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**(2015) Activities and participation of children with cerebral palsy: Parent perspectives. *Disability and Rehabilitation* 14:1-10. [Epub ahead of print]**

## **Activities and participation of children with cerebral palsy: Parent perspectives**

### **Abstract**

**Purpose:** To explore parents' views of the activities and participation of children with cerebral palsy (CP) with a range of communicative abilities and the factors (personal and environmental) that influenced these.

**Method:** Thirteen parents of children with CP aged four to nine years participated in semi-structured individual interviews. Interviews were recorded, transcribed and analysed thematically. Identified codes and themes were mapped to the domains of the International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY).

**Results:** Parents' responses reflected all ICF-CY domains comprising activity, participation and environmental factors. Codes were primarily mapped to the domains *learning and applying knowledge, communication, mobility, and interpersonal interactions and relationships*. Key barriers identified included aspects of parents' own interactions with their child (e.g., not offering choices), unfamiliar people and settings, negative attitudes of others, and children's frustration. Facilitators included support received from the child's family and school, being amongst children, having a familiar routine, and the child's positive disposition.

**Conclusions:** Despite the barriers experienced, children participated in a range of activities. Parents placed importance on communication and its influence on children's independence, behaviour and relationships. Barriers and facilitators

identified highlight aspects of the environment that could be modified through intervention to enhance communication and participation.

## **Implications for Rehabilitation**

- 1) Children's activities and participation were largely related to early learning tasks (e.g., literacy), communication, mobility and interactions.
- 2) Intervention aimed at improving activities and participation may address the various child, impairment, social and environment factors identified here as impacting on activities and participation (e.g., the child's personal characteristics, communication and physical impairments, the support and attitudes of others, and the familiarity of the environment).
- 3) Therapists will need to consider (and manage) the potential negative impact communication deficits may have on children's behaviour, independence and social skills which may in turn detrimentally impact on activity and participation.

## **Introduction**

Maximising the participation of children with communication disorders is recognised as a clinician's 'ultimate' goal [1]. The importance of communication in facilitating participation in daily activities is widely known [2,3]. At present, however, limited information is available regarding the activities and participation of children with cerebral palsy (CP) with associated communication disorders, posing challenges on how to best assess and manage communication deficits at a functional level in this population.

Communication is one of many factors that influence the participation of children with CP [4,5]. The pattern of participation demonstrated by children with

associated communication disorders has largely focused on those with complex communication needs (CCN) [6-9], i.e., children with severe communication impairments who often rely on methods other than speech to communicate. For instance, Thirumanickam et al. [9] examined the participation of five children (two with CP) with CCN aged 6 to 9 years. In comparison to peers without a physical disability, children with CCN participated in fewer activities, engaged predominately in activities within the home and were less likely to interact with friends or peers [9]. Similar findings have also been reported in older children with CP and CCN aged 10 to 15 years [8], highlighting the potential impact of severe communication disorders.

In terms of the wider group of children with CP with communication disorders, little is known about which aspects of activity and participation are most relevant to this subgroup. Communication difficulty has been associated with participation in fewer formal (structured/pre-planned) activities [10]. In contrast, better communication skills have been linked to greater diversity in informal (spontaneous) activities [11] and fewer physical activities (possibly due to increased involvement in social activities) [12]. Fauconnier and colleagues [13] have provided the largest study (n=818) to date examining the impact of communication impairment on participation in children with CP. Authors found that communication impairment was associated with reduced participation on eight of the eleven domains of the Assessment of Life Habits. Specific domains affected included health hygiene, communication (i.e., communicative participation), home life, mobility, responsibilities, relationships, school and recreation. Thus, communication disorders in this population can have far reaching impacts.

Moreover, there is currently a lack of information regarding the specific factors that influence the activity and participation of children with communication disorder. Based on research concerning children with complex communication needs (due to a range of medical diagnoses, including CP), level of participation appears to be best predicted by personality, the impact of childhood disability on the family [6], younger age and the ability to produce some intelligible speech [7]. In studies focused specifically on children with CP (with and without communication impairment), similar findings have been reported. For example, Voorman et al. [14] found that social functioning in 110 children with CP aged 9 to 16 years was negatively impacted by older age, specific impairments (i.e., speech problems, epilepsy, and greater gross motor impairment) and externalising behaviour problems (e.g., delinquency, aggression).

The studies described thus far are quantitative in nature. No study has yet explored the activities and participation of children with CP with communication disorders using methodologies that enable in-depth explorations of participant experiences and opinions that do not emerge in quantitative research. The use of qualitative methodologies enables understanding of the influence of personal and environmental factors on the activity/participation and quality of life of children with CP who have communication disorders. This in turn could lead to improved understanding of how activity and participation should be assessed and managed for this subgroup.

