

Exploring the lived experiences of  
children with specialised wheelchair  
and seating needs from a family  
perspective

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# **Exploring the lived experiences of children with specialised wheelchair and seating needs from a family perspective**

## **Abstract:**

The purpose of this study is to describe the lived experience of children who have specialised wheelchair and seating needs from a family perspective with a view to facilitating family-centred practice in wheelchair and seating services. Concepts of acceptance and adjustment for the family, integration into the home and community environments, experiences with service providers, perceptions of family-centred practice, and general views and opinions regarding wheelchair and seating services were of interest in this study. Participants were recruited under the Enable Ireland remit. An interpretative phenomenological approach was used and data was gathered through semi structured interviews with three families.

The research provided an insight into how family members viewed the impact of the phenomenon and adjusted to life with a child who has specialised wheelchair and seating needs. Four main themes emerged from the data: Acceptance and adjustment, learning new ways of doing, being independent and interactions with service providers. Findings from the study suggest that caring for a child with specialised wheelchair and seating needs is a family affair and affects the entire family unit. Using a holistic approach to wheelchair and seating service provision which encompasses the philosophy of family centred care is optimal to support family health and wellbeing.

## **Introduction:**

Occupational therapy is traditionally focused on delivering a holistic and client centred approach to health care. More recently, this holistic framework has broadened to encompass the assessment of family needs and the impact of disability on the family unit.

McKean et al (2005) define family-centred care as “placing the needs of the child in the context of their family and community” (McKean et al 2005, p.75). They conceptualise that professionals should view the client and their family as a collective and that services should therefore be aimed at accommodating for the needs of both the client and the family.

Principles of family-centred care stipulate the need to consider people in terms of their everyday routines and in the context of the environment in which they function so as to deliver a service that is holistic and conducive with the client's life (Rodgers and Hogan 2003; Bernheimer and Weisner 2007; Diamond and Kontos 2004 ). These principles apply to wheelchair and seating systems also as wheelchairs are a primary assistive device (Gowran 2011) and therefore, like any other dimension of disability, have a significant impact on the family system.

The objective this phenomenological study is to support a family-centred framework in wheelchair and seating service provision through exploring the question: What is the lived experience of families with children who use specialised wheelchair and seating systems?

## **Literature Review:**

Pettersson et al (2005) highlight the essential fact that assistive device users do not function in isolation. They perceptively state that assistive technology affects not only the user but carers and families also. This supports findings from Gowran (2011) who reports the wheelchair as being an essential component of the life of the whole family. Similarly, in the context of children with disabilities and making specific reference to wheelchair users, Brotherson et al (1996) point out that any change to the family system affects the entire family unit.

Research into the health and wellbeing of families with children with disabilities points to two key concepts in relation to service delivery; the importance of involving the family in goal setting and decision making, and the need to consider the child in terms of their family and

home environment (Law et al 2003, Davis and Gavidia-Payne 2009, Bernheimer and Weisner 2007). Family centred services that acknowledge the effect of disability on the entire family unit and promote a positive service experience for both the child and their family, can support family health and wellbeing and improve quality of life (Davis and Gavidia-Payne 2009; Hughes 2007). Therefore like any other service, wheelchair and seating provision is a family affair and should be delivered in a family-centred context.

### The family experience

Family focused studies support the implementation of family-centred philosophies into practice through describing the lived experience (McKiernan and McCarthy 2010).

Considerable research has been carried out which focuses on the experience of families with children who have a disability (Dowling and Dolan 2001; King et al 2003; Resch et al 2010; Ryan and Runswick-Cole 2008; Bourke-Taylor et al 2010). There has also been some research which has looked at the experience of families in using assistive devices in general (Brotherson et al 2008; Morse et al 2000; Huang et al 2008; Parette and Brotherson 2004; Ostensjo et al 2005). However this literature review found little consideration for wheelchair and seating devices in particular. The purpose of this study was to overcome this gap in the literature.

### Current practice

Findings by Kane (2000) suggest a lack of uniformity in the provision of wheelchair and seating systems in Ireland and highlight the need to move towards a more sustainable system of provision to meet people's needs. The benefits of family-centred service delivery for both families and service providers have been highlighted in literature and research to date (Law et al 2003; MacKean et al 2005; Bernheimer and Weisner 2007; Angelo et al 1995). However, findings by Wright et al (2010) show a lack of consistency in seating assessments in the UK and Ireland, notably in terms of the way in which the family is considered. This concurs with findings in overseas studies (Parette and Brotherson 2004; MacKean et al 2005) where it is reported that there is disparity between family centred theory and family-centred practice. This research has the potential to facilitate such practice by means of informed research into the lived experiences of families.

