCS IV and V could learn and use in daily life. However, the lack of standardised measures to evaluate performance and change, and the small number and complexity of participants limited any generalisation of the findings. The difficulty in researching this topic may be due to the complexity and variability of the children, the small numbers that may be available for recruitment, and the subtlety of the functional changes that occur in children at GMFCS IV and V. While there were identified limitations, information from the studies did highlight some key areas for consideration and future research.

Learning of skills for children at GMFCS IV and V may take a long time, and measuring skill development may need to be undertaken over longer periods or across the lifespan. This can be difficult, time consuming and complex for researchers. Some studies highlighted that learning was dependent on providing opportunity and a supportive context. Children may be capable of learning subtle and complex skills involved in communication and eating given opportunity, a supportive carer and structured learning environment. Attaining motor skills such as sitting in childhood may be useful in adulthood, and children may need more time and opportunity to learn complex, but important skills such as continence. The included studies identified that communication, independent sitting, head control and oral motor skills are useful skills for children at GMFCS IV and V during their daily routines. However, there are many other motor, communication, cognitive and sensory skills that could impact on the children's function in everyday life, that are not well understood and require further investigation. Further research is required to investigate functional performance of children at GMFCS IV and V during daily routines.

Standardised measures of skills, performance and change in performance are lacking for children at GMFCS IV and V. Through structured analysis and comparisons of video footage of children completing tasks, one study that aimed to assess subtleties in performance of eating skills, was able to identify small changes in performance over time. This supports the need for more sensitive measures to calculate small units of change in children with complex learning needs to highlight their success and achievement.

The cerebral palsy classification systems are important tools that can be used to describe research participants. The earlier studies did not include the classifications as they were not available or in general use at the time of publication. As the population of children

with cerebral palsy at GMFCS IV and V is complex and varied, research that adequately describes children across all functional domains is required to assist readers of research to consider the findings for their own clinical populations.

### **Limitations of the review**

The results of the review may be influenced by the use of a single reviewer. An additional independent reviewer would have strengthened the internal validity. The topic of interest was known to be not well represented in the literature, so consideration of the available studies was important for informing the research direction of this study. As the purpose of the review was narrative, and the articles were not of high methodological quality, the conclusions drawn must be used with caution.

### **Implications for research**

Developing skills in the context of daily routines requires information about what might be possible for children at GMFCS IV and V to achieve. Learning to actively engage in daily routines could involve a set of skills that may not be part of a typically developing child's self-care repertoire. This is yet to be well understood and requires further research. Progressing skills in daily life may also need to extend beyond assessing whether a child can complete an entire functional task or routine. Therefore, measures of performance and change over time need to be established that are sensitive to the subtle changes that are likely to occur in children at GMFCS IV and V.

It is likely that with support, children and carers have the capacity to learn, change and develop useful skills gradually over time, but the means of achieving this is not well understood. Because children at GMFCS level IV and V will always need assistance, learning

useful skills is likely to be embedded in the interactions between the child and carer and the context of daily life. Information about the specific daily routines undertaken by children and their carers is required, as it is during these routines that skills develop, and are repeatedly used and practiced. Children at GMFCS IV and V have high care needs and their skills and development are closely linked to the carers who support them to achieve daily routines. There is already a large amount of evidence about the health and well-being of carers of children with disabilities, and although this is a critical aspect of understanding how children function in daily life, exploring this in depth is beyond the scope of this research. Further research is however required to understand the functional, necessary skills that children at GMFCS IV and V and their carers use during daily routines, and how they contribute to the ease of care provided by the carer and active engagement in daily life for the child.

Therefore, the specific research questions for the current research were:

1. What daily routines are important for children at GMFCS IV and V and their carers?
  - a. Is there a difference between what children identify and what carers identify as important daily routines?
  - b. Do carers and children at GMFCS IV identify the same daily routines as important as compared to carers and children at GMFCS V?
2. How do children at GMFCS IV and V and their carers rate important daily routines according to the difficulty of the task/activity and the level of assistance the child requires?
  - a. Is there a difference between how children rate and how carers rate the difficulty and assistance required to complete important daily routines?
  - b. Do carers and children at GMFCS IV rate the same levels of difficulty and assistance required to complete important daily routines as compared to carers



and children at GMFCS V?

- c. Is there a pattern of responses that describes the relationship between rankings of importance and ability to complete daily routines?
3. What are the relationships between health-related quality of life and child functional level and carer wellbeing?
4. How do children at GMFCS IV and V and carers work together to complete the series of tasks that make up important daily routines?
5. What child related actions are useful in the transactions between children at GMFCS IV and V and their carers during important daily routines?

### **Conclusion**

The results of the background and review of the literature provided a small amount of evidence about the development of a few skills during daily routines of children at GMFCS IV and V. Motor skills such as independent sitting, oral motor skills and head control may be important for children at GMFCS IV and V to assist with completion of their daily routines. However, children at GMFCS level IV and V may need different motor skills to achieve functional tasks than typically developing children, and they may take longer to learn. Further understanding of the context of children's everyday lives was needed to support our understanding of skills and achievements of children at GMFCS IV and V. This research project aimed to explore and describe the daily routines of these children and their carers.

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### **CHAPTER 3: METHODS**

The purpose of the extended methodology is to provide information about the rationale for the design of the research, ethical considerations and participant recruitment. Information is provided about the methods of the first quantitative program of work, Study 1, including an outline of the measures and procedures for data collection and analysis. The methods for the qualitative study, Study 2 are detailed in Chapter 5.

#### **Rationale for overall study design**

This descriptive research used explanatory sequential mixed methods. Data collected from many children and carers was required to obtain a broad understanding of daily routines for children at GMFCS IV and V, this goal was best met using quantitative methods (Watkins & Gioia, 2015). Due to the variability of the children, and the complexity of the child and carers transactions, it was anticipated that the quantitative data could provide only part of the picture. The results from Study 1 were therefore explored in further detail using qualitative methods, thus providing a more complete understanding of the problem than was possible using either approach on its own (Creswell, 2014). Qualitative methods were identified as a suitable approach for the second phase of the study to obtain a more nuanced understanding of the transactions between a child and carer through exploring the lived experience (Watkins & Gioia, 2015). Because this transaction may be a key driver of change for children with cerebral palsy it was thought worthy of detailed attention.

### **Ethical considerations for the research**

The four key principles of ethical conduct of research are respect for human beings, research merit and integrity, justice, and beneficence (Australian Government National Health and Medical Research Council, 2017). Evidence for the respect for the people in this research included seeking and including the views of children, focusing on the strengths and abilities of a group of participants who had significant difficulties and the selection of research methods that aimed to reflect the language and give a voice to the participants. Respect for confidentiality and privacy was maintained throughout the research planning, including data collection, analysis and storage. Research merit was sought through the thorough review of literature, employing research methods appropriate to the population of children with cerebral palsy and the practical, clinical and research expertise of the research team at Australian Catholic University (ACU) and The Royal Children's Hospital, Melbourne. The researcher conducted the research with integrity by following recognised principles of research conduct and permitting scrutiny and contribution to public knowledge by communicating preliminary results in local research forums, a tertiary hospital and a scientific conference. Justice was sought through fair consideration of inclusion criteria, providing feedback to participants, and minimising burden and time demands on participants. Benefice was sought through design of the research that minimised risk to participants and through the provision of clear written material for informed consent. Ethics approval was obtained through ACU- Human Research Ethics Committee (HREC) on 29th June 2016 (2016-112H) (see Appendix E: Ethics approval form).

## Methods for Study 1

### Rationale for the study design

Study 1 used survey methods to address Research Questions 1, 2 and 3. A benefit of survey methods was sourcing data from individuals living in dispersed geographical areas (Fowler, 2002). This was appropriate given the target population of children was small, varied, complex and likely to be spread throughout Victoria. Participants were able to take their time to respond, and they were able to do so in their own homes. Survey methods allowed families and children to participate with a minimal time commitment of about 30 minutes (Portney, 2009). The survey was collated and prepared by the researcher to elicit practical information about daily routines, the results of which were anticipated to form the basis for further exploration of child and carer transactions.

### Ethical considerations for Study 1

**Consent.** Active consent was sought by inclusion of a form for families to sign and return with the survey. An information statement explained the study rationale, expected time commitments, and how the information gathered would be used (see Appendices F and G for Participant information form and Consent form Study 1). The information statement highlighted that participation in the study was voluntary. Participants were reassured that they were free to withdraw at any time without explanation, and that standard care for their child would continue whether or not they chose to participate in the research.

**Harms and benefits.** Minimal risk of harm was associated with participation in Study 1. Participation involved filling out a survey at a single time point. The invitation to participate identified that the survey included information about personal daily routines for children and their families. If families were uncomfortable providing this information they

could choose not to participate. It was anticipated that there would not be a high risk of distress to families, however if participants did become upset, they would have been directed to contact their usual health professional (e.g. General Practitioner) and the contact details of a 24-hour counselling service would have been made available.

## **Participants**

**Inclusion criteria.** Carers of children with cerebral palsy at GMFCS IV and V, who were aged 5 to 18 years and living in Victoria or Tasmania were invited to participate. Carers included any parent, grandparent, foster carer or other person who self-identified as one of the child's primary carers. Children with cerebral palsy have been shown to be capable of reporting on their own health related quality of life (Varni et al., 2005), therefore the views of children as well as their carers were sought. Children at GMFCS IV and V, aged 8 to 18 years who were able to communicate answers to the questionnaire by verbal speech, AAC, or pointing to the scaling, were invited to contribute their views. Parents have been shown to be accurate in their ability to discern whether their child is capable of completing a health-related quality of life questionnaire (Varni et al., 2005). Therefore, the child's ability to complete the survey was screened by a carer responding yes or no to the question "Is your child able to respond with or without assistance to a questionnaire about their daily routines?" It was anticipated that children over eight years who were functioning at Communication Functional Classification System (CFCS) level I or II would be able to contribute valid self-report data. Children functioning at CFCS level III were able to participate with assistance from a familiar helper. It was anticipated that children younger than eight years or children functioning at CFCS level IV and V would not be able to self-report. Therefore, children aged five to eight years, children functioning at CFCS level IV or V, or children whose carers report that they were unable to understand the questionnaire due to their cognitive limitations

were not able to participate. Information about the children who were not able to respond was only collected from the carers. There was insufficient funding to have the survey translated into other languages.

**Exclusion Criteria.** Children with cerebral palsy at GMFCS I, II and III and their carers, and carers with insufficient English language skills to complete the survey were not eligible to participate.

### **Sampling and recruitment**

The sampling frame was the Victorian Cerebral Palsy Register (VCPR). The most recent VCPR report at the time of data collection was collated in 2013, and was used to guide sample size estimates (ACPR, 2013). This report provided data about the 1,589 children born with cerebral palsy between 1993 and 2006 in Victoria, with about 27.4% ( $n = 416$ ) classified at GMFCS IV and V (ACPR, 2013). At the time of recruitment, there were 372 contactable children at GMFCS IV and V on the VCPR. A good response rate for a questionnaire was expected to be between 30- 60% (Portney & Watkins, 2009). This response rate would have provided a sample of between 111 (30%) and 223 (60%) of the contactable population.

Surveys were sent by post from VCPR staff to eligible families, and recruitment and distribution of survey packages occurred concurrently. The packages included an invitation to participate, consent form and the survey. Participants were given the opportunity to actively 'opt out' from receiving reminders by contacting the VCPR staff or the researcher using the reply-paid envelope, researcher's email or phone. They could opt in by returning the survey and consent form.

## Measures

The Caregiver Priority and Child Health Index of Life with Disability (CPCHILD) was the primary measure used in this research (Narayanan et al., 2006) and is described in detail later in this chapter. The CPCHILD was selected as it identifies daily routines that are specific to children who primarily use a wheelchair for mobility, was developed in consultation with parents and carers of children with severe disability. It also includes a Child-report version and a section to collect demographic data about the child and carer.

Child-related demographic data collected in the survey included sex, age, weight, address, highest school grade, motor type, topographical distribution, additional conditions. The cerebral palsy classification systems, the GMFCS, MACS, EDACS and CFCS, as described in Chapter 1 (see Appendices A to D) also provided data to describe the included children. For the carer, demographic data were collected about sex, relationship to child, date of birth, highest level of schooling completed, current work status. Child and carer demographics were collected using the CPCHILD, and the following questions about the child were added in the study specific survey:

1. *Weight of the child.* Children with cerebral palsy who use wheelchairs for mobility are likely to be lifted by their carer. A child's weight may have been relevant to the rating of importance, difficulty or level of assistance needed to complete daily routines.
2. *Motor type and topographical distribution of cerebral palsy of the child.* As these data were not provided by the VCPR, this question was asked to provide a description of the movement difficulties of the child.

3. *Child's address.* Socio-economic status by area was calculated by the child's home address using Socio-Economic Information for Areas (SEIFA) from the Australian Bureau of Statistics (ABS) website. The child's postcode was used to obtain a relative index of socio-economic disadvantage and advantage. The mean score and standard deviation was compared to the Victorian average of 1000 (*SD* 100).

The dependent variables were importance, difficulty and level of assistance required to complete 17 daily routines. Routines were assessed using the CPCHILD, including the difficulty and assistance ratings from Section 1 and 2 and the importance rating from Section 7. These data were used to answer Research Questions 1 and 2 about how important, difficult and how much assistance the children required to complete daily routines.

To answer Research Question 3, health related quality of life (HRQOL) was measured by the total scores on the CPCHILD, the independent variables describing the child's functional level by the GMFCS, MACS, EDACS and CFCS, and carer wellbeing was assessed by the Global Health Questionnaire.

**The CPCHILD.** The CPCHILD is described as measure of caregiver perspective on the health status, functional level and well-being and HRQOL of children with severe cerebral palsy (Narayanan et al., 2006) (see Appendix H: Survey booklet). The construct of CPCHILD total scores will be summarised as HRQOL for brevity in the thesis. The CPCHILD is a nine-page questionnaire anticipated to take approximately 20 minutes to complete and has both carer and child report versions.



The CPCHILD is divided into the following seven sections:

1. Activities of Daily Living/Personal Care (9 items)
2. Positioning, Transferring & Mobility (8 items)
3. Comfort & Emotions (9 items)
4. Communication & Social Interaction (7 items)
5. Health (3 items)
6. Overall Quality of Life (1 item)
7. Importance of Items to child's quality of life

*Difficulty and level of assistance.* The 17 items comprising the first two sections of the CPCHILD are analysed in detail in this study. The 17 items include carer or child responses to the difficulty and level of assistance required to complete personal care/activities of daily living and positioning, transferring and mobility activities. Examples of the daily routine items in the CPCHILD include: transferring in and out of a wheelchair, being dressed, and eating or being fed. The respondents are asked to consider how each activity was usually performed in the previous two-week period. Difficulty is measured on a seven-point ordinal scale: 0 = almost impossible; 1 = very difficult, 2 = difficult, 3 = slightly difficult, 4 = easy, 5 = very easy, 6 = no problem at all. Level of assistance required is measured on a four-point scale: 0 = total assistance, 1 = moderate assistance, 2 = minimal assistance/supervised, 3 = independent. Lower scores represent greater difficulty and an increased level of assistance required to complete the item. The two factors (difficulty and level of assistance) together create the participants' opinion of the "functional status" for each item.

**Importance.** The respondent is asked to consider the functional status, and then rate the extent to which each item is an important contributor to the child's overall quality of life. Importance is measured on a six-point scale; 1 = least important to 6 = most important.

**HRQOL- total scores on the CPCHILD.** Total scores are calculated from data from the first six sections following guidelines from the authors in the CPCHILD manual and interpretation guide (Narayanan, Weir, & Fehlings, 2007). Comfort and emotion are rated by frequency and level of intensity, communication is rated by difficulty and health is rated on a scale from poor to excellent. Raw scores are converted to standardised scores of 1 to 100 to calculate a total score. Lower scores indicate greater difficulties with communication and social interaction, greater amount of pain and discomfort, increased health issues including more medication and hospital visits and poorer rating of quality of life. Higher scores indicate better carer perspective of functional and health status and child HRQOL.

**Reliability and validity of the CPCHILD.** There is evidence to support the CPCHILD as a reliable and valid measure of caregiver perspective of the comfort, health status, wellbeing, functional abilities and ease of caregiving of their child with a severe disability (Narayanan et al., 2006). A high intraclass correlation coefficient (ICC) of 0.97 (95% confidence interval (CI) 0.95–0.99) was reported for the total scores when assessed for test-retest reliability (Narayanan et al., 2006). The CPCHILD was validated in a population of non-ambulatory Canadian children with cerebral palsy (Narayanan et al., 2006). Lower scores on the CPCHILD were correlated with increasing GMFCS level, indicative of known groups' validity. The sample of Canadian children at GMFCS IV scored a mean of 59.3 (*SD* 13.2; range 35–93). The children at GMFCS V had a mean score of 44.5 (*SD* 19.3; range 24.2–

81.5). The difference in the scores between the two groups of children was statistically significant (adjusted  $p = 0.021$ ) (Narayanan et al., 2006).

The CPCHILD has also been found to be reliable and valid for use as a proxy measure of caregiver priorities with Dutch (Zalmstra et al., 2015), Korean (Sung et al., 2015), German (Jung et al., 2014), Scandinavian (Pettersson, Bjerke, Jahnsen, Ohrvik, & Rodby-Bousquet, 2017) and Brazilian (Pellegrino et al., 2017) carers of non-ambulatory children with cerebral palsy. The CPCHILD was described as one of the two measures with the strongest clinical utility and psychometric properties in a systematic review of Quality of Life measures for children with cerebral palsy (Carlon et al., 2010). The CPCHILD was included in a study that identified a toolbox of valid and reliable measures for children with cerebral palsy that aligned with the ICF core sets (Schiariti et al., 2017). The total scores of the CPCHILD have been used in research as a HRQOL measure and as an outcome measure to evaluate the effect of interventions for Australian children with cerebral palsy at GMFCS IV and V (Copeland et al., 2014; Zarrinkalam, Rice, Brook, & Russo, 2011), providing support for the responsiveness of the tool.

***CPCHILD-Child report.*** The child report version of the CPCHILD collects the same data as the CPCHILD- Parent report, but the language has been changed to the first person (See Appendix I: CPCHILD-Child report). Children with complex communication needs have been reported to take up to twice as long to complete a questionnaire compared to other children (Raghavendra, Virgo, Olsson, Connell, & Lane, 2011). It was therefore anticipated that assisting a child to complete the questionnaire would take additional time depending on the child's abilities and limitations. For participating children, a carer who was familiar with the child's communication system was asked to provide, and document, the type of assistance the child required. The carer was guided to ask for assistance from the child's own speech

pathologist if required and was given the contact details of the researcher if they wished to have further support for the child to complete the questionnaire.

**The cerebral palsy classification systems.** The four functional classification systems the GMFCS, MACS, CFCS and EDACS were outlined in the introduction of this thesis (see Appendices A to D). The classification systems were designed to be used by parents, carers or someone who knows the child well. Rating the child on the classification tool involves a respondent circling from I to V the level that best describes the child's actual performance on a day-to-day basis.

***The Gross Motor Functional Classification System (GMFCS).*** The GMFCS has five levels describing the daily mobility of children with cerebral palsy. Children classified at level I and II walk independently, at level III use a walking aid, and at level IV and V use wheeled mobility most often to access their environment (Palisano, Cameron, Rosenbaum, Walter, & Russell, 2006). It is reported to be stable with a weighted kappa coefficient of  $\kappa = 0.89$  between the first and last ratings for children 6 years or older, indicating excellent chance-corrected agreement (Palisano et al., 2006). In a test of validity, there was a Pearson correlation of  $r_p = -0.91$  ( $p < 0.0001$ ) between GMFCS levels and the gross motor function measure (GMFM) (Palisano et al, 2000). The agreement between families and professionals' ratings of GMFCS levels had an ICC of 0.94 (95% CI 0.90 to 0.96) suggesting the GMFCS is a reliable measure of gross motor function (Morris, Galuppi, & Rosenbaum, 2004).

***The Manual Ability Classification System (MACS).*** The MACS has five scales describing how children with cerebral palsy use their hands in age appropriate daily activities. Children classified at level I and II are independent, at level III have some degree of independence with adaption to the environment, at level IV they need continuous assistance

or can meaningfully participate in only part of the task and at level V have limited abilities (Eliasson et al., 2006; Ohrvall, Eliasson, Lowing, Odman, & Krumlinde-Sundholm, 2010). The interrater reliability between therapists was tested with a reported ICC of 0.97 (95% CI 0.96–0.98) and an ICC between parents and therapists of 0.96 (95% CI 0.89–0.98) indicating that the MACS is a reliable measure of hand skills of children with cerebral palsy (Eliasson et al., 2006).

*The Communication Function Classification System (CFCS).* The CFCS describes the communication abilities of children with cerebral palsy. It is in the relatively early stages of development and has been validated for use with children with cerebral palsy (Hidecker et al., 2011). The weighted kappa interrater reliability between two professionals, was reported to be 0.77 (95% CI 0.66–0.89) for children over 4 years, with a weighted kappa test–retest reliability of 0.82 (95% CI 0.74–0.90) (Hidecker et al., 2011). The CFCS had moderate Spearman’s correlation coefficient with the GMFCS ( $r_s = 0.47$ ) and MACS, ( $r_s = 0.54$ ) suggesting that it may provide complementary description of a child’s communication ability (Hidecker et al., 2012).

*Eating and Drinking Classification System (EDACS).* The EDACS is in the early stages of development and has preliminary positive psychometric data to support its use in the rating of eating and drinking skills of children with cerebral palsy. In studies of its reliability, it has a reported Cohens’s kappa intrarater agreement of 88.3% ( $\kappa = 0.84$ , ICC = 0.95;  $p < 0.001$ ) and interrater agreement of 51.7% ( $\kappa = 0.36$ , ICC = 0.79;  $p < 0.001$ ) (Benfer et al., 2017). The EDACS has evidence for its validity, with a reported strong stepwise relationship between the EDACS and the Dysphagia Disorders Survey ( $r_s = 0.96$ ,  $p < 0.001$ ) (Sellers, Mandy, Pennington, Hankins, & Morris, 2014).

**The Global Health Questionnaire.** Information about the self-perceived health of the carer was collected by a Global Health Questionnaire. The questionnaire was sourced from the Patient Report Outcomes Measurement Information System (PROMIS) which provides an item bank of patient related outcomes measures, with demonstrated reliability, precision and construct validity (Cella et al., 2010). The Global Health Questionnaire for carers (PROMIS v.1.1.1 – Global Health) with 10 items was chosen as it was an efficient way to summarise a carer’s perspective of their own health (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009).

### **Procedures**

The survey package was collated for postage to eligible participants. It included a general letter of introduction from the VCPR (see Appendix J), a participant information letter, consent form, survey booklet, reply paid envelope and a child report version of the CPCHILD. The booklet was designed with the intent of being easy to read and complete. It was proofread by people who were unfamiliar with the content and amended as needed.

Each page of the carer report of the CPCHILD questionnaire, and the original documents for the cerebral palsy classification systems, the GMFCS, MACS, EDACS and CFCS, were copied and included as part of the survey booklet. The web address where the documents are freely available on line was provided next to an “information” symbol. This gave participants the opportunity to read further about the included tools if they wished. The items on the Global Health Questionnaire were retyped as the PROMIS format was difficult to read when transferred to paper. The booklet was printed on green paper and the reply-paid envelopes were gold so that the survey was likely to be visible in the family home. The consent form had the words “please return” highlighted in pink.

The VPCR staff posted the survey packages to the 372 children on the VCPR who met the eligibility criteria on July 11, 2016. This number of children was slightly more than the 360 who were deemed contactable during initial discussion with the VCPR. The collated survey packages were provided to the VCPR staff who applied the address labels and put them in the post. The reply-paid envelopes were addressed to the researcher at ACU.

Contact details of the researcher were provided for participants to discuss any aspects of the project. Participants were asked whether they agreed to be contacted for further participation in Study 2 on a removable page in the survey booklet. If they choose not to participate in Study 2, and their survey was returned and completed, the page was removed making the survey data non-identifiable from that point. If they agreed to be contacted for Study 2, the page remained in the survey until Study 2 had been completed.

Sending reminders at appropriate time intervals has been shown to be an important strategy to optimise response rates to postal surveys (Mangione, 1995). Therefore, two weeks after the initial mail out, the researcher sent a reminder by email, post or phone to non-responders. This reminder process occurred again four weeks after the initial mail out. When surveys were received, they were reviewed for missing data. Missing data were obtained by phone and email from the carers who consented to follow up. Where the phone or email details were not available, a copy of the incomplete items were posted with a prepaid envelope.

**Data management.** To obtain total scores on the CPCHILD, data were first entered from paper copies into an excel spreadsheet that was developed following the scoring guidelines in the CPCHILD manual (Narayanan et al., 2007). Study data were transferred

manually from paper surveys for management in the Research Electronic Data Capture (REDCap) tool hosted at ACU (Harris, 2009). The REDCap database was designed to include the study specific questionnaire, the CPCHILD-Parent report and CPCHILD-Child report. The CPCHILD total scores were manually entered from the excel spreadsheets into the study specific section of the REDCap data set. In the process of collating the survey booklet, one question was left out of the PROMIS carer Global Health Questionnaire section of the questionnaire by error. Following the guidelines from the authors, one or more missing responses rendered the PROMIS scoring tables unusable. Unfortunately, the error was not detected until the data had been returned. Therefore, the total scores on the measure could not be calculated and the data on carer health were analysed as individual items.

**Data cleaning.** Once all data were entered, REDCap software was used to highlight field validation errors. Outliers were identified and reviewed. Ten participant data sets were selected randomly, using an online random number generation. These data sets were checked in detail for errors. Seven errors were noted and corrected. A further ten participant datasets were checked, and two errors were detected. Subsequently, all 83 REDCap data sets were checked against the hard copies.

**Data security.** Surveys were de-identified and tracked by a code that linked the survey to the participant's demographic and classification data. Paper surveys were stored in a locked filing cabinet at ACU. All electronic data were stored on a password protected computer. Only the researchers had access to the data.



## Data analysis

**Demographic data.** Child characteristics, carer demographics and cerebral palsy classification data were summarised by frequency and percentage for the two categories of children, those at GMFCS level IV and V. Carer health was summarised by mean and standard deviation as a total group and by GMFCS levels. The pain items from the carer health section was adjusted from a ten-point scale to a five-point scale for consistency of reporting. Due to the design of the survey, it was possible for participants to select more than one response to items about work status, motor type and additional conditions. Where this occurred, a single response was selected by the author with consistent rules as outlined in Appendix K.

**Analyses of daily routines and carer well-being.** To answer Research Question 1 and 2, descriptive statistics were used to summarise ratings of importance, difficulty and level of assistance required to complete daily routines. The mean importance and difficulty were ranked from highest to lowest. The mean level of assistance was ranked from lowest to highest, with less assistance implying a greater level of independence. Responses related to children at GMFCS IV were compared to children at GMFCS V, and carers' responses were compared to child responses where a CPCHILD-Child report was available.

To answer Research Questions 1a to 1b and 2a to 2c, evidence of potential patterns of difference in rankings between groups was sought. The 17 items from the CPCHILD were reviewed individually by the researcher as to how they were ranked by difficulty, level of assistance and importance. Differences of ranking of individual items of more than four levels between groups were deemed to be of importance, as that represented approximately a 25% ( $4/17 = 23\%$ ) difference in level. Clusters of items that had similar patterns of ranking, for example low importance, low difficulty and low assistance were also identified.

Descriptive analysis of the patterns with consideration of possible clinical implications was undertaken by the author.

To provide information to inform Research Question 3, the total scores on the CPCHILD were calculated to report child HRQOL. The total scores were also used to assess the likely similarities of this study sample to prior study samples. Because the data are ordinal, median (and interquartile ranges) of the groups' standard scores were reported by the two categories of GMFCS; level IV and level V. The medians of GMFCS IV and V were compared using a Mann Whitney *U* test. As the authors of the CPCHILD have reported and published the mean total scores for GMFCS levels, the mean total scores were also calculated and reported for GMFCS levels.

Total scores on the CPCHILD were summarised for children by MACS, CFCS and EDACS level. Relationships between total CPCHILD scores and independent child and carer variables were reported using Spearman's *rho* correlation analysis. Analyses were undertaken using software Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, 2017). The results from the data collection conducted in Study 1 are outlined in Chapter 4, presented as a manuscript that has been prepared for publication.

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**CHAPTER 4a: MANUSCRIPT REPORTING THE RESULTS OF STUDY 1**

This chapter contains the manuscript of the results of Study 1 prepared for publication in the journal *Disability and Rehabilitation*. Results tables are included at the end of the manuscript. Further discussion of the results of Study 1, and supplementary tables that have not been included in the manuscript are in Chapter 4b.



**A descriptive study of the daily routines of children with cerebral palsy, who are non- ambulatory, and their carers**

Heesh, Robyn \*<sup>a</sup>, Greaves, Susan<sup>b</sup>, Sheppard, Loretta<sup>c</sup>, Imms, Christine<sup>a,c</sup>.

*<sup>a</sup> School of Allied Health, Australian Catholic University, Fitzroy, Vic Department;*

*<sup>b</sup> Occupational Therapy Department, The Royal Children's Hospital, Parkville, Vic, Australia;*

*<sup>c</sup> Centre for Disability and Development Research, Australian Catholic University, Fitzroy, Vic, Australia.*

\*Correspondence to Centre for Disability and Development Research, Australian Catholic University, Locked Bag 4115, Fitzroy, Vic. 3065, Australia. E-mail: [christine.imms@myacu.edu.au](mailto:christine.imms@myacu.edu.au) ORCID ID: 0000-0002-5946-2651.

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## **A descriptive study of the daily routines of children with cerebral palsy who are non-ambulatory and their carers.**

### **ABSTRACT**

**Aim:** To explore and describe the important daily routines of non-ambulatory children with cerebral palsy (CP) and their carers.

**Method:** Participants included carers of, and children with, CP classified at Gross Motor Functional Classification (GMFCS) level IV or V, aged 5-18 years. The measures included a study-specific survey and the Caregiver Priority and Child Health Index of Life with Disability (CPCHILD). Routines were summarised descriptively and ranked according to importance (score range 1-5), level of assistance (0-3) and difficulty (0-6).

**Results:** Data were obtained from 78 carers of children with CP (mean age 12.3 years, *SD* 3.7 years, female  $n=39$ , GMFCS Level IV  $n=23$ ). Nine children completed a CCHILD-Child report. All daily living items were deemed important (mean scores  $\geq 3.1/5$ ). Combining importance, difficulty and assistance data enabled routines to be clustered to describe children and carers' performance. Carer fatigue and mental health were associated with lower CCHILD total scores

**Interpretation:** Children with CP at GMFCS IV and V could contribute to some easy daily routines when assistance was provided. Further exploration of how children contribute to daily routines is needed to inform future interventions to support children and carers.

Keywords: cerebral palsy, activities of daily living, skills and learning

### **What this paper adds**

- Children with significant impairments can contribute to some daily routines with support.
- Understanding daily routines can help guide practical learning for carers and children
- Child respondents indicate they contribute more to tasks than carer think
- Health related quality of life relates to carer mental health and fatigue

**A descriptive study of the daily routines of children with cerebral palsy who are non-ambulatory and their carers.**

Functional outcomes for children with cerebral palsy vary considerably and can be described using the internationally accepted classification systems. The Gross Motor Functional Classification System (GMFCS) [1] describes the daily mobility of children. It has five levels where children at level I have the highest functional skills in mobility. The focus of this study was on children with cerebral palsy classified at GMFCS IV and V (subsequently referred to as ‘children at GMFCS IV and V’). Children at GMFCS IV and V use wheelchairs as their primary mode of mobility and are likely to always require assistance from an adult to perform many activities of daily living. Children at GMFCS IV may use a supported walker for short distances with assistance or use a powered wheelchair for mobility; children at GMFCS V are limited in head and trunk movements against gravity and require maximum assistance to mobilise in a wheelchair [1].

