

**Quality versus Quantity?  
A time use study of father-mother pairs with a  
disabled preschool child**

**by**

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A thesis submitted in partial fulfilment for the requirements of the degree of  
Doctor of Philosophy at the University of Central Lancashire

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## ABSTRACT

Time use studies are an effective way of finding out more about individuals' daily lives and when used with semi-structured interviews can provide a form of participant observation. Large multinational studies have been performed over the past 40 years providing comprehensive data on general populations, including couples with children. However, little is known about the daily lives of couples with children with complex disabilities, and whether there are differences in time use decisions and quality of life for this group of parents. Quantities of time spent on different activities can affect quality of life; the way activities are performed can affect their quality. This study considers these issues of quality versus quantity in the time use of parents.

**Aims and Objectives:** 1) To explore the time use of parents with a young child with complex disabilities and compare this with the time use of similar parents with young children without any identified disabilities; 2) To explore what factors influence parents' time use decisions, and relate these to quality of life and parental satisfaction and 3) To use this knowledge to guide service delivery.

**Methodology and Methods:** This is a critical ethnographic mixed methods study. Three groups of parents participated: 1) Parents with a preschool child with complex health needs dependent on technology; 2) Parents with a healthy preschool child with autism and 3) Parents with a healthy preschool child without any identified disabilities. All parents completed the PedsQL<sup>TM</sup> Family Impact Module Survey followed by a specifically designed precoded time use diary for seven consecutive days. Parents in groups one and two were then interviewed to explore their feelings around time use and family life. Secondary analysis of the Multinational Time Use Survey (MTUS) data from the UK 2000/1 provided a further comparison data set.

**Results:** Data are available on 28 couples and an additional 200 couples from the MTUS data. Significant differences in time use were found between the groups with regard to sleep, leisure, social contact, work, and quality of life measures with parents in groups one and two disadvantaged in these aspects compared to the parents in group three. Five main themes emerged from analysis of the interviews: 'feeling trapped at home'; 'twenty-four seven caring'; 'trying to achieve a balance'; 'discovering a whole new world'; and 'evolving roles' with 'trust' emerging as a unifying theme. Trust was found to provide the threads that linked parents in a complex web of relationships. The quality and quantity of these trust threads affected parents' time use decisions and quality of life as highlighted by the reduced quality and quantity of sleep and leisure experienced. The interparental trust relationship varied between couples with different levels of trust defining 'dictatorship', 'coalition' and 'democracy' groups.

**Conclusion:** Quality and quantity of sleep and leisure time are reduced for parents with a disabled preschool child. This decreases opportunities for parents to 're-charge' and hence can impact on parents' health and wellbeing. Levels of trust between mothers and fathers influence parental time use and are an important determinant of parental quality of life.

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*Trust in the LORD with all thine heart; and lean not unto thine own understanding. In all thy ways acknowledge him, and he shall direct thy paths.* Proverbs 3:5-6 (KJV)

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## CHAPTER 1 INTRODUCTION

*There is a time for everything, and a season for every activity under  
heaven*

Ecclesiastes 3 v 1 NIV

There have been huge advances in medical science and technology over the past several decades. However, despite these advances, the best predictor of the long-term outcomes for a child, with or without additional needs, continues to be their parents (Baxter & Smart 2010; Washbrook 2010). From working with families with a child with complex disabilities over many years, I have found that for many families, the aim is not to find a ‘cure’ but to achieve a reasonable quality of life for their child, for any other children they may have and for the parents themselves. I hope that the information and knowledge gained through this study will help families with children with disabilities to achieve that aim.

This first chapter provides an introduction and overview of the study. This includes a description of the aims and objectives of the study, a discussion about the importance and difference between quality and quantity and a brief consideration of the nature of time, as well as an overview of the subsequent chapters of the thesis.

### **1.1 Aims and Objectives**

The aims of this study are to learn more about the time use of parents with a young child with complex disabilities and how this compares and contrasts with the time use of similar parents with young children without any identified disabilities. The aim is that this knowledge not only encompasses how parents spend their time, but also what factors influence their time use decisions, and how these factors and parents’ time use, relate to quality of life and parental satisfaction with their different parenting roles. The objective in acquiring this knowledge is to use it to guide service delivery for children and their families, to be both flexible and responsive to the dynamics of different families, and to support and empower families’ to achieve their own objectives.

Throughout the thesis there is a consideration of the balance of time use and the compromises, decisions, benefits and disadvantages of quality versus quantity. Over the past fifteen to twenty years there has been an increasing appreciation that the

absolute quantities of time that a parent spends with a child do not correspond directly to the child's developmental and socioeconomic outcomes (Pleck 2010b). Rather, the concept of quality and what is happening during those hours is recognised to be of major importance. Nevertheless, it is apparent that too little time in an activity cannot be completely compensated for by the quality of that time, leading in these situations to a deficit. In contrast, too much time on an activity can become a burden, such as with long hours at work or long hours caring for children. Thus, the quality and quantity of time spent on different activities are important and have an impact on quality of life.

Parents with children with complex disabilities have numerous competing priorities for their time and while the writer of Ecclesiastes highlights that there is 'a time for everything', finding the time for all these different activities can present a challenge. While all parents with young children have multiple demands on their time, two groups of families stand out for me as having very high demands on their time: families with a child with complex health needs dependent on technology and families with a child with an autism spectrum disorder. Although, in many ways the children's presenting problems could not be more different, the time demands and need for multidisciplinary and multiagency services are similar. This study focuses on these two groups of families with children with additional needs and a group of matched comparison families.

Having lived in a number of different countries and cultures particularly during my childhood, I find the concept of time and the different cultural influences on it fascinating. Time can appear to be a deceptively simple concept but it is actually multifaceted and complex and while everyone has some understanding of it, this understanding is not universally the same. For instance, while living in Africa and having visited a number of different African countries, I am aware of the more relaxed concept of time in many parts of Africa, where people are less constrained by the strict 'clock-time' of western cultures. In contrast, in Thailand, time is very influenced by hierarchy and the correct time for an event to start is not judged by the clock but the arrival of the most important person.

Therefore, while time can be objectively measured, it is also subjectively experienced. It is also a social construct with an artificial division into seconds, hours, days, weeks, months and years. Not only do different cultures experience time differently, but also the perception of time may vary according to age and gender. Indeed, it is common for people to share how time seemed to pass more slowly when they were children compared to when they became adults.

A further important aspect of time is that everyone has an equal amount of time in the day, 1440 minutes, and while it is sometimes considered the fourth dimension, it only goes in the one direction. Therefore, once time has passed it cannot be re-gained and the more time that is spent on one activity the less time there is available to be spent on other activities. This gives time a precious quality and it is variously thought of as a commodity, in economic terms, and as a gift as well as increasingly something that people do not have enough of (Goodin et al. 2005). For parents of young children with disabilities time can be regarded as a “*fundamental resource and a constraint*” (Brotherson & Goldstein 1992).

Despite the importance of time to the families of children with disabilities (Dunlap & Hollinsworth 1977) there are few time use studies available involving this population, and no studies the same as the one presented in this thesis. One of the key strengths and uniqueness of this study is the equal involvement of both mothers and fathers, the use of mixed methods and the consideration of time use throughout the full 24 hours for a complete week. This has enabled important issues to be identified with regard to sleep and leisure and that quality and quantity do not only apply to time, but also to parents’ trust relationships.

## **1.2 Outline of the Thesis**

The following chapter, Chapter 2, provides a review of the relevant literature. This covers a wide range of different areas including time use, trends in childhood disabilities, what is known about providing supportive services to families with children with disabilities, the importance of fathers as well as mothers to children, and the economic and political context of disability in the UK.



Chapter 3 describes the methodology and methods used and the reasons for the mixed methods design and particular methods chosen as well as a consideration of the ethical implications of the study. It also includes a description of the development of the time use diary designed specifically for this study.

Chapter 4 is the first of the three chapters addressing the findings of the study. This chapter focuses on the quantitative data from the time use diaries and the quality of life survey. The data presented are drawn from both the time use diaries designed for the current study and also from the 2000/1 UK diaries from the Multinational Time Use Study data set. Demographic information is presented followed by data concerning sleep, work and travel, location, social contact and intensity. Following the time use data, the analysis of the data from the PedsQL™ Family Impact Module Version 2.0 survey is presented.

Chapter 5 focuses on the qualitative findings from the analysis of the 34 semi-structured interviews. The themes and subthemes are presented and related to the results of the quantitative data analysis. Following analyses of the data, the concept of trust emerged as a unifying theme. This finding is further discussed in Chapter 6 where it is interwoven within a framework of interparental trust relationships.

Finally, Chapter 7 provides a discussion of the quality and quantity of time use of parents with a disabled preschool child and suggests ways of providing enabling and supportive services particularly by promoting quality trust relationships. The thesis concludes with recommendations arising from the study, acknowledgements of the limitations of the study and suggestions for further research.

### **1.3 Summary**

This time use study of parents with young children with complex disabilities provides the opportunity to consider both objectively and subjectively, the quantity and quality of time spent by parents on different activities and thus draw conclusions with regard to quality of life and parenting issues. The quantitative and qualitative methods used facilitate this process to achieve the aims of the study which have been outlined above. The literature reviewed in the following chapter provides the context for this study and highlight the gaps in knowledge that this study has helped to fill.

## CHAPTER 2 LITERATURE REVIEW

*“Life is a precious gift to be cherished and nurtured the best way you know how. It is not some elusive dream, nor is it to be taken for granted and wasted. Life is not some fragile vase to be perched on a pedestal to exist in a vacuum of artefacts. Life is to be lived – risks and all.”*

Bob Dale (1995) Creating Answers. In Meyer D.J (Ed) *Uncommon Fathers* (pg3)

### 2.1 Introduction

The time use of parents with a young disabled child, and how knowledge of this could potentially guide service delivery, crosses many different areas of research. This chapter highlights the relevant research in these different areas and how this has guided my own study.

I start by describing the evolution of time use research from its broad beginnings in the early nineteen hundreds, to focusing on why time use methodology lends itself to the study of family life and is a useful methodology for this study. The available literature on the time use of parents with a disabled child is then presented and the relative lack of published research in this area, particularly with regard to the time use of fathers with a disabled child, is emphasised. I then highlight the reasons why I have chosen to focus on families with a child with either autism or complex health needs dependent on technology, rather than a broader or more diverse group of disabilities. As the purpose of this study is to achieve a greater understanding of the lives of parents with a child with a disability in order to guide service delivery, literature about families’ views on the ways services have been offered including the tension between models which are either more medical or social in their orientation is explored. This literature, while often referring to parents, is predominantly from a maternal perspective.

The lack of information about fathers’ time use in families with a disabled child has guided the design of this study to ensure that fathers have an equal voice to mothers. Therefore fathers’ time use, that is their actions, and their views and opinions have been obtained from fathers directly and not from someone else reporting on their behalf. While it is widely accepted that mothers have an important role to play in the lives of their children, and in particular their young children, the importance of fathers

in the lives of young children has only been widely appreciated more recently (Lamb 2010b). The current thinking about this topic is therefore discussed including the impact of gender and masculinities. This leads on to considering these issues in relation to fathers with a disabled child and their experiences of fathering a disabled child. Finally, I briefly describe the political and economic background to healthcare in the UK and the implications for individuals with disabilities and their families.

