

**The impact of caregiving for physically disabled children who
use wheelchairs on their caregivers' occupational
performance, health and satisfaction.**

A Report to the Posture and Mobility Group June 2013

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TITLE: The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction.

Summary Report

Background

Recommendations from the "Proposals for the Reform of the Northern Ireland Wheelchair Service" (DHSSPS 2008) identified the need to respond to the individual needs of each service user, including their physical and lifestyle needs to ensure maximum independence, social inclusion and quality of life. These recommendations did not however, recognise that for many clinicians working in children's services there can often be a fine balance between child/client-centred and family-centred practice. These children who depend upon a wheelchair for all their mobility are dependent upon support and facilitation by their parent caregivers. These caregivers can often find that their lives evolve around providing for the needs of these children. There are over 25,500 people in Northern Ireland who are wheelchair users who have been provided with a wheelchair via the National Health Service (Regional Disablement Services, Northern Ireland Statistics and Research Agency, 2011). Of this population there are 2562 NHS service users who are children i.e. under the age of eighteen.

The role of caregiving can be stressful and has been found to negatively influence the health and wellbeing of caregivers (Bourke-Taylor et al 2010; Raina et al 2005; Quittner et al 1992; Breslau 1983). Some researchers have found that caregiving for children with complex needs can create both emotional and physical demands upon the parent caregiver (Ryan et al 2007). In particular, caregiving for children who have cerebral palsy (Button et al 2001), Down's Syndrome (Byrne & Cunningham 1988), or autistic spectrum disorders (Tobing & Glenwick 2002) can result in greater levels of stress for these parents than for parents whose child does not have a disability.

However, little is known regarding the impact on the health, wellbeing and occupation of parent caregivers of physically disabled children who use wheelchairs. Indeed it has been hypothesised that the provision of assistive technology such as a wheelchair should reduce the stress and burden upon parent caregivers (Ryan et al 2007).

Design

A mixed methods design was adopted for this pilot study to gather the information determining the impact of caregiving for a physically disabled child who uses a wheelchair. Quantitative data was gathered through the completion of a demographic form and administration of two questionnaires (Parent Satisfaction Index; Short Form Health Survey SF-36). Qualitative data was obtained using semi-structured interviews designed to ascertain the caregivers' perspective of caring for their child, their satisfaction with this role and the impact it has had upon their own life.

Ten parent caregivers of children aged between 6 and 11 years, were recruited for this study through the Regional Wheelchair Service based in the Belfast Health & Social Care Trust, and Muscular Dystrophy Campaign.

Research Questions

RQ1. How satisfied are parents, of physically disabled children who use a wheelchair, with their daily life activities?

RQ2. What is the possible impact on health and wellbeing of children's wheelchair use on their caregivers?

RQ3. What is the effect of caring for a physically disabled child who uses a wheelchair, on time use of their caregivers?

Key Findings & Recommendations

RQ1. Satisfaction with caregiving

There seemed an overall sense of acceptance among the majority of caregivers and an embracing of this role as their sense of purpose and being. However, it was at the expense of engaging in paid employment, having friends outside of the 'disabled world' and personal relaxation time. Despite these parent caregivers reporting satisfaction with this role, they reported experiences of stress and time in advocating for and following up on the provision of a wheelchair for their child.

Recommendation: In an effort to manage stress and time parent caregivers would benefit from having regular and timelier access to services for assistive technology equipment repair and review.

RQ2. Health and wellbeing of parent caregivers

Caregivers experienced physical strain, disrupted sleep and emotional distress as a result of caring for their child. Many reported the loss of previous work roles, friends and social opportunities as a consequence of caregiving for their child.

Recommendation: Greater consideration should be given to helping these parents to access social and emotional support to secure a healthy balance between tasks they undertake directly for or with their child, and those for themselves, to protect their own identity, health and wellbeing. They should be signposted to social services departments and or local charities and organisations to access this support.

RQ3. Time use of caregivers

Parent caregivers spent most of their time around providing for the needs of this physically disabled child who uses a wheelchair. These activities included caregiving, therapeutic exercises, giving medications, managing or following up on equipment for the child. The majority did not partake in external activities unless these concerned the child. Few felt able to maintain any external friendships other than those from within the

‘disabled world’. Most did not avail of any external care support to share the task of caregiving for this child.

Recommendation: Efforts should be focused on exploring how these caregivers can be encouraged to utilise respite support services available through social services in the management of their child’s needs. Parent caregivers should be given the opportunity to maintain their roles outside of caregiving for their physically disabled child. It is important that parents do not feel guilty about having time for themselves without the child present, and that they have access to support that they trust to provide care for their child in their absence.

Summary

Recognising the limits of this small-scale pilot study several key findings emerged. These parent caregivers continue to experience physical and emotional stress as a result of caregiving despite government recognition that their needs must be addressed so that they can continue to stay well and look after their child. Their daily lives continue to evolve around the needs of their child who uses a wheelchair, rather than the child’s needs being a part of a balance of activities for themselves, the child and other family members.

A major concern for parents was around the provision of assistive technology, mainly the wheelchair. There is a need for accurate prescription which meets the current needs of the child, but also allows for some growth or change in the child’s condition; and for this provision to be more timely and complete as the caregivers expressed spending considerable time following up on delivery, maintenance or re-referral for the wheelchair.

The parent caregivers were aware of their limited social activity and how this could be a useful source of support for them. They did not however, feel comfortable in accepting respite support to let them maintain friendships or activities outside of the home and caregiving for this child. Efforts must focus on exploring how parents can be supported in

having a role outside of caregiving, even for short periods of time within the week. In addition, energy needs to continue to be directed at promoting inclusion and accessibility so that it is easier for these parent caregivers to bring their child in his/her wheelchair out and about the community.

Acknowledgements

The Project was funded by a research grant from the Posture and Mobility Group, a national charity supporting research into the field of posture and mobility (www.pmguk.co.uk). The data was collected between March 2010 and March 2012.

The lead researcher Jackie Casey, University of Ulster, was supported by co-researcher Dr Rachael McDonald, Monash University in completing this project.

We would like to thank the ten parents who supported this project by sharing their stories and experiences; and the Muscular Dystrophy Campaign. Particular thanks go to Sharon Allen, Dr Laura McKeown, and Eileen McGuinness who assisted in recruitment, and Lyndsay Gittins who assisted in data analysis.

Implications of the Findings

Implications for health & social care practice

- Clinicians should maintain some form of regular contact with the parent caregivers of children who use wheelchairs so that revisions to the wheelchair script can be made more speedily.
- Services need to extend beyond the wheelchair prescription in order to enable parent caregivers to participate in all their occupations.
- Attention needs to be directed at providing respite support to these families and enabling them to accept this.

Implications for clinical education

- Training in how to complete seating assessment and translating this into prescription should be included in undergraduate education programmes. Similar

training should be accessible for clinicians to update their skills and competency in this area of practice.

Currently University of Ulster have introduced into the undergraduate curriculum a practical skills class on how to take critical measures for a seating assessment; and have also developed a suite of masters degree level modules on seating assessment and provision, and pressure ulcer prevention & management. Further the primary author of this report is working on an All Ireland basis with OT lecturing colleagues to incorporate some degree of training into other OT degree programme curricula.

- Fuller attention must be given to the impact that the provision of assistive technology can make to the user and their caregivers participation in activities, and their health and wellbeing.

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Full Report

PART TWO: INTRODUCTION & BACKGROUND

INTRODUCTION

The original idea for this project arose as a follow on to research work previously carried out by one of the authors, Dr Rachael McDonald, where she had interviewed parents and therapists on their views of their child's seating systems. McDonald et al (2003) found that the parent caregivers were primarily concerned with how the use of assistive technology (AT) with their children could assist them with functional and day-to-day management issues. This, coupled with the awareness that there is very little recorded on how caregiving affects parents led to this project.

BACKGROUND

Much of the current research work explores the content of best static and dynamic seating assessments (Wright et al 2010), determining appropriate prescriptions and optimising the mobility of children who use a wheelchair. However, little continues to be recorded regarding the impact of caregiving for physically disabled children (Newman 2005), and specifically wheelchair prescription and its use upon the parents and caregivers of these children.