The present study aimed to explore parents' perspectives of the activities and participation of children with CP with a range of communicative abilities and the

factors (personal and environmental) that influenced these. The International Classification of Functioning, Disability and Health – Children and Youth Version (ICF-CY) [15] was used as a framework to analyse participants' responses. The activity and participation component of the ICF-CY encapsulates a range of daily activities that are relevant to children with communication disorders [16]. Given its clinical relevance in managing communication disorders [17], the ICF-CY model was used to provide an indication of domains that are relevant to children with CP. Here we conceptualised activity and participation as per the ICF-CY, that is, where activity relates to the execution of tasks, and participation refers to children's involvement in life situations [15]. O'Halloran and Larkins [18] summarised various perspectives on distinguishing between activity and participation. They suggested that activity focuses at the level of the individual and is related to the impairment, whereas participation focuses at the societal level and is related to quality of life [18]. Another key component of the ICF-CY is its inclusion of contextual factors (environmental and personal) that may impact on children's activity and participation. Aspects taken into consideration in the environmental factors component of the ICF-CY include assistive devices, the attitudes and support of others, and the child's environment. Personal factors are not classified by the ICF-CY due to the "large social and cultural variance associated with them" [15, p. 8]. Hence we were interested in exploring parents' perception of the personal factors that influence their child's activity and participation.

## **Methods**

This study was based within an interpretive paradigm, that is in which there are multiple realities and truths about how the world is, and what the nature of reality

is [19]. Our interest was to investigate those realities and experiences for parents of children with CP. Individual, semi-structured interviews were conducted with parents since they were most likely to provide the strongest and most relevant information [20] given that children predominately participate in family-based activities [21]. Individual parent interviews offered flexibility in the time and location of the interview and enabled exploration of intricacies and depth of knowledge rather than shared views [22]. Ethics approval for the study was obtained from The Royal Children's Hospital (RCH), Melbourne, Human Research Ethics Committee (#30048).

## **Participants**

Thirteen families were recruited from a range of specialist services for children with CP to enable strategically focused recruitment of participants [20]. All were based in Victoria, Australia, including RCH, Yooralla (a community based agency providing services to children and adults with disabilities), the Cerebral Palsy Education Centre (a specialist education service for children with CP), Melbourne, and the Kids Plus Foundation, Geelong (an organisation providing services to children with neuro-physical disabilities). Families were recruited through i) flyers and the first author (CM) approaching eligible families prior to their child's outpatient appointment at RCH; and ii) therapists providing eligible families with the information statement and consent form.

Families were eligible if parents had sufficient English language skills to participate in an interview, and children had a primary diagnosis of CP and were aged between 4 years, 5 months and 10 years. This age limit was chosen as children

participate in similar activities within this age range. Children with a range of communication abilities were recruited. Data collection occurred concurrently with data analysis [23] enabling the incorporation of additional questions on emerging ideas. Recruitment of families continued until data saturation was reached. Data saturation occurred when the researcher was no longer identifying new themes in the interviews with parents [24]. Clinical and demographic characteristics of the child and family were reported by parents, as detailed in Table 1.

*Insert Table 1 about here*

## **Procedure**

Semi-structured interviews were conducted to gather rich descriptions of children's activities and participation in a range of settings (e.g., home, pre-school/school and community). Interview questions were developed with reference to the ICF-CY to prompt discussion around activity and participation (see Table 2). Parents were provided with definitions and examples of these concepts. Activity was defined to parents as the actions or tasks their child completes, whereas participation was defined as their child's social involvement during everyday situations. An example provided to parents was if a child is unable to eat orally, they would be unable to complete the activity or action of eating, but they can still participate or be socially involved during mealtimes by sitting at the table with their family during mealtimes. Extension questions were used where further clarity regarding parents' responses was needed [28]. Parents also had the opportunity to discuss relevant issues that had not arisen in the specific interviewer questions. Interviews were undertaken by CM in the family's home (n=7), RCH (n=5) and The University of Melbourne (n=1). Interviews lasted 35 minutes to 1.5 hours and were audio recorded for later

transcription. At the conclusion of each interview, the interviewer verbally summarised the discussion to verify their interpretation. Parents were also given the opportunity to receive a copy of the transcript to confirm its accuracy. One transcript was returned with minor changes in relation to grammar rather than content that did not alter study findings.