## **2.2. Evolution of Time Use Research**

Time use surveys were first used at the turn of the 20th century with the earliest known studies recording the pattern of daily life in Britain by Pember-Reeves, and in America by Bevan, both in 1913 (Harvey & Pentland 1999, pg 66). Since then there have been more than sixty national-level studies from at least thirty countries, including the UK. There have also been many studies looking at the time use of subsections of the population (Gershuny 2000).

A pivotal event in the evolution of time use survey research was the 1965 Multinational Time Budget Study organised by Alexander Szalai (Szalai et al. 1972). This was a huge undertaking collecting data from 12 different countries and 15 different survey sites. For the first time it was attempted to collect data in a consistent and uniform way to enable meaningful comparison of data collected not only by different teams of workers but also from different countries. While Szalai et al's (1972) study was designed to consider time use in economic terms it revealed the untapped potential of time use research.

The Multinational Time Budget Study involved participants completing single diary days, or where this was not possible due to reluctance to complete the diaries or literacy problems, a 'fresh interview' was performed. This was where the interviewer completed the diary for the previous day by asking the respondent to recall the events of the day in sequence. While it was acknowledged that it was preferable to complete more than 24 hours data collection for each respondent, it was decided that this was not feasible in such an extensive time-budget survey. However, having large numbers of participants each completing different single days allowed the data to be pooled, giving information trends over a whole week period. Appropriate weightings were applied to ensure each day was represented equally.

Much work is now being carried out by time use researchers in centres throughout the world to ensure that collected data can be used for comparison purposes, none more so than the work being done by the Centre for Time Use Research in Oxford. The potential to harmonise different data sets dating back to Szalai's Multinational Time Budget Study has been the basis of the Multinational Time Use Study (MTUS) first developed in the early 1980's. The MTUS now encompasses over 60 datasets from 22 different countries and continues to grow (Gershuny & Fisher 2010). This means that time use data are available for more than 40 years which enable trends in work patterns, gender roles and leisure activities to be explored over this period.

With large data sets looking at population trends, single day diaries can be pooled to enable meaningful analysis. However, in contrast, looking at smaller subpopulations such as families with a disabled child or at particular issues necessitates a longer period of data collection to ensure that less frequent activities are not missed or over represented (Gershuny 2000). In particular it is clear that activities performed at the weekend are likely to differ from those performed during the week and therefore some studies have used one week day and one weekend day. However, the most common recommended period is seven days, that is one week, as many aspects of life are scheduled over this time frame (Harvey et al. 2003). This is the case when studying parental childcare responsibilities, or time use of couples, when paired diaries (mother-father) of the same seven-day period provide the best data. As Fisher highlights on the Centre for Time Use Research website (Fisher 2007) in most families work, leisure and childcare activities tend to be organised on a weekly rather than a daily basis. The UK has a number of such studies dating back over more than 30 years which provide a valuable resource both to look at changes over time and to compare the findings of this study to.

It is evident that there are many ways of conducting time use surveys but an important consideration is whether the information is collected retrospectively or prospectively. Data can be collected retrospectively looking at the preceding 24 hours, month or even year, with participants asked to recall how they have spent their time. Alternatively time use diaries can be completed for the next 24 hour period, seven day period or at particular times only.

Robinson (1999) has provided evidence to suggest that retrospective time use interviews requiring an individual to estimate how much time they have spent on particular activities are prone to error, with the total number of hours spent on activities during a week exceeding the total number of the actual hours available. Even activities that might be anticipated to be accurately recalled, such as paid work, have also been shown to be overestimated when compared to time diary records (Robinson & Bostrom 1994). Gershuny (2000) in his substantive book “Changing Times” discusses how the construction of a diary that encourages the participant to recall a sequence of events, with estimates at what time these events occurred, (for example when they got out of bed), enables more accurate aggregate totals of time use categories to be achieved. He also suggests that the less time between recall and recording, the more accurate the data, which is consistent with what would be expected.

Participants completing their own diaries enable large numbers of individuals to be included in a survey. Some time use surveys, particularly national ones, have involved thousands of respondents. The diaries can be completed using free text or precoded light diaries. While the precoded diaries require less effort on the part of the participant, if the codes are not explicit participants can become frustrated trying to determine which code their activity falls under. This can lead to non-compliance or incomplete diaries which are then either very difficult to interpret or unsuitable for analysis. However, an additional advantage of precoding is that it can focus data collection on particular areas of interest including health and disability issues.

Free text provides more comprehensive and richer data but requires a higher level of time and effort both to complete and to code afterwards. Some diaries use a mixture of free text and precoded sections. Response rates for any type of self-completed diary can be improved by delivering and explaining the diaries and collecting them afterwards. The collection of the diaries allows the data to be checked and any missing entries queried ensuring more complete and usable data.

The meaningful interpretation and analysis of the diary data requires additional information such as the participants’ demographic data. In addition further insights can be gained by using the diaries as a basis for a subsequent interview. The ‘diary:

diary interview' method first described by Zimmerman and Weider (1977) allows the entries and circumstances during the diary period to be explored, clarified and elaborated. The use of this method of self recorded diaries and subsequent interview produces a form of participant observation.

### ***2.2.1 What time use diaries reveal about parental time use***

There are many time use studies looking at parental time use, and the gender convergence that has occurred over the last 40 years with regard to participation in the paid workforce and childcare, in developed countries. Looking at UK data, men have historically worked full-time with low levels of participation in childcare activities particularly when their children are very young. Women have been homemakers taking the main responsibility for childcare and domestic activities, again particularly when their children are preschool. When women have participated in the paid workforce, this has most often been on a part-time basis (Gershuny 2000).

Childcare is an activity that has been subject to different interpretation in different studies and has been entered under different codes. It is commonly under-reported, particularly in studies only recording the primary activity, as childcare is often not regarded as the main activity an individual is doing. For instance, while cooking the dinner the parent maybe also looking after the children, but is more likely to record the dinner preparation as the primary activity. In time use studies that record secondary activities in addition to the primary activity, there is still the potential for under-reporting or variation in how individuals interpret childcare. For instance does 'childcare' refer to the whole period during which an individual is responsible for the child, for example including while they are asleep, or just when directly doing an activity with them, or when supervising the child though not directly engaged with them (Allard et al. 2007; Gray 2006). Therefore, it is important before drawing conclusions from previous studies or comparing data between studies, that there is a clear understanding of the criteria and definitions used. Nevertheless, a clear trend can be identified in many developed countries including the UK and USA, of fathers becoming more involved in the care of their children including their preschool children, and many more women participating in paid employment (Bianchi 2000; Fisher, McCulloch, & Gershuny 1999; O'Brien 2005; Sayer, Bianchi, & Robinson 2004).

There are many reasons for these noted changes in work and childcare participation including changes in employment patterns with an increase in part-time working and more shift working (Family and Parenting Institute 2009). These changes affect both men and women so that more men are working part-time than previously and there are more part-time jobs available that are accessible for women with other commitments such as children. Society is now operating increasingly on a 24-hour basis and there is a change in the types of jobs available with a greater proportion of jobs occurring in the service industry and a reduction in heavy industrial work (Family and Parenting Institute 2009).

Interestingly, although fathers' participation in childcare has increased, the level of mothers' participation has also increased (Bianchi 2000; Fisher, McCulloch, & Gershuny 1999; O'Brien 2005; Sayer, Bianchi, & Robinson 2004). These increases in both mothers' and fathers' participation are again at least partly due to changes in society and also to changes in cultural expectations. Sayer et al (2004) suggested a number of reasons for these participation changes. Firstly, they suggested that the more voluntary nature of parenthood due to the availability of effective contraceptives results in those men and women who choose to become parents being more willing to spend time with their children. Secondly, Sayer et al (2004) suggested that greater fears about a child's safety is leading to less unsupervised play at all ages and an increase in the amount of time spent transporting children to different venues, and thirdly that there is the perception among some parents of the need to invest in their child's future and engage in 'quality time' with their children. Furthermore, there is an increasing expectation upon children and young people to achieve, and an increasing expectation that parents will fulfil a range of responsibilities to enable these achievements.

Lesnard (2004) has studied couples' time use in France and has noted that many couples, particularly those with children are leading desynchronised lives with parents arranging their work patterns and childcare responsibilities around each other but having very little time together. He found that 20 percent of couples who both worked full-time had more than 50 percent of their time 'desynchronised' that is when one partner was working the other partner was not. In fact, some of the couples led completely desynchronised lives. This desynchronisation was noted to have

dramatically increased between 1985 and 1998. Lesnard's work also highlights the importance of not just looking at absolute totals of time spent on different activities, but that the sequences of these activities and how they relate together provide a much more accurate and meaningful picture of an individual's or couple's time use.

### ***2.2.2 Time use of parents with a disabled child***

Despite all these data on fathers' and mothers' and couples' time use, there are few data available on the time use of parents with a disabled child. Studies looking at these issues on a large scale have only been performed in the last ten years with time use diaries being developed to include codes for 'caring' activities and specifying whether this is for a disabled adult or disabled child (see for example the 1997 Australian time use study (Brandon 2007)).

There are also very few studies looking specifically at the time use of parents with disabled children and those that have been performed have almost exclusively looked at the time use of mothers (Breslau 1983; Crowe & Florez 2006; Crowe, VanLeit, & Berghmans 2000; Curran et al. 2001; Gevir et al. 2006; Johnson & Deitz 1985; Lucca & Settles 1981). The reasons for this have usually been the perception that mothers perform the majority of the care of children and therefore it is the impact on their time use that is most important. However, the few studies including father's time use have shown it is also affected. Barnett and Boyce (1995) found that fathers' of children with Down Syndrome spent four hours a week more on child care and two hours a week less on social activities compared to fathers with typically developing children. The authors comment that although these changes are small relative to the estimated effects on mothers' time use, the effects are large compared to the time men typically devote to child care and social activities. Smith (1986) in a study of Saturday time use of parents with a physically disabled child found an increase in total child care time for both parents compared to parents in a nationwide sample. However, this was more marked for fathers who contributed 45.6% of their households' total child care time in comparison to fathers in the nationwide sample who contributed 28.9%.

Studies of maternal time use in families with a disabled child have produced different results when looking at particular aspects of time use. Gevir et al (2006) highlight some of the differences found in earlier studies. The majority of these studies showed



an increase in the amount of time spent on child care activities compared to mothers with typically developing children. Some of these studies showed differences in the amount of time mothers had for leisure, self care and social activities while Breslau (1983) found an increase in the amount of time spent on housework but not on child care. Some of the reasons for these discrepancies are that different methods were used to collect the data, and the group of children in the disabled groups have generally been very varied. Therefore care has to be taken when comparing these studies and their findings cannot be generalised (Crowe 1993).