The GMFCS level alone, however, does not provide a full picture of the ability and performance of a child. The Manual Ability Classification System (MACS) classifies the ability of children to handle age appropriate objects during daily activities [2], the Communication Function Classification System (CFCS) describes the effectiveness of communication performance as a sender and receiver [3], and the Eating and Drinking Ability Classification System (EDACS) describes the eating and drinking skills of children with cerebral palsy [4]. All the cerebral palsy classification systems have scales ranging from I to V: level I describes children with higher level of ability and level V describes children who require maximum assistance in a specific functional area. The classification systems are important tools to describe and highlight the variability of the skills and abilities of children with cerebral palsy. The cerebral palsy classification systems are important in this research as

the child's functional abilities may impact child and carer perceptions of daily routines and reported levels of health-related quality of life.

Children at GMFCS IV and V require varied, complex, time consuming and often costly supports to ensure they are cared for, live healthy and meaningful lives and participate in their communities [5]. Currently, there is little evidence to guide clinicians in their selection of interventions for children at GMFCS IV and V, with most research that includes children at GMFCS IV and V focusing on medical and surgical interventions rather than interventions specifically designed to impact daily routines [6]. Interventions to support achievement of daily living skills within the context of family routines are often important goals of intervention, with expectation and aspirations being unique to each family [7]. There is some evidence that children can learn functional skills through practice in the daily routine [8]. However, there is currently limited evidence about how children at GMFCS IV and V complete daily routines to inform goal setting and expectations of families and children.

Daily routines are made up of simple or complex actions and tasks that are undertaken during everyday life such as getting dressed, having a shower or eating a meal [9]. It is likely that the actions and sequence of tasks that make up a daily routine for a child with cerebral palsy aged 5 to 18 years and their carer are different to that of a typically developing child who will usually be independent in these activities by five years of age [7].

Due to the variability of abilities and limitations in children at GMFCS IV and V, a meaningful contribution to a daily routine might involve learning an easy action that assists with task completion. This is distinct from the expectation that improved functional performance requires the ability to complete an entire task independently [10]. Although children at GMFCS IV and V may not attain complete independence in daily routines, these children can still be, or learn to be, active participants in daily life. The daily routines specific

to children at GMFCS IV and V and their carers therefore require further exploration.

Children at GMFCS IV and V, who have significant limitations in functional performance, are likely to have many interactions with a carer who provides them with assistance across the day. Providing assistance for a child with a disability can impact on the mental health and quality of life of the carer [11]. Therefore, consideration of the characteristics, needs and views of both the carer and the child are important when exploring the daily routines for children at GMFCS IV and V. The term ‘carer’ in this research refers to a self-identified primary care-giver of the child including a parent, grandparent or foster parent.

The purpose of this study was to explore and describe the daily routines of children at GMFCS IV and V, with the aim of supporting the design of interventions that are relevant to the daily lives of children and carers. Children with cerebral palsy have been shown to be capable of reporting on their own health-related quality of life, therefore the views of young people as well as their carers were sought [12]. Understanding what daily routines were important was required to provide insights about what are the highest priority for families in daily life. The difficulty level of daily routines was sought to provide information about what may be harder or easier for children and carers to achieve. Identifying daily routines where children required the least amount of assistance was sought to inform where children may be able contribute to routines. Information from this study is likely to be highly informative to families, children and clinicians during therapy goal setting and intervention planning.

In this study, the following research questions were addressed:

- 1) What daily routines are important for children at GMFCS IV and V and their carers?
  - a) Is there a difference between what children identify and what carers identify as important daily routines?
  - b) Do carers and children at GMFCS IV identify the same daily routines as important as compared to carers and children at GMFCS V?
- 2) How do children at GMFCS IV and V and their carers rate important daily routines according to the difficulty of the task/activity and the level of assistance the child requires?
  - a) Is there a difference between how children rate and how carers rate the difficulty and assistance required to complete important daily routines?
  - b) Do carers and children at GMFCS IV rate the same levels of difficulty and assistance required to complete important daily routines as compared to carers and children at GMFCS V?
  - c) Is there a pattern of responses that describes the relationship between rankings of importance and ability to complete daily routines?
- 3) What are the relationships between health-related quality of life and child functional level and carer wellbeing?

**Method***Design*

This was the first study in a program of descriptive research using explanatory sequential mixed methods. In this study, survey methods were used to answer the research questions, and to inform the development of the subsequent qualitative study which investigated how children and carers worked together to achieve important daily routines.

*Ethics*

Ethical approval was received through Human Research Ethics Committee (HREC), at Australian Catholic University (HREC registration number 2016- 112H). Written consent to participate was sought and obtained from the participants.

*Participants and recruitment*

Eligible participants were children with cerebral palsy classified at GMFCS IV or V, aged 5 to 18 years, living in Victoria or Tasmania. The sampling frame was the Victorian Cerebral Palsy Register (VCPR). Children who were born in Victoria and have subsequently moved to Tasmania, or who live in Tasmania and receive services in Victoria are included on the VCPR. Children at GMFCS IV and V are likely to have high ascertainment rates on the VCPR as they are likely to access services due to their increased functional needs and comorbidities, and therefore able to be identified [13]. Surveys were posted by VCPR staff to the carers of 372 children who met the inclusion criteria at the time of recruitment. Carers and children consented by completing and returning the survey.

*Measures*

Data was collected using the Caregiver Priority and Child Health Index of Life with Disability (CPCHILD), and a study specific survey.

*Participant characteristics*

Carers rated their child's functional ability using the GMFCS, MACS, CFCS and EDACS.

The GMFCS is reported to be valid [1], stable [14] and reliable when used by parents [15] to measure mobility levels. The MACS is a valid and reliable measure of how children use their hands in daily activities [2, 10]. The CFCS has been validated to describe communication abilities [3]. The EDACS is reported to be a reliable tool to describe eating and drinking abilities [4]. Demographic data collected within the CPCHILD and the study-specific survey included; (a) Child characteristics - sex, age, topographical distribution, motor type, additional conditions, address and weight; and (b) Carer characteristics - sex, relationship to child, date of birth, highest level of schooling completed and current work status. The Global Health Questionnaire was included for an overview of carer health [16].

#### *Daily routines*

The CPCHILD was selected for this research as it identifies daily routines that are specific to children who primarily use a wheelchair for mobility, was developed in consultation with carers of children with severe disability and includes a child report version [17]. The CPCHILD is reported to be a valid measure of the caregiver perspective of the comfort, health status, wellbeing, functional abilities and ease of caregiving of children with severe disabilities. Together these constructs combine to provide a total score reporting health related quality of life (HRQOL). When assessed for test- retest reliability, a high ICC of 0.97 (95% confidence interval 0.95–0.99) was reported for the total scores [17].

Of primary interest to this study, were the ratings within the CPCHILD of importance, difficulty and level of assistance children required to complete daily routines. To complete the questionnaire, the participant rates the difficulty and level of assistance required to complete personal care and positioning, transferring and mobility activities, referred to in the CPCHILD as items. Difficulty scores range from 0 (almost impossible) to 6 (no problem at all); level of assistance scores range from 0 (total assistance), to 3 (independent); and importance scores from 1 (least important) to 6 (most important). Raw scores are converted



to standardised scores to calculate total CPCHILD scores (range 0-100). Total scores were collected to provide an overall understanding of the included participants and assess the relationship between HRQOL and child and carer wellbeing. The authors of the CPCHILD provide data to describe expected scores for children according to GMFCS level, with a mean score for children at GMFCS IV of 56.3 (*SD* 8.1), and GMFCS V of 44.4 (*SD* 12.6) [18].

Lower scores represent a poorer rating of HRQOL.

#### *Data collection procedures*

The CPCHILD, the study-specific survey and participant information forms were posted to eligible carers. A CPCHILD-Child report was included in all the survey booklets to seek the views of children. Reminders were sent at two and four weeks.

#### *Data management and analyses*

Missing data were obtained by phone and email from carers who consented to follow up. Descriptive statistics were used to describe the sample and compare to other published data to determine whether the sample was representative of the population of children at GMFCS IV and V. The SEIFA scores, derived from the postcode of the child's address using data from the ABS website, were compared to the Victorian mean of 1000 (*SD* 100) to describe the sample. Descriptive statistics were used to summarise and rank ratings of importance (range 1-6; high scores = more important), difficulty (range 0-6; high scores = least difficult) and level of assistance (0-3; high scores = least assistance) as reported using the CPCHILD. To address Research Question 1, items that were the most important were identified. Items that were least difficult and required the least amount of assistance were highlighted to answer Research Question 2. Responses were compared by GMFCS level, and carers' responses were compared to child responses, where a CPCHILD-Child report was available, to answer Research Questions 1 and 2. To inform research Question 3, total scores on the CPCHILD were summarised by GMFCS, MACS, CFCS and EDACS levels, and relationships between

total scores and independent child and carer variables were assessed using Spearman's *rho* correlation analyses. The median scores for children at GMFCS level IV and V were compared using a Mann Whitney *U* test. Analyses were undertaken using Statistical Package for the Social Sciences (SPSS).

## RESULTS

Surveys were returned by 81 (22.3%) families and two (0.5%) were completed during reminder phone calls. Figure 4.1 displays the flow of participants through the study. Final analyses were undertaken using data from 78 carers and nine children who also returned a CPCHILD-Child report. Participants reported that the average time taken to complete the survey was 29.7 minutes (*SD* 12.7, *n*= 65, range 10 to 90 minutes) for carers., and 44.4 minutes (*SD* 28.4, *n*=9, range 20 to 90 minutes) for children.

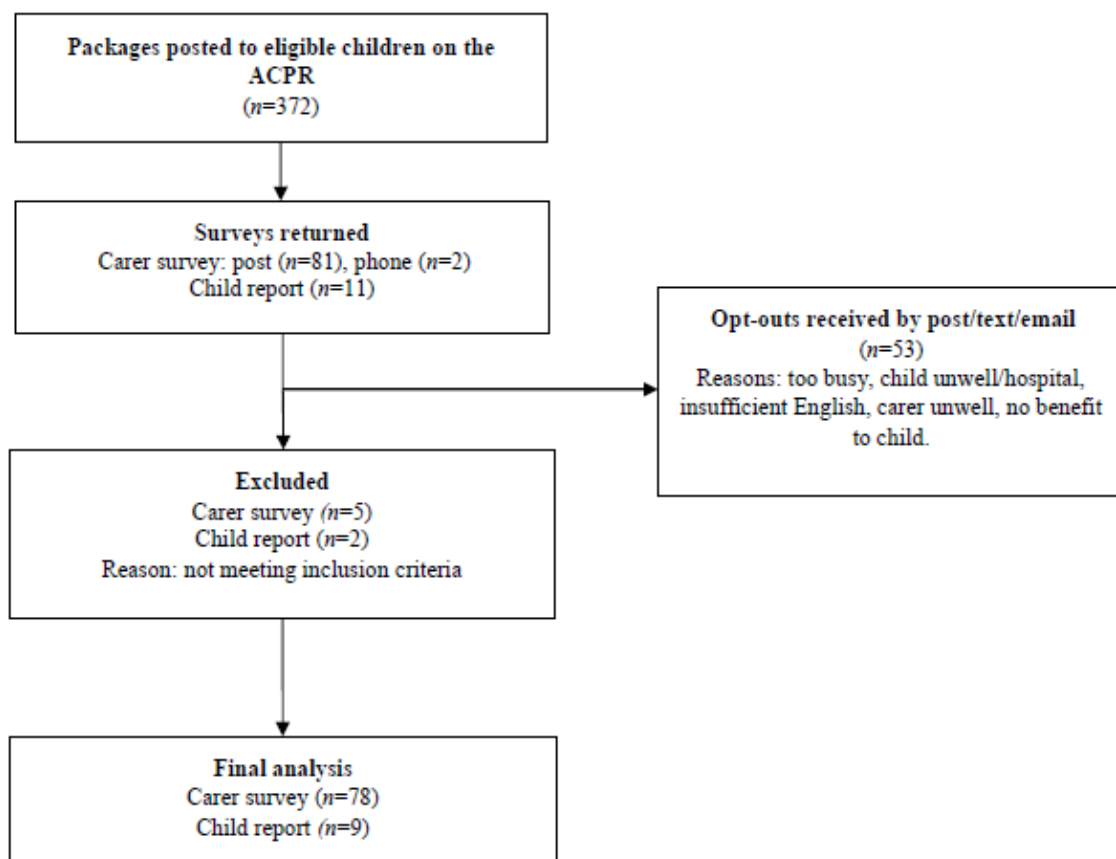


Figure 4.1 Flow diagram of participant recruitment

### *Participant characteristics*

Child characteristics are displayed in Table 4.1, along with comparative population data from other research samples. There was a strong relationship between MACS and GMFCS with 67 (85.7%) of participants also classified at MACS IV and V. However, greater variability was evident in CFCS and EDACS levels. Only four children (all GMFCS IV) were reported to have no additional conditions or co-morbidities, and 11 (14%) had four or more additional conditions. Twenty-five children (32%) had no reported intellectual impairment or learning difficulty. Comparative data from prior research suggest that the sample had similar patterns of characteristics to other populations of children with cerebral palsy at GMFCS IV and V.

Insert Table 4.1 here

The nine children who responded ( $n = 6$  girls;  $n = 5$  GMFCS IV, age range 9-18 years) were

classified at varied MACS and EDACS levels (See Table 4.2). Five children at CFCS level I completed the survey on their own, or with carer assistance, and four children at CFCS level III used alternative and augmentative communication (AAC).

Insert Table 4.2 here

Carer characteristics and rating of carer health are presented in Table 4.3. Mothers were the main respondents ( $n = 66$ , 84.6%). All of the carers were aged 30 years or older, with one carer over 70 years. There was an even spread of carer educational levels, and less than half worked outside of the home ( $n = 35$ , 44.9%). Carers reported low satisfaction with their own social life, emotional problems, fatigue and pain. Carers experience of pain and fatigue varied: 15 (19.2%) reported no pain, and 16 (20.6%) reported high levels of pain (3-4/5) and 14 (17.9%) reported severe to very severe fatigue levels with only four (5%) reporting no fatigue. There was little difference between GMFCS IV and V group ratings of carer health and well-being. The mean SEIFA score was 1011.47 ( $SD$  59.6), compared to average of 1000 ( $SD$  100) for Victoria [19].

Insert Table 4.3 here

***Importance, difficulty and level of assistance to complete daily routines.***

All 17 daily living items were rated as important (see Table 4.4 - Importance) with mean ratings ranging from 3.17 ( $SD$  1.32) to 4.32 ( $SD$  0.68). *Sitting in a chair, moving indoors, eating, toileting and transferring in and out of a chair* were the five items rated as the most important. *Standing for transfers* were rated as the most difficult item, with a mean of 1.81 ( $SD$  1.52) range 0 to 6; (see Table 4.4 - Difficulty). *Eating* mean 3.13 ( $SD$  1.67) and *sitting in a chair* 3.63 ( $SD$  1.54) were the easiest items, although the GMFCS V group still rated them as slightly difficult. The children in this study required high levels of assistance with all daily living items: mean scores ranged from 0.08 ( $SD$  0.31) to 0.62 ( $SD$  0.99) (see Table 4.4- Assistance). The four items that required the least carer assistance were *sitting in a*

*wheelchair, moving indoors, moving outdoors and eating.*

### ***Comparisons between GMFCS IV and GMFCS V.***

Although there were similarities between the groups on ranking of importance, difficulty and level of assistance, there were some important differences. The largest difference in ranking of importance was for *standing for transfers* (GMFCS IV, 8<sup>th</sup>, GMFCS V, 15<sup>th</sup>) (see Table 4.4, in bold text). children at GMFCS IV ranked *Getting in and out of a car* as the 2<sup>nd</sup> most difficult, and GMFCS V was ranked it as 11<sup>th</sup> most difficult (see Table 4.4, text underlined); carers of children at GMFCS V ranked upper body dressing as the 2<sup>nd</sup> most difficult item compared with the GMFCS IV group who ranked it 9<sup>th</sup> (see Table 4.4, text underlined).

Insert Table 4.4 here

### ***Comparisons between carers and children's' responses***

Carers and children were similar in how they rated the importance of items, however there were some differences (see Table 4.5). Children ranked *moving outdoors* and *visiting public places* as the 1<sup>st</sup> and 2<sup>nd</sup> most important, while carers rated *moving indoors* 1<sup>st</sup> in importance. The greatest difference in ranking of importance was for *changing continence aids* with children rating this as more important than carers (carers 11<sup>th</sup>; children 6<sup>th</sup>) (See Table 4.5, in bold text). The greatest difference in rankings of difficulty, was for *footwear on and off* (carers 5<sup>th</sup>; children 1<sup>st</sup>) and *oral hygiene* (carers 16<sup>th</sup>; children 10<sup>th</sup>) with children rating these items as more difficult than carers (see Table 4.5, in bold text). Children rated the level of assistance they required slightly lower than their carers on all items (See Table 4.5).

Insert Table 4.5 here

### ***Relationship between importance, difficulty and assistance***

Items that were rated with higher importance, lower difficulty and lower assistance (*moving*

*indoors, eating, moving outdoors, and sitting in wheelchair*) are highlighted in grey in Table 4.4. *Footwear on and off, lower body dressing and haircare/grooming* were rated with lower importance, lower difficulty and higher levels of assistance and are bolded and italicised in Table 4.4.

### ***HRQOL- CPCHILD***

The sample's CPCHILD total scores were as expected for GMFCS level [18], with the mean for GMFCS IV being 55.98 (*SD* 11.28) and for GMFCS V being 46.63 (*SD* 12.88), with a statistically significant group difference (Mann-Whitney  $U = 347$ ,  $p = 0.002$ ). Relationships with other cerebral palsy classifications are reported in Table 4.6, and other variables in Table 4.7. Increasing levels on each classification system showed a trend toward decreasing median total scores on the CPCHILD. However, children at CFCS level III had a slightly higher median than CFCS level II, and children at EDACS level IV had a higher median than EDACS level III (see Table 4.6). There was a medium negative association between scores on the CPCHILD and carer fatigue ( $\rho = -0.395$ ) and carer mental health ( $\rho = -0.402$ ). There were weak negative relationships between CPCHILD total scores and other variables (see Table 4.7).

Insert Table 4.6 here

Insert Table 4.7 here

## **DISCUSSION**

Daily routines need to be completed so that children and carers can focus on what is important to them in their broader world, which could include attending and participating in school, recreation and family life. The aim of this research was to gather evidence that could support the design of interventions that are practical and relevant to the daily lives of children and carers. The findings of this study provided a description of the daily routines of children at GMFCS IV and V with a focus on what carers thought about the importance, difficulty and

level of assistance the child required to complete them. Although each carer and child and the transactions that occur between them are unique, understanding daily routines that are specific to children at GMFCS IV and V can help clinicians guide practical learning for carers and children.

All daily living items in the CPCHILD were rated as important to the children and carers. This is not surprising as items were developed by the CPCHILD authors through close consultation with carers of children with significant motor impairments [17]. Rating of what was difficult yielded information about which routines might be easier. Items that were easier were of interest as they provided insights into when children may have assisted more with a routine, and therefore what could become a focus of intervention. While many children required total assistance to complete daily routines, the specific skills or actions that the child may have contributed to task completion are not assessed in the CPCHILD. These small differences in the rating level of assistance may provide clues as to where children were likely to be more active in contributing to task completion. Children rated their level of independence in daily routines slightly higher than their carers, suggesting that they believed they required less assistance than their carers thought they needed. It is possible that the children thought they were helping to achieve the tasks and felt they were contributing more to the task than their carers thought they were. It is also possible that the children were putting effort into assisting with the task, but from the carer's perspective, as assistance was still required for all aspects of the routine, they were still rated by the carer as requiring total assistance. It may be that carers need support to recognise and reinforce a child's efforts as these actions might be subtle but still contribute to daily routines.

Items rated with higher importance, lower difficulty and lower levels of assistance, included *sitting in wheelchair, moving indoors, moving outdoors, and eating*. This indicated that *sitting*

*in a wheelchair*, with any degree of supportive seating, was an important skill that some children may be able to learn and achieve. As would be expected, children at GMFCS IV and V use assistive technology such as wheelchairs to support their function and ease of care [20]. Although information about equipment was not collected in this study, the type of seating a child uses is likely to be relevant to this item, but an underlying ability to maintain a seated position is still a skill of value. The task of *moving indoors* might have included children independently rolling or creeping on the floor at home. It might also have included the use of powered mobility which is known to have positive outcomes on independent mobility and overall development of children [21]. The relative ease and less assistance required to achieve indoor and outdoor mobility might have reflected the relevance of powered mobility for the children in this study. Children may need assistance to get in and out of a powered chair, yet when seated may be able to move independently, which is likely to be of importance to children and carers.

Mealtimes also appeared to be important for children and carers, and *eating* was rated as one of the easier tasks for children. This supports other studies that have shown that children at GMFCS IV and V were able to develop the subtle oral motor and postural skills required during eating, given the right level of challenge and time to practice [22]. Given eating involves both oral motor skills and hand function, both the EDACS level and MACS level may be useful in guiding goals for mealtimes.

Items that carers rated as lower importance, lower difficulty and required a greater amount of assistance, such as *taking footwear on/off*, *lower body dressing*, *haircare* and *grooming* may represent lower priority goals. It is possible that these items were rated as low difficulty by carers, because the carers themselves found them easy to do. The children who responded rated these items as more difficult than their carers as the children may have found them



difficult to do. For example, *haircare* and *footwear on/off* items require fine manipulation, are complex and likely to require a refined outcome for personal satisfaction. To be independent, a child may need to reach to their feet, or above their head. It is likely to be quicker and easier for an adult to complete these tasks. Hair groomed to suit personal style, or shoes fastened adequately to remain in place and be comfortable are likely to be challenging tasks where the quality of the outcome may be important. They are likely to take a long time for a child at GMFCS IV or V to learn or complete, if at all possible, and therefore may be a lower priority goal for children. This information about the routines of haircare and putting on footwear, may be examples of how children and carers decide who, within the pair, completes what aspects of tasks, and how families accommodate expectation about what is possible based on level of impairment [23].

Knowledge about how children function across the cerebral palsy classifications might also highlight what is important and possible for children. For example, children classified at MACS I-IV are likely to be able to use their hands for daily routines such as eating: either independently or with assistance [2]. Although both GMFCS groups rated *eating* as one of the easiest items, children at GMFCS IV required less assistance overall for *eating* than children at GMFCS V, reflecting the greater range of MACS levels in the GMFCS IV group. The children at GMFCS V in this study had a higher number of children at MACS IV and V, and *upper body dressing* was rated as more difficult by carers and children at GMFCS V. This suggests that certain daily routines, such as dressing stiff and less active upper limbs might become more difficult as MACS levels increase. The results of this study provide examples of the usefulness of the MACS alongside the GMFCS to highlight possible priorities and goals for children and carers.

The differences in the ratings of *standing for transfers* between groups in this study appeared

to align with the difference in GMFCS classification criteria [1]. Children at GMFCS V do not usually complete standing transfers. Some children at GMFCS IV may do so with assistance. Children at GMFCS IV and V are also less likely to maintain the ability to stand with increased age [24]. An ability to use a skill may increase the rating of importance. For example, if a child and carer do not use a standing transfer, it may be rated less important, an example of how families accommodate expectation based on what is possible [23]. The combination of MACS and GMFCS levels have been shown to be useful to guide potential goal areas for intervention for all children with cerebral palsy [10]. Further work is warranted to highlight the abilities of children at GMFCS IV and V rather than simply comparing skill development across all GMFCS levels. This could include further research involving a larger number of children that would allow greater exploration of subgroups.

The CPCHILD total scores reported in this study are consistent with those reported elsewhere [17] supporting the validity of the instrument and information about caregiver perspective on HRQOL. Carers of children at GMFCS V reported lower total scores on average than carers of children at GMFCS IV (see Table 4.6), reflecting outcomes of other studies that poorer motor abilities indicate lower HRQOL [25]. The overall association between scores and carer and child variables indicated that poor carer mental health and increased fatigue had the strongest association with lower total scores on the CPCHILD. This highlights the need to attend to the wellbeing of the carers of children at GMFCS IV and V [26]. Increasing the ease of completing daily routines by supporting children to learn to contribute towards tasks in daily life may be one way to support carer well-being.

It is important to design research that includes the views of young people [12]. It is challenging to gather the views of children with cerebral palsy, and particularly children with complex motor impairments as they are likely to have higher rates of communication and

intellectual impairments [27]. Using AAC to complete a survey is likely to be time consuming and may be tiring for the child and carer. The fact that nine young people chose to complete the survey in this study, some taking up to 90 minutes to do so, suggests that those young people were keen to have their voices heard.

While this study provided an overview of the opinions of carers and children about daily routines, more research is required to explore how children and carers learn and work together to achieve daily routines. Children at GMFCS IV and V require support from a carer to complete daily routines, but how they do so is likely to vary between individual carer and child pairs due to the variability of functional skills of children, carer health and abilities and contextual factors. As the current measures of functional skills may not detect subtle changes within a child, the way children and carers interact in the context of daily routines may be an important focus of intervention that requires further investigation.

## **LIMITATIONS**

The generalisability of findings may be limited by the culture and demographics of a South-East Australian population. The results must be considered with caution due to the low response rate of 22.8%. The population of interest were children who have high care needs who may be a particularly vulnerable group which may have contributed to the low response rate. Comparison of the sample to other population data however suggest that the sample was broadly representative of children with cerebral palsy at GMFCS IV and V in Victoria. Carers with insufficient literacy or English language skills were excluded, and it is likely that carers who were very busy or stressed may not have chosen to take part. Two interviews were conducted over the phone, and impact of this data collection method, in comparison to the self-report mail survey is unknown. Children who responded to the survey required assistance from a carer. How much assistance the child was given was unable to be accurately recorded due to the survey design. The impact of the carer influence on the child responses is largely

unknown. In the process of collating the survey booklet, one question was left out of the carer Global Health Questionnaire [16] section of the survey by error. Therefore, the total scores on the measure could not be calculated and the data on carer health were analysed as individual items. The descriptive statistics used to analyse the trends in importance, difficulty and level of assistance required cannot be used to make assumptions about all children at GMFCS IV and V.

## **CONCLUSION**

Data from this study suggest there are patterns in how routines are viewed according to importance, difficulty and the level of assistance required, that may help clinicians and families guide and influence task achievement. Although children at GMFCS IV and V require moderate to total assistance with many daily routines, children may be able to contribute to aspects of some routines. This suggests the potential for children to learn skills, for example, to assist with moving indoors, eating, moving outdoors and sitting in their wheelchairs. Any contribution by the child may ease the completion of the task and potentially improve both carer well-being and child health related quality of life.

The cerebral palsy classification systems are useful tools that highlight and describe the variability in children and can provide guidance about where to focus intervention. Skills needed for daily routines and priorities may differ for children at GMFCS IV compared to children at GMFCS V, highlighting that there is also variability between these subgroups. Understanding routines that are specific to children at GMFCS IV and V can help clinicians and families to see potential areas of learning that then can, and must, be tailored to each individual circumstance.

## **CONFLICT OF INTEREST**

The authors stated they had no interests that might be perceived as posing conflict or bias.

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Table 4.1

*Child characteristics Study 1**Population data from other studies*

	Total <i>n</i> =78	GMFCS IV <i>n</i> =23	GMFCS V <i>n</i> =55	GMFCS IV	GMFCS V
Sex, <i>n</i> (%)					
Female	39 (50)	14 (60.8)	25 (45.4)	-	-
Male	39 (50)	9 (39.2)	30 (54.6)	-	-
Age, <i>n</i> (%)					
5-11 years	31 (39.7)	8 (34.8)	23 (41.8)	-	-
12-18 years	47 (60.3)	15 (65.2)	32 (58.2)	-	-
MACS level, <i>n</i> (%)				Eliasson et al, (2006) <sup>a</sup> <i>n</i> =32	<i>n</i> =26
I	1 (1.3)	0 (0)	1 (1.8)	0 (0.0)	0 (0.0)
II	3 (3.8)	2 (8.7)	1 (1.8)	2 (6.2)	0 (0.0)
III	7 (9.0)	4 (17.4)	3 (5.5)	9 (28.1)	0 (0.0)
IV	20 (25.6)	14 (60.9)	6 (10.9)	17 (53.1)	6 (23.0)
V	47 (60.3)	3 (13.0)	44 (80.0)	4 (12.6)	20 (77.0)
CFCS level, <i>n</i> (%)				Hidecker et al, (2012) <sup>b</sup> <i>n</i> =26	<i>n</i> =49
I	6 (7.7)	3 (13.0)	3 (5.5)	6 (23.0)	3(6.2)
II	3 (3.8)	1 (4.3)	2 (3.6)	3 (11.6)	7 (14.4)
III	17 (21.8)	9 (39.1)	8 (14.5)	10 (38.4)	13 (26.7)
IV	27 (34.6)	8 (34.9)	19 (34.6)	5 (19.3)	15 (30.2)
V	25 (32.1)	2 (8.7)	23 (41.8)	2 (7.7)	11(22.5)
EDACS level, <i>n</i> (%)				Sellers et al, (2014) <sup>c</sup> <i>n</i> =33	<i>n</i> =66
I	9 (11.6)	5 (21.7)	4 (7.3)	6 (18.2)	1 (1.5)
II	14 (17.9)	7 (30.4)	7 (12.7)	8 (24.3)	7 (10.6)
III	13 (16.7)	6 (26.2)	7 (12.7)	11 (33.3)	15 (22.7)
IV	14 (17.9)	2 (8.7)	12 (21.8)	6 (18.2)	20 (30.4)
V	28 (35.9)	3 (13.0)	25 (45.5)	2 (6.0)	23 (34.8)
Topographical distribution, <i>n</i> (%)					
Unilateral	2 (2.5)	1 (4.3)	1 (1.8)	-	-
Diplegia	8 (10.3)	4 (17.5)	4 (7.3)	-	-
Quadriplegia	64 (82.1)	17 (73.9)	47 (85.4)	-	-
Don't know	4 (5.1)	1 (4.3)	3 (5.5)	-	-
Motor type, <i>n</i> (%)					
Spasticity	28 (35.8)	9 (39.2)	19 (34.5)	-	-
Dystonia	10 (12.8)	4 (17.4)	6 (10.9)	-	-
Mixed	25 (32.1)	6 (26.1)	19 (34.5)	-	-
Ataxia	1 (1.3)	0 (0.0)	1 (1.8)	-	-
Hypotonia	11 (14.1)	2 (8.7)	9 (16.5)	-	-
Don't know	2 (2.6)	1 (4.3)	1 (1.8)	-	-
missing	1 (1.3)	1 (4.3)	0 (0.0)	-	-



% of children with each additional condition <sup>d</sup> n (%)	ACPR (2016) <sup>e</sup>			
	n = 1930			
None	4 (5.25)	4 (17.4)	0 (0.0)	-
ID	45 (57.7)	10 (43.5)	35 (63.6)	826 (48.2)
LD	8 (10.3)	4 (17.4)	4 (7.3)	0 (0.0)
Visual	31 (39.7)	6 (26.1)	25 (45.5)	544(31.2)
Hearing	12 (15.4)	4 (17.4)	8 (14.5)	234 (12.1)
Epilepsy	46 (59.0)	11 (47.8)	35 (63.6)	594 (31.9)
Other	18 (23.1)	4 (17.4)	14 (25.5)	-
Don't know	2 (2.6)	1 (4.3)	1 (1.85)	-

*Note.* GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Functional Classification System; EDACS = Eating and Drinking Classification System; ID = Intellectual impairment; LD = Learning disability.