*Insert Table 2 about here*

### **Data analysis**

Interviews were analysed thematically by CM and involved repeatedly moving back and forth between the transcripts, coding responses, creating categories to link codes and identifying themes [23]. Discussion of emerging codes and themes occurred with the research team (AM, JG) to ensure analysis and interpretation was anchored in the data [29]. Key quotes illustrating themes were identified [30]. The codes identified were then mapped to the ICF-CY category that most precisely corresponded to the code. For example, the thematic analysis code “making choices” was mapped to the ICF-CY category of “d177 making decisions” (see Table 3 for examples). Responses relating to children’s activities and participation were divided into the following ICF-CY domains i) learning and applying knowledge, ii) general tasks and demands, iii) communication, iv) mobility, v) self-care, vi) domestic life, vii) interpersonal interactions and relationships, viii) major life areas, and ix) community, social and civic life.

Reported barriers and facilitators of activity and participation were categorised according to the contextual factors component of the ICF-CY, which addresses the following: i) products and technology; ii) natural environment and human-made

changes to environment, iii) support and relationships, iv) attitudes, v) services, systems and policies, and vi) personal factors. To confirm the accuracy of findings, results from the thematic analysis and the mapping of codes to the ICF-CY were discussed among authors until a consensus was reached.

*Insert Table 3 about here*

## **Results**

### **Activities and Participation of Children**

All nine ICF-CY domains encompassing activity and participation were reflected in parents' responses (see Table 4, results from the thematic analysis appear in Table 5). Findings were mostly mapped to the domains *learning and applying knowledge, communication, mobility, and interpersonal interactions and relationships*. Although children participated in a range of activities, limitations were apparent across a range of settings (i.e., home, school and community).

*Insert Tables 4 and 5 about here*

#### ***Communicating with Others***

##### ***'His choices, his decisions so that he feels like he's living his life'***

Within the domain *learning and applying knowledge*, early learning tasks (e.g., playing, literacy and numeracy) were considered important, as was making choices. Having the ability to make choices provided children with the opportunity to control their environment and engage in preferred activities. For example:

*Letting Jai have a choice, that's the biggest thing because we tend to try and do everything for them because they have a disability and we think they're hard*

*done by so we try and make it easier for them when in actual fact it's not like that. They can think for themselves.*

***'If he couldn't talk then there'd be a lot of things that he'd probably be left out of'***

All parents spoke about the importance of communication and children being able to indicate their basic needs. This was particularly highlighted by the mother of Max who expressed that *"every activity that he does involves communication to some degree."*

In some instances, parents reported that children's communication needs were greater than their physical limitations. This was particularly apparent for children with limited verbal communication abilities:

*If I could choose whether my child could walk or talk, I'd choose talk totally because if you can communicate you are just so much more empowered (mother of Max).*

Being a successful communicator provided children with the skills to develop independence, facilitated the formation of friendships, and increased children's confidence to interact with others. Parents spoke about the importance of children expressing their needs, asking questions, requesting objects, being understood by unfamiliar people and indicating when in pain. Parents of non-verbal children expressed their struggles in not always knowing their child's needs, as discussed by James' mother:

*That's probably one of the hardest things. He can't say 'mummy, my throat's sore.' I have to wait until literally he's crashed and he's quite ill.*

In terms of the impact of communication impairments, parents recognised that deficits affected their child's independence, formation of friendships and behaviour. Furthermore, parents described the stress and concern caused by their child's communication impairment.

***'This little boy would just be so frustrated that he'd just lash out...it was awful'***

Children's frustration, reflected in the *general tasks and demands* domain, often resulted from reported limitations in mobility, language impairment or reduced speech intelligibility. Frustration resulting from communication breakdowns often impacted negatively on children's behaviour, as highlighted below:

*That's probably the biggest thing with his lack of communication...the frustration. It just brings out behavioural issues. I think if he could speak a lot clearer and thinking about what he's saying quicker so that it comes out quicker, he wouldn't get as frustrated (mother of Mason).*

### ***Child's Leisure, Early Learning and Educational Activities***

Children engaged in a range of activities within the home and school (e.g., playing in the playground, completing classroom group tasks and home leisure activities such as watching TV, playing board games and reading books). Within the school environment, parents spoke about the physical limitations experienced by their child particularly in the playground and during mat/floor time activities. As

highlighted by the mother of Logan, these limitations did not necessarily prevent participation:

*The main thing he struggles with is floor time where they are all sitting on the floor and they're doing active music songs where you actually have to stand up, sit down and things like that. He needs assistance with that, but he can sing along, you know, that's not a problem, it's just...it's just the movement again.*

### ***Child's Independence within the Home***

Parents spoke about their child's ability to assist with household chores and complete self-care tasks such as bathing, toileting, dressing and feeding oneself independently or with assistance. As highlighted below, requiring physical assistance to complete self-care tasks limited children's opportunities to engage with friends.