## Methods

### Design and Sample

A qualitative phenomenological design was used to gather data for this research project. Phenomenology was chosen as it is concerned with exploring experiences from the perspective of the individual (Warren & Kramer 2010). Interpretative phenomenological analysis (IPA) is a specific approach which seeks to “gain access to research participants’ life worlds” (Willig 2009, p56) and therefore is in line with the overall focus of this research. “Through using IPA, it is possible for occupational therapists to develop a deeper understanding of the experience of clients, carers and colleagues, which in turn may facilitate reflection on current practices and lead to changes that enhance service provision” (Clarke 2009, p37).

Participants were recruited for this study through a gate keeper at Enable Ireland. A sample of 5 family members from 3 separate families was chosen. The breakdown of family members interviewed was three mothers and two fathers. This sample size is consistent with IPA principles where studies are conducted on relatively small sample sizes (Smith et al 2009). The inclusion criterion was purposeful with the participants being selected for their knowledge and experience of being a family member of a child with specialised wheelchair and seating needs. The inclusion criteria were that the family member:

- have a child in the age bracket of 15 to 18 years living with a disability,
- have a child who is a regular user of wheelchairs and specialised seating,
- be the primary caregiver for the child,
- is able to speak and understand English.

**Table 1: Participant Characteristics**

	<b><u>Interview 1:</u></b>	<b><u>Interview 2:</u></b>	<b><u>Interview 3:</u></b>
<b><u>Relationship to child</u></b>	<b><u>Mother and Father</u></b>	<b><u>Mother and Father</u></b>	<b><u>Mother</u></b>
<b><u>Age of child</u></b>	<b><u>18</u></b>	<b><u>13</u></b>	<b><u>18</u></b>
<b><u>Child’s diagnosis</u></b>	<b><u>Cerebral Palsy- Spastic Diplegia</u></b>	<b><u>Cerebral Palsy-Spastic Quadriplegia, Di George Syndrome</u></b>	<b><u>Osteogenesis Imperfecta</u></b>

## Ethics

Ethical approval was obtained from the Enable Ireland Research Ethics Committee and permission to access the participant group granted through the Occupational Therapy Manager at the Enable Ireland Centre.

In order to ensure confidentiality of participant's personal details the researcher had a limited role in the selection process. Participant suitability criteria and details of the research project were produced by the researcher and forwarded on to the gate keeper. Enable Ireland then selected suitable and willing participants. Allowing the participants to remain essentially anonymous to the researcher removed the risk of exposure of personal information during the writing up stage of the research process.

The researcher was cautious that sensitive issues may arise during the interview process which could have caused discomfort for the participants. In order to reduce the possibility of this, informed consent was sought prior to the interview which provided the participants with detailed information regarding the nature and purpose of the research and how confidentiality and anonymity will be approached (see appendix A and B).

## Data collection and analysis

Semi structured interviews with open ended questions were used to gather data from participants. This is the recommended and most commonly used approach for data collection in interpretative phenomenological research (Smith et al 2009; Willig 2009). Spouses were interviewed together; totalling three interviews in all. Participants were given the freedom to choose a location for the interviews to take place. All participants chose to conduct the interviews in a quiet room within the Enable Ireland centre. With the permission of participants, interviews were recorded and the researcher also took field notes. Interviews were transcribed verbatim by the researcher and transcripts were sent to the participants for member checking. (See appendix C for interview questions)

Analysis of data collected through the interviews followed a systematic process as per the IPA framework (Smith et al 2009; Willig 2009). The first stage involved reading and re-reading of individual participant transcripts. At this stage the researcher documented some points which

arose from initial interpretation of the texts. Stage two required the researcher to identify themes from throughout the texts. Stage three focused on building structure into the data analysis by looking for relationships between the themes and forming some overarching themes. At stage four the data collected took the form of narrative accounts supported by direct quotations from the transcripts. At this stage the researcher incorporated some of her own analytic interpretation and, together with the verbatim extracts, the findings of the study were formulated.