<sup>a</sup>Data about MACS levels by GMFCS is from Eliasson, et al (2006); <sup>b</sup> CFCS levels from Hidecker et al, (2012); <sup>c</sup> EDACS levels from Sellers et al (2014).

<sup>d</sup>Many children had more than one condition, so sums do not tally to 100%.

<sup>e</sup>Data about % of all children with cerebral palsy from Victoria who have each additional condition from ACPR (2016).

Table 4.2  
*Carer characteristics*

Characteristic	GMFCS IV <i>n</i> =23	GMFCS V <i>n</i> =55	Total <i>n</i> =78
Relationship to child, <i>n</i> (%)			
Mother	22 (95.6)	44 (80.0)	66 (84.6)
Father	1 (4.4)	4 (7.3)	5 (6.4)
Parent (gender unspecified)	0 (0.0)	3 (5.4)	3 (3.9)
Guardian/foster parent/other	0 (0.0)	4 (7.3)	4 (5.1)
Age in years, <i>n</i> (%)			
30-39	3 (13.3)	8 (14.5)	11(14.1)
40-49	14 (60.8)	28 (50.9)	42 (53.8)
50-59	4 (17.3)	8 (14.5)	12 (15.5)
60-69	0 (0.0)	5 (9.1)	5 (6.4)
70+	0 (0.0)	1 (1.9)	1 (1.3)
missing	2 (8.6)	5 (9.1)	7 (8.9)
Highest level of education, <i>n</i> (%)			
Professional or graduate degree	5 (21.7)	12 (21.8)	17 (21.8)
College or university degree	5 (21.7)	12 (21.8)	17 (21.8)
Vocational school/some college	5 (21.7)	8 (14.5)	13 (16.7)
High School Diploma	2 (8.8)	9 (16.4)	11 (14.1)
Some high school or less	5 (21.7)	10 (18.2)	15 (19.2)
Not indicated	1 (4.4)	4 (7.3)	5 (6.4)
Work status, <i>n</i> (%)			
Not working due to child health	7 (30.4)	15 (27.3)	22 (28.2)
Not working-other reason	2 (8.7)	1 (1.8)	3 (3.8)
Looking for work outside home	1 (4.3)	1 (1.8)	2 (2.6)
Working full or part time	10 (43.5)	25 (45.5)	35 (44.9)
Full time homemaker	3 (13.1)	10 (18.2)	13 (16.7)
Missing	0 (0.0)	3 (5.4)	3 (3.8)
Carer rating of their own health and well-being			
	GMFCS IV <i>M (SD)</i>	GMFCS V <i>M (SD)</i>	Total <i>M (SD)</i>
1. General health <sup>a</sup>	2.52 (0.9)	2.55 (0.83)	2.54 (0.85)
2. Quality of life <sup>a</sup>	2.83 (0.94)	2.58 (0.87)	2.65 (0.9)
3. Mental health- mood and ability to think <sup>a</sup>	2.83 (1.03)	2.67 (1.04)	2.72 (1.0)
4. Satisfaction with social activities and relationships <sup>a</sup>	3.00 (0.9)	2.93 (0.94)	2.95 (0.92)
5. Extent able to carry out roles and social activities <sup>a</sup>	2.83 (1.03)	2.69 (0.96)	2.73 (0.98)
<i>1- excellent to 5- poor</i>			
6. Extent able to complete daily physical activities <sup>b</sup>	1.57 (1.12)	1.51 (0.92)	1.53 (0.98)
<i>1- completely to 5- not at all</i>			
7. How often bothered by emotional problems e.g. anxiety, depression <sup>c</sup>	3.0 (0.9)	2.91 (0.75)	2.94 (0.8)
<i>1- never to 5- always</i>			

8. Fatigue on average <sup>d</sup> <i>1- none to 5- very severe</i>	2.83 (0.89)	2.91 (0.89)	2.88 (0.88)
9. Pain on average <sup>e,f</sup> <i>No pain to 5-worst possible pain</i>	1.61 (1.18)	1.67 (1.2)	1.66 (1.18)

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*Note.* Carer rating of their own health and well-being on a five-point scale from 1 (most desirable) to 5 (least desirable).

<sup>a</sup> 1-excellent, 2-very good, 3-good, 4-fair, 5-poor.

<sup>b</sup> 1-completely, 2-mostly, 3-moderately, 4-a little, 5-not at all.

<sup>c</sup> 1-never, 2 rarely, 3-sometimes, 4-often, 5-always.

<sup>d</sup> 1- none, 2-mild, 3-moderate, 4-severe, 5-very severe.

<sup>e</sup> 0-no pain, to 5-worst possible pain

<sup>f</sup> pain recoded from a 10-point scale to a 5-point scale.

Table 4.3  
*Characteristics of children who completed CPCHILD-Child report*

Child Characteristics	<i>n</i> = 9
Sex, <i>n</i> (%)	
Female	6 (66.7)
Male	3 (33.3)
Age in years, <i>n</i> (%)	
9-12	3 (33.3)
13-15	3 (33.3)
16-18	3 (33.3)
GMFCS level, <i>n</i> (%)	
IV	5 (55.6)
V	4 (44.4)
MACS level, <i>n</i> (%)	
I	1 (11.1)
II	1 (11.1)
III	4 (44.4)
IV	2 (22.2)
V	1 (11.1)
CFCS level, <i>n</i> (%)	
I	5 (55.6)
III	4 (44.4)
EDACS level, <i>n</i> (%)	
I	4 (44.4)
II	1 (11.1)
III	1 (11.1)
IV	1 (11.1)
V	2 (22.2)

*Note.* CP = Cerebral Palsy; CPCHILD = Caregiver Priority and Child Health Index of Life with Disability; GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Functional Classification System.

Table 4.4

*Daily living items from the CPHILD ranked by importance, difficulty and level of assistance required and GMFCS levels*

<b>Importance of items to child's overall quality of life</b>										
Total <i>n</i> =78	<sup>a</sup> R	<sup>b</sup> <i>M</i> ( <i>SD</i> )	GMFCS IV <i>n</i> =23	<sup>a</sup> R	<sup>b</sup> <i>M</i> ( <i>SD</i> )	GMFCS V <i>n</i> =55	<sup>a</sup> R	<sup>b</sup> <i>M</i> ( <i>SD</i> )		
Sitting in chair	1	4.32 (0.68)	Moving Indoors	1	4.17 (0.65)	Sitting in chair	1	4.46 (0.57)		
Transfer in/out of chair	2	4.17 (0.78)	Eating	2	4.04 (0.98)	Transfer in/out of chair	2	4.25 (0.67)		
Moving Indoors	3	4.12 (0.84)	Toileting	3	4.00 (0.85)	Eating	3	4.13 (1)		
Eating	4	4.10 (0.99)	Sitting in chair	3	4.00 (0.8)	Moving Indoors	4	4.09 (0.91)		
Toileting	5	4.05 (0.98)	Transfer in/out of chair	5	3.96 (0.98)	Toileting	5	4.07 (1.03)		
Change continence aids	6	4.00 (1.10)	Change continence aids	5	3.96 (1.15)	Moving outdoors	6	4.04 (1.05)		
Moving outdoors	7	3.97 (0.98)	In/out car	7	3.91 (1.2)	Change continence aids	7	4.02 (1.1)		
In/out car	8	3.96 (1.2)	Moving outdoors	8	3.83 (0.78)	Visiting public place	8	4.00 (0.94)		
Visiting public place	9	3.92 (0.91)	<b>Standing for transfers</b>	8	3.83 (1.19)	In/out car	9	3.98 (1.21)		
Bathing	10	3.88 (0.95)	Bathing	10	3.78 (0.85)	Bathing	10	3.93 (1)		
In/out of bed	11	3.77 (1.16)	Visiting public place	11	3.74 (0.81)	In/out of bed	10	3.93 (1.02)		
Oral hygiene	12	3.64 (1.21)	Oral hygiene	12	3.43 (1.12)	Oral hygiene	12	3.73 (1.24)		
<b>Standing for transfers</b>	13	3.36 (1.75)	In/out of bed	13	3.39 (1.41)	Upper body dressing	13	3.29 (1.37)		
Upper body dressing	14	3.27 (1.27)	<b>Footwear on/off</b>	14	3.32 (1.25)	<b>Lower body dressing</b>	14	3.25 (1.34)		
<b>Lower body dressing</b>	15	3.22 (1.28)	Upper body dressing	14	3.22 (1)	<b>Standing for transfers</b>	15	3.17 (1.92)		
<b>Haircare/grooming</b>	16	3.18 (1.36)	<b>Haircare/grooming</b>	14	3.22 (0.95)	<b>Haircare/grooming</b>	16	3.16 (1.51)		
<b>Footwear on/off</b>	17	3.17 (1.32)	<b>Lower body dressing</b>	17	3.13 (1.14)	<b>Footwear on/off</b>	17	3.11 (1.36)		

			<b>Difficulty</b>								
Total <i>n</i> =78	<sup>c</sup> R	<sup>d</sup> <i>M</i> ( <i>SD</i> )	GMFCS IV <i>n</i> =23	<sup>c</sup> R	<sup>d</sup> <i>M</i> ( <i>SD</i> )	GMFCS V <i>n</i> =55	<sup>c</sup> R	<sup>d</sup> <i>M</i> ( <i>SD</i> )			
<b>Standing for transfers</b>	1	1.81 (1.52)	<b>Standing for transfers</b>	1	2.30 (1.22)	<b>Standing for transfers</b>	1	1.60 (1.59)			
Transfer in/out of chair	2	2.51 (1.40)	<u>In/out car</u>	2	2.48 (1.38)	Transfer in/out of chair	2	2.40 (1.46)			
Upper body dressing	3	2.62 (1.41)	Bathing	3	2.70 (1.22)	<u>Upper body dressing</u>	2	2.40 (1.59)			
In/out of bed	4	2.69 (1.49)	Transfer in/out of chair	4	2.78 (0.74)	In/out of bed	4	2.56 (1.63)			
Visiting public place	5	2.71 (1.48)	Visiting public place	5	2.87 (1.22)	Toileting	5	2.60 (1.58)			
Toileting	5	2.71 (1.69)	Change continence aids	6	2.91 (1.35)	Visiting public place	6	2.64 (1.58)			
In/out car	5	2.71 (1.55)	Toileting	7	2.96 (1.46)	Oral hygiene	7	2.65 (1.66)			
Bathing	5	2.71 (1.48)	In/out of bed	8	3.00 (1.04)	<b>Lower body dressing</b>	8	2.67 (1.47)			
<b>Lower body dressing</b>	9	2.82 (1.37)	<u>Upper body dressing</u>	9	3.13 (1.14)	Bathing	9	2.71 (1.58)			
Oral hygiene	10	2.83 (1.61)	<b>Lower body dressing</b>	10	3.17 (1.07)	<u>Moving Indoors</u>	10	2.75 (1.82)			
Change continence aids	11	2.91 (1.58)	Oral hygiene	11	3.26 (1.42)	<u>In/out car</u>	11	2.80 (1.81)			
<b>Footwear on/off</b>	12	3.01 (1.55)	<b>Footwear on/off</b>	12	3.35 (1.37)	<b>Footwear on/off</b>	12	2.87 (1.61)			
<u>Moving Indoors</u>	13	3.06 (1.8)	<u>Moving outdoors</u>	13	3.61 (1.56)	<u>Moving outdoors</u>	13	2.89 (1.80)			
<u>Moving outdoors</u>	14	3.10 (1.75)	<b>Haircare/grooming</b>	14	3.74 (1.10)	Change continence aids	14	2.91 (1.68)			
<b>Haircare/grooming</b>	15	3.37 (1.64)	<u>Moving Indoors</u>	15	3.83 (1.53)	<b>Haircare/grooming</b>	15	3.22 (1.80)			
<u>Sitting in chair</u>	16	3.63 (1.54)	<u>Eating</u>	16	4.35 (1.14)	<u>Sitting in chair</u>	16	3.31 (1.51)			
<u>Eating</u>	17	3.73 (1.67)	<u>Sitting in chair</u>	17	4.39 (1.34)	<u>Eating</u>	17	3.47 (1.80)			

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**Level of assistance required**

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Total <i>n</i> =78	<sup>e</sup> R	<sup>f</sup> <i>M</i>	( <i>SD</i> )	GMFCS IV <i>n</i> =23	<sup>e</sup> R	<sup>f</sup> <i>M</i>	( <i>SD</i> )	GMFCS V <i>n</i> =55	<sup>e</sup> R	<sup>f</sup> <i>M</i>	( <i>SD</i> )
Sitting in chair	1	0.62	(0.99)	Sitting in chair	1	1.22	(1.17)	Sitting in chair	1	0.37	(0.78)
Moving Indoors	2	0.49	(0.95)	Moving Indoors	2	1.04	(1.22)	Moving Indoors	2	0.26	(0.71)
Moving outdoors	3	0.39	(0.93)	Moving outdoors	3	0.74	(1.21)	Moving outdoors	3	0.24	(0.75)
Eating	4	0.32	(0.71)	Eating	4	0.61	(0.94)	Eating	4	0.20	(0.56)
Standing for transfers	5	0.25	(0.52)	Standing for transfers	5	0.57	(0.59)	Visiting public place	5	0.19	(0.68)
Visiting public place	6	0.22	(0.64)	In/out of bed	6	0.52	(0.85)	Bathing	6	0.11	(0.42)
In/out of bed	7	0.21	(0.57)	Transfer in/out chair	7	0.48	(0.59)	Oral hygiene	6	0.11	(0.42)
Oral hygiene	7	0.21	(0.61)	Oral hygiene	8	0.43	(0.90)	Standing for transfers	6	0.11	(0.42)
Transfer in/out chair	9	0.19	(0.46)	Visiting public place	9	0.30	(0.56)	Upper body dressing	6	0.11	(0.37)
Upper body dressing	10	0.17	(0.47)	Upper body dressing	9	0.30	(0.63)	In/out car	10	0.09	(0.35)
In/out car	11	0.14	(0.42)	In/out car	11	0.26	(0.54)	<b>Haircare/grooming</b>	10	0.09	(0.35)
<b>Lower body dressing</b>	12	0.12	(0.39)	<b>Lower body dressing</b>	12	0.17	(0.49)	<b>Footwear on/off</b>	10	0.09	(0.35)
Bathing	12	0.12	(0.39)	Toileting	13	0.13	(0.34)	<b>Lower body dressing</b>	13	0.09	(0.35)
<b>Haircare/grooming</b>	14	0.09	(0.33)	Bathing	13	0.13	(0.34)	Transfer in/out chair	17	0.07	(0.33)
<b>Footwear on/off</b>	15	0.09	(0.33)	<b>Haircare/grooming</b>	17	0.09	(0.29)	In/out of bed	17	0.07	(0.33)
Toileting	15	0.09	(0.33)	Change continence aids	17	0.09	(0.29)	Change continence aids	17	0.07	(0.33)
Change continence aids	17	0.08	(0.31)	<b>Footwear on/off</b>	17	0.09	(0.29)	Toileting	17	0.07	(0.33)

Note. <sup>a</sup> Items ranked from higher score (greater importance) to a lower score (less importance).

<sup>b</sup> Mean (and standard deviation) of participant rating of importance for daily living items on the Caregiver Priorities and Child Health Index of Life with Disability (CPCHILD); 5-most important, 4-very important, 3-fairly important, 2-slightly important, 1-not very important, and 0- least important.

<sup>c</sup> items ranked from lower score (more difficulty) to higher score (more ease/less difficulty).

<sup>d</sup> Mean (*SD*) participant rating of difficulty for each daily living item on the CPCHILD; 0- not possible (almost impossible), 1-very difficult, 2-difficult, 3-slightly difficult, 4-easy, 5-very easy, 6-no problem.

<sup>e</sup> Items ranked from higher score (most independence) to lower score (less independence/more assistance). High amount of assistance from a carer implies less child independence, and less carer assistance implies more child independence.

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<sup>f</sup>Mean (*SD*) participant rating of level of assistance required to help child perform each daily living item on the CPCHILD; 3-independent, 2-minimal/supervised, 1-moderate assistance, 0-total assistance.



Table 4.5

Items from the CPHILD ranked by importance, difficulty and level of assistance required. Child responses compared to carer responses

Importance of items to child's quality of life							
Carer $n = 9$	<sup>a</sup> R	<sup>b</sup> M	(SD)	Child $n = 9$	<sup>a</sup> R	<sup>b</sup> M	(SD)
Moving Indoors	1	4.33	(0.50)	Moving outdoors	1	4.56	(0.53)
Moving outdoors	2	4.22	(0.67)	Visiting public place	2	4.44	(0.53)
Toileting	2	4.22	(1.09)	Moving Indoors	2	4.44	(0.73)
Visiting public place	4	3.89	(0.6)	Bathing	4	4.33	(0.71)
Sitting in chair	4	3.89	(1.17)	Toileting	5	4.22	(1.39)
Transfer in/out of chair	4	3.89	(1.17)	Eating	5	4.22	(1.09)
Bathing	7	3.78	(1.09)	Haircare/grooming	7	4.00	(0.71)
Eating	7	3.78	(1.48)	<b>Change continence aids</b>	7	4.00	(1.58)
In/out of bed	9	3.67	(1.66)	Transfer in/out of chair	9	3.89	(1.36)
Footwear on/off	9	3.67	(1.41)	Sitting in chair	10	3.78	(1.48)
Haircare/grooming	11	3.56	(1.33)	In/out car	11	3.67	(1.66)
Upper body dressing	12	3.44	(1.42)	Oral hygiene	11	3.67	(1.12)
Oral hygiene	12	3.44	(1.33)	In/out of bed	13	3.22	(2.05)
In/out car	14	3.33	(2.12)	Standing for transfers	14	2.89	(2.09)
Standing for transfers	14	3.33	(2.06)	Footwear on/off	15	2.88	(2.03)
Lower body dressing	14	3.33	(1.32)	Upper body dressing	16	2.78	(1.79)
<b>Change continence aids</b>		3.00	(2.24)	Lower body dressing	17	2.75	(1.58)
	17						
Difficulty							
Carer $n = 9$	<sup>c</sup> R	<sup>d</sup> M (SD)		Child $n = 9$	<sup>c</sup> R	<sup>d</sup> M (SD)	
Standing for transfers	1	1.56	(1.33)	<b>Footwear on/off</b>	1	0.89	(2.03)
In/out car	2	2.11	(1.62)	In/out of bed	2	1.00	(1.41)
In/out of bed	3	2.22	(1.09)	In/out car	3	1.38	(1.51)
Transfer in/out of chair	4	2.33	(1.22)	Lower body dressing	4	1.44	(2.01)
<b>Footwear on/off</b>	5	2.44	(1.81)	Standing for transfers	4	1.44	(1.51)
Lower body dressing	6	2.78	(1.56)	Upper body dressing	6	1.56	(1.51)
Upper body dressing	7	2.89	(1.27)	Transfer in/out of chair	7	1.67	(1.940)
Toileting	8	3.00	(1.5)	Change continence aids	8	1.75	(2.31)

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Change continence aids	9	3.11	(2.2)	Haircare/grooming	9	2.11	(2.09)
Visiting public place	10	3.33	(1.32)	<b>Oral hygiene</b>	10	2.67	(2.69)
Bathing	11	3.44	(1.67)	Bathing	10	2.67	(2.0)
Haircare/grooming	12	3.67	(0.87)	Toileting	10	2.67	(2.29)
Moving outdoors	13	3.89	(1.54)	Visiting public place	13	2.78	(2.17)
Moving Indoors	14	4.22	(1.39)	Eating	14	3.33	(2.5)
Sitting in chair	15	4.33	(1.22)	Moving outdoors	14	3.33	(1.94)
<b>Oral hygiene</b>	16	4.44	(1.59)	Moving Indoors	16	3.44	(1.81)
Eating	17	4.67	(1.22)	Sitting in chair	17	4.67	(1.58)

Level of assistance required

Carer <i>n</i> = 9	<sup>e</sup> R	<sup>f</sup> <i>M</i>	( <i>SD</i> )	Child <i>n</i> = 9	<sup>e</sup> R	<sup>f</sup> <i>M</i>	( <i>SD</i> )
Sitting in chair	1	1.78	(1.2)	Sitting in chair	1	2.00	(1.32)
Moving Indoors	2	1.67	(1.41)	Moving Indoors	2	2.00	(1.12)
Moving outdoors	3	1.56	(1.51)	Moving outdoors	3	1.78	(1.3)
Visiting public place	4	1.00	(1.22)	Visiting public place	4	1.44	(1.33)
Oral hygiene	4	1.00	(1.22)	Eating	5	1.11	(1.36)
Eating	6	0.89	(1.05)	Oral hygiene	6	1.00	(1.12)
<b>Standing for transfers</b>	7	0.56	(0.88)	Toileting	7	0.89	(0.93)
Transfer in/out of chair	8	0.56	(0.88)	Haircare/grooming	8	0.67	(1.0)
Bathing	8	0.56	(0.88)	Bathing	8	0.67	(0.87)
In/out car	10	0.44	(0.73)	In/out car	10	0.56	(0.73)
Haircare/grooming	10	0.44	(0.73)	<b>Standing for transfers</b>	10	0.56	(0.88)
<b>Upper body dressing</b>	10	0.44	(0.88)	Transfer in/out of chair	10	0.56	(0.88)
Toileting	10	0.44	(0.73)	<b>Lower body dressing</b>	10	0.56	(0.73)
In/out of bed	14	0.33	(0.71)	In/out of bed	14	0.44	(0.73)
Footwear on/off	15	0.22	(0.67)	<b>Upper body dressing</b>	14	0.44	(0.73)
<b>Lower body dressing</b>	15	0.22	(0.67)	Change continence aids	16	0.38	(0.74)
Change continence aids	15	0.22	(0.67)	Footwear on/off	17	0.33	(0.71)

Note. <sup>a</sup>R = items ranked from higher score (greater importance) to a lower score (less importance).

<sup>b</sup> Mean (and Standard deviation) of participant rating of importance for daily living items on the Caregiver Priorities and Child Health Index of Life with Disability (CPCHILD); 5-most important, 4-very important, 3-fairly important, 2-slightly important, 1-not very important, and 0- least important.

<sup>c</sup>R = items ranked from lower score (more difficulty) to higher score (more ease/less difficulty).

<sup>d</sup> Mean (*SD*) participant rating of difficulty for each daily living item on the CPCHILD; 0—not possible (almost impossible), 1-very difficult, 2-difficult, 3-slightly difficult, 4-easy, 5-very easy, 6-no problem.

<sup>e</sup> R = items ranked from higher score (most independence) to lower score (less independence/more assistance). High amount of assistance from a carer implies less child independence, and less carer assistance implies more child independence.

<sup>f</sup> Mean (*SD*) participant rating of level of assistance required to help child perform each daily living item on the CPCHILD; 3- independent, 2-minimal/supervised, 1-moderate assistance, 0-total assistance.

Table 4.6

*Total Scores on the CPCHILD by cerebral palsy functional classification level*

CP classification system		<i>n</i>	CPCHILD-Total scores <sup>a</sup>		
			<i>Median</i>	25 percentile	75 percentile
GMFCS level					
	IV	23	57.63	45.93	57.63
	V	54	46.33	41.19	46.33
MACS level					
	I	1	73.94	-	-
	II	3	65.85	64.51	-
	III	7	59.78	52.16	66.61
	IV	20	48.41	44.99	58.17
	V	46	45.99	40.39	53.15
CFCS level					
	I	6	70.27	63.19	75.89
	II	3	52.16	44.76	-
	III	17	53.14	45.99	60.41
	IV	27	46.55	42.19	58.86
	V	24	44.91	33.5	48.29
EDACS level					
	I	9	59.78	55.26	70.29
	II	14	48.41	44.17	64.21
	III	13	45.93	45.02	55.74
	IV	14	48.30	41.90	58.91
	V	27	45.94	35.30	53.89

*Note.* CP = Cerebral palsy; CPCHILD = Caregiver Priority and Child Health Index of Life with Disability; GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Functional Classification System; EDACS = Eating and Drinking Classification System.

<sup>a</sup>Total scores calculated using the CPCHILD© Manual & Interpretation Guide [19]

Table 4.7

*Relationships between CPCHILD total scores and child and carer variables*

Child variables	CPCHILD	
	Total scores	
	Spearman's <i>rho</i>	Sig. (2-tailed)
Weight ( <i>n</i> = 75)	-0.061	0.605
Height ( <i>n</i> = 57)	0.088	0.514
Sex	0.153	0.183
Age	-0.111	0.338
Topographical distribution of cerebral palsy		
Unilateral	0.231	0.043
Diplegia	0.086	0.456
Quadriplegia	-0.117	0.312
Motor type		
Spasticity	0.106	0.359
Dystonia	-0.112	0.332
Ataxia	-0.051	0.660
Hypotonia	-0.062	0.595
Additional Conditions		
Total no. of additional conditions	-0.203	0.076
Visual impairment	-0.197	0.087
Hearing impairment	-0.217	0.058
Epilepsy	0.001	0.992
Intellectual impairment	-0.086	0.456
Learning disability	-0.199	0.082
Carer variables		
Age ( <i>n</i> = 71)	-0.038	0.751
Carer health		
General health	-0.270	0.018
Quality of life	-0.173	0.133
Mental Health	<b>-0.402<sup>a</sup></b>	0.000
Social satisfaction	-0.173	0.133
Social Roles	-0.283	0.013
Physical activity	-0.140	0.225
Emotional problems	-0.223	0.051
Fatigue	<b>-0.395<sup>a</sup></b>	0.000
Pain	-0.220	0.056
SEIFA	0.054	0.640

*Note.* *n* = 77 unless otherwise indicated. CPCHILD = Caregiver Priority and Child Health Index of Life with Disability; GMFCS = Gross Motor Functional Classification System; MACS = Manual Ability Classification System; CFCS = Communication Functional Classification System; EDACS = Eating and Drinking Classification System.

<sup>a</sup> denotes a medium association between variable and CPCHILD total score.

## **CHAPTER 4b: EXTENDED DISCUSSION OF STUDY 1**

Further details about Study 1 that were not included in the manuscript are outlined in this chapter. Also included are supplementary tables of participant characteristics and further discussion about participant characteristics and results.

### **Participant characteristics results**

There was an equal distribution of boys and girls, and a higher number of children at GMFCS V than IV (see Table 4.1). Most children had a topographical distribution of quadriplegia. Approximately one third of children had a motor type of spasticity, and another one third had mixed tone with fewer children being described as having dystonia, hypotonia or ataxia (see Table 4.1). Most children had one or more condition in addition to cerebral palsy (see Supplementary Table 4.8). Children demonstrated an increase in weight with age (See Supplementary Table 4.9). Comparing these data about child weight to other samples, the GMFCS IV data tracks just above or below the 75th percentile line growth charts for boys in the US with cerebral palsy classified at GMFCS IV. The GMFCS V data are just above or below the 75th percentile line, with a drop in the 13 years of age category to below the 50th percentile (Brooks, Day, Shavelle, & Strauss, 2011)

Supplementary Table 4.8.

*Child characteristics; Number of additional conditions*

Number of additional conditions <i>n</i> (%) <sup>a</sup>	GMFCS IV <i>n</i> = 23	GMFCS V <i>n</i> = 55	Total <i>n</i> = 78
0	4 (17.4)	0 (0.0)	4 (5.1)
1	4 (17.4)	17 (30.9)	21 (26.9)
2	8 (34.8)	17 (30.9)	25 (32.1)
3	5 (21.7)	10 (18.2)	15 (19.2)
4 or more	1 (4.3)	10 (18.2)	11 (14.1)
Don't know	1 (4.3)	1 (1.8)	2 (2.6)

*Note.* <sup>a</sup> additional conditions include intellectual impairment, specific learning disability, visual impairment, hearing impairment, epilepsy.

Supplementary Table 4.9.

*Child characteristics; Child's weight by age from carer report on the CPCHILD*

Child age in years	GMFCS IV		GMFCS V		Total	
	<i>n</i>	weight in kg <i>M</i> ( <i>SD</i> )	<i>n</i>	weight in kg <i>M</i> ( <i>SD</i> )	<i>n</i>	weight in kg <i>M</i> ( <i>SD</i> )
5	0	0.0 (0.0)	1	17.5 (0.0)	1	17.5 (0.0)
6	2	17.5 (3.5)	5	17.9 (2.4)	7	17.8 (2.4)
7	1	28.0 (0.0)	3	19.7 (0.6)	4	21.8 (4.2)
8	2	23.5 (4.9)	3	21.5 (4.4)	5	22.3 (4.1)
9	2	22.0 (0.0)	1	26.0 (0.0)	3	23.3 (2.3)
10	0	0.0 (0.0)	4	25.9 (2.5)	4	25.9 (2.5)
11	1	42.0 (0.0)	6	27.3 (3.3)	7	29.4 (6.3)
12	4	29.5 (4.5)	4	30.8 (7.9)	8	30.1 (6.0)
13	2	37.0 (7.1)	2	21.5 (7.0)	4	29.3 (9.8)
14	1	40.3 (0.0)	3	33.0 (4.0)	4	34.9 (4.9)
15	4	48.3 (8.9)	6	39.4 (6.6)	10	43.0 (8.5)
16	2	51.5 (3.5)	8	36.2 (8.0)	10	39.2 (9.6)
17	1	39.5 (0.0)	4	48.0 (20.2)	5	46.3 (17.9)
18	0	0.0 (0.0)	3	45.7 (6.0)	3	45.7 (6.0)
Missing	1		2		3	
Total ( <i>n</i> )	23		55		78	

*Note.* GMFCS – Gross Motor Functional Classification System.

## Further discussion of Study 1

### Participant Characteristics

The results from Study 1 show a trend similar to other studies that many children who are GMFCS V, also tend to be V on the CFCS, EDACS and MACS. Children at GMFCS IV tend to have a wider range of levels on these classifications. Children who have more complex seating and mobility needs tended to have poorer hand function, whereas the children who were more independent in their mobility had more variability in their functional hand use.

Most carers identified that their child had a topographical distribution of quadriplegia. This was expected as this distribution is most likely to result in the use of a wheelchair as a primary source of mobility. Two children were identified as having unilateral/hemiplegia cerebral palsy. This is not a common motor distribution for children who are also GMFCS IV and V. One of the children with hemiplegia also had epilepsy which could be a factor in the child's use of a wheelchair as their primary mobility. The other child was classified as GMFCS IV and had additional conditions of hearing and visual impairment, epilepsy as well as the carer adding that the child also had developmental delay. It is possible that this child required the use of a wheelchair for mobility for these other reasons.

There is much discussion in current literature about the complexity of defining and describing muscle tone in children with cerebral palsy (Stewart & Harvey, 2018). However, only 3 (3.9%) of carers ticked "don't know" or had missing data for the question about motor type, suggesting that the words to describe muscle tone were familiar and carers were confident about identifying their child's motor type.



Intellectual function was assessed by carer report. It is not known if the rating was based on the carers' knowledge of previous formal assessment of the child's intellectual capacity, or the carers' own assessment of the child's performance and capacity. Carers may not have been able to distinguish between an intellectual disability and a specific learning disability, and many carers indicated that children had both. A method for data interpretation if the response was not clear was devised and is described in Appendix K. Studies predict that up to 50% of all children with cerebral palsy have an intellectual impairment (Reid et al., 2016). The results of Study 1 indicated that 53 (68%) children had a reported intellectual impairment or learning difficulty, which indicates a higher rate of intellectual impairment in this sample of children with more severe motor disability. The presence of intellectual or learning disability is likely to have an impact on a child's learning of daily routines. Information from this study indicates that many children at GMFCS IV and V do not have intellectual difficulties therefore assumptions about intellectual capabilities should not be made.