These studies also tended to examine only a few of the ways that a mother used her time, for example on physical child care. Among some researchers there is the perception that completing a full diary can be overburdening for parents who already have so many demands on their time (Curran, Sharples, White, & Knapp 2001; Johnson & Deitz 1985). However, parents who understand the reason for a study can be well motivated to complete 24 hour diaries, even finding aspects of the diary completion process enjoyable (Thomas et al. 2011). Therefore, while the burden on participants is an important consideration, not completing a full 24 hour diary means that the information gathered on particular activities such as care-giving cannot be interpreted in light of information about how other activities have been affected. As there are only 1,440 minutes in a day, if more time is spent on one activity, less must be spent on something else. An indication of what activities are being 'sacrificed' can be obtained by collecting information about all activities and comparing these with the activities that parents with non-disabled children participate in. This may be another reason why different studies have given conflicting results about the time use of parents of children with disabilities compared to families with a typically developing child.

It is also important that we consider the time use of parents with a disabled child as families themselves regard their time use as very important. In a study by Dunlap and Hollinsworth (1977) 404 families were asked to identify the major issues due to their child's disability that were impacting on family life. 'Time demanded' was the most commonly mentioned (45%), followed by 'money problems' (27%) and then the 'physical demands of caring for their child' (23%).

### **2.3. Trends in Childhood Disability**

This gap in knowledge about the time use of parents with a disabled child is an increasingly important issue due to recent trends in childhood disability. According to statistics from Contact a Family, a UK based registered charity supporting families with disabled children, the numbers of disabled children in the UK have increased by 62% between 1975 and 2002. This is an increase of 294,000 children (Contact a Family 2009). Over this period there has also been a conspicuous increase in two particular groups of children with high level additional needs. Although these groups are actually very different from each other they are both sometimes confusingly referred to as having complex needs. These two groups are children with a diagnosis of an autism spectrum disorder and children with health needs dependent on technology.

Unfortunately the statistics available on absolute numbers of children with disabilities are limited (Mooney, Owen, & Statham 2008) and this is also the case for information about numbers of children in different diagnostic groups. Figures often rely on proxy measures such as applications to the Family Fund. While acknowledging that their figures are likely to be underestimates, workers at The Office of National Statistics comparing the trends between 1990 and 2000, have shown that the percentage of children diagnosed with an autism spectrum disorder increased from four percent to 25% of the total number of children with a severe disability (Nessa 2004). Information on numbers of children dependent on technology is only just starting to be collected but studies do indicate the numbers are increasing (Glendinning et al. 2001; Noyes, Godfrey, & Beecham 2006). Other studies have suggested a 77% increase in the number of children who required assisted ventilation at home between 1997 and 2000, (although this could also reflect the move to manage children with increasingly complex medical needs at home rather than just an increase in absolute numbers) and an increase in the number of children who are tube fed (see HM Treasury & DfES 2007, pg 60).

There is an ongoing debate about whether the rise in the number of children with a diagnosis of an autism spectrum disorder is due to an increase in affected children or an increase in rates of diagnosis (Taylor 2006). Some individuals with autism will have additional health needs but the majority are physically healthy with their

difficulties confined to the areas of communication, social interaction, and behaviour.

The ICD-10 classification of childhood autism is:

*“A type of pervasive developmental disorder that is defined by:  
(a) the presence of abnormal or impaired development that is manifest before the age of three years, and  
(b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour.  
In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.”* (World Health Organisation 2007)

The definition of children with health needs dependent on technology is even less well defined. There is no ICD-10 classification though in chapter XXI “Factors influencing health status and contact with health services”, there is mention of the different types of health problems that maybe included in this group such as tracheostomy or gastrostomy, but no mention of dependence upon technology. Indeed there is no accepted UK definition of technology dependence (Glendinning, Kirk, Guiffrida, & Lawton 2001). The definition used in the Technical Memorandum on Technology Dependent Children by the US Congress Office of Technology Assessment is:

*“one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability”* (US Congress 1987, pg3)

This definition is widely used in the UK (Glendinning, Kirk, Guiffrida, & Lawton 2001; Heaton et al. 2003) as well as America but is still open to interpretation particularly with regard to the amount of nursing care it includes. However the definition does continue *“this definition is independent of the setting of care or the particular credentials of the caregiver”* (US Congress 1987, pg3).

One of the problems with some of the previous time use studies highlighted above is the amalgamation of families with children with very different disabilities and additional needs. This has the potential to mask the effect having a disabled child has on parental time use. It is never going to be appropriate to view all parents with a disabled child as a homogenous collective for many reasons. However the problems with definitions, diagnostic criteria and the heterogeneity of children with the same

diagnosis mean that even grouping families by the diagnosis of the child leads to a very diverse group. Therefore when considering the two groups for consideration in this study, additional factors and clarification of characteristics are required to try and ensure that the children with a disability within a group are sufficiently similar to allow some comparisons, and the children between groups are sufficiently different that any differences can be readily identified. One of the ways that this can be achieved is by looking at the type and level of services required rather than just concentrating on diagnoses.

#### **2.4. Supporting Families with a Child/children With Disabilities**

The increasing number of children with complex disabilities has occurred over a period where society's expectations and Government policies have changed enormously. Children are now expected to live with their families in their family homes where previously many would have remained in hospital or been placed in institutions (Carnevale et al. 2006; Department of Health 2011; Kirk & Glendinning 2004; Yantzi, Rosenberg, & McKeever 2006). In addition, more parents are expected to work and to find appropriate child care often from non-family sources.

Expectations about what children with disabilities can achieve have also changed. All children are now recognised to have potential but this expectation leads to pressure on parents to engage in an ever increasing range of early intervention programmes (Isaacson 2009; Venables 2007; Woodgate, Ateah, & Secco 2008) and manage increasingly complex medical situations (Heaton, Noyes, Sloper, & Shah 2003) in order to try to enable their child to fulfil their potential. Assumptions are often made by professionals that parents will take on these responsibilities without clear negotiations or appreciation as to the possible impact on parents (Kirk & Glendinning 2004). There is now the expectation that parents with a disabled child will be not only parents, nurses, therapists, and teachers (Bennett 2009; Kirk, Glendinning, & Callery 2005) but also enable their families to live 'normal' lives (Bennett 2009; Carnevale, Alexander, Davis, Rennick, & Troini 2006; Wang & Barnard 2004).

While there has been an increasing appreciation the impact of having a child with a disability can have on the family these considerations have usually focused on the mother (Beresford 1994; Hornby 1994). Over recent years there has also been a

change in emphasis over the interpretation of this impact from it being viewed as universally negative and a ‘tragedy’ to recognising the possible positive outcomes. In addition the variable ways that different families experience and cope with similar events are being acknowledged (Ferguson 2002; Goodley & Tregaskis 2011; McLaughlin et al. 2008; Trute 1995). For many families there is the experience that their daily situation encompasses both positive and negative aspects described by Carnevale et al (2006) as “*daily living with distress and enrichment*”.

Although not underestimating the need for supportive services to meet the additional needs associated with having a child with a disability, it is often the socio-historical context that influences how parents interpret the events associated with having a disabled child and facilitates their positive adaptation to their new situation or impedes it (Ferguson 2002). There is also a recognised need to determine what family characteristics, including demographics such as the age of the parents, birth order, and financial stability, facilitate positive adaptation.

Many families with a disabled child in developed countries such as the UK, USA and Australia perceive that their child is not valued by society and some parents believe that their child is not valued by their health care providers either (Carnevale, Alexander, Davis, Rennick, & Troini 2006). This can contribute to parents feeling very socially isolated and excluded, compounding the physical challenges of finding the time and energy to go out (Gray 2002; Woodgate, Ateah, & Secco 2008).

When considering outcomes for children it is important to remember the family’s fundamental role. As Seligman and Darling (1997) emphasise, partnerships between professionals and families are essential to achieve effective intervention. To achieve this partnership and help families they state:

*“We must do it on their terms, within the context of their system of meaning. Only through such a systems perspective can we hope to improve the quality of life for ordinary families who happen to have children with out-of-the ordinary needs”* (Seligman & Darling 1997, pg278)

The systems perspective referred to above recognises that whatever influences one family member, or whatever action one family member performs, will have an impact

on other family members. However, many service delivery models fail to take the family systems perspective described by Seligman and Darling (2007) into account. Therefore, knowledge and skills are often imparted to only one parent, usually the mother. While this increases the mother's involvement and ability to care for the child it can inadvertently lead to the father feeling both less aware of what is happening and less competent. As the mother becomes more involved, the father can feel more marginalised and may further withdraw from caring for the child. Thus the caring balance may become ever more unequal with feelings of resentment and frustration growing as the mother feels more put upon and trapped and the father feels increasingly alienated and rejected (One Plus One 2007).

Many professionals, not just those from health, often concentrate on identifying the problems and needs of the disabled child and seek to address and ideally cure these. While this medical model is also the starting point for many parents when they discover their child has additional needs, there is also the need to incorporate the social model which identifies that the reasons for an individual's disability is as much, if not more, about the environment within which they live and the way society is constructed as any problem within an individual. Both models have valuable aspects and limitations and a balance needs to be maintained between the two.

Fisher and Goodley (2007) refer to a linear medical model of disability where progress is defined by experts and much of what is being done in the form of intervention is to achieve future goals. One of the negative aspects of this model is never enjoying the present but always striving to achieve a perhaps never achievable situation. Some of the mothers in their study, (that only involved mothers), had adopted an alternative approach described as "*the philosophy of the present and becoming*" where the current uncertainties were accepted, the present was enjoyed for what it is and the journey or the 'becoming' was acknowledged rather than always striving for a future goal.

Not only do professionals tend to look for problems within the child they also tend to look for problems within the family rather than identifying family strengths (Dunst, Trivette, & Deal 1988). It is important to recognise the family's strengths and abilities and listen to what the family highlights are the important issues for them rather than

what the professionals believe are the issues or priorities. Dunst et al (1988) suggest that if parentally identified unmet needs are not addressed then there is an increased probability that the parents will not carry out the suggested child-level interventions. The higher the number of unmet needs, the higher the probability the interventions will not be performed (Dunst, Trivette, & Deal 1988, pg24).

Coping strategies and styles have been highlighted as important predictors as to how positively individuals adapt to and manage potentially stressful situations such as having a child with a disability or living with chronic health needs (Abbott et al. 2001; Abbott 2003; Tetreault, Weiss-Lambrou, & Vezina 1994; Trute 1995). Different ways of coping have been suggested to influence the likelihood of treatment regimes being followed (Abbott, Dodd, Gee, & Webb 2001), the perception of burden (Tetreault, Weiss-Lambrou, & Vezina 1994) and the development of depression (Trute 1995). Positive or optimistic coping is increasingly considered to improve quality of life but in certain situations avoidance coping may be the most effective way of maintaining quality of life particularly when the situation is uncontrollable (Abbott 2003).

Interestingly, Tetreault et al (1994) included sleep as a coping strategy which was considered to 'always be helpful' by 54.2% of the mothers in their study. Many authors highlight that sleep deprivation is a major issue for parents with child with technology needs or autism (see for example Bennett 2009; Brotherton, Abbott, & Aggett 2007; Heaton, Noyes, Sloper, & Shah 2003; Isaacson 2009; Venables 2007; Wang & Barnard 2004) but the extent of this sleep loss has not been documented to date, not even in time use studies.