Parent caregivers of physically disabled children, have been identified as providing extra care beyond that expected of 'the reasonable parent' and subsequently being particularly vulnerable to stress (Raina et al 2005; Quittner et al 1992) and additional responsibilities (Nicolson et al 2012). For caregivers of children who use wheelchairs, there are the further environmental barriers to participation such as kerbs and doorways (Düger et al 2003), as well as the extra physical demands on the parents of moving and handling their

child and equipment. It is as a result of this extra care that they need support in meeting the demands of this role and in being facilitated in completing other aspects of their own daily life beyond their caregiving role. Indeed UK government legislation, for example, Carers and Disabled Children Act 2000; Carers (Recognition and Services) Act 1995; Carers (Equal Opportunities) Act 2004, now recognizes that central to ensuring the wellbeing of disabled children is the importance of supporting the caregivers in their role as a capable and satisfied caregiver but also in having occupations and an identity of their own. Alongside this responsibility occupational therapists have the responsibility of meeting the recommendations from the “Proposals for the Reform of the Northern Ireland Wheelchair Service” (DHSSPS 2008) which identified the need to respond to the individual needs of each service user, including their physical and lifestyle needs to ensure maximum independence, social inclusion and quality of life.

Parents of children who are disabled have been identified as particularly vulnerable to stress, which may result from the extra demands of caring for a child who requires increased time and resources (Bourke-Taylor et al 2010; Breslau 1983), and debt worry as a result of caring (Carers UK 2012). Parental stress has been shown to affect the development of the child, and has been identified as an important reason why children are put into residential care (Morris et al 2002). Whilst this information is not specific to children who use wheelchairs, the use of a wheelchair provides an environmental barrier to participation, as well as the extra physical demands on the parents acting as the caregivers.

Studies with caregivers of other adults and or children with various disabilities have identified how caregivers can present with increased rates of depression and anxiety (Salter et al 2010; Singer 2006; King et al 1999; Cadman et al 1991), and poorer physical health as a result of caregiving (Concha & Radical 2011; Byrne et al 2010; Plant & Sanders 2007; Singer 2006; Newman 2005; Ones et al 2005; Rone-Adams et al 2004; Nelson 2002; Wade et al 2002; King et al 1999). Further this caregiving role can be perceived as a burden eroding family relationships or marital quality unless there is resilience amongst the family members (Datta et al 2009). Worryingly, it has been found

that individuals who reported “strain” associated with their caregiving had significantly higher rates of mortality (Schulz & Beach 1999). Caregiving for disabled children is a difficult and often complex task (Stewart & Neyerlin-Beale 2000) and the effects often many and cumulative (Hankey 2004). However, it is important to note that not all influences on the caregivers experience are characterised as negative (Hasselkus and Murray 2007). Systematic reviews by Mortenson et al (2012) and Nicolson et al (2012) suggest that some reduction in the emotional and physical burden and efforts can be facilitated for these informal caregivers, through the use of assistive technology. Some of the benefits and rewards of caregiving can include improved relationships with family members (Beach 1997), increased self esteem, feeling appreciated (Nelis et al 2007; Cohen et al 2002) and an enhanced sense of meaning or purpose (Hentinen & Kyngas, 1998), and indeed diverse experience can be gained from caring for children with disabilities (Springsteen et al 2010).

Nevertheless the overall sense within the published research to date appears to lead to the view that over one third of all caregivers experience significant levels of stress or distress (Oyebode 2003).

Furthermore recent studies (Rudman et al 2006) with adult stroke survivors have shown that use of a wheelchair is a significant predictor of how well a person and their caregiver copes with their residual disability. To date this has not been explored with children who use wheelchairs and their families. With the cost of wheelchairs increasing by approximately 7% per year there is an increasing demand evident upon both service providers and caregivers. Even though some cost is related to an increase of frail elderly, there is also reported an increase in the severity of disabilities of children and young people. These higher care needs, are typically met by the caregivers in a voluntary capacity.

In addressing the increasing numbers of children and young people being referred to wheelchair and occupational therapy services professionals have followed guidance on assessments for children and their parents from the generic Children in Need Framework

(DOH 2000). This prioritizes meeting the needs relating to the child's safety and well-being and largely overlooks the additional carer related needs of disabled children and the well being of the family and caregivers. Recently carer related outcomes identified by parents with disabled children have started to become the focus of exploration in efforts to identify what if any additional support these caregivers require (Nicolson et al 2012; Demers et al 2009; Ostensjo et al 2005). This is particularly important as parent and family support is central to government policy on ensuring the well-being of children. Long-term caregiving for a disabled family member is an activity with both potential benefits and burdens for the caregiver and the disabled person. For some of these caregivers the impact of caring on a daily basis for their disabled family member, may result in them experiencing physical and mental health problems (Witt et al 2009; Chow et al 2007; Eker & Tüzün 2004; Pinquart & Sorenson 2003; King et al 2001), as well as fatigue and unmet needs (Aitken et al 2009; Emerson 2003), and considerable time and financial expenditure (Anderson et al 2007; Parish & Cloud 2006; Post et al 2005; Blanchard et al 2006; Brehaut et al 2004; Lukemeyer et al 2000; Leonard et al 1983). Therefore it is imperative that further research exploring the impact of caregiving is completed so as to minimize the effect where possible of any of these factors upon the health and well-being of the disabled child, their caregiver and additional family members.

AIMS OF THE STUDY

The overall aim was to explore the effect on the caregiver of caring for a physically disabled child who uses a wheelchair.

Specifically to determine how caregiving has impacted upon their health, wellbeing, and occupational time use.

SERVICE USER CONSULTATION

During the conceptualising of this project the primary author (JC) scoped the idea with a caregiver of a child with cerebral palsy who is a wheelchair user to determine the relevance of pursuing this idea further. This was met with a positive response.

The project was then developed and reviewed by the then regional advisor for Muscular Dystrophy Campaign Northern Ireland, Dr Laura McKeown, who also was very encouraging of the need to explore these issues for parents of children with muscular dystrophies.

DEFINITION OF A CAREGIVER

Caregivers are those individuals who “provide unpaid care by looking after an ill, frail or disabled family member, friend or partner” (Carers UK 2012). They provide assistance which goes beyond that expected in everyday life of family members towards each other (Walker et al 1995).

Currently in the UK there is estimated to be over six and a half million caregivers in the UK, with 8% of these carers caring for a disabled child (Carers UK 2012).

PART THREE: METHODOLOGY AND ETHICAL APPROVAL

ETHICAL APPROVAL

Ethical approval and research governance was sought and obtained from the University of Ulster filter committee, OREC Northern Ireland, and Belfast Health & Social Care Trust (through which potential parent participants would be recruited).

Approval was obtained on first attempt from the University; and from OREC on 05/October/2009.

Trust governance took longer than was expected, and minor amendments were requested, with full approval granted on 10/Jan/2011.

The time period to complete this study had to be extended in order to secure the optimum sample size. A request for time extension was submitted to both OREC and Belfast HSC Trust, during which all project work ceased until this was obtained. As part of this process with the Trust, a re-application for an honorary contract and updated police checks were completed. Full approval was once again granted by both organisations.

DESIGN

This was a mixed methods design study using both qualitative and quantitative outcome measures. As this is an under researched area, the combination of methods in this pilot project would help ensure that we were able to capture both the richness of the caregiver's experience, whilst addressing quantitative research questions.

RESEARCH QUESTIONS

- 1) How satisfied are parents, of physically disabled children who use a wheelchair, with their daily life activities?
- 2) What is the possible impact on health and wellbeing of children's wheelchair use on their caregivers?

- 3) What is the effect of caring for a physically disabled child who uses a wheelchair, on time use of their caregivers?

SAMPLE

The eligibility criteria for parents was that (1) they had to be the primary caregiver for a child aged between 6 and 11 years; (2) the child used a wheelchair for all their mobility; (3) the child had to have a primary diagnosis of either cerebral palsy or muscular dystrophy; and (4) the parent consented to being interviewed.