*I've sent <Mason's brother> off to the neighbours and Mason wants to go, but I can't let him. He can't go over there without me being there...I just don't feel that I can put that on someone else because if he wants to go to the toilet (because he still needs a bit of help to get on the toilet), or he can have an accident and it can go everywhere.*

### ***Child's Engagement within the Community: 'Participation: we're working on it'***

Within the community, children mainly participated in family-orientated activities such as shopping, going to the park and visiting relatives or family friends. Future challenges children may face within this environment caused particular

concerns for parents. These concerns (as described in the following quote) were expressed by parents of children who were severely limited in their mobility and communication abilities.

*Eventually he has to live with the outer community ... how are they going to understand him? Will he constantly live a sheltered life? The fact that he will require to become independent or fully functional in society is a big concern.*  
(mother of James).

### **Barriers and Facilitators Affecting Children's Activities and Participation**

Parents identified a range of environmental and personal factors affecting their child's activities and participation (see Table 6, see Table 5 for the thematic analysis results). All five ICF-CY domains relating to environmental factors were of relevance. However, there were some environmental barriers/facilitators identified by parents that did not have a specific category within the ICF-CY (e.g., unfamiliar settings, crowded areas, and being provided with a model).

*Insert Table 6 about here*

#### ***Environmental Factors***

##### ***Child's Social Environment and Networks***

***'He's chirpy as, but if you put him in an environment like that he won't cope'***

The effect of the environment (e.g., unfamiliar setting, loud environment and crowded areas) varied from no influence to significant impact. Environmental barriers also had repercussions on parents' social well-being and ability to maintain friendships as it limited their opportunities to attend social events.

***‘A good family base goes a long way’***

*Support and relationships* from a range of sources (e.g., immediate family, school, and community members) were key facilitators. In some instances, the support provided by parents, such as not providing the child with choices or opportunities to request items, although intended to assist children, was perceived as a barrier, as illustrated below:

*Probably myself...probably not taking a step back as I probably should in terms of making her ask for something... Like, I sort of know what she wants so I anticipate it instead of making her ask for it (mother of Ruby).*

***‘Some people see a kid like Ruby and take two steps back’***

Although not unanimously experienced, the negative attitudes of peers, family members and strangers were viewed as a barrier. Negative attitudes included being stared at in the community, extended family members doubting the child’s capabilities and exclusion during play, as explained by Ruby’s mother:

*She attended mainstream kinder[garten]. No kids played with her, no kids. You know, I’m sort of glad for once of her lack of understanding because it would have been...like, if I was in that situation and I understood, that would have been awful.*

***Healthcare Services***

***‘It’s a brilliant device...but he can never set that up on his own’***

*Products and technology* (e.g., alternative and augmentative communication (AAC) devices) were primarily viewed as a facilitator as they provided children with a means to communicate. However, devices' usability limited children's opportunities to communicate, as described below:

*He could never take that [DynaVox] out of the bag, put it on the table; he just couldn't. It's too heavy. It's too cumbersome. I can see it will be a useful tool, but it's not an independent [one]* (mother of Max).

### ***'I can't fill that sort of gap'***

Parents of children who received speech pathology intervention spoke about the subsequent improvements in children's activities and participation. Overall, parents were pleased with access to speech pathology services, however, negative experiences were reported:

*They didn't have a speech pathologist and they couldn't get one, so she missed out...Even if I could have gotten something that I could have implemented myself. It was a major downfall for her. She could get access to other areas but not what she needed the most in my opinion* (mother of Ruby).

### ***Personal Factors***

#### ***Child's Disposition and Intrinsic Factors***

##### ***'He definitely wants to be a part of this world'***

A key personal factor limiting children's activities and participation was the child's disposition (e.g., being shy, reduced confidence and the child's mood). In

contrast, children's determination, demonstrated by a will or motivation to complete activities, was perceived as a facilitator.

***'Communication is going to be his biggest challenge in participating'***

Children's impairments (specifically involving communication and mobility) affected children's activity and participation. Communication impairments particularly impacted on situations outside of the home that involved peers or unfamiliar communication partners, for example.

*At kinder[garten] it stopped him from doing a lot of things, certainly limited his interaction with his peers and his development of friendships. I definitely think at school and out in the community his inability to communicate or communication breakdowns are a problem and I can see that they will continue throughout his life (mother of Max).*

Despite the challenges communication impairments posed on children's activities and participation, all but one parent discussed the facilitative effect of their child's communication skills (e.g., being able to communicate their needs and preference for activities).