## **2.5. Fathers**

For many years the emphasis when considering parenting has almost entirely been on the mother (Lewis 1986). Fathers were a more distant figure, responsible for breadwinning and sometimes enforcing discipline (Doyal 1979; Lamb 2010b). However, there has been a change in society's perception of what an ideal father is and also the importance of the father's role in optimising child outcomes (Lamb 2010a; Lewis 1986; O'Brien 2005; Pleck 2010b). Therefore there has been an explosion of research and published literature in this area and quite a rapid change and evolution of thinking over the past 30 years. The literature presented in the following

sections will be predominantly in relation to the perception of fathering in the UK, due to the location of this study. Likewise, due to the focus of this study, the literature focuses on fathers involved in a heterosexual ongoing relationship where both parents are living together.

### **2.5.1 Fathers' role(s)**

When considering the role of fathers and the concept of 'fathering' there is not one role but many different roles that fathers undertake and these are sometimes different in different families, for different men and at different times in their life course. Fathers' roles include being companions, protectors, partners, moral guides and teachers (Lamb 2010a).

While the initial emphasis and expectation with regard to the father's role in the family was on 'breadwinning' and being a 'provider', there has been a shift in focus over the past 20 to 30 years towards 'involved' fathering. What 'involved fathering' entails has been debated but its earliest construct in the mid 1980's, sometimes referred to as the Lamb-Pleck conceptualisation, had three components and despite various expansions and further divisions of these components by subsequent researchers, I consider these original three components are particularly pertinent to this study. These components are:

- "a) paternal engagement (direct interaction with the child)*
  - b) accessibility (availability)*
  - c) responsibility (making sure the child is taken care of)"*
- (Pleck 2010b)

Many of the subsequent expansions and redefinitions of this conceptualisation have been to try and establish which components of fathers' involvement have an impact on child development as when all these concepts are merged it has been difficult to clearly detect a benefit to children's outcomes. This is not really surprising as the father's individual circumstances are likely to be of relevance. For instance, if a father is unwillingly unemployed and therefore forced by circumstances to spend large amounts of time with his child this is likely to have a different impact on his child's developmental outcomes than a father who is actively prioritising spending time with his child. In this way it is apparent that quality of time and not just absolute quantities of time are important. Therefore issues like parenting style, warmth and



responsiveness and time engaged in positive engagement activities rather than total paternal engagement time have been considered important (Pleck 2010b). Much of the initial work on paternal engagement, that is the total amount of direct interaction time with the child, was based on time use diaries (Pleck 2010b).

Responsibility has two main components to it, indirect care and process responsibility. The definition actively excludes ‘breadwinning’ as the provision of economic support was already the subject of much research. Pleck (2010b) emphasises “*the intent of the involvement construct was to identify new dimensions of fathering that appeared to be changing and that previously received little attention*”. Therefore, while responsibility would intuitively suggest ensuring economic support this was specifically excluded in the Lamb-Pleck conceptualisation of involved fathering. Instead the indirect care component of responsibility referred to activities for, but not directly with the child, such as arranging child care or medical appointments, while the process responsibility component referred to the more ‘mental work’ involved. This means taking the initiative and noticing what needs to be done and ensuring that it is done rather than waiting to be asked to do a task (Pleck 2010b, pg66).

When different aspects of involved fathering are looked at and other confounding factors such as socioeconomic status and the impact of mothers considered, a positive benefit to involved fathering is detected and this persists well into adult life in a range of different positive outcomes. These include better exam results at 16 and higher educational attainment at 20, as well as increased likelihood of escaping from deprivation or poverty in adult life (Fatherhood Institute 2010).

It is important to remember that many of the positive effects of involved fathering are indirect rather than direct. For instance, emotional and instrumental support of the mother, provision of economic support and security, and the quality of the relationship with the mother are all relevant factors (Lamb 2010a, pg 9). In addition, other relationships are also important including the relationship with the child. As Pleck (2010b) explains, fathering is subjected to “*reciprocal influence*”. If the family process view is considered then:

*“Paternal involvement is not just an exogenous paternal behaviour but a relational process between father and child that is embedded in other family relationships” (Pleck 2010b, pg 81).*

As mentioned earlier these different relationships and especially the father’s relationship with the mother need to be considered when any intervention or support is being offered. Featherstone’s “Contemporary Fathering” (2009) which is written from a predominantly feminist perspective, stresses the importance of exploring ways fathers can be involved without promoting male power and masculinity and oppressive gender relations. She highlights the need to promote positive father involvement within the context of that couple’s relationship. If practitioners enforce their ideas about what an involved father should do to promote positive outcomes for a child they may instead cause negative outcomes by upsetting the negotiated roles and responsibilities in that family. It is not the practitioner’s role to decide what a perfect family or a perfect relationship or a perfect mother or father should do. The practitioner’s role is to support parents in their identified roles and further extend or enable these roles if that is what the family want. Alternatively, the practitioner’s role is to provide different possible scenarios for consideration, or to remove barriers that are stopping families achieving the roles they want. There is a danger that if practitioners promote both parents as performing the same roles, while this may work for some families it may lead to role conflict or gaps in others. It is also important to look at the father and mother in the context of their wider family, friends and society and what roles these other people play. Featherstone concludes *“our increased understanding that ‘fathers matter’ must be located within an appreciation of how ‘mothers matter’ also”* (Featherstone 2009, pg 190).

### ***2.5.2 Impact of masculinities and gender on fathers’ roles***

Masculinity is not a static or even a single concept but a plurality of feelings, perceptions, ideals and actions that together construct a gender identity or role. Therefore masculinity is often referred to as masculinities as there is not one definition that encompasses all the different elements and relates to all men regardless of social context, race or economic status (Connell 2000). In his 1995 book ‘Masculinities’, Connell highlights the key relational aspect and attempts the following definition

*“ ‘Masculinity’, to the extent the term can be briefly defined at all, is simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture”* (Connell 1995, pg 71)

Although different expressions of masculinity are acknowledged there are dominant forms and expectations of the masculine gender role within different cultures. In modern Western society the “*hegemonic*”, dominant or “*culturally exalted*” (Connell 1995, pg 77) form of masculinity expects men to be achievers, heterosexual, employed, good at sport and ‘antifeminine’ (Pleck 1995). Indeed one of the essences of masculinity has been its contrast to femininity but this polarity between the two genders is increasingly being debated as more and more researchers find that there are more differences within groups of men than between groups of men and women (Gadas 2009; Petersen 2009). This is also the case in parenting with Pleck (2010a) highlighting that

*“three important qualifications are required about average gender differences in parenting: average difference by parental gender are not large, within-gender variation is substantial, and as a result the overlap in fathers’ and mothers’ distributions on parenting variables is considerable”* (Pleck 2010a)

Researchers commonly interpret masculinity orientation in one of two ways and then focus on one of these aspects in their studies. The first way is with regard to the man’s “*gender typed personality disposition or constellation of traits*” and the second is with regards to the man’s “*attitudes and beliefs*” (Pleck 2010a). That is researchers are looking at either an individual’s actions (governed by his personality), or what an individual believes in as an ideal, but does not necessarily conform to himself. The study reported in this thesis will provide the opportunity to look at both aspects; what fathers do and what they regard an ideal father would do, as well as considering mothers in this regard.

Expectations of fathers and fathers’ understanding of their role(s) are fundamentally affected by cultural expectations of men in general. As men become fathers they negotiate this change to their new role and, for some, it may challenge their previously held views about masculinity. The extent to which they become involved in active childcare and housework will be influenced by their conceptualisations of an

ideal father but also their perceptions of what it is appropriate for a man or a woman to do (Coltrane 1996). The extent to which they are encouraged or allowed to become involved in these activities will also be influenced by their partner's interpretation of fathers' and mothers' roles (Allen and Hawkins 1999).

### ***2.5.3 Maternal gatekeeping***

Maternal gatekeeping refers to the idea that the amount of involvement that a father has in household activities or childcare is mediated by the mother. This concept has been mentioned by a number of researchers since the 1980's but the first attempt to really define and measure maternal gatekeeping was made by Allen and Hawkins (1999). They identified three related dimensions of gatekeeping: "standards and responsibility", "maternal identity confirmation" and "differentiated family roles". Standards and responsibility refer to the mothers' insistence in things being done in a certain way and in either not accepting or negatively judging tasks done in a different manner. Mothers' reluctance to allow fathers' involvement, or only allowing it after detailed instructions have been given as to how a task is to be undertaken, is very similar to the manager-helper relationship model (Coltrane 1996). By retaining control of activities, mothers also limit the development of the fathers' skills and competence so that he continues in his helper role rather than assuming more responsibility. However, fathers may also wish to maintain this balance and actively support maternal gatekeeping as they do not want to take on more responsibility for family work (Allen & Hawkins 1999).

Maternal identity confirmation relates to how much the mother has taken on board dominant cultural ideals about the mothers' role being at the centre of family life. In this way much of her identity and satisfaction is linked to and judged by how well she performs related tasks such as maintaining a tidy home and the successful raising of her children. Not only does she judge herself by these domains, she also feels that others judge her by these factors also. Therefore allowing or encouraging fathers' involvement in family work may lead to feelings of guilt in the mother and that they are not fulfilling their maternal role (Allen & Hawkins 1999).

The last dimension, differentiated family roles, is related to the mothers' expectations as to how the work should be divided up within the family. If a mother has clear

perceptions that certain roles are definitely to be performed by one parent or the other this will influence who does what within that family.

In Allen and Hawkins' (1999) study 21% of the mothers were defined as gatekeepers with the other mothers being less well defined as collaborators or an intermediary group. Mothers who were defined as gatekeepers scored highly in all three dimensions of gatekeeping. However a drawback to this study was the focus being entirely on mothers including asking mothers to estimate the time and involvement their partners had in 'family work'. A subsequent study (Fagan & Barnett 2003) also only obtained information from mothers and not fathers. Their findings suggested that mothers' perception of fathers' competence significantly influenced how much time fathers spent with their children.

Gaunt (2008) included both fathers and mothers in her study of 209 Israeli couples. She found that mothers' self esteem was closely correlated with the standards and responsibilities dimension with the lower a mothers' self esteem the greater her gatekeeping tendencies. The mothers' feminine gender orientation and the more she valued her maternal identity also positively influenced gatekeeping. Gatekeeping was also associated with other background variables with religiosity, fewer work hours, less importance attached to her work by the mother and lower income and education levels all being associated with maternal restriction of paternal involvement in family work.

It is also important to consider how other peoples' beliefs and actions impact on or contribute to maternal gatekeeping. For instance, other family members such as grandparents or neighbours perceived or actual 'judging' of parents can be very influential (Coltrane 1996). Practitioners and health care providers can also consciously or unconsciously project the attitude that mothers should be undertaking certain tasks or maintaining the responsibility for the health and care of their children by their interactions with and comments to parents (Williams & Robertson 1999).