### Reflexivity

Reflexivity is a key concept in qualitative and IPA studies (Smith et al 2009, Warren and Karner 2010). It required the researcher to be aware of the way in which personal meanings are constructed throughout the research process and the influence that this can have on the outcomes of the study. Care was taken to ensure that the findings of this study remained grounded in the participants' accounts through including verbatim quotes throughout the writing up stage and validating the data with the participants. The researcher also made use of a reflective diary to record and raise awareness of personal points of view, perspectives, emotions and thoughts. On-going reflecting meant that the researcher was less likely to impose personal perspectives on the accounts and actions of the participants.

## **Findings**

This research identified four main themes which emerged from the data collected: Acceptance and adjustment, learning new ways of doing, being independent and interactions with service providers.

### Acceptance and adjustment

Participants spoke about the early stages of wheelchair provision. Initially marked by disbelief and sadness, the experience gradually moved to a stage of acceptance. One participant spoke about this transition towards acceptance in relation to a loss of control over the situation, whereby the transition to wheelchair became inevitable:

“Nobody wants anybody to be in a wheelchair really but like you know when you see her sort of getting worse and worse and worse and there was no option but to have a wheelchair. There was nothing we could really do about it our hands were tied and that was it.” “Both her and ourselves gave in really like and we had to have it and that was it.” (Dad 2)

For another participant, the period of acceptance and adjustment to the situation was helped by the fact that the child was of a young age. She felt that this made it somewhat easier to adjust and fit it in to the families everyday functioning:

“I think maybe the younger you are it just becomes a part of everyday life whereas if you were an adult it’s completely different... whereas he's in it since he was a small child like. So we just you know... we’re just so used to it now at this stage.” (Mum 3)

For some, adjustment to their own experience was helped by comparison with others. Participants gained perspective through downward comparisons- looking at someone who they perceived to be worse off than they were:

“You see things that’s worse than what you’ve got yourself you see. And then you’d appreciate what you have you know.” (Dad 2)

### Learning new ways of doing

Family members spoke about their inexperience with wheelchairs and the newness of the whole situation in the beginning. It was seen as a learning curve for the entire family. They faced situations which required them to adopt new means and methods to activity.

“It was completely different like I would never have met anybody in a wheelchair before, it’s different” (Mum 3)

“We’re new to it as well I suppose. We’re learning all the time as well you know, with wheelchairs and with walkers.” (Mum 2)

Having surmounted the learning curve, participants came to realize that it is only through the lived experience that the phenomenon can be understood. People who have not experienced it therefore cannot truly understand it or relate to their lives. This can be seen reflected in the following participants' accounts:

“You'd notice it like but people that don't have wheelchairs and don't have anybody in a wheelchair would not. They'd just take it for granted you know everybody can walk and that's it.” (Dad 2)

“I suppose you could see where people not in a wheelchair might not understand it because they haven't experienced it but it does change things definitely yea” (Mum 3)

### Being Independent

Family members described the wheelchair as being a prerequisite for independence; it made participation possible for the users. One participant spoke about the transition from manual to electric wheelchair which her daughter is currently in the process of. She describes how this transition will enable her daughter to have more independence with her friends:

“She will go down town with us but she wants to go down with her friends. They're starting to go down town. And I said before like they don't want to be pushing her up the hill. I wouldn't blame them either”  
“it's pushing her around it's tiring like you know. But anyway so when she's the electric one now she'll be able to do it herself.” (Mum2)

However, experiencing independence was threatened when environmental factors limited participation. Over time, family members became adept at overcoming obstacles. Some participants reflected on situations which involved being innovative so as to overcome adversity and support participation for their child. The following accounts illustrate this:

“There's a roller blade thing below in am (name of place)

and she had a party there one day...” “We took her out of the chair and we caught her up and put roller skates on her to make her feel included... but they [her friends] took her out in the chair then as well because they said oh you’ve wheels too you know.” (Dad 2)

### Interactions with service providers

Participants spoke about how they gained knowledge from the service providers they came in contact with and used their experiences as a source of guidance:

“They see problems there that we don’t even see at all and they’d be on it straight you know. Like we don’t see them things at all and we’d be looking at him all the time.” (Dad 1)

“they’d even show you things that if you were with her every day of the week that you wouldn’t see at all yourself if you know what I mean” (Dad 2)

Service providers were seen as a source of support and also helped in the adaptation process. Some participants viewed them as companions, someone who they could relate to and who would understand what they were going through:

“To have somebody to talk to who knows what we were on about...” (Mum 3)

“...the fact that they’ve went through it already. They’ve seen things that we’ve never seen and they’ve seen things that that we never will see.” (Dad 2)

One participant recalled how she was given support to cope with concerns not just directly related to her child but also her own worries:

“I didn’t know what I was doing and I was going to counselling myself” “they were very good on you know other things besides (child’s name) like. It was great; there was good support here like.”