RECRUITMENT

Parent participants were recruited through two channels. These were the database of the Regional Wheelchair Service (RWS) for Northern Ireland, based in Belfast Health & Social Care Trust; and the Muscular Dystrophy Campaign (MDC). Administrators within each organisation forwarded invitation letters, study information sheets and reply slips to potential parent participants. Parents expressing an interest to participate returned the reply slip in the stamped addressed envelope to the chief investigator (JC) giving permission to be contacted.

MDC had a regional advisor who had recently taken up post and was not familiar yet with all of the parents in N.Ireland. She was not able to identify many parents who met this criterion, with most children either only going into their wheelchairs or being older than 11 years. Conversely, at the time of recruitment the RWS did not track children by their diagnosis. However, when requesting the time extension for the study this became possible and the remaining parents could be identified through their database.

Some of the parents who initially expressed interest later chose not to participate when they realised that participation in the study would take approximately 1.5 to 2 hours for the interview and questionnaire completion.

A sample size of 10 parents was the target for this study – which was achieved.

DATA GATHERING TECHNIQUES

The chief investigator (JC) met with the parent participants in their own homes at a mutually agreeable time. The outcome measures were completed with the parents, and the semi-structured interviews audiotaped.

Many of the parents found this a cathartic experience, with some crying during their interviews. All parents completed their interviews despite being given the opportunity to discontinue.

OUTCOME MEASURES

A battery of self-complete structured questionnaire tools was used with the caregivers. This battery included a number of validated outcome measures, as well as a 24 hour temporal context analysis in the form of a time use diary.

The outcome measures were:

- (1) Demographics of the parent/caregiver – this gathered detail on the age of the caregiver, and child; marital status; employment status; family make-up; and if caregiving is shared with anyone.
- (2) Time use diaries – these diaries were used to enable the caregivers to capture how they spend their time in a typical day. The information gathered has been used within occupational therapy with caregivers and clients to give a 24 hour temporal context analysis (McKenna et al, 2007; Curran et al, 2001; Farnworth, 2000; Cole & Tufano 2008). The information can be used to present the daily balance of occupations the caregiver typically undertakes in a 24 hour period.
- (3) Short Form Health Survey (SF-36) – this outcome measure comprises 36 questions covering eight health domains. These domains are physical function, role limitations due to physical problems, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health. The score for each domain ranges from zero (poor health) to 100 (good health) (Wiles et al, 2001).
- (4) Parental Satisfaction Index (McConkey et al, 2007) – this measure can be used to determine the satisfaction the carer gets from caring for their disabled child. It consists of

14 statements taken from past studies in which mothers noted the benefits to them and their family such as “My child gives me a new or increased sense of purpose in life” or “I get pleasure in providing care for my child”. This tool has been used in this form in Northern Ireland in similar work carried out by Professor McConkey et al (2007) with carers of children with learning disability.

QUANTITATIVE DATA ANALYSIS

Descriptive analysis was used to explore the demographic details, SF-36, Parent Satisfaction Index and 24hour time use data for the parent caregivers. The findings from these are presented in tabular format.

QUALITATIVE DATA ANALYSIS

Interpretative phenomenological analysis methods were used to interrogate the data gathered from the semi-structured interviews. This approach can be used to explore and understand the meanings of experiences of individuals who have experienced a particular phenomenon of interest (Creswell 1998). It can be used to build a deeper level of understanding of the experiences of clients and their carers and this in turn can enable the researcher to reflect upon the mode of service delivery and may subsequently lead to changes in practice or service delivery in order to improve and enhance the lives of service users (Clarke, 2009). Exploration of the experiences of the parent caregivers of physically disabled children who use wheelchairs can give an insight into the complex issues associated with caring for these children, and with promoting the health and wellbeing in daily activities of both the caregivers and these children.

Typically in phenomenological research it is recommended that the number of participants required in order to have an adequate sample size number, or achieve saturation of the data is typically between 5 and 25 participants (Polkinghorne 1989).

The transcripts were reviewed whilst data collection progressed. It was felt that by the fifth interview, no new themes were emerging, however, in order to be sure, the interviews were continued to the target of ten.

PART FOUR: RESULTS

QUANTITATIVE RESULTS

(1) Demographics of Participants

Participant demographic details are summarised in Table 1 on next page.

Ten parent caregivers participated in this study (9 female, 1 male; age range 32 – 46 years) with a child diagnosed with either muscular dystrophy or cerebral palsy, and who uses a wheelchair for their primary mobility. Of these ten participants six had a child with cerebral palsy and four with muscular dystrophy. All the children were aged between 6 and 11 years. Further details on the caregivers' child who uses a wheelchair is presented in Table 2.

All participants completed the two questionnaires, gave a description of 24 hour time use, and a semi-structured interview.

Table 1: Parent Participant Demographics

Parent Participant	
Age Range	32- 46 yrs (mean age 37.7yrs)
Gender	9 female 1 male
Marital status	2 single 7 married 1 divorced
Living arrangements	3 live alone (no other adult in household) 7 live with spouse/ partner
Accommodation	7 own home 1 partner's home 2 public housing
Location of household	6 urban 4 rural
Number of children in household	1 n=2 2 n=4 3 n=2 4 n=1 5 n=1
Any of these sibling children have a disability	Yes n=1 No n=8 No other children n=1
In paid employment	Yes n=3 No n=7
If in paid employment how many hours worked?	N=1 30hrs/wk N=2 36+hrs/wk
If no, did you previously work	Yes n=4 No n=1 Not reported n=2
Reasons for no longer being in paid employment	N=5 result of caring for this child N=1 no reason given
Undertake voluntary work?	Yes n=2 – church and charity work related to child's condition. No n=8

Table 2: Demographics of Participants' Child who uses a Wheelchair

Child	
Gender	6 Male 4 Female
Age of primary child	6 yrs n=3 7 yrs n=1 8 yrs n=2 9 yrs n=2 10 yrs n=0 11yrs n=2
Primary disability	6 Cerebral palsy 4 Muscular dystrophy
Primary type of wheelchair used	2 self propelling 3 powered 5 attendant controlled * 2 of the powered wheelchair users have a manual in reserve.
How long has child used a wheelchair?	Less than 12mths n=2 1-2yrs n=4 2-3yrs n=1 4+yrs n=3

(2) Parenting Satisfaction Index

1. I get pleasure in providing care for my child

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
7	2		1	

2. My child is a source of joy and happiness in my life

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
9			1	

3. I get a sense of accomplishment in having done one's best for the child

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
8				1

One caregiver opted not to respond to this question.

4. My child gives me love and affection

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
8	1		1 *	

*Caregiver explains that here child also has autism which is associated with DMD, and so he expresses his love and affection in his own way.

5. My child provides me with a challenge and an opportunity to learn and develop.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
8	1	1		

One caregiver reports that everyday is a challenge, whilst another does not see 'it' as a challenge

6. My child has strengthened our family and/or marriage.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree	
5		4	4		Totality
1	-	4	-	-	Family
1	-	-	3	3	Marriage

All the caregivers answered, but many found this difficult to respond to, feeling that they wanted to separate out family and marriage.

7. My child gives me a new or increased sense of purpose in life.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
8	1		1	

8. Having a child has led me to develop new skills and abilities

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
9	1			

9. I have become a better person – less selfish, more tolerant, compassionate

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
7	2	1*		

* This caregiver felt that she had become less tolerant of certain things.

10. My personal strength and confidence has increased.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
7	2	1		

11. My social and community networks have expanded

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
2	1		1	6

Two caregivers stated that they agreed that their networks did expand, however, within the “world of disability” [P04, P06].

12. My spirituality or trust in God has increased

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
2	1	3 ±	4 *	

* One caregiver reports that she disagrees, and that she finds that she questions things much more now. She also reported going on a spiritual retreat 18months prior in an effort to reconnect [P06].

± One caregiver reports that she believed in focusing on positives now [P05].

13. My perspective on life has changed – I am more aware of what is important in life.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
9	1			

14.I make the most of each day; live life at a slower pace.

Strongly agree	Agree	Not sure	Disagree	Strongly disagree	
5	1		2	2	Totality
4	3	-	-	-	Each day
-	1	-	4	2	Slower pace

Again, several of the respondents wanted to answer this question as a whole, and also as two separate sections.