### **Carer Characteristics**

Mothers were the highest rate of responders with few fathers ( $n = 5$ , 6.4%) returning a survey. There were no carers under the age of 30, likely due to the age range of the included children. The paper-based survey method may also have deterred younger carers who are perhaps more used to responding on line. Although most carers were in the 40-49 years age group there was evidence of people caring for children in their 60's and even 70's. The impact of being an aging or elderly carer on the transactions between the child and carer is unknown. The equal spread of carer education levels suggests that there was an over representation of more educated people in this sample compared to the education level of the general Victorian population. There was also a discrepancy in responses about work. Many of

the carers who worked outside of the home also indicated that they were full time homemakers. These carers may feel that whilst they also do work outside the home, they were also the primary person who did the practical running of day-to day lives of their children.

### **Importance, difficulty and level of assistance required to compete daily routines**

*Sitting in a wheelchair, moving indoors, eating, and moving outdoors* were identified through the CPCHILD as having high importance, low difficulty and a high level of independence. According to the survey responses, some children were able to contribute to, had some independence in, or were able to do some of the task themselves. This could mean that goals set in these areas could be achievable for some children and families. Building on existing performance in these tasks could provide critical opportunities to develop confidence and feelings of self-worth in children. The rating of increased independence in *outdoor mobility* could reflect the relevance of powered mobility for this sample. Access to this technology can contribute to self-worth, and educational and social successes (Kenyon, Hostnik, McElroy, Peterson, & Farris, 2018). Additionally, children may be able to assist with self-feeding once set up. Independence in eating could be related to how children use their hands. The 31 children (39%) classified at MACS I-IV in Study 1 could possibly use their hands for daily routines either independently or with assistance. They may require some assistance with set up but then be able to perform part of the task thereafter.

*Putting footwear on and off, lower body dressing, hair care and grooming* were items that had ratings of lower importance, lower difficulty and lower independence as indicated by survey responses. As discussed in the manuscript, it may be that goals in these tasks would be a lower priority as ratings of lower difficulty may mean that carers find them easy to do.

Achieving improved performance in these tasks may be too far beyond the child's capabilities and therefore less likely to be attempted, so therefore the child rated them as low difficulty also. A score of "0" on the level of assistance rating on the CPCHILD could mean an item was very difficult to execute, or not attempted. This does not imply that some children are not capable of achieving these goal if they choose to do so, rather that learning these tasks may take considerable time and effort to learn and may be tiring to complete.

*Putting footwear on/off, lower body dressing and hair care* require the child to reach to their feet, to reach above their head, fine manipulation of objects and require a refined outcome to be satisfactory. The postural control and sitting balance required to support large arm movements may be difficult for children at GMFCS V who require support to maintain upright position against gravity (Palisano et al., 2000). These tasks also require an ability to hold and move objects in the hands in combination with reach, which may be difficult for children even at higher MACS levels (Eliasson et al., 2006). The outcome of the daily routine of *putting footwear on/off* is likely to require a certain standard, for example the child needs to have shoelaces fastened tightly enough to keep the shoe in place and be comfortable. Up to 70% of children at GMFCS IV and V are also likely to wear ankle-foot orthoses (AFO) as well as shoes (Wingstrand, Hägglund, & Rodby-Bousquet, 2014). Putting on shoes and AFOs is likely to require a sequence of movements that include postural control to lean forward to the feet and return to an upright posture, refined hand function to adjust AFO straps or shoe laces, use of vision or tactile feedback in the hands, and the motor planning ability to sequence the many small steps within the task. It may also require a child to relax tight muscles in the legs to allow AFOs or shoes to be put on or off. Putting footwear on and off is a task that might occur throughout the day when time may be limited, for example getting ready to go to school in the morning, changing for swimming or sport at school. The example

of putting footwear on and off highlights that there many steps involved in some daily routines that may be challenging for all children with cerebral palsy and likely extremely difficult for children at GMFCS IV and V. It is therefore likely that it may be quicker and easier for an adult to complete some of these routines on a day-to-day basis and that the outcome may be more acceptable to the child.

There were other items that had ratings of importance, difficulty and level of assistance that could provide relevant information for children at GMFCS IV and V and their carers. *Transferring in and out of a chair* or wheelchair was an important task. This is an example of a routine that is rare in the typical population and for children at GMFCS I and II. Children at GMFCS III may need to transfer in and out of a chair but are likely be independent or only require minimal assistance. Moving in and out of a wheelchair and chair, however, is likely to occur often for a child at GMFCS IV and V. *Transferring in and out of chair* was ranked second in importance with a mean of 4.17 (0.78) and high difficulty with a mean of 2.51 (1.4) and very low levels of independence 0.19 (0.46)). Although data on equipment was not requested in the survey, five respondents added a comment that they use a hoist for transfers. Set up and equipment as well as the child's ability may be important for ease of transferring in and out of a chair,

It is possible that the availability of other suitable equipment may impact some other ratings of ease or difficulty of daily routines. Children at GMFCS IV and V are likely to require the use of a range of specialist equipment in the daily routines (Palisano et al., 2010). For example, whether a family have a modified vehicle may have influenced the difficulty rating of *transferring in and out of a car*. Although data on the use of a modified vehicle was not specifically requested in the survey, seven carers added an extra comment that they had a

modified van, and two commented that lack of a modified vehicle increased the difficulty of this item.

Toileting is a private task completed independently by most people in the broader population. *Changing continence aids* and *toileting* routines for children at GMFCS IV and V is a complex task requiring transfers, dressing and cleaning. Children rated *changing continence aids* of higher importance than carers (See Table 4.5). The reason for this is not known but could be because changing a continence aid has more immediate impact on the comfort of the child than the carer.

### **Child and carer responses**

Carer responses were similar to the responses of children in this sample. It may be that the child and carer are ‘in-tune’ with each other because they work together to complete routines. As children are likely to always need assistance from their carers, negotiation, discussion and planning to improve the efficiency and comfort of the routine probably occurs daily. This familiarity may also account for the similarity in responses. As many of the children were likely to have required assistance from their carer to complete the survey, it was possible that the carer and child discussed it, thus influencing the outcome. There were no prompts from the researcher to request that the carer did not influence the child’s responses, so it is largely unknown as to how much the carer actually assisted the child.

Children who responded to the survey had higher cognitive and communication abilities. Data about the other children were collected by proxy from a carer. The data comparing child and carer responses were therefore from a subgroup of children who had minimal intellectual impairment, and either verbal communication skills or were proficient

users of AAC, with time and motivation to respond to the survey. It is possible that children with different functional profiles may have a different experience of how they perceive they contribute to daily routines.

### **Conclusion**

The information gathered about daily routines through Study 1 provided a snapshot of the carer and child's views. It reflected the carer's and child's perspectives of what the child did in their daily routines. The ratings of importance, difficulty and level of assistance collected from the CPCHILD generated patterns that can provide practical insights for this group of children and carers.

All daily routine items in the measure had some level of importance to the children and carers, though some more than others. Rating of what was difficult also yielded information about what was easy. Items that were easy were of interest as they provided insights into what may be possible and achievable for children and carers. There were many children who were reported to require total assistance with almost all aspects of their care. Small differences in the rating of level of assistance were therefore important as they may provide clues as to where children may be able to contribute to task completion. The contribution to task completion could be small, subtle or possibly consist of only part of task completion. This was not addressed through the survey. Further research was required to address the questions about how children and carer worked together in daily routines and what child related action were used. The aim of the qualitative phase of this research was to build on the results of Study 1 to answer research questions four and five. The methodology used, and the results of Study 2 are outlined in Chapter 5.

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## CHAPTER 5: METHODS FOR STUDY 2

In this chapter is an outline of the theoretical stance guiding the qualitative methodology used in Study 2 and a description of the recruitment procedures, measures and process of data collection and analysis. The aim of this study was to inform Research Questions 4 and 5: *How do children at GMFCS IV and V and carers work together to complete the series of tasks that make up important daily routines?* and *What child related actions are useful in the transactions between children at GMFCS IV and V and their carers during important daily routines?*

### Rationale for Study 2 methods

Qualitative methods, based on a philosophy of phenomenology, were selected to address Research Question 4 and 5. Phenomenology involves studying the way a person experiences the world. An aim of qualitative research in the health field is to undergo meaningful analysis of the lived experience that generates knowledge for practice (Sandelowski & Barroso, 2002). Understanding was sought by asking participants to discuss and describe their experiences (Wilson, 2014). The aim of the researcher was to sit alongside the participants to listen to, describe and interpret their experience. Empowering participants to tell their stories was an important process for this study as the target population are under-represented in the literature and the transactions between children and carers that occur in daily routines are yet to be thoroughly investigated and therefore not well understood. “A well-conducted phenomenological study will open or extend a conversation that continues to push at the boundaries of what is known and what is yet to be understood” (van Manen, 1997 in Wilson, 2014, p.42)

### **Ethical Considerations**

Ethical approval was obtained from the Australian Catholic University (ACU) – Human Research Ethics Committee on 29th June 2016 (2016-112H) (see Appendix E).

### **Consent**

Families that consented to being both a part of the survey component of Study 1 and to be contacted about involvement in Study 2 were approached to participate. Additional consent was obtained for the collection of video footage and participation in Study 2 on the day of filming and interview (see Appendix L: Consent form Study 2). Three carers consented on behalf of their child. Two children were able to sign their own consent form. Children who were able to participate in the interview and video analysis were invited to do so. If the child was unable to participate, or chose not to be involved, the semi-structured interview occurred with just the carer and researcher. Participation in the study was voluntary and participants were free to withdraw at any time without explanation. Standard care for their child continued whether they chose to participate in the research or not.

### **Harms and benefits**

The invitation to participate in Study 2 outlined that the research would occur in the natural environment of the child and family in line with the stated aims of exploring personal daily routines for children and their carers. If participants were uncomfortable about being involved in research in their homes, they could choose not to participate. It was explained to the family that there were no right or wrong routines, and that the researcher was interested in what occurred during daily routines. The researcher did not intend to change or judge the routine, but to record and describe what occurred. The researcher sought to reduce potential

discomfort of the carer or child by making this explicit within the written information and initial phone contact.

The very personal routines of toileting and dressing were selected by some families. Through discussion with the family, the routines were modified to respect the dignity of the child, whilst still demonstrating the key aspects of interest. This included filming the removal of only outer layers of clothing during dressing routines, and transferring onto a shower chair, toilet or bed, fully dressed.

A protocol for safety for the researcher during the home visits was established and followed to manage potential risks associated with field visits into participant's homes (see Appendix M: Home visit planning and risk assessment form). Additionally, if the researcher observed a situation where the child was at risk of harm the following procedures were planned:

- In instances where risks appeared due to a lack of knowledge or skill on the part of the carer, the researcher was to discuss this immediately with the family, if appropriate, and offer assistance to refer to support agencies.
- In instances where risks appeared related to carer stress, the researcher was to assist the carer to contact their local General Practitioner (GP) or counselling service.
- In instances where the child appeared at risk of abuse or harm, the researcher was to end the home visit, discuss the situation immediately with the research supervisors and determined the need for notification to the Department of Health and Human Services.

Only a low degree of risk of distress to families as a result of engaging in the research was anticipated, but if participants did become upset, they were to be directed to contact their

usual health professional (e.g., GP) and provided with the contact details of a 24-hour counselling service.

The time commitment for the participants involved a video session taking 30 minutes and a semi-structured interview taking between 30 minutes and one hour, suggesting low level of inconvenience associated with study participation. The use and storage of the video footage was carefully outlined to participants so that they were fully aware that the footage was to be used only by the researcher for analysis of findings and would be stored confidentially in a secure location and not shared further. Permission was sought from carers and children for video footage to be retained for future, subsequently ethically approved analysis. If not given, video footage will be retained for five years after study completion following ACU guidelines for management of routine research data. (Australian Catholic University, 2013).

### **Rigour**

Embedding rigour into the research processes ensures that the complexity of the data collection and analysis is explicit, and readers can make a judgement about the quality of the research and credibility of the findings. The aim of this study was to produce findings that were trustworthy and believable, therefore four elements of rigour relating to credibility, confirmability, dependability and transferability were attended to in the design and conduct of this study.

**Credibility.** Credibility involves "...being faithful to the phenomenon, and describing it well" (Finlay, 2011, p 72). The purpose of the interview was to create a conversation and an opportunity for the child and carer to tell their story to inform the research questions (Josselson, 2014). Through the language of the telling, participants shared the human,

personal and deeper meaning of their experiences of being and/or caring for a child with cerebral palsy. Rather than just providing information, the participants were viewed as a source of understanding, explication and uncovering (Wilson, 2014). The interviews were constructed to attempt to represent the real-life experience of the participants, including the use of video to record the daily routine, rather than relying on participant recall or researcher observation. Through the process of data analysis, the researcher aimed to accurately record the views of participants. The researcher allowed time to listen to and feel immersed in the interviews. Some of the stories told by the participants were emotionally moving as they highlighted the difficult aspects of having a child with a significant disability. The researcher allowed time to respond to the stories in a human way, to connect to the meaning behind the story, and to attempt to further understand the perspectives of the participants. This deep listening supported credibility by endeavouring to stay true to the intent and stories of the participants which contributed to the resonance and interest of the outcomes of the study.

**Confirmability and Dependability.** Confirmability involves transparency of data collection, management and analysis to assist the reader to scrutinise and assess the quality and reliability of the findings. Confirmability is sought through an audit trail of clear documentation of the procedures undertaken and acknowledging how the researcher's personal attributes contributed to the findings of the study through a process of reflexivity.

**Audit trail.** A clear outline of the process of recruitment, participant selection, interview preparation, data collection has been included. Data analysis occurred through a process of triangulation with the primary researcher and three supervisors. Preliminary results were emailed to participants and opportunity to provide feedback was offered.

**Reflexivity.** The personal beliefs and perspectives of the researcher are known to influence how data are analysed (Liamputtong, 2013), and this reflexivity required consideration during data collection and analysis. The researcher had personal views that all children were capable of learning, and that the carer-child relationship was a key agent of learning for children with significant disability. The researcher also had extensive clinical expertise in teaching children how to move, identifying functional actions to assist in task completion and teaching carers how to incorporate this learning into a daily routine. Practical methods to achieve reflexivity were discussed with the research team during formal supervision. The phone calls and discussions with families were carefully planned and documented so that families were clear that the role of the researcher was to listen to and record participant's views. Clarity around the difference between a research-based interview and a therapy interview was discussed initially with the research team and then with participants. The researcher explained to families that no intervention was being offered, and that the researcher was not acting or responding in the usual role of a clinician. This role change was clearly acknowledged.

This process of reflexivity was important in acknowledging the potential power imbalance between "expert" and participants (Grbich, 1999). The researcher acknowledged that her presence and the presence of a video camera may have changed what occurred. This was actively deconstructed by the researcher by taking on the role of curious onlooker, while the carer and the child were supported to be the experts in the filming and interview process.

**Transferability.** Transferability involves providing adequate information about the participants and procedures for readers of the research to make their own assessments about how the findings might relate to their own populations or situations (Finlay, 2011).

Information that described the consenting participants was collected. This included the use of the internationally recognised cerebral palsy classification systems to describe children, key characteristics of the carers and an outline of the routine and equipment used in the filming. Clear documentation of the procedures undertaken by the researcher contributed to the possibility of the repeatability of the study. The process of filming daily routines in the home is replicable due to the ready availability of handheld recording devices without the need for researchers to set up structured filming environments.

### **Participant selection and recruitment**

The research design, explanatory sequential mixed methods, involved the use of purposive sampling in the qualitative component (Creswell, 2014) by selecting participants who had the appropriate knowledge and experiences to answer the research questions and be good informants for the study (Portney & Watkins, 2009). Participants from Study 1 were asked to provide their contact details if they were interested in further participation in Study 2. Of the 78 respondents in Study 1, 37 agreed to be contacted. All 37 met the eligibility criteria of the study, had demonstrated their suitability to answer the research questions and had the relevant personal experience that could be explored.

Five dyads were sought as this was within the scope of a single researcher conducting the interviews, and was an adequate sample for in depth analysis of the lived experience of the participants (Finlay, 2011). As there were more people who agreed to participate than was possible to include for Study 2, a further selection process was required. The travel time for the researcher to reach potential participants homes was estimated to identify participants within a two-hour radius. Nine participants were removed as a result. The first two participants were then selected randomly, using an online random number generator. This method was used to avoid any potential bias in selection of first participants. The next three

participants were selected purposively based on attaining variation within the sample. As the research aims involved analysis of the interactions between children and carers, collecting the views of children was important. Carer and child pairs who returned a child report version of the survey in Study 1 were therefore sought. Of the 26 potential participants, five children had contributed their views along with the carer data. Of these, four children had participated verbally, and one child had used AAC. The child who had used AAC to complete the survey was sought, as this is a unique perspective that is often difficult to capture.

### **Data collection**

Demographic data of the child and carer were available from Study 1 including ratings on the cerebral palsy classification systems and CPCHILD total scores. Additional information about the setup of the chosen daily routine was requested during initial contact, including a brief description of assistive technology and equipment used.

Video footage of the carer and child completing a daily routine of their choice in their own home was used as a point of discussion for a semi-structured interview. The video provided an opportunity for carers and children to reflect and report on a process that is habitual and that they may not generally think or talk about. It allowed the participants to watch and reflect on their own actions, rather than relying on the researcher's interpretation or their own recall of the routine. Use of video was considered important due to the assumption that the phenomenon of interest was largely an intuitive process that occurs naturally during the daily routine. Additionally, video recording of the routine allowed analysis of details and interactions between the carer and child, such as where someone was looking, or individual gestures that could not be recorded in any other way (Bloor & Wood, 2006). Compared to written text alone, it allowed the transactions to be described and



analysed in detail after the event. Video footage alongside narrative text provided the possibility that the complex and sometimes creative processes that occurred in these transactions could be brought to light (Secrist, 2002). The video elicited interviews were conducted in the child and carer's family home, immediately following the video capture, as this was the natural environment and the context within which the phenomenon occurs.

### **Procedures**

An initial contact form was used to plan and document the phone conversation with the carer (see Appendix M). During the phone call, the carer was asked to identify a routine that they felt comfortable being filmed, where the child required assistance, and which could potentially demonstrate how the child and carer worked together to achieve the routine. Time and dates for the interviews were made that suited the child and carer. Confirmation text messages were sent the day before. Upon arrival at the home, after initial greetings, an outline of the procedure was reviewed. The carer was asked to confirm and provide a brief overview of the selected routine. Filming involved the researcher moving around the room to accommodate the movement and interaction of the child and carer, attempting to minimise disruption whilst still accurately recording the routine. The carer was asked to indicate when the routine had ended.

The researcher downloaded the footage onto a laptop and briefly reviewed the prepared interview questions before meeting with the participants. The researcher set the video up on the laptop on a table in the home and invited the family to begin the interview. A sound recording device was placed on the table in full view of the family. During the interview several questions were asked to prompt the family about the routine. Examples of interview questions included:

- Can you tell me about this daily routine? Why did you choose this one? (watch video)
- Can you describe for me how you and your child work together to complete this daily routine?
- Tell me about the things that are helpful and unhelpful.
- What is your child/ are you doing? Is it helping?
- What could your child /you do/learn to be more independent?
- What could the child do/learn to make this easier for the carer?
- Do you think this was a good routine to watch and discuss? Why?
- Is there something else you think I should know to understand this aspect of your daily life better?
- Given your experience looking after your child/ being a child with cerebral palsy would you have any advice for a carer of a child newly diagnosed with cerebral palsy as to how to make daily routines easier?

### **Data Analysis**

The process of Interpretive Phenomenological Analysis (IPA) as described by Finlay (2011) based on the work of Smith et al. (2009) was used for data analysis. IPA is a process where personal experiences of individuals are gathered and then interpreted to propose a description of the overall phenomenon. The interpretation aims to maintain strong connections to the individual by using, and staying faithful, to the language and content of the interview text. Data were analysed with the aim of maintaining a close link between the material collected and the results that were produced (Finlay, 2011). Interpretation of data is a process whereby the researcher creates a meaningful representation of not only the stories of the individuals, but how the stories fit together and may be broadly relevant and of interest to others (Sandelowski & Barroso, 2002). Through the process of reflexivity, the researcher

used personal experience and knowledge to meaningfully reflect the stories of participants and create findings that could resonate with a wider audience.

Interviews were professionally transcribed. The researcher listened to the transcriptions of interviews and edited and corrected any errors, including deciphering words that were unclear to the transcriber. The interview text was de-identified by assigning pseudonyms to the children and carers. The five interviews were imported as text into a qualitative computer analysis program, NVivo (QSR International, 1999-2017). NVivo was used to organise, sort and search for information.

The interviews were listened to, read and re-read. A brief initial coding was completed to obtain a high-level understanding of the data. This first phase, called coding, involved the identification of words, phrases, sentences or paragraphs from the interview transcripts that described relevant ideas or concepts. These discrete examples of text were grouped together to form “nodes”. Nodes are defined as a virtual container used to group together related concepts from many sources.

Following discussions with the research team about the initial coding, the data were re-coded to remain closer to, and more clearly reflect, the language of the participants. The supervisors provided feedback to the primary researcher about the results of the second coding including the relevance of the discrete text reference to the emergent themes, and the connections across cases that generated broader themes. The nodes were reviewed again to ensure that the themes reflected the raw data from the interviews. Key quotes from participants were highlighted to demonstrate the source of themes.

Broad themes were identified from the data. Effort was made to ensure that the language of the outcomes stayed true to the language used by participants. Smaller themes were reorganised under each broader theme using a mind map. The mind map was drafted and refined to create a visual representation of the relationships between themes. The interviews were then probed for ideas and inspiration for a visual concept or metaphor to summarise the themes. The mind map was transformed into a visual diagram based on a comment from one of the participants and further developed by the primary researcher. The visual diagram was sent to families and discussed with people unfamiliar with the content to ascertain whether it made sense and was authentic to the findings.

The results of the analysis of the interviews are reported in Chapter 6. A diagram of how children and carers navigate daily routines is proposed. The child related actions that occurred in daily routines are reported and discussed.

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## CHAPTER 6: FINDINGS OF STUDY 2

In this chapter is a description of the participants of Study 2. The results of the analysis of the interviews and discussion are presented to answer Research Questions 4 and 5. A diagram representing how children and carers were found to navigate routines is proposed and described. The child related actions that were used in the daily routines are also identified and described.

### Participant Characteristics

The characteristics of the five child (Y1-Y5) and carer (C1-C5) dyads are presented in Table 6.1. The topographical distribution for all children was identified as quadriplegia. Only one child had no additional medical conditions and two of the five children had no intellectual or learning difficulties. The carers included one father and four mothers, aged from 33 to 54 years. Two of the five carers worked outside the home. The equipment used and the daily routines that were filmed for the video elicited interviews are summarised for each dyad (see Table 6.1). The CPCHILD total scores are also included from data collected in Study 1. The child of Carer 3 had a very low CPCHILD total score and functioned at level V on the GMFCS, MACS and EDACS, and level IV on the CFCS. Children who completed the CPCHILD-Child report had higher total CPCHILD scores than their carers.

Two children classified at CFCS level I participated in the interviews verbally. One child at CFCS III used AAC to participate. The communication system used was partner-assisted auditory scanning using a pragmatically organised dynamic display (PODD) book. One child at CFCS IV participated socially by laughing, smiling and vocalising in response to parts of the discussion and the other child at CFCS V rested in another room during the interview.

Table 6.1.

*Child and carer characteristics*

Child	Y1	Y2	Y3	Y4	Y5
Sex	Female	Female	Male	Male	Female
Age in years	8	13	10	18	16
Weight (kg)	27	32	29.5	45	49
GMFCS	IV	IV	V	V	IV
MACS	IV	IV	V	II	III
CFCS	V	III	IV	I	I
EDACS	II	V	V	I	I
Motor Type	Spasticity	Mixed	Mixed	Spasticity	Dystonia
No. additional conditions	2	1	3	2	0
Additional condition	Intellectual impairment, epilepsy	Epilepsy	Intellectual impairment, visual impairment, epilepsy	Intellectual impairment, visual impairment	None
Carer	C1	C2	C3	C4	C5
Relationship to child	Mother	Mother	Mother	Father	Mother
Age in years	33	47	38	54	50
Highest level of education	Professional or graduate degree	College or university degree	Professional or graduate degree	Vocational or some college	Professional or graduate degree
Work status	Full time homemaker	Not working due to child health	Not working due to child health	Working full or part time	Working full or part time
Daily routine	Mealtime, transfer MWC to floor	Transfer MWC to bed, changing continence aid	Transfer MWC to bed, dressing	Transfer PWC to bed, dressing	Stand transfer PWC to bed/toilet
Equipment/ AT used	MWC and tray	PODD book, MWC, adjustable height bed, ceiling hoist	MWC, adjustable height bed	PWC, adjustable height bed, shower chair	PWC, adjustable height bed, toilet rail



CPCHILD Total Scores					
Parent report	49.09	53.14	35.03	64.51	59.26
Child report	-	58.82	-	66.36	60.40

*Note.* GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Functional Classification System; EDACS = Eating and Drinking Classification System; AT = assistive technology; MWC = manual wheelchair; PWC = power wheelchair; PODD = Pragmatically Organised Dynamic Display communication book; CPCHILD = Caregiver Priorities and Child Health Index of Life with Disability;.

### **How do children and carers complete daily routines?**

How children at GMFCS IV and V and carers worked together to complete the series of tasks that make up important daily routines was explored to answer Research Question 4. Carers and children were well-practiced in daily routines. The children were well cared for and routines were successfully achieved. There were three overarching themes that emerged that illustrated how carers and children completed daily routines and are represented in Figure 6.1 *How children and carers negotiate daily routines*. This visual concept was inspired by a participant comment: the “straightest line to achieve what we need to in a day” (C2). The success of achieving the routine is represented by the green rectangle on the right. How children and carers achieved the daily routine was variable and is represented as different cars going along a road.

The three different cars representing ways that carers and children negotiated daily routines were:

1. The racing car: Carers and children achieved routines in the quickest and easiest way to be efficient as possible in a busy life.
2. The tractor: Disruptors occurred during the task that made daily routines slow and hard work.
3. The Sports Utility Vehicle (SUV): There were some days and times that carers and children had time to negotiate opportunities for learning, adapting for change, and skill development.

There were factors that affected what ‘car’ and ‘road’ carers and children were on at any given time. These factors, or subthemes, are italicised in the following descriptive paragraphs and included in Figure 6.1 as enablers (green squares) disruptors (red triangles) or opportunities (yellow circles) along the road. Quotes are included from the carers (C1-C5) and children and adolescents (Y1-Y5) to articulate the connection between the data and the findings.

**HOW CHILDREN AND CARERS NEGOTIATE DAILY ROUTINES**

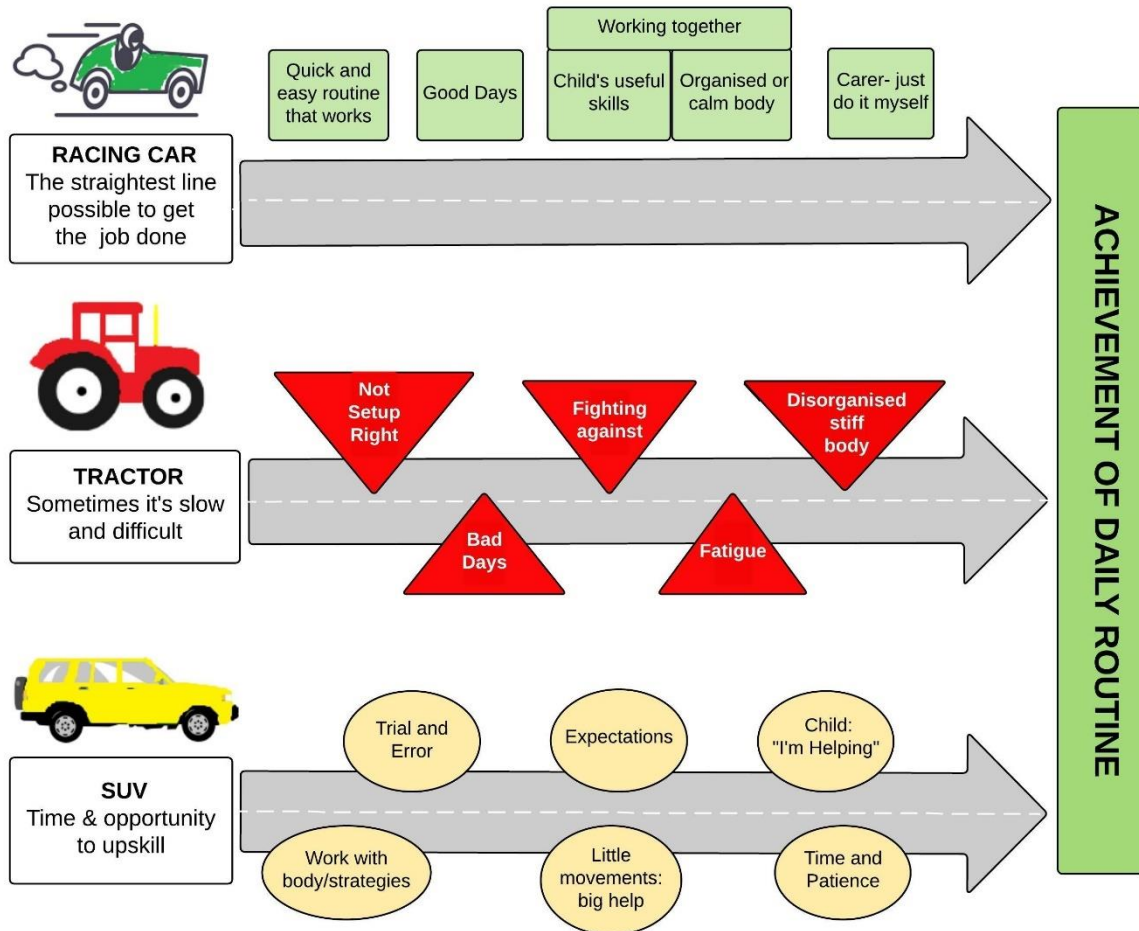


Figure 6.1 How children and carers negotiate daily routines.

**Theme 1: Quickest and easiest - The Racing Car**

“The straightest line to achieve what we need to do in a day” (C1).

Carers and children talked about living a “crazy life” (Y5) which included meeting the needs of all people in a family, time constraints, work commitments and other household tasks. Carers did what was required to look after their child in the *quickest and easiest* way. The routine was intuitive, and carers did what needed to be done without thinking too much about it. While carers were aware of strategies and techniques that they had learned about the safest way to care for their child, they identified that they often chose not to do the “right thing” (C1) but did the routines in their own way as it was the *easiest and quickest* way to get the job done.

We’ve got so many other things that we’ve got to get done and having to set up everything ... it’s that real tug between doing the right thing to preserve our backs ... versus reality, and we’re not cutting corners just because we’re lazy; we’re doing it because we have to...find the...straightest line to achieve what we need to do in a day (C1).

Some days were described as *good days* when everything worked well. Non-child related aspects such as the right set up, equipment working well and being in the right place within easy reach of the carer, aided the efficiency of the routine. The carer having a feeling of being organised contributed to a day being *good*. One child talked about how he worked with his carer during daily routines:

After 18 years, I guess you kind of just know each other’s patterns. He (carer) knows

what I'm good at and what I'm not good at. He knows how long it takes and we just work together and somehow, we just get things done. I think that's great (Y4).

Children had days and times when their bodies felt more *organised* and moved more freely. An *organised body* included the child being *calm*, being able to actively move or alternatively to keep still. When a child's body was calm, the child was more likely to listen to the carer. The child was more able to try and keep still or reduce the amount of extra movements to allow the carer to complete an aspect of the routine. The child was more likely to be able to complete a small active movement when their body felt ready and organised.