Another family member also emphasised the comfort in familiarity with staff members and in the continuity of care over time:

“They’ve actually seen her the same as us going from where she was to where she is now you know. And their all pretty familiar with her you know... the way she’s going and that.” (Dad 2)

Reflecting on their interactions with service providers over the years, family members described what they felt to be the most important features which allowed for a positive experience. One participant spoke about the importance of recognising the individuality of each client:

“Some people will go by the book; you do this, this, this and this. Whereas, that doesn’t always work like. Every case is different and you have to treat every child as different ...” (Mum 3)

## **Discussion**

Family’s stories offer a window of insight into the way in which families make sense of their world. This research identified four main themes in relation to the family experience which will be discussed in the context of existing literature.

### Acceptance and adjustment

Participants spoke about a stage of reluctant acceptance whereby the transition to wheelchair became necessary and inevitable. Family members did not want their child to use a wheelchair but recognised that as the child got older there was no alternative. For family members, there is an emotional adjustment that occurs, including the recognition of new or increasing disability and an unnerving relinquishment of control over their child’s life. This is

similar to the work of Begay et al (2009) who refer to a stage of ‘emotional turmoil’ (p94) which families experience when their child is diagnosed with a disability. Begay et al (2009) observed that parents of children with disabilities can experience a real or perceived loss of control in their parenting role, particularly when they must seek out assistance from persons outside the family unit. Furthermore, when something happens that is beyond the parent’s control, it can leave them feeling disempowered and disenfranchised. Service providers play a key role here in ensuring that families receive the support they require, while also providing opportunities for families to exercise control over their lives and the services they receive.

### Learning new ways of doing

Family members had to acquire the knowledge and skills needed to not only care for their child but also to ensure that their child continued to experience participation. The world is now seen differently, not always catering to the requirements of a person in a wheelchair and families were required to be innovative in the face of new challenges. This resonates with the notions proffered by Brotherson et al (2008) where families are shown to play a key role in providing, maintaining, and regulating children’s opportunities and experiences in everyday life. Brotherson et al’s (2008) study discusses how the level of determination within the family can either support or hinder participation for the child. Family members in the present study displayed their fortitude as they highlighted their methods to ensure inclusion for their child even when faced with an unreceptive environment.

Through their experiences, family members gained a new world perspective which is seen as being unique and not one that is shared by everyone. Participants discussed how they learned to adjust and cope with the changes and challenges they faced and as a result were opened up to a new and exclusive life perspective. This finding supports that by Scorgie and Sobsie (2010) who discuss in their study the transformations in the lives of parents with children with disabilities. Scorgie and Sobsie’s (2010) study explore parents’ self-reported changes in how they view the world around them and how the most basic of assumptions can be challenged on a daily basis.

### Being independent

Throughout the participants’ accounts, the wheelchair was described not in terms of its technical features but in terms of the opportunities which it afforded the user; largely the

opportunities to participate in societal life. The wheelchair was viewed as being a prerequisite for independence; it made activity and participation possible. So, rather than being about the disability, the wheelchair became about what the child can now do. Through prescribing this meaning to its function, parents became more accepting of the wheelchair. As in the Pettersson et al (2005) study, it was viewed by family members as enabling possibilities for the user and this concept outweighed any negatives. Resonating with Pettersson et al's (2005) view on assistive devices being incorporated with the user's body, participants in this present study stated that without the wheelchair the child could not go on living independently. As one parent noted, without it "he'd be just clamped there" (Dad 3). The wheelchair is viewed as being as much a part of the person as anything else and it's this concept that constitutes its essentiality.

Similar to the meaning-making processes discussed here, Patterson (2002) offer an interesting discussion on family resilience and family coping strategies. Patterson's (2002) study states that attributing positive meaning to a situation is a central process associated with family resilience and can directly influence the family's experience. By changing the way in which they think about their situation the family is better able to cope and successfully manage challenging life circumstances, thus minimizing the risk of family crisis.

#### Interactions with service providers

Family members in this study clearly articulated a need for information. The level of knowledge that service providers had in relation to the child's needs and about wheelchair and seating systems in general was highlighted as a key feature. Allied to this was a sense of trust that service providers will keep families informed. Service providers were seen as being the gateway to ensuring that the family's informational needs were met. This is congruent with findings by McKiernan and McCarthy (2010) where family members expressed a feeling of security and reassurance in knowing that staff will keep the family up to date with information regarding the client's needs.