Total Overall Satisfaction Towards Role of Caregiving:

Positive	Ambivalent	Negative
9	1	0

Additional comments recorded during completion of questionnaire:

The caregiver ***occupational wellbeing*** was also explored. Whilst these parents described their role of caregiving as personal care, they often went on to identify how it became a job.

“caregiving becomes a job, with the most time consuming part is the time spent on the phone and chasingappointments” and equipment [P05];

“I consider caring for my child as a work activity especially as he child gets older” [P04].

Where the parent caregiver is in paid employment the balance in roles and responsibilities is very carefully regulated and when the scales are tipped too far in one direction all family life can seem to hit a crisis point.

“You can keep on going for what seems like years, and then it just hits you and realise you’re body can’t shut down and you’re on alert and you don’t know you’re on alert and it is a stress response” [P11].

One caregiver described how she felt that there was a

“sense of de-valuing what you do as a parent caregiver. I’m no longer a professional or employee. It decreases your self worth and decreases respect from others” [P04].

Another caregiver described how time itself becomes a very valuable resource [P08].

Caregiver Activity Selection

Activity selection for all these parents is dictated by what time remains available after caring for this child, what social networks remain, and can adequate and competent (in the needs of caring for a disabled child) childcare be secured; and thereby remains very ad hoc in nature.

(3) SF-36 Health Survey

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
2	1	3	2	2

2. Compared to one year ago, how would you rate your health in general now?

Much better now than a year ago	Somewhat better now than a year ago	About the same as one year ago	Somewhat worse than one year ago	Much worse now than one year ago
		7	3	

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so how much?

a. Vigorous activities such as running, lifting heavy objects, participating in strenuous sports.

Yes, limited a lot	Yes, limited a little	No, not limited at all
3	2	5

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?

Yes, limited a lot	Yes, limited a little	No, not limited at all
2	2	6

c. Lifting or carrying groceries

Yes, limited a lot	Yes, limited a little	No, not limited at all
2	2	6

d. Climbing several flights of stairs

Yes, limited a lot	Yes, limited a little	No, not limited at all
0	3	7

e. Climbing one flight of stairs

Yes, limited a lot	Yes, limited a little	No, not limited at all
0	1	9

f. Bending, kneeling or stooping

Yes, limited a lot	Yes, limited a little	No, not limited at all
2	3	5

g. Walking more than one mile.

Yes, limited a lot	Yes, limited a little	No, not limited at all
1	1	7

+ One caregiver did not respond.

h. Walking several streets

Yes, limited a lot	Yes, limited a little	No, not limited at all
0	1	8

+ One caregiver did not respond.

i. Walking one street

Yes, limited a lot	Yes, limited a little	No, not limited at all
0	0	9

+ One caregiver did not respond.

j. Bathing or dressing yourself

Yes, limited a lot	Yes, limited a little	No, not limited at all
0	1	8

+ One caregiver did not select a response, but rather replied not personal time to relax.'

4. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
NB – one caregiver did not respond to this question. Therefore total n=9

a. Cut down the amount of time you spend on work or other activities

YES	NO
4 *	5

* One caregiver reported having morning stiffness with night time pain; another reported that the 'activities still need to be done.'

b. Accomplished less than you would like?

YES	NO
5	4

c. Were limited in the kind of work or other activities

YES	NO
5 *	4

* One caregiver reports being 'exhausted.'

d. Had difficulty performing the work or other activities (for example, it took extra time)

YES	NO
5	4

5. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)

a. Cut down the amount of time you spend on work or other activities?

YES	NO
6	4

b. Accomplished less than you would like?

YES	NO
7	3

c. Didn't do work or other activities as carefully as usual.

YES	NO
4	6 *

* One caregiver attends the gym to maintain back health – strong and flexible back [P08].

6. During the past 4 weeks to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
4	2	2	2	

7. How much bodily pain have you had during the past 4 weeks?

Not at all	Slightly	Moderately	Quite a bit	Extremely
5	1		3	1

8. During the past 4 weeks how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	Slightly	Moderately	Quite a bit	Extremely
4	1	1	2	1

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

a. Did you feel full of pep?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1	2	1	1	3	1

b. Have you been a very nervous person?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1	1	1	3	2	2

c. Have you felt so down in the dumps nothing could cheer you up?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
0	1	1	1	2	5

d. Have you felt calm and peaceful?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
0	1	0	6	1	2

e. Did you have a lot of energy?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1	2	1	3	0	3

f. Have you felt downhearted and blue?

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1	0	0	2	6	1

In summary, responses to these questions identified that the physical and or emotional health of these caregivers:

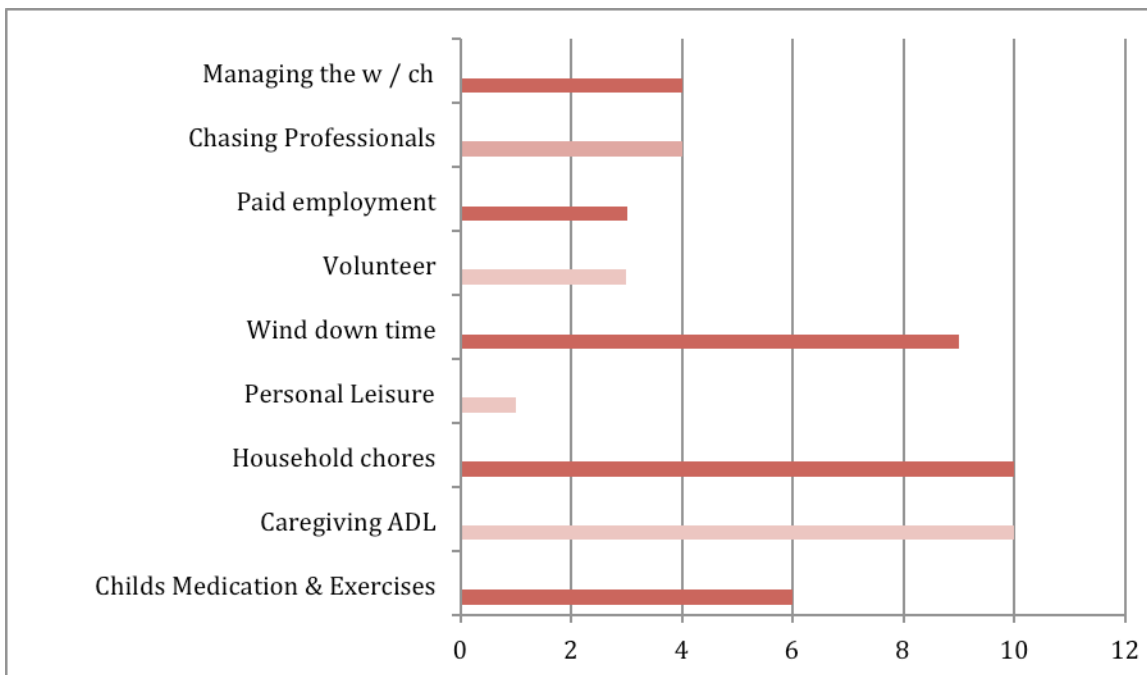
- resulted in them accomplishing less than they had hoped;
- had difficulty performing activities or it took longer to do these;
- had less time to perform other activities;
- interfered with their social and family activities.

Further, nine of the ten participants reported having felt 'downhearted or blue' within the previous four weeks.

(4) 24 Hour Time Occupation

Caregiver time was spent mainly performing personal activities of daily living for the child and parent; completing household chores whilst the child was at school; travelling to and waiting about for health/social/education appointments; and battling against 'the system' to access assistive technologies.

Bar Graph: Activities undertaken by parent caregivers



All ten caregivers identified completing a range of activities classified as caregiving activities of daily living (ADL) for their child. These included feeding, toileting, washing, dressing, moving and handling their child. Additionally six caregivers identified that their role included completing the child's prescribed therapeutic exercises and medication administration – serving to highlight the additional skills these parents have had to acquire.

Three of the caregivers were in paid employment of various hours per week duration, another one worked in a voluntary capacity and a further two volunteered each day in their child's school as a care assistant for their child.