## **Discussion**

Parents' responses from this study confirm the activity limitations and participation restrictions experienced by children with CP [8] and the impact of various child and environmental factors [31,32]. Furthermore, findings highlight the

potential negative impact of communication limitations on the activities and participation of children, particularly in the areas of relationships and independence.

### **Activities and participation**

Children typically participated in home-based activities and many found it difficult to form friendships with their peers. This is in line with previous research findings [8-10]. Participation in school and community-based activities was often challenging due to children's limited communication or social skills, the inability to keep up physically with other children, and parents avoiding certain settings that were not suitable for their child's physical needs (e.g., playgrounds). Although participation restrictions within the school environment were reported, teachers were described as being supportive in modifying activities to ensure participation.

It is perhaps not unexpected that parents viewed communication as providing a foundation for their child's ability to interact and form friendships. In a previous qualitative study [33] investigating the experiences of 11 parents of children who use AAC (9 were diagnosed with CP), authors found that difficulties in communicating impacted on children's social inclusion and ability to establish friendships. These social restrictions were further highlighted by McCormack et al. [16] who found that parents of children with speech impairment (without a physical disability) identified interpersonal interactions as a prime area of difficulty for their child.

Although the study was not designed to quantify differences in the activity and participation of children with and without communication disorder, there were some notable differences between these two groups. When comparing the thematic analysis

codes of children with and without communication disorders, communication related activities (e.g., requesting objects or help, making choices) were more likely to be raised by parents of children with impaired communication. This may have possibly been due to their increased awareness of their child's communicative abilities. Within the home environment, children with impaired communication were more likely to engage in indoor activities (e.g., watching TV, reading, playing board games), whereas those with no communication disorder participated in outdoor physical activities (e.g., bike riding, swimming). However, this finding may be influenced by children's gross motor abilities since all children who engaged in home-based outdoor activities were classified at GMFCS level I. In terms of out-of-home activities, children with impaired communication were less likely to play at their friends' homes. Interestingly, only parents of children with communication disorders raised concerns about their children's independence within the community. It is important to consider that the above restrictions experienced by children with communication disorders may result from multiple factors including the child's own abilities (e.g., mobility, communication, cognition) and their environment.

### **Contextual factors**

Children with CP face numerous barriers in completing activities and participation. Children's personal factors and the support received from others (particularly immediate family members, the child's school and community) were pertinent facilitators. These results are consistent with previous findings within the areas of CP [10,31] and communication [17].

In terms of environmental and personal factors specific to children with impaired communication, barriers included the negative attitudes of others, the lack of speech pathology services and being amongst unfamiliar people (due to increased communication breakdowns). Key facilitators were a familiar or quiet environment, being around familiar people or people with a positive attitude, and having access to AAC devices. These factors are similar to those reported in adults with CP and dysarthria [34]. However, some of these factors (i.e., the attitudes of others) have also been reported in the whole population of children with CP and not just those with communication deficits [32,35]. Further research is required to delineate the relative involvement of these factors in children with and without communication disorders.

Although AAC devices were perceived as a facilitator by parents, evidence reported by Clarke et al. [7] suggests that, at a group level, parents' perceived effectiveness of AAC is not a primary facilitator of participation. In a sample of 69 children (46 with CP) with complex communication needs, younger age and having some intelligible speech were associated with increased participation [7]. In contrast, communication aid effectiveness was not associated with level of participation [7]. This perhaps highlights the importance of qualitative opinions in capturing the individual needs of children.

One of the more striking results emerging from this study is that parents identified aspects of their own interaction with their child as a barrier. Parental behaviours, such as anticipating their child's needs rather than allowing the child to voice them, were thought to impede children's opportunity to communicate and this then affected activity and participation. This reflects the views of McConachie et al.

[21] who described the participation of younger children with a disability as being intertwined with that of their family and that family members are a potential key influencing factor affecting participation. Within the CP literature, parental factors such as stress [10] and self-efficacy [36] have been shown to impact on children's participation, yet parents identifying themselves as a barrier has not been widely reported. Similar quantitative findings have been reported by Rosenberg and colleagues [37] who found that parents of children with mild developmental disabilities perceived that their child's participation was most restricted by parental habits. Our finding suggests parents should be made aware of techniques to develop communication to facilitate participation, and in turn this may lessen their own perceived hindrances on their child's participation.

