

**Parental views regarding seating and participation for young children with cerebral palsy**

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**Abstract**

*Aim:* To explore the views of parents regarding seating for children with cerebral palsy.

*Method:* Two interviews with parents were conducted. These were transcribed verbatim and thematic analysis was conducted.

*Findings:* This small study outlines three themes: 'the importance of seating', 'seating and participation', and 'the parental role in supporting participation'.

*Conclusion:* The parents in this study viewed seating as beneficial to support participation by enhancing energy conservation and promoting upper limb use. Barriers may relate to equipment provision and poor community access and parents may perceive themselves to play a role in overcoming barriers by adopting an advocacy role.

**Keywords:** Cerebral palsy, occupational therapy, participation

## **Background**

Cerebral palsy is an umbrella term used to describe a group of disorders affecting movement, motor function and/or posture which are permanent but changeable in presentation (Surveillance of Cerebral Palsy in Europe, 2000). According to Bax et al. (2005) cerebral palsy can impact on a child's motor development, affecting postural control and balance which can lead to difficulty with co-ordinated voluntary movement resulting in activity limitation. This has important implications for children's ability to perform activities that require independent mobility, sitting and controlled movement (Rigby et al., 2009).

Occupational therapists regularly recommend seating systems to overcome limitations in order to enhance a child's participation and performance in activities and it appears supportive seating can have a positive impact on family life (Ryan, 2016; Ryan et al., 2009). According to Rigby et al. (2009) adaptive seating systems enhance the occupational performance of children with cerebral palsy by overcoming participation restrictions in activities of daily living including play. In particular adaptive seating systems are commonly recommended to improve posture thereby enhancing volitional upper limb function in children with disabilities (Cook & Polgar, 2015). However, McDonald et al. (2003) state that the use of adaptive seating systems can be difficult for families and that practitioners and parents do not always agree.

The most important variable to predict participation in activities of daily living and mobility for children with cerebral palsy is their level of gross motor function (Phipps & Roberts, 2012). According to Bult et al. (2013) children's independent mobility and level of social skills are the strongest predictors for participation in later life. There is evidence to suggest also that young people with disabilities, aged 9-21 years, view participation as meaningful if

they are able to be social, learn skills, be independent, have fun and reach personal goals (Shimmell et al., 2013). Shimmell et al's (2013) study gathered data mainly from adolescents as well as from parents and provides findings that may resonate with parents of younger children.

Ryan et al. (2014) examined changes in child and family outcomes following provision of an adaptive seating system via the use of a standardised outcome measure with 70 parents of children with disabilities whose age ranged from 1 to 17 years. They concluded that there is an association between the use of adaptive seating and functional change in children which increases as the child ages, raising questions as to the experience of families who use complex seating systems with children of different age cohorts (Ryan et al., 2014). Similarly, Stier et al. (2016) found, via a study using outcome measures and interviews, that the use of adaptive seating for children aged 6-9 years with disabilities can enhance function. They concluded however that seating provision is complex and practitioners are advised to find out what is meaningful and important for children and their families when considering outcomes (Stier et al., 2016). These studies provide informative findings which consider the impact that adaptive seating may have on everyday functioning for children with cerebral palsy, however the evidence base remains limited (Novak et al., 2013; Ryan, 2016).

Hammel et al. (2013) explored the perceptions of adults who use adaptive seating and found that they are viewed as helpful to enhance choice, control and social integration. In relation to children, adaptive seating seems to have a positive impact on children's and family functioning, with the greatest factor being the parent's perception of enhanced safety and autonomy for the child (Ryan et al., 2009). A child's occupational performance, particularly

in relation to self-care, has been shown to be enhanced following the introduction of adaptive seating (Rigby et al., 2009).

There is evidence to suggest that barriers to participation are often experienced in relation to the attitude of others and the social and physical environment (Lawlor et al., 2006). In addition parents have raised the issue of cost and availability of equipment which are commonly regarded as barriers to participation for children with cerebral palsy as well (Law et al., 2013). As a consequence, in the United Kingdom (UK) parents are increasingly seeking support from charities such as Whizz-Kidz, to secure adaptive seating systems that are not always available through publicly funded services (Sharma & Morrison, 2007).