Only one caregiver reported taking time out for their own personal interests such as meeting friends or going to the gym. Nine of the ten caregivers recorded availing of “wind down” time each day. This time mainly involved reading or watching television. Two of these nine specifically identified making time to spend with a spouse/partner and this time was found when the child/ren was/were in bed.

All ten participants described taking time to complete various household duties. This may have been a culturally desirable response. One participant commented during the questionnaire completion that she believed that as a parent you often feel that your home needs to be clean and tidy to demonstrate to others your ability to cope.

Nine of the caregivers reported having less than seven hours per night of sleep opportunity and all of these nine described how the sleep cycle is variable and dependent on whether the child needed medications, was uncomfortable, woke, or cried. They would get up with the child and try to settle them or move them.

QUALITATIVE RESULTS

Firstly all the audiotapes were transcribed. The first tape was member checked for accuracy (ie. the participant read the transcript and was in agreement that it was an accurate representation of the interview). The transcripts were then read and re-read independently by the primary author (JC) and Lyndsay Gittins (research assistant) for recurring points. These were then grouped and the two reviewers agreed these groups. These groups were further categorised into larger themes, which were then used to report the key findings from within this data set. The themes explore the different aspects of life, and occupational engagement for these caregivers. These themes are presented here, initial denial, professional dependency, caregiver health and wellbeing, attitudes of others, impact on siblings.

Theme: *Initial denial – non-acceptance*

This theme refers to the symbolism of the wheelchair for these caregivers and their families. The wheelchair often represents a loss of skill, deterioration of their child's condition, a last option or the loss of hope for their child. One participant reported that the wheelchair

“sat in mummies cupboard” in the grandmother’s house,
or she “folded it up and put it in the cupboard” [P01].

The caregivers appeared to delay the full time use for as long as possible, and they seemed to externalise the reason as to why they and the child ultimately engaged in using the wheelchair. For example,

they only used the wheelchair “as the child kept tripping and was a risk of tripping over the others [children]”;
or the “physio wanted to use it in school” [P01].

The caregivers needed time to adjust to having the wheelchair and then to accept its use.

“Initially I felt like we were drawing attention to the muscular dystrophy. We were having to face it and deal with it out in public. His first day using it at school, I was very upset. It was as if it was the next stage in the progress of the disease” [P08].

This acceptance was helped by the acknowledgement of the child in a powered chair having a greater sense of control over their mobility and environment, and a recognition that being able to self-propel resulted in the child being less dependent on others.

“We discovered though that one she feels [daughter] she has a sense of control of being able to get herself out of the situation by controlling her wheelchair and mobility, and her startle and upset were reduced. She knows she can physically get herself out of the situation now” [P05].

Theme: *Professional dependency*

Here the recurring points identified both the **control** that the professional has over the identification of needs and prescription, as well as the **communication** involved in provision of the wheelchair and any other assistive technologies the child may have needed. There was an apparent sense of frustration when caregivers felt that professionals were not responsive in a time acceptable to the caregiver; or when the wheelchair breaks, becomes too small, will not last long enough, or there is a delay in it arriving for use.

“OTs need to assess for the future and not just the here and now, so that the equipment that takes time to access will be suitable for my child when it arrives and be right” [P02].

One parent caregiver, when asked about comfort of her child in his wheelchair replied:

“He must be. The physio said he’s more comfortable, so they must know” [P04].

There was also frustration expressed in how professionals do not always seem to communicate with each other and how this subsequently impacts on the child’s needs

being met and additional burden on the caregiver. One caregiver referring to disgust at professionals

“who think they know it all and won’t talk to others about what to expect or what will work” [P03] and how this resulted in longer time needed to get the wheelchair right for their child.

Another parent caregiver expressed her concern that one professional can have so much say over whether they can access not only the wheelchair but also the associated housing adaptations for their child when

“we had to get the OT to agree. I was devastated because how can someone have so much control when we really needed an bungalow to manage” [P10].

She did not go on to explain if the OT and she agreed on the final recommended housing adaptations, or how successful these were for their situation.

In antithesis, one caregiver found that

“the support she received from physio and OT is excellent” [P08], and she was openly happy to express this.

But this positive experience was not commonly reported during the interviews, with the parents tending to focus on the negatives of accessing equipment in a timely manner to meet the needs of the their child and themselves.

An irritated caregiver noted “ I want to be my child’s mammy. I don’t want to be his keyworker.....if they [professionals] would just do their job, and do it right the first time, don’t get it wrong, because then I’m left to pick up the pieces” [P02].

Theme: *Caregiver health and wellbeing*

The caregivers described life as a “revolving pattern” [P01] consisting of life evolving around the needs of their child and having no sense of purpose of their own. There was pain and hopelessness where one caregiver stated that

“you become robotic and you just go through the motions.... you get past the point of being able to feel” [P02],

and with no outward release such as friends or social outlets. Another parent reported, “there is no let up. You are constantly doing things. There is a growing list of work and tasks to do. The list never ends” [P05].

More than one caregiver reiterated the need to have coping skills such as planning and being organised. Most felt the desire and need to be present for their child, and not feeling confident enough to entrust the child with non-family carers in order to have a break for themselves.

“We never leave him. My sister is the only one that we would leave him with” [P10].

“You can get carers in and all that... but I’m not into that” [P01].

The impact can be not only upon the physical health of the caregivers but also upon their mental health. Indeed seven of the ten caregivers reached a point of tearfulness during the interviews thereby further highlighting the pain and the tight rope of life that they are balancing upon. They described difficulties sleeping, impact upon emotional stability, and on their immune system with the increased stress levels of worrying about the child, and accessing the assistive technology their child needed.

“There is a knock on effect of having interrupted sleep [gets up to check child at night]. Lack of sleep is so draining. It affects your emotional stability greatly” [P05].

“It’s a different life that I never thought I would have. I don’t think too much about the future. I would get too upset. Just try to remain positive, taking one day at a time” [P08].

The sense of loneliness was demonstrated when one caregiver said “you get so caught up with your child that you have no real friends left to meet up and have time with for yourself” [P06]. Another stated that “all I do is look after [child] and do my work, I don’t go

out, I have no social life and I have no nothing, and that's all I do" [P02]. This same caregiver reported how her role of caregiving had "strengthened [my] relationship with my boys, but it destroyed my marriage" [P02].

Theme: *Attitudes of others*

Caregivers referred to the manner in which others spoke to, or reacted to them. This included the **professionals** who "looked at the clock" [P01] during their consultation, or who did not prioritise the caregiver's needs; or did not know how to speak to their child.

"If they [professional] do talk to him [son] then they do it very condescendingly, patronising him in the way she speaks to him" [P02].

Also, this same parent identified how

"whenever you cried, they couldn't deal with it" [P02],

and further suggesting the lack of empathy and understanding of the needs of this family by the health care professional.

Several of the caregivers identified how their lives have changed in that their **previous friends have** disappeared mainly, and are no longer around to offer support; despite there having been "a big group of us" [P01]. This parent felt this was a result of her friends not knowing how to include her child and possibly thinking that their needs are so different from each other. There was definite disappointment at the loss of these friends and no longer having the relationship to meet up when the child would be receiving an occasional respite weekend and the caregiver would be free.

The caregivers described how they dealt with the attitudes of **other adults** within the public domain. They reported a variety of experiences of "when you are out and about, people staring and all that" [P01], and coping mechanisms to how they managed when "others stare or make inappropriate comments in the street. I just speak loudly that there's too many nosey people" [P04]. Another parent says that "you feel like saying 'what are you staring at, you're nothing to look at yourself'" [P01].

Mainly they had a sense of others “just saw the physical disabilities” [P05], or held “an assumption, ...that they [child] are stupid because they are in a wheelchair” [P02]; or that “some people just give a sympathetic look, whilst others just stare” [P08]. One parent also expressed how she found “other people’s ignorance more stressful than looking after [child] which isn’t stressful at all” [P10].

The caregiver also reported upon the ***on-going battle with local authorities*** to develop inclusive environments with adequate parking bays and low kerbs. Although for one caregiver she was pleased that her child’s school was “very determined in treating [child] just like he was one of the other pupils” [P08].