Carers indicated that sometimes the child completing part of a movement made it easier for the carer - one less thing for the carer to do. For example, one carer described how useful it was for the child to take their feet off the footplates of a wheelchair during a transfer: "If she's lifting them (the child's feet), I'm not." (C5). The child used the action to help the carer, and the child and carer worked well together. The carer described how the child and carer regularly used standing transfers to move the child in and out of a wheelchair during daily life:

Well, if she (the child) doesn't help or if she doesn't take her weight (in standing), then physically I just can't move her. So, it would then be a whole different story and there'd be hoist transfers and things like that. But the fact that she's helping out and doing what she can, means that I can do that...transfer...on my own and I can do it without using a hoist, which means we can do it quickly and it fits in with everything else we need to do in life (C5).

On many days, carers and children were “under the pump” (C4) with not enough time for the child to be independent in any aspect of the routine. It was *quicker and easier* for everyone for the *carer to complete all of the tasks*. It was difficult to implement new routines and learn new skills when rushing to do what needed to be done in a busy life. The way the routine was completed was what worked for the family. Carers tended to help the child complete the routine in the *quickest* possible way, while acknowledging that this may not give the child opportunity to learn how to do a task or to practice it. One carer talked about the prompt needed for a child to put his own hand through a sleeve during upper body dressing:

Everyone else does it in practice (at school) but often I am too busy in my own brain to focus on letting him know (C3).

Carers and children identified that the carer completing all of the routine for the child may not be the best way, but that it was done that way by choice as it was easiest and quickest to get the job done.

It was just one of those time-based things, that we just needed to get it done quickly. You tend to do it instead of taking that extra time. It might only be five minutes to have the child at least have a go.... If you keep doing it for your child, then they never get the skill set to be able to do it for themselves. There's a fine line. (C4)

C5: I think what it really comes down to, at the end of the day, is I've got two other kids, I work, and even though I know that it would be better for her in the long (run) if I just stopped and let her do more for herself. But, the reality of life is that...

Y5: It's not practical.

**Theme 2: The slow and difficult times - The Tractor**

“Sometimes you are crazy on Tuesday” (C2).

On some days and times, routines were achieved, but it was slow and hard work. Disruptors that contributed to a *bad day* and made the routines slow and challenging, included carer and child *fatigue*, issues with equipment in the immediate context (*not the right set-up*) and the disruptions of other commitments of work, family and life. Any one of the disruptors could occur at any time so that the routine (and road) swerved from a *good day* into a *bad day*.

It’s the chicken and the egg. Like if one goes off and that’s it, we lose the plot together (C2).

One carer identified that although they were often highly efficient and got a lot done, being organised all the time was not always possible:

You have to be organised, and sometimes you just can’t be organised 24/7. Even the most organised of us, I think, have lapses and we just survive (C1).

Completing routines took a lot of time, which was at times a challenging and required patience. Carers and children acknowledged and accommodated for this in daily life.

The other thing too is no one wins by rushing dressing and daily routine stuff. You’ve got to factor in it’s going to take more time than it would for a regular kid at that age.

You’ve just got to factor it in (C4).

On some days children's *bodies were disorganised* or just couldn't do what was required. Carers and children both spoke about the child needing time to "balance up" (Y4) and get their bodies organised. Some children were *stiff* and need time to work with their bodies to "break the tone" (Y5) so they could move. Children talked about their legs and arms not being able to respond quickly enough, or that moved in ways that were not helpful. One child, when watching themselves on the video in sitting, noted their hand going up and expressed irritation about this. The child thought their hand needed to go down to help to their balance in sitting. The children and the carers felt and observed *stiffness* in the child's body. Carers and children talked about different ways they dealt with *bad days* including other family members stepping in, so the carer can walk out and have a break, asking siblings to assist, giving themselves more time, and being resigned to this being the way it is. Participants also used physical strategies such as the carer providing more assistance to the child on *bad days*.

Facilitator: So, when you have those bad days, what sorts of strategies ... do you use that are different?

Y5: Breathing mainly, because some of it is also to do with my anxiety.

C5: I think I intervene more don't I? I physically get down and lock that left leg and hold it into place. I probably use my body more then, than what you saw in that video for those times when she's not as well.

But you tell me too. You'll say when it's a really a bad day. I can see it anyway. I can just look at you and know that your muscles are behaving badly. But you will actually say I don't really feel up to it, my legs are really hurting, my body is being tricky, and can you help me (C5 talking to Y5).



Sometimes, children actively *fought against* the carer, or actively didn't help which made the routine difficult or impossible to complete. This was attributed to child *fatigue*, the *expectations* placed on the child, or the child's behaviour such as being "cheeky" or not listening. When "*fighting against*" during the routine, (C2, C3) the child could kick or "plank." This was described by C4 as "hips thrust up, body straight, but upper body twist to the left". "Planking" was disruptive and made the routine difficult. Some carers expressed concern as to how they would manage "planking" by their child as they grew and had a larger and stronger body.

One carer explained that their child's movements, though difficult for the child to control, were highly linked with the child's behaviour. If expectations were not placed on the child to help, the opposite could occur, and the child could choose to be actively unhelpful. Other children were inconsistent due to their health status and had periods of being unsettled, and difficult to move and manage that was not related to the child's understanding or intent. Strategies to deal with these days were to lower expectations of what could be achieved and allowing the child and carer time and space to rest.

One child spoke about the change of skills due to getting older. He identified that when he was younger, he used to be able to roll over in bed easily, but his skills had changed.

Facilitator: So, as you've got older do you think things are easier or harder or just different?

Y4- Different. I wouldn't say it would be hard – depending what it is. Some things are easier, and some things are harder. As I said, turning (rolling) used to be a breeze, now it's a pain.

**Theme 3: Time to learn and practice - The Sports Utility Vehicle (SUV)**

“Opportunities to upskill” (C5).

There were some days and times where carers and children identified that they allowed time for the child to learn and practice new skills and took the time to change and adapt routines. Allowing time to learn and upskill however, did not tend to occur on a busy school day, but at other times when life was less hectic.

... weekends and holidays and times when her dystonia is better controlled, then we do stop and take the time to allow her to do more (C5).

Learning new things was difficult due to lack of time. Allowing the child to learn and contribute skills took time and patience from the carer. Carers did make time to do this, but it could be difficult for the carer.

I’ve had to learn to wait a lot of the time, just to give her the opportunity to do and not expect her be able to do it instantly, probably the most important thing I think is to keep asking, not to give up and do it myself, just say come on you can do it (C2).

An SUV day was when children and carers took the opportunity to work things out together. Carer and child pairs identified that there were times when they checked in with each other and communicated about how they worked together in the routine. They anticipated each other’s movements and knew when the other person was doing the right

thing. They were tuned into each other's mood and needs and noted when the child was able to be helpful.

I'm more patient if you are more helpful, and you are more helpful if I'm more patient (C2 talking to Y2).

There was evidence of children and carers prompting each other and reading each other's movements. The child completed part of the action; "little movements that were a big help" (Y4), and the carer stepped in to guide and adjust when needed. One carer described the prompting and attention to detail required to complete a sit-to-stand transfer from an adjustable height bed to power wheelchair, highlighting the moment of preparation as the child sat on the edge of the bed ready to stand up:

...(I'm) holding on to the (child's) left hand and just gently guiding, rather than pulling and... guiding and helping her to stay in the right position. I was also watching her feet, so that they would land in a place that would mean that when she stood up, that she didn't collapse. I was particularly watching her left foot and giving it a nudge with my foot to make sure it landed in the right place, so we could transfer her safely (C5).

Communication was also identified as an important factor to assist learning of skills. Carers talked about working with the child to learn new skills through trial and error. One carer explained how they communicated with their child, using trial and error and collaboration to achieve what needed to be achieved during daily routines:

I think communication is where it's at. It's one thing to say to a child I need you to do this, but if you actually explain why it's beneficial for both of us that that happens, then that gives a real understanding of the end result that everyone is looking for, and you're working in collaboration with one another. So, it's not so much a telling, it's let's try it this way and let's see what happens, and this is what we need, and this is what we're trying to achieve. (C4)

Carers acknowledged that they needed to clearly outline what was expected of the child. One carer talked about the concept of learned helplessness, and how if the carer continued to provide more assistance than was necessary, the child could become more passive.

So, you need to spell it out, particularly as youngsters, all along the way. Otherwise they can kind of go a bit lazy – this learnt helplessness. They don't understand how... beneficial it is for the carer if they just go and lift their hand another six inches. They think what's the difference between here and here, (gesturing to indicate approx. 30 cm) but in dressing it can be enormous. So, communication is where it's at; one what you would like, and two why you like it that way – if you can get it (C4).

Expectations of the child, the expectations of the carer on themselves, and the perceived expectation on the carer from other people, were factors that affected performance of daily routines. Some children rose to high expectations and this meant they were more helpful in the routine. Children learned skills at school and at home, but the use of actions could occur differently in different environments and with different people.

She knows what's happening and she can differentiate between home and school. By us spoon feeding her yoghurt over the holidays, when she goes back each year she hasn't lost those skills at school. She knows where she likes to use certain skills and what's expected of her and what isn't (C1).

Carers had a range of strategies that they had collected and integrated into their routine over time, and the routines also changed gradually over time through trial and error. Children's abilities also changed over time. Some skills were retained, and others become more difficult. Children identified that some skills they had learned in early life were still useful in daily routines, such as sitting up and using their hand to support themselves on the side of the bed for dressing. However, as the child grew, strategies such as requiring more time and extra assistance for the child were sometimes required.

It's not because the disability has increased, it's because the dynamic of his body has changed enormously.... techniques have changed at different times during your (his) life because the ability to do something has changed. (C4)

Carers indicated that they may have had to change the way they do a routine due to increase in the child weight and size. This was seen by some families as an opportunity for the child and carer to develop a new strategy. This included expecting the child to take weight in standing instead of being lifted, whilst also introducing the use of equipment to accommodate a child's increase in size. A change in carer's health, such as pregnancy or back pain was another time that the routine was adapted. Changes in the routine included the carer asking for assistance, for example asking siblings or other family members to help lift the child, or increasing the use of paid home carers. Respite workers, carers who came in to

the home, therapists, doctors and other families with children with disabilities were identified by participants as a source for learning practical strategies.

### The child related actions used during routines

The child related actions that are useful in the transactions between children at GMFCS IV and V and their carers during important daily routines are outlined below to answer Research Question 5. As well as describing how children and carers complete routines, information was collected about the actions and movements that the child used during daily routines. The child related actions that were useful and/or disruptive during daily routines are summarised in Table 6.2. Some of the skills and actions were observed by the carer and child whilst watching themselves on the video. Others were identified during the discussion of the broader daily routines.

Table 6.2.

#### *Child related actions used during daily routines*

Body part	What the child did	How this was <i>helpful</i>	
Hands	Held on to a rail in standing	Facilitated a stand transfer from wheelchair to toilet	
	Held on around carers neck	Assisted a one-person lift into bed	
	Kept hands still		Did not interfere to get through a doorway
			Kept hands out of way during changing continence aid in lying
			Carer didn't get hit during routine
			Child stayed in the sling during hoisting
	Retained object in hand		Allowed face cleaning
			Prevented injury during van transfer
Put hands down		Self-feeding- holding spoon, finger food, cup	
		Balanced in sitting on side of bed for dressing	
		Pushed arm through sleeve	
Made a fist, retained a fist		Fitted through doorway in wheelchair (hands on lap)	
Made a fist, retained a fist		Pushed hand through sleeve	
Pushed a button		Operated a mechanical hoist	

Pushed down with hands on arm rest or bed	Allowed the child to slide bottom back in chair Child pushed up from lying to sit on side of bed
Picked up a mealtime object	Allowed self-feeding
Used hands to communicate: reached out, tapped, hand down from mouth	Assisted communication of needs and wants
<hr/>	
Bottom	
Stayed down	Helped when sliding bottom back in chair & wheelchair Maintained lying position for dressing/changing
<hr/>	
Trunk & head	
Child came forward to organise body	Maintained seated/flexed position in sling during hoist transfer Reduced chance of carer being kicked/hit by uncontrolled movements Assisted child to keep still to allow carer to move child Relaxed body to break tone to move from sit to stand Assisted "breaking tone" to reduce stiffness so child was ready to move
Came forward in sitting	Allowed sling to be placed behind back for hoist transfer Facilitated wiping of bottom by carer Initiated stand transfer onto toilet Child reached to feet to undo foot straps Child could slide bottom back in chair
Coming forward in side lying	Child kept head & arms out of the way to allow lower body changing/dressing Prevented injury from pushing back out of the bed
Brought head forward	Child could use head nod & shake for communication Kept head in the middle during transfers/lift. Assisted carer to put on bibs (clothing protectors) Assisted visual attention to look toward button during hoist transfer Allowed carer to take a sling out from behind child Assisted with dressing- taking clothes over child's head Assisted with head position to optimise safety during vomiting
Stayed upright in sitting	Assisted maintenance of seated position on side of bed for dressing Assisted when coming forward -stand transfer to bed

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Legs & feet		
	Lifted leg up in sitting	Allowed carer to slide sling under knee Lifted foot off foot-plate to prepare for standing and hoist transfer
	Took weight through feet	Assisted stand transfer onto toilet, into wheelchair, into bath, from floor to wheelchair Allowed sliding bottom back in chair
	Soften knee	Allowed knee bending to assist with lower body dressing: putting shoes on
Body part	What child the child did	How this was <i>unhelpful</i>
Whole body	“Planking”	Affected safety whilst hoisting or transferring Child couldn’t bend to get into chair/fasten seat belt Resulted in difficult & messy changing of continence aids
	Head backward	Child couldn’t bend to get into chair Carer had difficulty getting clothes over child’s head Child was unsafe during lifting & hoisting
	Hips forward /bottom up	Child couldn’t get bottom back in chair Carer couldn’t do up pelvic support in wheelchair Child couldn’t stand up Made it difficult to fasten continence aid

One child described the skills that they used during their daily routines, and how they relied on a carer who knew them well to notice how these skills contributed to task completion:

I think knowing what the person that you’re dealing with is capable of, because if you give them the expectation of ‘go and put your pants on’ – well I’m not capable of that. It may not be the big things that matter, it’s the small, minor details that a normal person would go (*shoulder shrug*). The smaller details are bigger than the bigger details. Basically, it’s what you can’t see or what you don’t notice that’s a big thing (Y4).



Other examples of subtle actions of the child that were observed on the videos and noted by the participants included: a child leant forward in sitting to allow a sling to be placed behind them, a child reached up to hold on around a carers neck during a one-person lift and a child kept their hands down on their lap while sitting in a wheelchair to go through a doorway. One carer observed on the video how the child lifted a leg in sitting to take their foot off a footplate to allow a sling to be placed under their leg:

C2 to Y2: You did lift your leg up when we got the sling under, so that was helpful... it's probably one of the things that you help most consistently with - lifting your leg up.

Facilitator: Does that make it easier for you to do?

C2: Much easier. otherwise, you're fighting against her strength and her tone is a lot harder. She just has to lift it a tiny bit and then I can work with it.

Facilitator: What happens if she doesn't lift her leg then?

C2: It's a bit of a battle and there's swearing that you didn't hear [laughs].

Participants identified actions of the children that assisted ease of routines as being either relaxing, letting go, softening movements or keeping still, being calm and organised movements. Some of these actions and movements were able to be controlled by the child. Some children had times when their movements were extremely disruptive, described in the 'Tractor day' routine in Figure 6.1 as a *disorganised body*, where the child "planked". These movements were disruptive, and carers expressed concern that they could cause injury to themselves and their child. One child found these movements amusing and this was a point of tension between child and carer.

The act of thinking about being helpful was particularly important for the completion of actions during routines for one child and carer dyad. During the filming of a bed to wheelchair hoist transfer, the child extended her body back in the sling, so was therefore unable to be flexed into a seated position to move into the wheelchair. The carer told the child to assist by pressing the controller on the hoist, even though the carer knew the child could not physically achieve the task. The carer waited, the child looked forward to the controller, and when the carer assisted the child to place her hand on the controller, the child's whole body flexed and was then safely transferred into the wheelchair. The child watched this part of the video and used her PODD book to say: "I was helping" (Y2). The carer explained that increasing the expectation on the child improved the ease of performance of the routine. The child also responded to different situations and people in different ways. If the child was working with someone new and who did not have expectation that the child could help, the routine could be unsuccessful due to the child's behaviour. As the child's abilities were not easily identified, the carer needed to carefully train new staff about the subtle actions of the child and the importance of the carer having appropriate expectation of the child.

If people say, "No, I know you can do better than this, you need to be helpful, take your deep breath and try harder", then she will (C2).

It was useful, and at times necessary, for the carer to have one hand free during care routines. This was sometimes achieved by the child assisting with part of the task. One child (Y4) actively used his "core," that is being active in his trunk, to maintain upright sitting on the side of the bed for dressing. This was important as the carer then only needed one hand to support the child to sit, and therefore had the other hand free to obtain items and complete the routine. Another child could not roll from back to side without assistance but could remain

lying on her side once placed during a changing routine. If the child maintained this position without carer assistance, the carer had one hand free to wipe/change the child and complete the hygiene routines. If the child was not able to maintain the side lying position, the routine was difficult: "...I have to hold her with two hands, there's no hand left to wipe." (C2).

### **Use of video to analyse routines**

The use of video to analyse daily routines was a data collection method, but participants provided feedback about the usefulness of the process which is of interest to this research. Carers and children generally enjoyed the process of watching themselves on video. Three families expressed surprise at how quick and efficient they were and expressed pride in themselves. One carer commented on a bed to chair transfer on the video: "It's quick, isn't it? I notice how quick I do it. Over the years, I've just got fast." (C 5)

Although adaptation of the routine was not the researcher's intent, one carer initiated ideas about equipment that could make the observed routine easier. Watching the video prompted participant to think about how they achieved the routine:

I actually took more out of...watching it...rather than just someone...saying you need to change this. Actually, visually seeing it...(C4).

### **Discussion**

Families function in a busy world and carers and children aimed to complete their routine in the most efficient way so they could focus on the rest of their lives. Carers and children completed routines in their own way based on what worked best for them. Some of the influences on the daily routines that were identified in this study are also evident in other literature. These included factors that impacted on the carer, the child and context.

There were factors during all of the routines that were related to the carer. The carers feeling that they need to be highly organised, which was a factor in the difference between a *good day* and a *bad day*, was shown to be an issue that challenged other mothers of children with a disability (Bourke-Taylor, Howie, & Law, 2010). Disruptions to maternal sleep, and therefore *fatigue*, have also been shown to be common in other samples of mothers of children with disabilities (Bourke-Taylor, Pallant, Law, & Howie, 2013), and was also highlighted as a factor that affected how routines were negotiated in this study.

There were child related factors that affected the way daily routines were negotiated. The movement patterns of children with cerebral palsy, that were described in this study as *organised or calm body*, *disorganised or stiff body* and evidenced in the factor of *fighting against* are explored widely in the literature, although less so in relation to daily routines (Stewart & Harvey, 2018). Performing activities in daily life, or *helping*, during daily routines was an important element in a SUV day. Having some level of independence in daily routines has also been shown to be important for personal growth and for forming identity in other sample of young adults with cerebral palsy (Bergqvist, Ohrvall, Himmelmann, & Peny-Dahlstrand, 2017).

The way that routines were navigated was affected by the context. Children at GMFCS IV and V have been shown to require higher amounts of specialist equipment and home modifications than children with milder forms of cerebral palsy, which supports the importance of the *right set up* on the completion of daily routines in this study (Ostensjo, Carlberg, & Vollestad, 2005). Giving children *time to help*, which required *time and patience* from the carer could be an example of a supportive social context which has been shown to be important to build child capacity and participation in everyday daily life in other samples

of children and carers (Batorowicz, King, Mishra, & Missiuna, 2015). Having *expectation* of the child and prompting and noticing small actions were evident in the transactions in the dyads of this study. This is supported in other literature that shows that children learn in contingency rich environments, which includes the right level of *expectation* to support child active engagement and learning (Dunst, Trivette, Raab, & Masiello, 2008).

The participants in Study 2 were active and able to assist to complete many tasks in their daily routines. This may or may not be evident in other settings. The inconsistency evident in the way routines were negotiated is perhaps consistent with an understanding of the differences between a child's capacity; what they can do in a structured environment, and their performance; what they do in real world contexts (Holsbeeke, Ketelaar, Schoemaker, & Gorter, 2009). The findings from Study 2 highlighted that children and carers were reliant on each other to perform many parts of the daily routines. This study did not investigate whether children perform better in some settings than others. Children may perform more poorly without a supportive context and a well-known carer, but conversely, they may at other times perform better outside the time pressures of daily life. For example, a child may be able to eat independently once set up in a school environment as they have one to one help, and an hour to eat their lunch, conversely, they may be fully assisted to eat breakfast at home as it is quicker and neater in a busy morning routine. The opposite scenario is that a child may be able to complete a stand transfer at home with a well-known carer but is transferred by a hoist by carers in the school environment. The results of this study support the idea that children's ability to be actively engaged in routines is variable and reliant on a range of individual factors affecting the child, carer and context.

The results of Study 2 also suggest that the use of video recording to analyse daily routines could be useful in coaching parents and carers to design their own solutions to issues in daily routines. Engaging carers and children to analyse and reflect on their own performance of daily routines has support in the literature as the basis of family centered practice (Graham, Rodger, & Ziviani, 2009).

### **Summary**

Carers and children in this study completed routines in three ways: (a) in the quickest and easiest way to get the job done, (b) with great effort which was slow and difficult, and (c) allowing time and opportunity to learn and upskill. Each theme included subthemes which illustrated how the child and carer experienced their routines that could change on a daily or even hourly basis. The factors that affect all three are fluid, as they are influenced by the experiences that the family is undergoing on any given day (or moment), the skills of the child and the demands of daily life on the carer. The potential to progress skills or change routines to improve ease of caring is affected by the carer, the child and context.

### **Strengths and limitations**

The sample size of five child and carer dyads in Study 2 was consistent with recommendations for the chosen research design, Interpretive Phenomenological Analysis, which proposes in-depth analysis of three to six cases. The sample appeared adequate to provide an in-depth understanding of the lived experience to answer Research Question 4. However, including further cases could be useful to further inform Research Question 5 – the child related actions used in the daily routines of the varied population of children at GMFCS IV and V. The findings of Study 2 were based on the children and carers completing one daily routine, and although varied routines were observed across the five dyads, the actions

identified may not be applicable to other children completing routines under different circumstances. The results would be strengthened by including further children completing a broader range of routines. Comparing skills and experiences between GMFCS levels and other cerebral palsy classification levels was not possible due to the small sample size, but would be of benefit to strengthen the outcomes. .

Use of video recording to capture the daily routines contributed to the credibility of the results of Study 2 as the participants, both children and carers, were able to reflect on their own routines without relying on memory or a third person interpretation of what occurred. Data collection occurred in the family homes, which added to the credibility of the findings by closely reflecting the lived experience of the participants. This did, however, increase the time required to collect the data. Discussion about the outcomes of Study 1 and Study 2, the strengths and limitations and clinical implications are further detailed in Chapter 7.

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## CHAPTER 7: DISCUSSION

This research provided an exploration and description of some of the unique aspects of the daily lives of children with cerebral palsy at GMFCS IV and V and their carers. Study 1 gathered information to develop a broad understanding of daily routines, with insights gained about the importance, difficulty and level of assistance children required. Study 2 built on the information gathered in Study 1 by conducting detailed analysis of individual child-carer dyads undertaking everyday tasks in the natural context of daily life. Study 2 explored what children were able to do to contribute to each daily routine, the ease and difficulty of completing daily routines, the factors that influenced these routines and how learning opportunities could be incorporated into daily life. In this final chapter is a discussion of the findings of the overall research, the strengths and limitations of the research, clinical implications and applications, suggested directions for further research and conclusions.

### **How children contribute to daily routines**

#### **Contribution to daily routines can be subtle**

The findings of the current research suggested that there are child related skills that children at GMFCS IV and V and their carers find useful in daily routines, and that these skills may be important to develop and measure. Skills that children at GMFCS IV and V use during a daily routine may be difficult to capture and define. It is possible that how children contribute is either so subtle it is overlooked, is taken for granted, or is only a small part of the overall task. The contribution may therefore not make a noticeable difference to how much assistance carers feel they need to give their child. There are also likely to be a small number of children who are not able to contribute at all to daily routines due to the complexity of their health, learning and movement difficulties. However, results from this

research indicated that many children are actively engaged in daily routines and can contribute a range of skills and abilities, even if quite subtle and only part of the task.

To measure achievement of daily living skills, assessments such as the Pediatric Evaluation of Disability Inventory (PEDI) (Haley, 1992), are routinely administered in clinical settings, and are subsequently used to guide goals for interventions. Tools such as the PEDI might be suitable for typically developing children, who are likely to achieve independence in daily routines by age five years (Bundy, 2012), and children with milder forms of cerebral palsy who may take longer to achieve independence but are still likely to do so (Ohrvall, Eliasson, Loring, Odman, & Krumlinde-Sundholm, 2010). However, for children at GMFCS IV and V, current assessments may not be sensitive enough to pick up the subtle contributions of children or have small enough increments of achievement to guide intervention for these children.

Skill use during daily routines in this research was shown to be highly variable, dependent on many factors and to include very subtle abilities. Skills children contributed towards task completion during daily routines were based on the child's individual abilities. For example, different children were found to contribute different types of skills during dressing routines explored in Study 2. One child could sit independently on the side of a bed and reach his arms through a sleeve held by a carer but needed full assistance to take their shoes on and off; another child could lean forward for sling placement during a hoist transfer into bed; while another child required full physical assistance, but could breathe and relax his body to make dressing easier for the carer and chose clothing using eye gaze. These examples of contribution to dressing routines could all be described as requiring full assistance yet demonstrate varied yet valuable contributions by each child.

A review of the literature provided limited information about the skills that children at GMFCS IV and V may be contributing to task completion during daily routines. There is however some emerging interest in the subtle motor skills of children with severe and multiple disabilities (SMD) including children with cerebral palsy at GMFCS IV and V (Mensch, Rameckers, Echteld, & Evenhuis, 2015). A recently developed assessment, the Movacik, that was not available at the start of this research project, was designed to help define and measure some of the subtle motor abilities of children with SMD (Mensch, 2017). The Movacik identifies a range of motor ability items, the positions the children are in when attempting the movement (lying, sitting or standing), the amount of physical support required, how active the child is and the facilitation from an adult the child needed to perform the movement (Mensch, 2017). This assessment is of interest to this research as many of the motor abilities identified by Mensch (2017) were also apparent in the daily routines of children in Study 2 (See examples in Table 7.1). The overlap of movements of children identified in this study with motor ability items in the Movacik suggests that there may be skills that are common across many children at GMFCS IV and V. The design of the Movacik also aligns with the idea proposed in this research that children are likely to need assistance and support to achieve these movements. Further work with a larger sample of children and carers, would be required to substantiate the motor abilities that children use in daily routines.

Table 7.1

*A comparison of the motor ability items from the Movakic and active movements of children during daily routines from Study 2*

Movakic motor ability items	Examples of use of active movements in daily routines in Study 2
1. Maintaining position	Maintaining side lying in bed for dressing/changing continence aid
2. Duration maintaining position	Sitting on side of bed for dressing
3. Turning head	Moving head forward for dressing
4. Upright head	Keeping head up and forward for safe hoist
5. Maintaining upright head position	transfer from bed to chair
6. Reaching with the arms	Using hands to communicate (signing)
7. Take support forearms	Pushing up with hands to move from lie to sit for dressing/bed transfer
8. Take support hands	Holding armrest with hands to help slide bottom back in chair
9. Grasping with the hands	Holding rail for toilet transfer Holding food for eating
10. Roll over to the left	Rolling over on the bed for dressing,
11. Roll over to the right	placing a sling and changing continence aid.
12. Roll over to prone	
13. Roll over to supine	
14. Transfer from lying to sitting	Transferring from bed to chair
15. Transfer from sitting to lying	Transferring from chair to bed for dressing in lying on bed
16. Transfer from sitting to standing	Standing transfer from sitting on edge of bed to wheelchair
17. Transfer from standing to sitting	Standing transfer from wheelchair to toilet
18. Pivoting	Dressing on bed Preparing to transfer from bed to wheelchair
19. Minor voluntary postural changes <sup>a</sup>	-
20. Move on <sup>a</sup>	
21. Distance <sup>a</sup>	

*Note.* Mobility items are from “Movakic, motor abilities in children with severe multiple disabilities; - small steps, big changes” by S. Mensch, 2017. Erasmus University, Rotterdam.

<sup>a</sup> insufficient definition of items to provide examples.

**Managing whole body movements can influence ease of care**

Although children were shown to complete a range of subtle active movements during daily routines, the ease of daily routines was also influenced by how the child's whole body moved. The whole-body movement abilities of *keeping still*, and *relaxing* or *reducing stiffness* were found to be important in this study. This stiffness or extraneous movement needed to be managed, before the child or carer could attempt movements such as reaching, sitting or transitions from lie to sit, or sit to stand during daily routines. The process of the carer and the child working together get the child's body organised or ready to move, was likely an effort to reduce or "*still*" the effects of dystonia. Dystonia is defined as muscle contractions that causes twisting, repetitive or abnormal posturing that is common in children with cerebral palsy (Sanger, Delgado, Gaebler-Spira, Hallett, Mink & Task Force on Childhood Motor Disorders, 2003). Dystonia literature also describes the issues of close association of an unwanted movement with an intended movement, and defines this as overflow movement (Sanger et al., 2010). The disruptive movements of planking and thrashing, described in the findings of Study 2, were likely to be examples of overflow movements of a hyperkinetic movement disorder. It is also known that dystonic and overflow movements increase when there is effort to produce a voluntary movement (Sanger et al., 2010). This makes producing a meaningful intentional movement even more difficult for children with dystonia, and explains why children may need to "get organised" before they move. This knowledge about dystonia is important as it helps explain why children's performance of daily routines were inconsistent and the assistance they required was varied.

Families are likely to benefit from practical ways to manage dystonia in children with cerebral palsy to assist care needs. Although some studies highlight the need for physiotherapy, occupational and speech therapy intervention to support children with

dystonia, much of the current research focuses on the pharmaceutical, medical and surgical treatments of dystonia (Lumsden, 2018). The findings from Study 2 provided some examples of practical strategies the families used to help control or manage unwanted whole-body movements, likely to include dystonia. These included engaging the child in helping with the task by breathing to relax their body, leaning forward to reduce stiffness, bending the child's leg to "break the tone" and providing more carer support when the child had increased episodes of dystonia. Practical strategies used to help reduce stiffness and to control unwanted movement were not included in Mensch et al.'s study and were not identified in the literature review in relation to daily routines. Engaging a child to learn to reduce extraneous movement or reduce stiffness to ease the completion of daily routines is therefore potentially a skill of value that requires further investigation.

### **Active involvement in daily routines may be important for child well-being**

Building personal capacity in daily routines, which could also include an ability to direct and make decisions about their own care, may be important for children's transition to adulthood and ongoing wellbeing (Bergqvist, Ohrvall, Himmelmann, & Peny-Dahlstrand, 2017). The research suggested that successful completion of routines was could be reliant on the carer and child knowing each other well and working well together. Conversely, carers also reported that some children performed differently in different settings and adapted their skills accordingly. As children at GMFCS IV and V grow, it is likely that they will require support from a variety of people, such as school assistants or paid carers, that may not be a well-known parent or carer. It may therefore be important to make explicit how children contribute during daily living transactions to ensure the skills of the child can be used and developed beyond the dyad of the well know carer and child. Self-determination is a human right for all people, but may be harder to achieve for a person with a significant disability

(Algozzine, Browder, Karvonen, Test, & Wood, 2001). Therefore, the ability to direct their own care may be an important skill for a person with cerebral palsy at GMFCS IV and V to start to learn in childhood.