The UK government has expressed commitment to increase access to equipment that maximises participation for children with complex conditions (Department of Health, 2013), and for the National Health Service (NHS), increasing functional participation for children with cerebral palsy is an objective of seating and wheelchair services (NHS England 2013). There is recognition that research regarding seating and children with cerebral palsy should be co-developed with people who use such equipment so as to better understand their perspectives (Ryan, 2016). Therefore it is important to understand the views of children with cerebral palsy and their parents who use seating systems. This small study aimed to explore the views of parents of young children with cerebral palsy regarding the use and benefit of adaptive seating systems.

## **Method**

### ***Ethics, recruitment and participants***

Following ethical approval from the authors' university three charities in the UK were contacted and informed of the study. Recruitment posters were disseminated and individual parents who expressed an interest were sent an information pack. Upon receipt of a signed consent form interviews were arranged. Participant names have been replaced with pseudonyms to ensure anonymity.

The study implemented purposeful sampling as outlined by Creswell (2013) to recruit parents of children with cerebral palsy. Participants were required to be the main carer of a child aged between 5 to 12 years with cerebral palsy who used an adaptive seating system. The study intended to recruit up to seven carers but only recruited two. The authors decided to proceed with this small number due to the limited literature on this topic but considered the project as a pilot study thereafter. According to Smith et al. (2009) small sample sizes are adequate in qualitative research, nonetheless the authors recognise that the study provided limited findings and the data analysis was therefore largely descriptive. The participants included a father of a 5 year old boy (Andrew) and the mother of a 6 year old boy (David).

### ***Study design***

The study adopted a qualitative exploratory approach broadly influenced by theory relating to social constructionism as participants were considered to probably have different perceptions and realities of the phenomenon under investigation (Gergen, 2015). It was the authors' view that parental perceptions were likely to be constructed through interactions with and observations of their child using their seating system. Semi-structured interviews

were used as this method allowed the participants' subjective and multiple views regarding seating and their child's participation to be explored (Creswell, 2013; Kvale & Brinkman, 2014).

### *The Interviews*

An interview schedule (appendix 1) influenced by literature was devised to guide questioning over the broad area of seating and participation (Boyle et al., 2014; King & Horrocks, 2010). Interviews lasted approximately 50 minutes, were audio-recorded, and questions were guided by relevant literature making use of introductory, key and closing questions (Boyle et al., 2014; Green & Thorogood, 2013; Kvale & Brinkman, 2014). These focused on background information, then progressed to direct, and specific questions. Open-ended questions were used to explore parental views relating to how their child used their seating system and the influence this had on the child's ability to participate in occupation.

### *Data analysis*

Thematic analysis was considered an appropriate method to analyse the data (Braun & Clark, 2006). To ensure anonymity any identifiable information was removed. Transcription of each interview was carried out by the first author allowing her to become close to the data at an early stage as outlined by Denscombe (2014). Data analysis by the first author identified codes and categories which facilitated understanding of what was said (Green & Thorogood, 2013). Initial considerations were then inductively developed by drawing codes together to identify themes as outlined by Braun & Clarke (2006).

To enhance trustworthiness the authors have endeavoured to provide a written account that genuinely reflects the views of the participants with the first and second authors discussing

and agreeing the main considerations of the study as suggested by Braun & Clark (2006). To help achieve this the first author kept a detailed reflexive journal outlining her involvement in the process with a particular emphasis on capturing her own biases and predetermined views, as recommended by Finlay & Ballinger (2006). According to Ormston et al. (2014) reflexivity is considered to be important in order to recognise the position of the researcher in the study and can enhance trustworthiness. This reflexive approach, according to Green & Thorogood (2013), can enhance credibility. In this way the authors endeavoured to avoid obvious, conscious or systematic bias.

## **Findings**

Three overarching considerations emerged from the data which led to themes as outlined below with a selection of individual quotations.

### ***Theme 1: The importance of seating***

The importance of adaptive seating to support a dynamic approach was highlighted by both parents. Their view was that seating needs to support a child's movement, ensuring that position does not remain static and that the child is provided with the opportunity for both stimulation and relaxation.