One caregiver described how she was constantly chasing up the wheelchair or other things their child needed; and that

“you can only fight so many battles....because you get too tired” [P05].

Another parent described,

“the bureaucracy between the Trusts is so frustrating and trying to get the bits of equipment is a nightmare. I just can’t believe that I’m going through all this again for her new wheelchair. Here we go again!” [P05]

Theme: *Impact on siblings*

Concern was expressed about the impact upon the siblings. Specifically, how the peers of the siblings reacted to the visual image of the child in a wheelchair. One caregiver stated that,

“there is probably stigma attached to it [the wheelchair] more than anything else” [P11].

They feel that there is a lack of support for the siblings to help them cope and that

“there’s no help for his brothers, but they’re expected to help” [P02].

Another parent reported how the siblings can become “overprotective of him” [P10] when with other children, even with cousins, and that they have “a special caring side for him” [P10].

The caregivers believed that the siblings are ***at risk of underperforming*** at school, and of having their lives put on hold. The whole family focus can easily become that of this child who uses the wheelchair, and that “ even for his brothers their world evolves around him too” [P02]. This made the parent feel guilty, and how the siblings’ lives were directly affected. Further, several of the parent caregivers described how the siblings could be affected, with them

“going off the rails” for a period of time, or “rebelled against me [mum]” [P03].

PART FIVE: SUMMARY FINDINGS AND RECOMMENDATIONS

SUMMARY

It is not surprising that these parent caregivers eventually get worn down emotionally by their constant struggling with others and the authorities to access the services that their child needs to make life easier. Caregivers should be signposted very early on to the range of support services available through the Health & Social Care Trusts/ Authorities as well as from charitable organisations. Further work needs to be done to help families to 1) accept respite care support, in its various forms before they reach a crisis point; 2) not feel guilty or lacking as a parent caregiver by accepting available support services; and 3) heighten the awareness of the range of respite and support services available and how to access it when these caregivers needs it. This acceptance of support may contribute to caregivers staying emotionally and physically well, and to providing a wider network for them and their child. These findings reflect that of other researchers, such as Bourke-Taylor et al (2010) that the parent caregivers can generally manage their physical health, but it appears that their emotional health is in more need of support.

Professionals must be responsive to the needs of families, and be so in a timely manner. Families appear to benefit from regular contact, even by telephone; to help them have a sense of support and to adjust to changes. Greater consideration should be given to siblings.

Caregiving continues to be mainly carried out by unpaid family members, despite the government recognising the importance of these individuals to securing the health and wellbeing of the individual with a disability. Although caregiving can be perceived as an enlightening experience that can bring families together greater consideration needs to be given to supporting the parent caregiver to have a sense of identity of their own.

These caregivers appear to spend so much time caring and advocating on behalf of their child that they frequently do not make time for themselves. Understanding of the “work-rest-play” paradigm suggests it is vital for one’s mental and physical health that some time is given to doing things for one-self. However, for these caregivers it is the ad-hoc or unpredictability as to when they had free time impacting on their ability to preserve space and friendships to undertake paid employment, education, leisure or social activities for themselves.

Much work continues to be needed within society to promote positive attitudes towards disability, inclusion and expectations.

RECOMMENDATIONS FOR FUTURE RESEARCH

Review of the caregiver responses to identify their lived experiences, barriers and facilitators to their ability to engage in a range of activities either for themselves or for their physically disabled child who uses a wheelchair has identified a few areas deserving of further exploration. These include:

- (1) exploration of the needs of siblings who may have to take second place to the needs of their brother/sister;
- (2) the significance of parent caregivers having accessible transportation. Several parents described the difficulty of folding wheelchairs and lifting these into cars, and not having easy access to take their child out with all their assistive technology and the full family.

USEFUL RESOURCES

Carers UK www.carersuk.org

Parent Line www.parentlineplus.org.uk

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PERSONAL CHALLENGES

There were a number of challenges presented to me during the undertaking of this study, which I have since learnt from and successfully planned for in subsequent project work.

- The first challenge was securing research governance through Belfast Health & Social Care Trust, which took longer than was expected. This was despite having received ethical approval very quickly from OREC to undertake the study. Personal contact with staff and regular communication checking the progress of the application appears to be a positive way to manage this delay.
- MDC, one of the partners through which recruitment was to be undertaken, carried out two national surveys with their members at the time when I was trying to recruit. Some parents gave this as a reason for not wishing to participate, as one of these surveys concerned their service use.
- Due to slow recruitment of participants along with juggling the balance of work activities of teaching, undergraduate programme lead, and research activities, the project end date was met and an extension of time had to be sought through both OREC and the Trust. This meant that no further recruitment could be undertaken whilst this was sought and then granted, which unduly delayed the study.

Despite these hurdles in recruitment my experiences of meeting these parents and hearing their stories inspired and obliged me to complete the study with a full sample, and to disseminate the findings as widely as possible so that there is documented evidence regarding their lived experiences and needs, and to challenge the future practice of occupational therapy students.

My further work has continued to explore the barriers, facilitators and attitudes of others towards the inclusion and occupational engagement of children who use wheelchairs.

Appendix 1 – Posture & Mobility Group

Appendix 2 – Research Governance

Appendix 3 – Study Information

Participant Information Sheet

OREC NI number: 09/NIR02/58

The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction.

This information sheet is for you to keep.

My name is Mrs Jackie Casey and I am a lecturer for the occupational therapy programme at the University of Ulster (Jordanstown Campus). I am involved in conducting the research project entitled, "The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction". This project has been funded by the Posture and Mobility Group UK & Ireland.

Why were you contacted as a potential participant?

In order to make contact with parents who care for children who have cerebral palsy and who use a wheelchair, I contacted the Regional Wheelchair Services (at Musgrave Park Hospital) and Muscular Dystrophy Campaign. These organisations then sent a letter to you asking you to return a permission slip, in a reply paid envelope, if you were willing for me to contact you and provide more information about the project. You sent back this permission slip and that is how I got your contact details.

Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do. Please read the following information and do not hesitate to ask any questions about anything that might not be clear to you. Make sure that you are happy before you decide what to do. Thank you for taking the time to consider this invitation.

What is the purpose of the study?

There is some research to suggest that being a caregiver, whilst being a very rewarding role, can create stress and ill-health for the caregiver. This study therefore aims to find out what impact if any caregiving for a physically disabled child who uses a wheelchair has on you as the caregiver. We hope to find out how satisfied you are with the daily activities that you carry out, and what these activities typically are for you; and to find out what your physical and mental health is like at present, and what factors influence this for you.

Why have I been chosen?

You have been chosen as you are the parent and caregiver for your physically disabled child who uses a wheelchair. Your name has been randomly selected from the databases held at the Regional Wheelchair Service based at Musgrave Park Hospital, Belfast, or Muscular Dystrophy Campaign, Northern Ireland.

You are one of twenty caregivers that have been selected to participate in this study.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form. If you choose to take part, you can change your mind at any time and withdraw from the study without giving a reason.

What will happen to me if I take part?

If you agree to take part you need to write your name and contact details on the consent form, sign it and return it to the researcher, Mrs Jackie Casey, in the stamped addressed envelope provided.

Next you will be contacted by Mrs Casey to arrange a time and place that she can visit you to ask you some questions, complete a questionnaire and a daily diary. These will ask you about your experience of caring for your child.

This visit will take approximately 1 to 1 ½ hours and if it suits you better can be carried out in two appointments.

What do I have to do?

All you have to do is after returning the consent form, agree to meet the investigator and answer the questions, and complete a daily diary for one day. This is all you are requested to do.

Risks?

There are no expected risks for you or your child in taking part in this study. This study aims to find out what your feelings and thoughts are about caring for your child, and how your child's wheelchair use may affect how you go about your daily activities.

At no point will it be possible to identify you or your child from the information that you share with the researcher. All the information will be coded using a reference number and no personal details will be used.

Possible benefits in taking part?

There are no immediate benefits of taking part in this study. However, it is hoped that we will better understand the impact on your life of caring for your child. It is hoped that this information will better prepare health professionals in understanding the balance of activities in your life and what the priorities are at different times for caregivers of physically disabled children.