### **Study strengths and limitations**

Strengths of the study are the inclusion of children with varying physical and communication abilities, and the recruitment of families residing in various geographical locations (i.e., rural, regional and metropolitan areas). However, being from a non-representative sample, the results reported here cannot be generalised at a population level. It is recognised that parents may have under- or over-estimated their child's abilities. Children's own opinions were not sought in the present study, which is acknowledged as an area for future research. Whilst an inductive thematic analysis approach was firstly conducted to interpret the meaning of parents' responses, framing the study within the ICF-CY model could have inadvertently resulted in a deductive analysis of the interviews, whereby the ICF-CY categories could have influenced the thematic analysis. Information regarding children's vision, cognition, hearing and language were not collected although impairments in these areas can

impact on communication, activities and participation. A final limitation is that we did not verify our results with participants, however, some researchers have stated that this step is not needed for establishing the rigor and validity of qualitative findings [38].

Although children's quality of life was not the focus of this study, it is important to consider the possible effect children's social restrictions may have had on their well-being. This is in light of evidence showing an association between speech difficulties and reduced quality of life in the area of parent-child interactions [39]. However, as none of the parents interviewed raised concerns regarding their child's quality of life, it may be possible that parents did not perceive such an effect.

### **Clinical Implications**

The ICF-CY provided a valuable framework for describing the activities and participation of children with CP with communication disorder, emphasising its clinical relevance. The in-depth opinions obtained from parents highlight key areas to consider in the management of communication in children with CP. For example, particular attention might be placed on examining children's activities and participation in the key areas identified (e.g., interpersonal interactions). The barriers and facilitators reported by parents provide a list of key environmental and personal factors to consider during the management of children with communication disorder. Barriers and facilitators that are identified as being relevant to a child can then be targeted through intervention to optimise activity and participation, enabling a more functional approach to management. Further research is needed to examine which barriers and facilitators are most relevant to children with communication disorder.

Lastly, parents' responses provide suggestions for areas to include in a structured measure of activity and participation for children with CP with communication disorders. Only one published measure of activity and participation currently exists for children with speech and language impairments (i.e., Focus on the Outcomes of Communication Under Six) [40]. This can be used with children of differing medical diagnoses (e.g., CP, autism spectrum disorder, Down syndrome). Responses reported in the present study provide the basis for developing an activity and participation measure specific to children with CP with communication disorder. Such a measure would assist in capturing and managing aspects of activity and participation that are most relevant to this subgroup.

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### **Declaration of Interest**

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Table 1. Child and parent demographic characteristics

Child variables								Parent variables		
Name	Age	Sex	CP motor type and distribution	GMFCS level	Speech rating <sup>a</sup>	Schooling	Birth order	Age	Level of education	Household members
Jai	6;0	M	Spastic, diplegia	IV	2	Special school	1 <sup>st</sup>	29	Secondary	Mo, Fa, 2 children
Ruby	6;5	F	Spastic, quadriplegia	II	4	Special school	3 <sup>rd</sup>	37	Secondary	Mo, Fa, 5 children
Gemma	6;9	F	Spastic, diplegia	III	1	Mainstream school	2 <sup>nd</sup>	42	Secondary	Mo, Fa, 2 children
Darcy	7;7	M	Spastic, quadriplegia	II	1	Mainstream school	3 <sup>rd</sup>	42	Secondary	Mo, Fa, 3 children
Cooper	5;8	M	Mixed: spastic-dystonia, quadriplegia	IV	4	Preschool	3 <sup>rd</sup>	35	Secondary	Mo, Fa, 3 children
Gracie	4;7	F	Spastic, diplegia	III	2	Child care	1 <sup>st</sup>	28	University	Mo, Fa, 3 children
James	5;5	M	Spastic, hemiplegia	II	4	Child care, preschool	4 <sup>th</sup>	47	Secondary	Mo, Fa, 4 children
Sebastian	6;3	M	Spastic, quadriplegia	V	5	Special school	1 <sup>st</sup>	38	University	Mo, Fa, 1 child
Harriet	9;1	F	Mixed: spastic-dystonia, diplegia	II	1	Mainstream school	2 <sup>nd</sup>	39	Secondary	Mo, Fa, 2 children
Isabelle	5;0	F	Spastic, hemiplegia	II	1	Child care, preschool	1 <sup>st</sup>	37	University	Mo, 1 child, grandparents
Mason	7;9	M	Spastic, diplegia	III	4	Special school	1 <sup>st</sup>	42	Secondary	Mo, Fa, 2 children
Logan	4;5	M	Spastic, diplegia	III	1	Child care, preschool	2 <sup>nd</sup> (twin)	36	University	Mo, Fa, 3 children
Max	6;4	M	Mixed: athetoid-ataxic, quadriplegia	III	3	Mainstream school	1 <sup>st</sup>	39	University	Mo, Fa, 3 children, aunt

Children have been provided with pseudonyms. Mo: Mother. Fa: Father. GMFCS: Gross Motor Function Classification System. Children's gross motor abilities were classified by parents using the GMFCS Family Report Questionnaire [26,27].