*'that is an important concept but I think this is my discovery  
also for children to be constantly using a dynamic approach, so the  
chair allows adjustment and flexibility' (Andrew's father)*

Participants highlighted that it is this dynamic approach which is essential for supporting a child's motor development. Both parents discussed the importance for seats to be adaptable for particular activities and environments to support participation. One parent highlighted

that their child's needs are always changing and this creates uncertainty about his future seating requirements. The other parent stressed there is a need across statutory services for an increased awareness that seating is of paramount importance.

It was discussed that appropriate pelvic support assists the child to maintain a good posture, which both parents viewed as crucial. Andrew's father explained that without such support his son would sometimes sit 'curved forward' or 'slumped'. Ethan's mother stated that his adaptive seat supported him to maintain a good posture, which without he would tend to 'slump'. Andrew's father considered that support should also extend to his feet, as a foot plate aids him to maintain good posture. He also identified that seating can create a safe environment that allows a child to relax. It was expressed by both parents that seating devices appear to help reduce the concerns of staff in school as children are considered to be in a safe position.

*'the seating is absolutely important to provide a safe environment, to provide for them the sense of support, to provide for them a sense of relaxation or allowing interaction in a different way that focuses on their safety' (Andrew's father)*

### ***Theme 2: Seating and participation***

The influence of an adaptive seating system on their child's skill development was highlighted by both parents. The seat was viewed to support upper limb function as the children did not have to use their arms to stabilise themselves. Parents perceived that when their child was in a seating system they could then focus on activities.

*'it was at that point I thought, oh well actually you can see why he's not doing it, because he's not able to develop his hand function because he's not sitting in a good position' (David's mother)*

David's mother described how the seat improved his 'midline crossing' and fine motor skills, particularly with letter forming and writing. She also noticed an improvement in his ability to participate in functional tasks such as eating. She identified further that his seating system was used for 'focused learning' or 'structured' time, as the seat enabled him to be more able when using his upper limbs.

Both parents acknowledged that the seating systems supported participation, as less energy is spent concentrating on maintaining a good position. Andrew's father highlighted that his son is much less likely to experience pain when in his chair and this is therefore a more relaxed environment for him. David's mother also described that it was the 'doing' of an activity that was important and a good seating system helps in this regard. She viewed this as highly beneficial also for her son's self-esteem.

*'energy is wasted on sitting somewhere and energy is spent on just adjusting to the wrong seat and then there is not much left to focus on other activities, but if the seating is good and it creates certainty and not much nociceptive input he can focus' (Andrew's father)*

The parents were divided however in the use of adaptive seating to support community mobility. Andrew's father stated that he only used an adaptive seat in the school environment and it was not used for community access. David's mother identified that her son primarily used his wheelchair as a 'transit chair' for outdoor mobility, although it was also used in community settings, for example in restaurants where there would not be any form of suitable seating otherwise. She reported also that they often came across barriers to participation due

to the physical environment when accessing public transport, leisure opportunities and attending appointments.

*'and actually going to the beach is really hard because  
you can't get onto the beach with a wheelchair very easily' (David's mother)*

### ***Theme 3: The parental role in supporting participation***

Andrew's father explained that parents often take on the role of researching about their child's seating needs. He commented that 'parents are experts', although he felt that this was not always valued by services. Both parents discussed the need to advocate on their child's behalf, but they were also aware of how this may be perceived negatively by professionals. Andrew's mother stated that as a parent 'you're fighting a system constantly'. Both parents valued open communication with services, with Andrew's father stressing the need for more collaborative involvement as 'contact with the parent is really important'. Both parents discussed feelings of frustration about the lack of information available and the level of communication with parents.

Both parents discussed that they often need to solve participation problems themselves. It was identified by Andrew's father that he often needed to create his own 'self-made' adaptive seating devices and source items through mainstream avenues, when services could not meet his son's needs. David's mother discussed how as a parent she often needed to explore in advance how she could support her son's participation by adapting the activities or being creative to overcome barriers.

Cost was considered as a formidable barrier to appropriate seating by both parents and resource availability via statutory services in accessing seating services and equipment was

also highlighted as a major issue. David's mother stated that she had used charities to help fund specialist equipment.