Children with severe and multiple disabilities have been shown to be less active and move less than other children, and are likely to benefit from intervention that increases their activity levels (Van Der Putten, Bossink, Frans, Houwen, & Vlaskamp, 2016). Children at GMFCS IV and V are likely to require external supports to assist them to participate in physical activity (Ostensjo, Carlberg, & Vollestad, (2003). As they already require assistance to complete daily routines, increased active movement could be imbedded into a daily routines. Frequent small opportunities to move throughout a day may be a useful adjunct to interventions, such as exercise programs, that aim to increase children's fitness and well-being.

### **The child's perspective of their own abilities and acknowledgment of their effort**

The inclusion of children's views provided useful insights related to children's self-perception of their abilities. This included what children think they can do and their effort versus outcome. Children rated their level of independence in daily routines slightly higher than their carers in Study 1 results. This increased level of self perceived independence in children was also evident in the results of Study 2. One child used AAC to state that she was helping during a daily routine, yet this "helping" was not immediately obvious to the carer or researcher through their observations of the video. The child is the only person that can report their own feelings and personal experience (Eiser & Varni, 2013), so therefore if the child feels that they are helping, it is important that we listen. It is also possible that children felt they were putting effort into a task during daily routines, but as the carer was still needed to



complete the task, this effort may not have been obvious. The child's input may also only have had a small impact on the outcome. Understanding the child's perceptions of their abilities is therefore important. It is possible that if effort and intention from the child is not acknowledged the child may give up and stop trying to contribute their subtle skills and abilities, and be at risk of becoming passive.

Children's ability to contribute to daily routines might also be influenced by the expectations placed upon them by others. The whole-body movements of some children in this study were more easily managed when there was an expectation that they could assist in a task. Interestingly, this also occurred in situations when the child could not actually physically assist in task completion. The expectation the child could help, and the child thinking about being helpful, was critical for the smooth completion of routines for some children and carer dyads in this study. Therefore, for some children, the intent to be helpful, could be just as important as the physical ability to do so. An intent to be helpful, could also lead to the ability to be helpful, though how this might occur would require extra investigation. It is therefore important to consider the child's perception of their own abilities and for carers to be supported to recognise and reinforce the child's subtle abilities and movements. This could be important to sustain continued effort and engagement of children in daily routines, which could benefit both the child and the carer.

### **Choosing what to focus on to influence daily routines**

#### **Being guided by the child's functional level**

While it is important for carers to recognise and promote overall subtle skills of children, it is also important to focus on skills that may be possible for children to achieve based on their individual functional profile. There is evidence that the cerebral palsy

classification systems, as well as assessment of achievement in daily living skills, are useful to guide goal selection and intervention (Ostensjo, Carlberg, & Vollestad, 2004). Developing functional goals for daily living skills, however, may be more difficult for children at GMFCS IV and V, as current assessment tools are not sensitive enough to guide or identify the subtle increments of skill attainment of these children. It still may be possible to guide decisions about what is broadly possible to achieve by using information gained from tools such as the CPCHILD and cross referencing this knowledge of children at different cerebral palsy classifications, such as the GMFCS.

Classification systems provide some guidance for families about what children at GMFCS IV and V may find difficult or possible to achieve, such as transfers and mobility. An example how the GMFCS could guide expectations of what is possible, is the goal of completing a standing transfer. A standing transfer is a useful skill during daily routines that may be possible for a child at GMFCS IV, but not likely for a child at GMFCS V (Palisano et al., 2000). Findings from the survey results of data from the CPCHILD in Study 1 demonstrated different ratings of importance of standing for transfers between GMFCS IV and V groups of children, consistent with the difference in the GMFCS classification criteria. Carers of children at GMFCS IV, who might frequently use a standing transfer as part of a daily routine, rated this skill as important. Whereas carers of children at GMFCS V, who may lift or hoist their child, as the ability to stand transfer may not be possible, rated this skills as less important. The ability to use a skill appeared to be linked to an increased rating of importance: if you can't do it at all, it isn't important. This supports the notion of shifts and trade-offs that can occur when determining what is meaningful and valuable to carers and children (Schwartz et al., 2006). This example demonstrates how the GMFCS could be used to guide goal selection. Families and children still however require guidance to identify the

range of subtle skills within these broader goals. The other classification systems can also be used to guide goal selection beyond mobility, such as using the MACS, EDACS and CFCS to guide how children could learn to use their hands to assist with daily routines, eating and communication.

### **Being guided by the time available**

Time had a major influence on how much children in this research could contribute to daily routines. It may be accepted that the child cannot contribute useful skills at particular times, so families may decide to use external supports such as equipment, or extra carers, or to adapt their lives to accommodate for impairments (Schwartz, Andresen, Nosek, Krahn, & Measurement, 2007). When a family doesn't have the time to focus on what is possible, the importance of tasks may change. Study 2 provided evidence that the times and places where children could contribute to daily routines were tempered by the need for routines to be quick and efficient. If two people are required to complete a task, the person who has the least time is also likely to drive the decision as to how the task is done. The carer's ability to allow time for the child to contribute, and the child having the willingness and ability to contribute was likely to be highly variable. The results of this study demonstrated that time constraints are part of daily life. Understanding this can help to guide clinicians and support families to set goals and design meaningful interventions to build capacity of children and carers in within a busy life.

### **Being guided by fatigue and effort**

It is possible that children may have the time to contribute to daily routines, but they don't for other reasons. There were times when due to child fatigue, the carers in this research provided more assistance and routines were more difficult. Alternatively, there were times

when children could contribute more to routines as they were less tired. Completing daily routines independently has been shown to have an impact of increased pain and fatigue on young people with cerebral palsy at MACS I-II (Bergqvist et al., 2017). The effort required for children at GMFCS IV and V to complete daily routines might also cause fatigue or pain. This outcome may need to be balanced against the child or carers desire for the child to be active in daily routines. Carers and children may therefore need, at times, to prioritise their time and energy into other parts of their life, for example, study, social and recreation pursuits, rather than using extra effort to actively engage in daily routines.

### **Learning in the context of daily routines**

Although carers and children can accommodate the child's impairments in daily life, improving children's ability to participate in daily routines have been shown to be important goals of intervention (Bundy, 2012). Children at GMFCS IV and V have high rates of learning difficulties (Reid et al., 2016) and have been shown to benefit from structured learning opportunities in everyday contexts (Ekström, Johansson, Granat, & Carlberg, 2005). Providing learning in the contingency rich environment of daily routines could provide multiple incidental opportunities to learn in a functional setting (Ekström et al., 2005). This could build on the relatively short structured learning time provided in a home program, classroom, or therapy setting. Interventions that are meaningful and relevant to daily life could make caring for a child easier and increase the chance that the cost and effort of interventions makes a positive difference to family life.

### **Targeting easy routines**

Information about what daily routines were difficult and easy was sought in this research. It was assumed that this would provide insights into what was possible and

achievable for children at GMFCS IV and V. One of the easier routines from the results of this research was *eating*. The findings of Study 2 included an example of child and carer transactions during an eating routine where the carer responded to the child's range of subtle hand skills and communication abilities. It is known that a range of subtle skills and child-carer exchanges were used during eating routines (Ferm, Ahlsén, & Björck-Åkesson, 2012), and that some children responded to structured challenges to develop subtle oral motor and postural control skills during eating (Pinnington & Hegarty, 2000). Mealtimes may be an example of a daily routine where there is opportunity for clinicians and carers to notice, and use small increments of skill development and work with the child to gradually increase his/her capacity over time.

### **Effective transactions in daily routines**

The transactions between carers and children at GMFCS IV and V during daily routines are complex, subtle and different for each individual dyad. Transactions between carers and children have been shown to shape learning in early childhood, and continue to influence behaviour in adolescence (Sameroff & Mackenzie, 2003). The results of Study 2 provided rich descriptions of transactions in daily life; children initiating actions, carers responding to children's actions, carers waiting for children to initiate or complete a movement and children and carers reading each other's moods and needs in a changing daily context. Transactions during daily routines were influenced by changes to the child, the carer or the context and were therefore dynamic and not necessarily consistent.

**Changes in the transactions related to the child**

There was evidence of families changing the contextual set up of daily routines, including the use of equipment, to accommodate for child growth. It remains unclear if increased age, and the potential change in the child's function with age, negatively or positively effects care needs (Murphy et al., 2007. Ward et al., 2014).). Findings from the current research, highlighted that although routines did change over time in responses to change in the child, they did not necessarily become more difficult. Some carers and children reported that as the child grew older, the strategies that had previously been used to look after a smaller child were not as effective. Also, some actions that were easy for a young child, were identified as being harder in a larger, stiffer, heavier body. This research also found, however, evidence of children developing new skills over time, and maintaining skills they had used as a younger child. Carers and children therefore appeared to adapt to and accommodate for changes in the child due to growth. This was supported by Study 1 results where there was no correlation between HRQOL scores and child weight. Other studies support this finding that although carers may worry about what will happen to their child in the future, carer burden does not necessarily increase with the child's age and size, and there are likely to be a range of other factors that impact on ease of care that involve the mother, the child, the family, services and the community (Bourke-Taylor et al., 2010).

**Changes in the transactions related to the carer**

Carer fatigue and the time pressures of a busy life may influence how routines are negotiated. The findings from Study 2 highlighted that carers at times used strategies that increased speed and efficiency of daily routines, but were potentially harmful to the carer's health, such as lifting a heavy child. Carers have been shown to be at risk of prioritising the needs of their children and other family members over their own health (Murphy, Christian,

Caplin, & Young, 2007). The carers in this study chose to complete routines in their own way, but still expressed guilt that they may be doing the “wrong thing.” There was however, also evidence of carers adapting routines in response to fatigue or changes in maternal health, that supported the health of the carer, such as requesting assistance from other family members to lift the child or introducing new equipment. The diagram (see Figure 6.1) might have a practical use in situations where routines are changed in response to carer health. It could be used to prompt conversations between a clinician and a carer who may be using strategies that are potentially harmful to their own health. The metaphor of a “racing car day”, where carers and children complete routines in the quickest and easiest way, highlights, without judgment, that this is likely to be common experience. It may be possible to use the diagram to support family centered practices where the family and carer are understood and respected as the experts in their own lives, and as capable of forming their own solutions to problems in their daily life.

### **Changes in the transaction related to the context**

Interactions between the child and carer during daily routines was influenced by the context in which they took place. The context included “the right set up”, which often involved specialised equipment. Equipment prescription is an important therapy intervention, as environmental modifications and assistive devices have been shown to lighten the care needs of children with cerebral palsy at GMFCS IV and V (Ostensjo, Carlberg, & Vollestad, 2005). Time and expense is also invested by families and clinicians in equipment prescription (Bourke-Taylor, Cotter, & Stephan, 2014), so it is important to ensure equipment is used effectively. Interestingly, findings from Study 2 suggested that equipment prescription was only the starting point. It is likely that the combined interactions of the child, carer and context contribute to successful use of equipment. A child and carer completing a hoist

transfer, as reported in the results of Study 2, provided an example; The child needed to lean forward, reduce extraneous movement and help to activate the hoist, the carer had the expectation that the child could help, and an effective home set up provided a supportive context. The results of this research reinforced that there may be further ways to increase the ease of completing daily routines once equipment is in place, as the right set up is only part of the overall picture.

### **How families negotiate daily routines in a busy life**

The diagram *How children and carers work together to complete daily routines* (See Figure 6.1) was developed to describe the variability and inconsistency of daily life of children at GMFCS IV and V and their carers in this study. There were three ways that children and carers navigated daily routines. These were represented by a *racing car*, *tractor* and an *SUV*. Each mode resulted in routines being successfully achieved, but may have had costs and benefits. Carers aspired to the *racing car* day as this was most quick and efficient. Ongoing completion of daily routines in the *racing car* mode, could however, potentially cause carer fatigue, impact on carer health and limit opportunity for child learning. Having *tractor days* where routines were slow are hard, appeared to be inevitable, but carers were shown to manage them through a range of strategies that demonstrated persistence and resilience. Tractor days were however, difficult, and remaining in this mode is likely to cause stress and strain on the carer, child and family. Families identified days when they created time and opportunity for children to practice new skills and accommodate to change, described in this study as an *SUV day*. Remaining in the *SUV* mode, however, is not likely to be possible as sometimes days were hard, or routines needed to be done quickly. It is possible that increasing opportunity for families to engage in an *SUV day* may require planning and support. It is possible that spending time learning new skills in the *SUV* mode, could benefit the efficiency or safety of the *racing car* day, and ease the difficulty of the *tractor* day. The



mindset of the *SUV* mode may need to be introduced into a busy life, and once families are aware of potential benefits, they may decide to take more “trips” in this mode over time. Therefore, it is proposed that families are likely to use all three types of cars, may need support and assistance to recognise when they are in each mode, and balance the use of each across time.

The car diagram acts as a synthesis of the study findings and is proposed as a tool to aid communication between clinicians, carers and children. It could be used to introduce the question: “How can therapy relate to my daily life?” and frame a discussion about what a child is capable of, what the child is able to do with support, and what could be important for the child to learn over time. This discussion would acknowledge the time constraints experienced by busy carers of children, and empower clinicians, carers and families to explore the question: “What is possible for my child to learn, and when is it best for my child to learn and practice with support?”. It highlights the reality that there are times when it is necessary for the carer to do everything for the child, however also opens a conversation about the continuum that exists from a child being active and contributing on one end, to being passive, inactive or disruptive on the other. This diagram highlights that learning could be supported by developing habits within daily routines that provide opportunity for practice acknowledging that children may take a longer time to learn skills. Carers are likely to feel empowered by making choices about when, where and how learning can occur, rather than trying to fit therapy goals that are not useful into a busy day.

### **Strengths and limitations of the approach**

Implementation of a study design that included both qualitative and quantitative methods was a strength of this research. This research was also strengthened by the inclusion

of the views of children and young people. This research was able to sample nine children at GMFCS IV and V in the survey. Many studies using the CPCHILD have not provided child data, reported as being due to the high rates of intellectual impairment in the samples (Narayanan, Weir, & Fehlings, 2007). It is difficult to obtain the views of children at GMFCS IV and V due to the high rate of comorbidities such as intellectual and communication impairments (ACPR, 2016), therefore the inclusion of child responses was a core strength of this research. This study however still provided only a small sample of child responses due to time and cost limitations. Findings from Study 1 indicated only small differences in carers and children's responses. Different outcomes may have therefore been discovered with a larger sample of child responses.

The results of Study 2 were based on five carer and child dyads. Although this was adequate for the qualitative methodology chosen, different outcomes may have been discovered if more carer and child dyads were involved or if carers had chosen to examine alternate routines. It was valuable to include a child who uses AAC in the interview process although this unique view takes extra time and effort to capture in research design. The process of conducting, transcribing and analysing the interview required expertise and understanding of the use of AAC to aid interpretation of result. The researcher's experience working with children with complex communication difficulties was therefore an important factor in enabling the child to be included. The involvement of a researcher with extensive clinical experience working with children with cerebral palsy at GMFCS IV and V and their families therefore increased the strength of the findings. However, this study only included one child who used AAC, therefore including further participants who were AAC users or had a range of communication abilities may have added different perspectives to the outcomes.

Participants opportunity to self-reflect and report on their own functional strengths and abilities through filming daily routines was highly informative for this research. Use of video was particularly helpful to detect the subtle and intuitive actions of the children and carers during their daily routines. The use of video is potentially an effective strategy to assist clinicians, carers and children to understand the nuances of daily living transactions and to support efficient functioning of the individual dyads.

### **Clinical implications and application**

This research proposed that interventions to support children and carers during daily living transactions could be enhanced through understanding the processes that occur during daily routines. The diagram, *Building capacity in daily routines* (Figure 7.1) provides a draft framework describing potential next steps for future research and translation into clinical practice. The aim would be to build understanding of capacity building of the child and carer transactions that occur during daily routines. The first part of the diagram, the blue circle with three surrounding circles, *Daily Living Transactions*, is an extension of the diagram from Chapter 6 *How children and carers negotiate routines* that describes the green racing car, red tractor and yellow SUV days (see Figure 6.1). The “roads” have been converted to concentric circles that surround the daily living transactions between the child, carer and context. This part of the diagram displays the how daily routines can spiral in and out of each type of “car” from day-to-day or within a day.

The second part of the diagram, the pink circle, aims to display *Capacity building* actions, representing community and clinician support of the daily living transactions. Useful strategies and skills to support capacity in the daily living transactions could be identified

through partnerships with families. Clinicians can work with carers and children to break down tasks in daily routines into achievable small steps to structure learning and celebrate success. Goals for intervention would therefore derived from, and integral to, what happens in the child’s daily life.

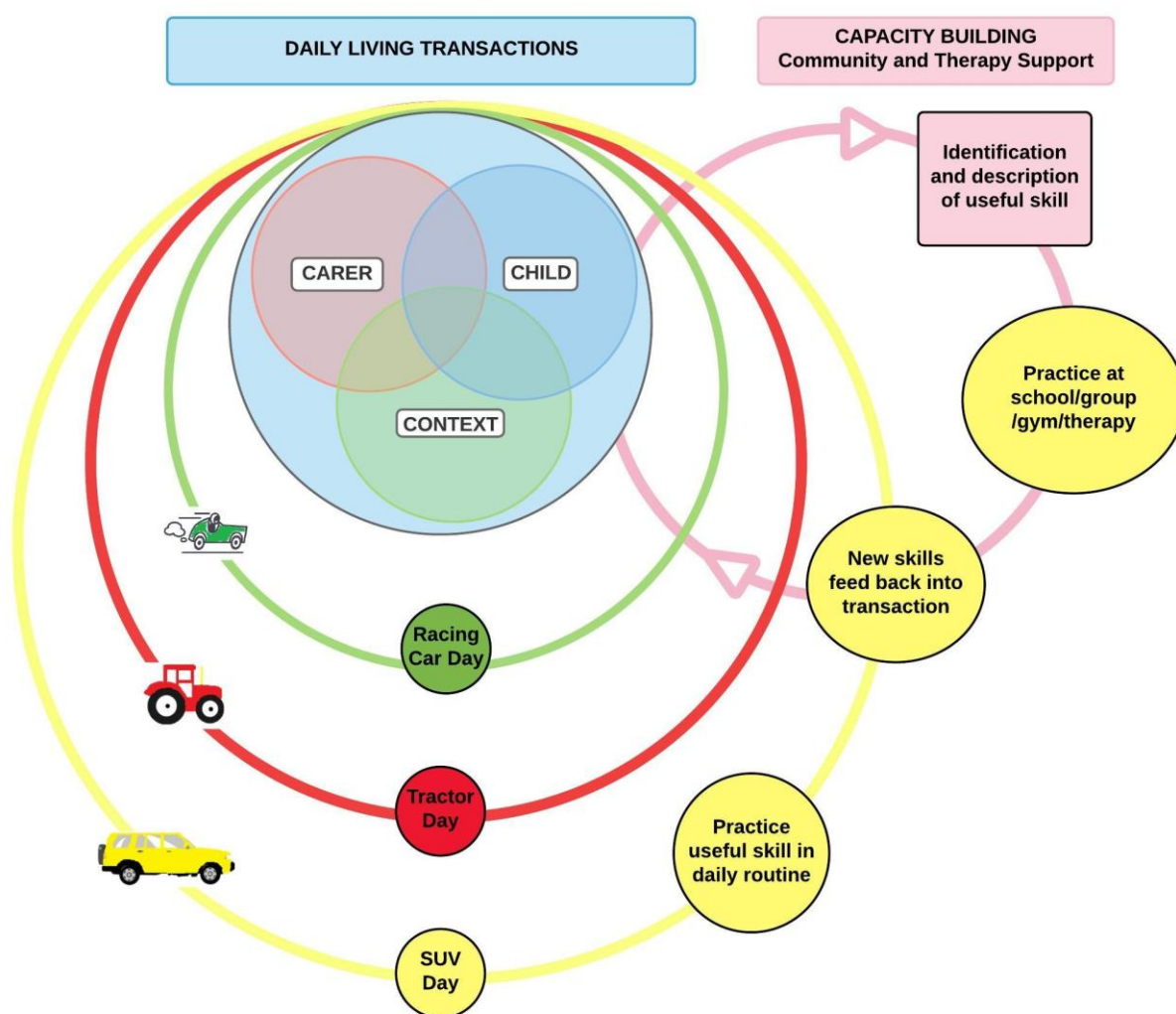


Figure 7.1 Building capacity in daily routines

The child and carer may benefit from the child having opportunities to learn and practice new skills in other contexts, as highlighted in the yellow circle, such as childcare, school, or with extended family. Families are busy and developing skills for children takes time. The family who regularly functions in the racing car mode may not always have

capacity to support the child to “give it a go,” and may need help. This is supported in the literature about family centred practice that identifies the informal social network and wider community support as an integral part of the support system of the family (Dunst & Trivette, 2009). Once new skills are established they could be integrated, over time, into the daily living transactions. This is illustrated by the yellow oval, *new skills feed back into transactions*, that overlaps the yellow *SUV day* and the pink *Building capacity* circle. These newly acquired actions may continue to be used inconsistently, but they form part of the child’s and carers tool kit.

*Building capacity*, the pink circle, purposefully crosses over all types of days in diagram. This proposes that intervention may be required on a *racing car day*, perhaps to assist carer health or child learning, or on a *tractor day* to potentially reduce difficulty and increase efficiency. Providing intervention on a *racing car day* may be important to support carer health and well-being. It is possible that focusing on the child learning new skills might assist carers to take care of themselves. Carers may complete routines as easily and quickly as possible, putting the needs of others before their own, which may result in using strategies that may impact on the carers own health. By focusing on the child learning, carers could make small adaptations to daily routines that assist child learning but are also of benefit to themselves and may make the routine easier and safer for both people.

### **Possible barriers for learning functional skills and possible solutions**

Using the diagram *Building capacity in daily routines* as a support for discussion and goal setting, the carer and clinician can acknowledge the inconsistency of children’s movement, the impact of a busy life on the child’s ability to contribute to daily routines and discuss identifying or creating time and opportunity for new learning. Clinicians are skilled at

assessing and identifying the best capacity of children's motor ability. Clinicians may assess what the child can achieve in an optimal environment, and then work toward that goal through an intervention. For example, a child may learn to complete a sit to stand transfer with a chair at an ideal height, minimal distraction, one to one attention and praise, and a therapist with expertise in facilitating movement. The carer may observe that the child is getting stronger and more capable in this setting, but may not make the link to daily life. The child may be able to learn how to move between sitting and standing in a clinical setting but is then lifted in daily life as the carer is legitimately too busy and needs to achieve routines in the quickest and easiest way. The carer may or may not be able to fit an exercise program and into a busy life, may not have the right set up to optimise performance, and may also feel guilty when they take "short cuts" for example picking the child up out of bed every morning. The therapist and carer can use the diagram to optimise time for learning and practice. For example, the child can practice sit to stand in the school gym, during a therapy session and when visiting a well-known relative. The family may then be able to introduce a stand transfer to get into bed at night time, or in and out of their wheelchair on the weekend. They may still need to be lifted in the mornings, and when the family is in a hurry. The diagram can be used to identify when and where exercise and learning can be meaningfully integrated into tasks that occur daily to gradually build capacity over time.

The current research explicitly voiced carer and child experiences as the experts in their lives. This approach is consistent with a philosophy of building capacity within families (Dunst & Trivette, 2009). Carers and children at GMFCS IV and V access a range of services to support their child to optimise function across all domains of their life, including daily routines, and this is likely to include therapy, medical and community supports. Clinicians and therapists have a role to work alongside families to support them to come up with

solutions to issues in their daily life. The current research highlights the importance of understanding and analysing the performance of daily routines to link the subtle motor skills of children to function in daily life. This suggests that occupational therapists who have expertise in task analysis and assessing occupation performance, may have a useful and unique contribution in supporting children at GMFCS IV and V and their carers (Schell, Gillen, & Scaffa, 2014).

### **Directions for future research**

Results of this research provided preliminary data about the potential of skill development for children at GMFCS IV and V. Further information is required to assess and track the progression of skill development of children at GMFCS IV and V over time and how these movements may be useful in daily life. More information is required about interventions aiming to support the development of subtle abilities over time and build capacity in daily living transactions of children at GMFCS IV and V and their carers.

The patterns of how children at GMFCS IV and V function on the other cerebral palsy classifications systems requires further research to more robustly describe and highlight the broad array of abilities of these children. Children at GMFCS IV and V have been grouped for the purposes of this research, yet there are differences between the groups, some of which have been highlighted in this study. Looking at GMFCS alone however, only provides part of the picture. It could be useful to further group children at each GMFCS level and describe patterns of how they function on the other classification systems as well as presence of additional conditions. For example, there was a group of children in this research who functioned at level V on all cerebral palsy classification systems. These children may have goals about care and comfort, such treatments to reduce stiffness in a child's wrists and hands

to improve ease of dressing or accessing switch technology. Another group of children who were classified at level V on the GMFCS had varied abilities across the other classifications systems. Goals for this group could differ and could include using eye gaze, academic achievement, powered mobility, as well as increased independence in daily routines.

Further research is required to explore whether increasing child contribution to daily routines increases the ease of care during the routines from the perspective of the carer. This research highlighted that routines vary from day-to-day and that there are likely to be times and places when the child's contribution to daily routines are more helpful and disrupted times when child contributions are less helpful. Further exploration is required to understand the ratio of different types of routines, for example some families may have more tractor days/racing car days than others, or certain types of routines may occur more frequently at particular periods of a family's life. Interventions and supports can vary accordingly if we understand more.

How the diagram *Building capacity in daily routines* could be used and implemented into practice requires further work. Feedback from therapists, carers and children is required to develop the tool for use in clinical practice. Although the diagram aimed to explore some of the unique aspects of caring for a child with a movement disorder such as cerebral palsy, the themes could potentially relate to the different ways of negotiating daily family life for other groups of people.

### **What this research contributes**

This research contributed new knowledge and ideas, and poses questions that require further research. Findings from this research are summarised in the following points:



- Children at GMFCS IV and V can contribute useful actions during daily routines with a supportive carer and context.
- Children, and carers, use strategies to reduce the disruptive influence of whole-body movements. They do this to help organise the child's bodies to allow an child initiated active movement to take place, or to assist the carer to complete a movement for the child during daily routines. These whole-body movements may precede and relate to a child's ability to complete subtle motor actions that are useful during daily routines.
- Actions of children that can contribute to daily routines may be subtle, and potentially be overlooked.
- The child's perception of their ability to help may be just as important as their actual ability to perform tasks. Acknowledging intention and effort may be important for the dignity and ongoing learning across their lifespan.
- Children and carers work successfully together to complete daily routines. Building capacity in this important functional transaction should include consideration of the skills and capacity of the child, the needs and skills of the carer, the individualised contexts that include varying time pressures, within an overarching inconsistency of daily life.
- Children and carers were shown to negotiate daily routines in three ways at different times, a) the quickest and easiest way, b) times when it is slow and hard work, and c) and taking the opportunities to learn and change.
- Developing capacity in the transactions that occur in daily life between carers and children has the potential to enhance child contribution to daily routines and make daily routines easier for carers.

### **Conclusion**

Children at GMFCS IV and V and their carers have unique, compelling and variable stories. The current research was undertaken with an assumption that people with significant disabilities are active participants in life and have the capability to use skills that contribute positively to the completion of daily routines. Building expectation and capacity in children during daily routines is likely to have an impact on children's dignity and self-worth, carers understanding of what is possible, and assist to positively enhance the broader community understanding of the capabilities of people with disabilities.

Although children may be able to learn in the context of daily routines, carers of children live extremely busy lives. Daily routines are activities that need to be completed so that children and carers can focus on what is important to them in their broader worlds. There are aspects of life that children appear to be able to contribute to more easily, and other areas that require higher level skills. All children are different and understanding the layers of daily life creates the possibility to target skill development for each child. There is opportunity for most children at GMFCS IV and V to contribute daily life and it appears that these children are already doing so, although it is difficult to define and capture. Further research is required to substantiate these findings and implement practical tools to guide meaningful interventions for this cohort of children and their families.

This research aligns with other studies that are aiming to assess and document progression in the subtle but useful skills that children with complex cerebral palsy can learn. We did not aim to compare the sample to other children or to highlight the decrease in function that occurs with aging and increasing GMFCS level that is evident in the literature. Instead, the findings of this research may be used to guide the development of services and

tools that are practical, have the possibility of being incorporated into normal routines, and are relevant to the daily lives of children and carers. Ultimately, this research explored and highlighted what children at GMFCS IV and V can do, and what they are able to achieve with assistance, to be active participants in their daily lives.

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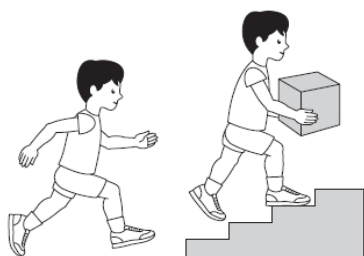
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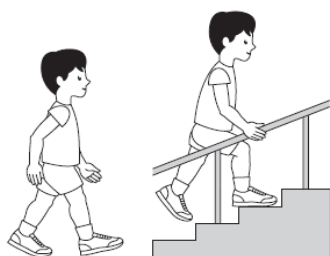


## APPENDICES

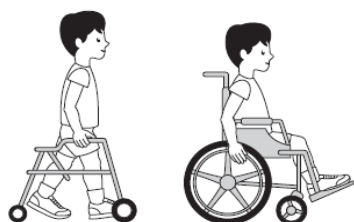
## Appendix A: Gross Motor Functional Classification System (Palisano et al., 1997)

GMFCS E & R between 6<sup>th</sup> and 12<sup>th</sup> birthday:  
Descriptors and illustrations**GMFCS Level I**

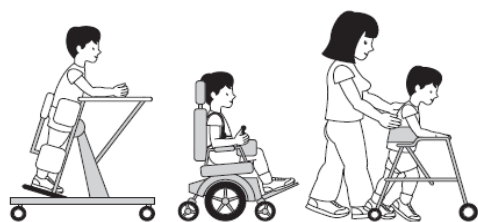
Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

**GMFCS Level II**

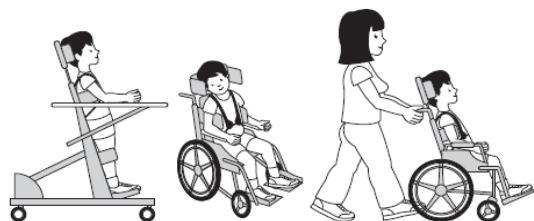
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

**GMFCS Level III**

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

**GMFCS Level IV**

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

**GMFCS Level V**

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

## Appendix B: Manual Ability Classification System (Eliasson et al., 2006)

# MACS

## What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

- I. **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.
- II. **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.
- III. **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.
- IV. **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.
- V. **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

### Distinctions between Levels I and II

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

### Distinctions between Levels II and III

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

### Distinctions between Levels III and IV

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

### Distinctions between Levels IV and V

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

Appendix C: Communication Functional Classification System (Hidecker et al., 2011)

## Communication Function Classification System (CFCs)

**I. Effective Sender and Receiver with unfamiliar and familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments. The communication occurs easily and at a **comfortable pace** with both **unfamiliar and familiar conversational partners**. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

**II. Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments, but the **conversational pace is slow** and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both **unfamiliar and familiar partners**.

**III. Effective Sender and Receiver with familiar partners.** The person **alternates between sender and receiver roles with familiar** (but not unfamiliar) conversational partners in most environments. Communication is **not consistently effective** with most **unfamiliar partners**, but is **usually effective** with **familiar partners**.