What if something goes wrong?

It is very unlikely that anything should go wrong by your participating in this study. The University of Ulster has procedures in place for reporting, recording and handling any adverse events. Any complaints that you have can be made directly to the investigator's line manager, **Dr John Winder**. His telephone number is **028 9036 8440**.

What will happen to the results of this study?

The results of this study will be analysed and a report written for the project sponsors. A paper will also be written for submission to a peer-reviewed journal and the findings presented at conference in order to publish them as widely as possible.

Who is organising and funding the research?

This study is being funded by the Posture & Mobility Group for UK & Ireland. They are a registered charity interested in seating and wheelchairs. Registered charity Number: 1098297

Who has reviewed this study?

This study has been reviewed and approved by PMG, and the research governance committees of the University of Ulster and by Belfast Health & Social Care Trust. It has received ethical approval from the Office for Research Ethics Committees for N.Ireland.

If you would like to contact the researcher about any aspect of this study, please contact:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
<p>Mrs Jackie Casey Lecturer in Occupational Therapy School of Health Sciences University of Ulster Shore Road Newtownabbey Co. Antrim BT37 0QB Tel: 028 9036 8042 Email: j.casey2@ulster.ac.uk</p>	<p>Professor Stephanie McKeown Director of the Health & Rehabilitation Sciences Research Institute University of Ulster Jordanstown Campus Shore Road Newtownabbey Co. Antrim BT37 0QB Tel: 028 9036 8440 Email: sr.mckeown@ulster.ac.uk</p>

Consent Form

The impact of caregiving for physically disabled children who use wheelchairs on their caregivers' occupational performance, health and satisfaction.

NOTE: This consent form is for the purposes of research and will remain with the University of Ulster researcher for their records.

I agree to take part in the University of Ulster research project specified above. I have had the project explained to me, and I have read the Information Sheet, which I keep for my records. I understand that agreeing to take part means that:

- I agree to be interviewed by the researcher ☐Yes ☐No
- I agree to allow interviews to be audio-taped ☐Yes ☐No
- I agree to participate in data gathering (during my usual waking hours) via use of a time use diary ☐Yes ☐No

I understand that I will be given a transcript of data collected concerning me for my approval before it is included in the write up of the research.

I understand that my participation in this project is voluntary; that I can choose not to participate in part of all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

Name of Participant

Signature of Participant

Date

Consent form administered and explained in person by:

Name and title

Signature

Date

Outcome Measures

- 1) Demographic Details
- 2) Themes to be used in the Semi-Structured Interviews
- 3) SF-36
- 4) Parental Satisfaction Index
- 5) Sample Time Use Diary (Occupational Questionnaire)

Background information (to be obtained in initial interview)

Participant ID: _____

Yourself

Current age of participant: _____yrs/mths

Gender: ☐ Male ☐ Female

Marital Status: ☐ Single ☐ Married ☐ Separated ☐ Divorced ☐ Widowed

Children

Number of children in house: _____ Current age of disabled child: _____yrs/mths

What disability (disabilities) does your child have: _____

Is this the only child with a disability: ☐ Yes ☐ No

Housing

Accommodation Type:

☐ Own Home ☐ Partner's Home ☐ Own & Partner's Home

☐ Public Housing (NIHE) ☐ Other (list): _____

Living Arrangements (Adults):

☐ Live alone ☐ Live with partner/ spouse

Location:

☐ Urban ☐ Rural

Wheelchair

Type of Wheelchair used:

- | | |
|--|--|
| <input type="checkbox"/> Self-propelling wheelchair | <input type="checkbox"/> Power-assist rim wheelchair |
| <input type="checkbox"/> Powered wheelchair | <input type="checkbox"/> EPIOCH wheelchair |
| <input type="checkbox"/> Attendant controlled wheelchair | |
| <input type="checkbox"/> Other: _____ | |

Number of wheelchairs: _____

How long has your child been in a wheelchair: _____yrs/mths

Employment

Paid:

Are you in paid employment: ☐ Yes ☐ No

If yes, How many hours per week do you usually work in this paid position: _____hrs

If no, did you previously work: ☐ Yes ☐ No

Why did you discontinue your paid employment (if applicable): _____

Voluntary:

Do you do voluntary work: ☐ Yes ☐ No

If yes, What is this work: _____

How many hours per week do you usually work in this voluntary position: _____hrs

Themes for Semi-Structured Interviews

Opening

How long has your child been in a wheelchair?

Can you **describe what disability** your child has and how this affects them?

Can you tell me about your **experience of** your child **using** his/her wheelchair?
(eg. Comfort, operation and control of the wheelchair, functional skills from the wheelchair, ease of use, aesthetics)

Tell me how you think the **wheelchair has affected** your life, or your child's life?

Do you **consider caring** for your child as a work activity or personal care?

What kind of activities do you have to do **for your child**?

How much do you **enjoy or other** being the main caregiver for your child?

Tell me about your **Health** and if it has been affected in any way as a result of caring for your child (name)?

What do you think your **child thinks of** using his/her wheelchair?

Tell me how your child being a wheelchair user affected his/her relationship with his/her **siblings**.

Tell me about whether you get to do everything you would **like to** be able to do.

Closing

Do you have **anything else** you would like to mention??

SF-36 Health Survey

Instructions for completing the questionnaire: Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by filling in the bubble that best represents your response.

Participant ID:

Date:

1. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

2. Compared to one year ago, how would you rate your health in general now?

- ☐ Much better now than a year ago
- ☐ Somewhat better now than a year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

c. Lifting or carrying groceries.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

d. Climbing several flights of stairs.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

e. Climbing one flight of stairs.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

f. Bending, kneeling or stooping.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

g. Walking more than one mile.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

h. Walking several streets.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

i. Walking one street.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

j. Bathing or dressing yourself.

- ☐ Yes, limited a lot.
- ☐ Yes, limited a little.
- ☐ No, not limited at all.

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

a. Cut down the amount of time you spent on work or other activities?

- ☐ Yes ☐ No

b. Accomplished less than you would like?

- ☐ Yes ☐ No

c. Were limited in the kind of work or other activities

- ☐ Yes ☐ No

d. Had difficulty performing the work or other activities (for example, it took extra time)

- ☐ Yes ☐ No

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

a. Cut down the amount of time you spent on work or other activities?

- ☐ Yes ☐ No

b. Accomplished less than you would like

- ☐ Yes ☐ No

c. Didn't do work or other activities as carefully as usual

- ☐ Yes ☐ No

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

7. How much bodily pain have you had during the past 4 weeks?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.

a. did you feel full of pep?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

b. have you been a very nervous person?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

c. have you felt so down in the dumps nothing could cheer you up?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

d. have you felt calm and peaceful?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

e. did you have a lot of energy?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

f. have you felt downhearted and blue?

- ☐ All of the time
- ☐ Most of the time
- ☐ A good bit of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

Participant ID:

Date:

Parenting Satisfaction Index

Parents who have a special needs child can get satisfaction from caring for their son or daughter. We would like to know if this is so for you. Listed below are 14 statements. For each one, please underline the response that best represents your opinion. Five choices are given:

Strongly agree Agree Not sure Disagree Strongly disagree

While you may not find a response that exactly states your feelings, please underline the response that comes closest to describing how you feel.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Underline only one response for each statement, and respond to all statements. If you need to change an answer, make an "X" through the incorrect answer and underline the correct response.

Thank you very much for your co-operation. All your answers are confidential to the researchers.

1 - I get pleasure in providing care for my child

Strongly agree Agree Not sure Disagree Strongly disagree

2 – My child is a source of joy and happiness in my life

Strongly agree Agree Not sure Disagree Strongly disagree

3 – I get a sense of accomplishment in having done one's best for the child

Strongly agree Agree Not sure Disagree Strongly disagree

4 – My child gives me love and affection.

Strongly agree Agree Not sure Disagree Strongly disagree

5 – My child provides me with a challenge and an opportunity to learn and develop.