#### ***2.5.4 Fathers with a disabled child***

In the same way that the majority of the research looking at parenting has focused in the past on mothers, much of the work looking at families with a disabled child has

focused on mothers' accounts (Beresford 1994; Hornby 1994). This focus appears to have spilled over into the way services have worked with families with fathers' describing themselves as the "*other parent*" (Meyer 1995), the "*peripheral parent*" (Herbert & Carpenter 1994) or as "*just a shadow, something in the background*" (West 2000).

Much of the literature on fathers' experiences of parenting a child with a disability has come from personal accounts reflecting on individual father's experiences (Appleton 2005; Harrison, Henderson, & Leonard 2007; Isaacson 2009; Meyer 1995; Venables 2007). While many of the accounts are powerfully written and thought provoking they have mostly been written by highly educated and articulate fathers who are not necessarily representative of fathers of disabled children. Therefore the Foundation for People with Learning Difficulties funded a project called 'Recognising Fathers' to find out more about fathers' experiences of parenting a child with a disability. The first study published in 2006 (Towers & Swift) was based on the interviews with 21 fathers. All these fathers had volunteered to be involved in this study by responding to advertisements or had been proposed by practitioners. Therefore, again, not necessarily a very representative sample as they are likely to be fathers who were highly involved in caring for their children or very motivated in some way to be involved. Indeed the fathers were found to have a very high level of involvement with their children and the majority of fathers felt that their child's disability had led them to be more involved in fathering. This is in contrast to earlier work which has suggested that fathers of children with intellectual disabilities tend to be less involved in child care or housework than fathers of children without intellectual disabilities (MacDonald & Hastings 2010). However a Canadian study of the experiences of fathers of children with juvenile rheumatoid arthritis, a chronic health condition that could be considered as a disability, also found that their child's condition acted as a "*catalyst for increased involvement and more meaningful relationship*" with their children (McNeill 2004).

The 'Recognising Fathers' project (Towers & Swift 2006) also found that most fathers felt that they shared responsibility with their partner with regard to looking after their children but many found that practitioners maintained gender stereotypical views with regards to the respective roles of mothers and fathers. Not surprisingly

some of the fathers expressed the desire to be respected and valued for the caring role that they performed.

A subsequent study, also called 'Recognising Fathers' (Towers 2009) consisted of a national survey of fathers of children with a disability in the UK. Two hundred and fifty one fathers completed this survey with 15 fathers from the North West being involved. The aim of the study was to test out some of the hypotheses and issues raised by the earlier qualitative study with a larger more representative group of fathers. This study again showed fathers to be very involved in the care of their children and while 90% of these fathers were living with their partners, only fathers' views were obtained as in the earlier study. Fathers reported that they felt they had a key role to play in supporting their partner as well as their child and again the majority of fathers felt that they were more involved with their child because of the child's disability.

In common with other studies Towers (2009) found that fathers looked to their partner for their main support (MacDonald & Hastings 2010; McNeill 2004). This highlights the importance of supporting the couple's relationship as fathers are most likely to obtain their support from their partner while mothers more often obtain support from external sources (MacDonald & Hastings 2010).

In the 'Recognising Fathers' study the child's disability was felt to have an impact on the father's health, with 41% of fathers reporting that they experienced stress most of the time. In addition many fathers reported disturbed sleep and a negative impact on their employment choices and opportunities (Towers 2009).

### ***2.5.5 Impact of masculinities and gender on health related issues***

The traditional view of men with regard to health related issues is that they are strong and robust, do not require or actively seek help, cope with pain and embrace risk taking as a positive behaviour (Courtenay 2009). There is a perceived reluctance that men will seek help for their own health care needs (Noone & Stephens 2008; O'Brien, Hunt, & Hart 2005; Robertson 2007) with such behaviour often being considered 'feminine'.

Men's construction of masculinity is commonly related to bodily performance and men who have a physical disability can find their disability challenges their perception of manhood and masculinity. A number of responses to this challenge have been described including trying to compensate for their physical disability by excelling in another physical domain; reformulating their view of masculinity to one that is now achievable or rejecting "*the hegemonic masculinity as a package*" (Connell 1995 pg 55).

Fathers of a disabled child therefore need to construct and perhaps reconstruct their masculinities in the context of these various challenges; that is fatherhood, the need for healthcare involvement with their family and fathering a disabled child. Depending on their individual endorsement of the hegemonic masculinity and their perception of their alignment or otherwise to it in their new circumstances, may lead to gender role strain (Pleck 1995) and additional stress and difficulties in adjusting to their new roles. However McNeill (2007) in a study of 22 fathers of a child with juvenile rheumatoid arthritis, a chronic health condition, found that many of the fathers "*embraced a richer and more holistic gender identity*". These fathers often retained traditional gender stereotyped ideals of providing for and protecting their family but also responded to their perception that their child needed them, by close and actively involved parenting. McNeill (2007) suggests that "*the degree of gender flexibility shown by fathers appeared to be associated with the level of involvement with their child*".

## **2.6. The Economic and Political Context of Disability in the UK**

When considering the way parents with a disabled child spend their time and interact with services and their community it is important to place these considerations into the context of the social and political environment in which the families live. This helps to understand some of the decisions, pressures and expectations on and of the families and to interpret some of their experiences.

The cost of health and social care is considerable in the UK and has increased substantially over recent years due to the increasing costs of technology, medicines and an expanding workforce. Decisions have to be made about what treatments will



be paid for and the priorities for healthcare delivery. So what are the political motivations for providing healthcare and how are these priorities established?

Doyal (1979) provides a thought provoking critique of health care both in the UK and developing countries over the last 150 years. While I may not agree with all her conclusions she makes a compelling argument that a key motivation for a government to provide health care is to produce an effective workforce. Thus health is defined in a functional way; that is a person's ability to perform an expected function

*“The defining of health and illness in a functional way is an important example of how a capitalist value system defines people primarily as producers – as forces of production. It is concerned with their ‘fitness’ in an instrumental sense, rather than with their own hopes, fears, anxieties, pain or suffering.”* (Doyal 1979, pg 34)

While it is clear that economic considerations are important and perhaps more openly discussed now than previously, this focus places certain groups of the population, such as disabled children, at risk of being devalued. Parallels can be drawn between the status of women in UK society particularly prior to the middle of the 20<sup>th</sup> century and the status of disabled individuals, and especially disabled children, today. These similarities include with regard to the perception of health with Doyal (1979, pg 219) referring to the ‘medical model’ of women, while the medical model of disability is a commonly debated and often criticised model at present. Doyal continues:

*“Two basic ideas seem to be central to contemporary medical definitions of women. The first is the tacit belief that men are ‘normal’, whereas women are ‘abnormal’. That is to say, the intellectual, emotional and physical potential of women is measured against the male standard and women are found to be essentially defective.”* (Doyal 1979, pg 219)

I consider the predominant UK society view of individuals with disabilities resonates strongly with what Doyal describes above. The intellectual, emotional and physical potential of children with disabilities are compared against the standard of typically developing children and found to be defective. ‘Normal’ is compared to what is considered ‘abnormal’ and abnormal judged to be inferior. The 1967 Abortion Act, while on the one hand offering choice to women also further devalues disabled members of society. It is agreed to be acceptable to have an abortion if *“there is a substantial risk that if the child were born it would suffer from such physical or*

*mental abnormalities as to be seriously handicapped*” (HMSO. 1967) thus suggesting that these individuals have less value or right to life than individuals without these differences.

Political correctness ensures that judgemental views about disability are increasingly covered up but nevertheless they continue to be a powerful undercurrent in influencing decision making and driving political agendas with regard to health care and the way disabled people are valued. For instance, the concept of DALYS (disability-adjusted life years) again ensures that all health decisions have an economic basis and decisions on whether to invest in certain treatments are based on the expected return for the investment with regard to a productive work force. Indeed the concept was conceived by the World Bank (1993) and the World Health Organisation. However, not everyone agrees with the idea of DALYS with the suggestion that “*valuing people’s lives in terms of a money metric, through their instrumental worth in production, is hard to defend ethically*” (Anand & Hanson 1997).

This continual judging of the worth of a human being against an economic return ensures that the majority of disabled individuals, and certainly those with complex needs and high levels of disabilities, are never going to be really valued by UK society. This is the case even from childhood as the five main outcomes of the ‘Every Child Matters’ illustrate:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- *achieve economic well-being* (my emphasis) (DfES 2004)

Against this background parents with a child with complex needs who is dependent on technology or who has an autism spectrum disorder will have to evaluate the worth of their own child, and often renegotiate their own value to society. Indeed some parents report that they feel they are often regarded as “*handicapped parents*” (Furneaux 1988) or describe themselves as “*disabled*” (Appleton 2005; Scott 2010) due to their child.

## **2.7. Summary**

The literature reviewed highlights why time use methodology is relevant and useful when studying family life and also areas where there are gaps in knowledge and understanding. While more is being understood about the impact of having a child with a disability on family life, both positive and negative, less is known from the father's perspective. In addition, little is known about how the time use of fathers and mothers of a disabled child varies throughout the day and night and over the course of a week compared to parents with typically developing children. Furthermore, very few studies have looked at both mothers' and fathers' interpretations of their parenting roles in the context of having a child with a disability. Although many services aspire to be family centred, practices still fail to take the systems perspective into consideration potentially damaging rather than strengthening fundamental relationships. In the next chapter I will outline how this study has been designed to address these gaps in knowledge to help guide future service provision.

## CHAPTER 3 METHODOLOGY

*“For if there was but one message I would wish to communicate to fellow fathers of children with special needs, it is the message of “we”. When it comes to meeting those special needs of our children, fathers cannot do it alone, and neither can mothers. As our children need us by their side and on their side, so do we need each other. To face the challenges which lie before us, we need the strength of our wives, and they need ours, and our children need us working on their behalf together”*

Henry Jay Karp (1995) *If Not Always the Victor, Always the Hero*. In Meyer D.J (Ed) *Uncommon Fathers* (pg112)

### 3.1 Introduction

In this chapter I describe the ontological, epistemological and methodological approaches that guide this study and the reasons for the specific methods chosen. I also highlight the challenges and tensions of embracing sometimes contradictory and opposing epistemologies, styles and methods in order to perform a mixed methods study as well as the reasons and benefits in doing so.

One of these tensions referred to above, is writing style. I have reflected on whether to make my voice explicitly heard and write in the first person in a genre more familiar in qualitative research, or whether to adopt a more traditional, ‘scientific’ writing style and to write in the third person. While my medical and scientific training make this latter style more natural to me there are certain parts of this thesis that I believe require my personal involvement to be highlighted and acknowledged. Therefore I have elected to write different chapters in different styles consistent with the nature of the particular chapters. This is considered an acceptable approach in mixed methods studies (Creswell & Plano Clark 2011, pg 253). My aim by doing this is to ensure that the information is presented both clearly and in a way that enables its critical evaluation. This chapter is written in the first person to reflect the key influence my complete personal history has on the design and conduct of this project.