*'I suppose the issue of getting a light weight chair is just funding' (David's mother)*

David's mother discussed that charities were an important source of support for trying new equipment and accessing training courses. She expressed concern regarding the eligibility requirements of statutory services for lightweight seats as a 'chicken and egg' situation, as children need to be competent in using the devices, but this is difficult to achieve when the equipment cannot be trialled. Andrew's father explained that he has often had to pay for private services and equipment, although this was not exclusive to seating equipment.

## **Discussion**

This is a small study but the limited findings do throw some light on parental perceptions on the use and benefit of using seating systems for children with cerebral palsy. Parents may perceive their child's participation to be enhanced if the seating system can respond to the child's changing needs as they grow, provides a safe environment whilst in a sitting position, and promotes skill development. The findings appear to suggest that a child's participation may be supported by the parents themselves, through advocating on their child's behalf, being experts on their child's condition and seating needs, and being able to problem solve when barriers to participation arise. Parents appear to perceive that appropriate seating may reduce the need for children to stabilise themselves due to the postural support provided and this may enable upper limb function and task engagement.

The interaction between stability and upper limb function has been discussed previously by Lacoste et al. (2009) who found that if a seat does not provide a child with pelvic stability then motor control and upper limb function in activities of daily living is compromised. The

parents in this study are of the view that adaptive seating helps their child to conserve energy which in turn might assist them to focus more on activities. According to Stavness (2006) an upright functional sitting position for children benefits upper limb function and reduces energy expenditure on maintaining position resulting in the child having more energy to focus on meaningful activity. Stavness (2006) also raised the importance of pelvic support, a flexible seat angle, having a surface for engagement, and support for the feet. The parents in the current study appear to have similar views.

Studies exploring the benefit of seating on occupational performance for children with disabilities, have found that seating systems can increase activity duration, engagement and overall function (Rigby et al., 2009; Ryan et al., 2014; Ryan et al., 2009). Hammel et al. (2013) explored the meaning and priorities of individual stakeholders who either use or prescribe mobility technology and found that mobility devices for disabled adults should be evaluated in relation to reduced energy expenditure and safety, in addition to activity performance. The current study encourages consideration of the benefits of postural supportive adaptive seating for young children. Specifically, both participants in this study perceived such seating as helpful for children with cerebral palsy to conserve energy thereby allowing them to focus more on activities.

The parents in this study perceived that adaptive seating provides a safe environment for their child which enhances participation in meaningful activities. Ryan et al. (2009) found that parents' perception of increased safety was highly influential in improving the function of children and their families. It appears this perceived benefit of seating can reduce parental anxiety thereby improving the quality of life for the whole family as parents are more content that their child is supported appropriately and less likely to experience pain. Fauconnier et al.

(2009) found that pain, as perceived by parents of children with cerebral palsy, can negatively impact on a child's abilities which should therefore be assessed carefully in clinical practice. As children with cerebral palsy can spend up to 11 hours a day in their seating system (Lacoste et al., 2009), and pain management is a primary objective of postural management in the UK (NHS England, 2013), then the views of the participants in the current study may be of interest for practitioners when considered in the light of previous studies.

Lenker et al. (2013) found disabled adults view assistive technology, such as mobility aids, as a means to facilitate participation through increased community mobility, productivity and opportunity. However, physical barriers to participation in the community were considered as a problem by the parents in this study, reflecting the findings of previous studies (Lawlor et al., 2006; Østenjøl et al., 2003; Roy et al., 2008). In response the UK government has called for initiatives to support individuals with disabilities to participate fully in their homes and communities by developing accessible communities and transportation through inclusive design (Department for Work & Pensions, 2014). The findings in the current study encourage consideration of physical barriers for young children with disabilities in particular, which may remain a problem for parents and children who use adaptive seating equipment.

Accessibility issues were not restricted to just the physical environment however. The ability to source equipment that meets their child's needs and the necessary funding were also considered as problems by the participants in this study. This reflects the findings of Law et al. (2013) who found that inadequate funding and unavailable services are the greatest barriers to participation. Both parents in the current study are of the view that publicly funded services are limited in what they can provide, that cost can be a barrier and that parents may be required to privately fund equipment or approach charities for support. This has also been

identified as an issue by the British charity Whizz Kids, who provide families with seating support (Sharma & Morrison, 2007).