**IV. Inconsistent Sender and/or Receiver with familiar partners.** The person does **not** consistently alternate **sender and receiver** roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is **sometimes effective** with **familiar partners**.

**V. Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners**.

**Key**

P Person

U Unfamiliar Partner

F Familiar Partner

— Effective

•••• Less effective

**I.**

**II.**

**III.**

**IV.**

**V.**

The difference between Levels I and II is the **pace** of the conversation. In **Level I**, the person communicates at a **comfortable** pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. In **Level II**, the person **needs extra time** at least occasionally.

The differences between Levels II and III concern **pace and the type of conversational partners**. In **Level II**, the person is an effective sender and receiver with all conversational partners, but pace is an issue. In **Level III**, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.

The difference between Levels III and IV is **how consistently the person alternates between sender and receiver roles with familiar partners**. In **Level III**, the person is generally able to communicate with familiar partners as a sender *and* as a receiver. In **Level IV**, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.

The difference between Levels IV and V is the **degree of difficulty that the person has when communicating with familiar partners**. In **Level IV**, the person has some success as an effective sender and/or an effective receiver with familiar partners. In **Level V**, the person is rarely able to communicate effectively, even with familiar partners.

## Appendix D: Eating and Drinking Classification System (Sellers et al., 2014)

### 7 Eating and Drinking Ability Classification System

#### DESCRIPTIONS OF DIFFERENT LEVELS

##### Level I Eats and drinks safely and efficiently

- Eats a wide range of different texture foods that are age appropriate.
- May be challenged by some very firm bite and chew foods.
- Moves food from one side of the mouth to the other; may close lips whilst chewing.
- Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.
- May cough or gag for very challenging textures.
- Eats and drinks at a similar speed to peers.
- Retains most food or fluid in the mouth.
- Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.

**Distinctions between I and II:** Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.

##### Level II Eats and drinks safely but with some limitations to efficiency

- Eats a range of food textures that are age appropriate.
- Challenged by some firm bite, effortful chew, mixed and sticky textures.
- Moves food slowly from one side of the mouth to the other using the tongue.
- May chew with lips open.
- Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.
- Coughs or gags on new or challenging textures or when tiring.
- May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.
- May tire if textures challenging and mealtimes will take longer than for peers.
- Loses small amounts of food or fluid especially challenging textures.
- Some foods will collect on some tooth surfaces and between cheeks and gums.

**Distinctions between II and III:** Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

### Level III Eats and drinks with some limitations to safety; there may be limitations to efficiency

- Eats puree and mashed food and may bite and chew some soft chew food textures.
- Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.
- It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.
- Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.
- May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.
- May drink thickened fluids more easily than thin and may need time between sips.
- May choose to drink only in certain situations such as with a trusted carer or with no distractions.
- Specific food textures and positioning of food in mouth are required to reduce the risk of choking.
- May cough or aspirate if fluid is fast flowing or large quantity taken in the mouth.
- May tire whilst eating if food requires chewing and mealtimes will be prolonged.
- Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums.

**Distinctions between III and IV:** Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to a number of different factors to swallow food and drink safely because of the significant aspiration and choking risk.

### Level IV Eats and drinks with significant limitations to safety

- Eats smooth purees or well mashed food.
- Challenged by food that requires chewing; choking may occur if lumps are eaten.
- May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
- It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
- May swallow lumps whole.

## 9 Eating and Drinking Ability Classification System

- May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.
- May choose not to drink fluids or to drink only in certain situations such as with trusted carer.
- Likely to need time between mouthfuls to swallow repeatedly before continuing.
- Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.
- May tire whilst eating and mealtimes are likely to be prolonged.
- Significant food and fluid loss from the mouth.
- Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.
- Supplementary tube feeding may be considered.

**Distinctions between IV and V:** Individuals at Level IV are able to swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely so that taking food or drink in to their mouths will cause harm.

### **Level V** Unable to eat or drink safely – tube feeding may be considered to provide nutrition

- May manage very small tastes or flavours.
- Ability to manage small tastes and flavours will be affected by positioning, personal factors and environmental features.
- Unable to swallow food or drink safely due to limitations to the range and co-ordination of movement for swallowing and breathing.
- It is likely to be challenging to control mouth opening and tongue movement.
- Aspiration and choking are very likely.
- Harm from aspiration is evident.
- May require suction or medication to keep airway clear of secretions.
- Alternative means of providing nutrition such as tube feeding may be considered.

**Appendix E: Ethics approval form**

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Human Research Ethics Committee  
**Approval Form**

<b>Principal Investigator/Supervisor:</b> Prof Christine Imms, Dr Loretta Sheppard, Dr Susan Greaves
<b>Co-Investigators:</b>
<b>Student Researcher:</b> Robyn Heesh (HDR Student)

<b>Ethics approval has been granted for the following project:</b> Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy.
<b>for the period:</b> 24/07/2018
<b>Human Research Ethics Committee (HREC) Register Number:</b> 2016-112H

This is to certify that the above application has been reviewed by the Australian Catholic University Human Research Ethics Committee (ACU HREC). The application has been approved for the period given above.

Researchers are responsible for ensuring that all conditions of approval are adhered to, that they seek prior approval for any modifications and that they notify the HREC of any incidents or unexpected issues impacting on participants that arise in the course of their research. Researchers are also responsible for ensuring that they adhere to the requirements of the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research* and the University's *Code of Conduct*.

Any queries relating to this application should be directed to the Manager, Research Ethics and Integrity ([resethics.manager@acu.edu.au](mailto:resethics.manager@acu.edu.au)).

Kind regards

A handwritten signature in black ink, appearing to be a stylized cursive name.

Manager, Research Ethics and Integrity  
Date 22 06 2018

**Research Ethics | Office of the Deputy Vice-Chancellor (Research)**  
Australian Catholic University  
T: +61 2 9739 2646  
E: [Res.Ethics@acu.edu.au](mailto:Res.Ethics@acu.edu.au)  
W: [ACU Research Ethics](#)

**Appendix F: Participant information form****PARTICIPANT INFORMATION LETTER**

**PROJECT TITLE:** Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy.

**PRINCIPAL INVESTIGATOR:** Robyn Heesh

**STUDENT'S DEGREE:** Masters of Health Science Research

Dear Participant,

You are invited to take part in a research project because you are a parent/carer of a child who is aged between 5 and 18 years, lives in Victoria and has cerebral palsy. Additionally, your child uses a wheelchair as their main type of mobility: i.e., is classified as a level IV or V on the Gross Motor Functional Classification System (GMFCS\*\*).

*\*\*Definition of GMFCS (Gross Motor Function Classification System): Functional outcomes for children with Cerebral Palsy vary considerably and can be described using classification systems in the domains of mobility, hand use, eating and communication. The Gross Motor Function Classification System (GMFCS) has five levels describing the daily mobility of children with cerebral palsy (Palisano, Rosenbaum, Russell, Walter, Wood, Raina & Galuppi, 2000). Children at level I and II walk independently, Children at level III use a walking aid, and child at IV and V use a wheelchair as their main form of mobility.*

***What is the project about?***

Daily routines can be difficult, and some children with cerebral palsy may always need assistance from a carer. We are interested in learning about, and describing how, carers and children work together in daily routines. This project will also explore whether there are useful skills that carers and children can learn to enhance a child's independence and make daily routines easier for the child and the carer.

The project has two studies. The first study will identify daily routines that families find important and challenging through a survey. This survey will also collect information to understand the abilities of the children and the health and well-being of the carers. The way children and carers work together in daily routines will be described further in a second study. This second study will use videos and interviews with a small number of participants.

***Who is undertaking the project?***

This project is being conducted by Robyn Heesh who is a qualified occupational therapist (Bachelor of Occupational Therapy). Robyn has 20 years of experience working with children with cerebral palsy and their families. She has worked in schools, community rehabilitation settings, hospitals and early interventions settings. This projects is being done as part of Robyn's Masters of Health Science



Research at Australian Catholic University (ACU), supervised by Prof Christine Imms, Dr Lorretta Sheppard and Dr Susan Greaves.

***What will I be asked to do?***

This project involves two studies. You can be involved in the first study only and choose not to be in the second study. You can only be in study two if you have been involved in study one first.

**Study one**

*A survey will be posted to you. You will be asked to fill it out and return it in a prepaid envelope.*

*The survey will include*

- Questions about you and your overall health and well-being.
- Information about your child's abilities. You will be asked to answer questions about your child's hand use, eating and drinking, communication and gross motor function.
- A questionnaire about daily living routines called the CPCHILD. This will ask you to rate the importance of daily routines to your child's quality of life. It will ask you how difficult daily routines are and how much assistance your child requires.
- You will be asked if you think your child is able to and/or would like to fill out a questionnaire (CPCHILD- Child Report).
- You may need to assist your child to complete the questionnaire if they need help.

*After you have completed the survey.*

- You can return the survey in the post in a prepaid envelope
- It is easy to sometimes miss pages or questions. You may be phoned after you post it back and we will ask you any questions you might have missed.
- You may be phoned or emailed to remind you to return your survey

In addition to completing the survey, you will be asked whether you agree to be contacted for further involvement in a second study.

**If you say yes**, you may be contacted and be invited to participate in a second study. Only about six people with CP and their carers will be in the second study.

**Study two**

If you have said you want to take part in study two, the researcher will ring you first. We will talk to you more about what is involved and make a time that suits you to come and visit you in your home. The researcher will film you and your child completing a daily living routine of your choice.

At a second appointment, you, your child and the researcher will watch the film together and talk about it. This will be recorded. The researcher will ask you questions about what you are doing and what your carer is doing on the video. What you and the researcher have talked about will be then turned into a written text. You will have the chance to check the written text to make sure you are happy with what was said.

We would like to understand the views of your child if possible. However, you can decide if your child is able to or wants to watch and talk about the video with the researcher. If your child isn't involved, the researcher will just talk to you instead.

***Are there any risks associated with participating in this project?***

We don't think that there are any risks to taking part in this project, however you may like to think about the following.

**Study one**

You will be asked questions about how you help your child wash, go to the toilet and get dressed. It will also include questions about you and your general health and well-being. If this makes you feel uncomfortable, you don't have to complete the survey.

The survey will take about 40 minutes for you to complete. If your child chooses to complete the questionnaire and has complex communication needs, this may take more time.

**Study two**

We would like to film you in your home as this where many daily routines take place. You will decide what daily routine you would like to do and where it will happen. You can talk about this with the researcher.

Routines of toileting, showering and dressing will be changed to respect the privacy of the child. For example, we would film your child removing an outer layer of clothing with other clothes underneath or transferring to a shower chair with bathers on. You can decide how this will happen.

The researcher does not want to change or judge what you do. We want to try to record and describe what actually occurs in your life on a daily basis. We know that by being there and filming, we might change what you actually do, but this is not our intention. We are interested in what actually happens for you day to day. Nothing you do will be judged as right or wrong. The researcher will not be offering an intervention.

***How much time will the project take?*****Study one**

40 minutes for you to fill out the survey and about 20 minutes for your child to fill out their survey. It might take more time to help your child if they have complex communication needs.

**Study two**

A home visit of one hour, and a follow up interview of one hour.

***What are the benefits of the research project?***

There is no direct benefit to you from taking part in this project.

You will be helping people like therapists and doctors to further understand what it is like to have a child cerebral palsy and what you do in your daily life. This may help to improve how therapy and support is provided to children with cerebral palsy and their carers.

***Can I withdraw from the project?***

It is your decision to take part in this project. If you agree to be involved, you can also change your mind and withdraw without having to give a reason.

Once you have posted back your survey, and your survey is checked to be complete, you will have two weeks to let us know you want to withdraw. *If you choose to withdraw before this time, we will shred your survey and the information will not be used. You will be told when we have done this.*

***Will anyone else know the results of the project?***

The researcher will write about the results of the project and publish them in a journal and present them at conferences. No one will be able to tell who you are. If you are involved in study two, your comments and views may be reported under a made-up name.

The information collected from the surveys may be used in future research. This will only occur with further ethical approval and only information that does not identify you would be used. Results from your survey may be reported on and used for further studies.

***Will I be able to find out the results of the project?***

A summary of the results will be sent to participants at the end of the project.

***Who do I contact if I have questions about the project?***

Participants can contact Robyn Heesh [robyn.heesh@myacu.edu.au](mailto:robyn.heesh@myacu.edu.au) or 0478 701424 if they have any questions about the project.

***What if I have a complaint or any concerns?***

The project has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2016 112H). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics  
c/o Office of the Deputy Vice Chancellor (Research)  
Australian Catholic University, North Sydney Campus  
PO Box 968, NORTH SYDNEY, NSW 2059  
Ph.: 02 9739 2519 Fax: 02 9739 2870 Email: [resethics.manager@acu.edu.au](mailto:resethics.manager@acu.edu.au)

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

***I want to participate! How do I sign up?***

Please sign both copies of the form and return by post / email [robyn.heesh@myacu.edu.au](mailto:robyn.heesh@myacu.edu.au) or phone 0478 701 424.

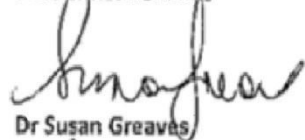
Yours sincerely,



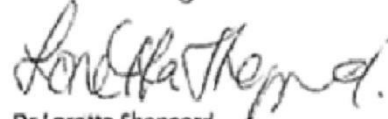
**Robyn Heesh**  
Researcher/ Occupational Therapist



Prof Christine Imms



Dr Susan Greaves



Dr Loretta Sheppard

Appendix G: Consent form Study 1



CONSENT FORM- Study 1
Copy for Participant to Keep

TITLE OF PROJECT: Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy.

STUDENT INVESTIGATOR: Robyn Heesh

SUPERVISORS: Prof. Christine Imms, Dr. Loretta Sheppard and Dr. Susan Greaves

I ..... (the participant) have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction.

I agree to participate in the following activities. (Please tick)

- Fill out and return a survey that takes about 40 minutes
Assist my child to fill out a questionnaire (if applicable)
To be contacted to follow up any missing or incomplete information by phone or email.

I realise that I can withdraw my consent at any time. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT:.....

SIGNATURE:..... DATE .....

SIGNATURE OF PRINCIPAL INVESTIGATOR:.....DATE.....

If you do not wish to be involved in this study, please email robyn.heesh@myacu.edu.au or phone/text 0478 701 424 or return this consent form with the package in the reply-paid envelope so that we know not to contact you any further.

I ..... (the participant) do not want to be involved in this study and do not want any further contact from the researcher for this project.

NAME OF PARTICIPANT:.....

SIGNATURE:.....DATE:.....




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**PARENT/GUARDIAN CONSENT FORM- Study 1**

*Copy for Participant to Keep*

**TITLE OF PROJECT:** Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy

**STUDENT INVESTIGATOR:** Robyn Heesh

**SUPERVISORS:** Prof. Christine Imms, Dr. Loretta Sheppard and Dr. Susan Greaves

I ..... (*the parent/guardian*) have read and understood the information provided in the Letter to the Participants. Any questions I have asked have been answered to my satisfaction. I agree **that my child, nominated below, may participate** in completing this survey realising that I can withdraw my consent without having to give reason. I agree that research data collected for the study may be published or may be provided to other researchers in a form that does not identify my child in any way.

NAME OF PARENT/GUARDIAN:.....

SIGNATURE:.....DATE:.....

NAME OF CHILD: .....

SIGNATURE OF PRINCIPAL INVESTIGATOR:.....DATE:.....

**ASSENT OF PARTICIPANTS AGED UNDER 18 YEARS**

I ..... (*the participant aged under 18 years*) understand what this research project is designed to explore how people with cerebral palsy and their carers complete daily routines. What I will be asked to do has been explained to me. I agree to take part in completing this survey, realising that I can withdraw without having to give a reason.

NAME OF PARTICIPANT AGED UNDER 18:.....

SIGNATURE:.....DATE:.....

SIGNATURE OF PRINCIPAL INVESTIGATOR :.....DATE:.....

**Appendix H: Survey booklet****Questionnaire for Carers**

**Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy.**

Thank you for agreeing to take part in this study!

This questionnaire will take about 40 minutes to complete. Most of the questions ask you to tick boxes. Your answers will help us understand how children who have cerebral palsy and their carers complete daily living routines.

It is easy to accidentally skip a question or a page. Please check over the survey once you have completed it to make sure this has not happened.

**If you would like some help to complete the questionnaire, please phone Robyn Heesh on 0478 701 424 or contact me at [robyn.heesh@myacu.edu.au](mailto:robyn.heesh@myacu.edu.au)**

Date Questionnaire completed \_\_\_\_\_

Who completed this questionnaire?

- Parent
- Guardian
- Other (please explain) \_\_\_\_\_

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## Questions about your child

1. Name of child \_\_\_\_\_
2. Child's address \_\_\_\_\_
3. Child's weight \_\_\_\_\_ and height \_\_\_\_\_
4. How your child's cerebral palsy (CP) presents is often described in two ways; the parts of the body that are affected (Hemiplegia/unilateral, diplegia, quadriplegia) AND the difficulty they have moving their body.

a. What type of CP does your child have (please tick)

- Hemiplegia/Unilateral (either left or right side is affected)
- Diplegia (Legs more affected than arms)
- Quadriplegia (both arms and legs affected)
- Don't know

b. What type of difficulty does your child have when they try to move?

- Spasticity (arm/s or leg/s tend to be stiff or rigid)
- Dystonia (arm/s or leg/s move involuntarily)
- Ataxia (arm/s or leg/s have tremors or shake)
- Hypotonia (body floppy or weak)
- Don't know

5. Does your child have additional conditions that may impact their abilities in daily routines?  
( please tick all that apply)

- Intellectual impairment ( this is usually described in relation to having low scores on IQ test)
- Learning disability (difficulty with some aspects of learning, for example, a specific reading difficulty)
- Visual Impairment
- Hearing Impairment
- Epilepsy
- Don't know

Other, please explain...

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**USING HANDS FOR AGE APPROPRIATE ACTIVITIES**

6. Please read the Manual Ability Classification System (MACS) information on the next page.

After you have read the information and the levels describing manual ability, **please tick only ONE** box on this page beside the description that best represents your child's ability to handle objects in everyday life.

- Level I      Handles objects easily and successfully
- Level II      Handles most objects, but with somewhat reduced quality and/or speed
- Level III      Handles objects with difficulty; needs help to prepare and/or modify activities
- Level IV      Handles a limited selection of easily managed objects in adapted situations
- Level V      Does not handle objects and has limited ability to perform even simple actions



Want to read more about the MACS?  
<http://www.macs.nu>

# MACS

## What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

- I. **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.
- II. **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.
- III. **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.
- IV. **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.
- V. **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

### Distinctions between Levels I and II

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

### Distinctions between Levels II and III

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

### Distinctions between Levels III and IV

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

### Distinctions between Levels IV and V

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

**MOVEMENT**

7. The Gross Motor Functional Classification System (GMFCS) describes the daily mobility of children with cerebral palsy.

**If your child is 6-11 years old**

Please read the GMFCS E&R between 6 and 12 birthday: Descriptors and illustrations on the next page.

**If your child is 12-18 years old**

Please read the GMFCS E&R between 6 and 12 birthday: Descriptors and illustrations on the following page.

After you have read the information and each level, for your child's age, please **tick only ONE** box on this page beside the description that best represents your child's movement abilities.

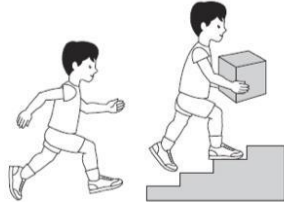
- Level I Walks on their own, can go up and down stairs without holding rail
- Level II Walks on their own, needs to hold rail up or down stairs
- Level III Can stand on their own, but needs a walking aid to walk
- Level IV Can sit on their own, but needs significant support to stand and walk
- Level V Needs support to sit. Needs to be lifted by another person to move



Want to know more about the GMFCS?

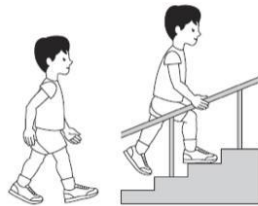
<https://www.canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r>

## GMFCS E & R between 6<sup>th</sup> and 12<sup>th</sup> birthday: Descriptors and illustrations



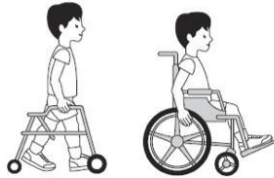
### GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



### GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



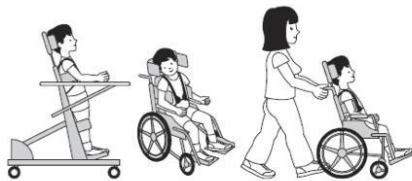
### GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



### GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



### GMFCS Level V

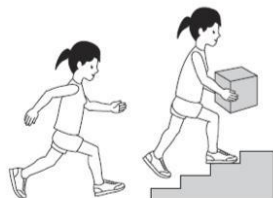
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,  
The Royal Children's Hospital Melbourne ERC151050

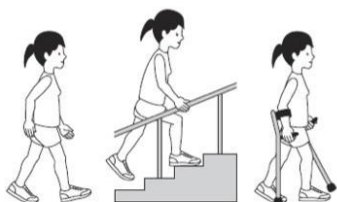
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## GMFCS E & R between 12<sup>th</sup> and 18<sup>th</sup> birthday: Descriptors and illustrations



### GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.



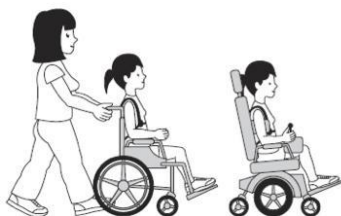
### GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.



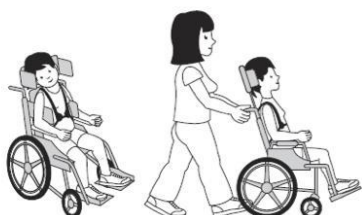
### GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.



### GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.



### GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

GMFCS descriptors: Palsano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,  
The Royal Children's Hospital, Melbourne ERC151050

**COMMUNICATION**

8. Please read the following descriptions of communication abilities from the Communication Functional Classification System (CFCS).

After you read the information and each level, please **tick only ONE** box on this page that best describes your child's ability to communicate as a receiver and a sender.

- Level I    Effective Sender and receiver with unfamiliar and familiar partners
- Level II    Effective but slower paced sender and receiver with unfamiliar and familiar partners
- Level III    Effective sender and receiver with familiar partners
- Level IV    Inconsistent Sender and/or receiver with familiar partners
- Level V    Seldom effective sender and receiver with familiar partners



Want to read more about the CFCS?

[http://cfcs.us/wp-content/uploads/2014/02/CFCS\\_English\\_2011\\_09\\_01.pdf](http://cfcs.us/wp-content/uploads/2014/02/CFCS_English_2011_09_01.pdf)

## Communication Function Classification System (CFCs)



**I. Effective Sender and Receiver with unfamiliar and familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments. The communication occurs easily and at a **comfortable pace** with both **unfamiliar and familiar conversational partners**. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

**II. Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.** The person independently **alternates between sender and receiver** roles with most people in most environments, but the **conversational pace is slow** and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both **unfamiliar and familiar partners**.

**III. Effective Sender and Receiver with familiar partners.** The person **alternates between sender and receiver** roles with **familiar** (but not unfamiliar) conversational partners in most environments. Communication is **not consistently effective** with most **unfamiliar partners**, but is **usually effective** with **familiar partners**.

**IV. Inconsistent Sender and/or Receiver with familiar partners.** The person does **not** consistently alternate **sender and receiver** roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is **sometimes effective** with **familiar partners**.

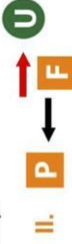
**V. Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners**.

Key	
P	Person
U	Unfamiliar Partner
F	Familiar Partner
→	Effective
••••	Less effective



I.

The difference between Levels I and II is the **pace** of the conversation. In **Level I**, the person communicates at a **comfortable** pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. In **Level II**, the person **needs extra time** at least occasionally.



II.

The differences between Levels II and III concern **pace and the type of conversational partners**. In **Level II**, the person is an effective sender and receiver with all conversational partners, but **pace** is an issue. In **Level III**, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.



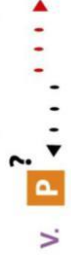
III.

The difference between Levels III and IV is **how consistently the person alternates between sender and receiver roles with familiar partners**. In **Level III**, the person is generally able to communicate with familiar partners as a sender *and* as a receiver. In **Level IV**, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.



IV.

The difference between Levels IV and V is the **degree of difficulty that the person has when communicating with familiar partners**. In **Level IV**, the person has some success as an effective sender and/or an effective receiver with familiar partners. In **Level V**, the person is rarely able to communicate effectively, even with familiar partners.



V.



3



**EATING AND DRINKING**

9. Please read the descriptions from the Eating and Drinking Ability Classification System (EDACS) on the following three pages.

After you read each the information and each section, please **tick only ONE** box on this page that best describes your child's ability to eat and drink.

- Level I Eats and drinks safely and efficiently
- Level II Eats and drinks safely but with some limitations to efficiency
- Level III Eats and drinks with some limitations to safety: there may be some limitations to efficiency
- Level IV Eats and drinks with significant limitations to safety
- Level V Unable to eat or drink safely - tube feeding may be considered to provide nutrition



Want to find out more about the EDACS?

<http://www.sussexcommunity.nhs.uk>

## DESCRIPTIONS OF DIFFERENT LEVELS

### Level I Eats and drinks safely and efficiently

- Eats a wide range of different texture foods that are age appropriate.
- May be challenged by some very firm bite and chew foods.
- Moves food from one side of the mouth to the other; may close lips whilst chewing.
- Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.
- May cough or gag for very challenging textures.
- Eats and drinks at a similar speed to peers.
- Retains most food or fluid in the mouth.
- Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.

**Distinctions between I and II:** Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.

### Level II Eats and drinks safely but with some limitations to efficiency

- Eats a range of food textures that are age appropriate.
- Challenged by some firm bite, effortful chew, mixed and sticky textures.
- Moves food slowly from one side of the mouth to the other using the tongue.
- May chew with lips open.
- Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.
- Coughs or gags on new or challenging textures or when tiring.
- May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.
- May tire if textures challenging and mealtimes will take longer than for peers.
- Loses small amounts of food or fluid especially challenging textures.
- Some foods will collect on some tooth surfaces and between cheeks and gums.

**Distinctions between II and III:** Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

### Level III Eats and drinks with some limitations to safety; there may be limitations to efficiency

- Eats puree and mashed food and may bite and chew some soft chew food textures.
- Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.
- It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.
- Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.
- May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.
- May drink thickened fluids more easily than thin and may need time between sips.
- May choose to drink only in certain situations such as with a trusted carer or with no distractions.
- Specific food textures and positioning of food in mouth are required to reduce the risk of choking.
- May cough or aspirate if fluid is fast flowing or large quantity taken in the mouth.
- May tire whilst eating if food requires chewing and mealtimes will be prolonged.
- Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums.

**Distinctions between III and IV:** Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to a number of different factors to swallow food and drink safely because of the significant aspiration and choking risk.

### Level IV Eats and drinks with significant limitations to safety

- Eats smooth purees or well mashed food.
- Challenged by food that requires chewing; choking may occur if lumps are eaten.
- May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
- It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
- May swallow lumps whole.

## 9 Eating and Drinking Ability Classification System

- May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.
- May choose not to drink fluids or to drink only in certain situations such as with trusted carer.
- Likely to need time between mouthfuls to swallow repeatedly before continuing.
- Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.
- May tire whilst eating and mealtimes are likely to be prolonged.
- Significant food and fluid loss from the mouth.
- Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.
- Supplementary tube feeding may be considered.

**Distinctions between IV and V:** Individuals at Level IV are able to swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely so that taking food or drink in to their mouths will cause harm.

**Level V** Unable to eat or drink safely – tube feeding may be considered to provide nutrition

- May manage very small tastes or flavours.
- Ability to manage small tastes and flavours will be affected by positioning, personal factors and environmental features.
- Unable to swallow food or drink safely due to limitations to the range and co-ordination of movement for swallowing and breathing.
- It is likely to be challenging to control mouth opening and tongue movement.
- Aspiration and choking are very likely.
- Harm from aspiration is evident.
- May require suction or medication to keep airway clear of secretions.
- Alternative means of providing nutrition such as tube feeding may be considered.

## Information about you

As a primary carer of a child with CP, we are interested in understanding more about your health and well-being. Please tick the boxes that best describes your experience and opinion.

In general, would you say your health is..?

Excellent	Very Good	Good	Fair	Poor
-----------	-----------	------	------	------

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

In general would you say your quality of life is..?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

In general, how would you rate your mental health, including your mood and your ability to think..?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

In general, how would you rate your satisfaction with your social activities and relationships..?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

In general, please rate how well you carry out your usual social activities and roles. This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend etc.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Completely	Mostly	Moderately	A little	Not at all
------------	--------	------------	----------	------------

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Never	Rarely	Sometimes	Often	Always
-------	--------	-----------	-------	--------

How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

None	Mild	Moderate	Severe	Very Severe
------	------	----------	--------	-------------

How would you rate your fatigue on average?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

How would you rate your pain on average?

Please circle the number that best describes your pain level

0	1	2	3	4	5	6	7	8	9	10
No pain										Worst possible pain

## Questions about you, your child and your daily routines

We would like to include the views of young people with cerebral palsy when possible.

Is your child... *(please circle)*

Aged 8-18 years old?	YES	NO
Willing and/or interested in participating	YES	NO
Able to understand the questions included in the questionnaire?	YES	NO
Able to express their views and score the questionnaire on their own?	YES	NO
Able to express their views and score the questionnaire with assistance? If Yes, what assistance do they require. <i>(Please tick)</i>	YES	NO

- Having the questionnaire read aloud
- Pointing to the numbers
- Use of a communication system eg PODD book, electronic communication device
- Other means – Please explain

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**If you answered NO to any of the above questions**, your child may not be able or willing to participate. You can now continue on to the next page to complete the **CPCHILD Carer report**. Please read the instructions on the next page carefully first.

**If you answered YES to all of the above questions**, your child is able to participate by filling in the **CPCHILD Child report**.

This is the same questionnaire that you are about to complete, in a child or young person version. It is included separately in your package.

If your child requires assistance, you may like to finish your questionnaire and then assist your child afterwards.

Please continue on to the next page to complete the **CPCHILD Carer report**.

**CPCHILD®**  
**Caregiver Priorities & Child Health Index of Life with Disabilities**

**Instructions**

1. This questionnaire is about your child’s health, comfort and well being, and about caring for his/her needs.
2. Please read the instructions carefully.
3. Please answer all questions by circling the number that fits best. You may write down any comments/clarifications in the space provided below each question.

**For example:**

						LEVEL OF ASSISTANCE					
Consider how each of the following activities is <b>usually</b> performed by/for your child.						T O T A L	M O D E R A T E	M I N I M A L	S U P E R V I S E D	I N D E P E N D E N T	
Rate how <b>difficult</b> each of these activities were in the past 2 weeks, <b>and</b> choose the <b>level of assistance</b> that was required to help your child perform these activities.											
During the <b>past 2 weeks</b> , how difficult was the following:	<i>Not Possible</i> <small>(Almost Impossible)</small>	<i>Very Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>No problem at all</i>						
<b>1. putting on / wearing footwear? (socks, shoes, braces, etc.)</b>	0	1	2	3	4	5	6	0	1	2	3

In the above example, the task of putting on / wearing footwear was rated as *very easy*, **and** the child required a *minimal / supervised* level of assistance to put on footwear.

4. At the end of each section there is space for you to add any items that you think are missing from the questionnaire, which you believe are important to your child’s health, comfort and well being.