As I believe that my personal history is of importance in determining the decisions I make and my interaction with the data and participants, I share some of my personal history as part of my reflections on the critical ethnographic approach I have adopted. I then introduce the mixed methods design before discussing time use methodology and its links with ethnography. This leads on to the description of the development of

the time use diary designed specifically for this project. The other methods employed, such as a standardised survey (PedsQL™ Family Impact Module Version 2.0) and semi-structured interviews are then discussed, before finally the data analyses methods are presented.

### **3.2 Critical Ethnography**

I have chosen a critical ethnographical approach to this study due to my close involvement as a paediatrician with families with children with disabilities over more than 14 years. In contrast to some other methodologies which highlight the need for distance and even naivety with regards to a subject prior to the start of a study, an appreciation and knowledge of context is considered essential in ethnography (Charmaz & Mitchell 2001, pg 171). Madison (2005) also recommends that researchers should have a good understanding of the field prior to commencing interviews or any formal interactions with participants.

My motivations in undertaking this study are both to understand more about the lives and experiences of parents with a disabled child and to critique current systems, particularly with regard to service provision and support. Therefore rather than being content with “*conventional ethnography that describes what is*” I want to adopt critical ethnography that “*asks what could be*” (see Thomas 1993, pg 4). However I am not an impartial observer but seek to bring change. Therefore as Thomas (1993) expresses it:

*“Critical ethnographers, by contrast, accept an added research task of raising their voice to speak to an audience on behalf of their subjects as a means of empowering them by giving more authority to the subject voice.....Critical ethnographers (instead) celebrate their normative and political position as a means of invoking social consciousness and societal change”* (emphasis in the original) (Thomas 1993, pg 4).

#### **3.2.1 Ontology**

Critical ethnographers’ ontological assumption is that all cultures are not equal leading to disadvantage and social oppression. By adopting this approach I aim to uncover what elements are involved in the lives of families with young disabled children that may be limiting participation, economic stability or quality of life with the purpose of using this information to bring about positive change. This will include

looking at differences between parents as it is often by exploring the exceptions that a greater understanding is achieved.

### **3.2.2 Reflexivity**

Not only am I a paediatrician, but I am also a mother. This influences my views on parenting and family life. While I have had periods at home being a ‘full-time mother’ I have also had periods where I have worked part-time while my husband worked full-time and more recently where I have worked full-time and my husband has been a ‘full-time father’. This has fostered my interest in different parenting roles and in fathering. It has also exposed me to the ongoing gendered expectations of parents by professionals, family members and colleagues. While I do not believe I can or even should bracket these experiences and influences from my role as a researcher, nevertheless it is vital to acknowledge them and reflect upon them. Reflexivity has become an important part of ethnography though the degree and way it is performed is still open to debate (O’Reilly 2009; Sherman Heyl 2001). My interpretation of the role of reflexivity resonates with O’Reilly’s in that we need to see the “*intrusive self as a resource*” and that we need to be transparent about our observations being “*filtered through our own experience, rather than seeking to provide the detached voice of authority*” (O’Reilly 2009, pg 191).

### **3.2.3 Epistemologies**

Ethnography has a number of epistemologies associated with it and is therefore not constrained to one particular view of how knowledge is achieved. Although it is commonly regarded as interpretivist, its roots are in the positivist tradition (O’Reilly 2009, pg 119). Indeed participant observation is based on positivism and that rigorous, direct observation will yield accurate scientific data (O’Reilly 2009, pg 158). Therefore, I believe that a critical ethnographical methodological framework is ideal for a mixed methods study which will inevitably need to embrace different epistemologies. The different approaches to and understanding of how knowledge will be generated will be referred to in the methods and data analysis sections.

### **3.2.4 Critical ethnographic methods**

Many different methods are used in critical ethnography though participant observation and interviews are two of the most common. Indeed participation and

observation can be regarded as characteristic features of ethnographic research (Atkinson et al. 2001). The use of the time use ‘diary: diary-based interview method’ as first described by Zimmerman and Weider (1977) provides an approximation to the method of participant observation. By having the participant self record their activities, observer effects are minimised as Zimmerman and Weider (1977) state:

*“While actual observation is to be preferred as an ideal in every case, the diary; diary-based interview affords at least the possibility of gaining some degree of access to naturally occurring sequences of activity, as well as raising pertinent questions about their meaning and significance” (Zimmerman & Wieder 1977, pg 485).*

Therefore, the time use diaries and semi-structured interviews are used in this project as a method of participant observation, thus enabling the study of the ‘culture’ of families with a child with disabilities.

### **3.2.5 Masculinities and gender**

In order to understand how mothers and fathers acquire their roles within the family unit, and how this understanding can lead to changes in the way services and potentially society interact with families with disabled children, I am guided by the theoretical framework of masculinities while also being aware of the effect of gender on women. While Petersen highlights the need to divert research away from questions of difference to those of sameness (Petersen 2009), it is clear that society has different expectations of men and women even if these gender roles are gradually blurring. Using Connell’s model of hegemonic masculinity (Connell 2000) or the dominant form of masculinity within society, I will explore how fathers interpret and demonstrate their fathering role when their child has a disability including the impact of mothers’ ideologies, characteristics and actions.

### **3.3 Methods**

Mixed methods studies have only been performed widely relatively recently and the best ways of performing them, their value and indeed even the definition of a mixed methods study are still being debated (Creswell & Plano Clark 2011). However key features of a mixed methods study are:

- The use of both quantitative and qualitative methods in a study;
- Clear mixing or integration of the quantitative and qualitative data; and

- A research design that incorporates the different methods and makes it clear the priority that each type of data have (Creswell & Plano Clark 2011, pg 5).

For a mixed methods design to be appropriate, the use of different methods needs to add value to the study and enable questions to be answered that a single method cannot achieve (Creswell & Plano Clark 2007). Mixed methods or integrated research approaches are now being used more frequently in time use research and Wilcock (1999) suggests:

*“For time use studies to be most useful in advising social, health and political planning, they need to have depth and be contextualised and critical. Probably the most useful studies will be those that combine methodologies that bring different dimensions to the study of how and why people use time.....They also show how together such data can validate findings to inform in a holistic way and to provide a base for critical action”* (Wilcock 1999, pg 208).

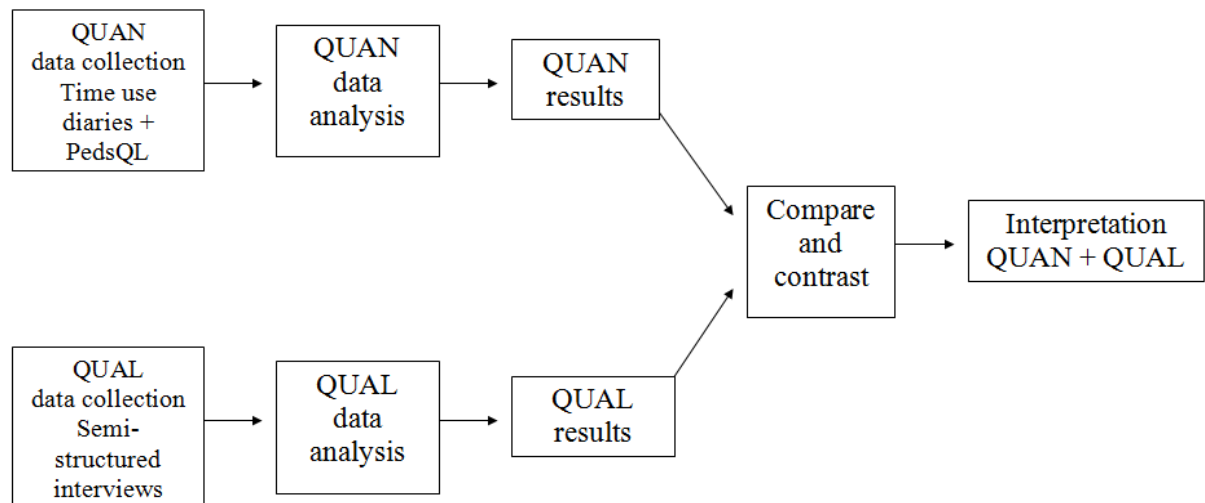
Therefore, I have chosen a mixed methods study design for this time use study. It provides both a form of participant observation and enables the quantitative data of parents’ time use from the time use diaries to be critically interpreted and contextualised by the data from the semi structured interviews. In addition, themes emerging from the interviews can guide further analyses of the time use data to identify patterns initially overlooked. Furthermore, the quantitative data from the PedsQL™ Family Impact Module Version 2 survey can be compared and contrasted with the other data sets to seek further insights about quality of life issues in relation to time use and parents’ reflections on their satisfaction with their time use and parenting roles.

The collection and merging of the data in this manner is consistent with the triangulation method described by Creswell and Plano Clark (2007) most closely resembling the convergence model though also having some elements of the explanatory design. Both types of data are given equal importance in this study design (Figure 3.1).

It is also important to consider issues of validity when merging different data sources. With regards to a convergent design, having similar sample sizes for both the quantitative and qualitative data and having the same population for both types of data



collection are highlighted as important (Creswell & Plano Clark 2011, pg 240). This is the plan for this study, but in order to look at whether the results can be generalised to other parts of the UK, some of the time use data will also be compared to large national time use data sets for couples with young children.



**Figure 3.1 Triangulation Design: Convergence Model<sup>1</sup>**

### 3.3.1 *Time use diaries*

In keeping with the critical ethnographic approach to the study, I wanted to use a form of participant observation to reveal more about the daily lives and experiences of parents with a young disabled child. However, key to the method chosen was the need to be able to obtain detailed data in a relatively constrained time period. Undertaking direct observation, which is the usual method of participant observation, has a number of potential drawbacks:

- It is likely to be considered intrusive and unacceptable to the majority of families to observe them 24 hours a day, including night times;
- It would be very time consuming for the researcher;
- More than one researcher would be required to observe both parents over the same time period as they would not be together all the time; and

<sup>1</sup> Based on Figure 4.1 on page 63 in *Designing and Conducting Mixed Methods Research* by Creswell and Plano Clark (2007) including using the recommended notation system: QUAN = Quantitative and QUAL = Qualitative, capitalisation to indicate equal importance of both methods and the four letter shorthand version of each word to indicate the equal stature of the two methods

- The observation itself would be likely to influence activity and not reflect normal life. For example the parent may talk to the observer as opposed to their child or partner, either out of politeness or enjoyment of a new person's company. Alternatively they might feel the need to have their house in a condition that reflects what they feel the observer would expect, such as much tidier or cleaner than normal. This would lead to an increase in the amount of time spent on these activities and therefore a corresponding decrease in time spent on other activities, and so on.

Although standard participant observation aims to overcome the problem of observer effects, by spending long enough in the field to be 'forgotten about' so that the observed act naturally, this is more readily achieved in some situations than others (O'Reilly 2009). Indeed this often relies on the type and degree of 'participation'. Within the family home there is no opportunity for participation without changing the whole dynamics of the family circumstances, therefore one can only observe (O'Reilly 2009).