As well as providing information, family members also described how they drew on staff members as a source of support and companionship. A number of different support networks were mentioned, including their own families and friends, but service providers were seen as being a primary supportive presence. Participants described the sense of reassurance in

knowing that service providers understood what they were going through and had experienced it all before. Beckman (2002) echoes the importance of social support from service providers and suggests that building a strong relationship with the family should be considered a form of intervention. In contrast, Resch et al's (2010) study demonstrates what can happen when family members don't receive the support they require and as a result become "paralyzed with the challenge" (p145) of coping with unfamiliar issues.

Studies such as that of Knox (2001) and Judge (2002) suggest that a family-centred approach translates to family members assuming greater responsibility and being in control during decision making processes. This resonates with MacKean et al's (2005) discussion on family-centred care in which they noted a strong emphasis on parents assuming greater responsibility over and above other important elements of family centred care. In contrast, while participants in the present study were appreciative of professionals who involved the family, they also valued the experience and knowledge that professionals had. Family members spoke about the level of trust that they had in service providers and there was less emphasis on the need for families to be in control. This was particularly evident during the initial stages of adjustment when participants were aware of their own inexperience and looked to the service providers for guidance and support.

#### Limitations of this study

Certain limitations should be highlighted in the present study. Firstly, participants in this study cannot be considered to be representative of all families with a child with specialised wheelchair and seating needs. It is possible that individuals who volunteered for this study are fundamentally different (e.g., parents who are possibly more active and involved in support groups) than other parents thus influencing their outlook on service experiences. Care must be taken in generalizing the results to the wider population. As well it cannot be assumed that participants were representing the views of other members of their own family. However the approach taken has enabled an exploration of the experiences and views of these family members.

Participants chose to conduct the interviews within Enable Ireland premises. Although the researcher made every effort to ensure participants were at ease, it should be noted that the

environment could have had an impact on the openness of participants (e.g. in discussing experiences with service providers).

### Recommendations

The concept of family-centred care is not a new one, particularly to occupational therapy practitioners. We have focused on providing therapeutic services in a holistic and family inclusive manner for some time now. However, despite its longevity, existing literature would suggest that it is yet a dynamic and evolving approach. Little research has been conducted to assess its application and significance in wheelchair and seating services in particular.

Therefore the findings of this study offer several important contributions to existing family centred literature and should be used to further enhance the application of family centred principles in wheelchair and seating services.

The family-professional relationship is a critical element of family-centred care and the present study highlighted the dramatic impact that this can have on the way in which the phenomenon is experienced. This study highlighted specific aspects of care which participants found to be core to effective collaboration between families and professionals. Further research could be conducted to explore the way in which professionals view this relationship. Studies could also address the experience of different family members. This could support an understanding of which strategies are particularly effective in establishing a family-professional partnership.

Another area which could be considered in future research is the impact of staff changes and staff irregularities on the family experience. Some participants pointed out the comfort in familiarity with staff members; an interesting concept which is lacking from existing literature. It seems only natural to find comfort in familiarity and consistency. In everyday life we seek this out (e.g. buying the same brand of food or products) and with this comes a sense of trust and control. People prefer familiarity to the uncertainty of the unknown. So, like any other dimension of life, stability and reliability of service providers is a particularly important aspect of care and should be considered in wheelchair and seating services.

## Conclusion

The findings suggest that caring for a child with specialised wheelchair and seating needs is a family affair and that any change to the family system affects the entire family unit. The transitions described by participants from buggy to manual wheelchair to electric wheelchair were seen as being pivotal moments for all involved. The phenomenon led the families through a new and uncertain journey which required them to adopt new methods of being and doing and with this journey came new a world perspective. Having overcome the learning curve, participants came to a realization that it is only through the lived experience that the phenomenon can be truly understood.

For all family members in this study, the experience of a child with complex wheelchair and seating needs was an ambiguous phenomenon which initially evoked mixed feelings of sadness, loss of control, concern for their child and uncertainty about how to meet their needs. Over time participants found themselves adjusting to the circumstance and becoming more accepting of the wheelchair system as they prescribed personal meaning to its function.

Participants described how service providers were a source of valuable information and guidance and with this came a sense of reassurance and support. Service providers were seen as a source of companionship; someone who understood what they were going through and could advise them at every step of the way. At times there is a sense of dependency on staff. Participants had to place a certain amount of trust in these professionals; trust that professionals will tell parents when they see things that they don't see and trust that they will keep parents informed.