<sup>a</sup>Speech rating scale devised with reference to the Australian Therapy Outcome Measures for speech pathology [25]: 1) no difficulties using speech to communicate messages; 2) some difficulty producing speech sounds but can be understood by strangers; 3) can communicate using speech but is unable to be understood by strangers; 4) able to produce some speech sounds that can be understood by familiar people; and 5) unable to produce speech that can be understood for communication.

Table 3. Examples of how parent responses were mapped onto the ICF-CY

Theme	Categories	Codes	ICF-CY domain	ICF-CY code/category
Communicating with others	Children making their needs known; Interacting with others	Making choices	Learning and applying knowledge	<b>d177 making decisions</b>
		Expressing needs and wants	Communication	<b>d330 speaking</b>
		Asking questions	Learning and applying knowledge	<b>d132 acquiring information</b>
		Initiating conversations	Communication	<b>d350 conversation (d3500 starting a conversation)</b>
Child's independence within the home	Household tasks	Assisting parents with household chores (e.g., hanging the washing, preparing meals, cleaning)	General tasks and demands Domestic life	<b>d210 undertaking a single task</b> <b>d630 preparing meals (d6302 helping prepare meals)</b> <b>d640 doing housework (d6400 washing and drying clothes and garments; d6402 cleaning living area; d6406 helping to do housework)</b>
	Child's activities of daily living	Bathing/showering	Self-care	d510 washing oneself (d5101 washing whole body)
		Eating	Self-care	d550 eating
		Dressing	Self-care	d540 dressing
		Toileting	Self-care	d530 toileting

Table 4. Activity and participation: ICF-CY codes identified by participants and examples of responses

ICF-CY chapter	ICF-CY codes	Examples/codes from the thematic analysis
Learning and applying knowledge	d110; d115; d130; d131; d132; d133 (d1330, d1331); d134; d135; d140; d150 (d1501); d155 (d1551); d160 (d1600); d163 (d1630); d166 (d1661); d177	Making choices, learning literacy and numeracy, listening to and watching others, engaging in pretend play, asking questions
General tasks and demands	d210 (d2100, d2104); d230 (d2300, d2302); d240; d250	Completing routine tasks, reading, making the bed, frustration with impairments
Communication	d310 (d3100, d3101); d315 (d3151, d3152); d320; d330; d331; d332; d335 (d3350, d3351); d350 (d3500, d3501, d3503, d3504); d360 (d3600)	Communicating verbally and nonverbally, initiating conversations, expressing needs and wants
Mobility	d410 (d4100, d4104, d4106); d430 (d4300, d4301); d435 (d4351); d440 (d4400, d4402); d445 (d4450, d4452); d450; d455 (d4552, d4553, d4554); d465; d470 (d4700, d4702); d475 (d4750)	Standing, lying down, riding a bike
Self-care	d510 (d5101); d520 (d5201); d530 (d5300, d53000); d540 (d5400); d550 (d5500); d560 (d5600)	Bathing/showering, dressing, brushing teeth, toileting, eating
Domestic life	d620 (d6200); d630 (d6300, d6301, d6302); d640 (d6400, d6401, d6402, d6403, d6406); d650 (d6505, d6506, d6507)	Shopping, assisting parents with household chores (e.g., hanging the washing, preparing meals, cleaning)
Interpersonal	d710 (d7104, d71040, d7106);	Initiating interactions, making

interactions and relationships	d720 (d7200); d730; d740 (d7400, d7402); d750 (d7500, d7501, d7502, d7504); d760 (d7600, d7601, d7602; d7608)	friends, playing with other children
Major life areas	d815 (d8151, d8152); d816; d820 (d8200, d8201, d8202, d8203); d860; d880 (d8801, d8802, d8803)	Paying for shopping items (with assistance from parent), taking part in school activities
Community, social and civic life	d910 (d9100, d9103); d920 (d9200, d9201, d9202, d9203, d9205)	Playing sports, going to the cinema or museum, visiting friends or relatives

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Table 5. Results from the thematic analysis