The enabling influence that parents can have on their child's participation was expressed by the participants. This has been examined previously by Piškar et al. (2012) who identified that parents of children with disabilities support participation by choosing suitable activities, advocating on their child's behalf, educating others and networking with other parents. The parents in the current study understood themselves to be experts regarding their child's needs, with a responsibility to advocate on their child's behalf and overcome barriers to participation, reflecting the findings also of Lawlor et al. (2006). According to McDonald et al. (2003) parents and practitioners may have different objectives regarding the use of seating systems with parents more interested in function and day-to-day management issues and the therapist more focussed on postural management. As the occupational therapy profession recognises the importance of meaningful activity (College of Occupational Therapists, 2017), it would seem reasonable then, that by acquiring a deeper understanding as to how parents facilitate participation for children with cerebral palsy might inform those practicing in seating services.

Law et al. (2003) recommend a family-centred approach that understands the unique quality of each family and that parents are the experts to work with in partnership. Appropriate provision of seating systems for children with cerebral palsy is a costly and complex process for which more empirical evidence is necessary as well as greater concentration on sharing decision making with children and families (Ryan, 2016). The current findings encourage recognition that parents may view themselves as experts regarding their child's condition and seating requirements, as well as their feeling that their 'expertise' is not always valued by

services. According to Almasri et al. (2014) a family-centred approach helps to reduce the level of overall need for families of children with cerebral palsy, particularly through the provision of accessible, supportive and respectful services. It may be worth exploring and considering therefore how seating services could work in partnership with parents in order to enhance children's participation in meaningful activity. This study considered the views of two parents only, however the findings may be helpful to inform the design of a more rigorous study to enhance understanding as to how adaptive seating supports participation for children with cerebral palsy.

### **Limitations**

The authors recognise that this was a small, descriptive study with findings that are informative rather than generalizable. There is a dearth of literature however that explores parental views regarding seating for children with cerebral palsy and this study does provide some tentative findings for practitioners and researchers to consider. It is of interest also to note the demands that parents of a disabled child experience and this may provide some reasoning as to the difficulty with recruitment.

### **Conclusion**

Adaptive seating systems are recommended by occupational therapists for children with cerebral palsy to provide postural support and overcome limitations to participation. Although only two participants were recruited the authors consider the content of the interviews to be of interest which may encourage further research in this area. It appears that the parents in this study perceive appropriate seating as beneficial to help conserve energy, increase comfort and reduce pain for their child. Use of seating systems in this way was considered by both participants as beneficial to support skill development through improved

upper limb function. Appropriate seating it seems may also provide postural support and an increased perception of safety for the child by the parent. This pilot study encourages consideration of the above issues as well as cost and availability of equipment, accessible communities, and collaboration between services and parents as areas for future research.

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## **Appendix 1**

### **Interview Schedule**

#### **Introductory questions:**

Could you tell me a little about your child, for example their age, gender and their type of cerebral palsy?

What adaptive seating system does your child use at home for support?

#### **Transition questions:**

What activities does .....like to do or they enjoy doing?

What are some of the activities that your child finds it difficult to do?

#### **Key Questions:**

Could you tell me a little about how their seat is used for (activities mentioned above) in the home environment?

#### ***Prompts:***

*How does it influence their access around the home?*

*How does it impact on their play?*

*How does it influence daily activities?*

Do you observe changes in your child when in their seating system and carrying out these activities?

What seating systems do you use outside of the home for support?

How do you view their seating system influences their engagement outside the home environment?

***Prompts:***

*Socialising with friends?*

*Accessing community activities?*

*Going to the park?*

*Family activities?*

***Further probing ideas if necessary:***

*Could you expand on that?*

*In what way do you see that their engagement has changed?*

*How do feel seeing that the seating system is enhancing their engagement*

*Could you tell me about any changes you observe in your child when in their seat?*

*What does that mean for you as a parent?*

*Are there activities that your child prefers to do not using their seating system?*

**Closing questions:**

Is there anything you would like to add or clarify?

Is there anything you would like to go over?