As previously mentioned time use diaries can be used to achieve a form of participant observation but with the respondents self recording their activities (Zimmerman & Wieder 1977). This can overcome each of the problems already highlighted. Although the process of recording activities in the diaries may itself have an influence on which activities are engaged in, the impact is likely to be less than using the direct observation method. By using the diary format, activities are placed in context and can be considered with regard to location, social contact and satisfaction. The diaries not only provide a record of the number of minutes in a day that are spent on a particular activity but also what sequence of activities occur and an indication of what activities are omitted in order to complete other activities. Sequences of activities reveal much about how lives are organised to achieve necessary objectives. In addition, as satisfaction with activities can be included as well as the information gathered on the variety and nature of the activities, time use diaries can provide an objective measure of quality of life.

Zimmerman and Weider (1977) suggest that by interviewing the respondents after they have completed their diaries, clarification of the activities, the meaning of these

events and the participants' feelings about them can all be explored, leading to a much greater understanding of an individual's life than recorded activities in isolation. This method is ideally suited to the critical ethnographical approach of this study, as it enables participants to have a clear voice in highlighting the relevant issues with regards to their time use. It also provides parents with the opportunity to offer their own interpretations about the value and challenges of their activities.

### ***3.3.2 Time use diary development***

The development of the time use diary used in this study occurred over several stages which will be described in this section. The diary's finished design is unique and specifically tailored to the needs of this project. However it is based on previously used diaries to allow comparison of data collected during this survey with historical data.

#### *3.3.2.1 Initial ideas*

The idea to use time use diaries came from listening to a presentation by Professor Margaret O'Brien, Co-Director of the Centre for Research on the Child and Family at the University of East Anglia, at the Recognising Fathers Conference in London in 2007. In her presentation Professor O'Brien shared information from time use diaries that gave actual figures to support the theory that fathers are spending more time with their children now than they were forty years ago. This identified a method of objectively looking at parental activities, particularly in relation to their children. When I discovered there were no data available looking at the time use of parents with disabled children I knew this was an excellent opportunity to contribute to new knowledge in this area.

Time use was a completely new area for me and therefore before I could develop my own diary tool I had to develop a better understanding of the methodology involved. A key text was Gershuny's 'Changing Times: Work and Leisure in Postindustrial Society' (2000). This provided an historical overview of both how gender roles have changed over the past 40 years in the UK and also how time use diaries have been able to capture and document these changes. It also highlighted the potential richness of the data that can be collected by time use diaries and also the many different ways diaries can be constructed. In addition, Gershuny identified a number of challenges to

be aware of. These included how to deal with missing data and to make adjustments for pooling single diary days to provide information on a whole week basis.

Reading this key text and accessing the Centre for Time Use website expanded my thinking of time use diaries from a way of collecting discrete total numbers of minutes on different activities, to beginning to grasp that I could also discover who family members spend their time with and where they spend their days, for instance at home or in different places. This could provide a much fuller and clearer understanding of the reality of the parents' daily lives. Later I would come to understand that diaries also provide information about sequences of activities and if collected by more than one person in a family unit can provide insights into the synchronisation of their lives (Lesnard 2004).

The challenge then became how to decide what information was crucial to collect to achieve the aims of my study and what information however interesting should not be collected. Only collecting the data that are required to answer a question is good research practice. It is also important when asking participants to complete time use diaries as the more information that needs to be collected the more burdensome this becomes.

The first decision I had to make was whether to have a free text or precoded diary. In a free text diary the respondent would be asked to write in their own words what they were doing. This could be at set time slots or by completing a new entry each time they changed an activity and documenting when this occurred. Although having respondents completing diary entries in their own words provides rich and interesting data it tends to be more burdensome than completing a precoded ('light') diary. However precoded diaries are only quicker and easier to use if they are well designed. If the predetermined codes are not well described or comprehensive enough the diary can become frustrating to complete. This can potentially result in incomplete, inaccurate or even meaningless data. When looking at the time use of a large, diverse population, it is evident that the possible activities that could be engaged in are enormous, and in these circumstances precoding could be restrictive or prohibitively complex. With this study looking at a small well defined group of two parent families with a preschool child, the possible range of activities is more limited and the

information I required about some of the activities very broad. For instance ‘at work’ but no other information required about what is being done there.

Free text diaries also produce a large amount of data that takes a long time to code afterwards. This is an important consideration as even in national samples it has been noted that data have not been fully analysed and this is at least in part due to the complexities and time consuming nature of this activity. Therefore despite the fact that some time use researchers do not feel that precoded diaries are as effective a tool as free text diaries, for the purposes of my study with a single researcher available to analyse the data and a study population of already very busy parents, I elected to use a precoded diary. This decision was fully endorsed by Dr Kimberly Fisher, an experienced time use researcher and current secretary for the International Association for Time Use Research.

Precoded diaries have a list of different activities and the respondent indicates, usually by a cross, which activity they are engaged in for each time slot; if the activity continues into the next time slot this can be indicated by a line. Primary and secondary activities can be recorded, usually with a dot indicating the secondary activity, along with location and who the participant is with. Time periods typically range from five minutes to half an hour. Again there is a trade off from the additional information achieved by having a short time period to the increased burden for respondents and higher likelihood of omissions in the data. Longer time periods are likely to miss certain short activities. As one of the main aims of this project is to look at the time use of parents with a disabled child, it is apparent that half an hour time slots may miss many of the activities that need to be captured. The administration of medicines, repositioning of a child, performing suction, stopping a child hitting the television set repeatedly might all only take a few moments but are important to know about.

Studies have been done comparing fixed time slots with open time intervals. Some of these studies have found little difference between the two, while others suggest there may be hidden problems, with the use of time slots and their size having more of an effect on certain activities than others (Harvey 1999, pg22). However, when analysing the data, times are often amalgamated into 96 periods of the day to create a ‘time-

points file', that is one point for each 15 minutes of the day (Harvey 1999, pg 27). Therefore, taking all these different aspects into consideration, I decided on 15 minute, fixed time slots, with the instruction to parents that if an activity took longer than five minutes to perform, it should be recorded in that 15 minute time period.

The next decision was how many diary days to ask each participant to complete. National samples of time use diaries typically involve a minimum of 2000 single diary days. The total number of diaries completed for each day of the week is counted and then weightings applied to correct for varying numbers of completed individual days. Thus a composite picture of how a community typically spends their time can be achieved. However, these adjustments are not perfect and in particular individuals often spend their time very differently at weekends as opposed to week days. Therefore, it is now often recommended at least one week day and one weekend day should be completed by each participant. Ideally each participant would complete a seven day diary but the burden on participants again becomes an issue when looking at longer time periods. This leads to a fall in compliance and incomplete and unusable diaries.

In certain situations the collection of a seven day diary becomes more crucial. For instance this is the case when looking at certain subsections of the population such as the time use of couples with children. In this situation the recommendation is that both partners complete a diary for the same seven consecutive days. This is because couples with children usually organise their schedules on a weekly rather than a daily basis (Fisher 2007).

It would clearly be completely impractical for a number of different reasons, for me to gather data from 2000 respondents resulting in 2000 diary days. However, as the group that I am studying consists of couples with children, the most appropriate collection period is seven days. This immediately removes the need for complicated weightings to adjust for different totals of single completed days. The target sample in this study of 40 father-mother pairs, which is 80 parents, would provide a total of 560 diary days if they each complete seven days. This would be considered a reasonable number of diary days to draw conclusions from. The use of a seven day

diary also makes the use of a precoded diary more important, due to the burden of seven as opposed to one or two diary days on participants.

Gershuny (2000) highlighted that another challenge is how to deal with missing data in diaries. There are various guidelines about how certain assumptions can be made if there is one missing time slot at certain times of day. For instance if the diarist indicates they have had breakfast and then there is an empty timeslot and then they are at work, and then at the end of work they travel by car for one time slot before coming home, it can be assumed that the diarist omitted to document the travel time, a common mistake. However, more often a number of assumptions have to be made to try and complete missing data entries and these obviously have the potential to introduce error. In addition, if more than a few timeslots are missing the diaries cannot be used.

One way of preventing problems with missing data entries is to go through the completed diaries with the respondents, clarifying with them any missing or conflicting data entries. An example of a conflicting data entry would be if the respondent indicated that they were alone while feeding their child. Therefore, in order to ensure that the data collected are high quality and complete and to maximise the number of usable diary days obtained, this checking period with each respondent would be included in the study.

### *3.3.2.2 Ensuring compatibility*

As already stated there are data available about the time use of UK parents over the past 40 years. Some of these data include the paired seven day diaries of parents. By ensuring the information collected is comparable with these historical data a number of important outcomes can be achieved. One of these is to compensate for the relatively small data set. Another would be to look at whether the results are able to be generalised. Families with a disabled child would be matched to comparison families with a child without disabilities. Comparing these 'comparison' families to national data sets will help to determine whether the comparison families time use is similar to the time use of a UK population of parents. If this is found to be the case, then the time use of parents with a disabled child is also more likely to reflect the time use of parents with disabled children in other parts of the UK. In addition the use of

matched pairs would enable more subtle differences in time use between the groups to be detected.

Therefore, it was important to look at the codes which have been used in previous time use diaries. Again the challenge was having sufficient codes to capture the information to be focused on, but not so many as to overwhelm the respondent or become unworkable. After reviewing a number of different coding systems and diary designs I elected to use the Omnibus Survey Short One Day Diary of Time Use from 2005 as an initial template (Lader, Short, & Gershuny 2006). The pre-coded diary used in the 2005 Omnibus Survey was developed over ten years by experienced time use researchers and shown to be an effective and reliable way of obtaining information about adults' time use. It was designed to be comparable with the UK 2000 Time Use Survey which was an 'own words' diary. Therefore, by basing my diary on this format I anticipated that the created diary would be effective and provide data comparable to previous data sets.

The 2005 Omnibus Diary has 30 main codes, as well as additional codes for mode and purpose of travel, and location of activity (see Appendix A for an example of the Omnibus Survey Short One Day Diary of Time Use from 2005). I examined each of these codes for relevance and re-worded some of the activity descriptions in order to simplify them. The 2005 Omnibus Diary was designed to be a recall diary completed by a trained interviewer for the previous 24 hours activities, while I wanted to ensure that parents would be able to complete the diaries themselves. I then expanded some of the codes in order to focus on specific areas of interest. For example, the section about child care was separated into care of the disabled child (or the matched comparison child) and the care of their other children. Additional codes were also included to capture activities related to different aspects of childcare, such as bathing or reading to their child, to give information about the proportion of time devoted to childcare that was spent on these different activities. The totals from these categories can be re-combined to compare with the single childcare totals from the other studies.

One of the strengths of time use diaries is that they can be designed to focus on particular areas of interest and a number have been designed to collect quite detailed information about the nature and purpose of travel. The Omnibus Diary included a



number of questions relating to travel and while this was of interest I decided that it was not one of the aims of my study. I therefore limited the codes about travel to mode: by car; public transport; friend's car or taxi; walk/bicycle.