Strongly agree Agree Not sure Disagree Strongly disagree

6 – My child has strengthened our family and/or marriage

Strongly agree Agree Not sure Disagree Strongly disagree

7 – My child gives me a new or increased sense of purpose in life.

Strongly agree Agree Not sure Disagree Strongly disagree

8 – Having a child has led me to develop new skills and abilities

Strongly agree Agree Not sure Disagree Strongly disagree

9 – I have become a better person, - less selfish, more tolerant, compassionate

Strongly agree Agree Not sure Disagree Strongly disagree

10 – My personal strength and confidence has increased

Strongly agree Agree Not sure Disagree Strongly disagree

11 – My social and community networks have expanded

Strongly agree Agree Not sure Disagree Strongly disagree

12 – My spirituality or trust in God has increased.

Strongly agree Agree Not sure Disagree Strongly disagree

13 – My perspective on life has changed – I am more aware of what is important in life

Strongly agree Agree Not sure Disagree Strongly disagree

14 – I make the most of each day; live life at a slower pace.

Strongly agree Agree Not sure Disagree Strongly disagree

Any comments you wish to make about the questions in this form?

Thank you very much.

24 Hour Time Use Diaries

Caregivers will be asked to record how they spend their wakened time in a typical 24 hour period at one snap shot of time. They will be asked to confirm if this snapshot was representative of a typical day.

The chief investigator (JC) will explain this diary or occupational questionnaire to the caregivers, and how to complete it.
These will be either returned by post to JC or collected at the request of the participant.

24 Hour Time Use Diary

Participant ID:

Now I would like to try to find out how you might typically spend your time from 4.00am in the morning though to 4.00am the next morning. If an activity is too personal, there's no need to mention it.

Please tick against each activity that you complete during your 24 hour period

ACTIVITY	EARLY MORNING											
	4.00 - 4.30am	You	Child	You	Child	You	Child	You	Child	You	Child	You
Who the activity was for:												
SLEEPING												
RESTING/ RELAXING doing nothing, 'time out'												
PERSONAL CARE washing, dressing, toilet												
EATING/ DRINKING/HAVING A MEAL												
TRAVELLING to places by car or public transport												
PAID WORK outside of the home												
UNPAID WORK outside of the home												
HOUSEHOLD CHORES/ HOUSEWORK												
HOBBIES and other LEISURE ACTIVITIES												
WATCHING TV and VIDEOS/DVDS												
Using COMPUTER/ INTERNET												
READING books, magazines												
VISITING a friend or relative												
SHOPPING												
STUDYING eg. For a course												
GARDENING												
ATTENDING APPOINTMENTS												
INTIMATE BEHAVIOURS with other or self												

24 Hour Time Use Diary

Participant ID:

ACTIVITY	MORNING											
	8.00 - 8.30		8.30 - 9.00		9.00 - 9.30		9.30 - 10.00		10.00 - 10.30		10.30 - 11.00	
Who the activity was for:	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child
SLEEPING												
RESTING/ RELAXING doing nothing, 'time out'												
PERSONAL CARE washing, dressing, toilet												
EATING/ DRINKING/HAVING A MEAL												
TRAVELLING to places by car or public transport												
PAID WORK outside of the home												
UNPAID WORK outside of the home												
HOUSEHOLD CHORES/ HOUSEWORK												
HOBBIES and other LEISURE ACTIVITIES												
WATCHING TV and VIDEOS/DVDS												
Using COMPUTER/ INTERNET												
READING books, magazines												
VISITING a friend or relative												
VISITING religious service												
SHOPPING												
STUDYING eg. For a course												
GARDENING												
ATTENDING APPOINTMENTS												
INTIMATE BEHAVIOURS with other or self												

24 Hour Time Use Diary

Participant ID:

ACTIVITY	MID AFTERNOON											
	12.00 - 12.30	12.30 - 1.00	1.00 - 1.30	1.30 - 2.00	2.00 - 2.30	2.30 - 3.00	3.00 - 3.30	3.30 - 4.00				
Who the activity was for:	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child
SLEEPING												
RESTING/ RELAXING doing nothing, 'time out'												
PERSONAL CARE washing, dressing, toilet												
EATING/ DRINKING/HAVING A MEAL												
TRAVELLING to places by car or public transport												
PAID WORK outside of the home												
UNPAID WORK outside of the home												
HOUSEHOLD CHORES/ HOUSEWORK												
HOBBIES and other LEISURE ACTIVITIES												
WATCHING TV and VIDEOS/DVDS												
Using COMPUTER/ INTERNET												
READING books, magazines												
VISITING a friend or relative												
VISITING religious service												
SHOPPING												
STUDYING eg. For a course												
GARDENING												
ATTENDING APPOINTMENTS												
INTIMATE BEHAVIOURS with other or self												

24 Hour Time Use Diary

Participant ID:

ACTIVITY	AFTERNOON/ EVENING											
	4.00 - 4.30	4.30 - 5.00	5.00 - 5.30	5.30 - 6.00	6.00 - 6.30	6.30 - 7.00	7.00 - 7.30	7.30 - 8.00				
Who the activity was for:	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child
SLEEPING												
RESTING/ RELAXING - doing nothing, 'time out'												
PERSONAL CARE washing, dressing, toilet												
EATING/ DRINKING/ HAVING A MEAL												
TRAVELLING to places by car or public transport												
PAID WORK outside of the home												
UNPAID WORK outside of the home												
HOUSEHOLD CHORES/ HOUSEWORK												
HOBBIES and other LEISURE ACTIVITIES												
WATCHING TV and VIDEOS/DVDS												
Using COMPUTER/ INTERNET												
READING books, magazines												
VISITING a friend or relative												
VISITING religious service												
SHOPPING												
STUDYING eg. For a course												
GARDENING												
ATTENDING APPOINTMENTS												
INTIMATE BEHAVIOURS with other or self												

24 Hour Time Use Diary

Participant ID: _____

ACTIVITY	EVENING		8.30 – 9.00		9.00 – 9.30		9.30 – 10.00		10.00 – 10.30		10.30 – 11.00		11.00 – 11.30		11.30 – 12.00	
	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child	You	Child
Who the activity was for:																
SLEEPING																
RESTING/ RELAXING doing nothing, 'time out'																
PERSONAL CARE washing, dressing, toilet																
EATING/ DRINKING/HAVING A MEAL																
TRAVELLING to places by car or public transport																
PAID WORK outside of the home																
UNPAID WORK outside of the home																
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Using COMPUTER/ INTERNET																
READING books, magazines																
VISITING a friend or relative																
VISITING religious service																
SHOPPING																
STUDYING eg. For a course																
GARDENING																
ATTENDING APPOINTMENTS																
INTIMATE BEHAVIOURS with other or self																

Appendix 4 – Dissemination

The preliminary findings have been presented by the authors as oral paper presentations and a presented poster at four International Conferences, namely ISS, PWM, ARATA, and OT Australia.

The presentations were:

- i) McDonald R & Casey J. The impact of caregiving for children who use wheelchair. Paper presentation. OT Australia, 12th- 13th November 2010, Victoria, Australia.
- ii) Casey J & McDonald R. Child wheelchair users: the impact on their caregivers. Paper presentation. Australian Rehabilitation & Assistive Technology Association National Conference, 11th – 13th August 2010, Hobart, Tasmania.
- iii) Casey J & McDonald R. Caring for children who use wheelchairs: how do parents spend their time? Poster Presentation. 4th International Interdisciplinary Conference on Posture and Wheeled Mobility 7-9th May 2010, Glasgow, Scotland.
- iv) Casey J & McDonald R. The impact of caregiving for physically disabled children who use wheelchairs on the health & wellbeing of their caregivers. Paper Presentation. 4th International Interdisciplinary Conference on Posture and Wheeled Mobility, 7-9th May 2010, Glasgow, Scotland
- v) Casey J & McDonald R. The impact of caregiving for children who use wheelchairs. Paper presentation. 26th International Seating Symposium, Vancouver, Canada, 10-13th March 2010, page 132-135.

An abstract will be submitted to PMG NTE 2013 Conference presenting final report findings.

Further, a manuscript is being drafted for publication in a peer-reviewed journal with the intention of disseminating the findings further.