<b>ACTIVITY &amp; PARTICIPATION</b>		
<b>Theme</b>	<b>Categories</b>	<b>Examples/Codes</b>
Communicating with others	Children making their needs known; Interacting with others	Making choices, expressing needs and wants, asking questions, having and initiating conversations, communicating verbally and nonverbally
Child's leisure, early learning and educational activities	Classroom activities; Playing in the playground; Duties at school	Taking part in school activities e.g., group tasks (e.g., mat time, morning circle) and regular classes (e.g., art, music, sport), engaging in class discussions, playing in the playground, playing with other children, listening to and watching others, making friends
	Leisure activities: Technology; Reading; Games/Playing; Outdoor activities	Watching TV, listening to or reading books, swimming, playing board games
Child's independence within the home	Household tasks	Assisting parents with household chores (e.g., hanging the washing, preparing meals, cleaning), making the bed
	Child's activities of daily living	Brushing teeth, bathing/showering, eating, dressing, toileting (independently or with assistance)
Child's engagement within the community	Recreational activities; Engagement with friends; Family activities; Independence within the community	Swimming, going to the park, going to parties, going to the cinema or museum, visiting friends or relatives, playing sports, shopping, paying for shopping items (with assistance from parent)
<b>BARRIERS &amp; FACILITATORS</b>		
<b>Theme</b>	<b>Category</b>	<b>Examples/Codes</b>
Child's disposition and intrinsic factors	Child's personal characteristics	Facilitators: Child's personality, wanting to do what other children do Barriers: Being shy, tired or sick, behavioural issues or stubbornness, lack of confidence
	Child's functional limitations	Facilitators: None identified Barriers: Vocal volume, impairments in swallowing, communication and mobility which may cause frustration
Child's social environment and networks	Child's social environment and peers	Facilitators: Being around other children, other children initiating play Barriers: Child physically being unable to keep up with other children / other children moving around too fast, other children excluding the child
	Support provided by parents and siblings	Facilitators: Having a routine, parents providing rewards

		Barriers: Not offering the child choices or opportunities to speak, parents not having enough time to take child to group activities
	Support provided by others	Facilitators: Support from teachers, peers and community members Barriers: None identified
	Characteristics of communication partners	Facilitators: Going to child's level, familiarity with AAC Barriers: Not understanding the child or speaking over them, inferring what the child has said
	Attitudes of others	Facilitators: Positive attitudes of others Barriers: Negative attitudes of others, being excluded during play
	Child's surrounding environment	Facilitators: Familiar setting and people, quiet environment, seeing others participate Barriers: Unfamiliar setting, people or activity, crowded or noisy environment, lack of community options
Healthcare services	Speech pathology services	Facilitators: Health services, speech therapy Barriers: Lack of speech therapy & funding, speech pathologists' expertise
	AAC devices	Facilitators: AAC devices – increasing opportunities for communication Barriers: AAC devices (e.g., cumbersome, complicated)
Public transport	Public transport	Facilitators: None identified Barriers: Access to public transport



Table 6. Contextual factors: ICF-CY codes identified by participants and examples of responses

ICF-CY chapter	ICF-CY codes	Examples/codes from the thematic analysis
Personal factors	NA	<i>Facilitators:</i> Child's personality, wanting to do what other children do <i>Barriers:</i> Being shy, tired or sick, behavioural issues, lack of confidence, impairments in communication, mobility or swallowing
Products and technology	e125 (e1250, e1251); e150 (e1501); e155 (e1551)	<i>Facilitators:</i> AAC devices (increases opportunities for communication) <i>Barriers:</i> AAC devices (e.g., cumbersome, too complicated)
Natural environment and human made changes to environment	e240 (e2400); e250 (e2500); e299	<i>Facilitators:</i> Familiar setting and people, quiet environment, seeing others participate <i>Barriers:</i> Unfamiliar setting, people or activity, crowded or noisy environment
Support and relationships	e310; e315; e320; e325; e340; e345; e355; e360	<i>Facilitators:</i> Support from teachers, peers and community. Providing child with a routine or rewards, going to child's level, communication partners' familiarity with AAC, other children initiating play <i>Barriers:</i> Not offering choices or opportunities to speak, parents not having enough time to take child to group activities, people not understanding or speaking over the child
Attitudes	e420; e425; e445	<i>Facilitators:</i> Positive attitudes of others <i>Barriers:</i> Negative attitudes of others (e.g., doubting the child's capabilities, being stared at, exclusion during play)
Services, systems and policies	e540 (e5400); e580 (e5800, e5802)	<i>Facilitators:</i> Health services, speech therapy <i>Barriers:</i> Lack of speech therapy and funding, speech pathologists' expertise, access to public transport