Want to read more about the CPCHILD?  
<http://www.sickkids.ca/Research/CPCHILD-Questionnaire>

SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING								LEVEL OF ASSISTANCE				
Consider how each of the following activities is <b>usually</b> performed by/for your child. Rate how <b>difficult</b> each of these activities were in the past 2 weeks, <b>and</b> choose the <b>level of assistance</b> that was required to help your child perform these activities.								T O T A L	M O D E R A T E	M I N I M A L /	S U P E R V I S E D	I N D E P E N D E N T
During the past 2 weeks, how difficult was the following:	Not Possible (Almost Impossible)	Very Difficult	Slightly Difficult	Easy	Very Easy	No problem at all						
1. eating/drinking or being fed? (in the usual way that it is done i.e. orally <u>or</u> by tube <u>or</u> both)	0	1	2	3	4	5	6	0	1	2	3	
2. maintaining oral hygiene? (keeping mouth and teeth clean)	0	1	2	3	4	5	6	0	1	2	3	
3. bathing / washing?	0	1	2	3	4	5	6	0	1	2	3	
4. toileting activities? (bladder & bowel function, hygiene etc.)	0	1	2	3	4	5	6	0	1	2	3	
5. changing diapers/underwear?	0	1	2	3	4	5	6	0	1	2	3	
6. putting on/taking off upper body clothing ? (shirt, jacket, etc.)	0	1	2	3	4	5	6	0	1	2	3	
7. putting on/taking off lower body clothing ? (pants, sweats, etc.)	0	1	2	3	4	5	6	0	1	2	3	
8. putting on/wearing footwear? (socks, shoes, braces, etc.)	0	1	2	3	4	5	6	0	1	2	3	
9. hair care (washing, drying, brushing/combing, braiding, etc.)	0	1	2	3	4	5	6	0	1	2	3	
1A. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3	
1B. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3	



**SECTION 2: POSITIONING, TRANSFERRING & MOBILITY**

								LEVEL OF ASSISTANCE				
Consider how each of the following activities is <b>usually</b> performed by/for your child. Rate how <b>difficult</b> each of these activities were in the past 2 weeks, <b>and</b> choose the <b>level of assistance</b> that was required to help your child perform these activities.								T O T A L	M O D E R A T E	M I N I M A L	S U P E R V I S E L E	I N D E P E N D E N T
During the <b>past 2 weeks</b> , how difficult was:	<i>Not Possible</i> <i>(Almost Impossible)</i>	<i>Very Difficult</i>	<i>Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>No problem at all</i>					
<b>10. getting in and out of bed?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>11. transferring into/out of a wheelchair/chair?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>12. sitting in a wheelchair/chair?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>13. standing for exercise/transfers?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>14. moving about in the home? (in whatever way possible)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>15. moving about outdoors? (in whatever way possible)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>16. getting in and out of a motor vehicle? (car, van or bus)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>17. visiting public places? (park, theatre, sightseeing, etc)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>2A. other activity?</b> Specify: _____	0	1	2	3	4	5	6	0	1	2	3	
<b>2B. other activity?</b> Specify: _____	0	1	2	3	4	5	6	0	1	2	3	

**SECTION 3: COMFORT & EMOTIONS**

<b>During the <u>past 2 weeks</u>, how often did your child experience pain or discomfort</b>							INTENSITY			
	<i>Every day</i>	<i>Very Often</i>	<i>Fairly Often</i>	<i>A few times</i>	<i>Once or twice</i>	<i>None of the time</i>	S E V E R E	M O D E R A T E	M I L D	N O N E
18. while eating/drinking or being fed?	0	1	2	3	4	5	0	1	2	3
19. during toileting? (bladder & bowel function, hygiene, diapering, etc.)	0	1	2	3	4	5	0	1	2	3
20. while dressing/undressing?	0	1	2	3	4	5	0	1	2	3
21. during transfers or position changes?	0	1	2	3	4	5	0	1	2	3
22. while seated?	0	1	2	3	4	5	0	1	2	3
23. while lying down in bed?	0	1	2	3	4	5	0	1	2	3
24. that disturbed your child's sleep?	0	1	2	3	4	5	0	1	2	3
3A. during other activity? Specify: _____	0	1	2	3	4	5	0	1	2	3
3B. during other activity? Specify: _____	0	1	2	3	4	5	0	1	2	3
<b>During the <u>past 2 weeks</u>, how often was your child</b>										
25. agitated, upset, or angry?	0	1	2	3	4	5	0	1	2	3
26. unhappy or sad?	0	1	2	3	4	5	0	1	2	3

**SECTION 4: COMMUNICATION & SOCIAL INTERACTION**

Consider how each of the following activities is **usually** performed by/for your child.  
 Rate how **difficult** each of these activities were in the past 2 weeks.

<b>During the <u>past 2 weeks</u>, how much difficulty did your child have</b>	<i>Not Possible</i>						<i>No</i>	
	<i>(Almost Impossible)</i>	<i>Very Difficult</i>	<i>Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>problem at all</i>	
	0	1	2	3	4	5	6	
27. understanding you? _____								
28. being understood by you? _____								
29. communicating with those who don't know your child well? _____								
30. playing alone? _____								
31. playing with others? _____								
32. attending school/child care? _____								
33. participating in recreational activities (swimming, interacting with family and friends, etc.)? _____								
4A. other social activity? Specify: _____ _____								
4B. other social activity? Specify: _____ _____								

**SECTION 5: HEALTH**

In the past 2 weeks	<i>Please circle the option that fits best</i>					
<b>34. How many times has your child had to visit the doctor or the hospital?</b>	<i>Admitted &gt;7 days</i>	<i>Admitted &lt; 7 days</i>	<i>3 or more times</i>	<i>Twice</i>	<i>Once</i>	<i>None</i>
<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
<b>35. How would you rate your child's overall health?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**36. List the medications your child has been taking in the last 2 weeks**

**0. No medications**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_

**SECTION 6: YOUR CHILD'S OVERALL QUALITY OF LIFE**

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
<b>37. How would you rate your child's overall quality of life?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

SECTION 7: IMPORTANCE OF ITEMS TO YOUR CHILD'S QUALITY OF LIFE						
How importantly do you think your child's current status with each item contributes towards his/her quality of life?	Least Important	Not Very Important	Slightly Important	Fairly Important	Very Important	Most Important
1. Eating / drinking or being fed	0	1	2	3	4	5
2. Maintaining oral hygiene	0	1	2	3	4	5
3. Bathing / washing	0	1	2	3	4	5
4. Toileting activities / hygiene	0	1	2	3	4	5
5. Changing diapers / underwear	0	1	2	3	4	5
6. Putting on/taking off upper clothing	0	1	2	3	4	5
7. Putting on/taking off lower clothing	0	1	2	3	4	5
8. Putting on / wearing footwear	0	1	2	3	4	5
9. Hair care / grooming	0	1	2	3	4	5
10. Getting in and out of bed	0	1	2	3	4	5
11. Transferring into / out of a wheelchair / chair	0	1	2	3	4	5
12. Sitting in a wheelchair / chair	0	1	2	3	4	5
13. Standing for exercise / transfers	0	1	2	3	4	5
14. Moving about indoors	0	1	2	3	4	5
15. Moving about outdoors	0	1	2	3	4	5
16. Getting in / out of a motor vehicle	0	1	2	3	4	5
17. Visiting public places	0	1	2	3	4	5
18. Comfort while feeding	0	1	2	3	4	5
19. Comfort during toileting activities	0	1	2	3	4	5
20. Comfort while dressing /undressing	0	1	2	3	4	5
21. Comfort during transfers or position changes	0	1	2	3	4	5
22. Comfort while sitting	0	1	2	3	4	5
23. Comfort while lying down	0	1	2	3	4	5
24. Comfort while sleeping	0	1	2	3	4	5
25. Emotional state or behavior	0	1	2	3	4	5
26. Happiness	0	1	2	3	4	5
27. Able to understand you	0	1	2	3	4	5
28. Able to be understood by you	0	1	2	3	4	5
29. Able to communicate with others	0	1	2	3	4	5
30. Able to play alone	0	1	2	3	4	5
31. Able to play with others	0	1	2	3	4	5
32. Able to attend school / child care	0	1	2	3	4	5
33. Able to participate in recreational activities	0	1	2	3	4	5
34. Minimizing doctor visits and hospitalization	0	1	2	3	4	5
35. Overall health	0	1	2	3	4	5
36. Minimizing number of medications	0	1	2	3	4	5

**SECTION 8: FACTS ABOUT YOUR CHILD**

<b>1. My child is a:</b>	<input type="checkbox"/> Male <input type="checkbox"/> Female
<b>2. What is your child's date of birth?</b>	____ / ____ / ____ Month    Day    Year
<b>3. What is the <u>highest</u> school grade your child has completed? (check only one grade)</b>	Preschool    ____ Kindergarten ____ 1 <sup>st</sup> Grade    ____ 2 <sup>nd</sup> Grade    ____ 3 <sup>rd</sup> Grade    ____ 4 <sup>th</sup> Grade    ____ 5 <sup>th</sup> Grade    ____ 6 <sup>th</sup> Grade    ____ 7 <sup>th</sup> Grade    ____ 8 <sup>th</sup> Grade    ____ 9 <sup>th</sup> Grade    ____ 10 <sup>th</sup> Grade    ____ 11 <sup>th</sup> Grade    ____ 12 <sup>th</sup> Grade    ____ Ungraded    ____  If ungraded, how many years attended? ____

SECTION 9: FACTS ABOUT YOU	
1. Are you:	<input type="checkbox"/> Male <input type="checkbox"/> Female
2. What is your date of birth?	____ / ____ / ____ Month    Day    Year
3. Which of the following best describes your current work status? (check all that apply)	Not working due to my child's health    ____ Not working for other reasons            ____ Looking for work outside the home        ____ Working full or part time (either outside the home or at a home based business)    ____ Full time homemaker                            ____
4. Which of the following best describes your relationship to your child?	Biological Parent                            ____ Step Parent                                      ____ Foster Parent                                    ____ Adoptive Parent                                ____ Guardian                                         ____ Professional caregiver                      ____ Other (please explain) _____
5. On average, how many days per week are you responsible for care giving activities for your child?	____ days per week
6. What is the highest level of school you have completed?	Some high school or less                    ____ High school diploma/GED                    ____ Vocational school or some college        ____ College or University degree                ____ Professional or Graduate degree            ____

How long has it taken you to complete this questionnaire only (in units of time): \_\_\_\_\_

**THANK YOU FOR YOUR PARTICIPATION!**

**FOLLOW UP**

After you post this to us and we check that your questionnaire is complete, this page will be removed from the questionnaire and be stored separately.

**All the information you have provided is strictly confidential.**

**DO YOU WANT TO DO MORE?**

We are planning a follow up study to further understand and describe how children with cerebral palsy and their carers' complete difficult daily living routines.

This second study will include about 6 pairs of children and carers. It will involve a home visit where we will film you and your child doing a daily routine of your choice. You will then have the chance to watch the video and talk about what you are doing with a researcher.

Please indicate if you agree to further contact regarding this next phase of the study:

- I **am** interested in being contacted for participation in a further study with my child.

Name \_\_\_\_\_

Address \_\_\_\_\_

Best contact (mobile, email phone) \_\_\_\_\_

- I am **not** interested in further involvement in study two.



**THANK YOU VERY MUCH FOR TAKING PART IN THIS RESEARCH!**

All responses will be kept confidential.

**Take a moment now to check that all questions have been answered on all questionnaires.**

PLEASE post the survey and questionnaires back to us in the reply paid envelope.

Your return pack should include;

- this booklet
- the signed consent forms

and

- the **CPCHILD Child report** if applicable.

**WE WILL SEND YOU A SUMMARY OF THE RESULTS IN 2018**

## Appendix I: The Caregiver Priority and Child Health Index of Life with Disability (CPCHILD)-Child report

*This is the child report version of the CPOCHILD.*

*It is to be completed by a child/young person aged between 8 and 18 years.*

### CPCHILD<sup>®</sup> Caregiver Priorities & Child Health Index of Life with Disabilities

#### Instructions

1. This questionnaire is about your health, comfort and well being, and about caring for your needs.
2. Please read the instructions carefully.
3. Please answer all questions by circling the number that fits best. You may write down any comments/clarifications in the space provided below each question.

**For example:**

							LEVEL OF ASSISTANCE				
							T O T A L	M O D E R A T E	M I N I M A L	S U P E R V I S E D	
Consider how you <b>usually</b> perform each of the following activities.											
Rate how <b>difficult</b> each of these activities were in the past 2 weeks,											
<b>and</b> choose the <b>level of assistance</b> you required to help you perform these activities.											
During the <b>past 2 weeks</b> , how difficult was the following:	<i>Not Possible</i> <small>(Almost Impossible)</small>		<i>Very Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>No problem at all</i>				
<b>1. putting on / wearing footwear? (socks, shoes, braces, etc.)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>

In the above example, the task of putting on / wearing footwear was rated as *very easy*, and you required a *minimal / supervised* level of assistance to put on footwear.

4. At the end of each section there is space for you to add any items that you think are missing from the questionnaire, which you believe are important to your comfort and well being.

Your name: \_\_\_\_\_

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

**SECTION 1: PERSONAL CARE / ACTIVITIES OF DAILY LIVING**

								LEVEL OF ASSISTANCE				
Consider how you <b>usually</b> perform each of the following activities. Rate how <b>difficult</b> each of these activities were in the past 2 weeks, <b>and</b> choose the <b>level of assistance</b> you required to help you perform these activities.								T O T A L	M O D E R A T E	M I N I M A L	S U P P L E M E N T A R Y	I N D E P E N D E N T
During the <b>past 2 weeks</b> , how difficult was the following:	<i>Not Possible</i> <small>(Almost Impossible)</small>	<i>Very Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>No problem at all</i>						
1. eating/drinking or being fed? (in the usual way that it is done i.e. orally <u>or</u> by tube <u>or</u> both)	0	1	2	3	4	5	6	0	1	2	3	
2. maintaining oral hygiene? (keeping mouth and teeth clean)	0	1	2	3	4	5	6	0	1	2	3	
3. bathing / washing?	0	1	2	3	4	5	6	0	1	2	3	
4. toileting activities? (bladder & bowel function, hygiene etc.)	0	1	2	3	4	5	6	0	1	2	3	
5. changing diapers/underwear?	0	1	2	3	4	5	6	0	1	2	3	
6. putting on/taking off upper body clothing? (shirt, jacket, etc.)	0	1	2	3	4	5	6	0	1	2	3	
7. putting on/taking off lower body clothing? (pants, sweats, etc.)	0	1	2	3	4	5	6	0	1	2	3	
8. putting on/wearing footwear? (socks, shoes, braces, etc.)	0	1	2	3	4	5	6	0	1	2	3	
9. hair care (washing, drying, brushing/combing, braiding, etc.)	0	1	2	3	4	5	6	0	1	2	3	
1A. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3	
1B. other personal care activity? Specify: _____	0	1	2	3	4	5	6	0	1	2	3	

**SECTION 2: POSITIONING, TRANSFERRING & MOBILITY**

								LEVEL OF ASSISTANCE				
Consider how you <b>usually</b> perform each of the following activities. Rate how <b>difficult</b> each of these activities were in the past 2 weeks, <b>and</b> choose the <b>level of assistance</b> you required to help you perform these activities.								T O T A L	M O D E R A T E	M I N I M A L	S U P E R V I S E D	I N D E P E N D E N T
During the <b>past 2 weeks</b> , how difficult was:	<i>Not Possible</i> (Almost Impossible)	<i>Very Difficult</i>	<i>Difficult</i>	<i>Slightly Difficult</i>	<i>Easy</i>	<i>Very Easy</i>	<i>No problem at all</i>					
<b>10. getting in and out of bed?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>11. transferring into/out of a wheelchair/chair?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>12. sitting in a wheelchair/chair?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>13. standing for exercise/transfers?</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>14. moving about in the home? (in whatever way possible)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>15. moving about outdoors? (in whatever way possible)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>16. getting in and out of a motor vehicle? (car, van or bus)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>17. visiting public places? (park, theatre, sightseeing, etc)</b>	0	1	2	3	4	5	6	0	1	2	3	
<b>2A. other activity?</b> Specify: _____	0	1	2	3	4	5	6	0	1	2	3	
<b>2B. other activity?</b> Specify: _____	0	1	2	3	4	5	6	0	1	2	3	

**SECTION 3: COMFORT & EMOTIONS**

During the <u>past 2 weeks</u> , how often did you experience pain or discomfort	<i>Every day</i>	<i>Very Often</i>	<i>Fairly Often</i>	<i>A few times</i>	<i>Once or twice</i>	<i>None of the time</i>	INTENSITY			
							S E V E R E	M O D E R A T E	M I L D	N O N E
18. while eating/drinking or being fed?	0	1	2	3	4	5	0	1	2	3
19. during toileting? (bladder & bowel function, hygiene, diapering, etc.)	0	1	2	3	4	5	0	1	2	3
20. while dressing/undressing?	0	1	2	3	4	5	0	1	2	3
21. during transfers or position changes?	0	1	2	3	4	5	0	1	2	3
22. while seated?	0	1	2	3	4	5	0	1	2	3
23. while lying down in bed?	0	1	2	3	4	5	0	1	2	3
24. that disturbed your sleep?	0	1	2	3	4	5	0	1	2	3
3A. during other activity? Specify: _____	0	1	2	3	4	5	0	1	2	3
3B. during other activity? Specify: _____	0	1	2	3	4	5	0	1	2	3

During the <u>past 2 weeks</u> , how often were you	0	1	2	3	4	5	0	1	2	3
25. agitated, upset, or angry?	0	1	2	3	4	5	0	1	2	3
26. unhappy or sad?	0	1	2	3	4	5	0	1	2	3

**SECTION 4: COMMUNICATION & SOCIAL INTERACTION**

Consider how you **usually** perform each of the following activities.

Rate how **difficult** each of these activities were in the past 2 weeks

<b>During the past 2 weeks, how much difficulty did you have</b>	<i>Not Possible</i>	<i>Very</i>	<i>Slightly</i>	<i>Easy</i>	<i>Very</i>	<i>No</i>	
	<i>(Almost Impossible)</i>	<i>Difficult</i>	<i>Difficult</i>	<i>Difficult</i>	<i>Easy</i>	<i>Easy</i>	<i>problem at all</i>
	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>27. understanding your parent/caregiver?</b>							
<b>28. being understood by your parent/caregiver?</b>							
<b>29. communicating with those who don't know you well?</b>							
<b>30. playing alone?</b>							
<b>31. playing with others?</b>							
<b>32. attending school/child care?</b>							
<b>33. participating in recreational activities (swimming, interacting with family and friends, etc.)?</b>							
<b>4A. other social activity?</b> Specify: _____							
<b>4B. other social activity?</b> Specify: _____							

**SECTION 5: HEALTH**

In the past 2 weeks	<i>Please circle the option that fits best</i>					
<b>34. How many times have you had to visit the doctor or the hospital?</b>	<i>Admitted &gt;7 days</i>	<i>Admitted &lt; 7 days</i>	<i>3 or more times</i>	<i>Twice</i>	<i>Once</i>	<i>None</i>
	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
<b>35. How would you rate your overall health?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

**36. List the medications you have been taking in the last 2 weeks**

**0. No medications**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_
7. \_\_\_\_\_
8. \_\_\_\_\_
9. \_\_\_\_\_

**SECTION 6: YOUR OVERALL QUALITY OF LIFE**

In the past 2 weeks	<i>Very Poor</i>	<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
<b>37. How would you rate your overall quality of life?</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

<b>SECTION 7: IMPORTANCE OF ITEMS TO YOUR QUALITY OF LIFE</b>						
How importantly do you think your current status with each item contributes towards your quality of life?	Least Important	Not Very Important	Slightly Important	Fairly Important	Very Important	Most Important
1. Eating / drinking or being fed	0	1	2	3	4	5
2. Maintaining oral hygiene	0	1	2	3	4	5
3. Bathing / washing	0	1	2	3	4	5
4. Toileting activities / hygiene	0	1	2	3	4	5
5. Changing diapers / underwear	0	1	2	3	4	5
6. Putting on/taking off upper clothing	0	1	2	3	4	5
7. Putting on/taking off lower clothing	0	1	2	3	4	5
8. Putting on / wearing footwear	0	1	2	3	4	5
9. Hair care / grooming	0	1	2	3	4	5
10. Getting in and out of bed	0	1	2	3	4	5
11. Transferring into / out of a wheelchair / chair	0	1	2	3	4	5
12. Sitting in a wheelchair / chair	0	1	2	3	4	5
13. Standing for exercise / transfers	0	1	2	3	4	5
14. Moving about indoors	0	1	2	3	4	5
15. Moving about outdoors	0	1	2	3	4	5
16. Getting in / out of a motor vehicle	0	1	2	3	4	5
17. Visiting public places	0	1	2	3	4	5
18. Comfort while feeding	0	1	2	3	4	5
19. Comfort during toileting activities	0	1	2	3	4	5
20. Comfort while dressing /undressing	0	1	2	3	4	5
21. Comfort during transfers or position changes	0	1	2	3	4	5
22. Comfort while sitting	0	1	2	3	4	5
23. Comfort while lying down	0	1	2	3	4	5
24. Comfort while sleeping	0	1	2	3	4	5
25. Emotional state or behavior	0	1	2	3	4	5
26. Happiness	0	1	2	3	4	5
27. Able to understand caregiver	0	1	2	3	4	5
28. Able to be understood by caregiver	0	1	2	3	4	5
29. Able to communicate with others	0	1	2	3	4	5
30. Able to play alone	0	1	2	3	4	5
31. Able to play with others	0	1	2	3	4	5
32. Able to attend school / child care	0	1	2	3	4	5
33. Able to participate in recreational activities	0	1	2	3	4	5
34. Minimizing doctor visits and hospitalization	0	1	2	3	4	5
35. Overall health	0	1	2	3	4	5
36. Minimizing number of medications	0	1	2	3	4	5



<b>SECTION 8: FACTS ABOUT YOU</b>
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<b>1. Are you:</b>	<input type="checkbox"/> Male <input type="checkbox"/> Female
<b>2. What is your date of birth?</b>	____ / ____ / ____ Month    Day    Year
<b>3. What is the <u>highest</u> school grade you have completed? (check only one grade)</b>	Preschool    ____ Kindergarten ____ 1 <sup>st</sup> Grade    ____ 2 <sup>nd</sup> Grade    ____ 3 <sup>rd</sup> Grade    ____ 4 <sup>th</sup> Grade    ____ 5 <sup>th</sup> Grade    ____ 6 <sup>th</sup> Grade    ____ 7 <sup>th</sup> Grade    ____ 8 <sup>th</sup> Grade    ____ 9 <sup>th</sup> Grade    ____ 10 <sup>th</sup> Grade    ____ 11 <sup>th</sup> Grade    ____ 12 <sup>th</sup> Grade    ____ Ungraded    ____  If ungraded, how many years attended? ____

How long has it taken you to complete this questionnaire only (in units of time): \_\_\_\_\_

**THANK YOU FOR YOUR PARTICIPATION!**

**Appendix J: Letter of introduction from the Victorian Cerebral Palsy Register**

[Date]

[Title] [First name] [Surname]

[Address line 1] [Address line 2]

[Suburb] [State] [Postcode]



Dear [First name],

**Re: Research Project: Daily Living Transactions: understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy.**

I am sending you information about this research study because [child's first name] is registered on the Victorian Cerebral Palsy Register and, to the best of our knowledge, uses a wheelchair as their primary source of mobility. This makes you and/or [child's first name] suitable to be included in the research, if you wish to participate. The research is being conducted by Robyn Heesh, an occupational therapist who works at the Royal Children's Hospital and is a student at the Australian Catholic University.

Please take some time to read the enclosed Information statement that describes the project in more detail. The research aim is to find out how, by working together, carers and children can learn useful skills that enhance a child's independence and make daily routines easier. Participation in the project involves completing a survey that takes about 40 minutes. The survey is enclosed.

***If you are interested in participating, please complete and return the survey and signed consent form to the researchers within the next 2 weeks in the stamped, self-addressed envelope provided.***

If we do not receive your completed survey, one of the research team will contact you in approximately 2 weeks to check that you received this invitation. If you have any questions about why you received this letter or do not wish to be contacted further about the study, please email me at [sue.reid@mcri.edu.au](mailto:sue.reid@mcri.edu.au) or phone me on (03) 9345 4807.

If you have further questions about the study itself, please email Robyn Heesh at [robyn.heesh@rch.org.au](mailto:robyn.heesh@rch.org.au) or phone/text Robyn on 0478 701 424.

With kind regards,

**Dr Sue Reid**

Manager – Victorian Cerebral Palsy Register

**Appendix K: Procedure for modifying multiple responses to a survey item to a single response**

**Work status**

Many participants ticked more than one response to the question about work status ( $n=10$ ).

The response options for this item were:

- (1) Not working due to child health;
- (2) Not working-other reason;
- (3) Looking for work outside home;
- (4) Working full or part time;
- (5) Full time homemaker.

Many participants chose one of the first four options but also added (5) Full time homemaker. Many carers may work outside the home or are looking for work but also view being a homemaker as another full-time job. A single response was nominated for each on a case by case basis as outlined in Table K1.

Table K1.

*Procedure for modifying multiple response to single response for work status*

Logic	Explanation	Outcome	<i>n</i>
If 1=1 and 5=1, then 5=0	The carer is not working due to their child's health and describe this as a full-time homemaker	1	5
If 4=1 and 5=1, then 5=0	The carer is working full or part time, but also views being a homemaker as another full-time job	4	1
If 3=1 and 5=1, then 5=0	The carer is looking for work while	3	1

	also being a full-time homemaker		
If 1=1 and 4=1, then 1=0	The carer is working but has also checked “not working due to child health”. The work status may be impacted by the health of their child, such as working part time instead of full time	4	1
If 1=1 and 2=1, then 1=0	There may be many reasons why the carer is not working, and one of these is the health of their child	2	1
If 1=1 and 3=1, then 1=0	The carer is currently not working due to their child’s health but is trying to change this status by seeking employment	3	1

---

### Motor type

Many participants ticked more than one response for motor type ( $n=39$ ):

- (0) Missing;
- (1) Spasticity;
- (2) Dystonia;
- (3) Ataxia;
- (4) Hypotonia;
- (5) Don’t know;
- (6) Mixed.

A single response was nominated as an outcome (see Table K2). The explanations for each decision are indicated by letter in the notes.

Table K2

*Procedure for modifying multiple response to single response for motor type*

Two motor types ( $n=28$ )	Outcome	$n$
If 1=1 and 2=1, then 1=0 and 2=0 and 6=1. <sup>a</sup>	6	17
If 1=1 and 4=1, then 4=0 <sup>b</sup> .	1	6
If 2=1 and 4=1, then 4=0 <sup>c</sup>	2	3
If 1=1 and 3=1, then 1=0, 3=0 and 2=1 <sup>c,d</sup> .	2	1
If 2=1 and 3=1, then 3=0 <sup>c</sup>	2	1
Three motor types ( $n=10$ )		
If 1=1, 2=1 and 3=1, then 1=0, 2=0, 3=0 and 6=1 <sup>a,c</sup>	6	2
If 1=1 and 2=1 and 4=1, then 1=0, 2=0, 4=0 and 6=1 <sup>a,b</sup>	6	5
If 1=1 and 3=1 and 4=1, then 1=0, 2=0, 4=0 and 2=1 <sup>c,d</sup>	2	2
If 2=1, 3=1 and 4=1, then 2=0, 3=0, 4=0 and 2=1 <sup>a,c,d</sup>	2	1
Four motor types ( $n=1$ )		
If 1=1 and 2=1 and 3=1 and 4=1, then 6=1 <sup>e</sup>	6	1

*Note.* <sup>a</sup> The presence of dystonia and spasticity together can be described as mixed tone. Pure dystonia, that is, dystonia without the presence of spasticity is uncommon.

<sup>b</sup> The explanation of hypotonia on the survey was “body floppy or weak.” Many children with mixed tone, dystonia and spasticity have a floppy or weak trunk, but this is not their primary motor type.

<sup>c</sup> The explanation for ataxia on the survey was “arms and legs have tremors and shakes.” Many children with mixed tone, dystonia and spasticity have tremors and shakes, but this is not their primary motor type.

<sup>d</sup> Ataxia is uncommon in this population of children. If spasticity is selected with ataxia, without spasticity, the primary motor type is likely to be dystonia.

<sup>e</sup> As the child was described as having all motor types, this would be best described by mixed

**Additional Conditions**

Participants were asked to identify the presence of additional conditions:

- (0) missing;
- (1) Intellectual impairment;
- (2) Learning disability;
- (3) Visual impairment;
- (4) Hearing impairment;
- (5) Epilepsy;
- (6) Don't know;
- (7) other.

Many carers ticked yes to 1 and 2 ( $n = 29$ ). The presence of an intellectual impairment will always include specific learning disabilities, therefore when both 1 and 2 were ticked, the primary additional condition was assumed to be 1 (intellectual impairment) and not a learning disability ( If 1=1 and 2=1, then 2=0; Outcome =1)



**Appendix L: Consent form Study 2** AUSTRALIAN CATHOLIC UNIVERSITY

PARENT/GUARDIAN CONSENT FORM- Study 2  
*Copy for Participant to Keep /Copy for Researcher*

TITLE OF PROJECT: Daily Living Transactions; Understanding how children and caregivers work together to complete daily living tasks and routines when the child has cerebral palsy

STUDENT INVESTIGATOR Robyn Heesh

SUPERVISORS: Prof Christine Imms, Dr. Loretta Sheppard and Dr. Susan Greaves

I ..... (*the participant*) have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction and I agree to take part in this study.

I realise that I can withdraw my consent at any time. I agree that video footage, what I say in the interview can be written about and provided to other researchers in a form that does not identify me in any way.

NAME OF PARENT/GUARDIAN:.....DATE:.....

SIGNATURE:.....DATE:.....

NAME OF CHILD:.....

SIGNATURE OF PRINCIPAL INVESTIGATOR:.....DATE:.....

**ASSENT OF PARTICIPANTS AGED UNDER 18 YEARS**

I ..... (*the participant*) have read and understood the information provided in the Letter to Participants. Any questions I have asked have been answered to my satisfaction. I agree to take part in this study.

I realise that I can withdraw my consent at any time. I agree that video footage, what I say in the interview can be written about and provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT AGED UNDER 18:.....

SIGNATURE:.....DATE:.....

SIGNATURE OF PRINCIPAL INVESTIGATOR:.....DATE:.....

**Appendix M: Home visit planning and risk assessment form****Initial Phone Contact****DATE**

Topics to cover	Tick	Carer questions/notes
Study rationale and procedure outlined (offered in writing)		
Natural environment-observation and learning, not offering intervention		
Participation is voluntary. Does parent consent?	Yes / No	
Signed consent form for video footage and digital voice recording will be required.		
Storage of digital material explained		
Child/young person to participate in interview?	Yes / No	
The daily routine selected?		
Privacy of child discussed (if applicable)		
Pre-visit Risk assessment completed?		
Equipment present?		
Suggested date and time of HV and interview		
Address and contact details of parent and researcher contact details confirmed		
Any questions?		



**PRE-HOME VISIT PROCEDURE**

Name and contact details of ACU administrator		
Address of visit expected time completed, mobile phone no logged with ACU administrator	Yes / No	
Car not parked in street (not driveway)	Yes / No	
Car keys and phone carried on person at all times	Yes / No	
Phone fully charged and reception available	Yes / No	
Are there signs of violence at property?	Yes / No	
Are animal restrained?	Yes / No	
Obstacles to access property?	Yes / No	

**POST HOME VISIT PROCEDURE**

ACU administrator contacted with time of leaving home visit	Yes / No	
Were there any concerns or risk?	Yes / No	If yes...
Field notes completed	Yes / No	