Family members identified specific aspects of care which support a positive experience with service providers, these include; open communication, being listened to, asking families about the level of involvement they desire, treating each person individually, familiarity and consistency of staff and availability of staff to family members. These findings are consistent with the principles of family centred care and support findings by Beckman (2002) who stated that family members desire a provider who is available and compassionate and who is able to build strong relationships with the family.

In conclusion, this study explored the experiences of family members of children with specialised wheelchair and seating needs. It has allowed for valuable insights into the way in which families make sense of their own family reality. Family members highlighted mostly positive experiences with service providers and identified specific aspects of care which contributed to this. While the involvement of family members in decision making processes was important, the sense of reassurance and security associated with the service providers' judgment was more significant to the overall process. This suggests that family centred services should take into consideration the family's preferences about their level of involvement.

With the increasing emphasis on family-centred care, family involvement and consideration of family needs must be of paramount importance in the delivery of wheelchair and seating services. The use of a strong and supportive family-professional relationship can dramatically impact how family members perceive and experience the phenomenon. The present study assists in gaining insight into the complex worlds of families and should be used to guide the implementation of family-centred care in wheelchair and seating services.

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## Appendix A



### Information Sheet

#### **What is this study about?**

This research will explore the lived experience of children with specialised wheelchair and seating needs from a family perspective. The study aims to explore how the family system could be better considered within wheelchair and seating provision. Aspects which will be approached include:

- The experience of using wheelchair and seating systems within the family from the first introduction of a device to the present day
- Some specific experiences of using these devices in community and social settings
- General opinions and views regarding wheelchair and seating services; more specifically in relation to the role of the family during the process.

#### **What does the study involve?**

I would like to talk to you about your views and experience so far. It will be an informal discussion lasting approximately one hour. The interview will take place in a convenient setting either on Enable Ireland premises or you will be given the opportunity to choose your own setting. Given your permission, the interview will be recorded and later transcribed. A copy of these transcripts will be sent to you in advance of the research 'writing up' stage for approval.

#### **Do you have to take part?**

No. This is a voluntary study. I will provide you with enough information so that you can make an informed decision as to whether or not you would like to become involved. If you choose to take part then you will be asked to sign a consent sheet. If you decide to take part but change your mind at a later date, you have the right to pull out of the study and anything you have contributed at this point can be disregarded from the study.

#### **What about confidentiality?**

All information gathered throughout this study will be treated with the upmost of confidentiality. Written documents will be stored in a locked cabinet on University of Limerick premises. Only the researchers directly involved in this study will have access. At no point will the public domain have access to any personal data. Pseudonyms will be used on all written documents so as to ensure the anonymity of participants. In the event that you would like to be acknowledged for your contributions to the study, this can be suitably organised.

**Appendix B**



**Consent Form**

Name: \_\_\_\_\_

I hereby give my voluntary consent to Susan Cronin to use any information or data obtained from the interview as part of her MSc Occupational Therapy final year project. I understand what is being asked of me as a participant in this study and I have been informed that all information is to remain strictly private and confidential.

Signature: \_\_\_\_\_

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

## Appendix C



### Sample Questions

1. Can you tell me about the first time you and your family were introduced to wheelchair and seating systems?
2. Did the experiences have an impact on the family unit?
3. Can you tell me about how you integrated the wheelchair and seating system into your family home?
4. Tell me about an everyday day experience involving these devices now?
5. Did it become easier to manage the wheelchair over time?
6. Can you tell me about your experiences using the devices in community and social settings?
7. Tell me about your experiences with wheelchair and seating providers in the beginning?
8. Did your experiences change over the years? If yes, how?
9. In what way, of at all, do you think that the family system is considered in wheelchair and seating service provision?

## Appendix D: Themes identified (Overview)

<p>Acceptance and Adjustment</p>	<p>Mixed Emotions, moving through the motions          Loss of control          Downward comparisons          Stage of life</p>
<p>Learning new ways of doing</p>	<p>New and uncertain phenomenon          Learning curve- inexperience and lack of knowledge          Innovation and overcoming barriers          Changing perspectives</p>
<p>Being Independent</p>	<p>Meaning making process          Positivity, hope,          Fitting in, doing what other children are doing, growing up          Participation</p>
<p>Interactions with service providers</p>	<p>Support          Companionship          Trust          The need to know, information sharing          Honesty, openness, communication          Familiarity and consistency          Dependency</p>