Location is another area that can be looked at and can provide very interesting insights into the reason and nature of activities. Some activities are constrained by their location. For instance, many sporting activities require specific facilities that mean an individual has to go to a certain location in order to engage in that activity. Other activities have traditionally been performed in a particular location but are increasingly being performed from home, such as paid work. When considering people's location, access also becomes very relevant. Issues regarding access include how easy it is to get there and how possible it is to engage in the desired activity once the location has been reached. This is particularly relevant when considering the time use of parents with a disabled child, as there are still many barriers in the community that make transport and participation challenging. Therefore, I decided that location was an important piece of information to collect but concluded that I would limit this to enquiring whether the parent was at home or elsewhere.

Another area I wanted to focus on was how much time parents spent with each other, and how much time they spent with all their children or just their 'study child'. The impression I have obtained over the period I have worked with families with a disabled child is that many families operate a kind of shift system, with each parent taking responsibility for the child with additional needs at different times, with a consequent impact on the amount of time the family spend together as a whole unit. Therefore I wanted to look at this specifically. Although it would also be interesting to look at how much time parents spent with other groups of people, I elected to focus on capturing information about direct family members only. If the parent was not with one of these direct family members, they would be arbitrarily classified as 'alone'. Some information about contact with other people would still be achieved through the codes for other activities, such as 'with friends, family in their home or your home'.

Collecting information on the location of activities and social contact during those activities, enables 'activity settings' to be considered which place time use in context.

These are based on the multidimensionality of activities (Harvey 1999). The following definition is given by Harvey:

*“‘activity settings’ incorporating spatial location (home, away from home), temporal location (morning, afternoon, evening, night), duration, (short, medium, long) and social contact (alone, family, friends, others)”* (Harvey 1999, pg38).

Looking at these different factors together can enable more meaningful interpretation of time use than just counting up total numbers of minutes spent on each activity a day, or for a week. They can provide clues as to why certain activities are engaged in or missing from a respondent’s diary. Looking at activity sequences can also reveal information about how individuals organise their day. Activity sequences relate a particular activity to the ones before and after it (Harvey 1999). For instance work away from home increases the chance that the following activity will be an out of home discretionary activity.

The final category of data I decided to include in my time use diaries was with regard to mood. This was after I had looked at the 2002/2003 BBC Daily Life Study (Griffiths & Holden 2004) which included a four point mood scale based on weather symbols (such as a sun to reflect happiness) that respondents were asked to complete every half an hour. This BBC Daily Life Study was also designed to be comparable to previous UK time use data sets. Although collecting information about mood has the potential to contribute to the richness of the data, I was aware that asking respondents to fill in an additional category for every time slot would add to the burden of completing the diary. In addition, as I would be exploring various aspects of the diary responses in the interviews, I already had an opportunity to draw out some of this information. I therefore decided to make the mood section optional. I also decided to increase the number of moods from the four in the BBC Daily Life Study, to capture a wider range of emotions and feelings. In order to try and make the mood section appealing and therefore encourage parents to complete it, I used a variety of cartoon faces to depict the moods and emotions. After presenting the suggested moods to friends and family for their feedback I settled on 15 faces arranged with similar types of emotion placed next to each other to aid their quick location. These were provided on a separate laminated card and numbered so that only a number needed to be recorded in the mood section (Appendix B).

### 3.3.2.3 *Expert advice*

Before proceeding further with my diary development I visited Dr Kimberley Fisher at the Centre for Time Use Research in Oxford to discuss the study. Dr Fisher was extremely helpful and generous with her time and experience. The general layout and codes for my diary were agreed to be appropriate and likely to be successfully completed by respondents. Dr Fisher also highlighted some useful practical considerations such as having the time interval titles at the top and bottom of the page as opposed to just at the top, and what types of pen to use when completing the diary. In addition, she suggested the inclusion of a section that could be completed by ticks indicating each time an activity of short duration was completed for the study child that would otherwise be missed by only including activities lasting five minutes or more. This would include activities such as giving medication, repositioning a child, suctioning secretions, or preventing the child climbing on a windowsill. Dr Fisher also recommended using high quality paper that would withstand the wear and tear and possible accidents of a typical family environment.

### 3.3.2.4 *Diary layout*

Having established the information that I wanted to collect, the time period for the collection both in terms of total duration and the length of time for each time slot, the codes to be used and some practical considerations in producing the diary, the next stage was to decide on the format.

I used Microsoft Excel spreadsheets to experiment with a range of different layouts. The aim was to produce a diary that was clear, not too bulky, easy to complete and aesthetically pleasing. After many different versions (see Appendix C for an early version) with several of the codes being further simplified, re-worded and relocated I finally produced a diary with six hours that is 24 time slots, on each A4 page, all the codes down the left hand side and times across the top and bottom. The diary pages were identical with the exception of the numbered time periods and two double sided A4 sheets formed a complete 24 hours.

In order to make it easier to differentiate between adjacent codes I introduced some colour shading. I also had the activities section in a different colour to those for social contact, location, mood and the tick section for care of the study child. This diary was

shared with my supervisory team who suggested some minor adjustments to the wording of some of the codes such as changing 'restrain' to 'keep safe'. They also suggested trying to colour code each of the different code categories to facilitate their easy location. Although this resulted in a diary that looks rather busy and overwhelming on first inspection the additional colour coding is useful. While a certain level of literacy is required to be able to independently complete a time use diary the precoded, colour coded format makes it more accessible to individuals with literacy problems (Thomas et al. 2011).

#### *3.3.2.5 Presentation of the diaries*

In August 2007 I attended a week long 'Collection and Analysis of Time Use Data' Course held at the University of Essex and led by Dr Kimberley Fisher. The course was excellent and not only increased my knowledge about time use methodology; it also gave me an opportunity to present my time use diary to a knowledgeable and interested audience of other time use researchers. The feedback that I received was very positive and did not suggest any further modifications to the diary. The next step was to pilot the diary.

#### *3.3.2.6 Pilot Study*

I approached three families with children who I knew socially to request their involvement in the Pilot Study and all consented. The Pilot Study consisted of one father-mother pair with four children, one mother with a single child under one year of age and one father with three children. None of these children had identified additional needs and all the families had at least one child younger than five years of age. I provided some written guidelines on how to complete the diaries and brief verbal instructions. To the father-mother pair this was just to the mother and over the telephone rather than face to face.

The Pilot Study aimed to establish how easy it was to complete the diaries; how long it took to complete them and whether they were acceptable to mothers and fathers. In addition, the quite different family compositions and range of children's ages would help identify whether the codes were easy to apply and relevant to a variety of different situations. The participants were asked to complete the diaries for a single 24

hour period and then to complete a questionnaire about their experiences. I also completed the diary for a 24 hour period but did not complete the questionnaire.

The diaries were generally well completed but two out of the four had some missing time slots. One father had eight missing time slots, the equivalent of two hours. The mother with the baby under one had 13 missing time slots equalling three and one quarter hours. The father's diary that did not have any missing time slots did however have some conflicting information recorded. While documenting that he was alone he also recorded that he was caring for and supervising his children as his only activity. Therefore, it is likely that he was also doing something else or that he was not alone. General guidance on the amount of time missing that is acceptable before the diaries are no longer usable is 90 minutes. Two of the four diaries had missing amounts of time greater than this.

The Pilot Questionnaire consisted of seven questions (Appendix D). The participants' responses to the first five questions are shown in Table 3.1. The final two questions asked for written responses with regard to whether any parts of the diary were confusing or unclear and whether the respondents had any other comments, suggestions or recommendations. The mother with the four children, spent the longest amount of time on the diary and found it the most difficult to complete out of the four respondents, but had no missing time slots or conflicting entries. She reported that she found some of the codes restrictive, the sections were too close together on the diary page and completing moods as well, which she did faithfully, was too much to do. In addition she was not clear about whom the 'who with' referred to and whether this meant the individual was just in the house or actually doing the activity with her.

The mother with one child under one year of age found the diary hard to fill out initially as there appeared to be a lot going on. However she said that "*once I started and understood the questionnaire and what to fill out it was easy.*" This mother also commented "*the answer sheet makes it look more complicated than it actually is*". The father with four children highlighted that he was often doing multiple activities and therefore it was hard to clarify which was the main activity. He also commented that he felt that uninvolved parents may overstate the amount of help they gave with their 'study child'. Interestingly the only comment the other father gave was that it

was “tempting to be on ‘best behaviour’ for the duration of the diary – may influence results”.

**Table 3.1 Pilot Questionnaire Responses**

Respondent	How easy to complete	Total time to complete (minutes)	Become easier to use if continued for longer	Willing to do for a week	Face Chart
Mother 1 child	OK	10 - 20	Easier	Yes	Easy to use
Mother 4 children	Difficult	30 - 60	Easier	Probably	Too much too complete as well Couldn't match face to feelings/ otherwise easy to use
Father 4 children	OK	10 - 20	Much easier	Probably	Easy to use/ found amusing
Father 3 children	Easy	10 - 20	Much easier	Probably	

The father with four children highlighted that he was often doing multiple activities and therefore it was hard to clarify which was the main activity. He also commented that he felt that uninvolved parents may overstate the amount of help they gave with their ‘study child’. Interestingly the only comment the other father gave was that it was “tempting to be on ‘best behaviour’ for the duration of the diary – may influence results”.

### 3.3.2.7 Pilot Study conclusions

The Pilot Study confirmed that with a minimum amount of guidance the diaries could be completed successfully. I was therefore confident that as I would be spending much more time going through the diaries and how to complete them with the study parents, they would be clearer on some of the issues that the Pilot Study parents had found difficult. The Pilot Study feedback highlighted some of the areas I needed to specifically talk about when explaining the diaries, including reassuring them that although the diaries looked overwhelming at first, other people had mostly found them straightforward to use. It also confirmed my own feeling that the diaries were likely to become easier to use with time as one became more familiar with the nature and location of the codes.

The fact that half of the diaries had missing entries for more than 90 minutes of time and one diary had conflicting information in it, confirmed the need to go through the

diaries with respondents afterwards, to ensure that these omissions and discrepancies could be rectified. While the two fathers both suggested that people may act or record their actions in such a way as to make them appear better, this is less likely to be possible for a seven day period. Also if certain entries were being changed it is difficult to do this consistently through all the information that needs to be recorded and I would be able to discuss any inconsistencies with the respondent. In addition, having fathers and mothers complete their diaries over the same time period, would potentially highlight any major inconsistencies on who was doing what, which could be clarified in the interview, including if there had been a marked change in behaviour by their partner over the diary week.

Three out of the four respondents indicated that it had taken between 10-20 minutes to complete the diary. This appeared to be an acceptable amount of time. The mother of four children, who had conscientiously recorded moods for nearly all the time slots when she was awake, had taken between 30-60 minutes and she felt this was too long. I therefore decided to emphasise to the study participants that the mood section was entirely optional. However, I concluded that no changes need to be made to the diaries themselves in light of the Pilot Study findings and that the diaries were in an acceptable format to submit for ethical review. An example of one page of the final version of the time use diary is to be found in Appendix E.

### **3.3.3 Multinational Time Use Data**

The 1965 Szalai Multinational Time Budget Study was the first study to facilitate comparison of time use between countries. In the early 1980's Professor Jonathan Gershuny, recognised the potential to harmonise time use datasets from different countries and undertaken at different times into a single dataset, with a common series of background variables and daily activities. This multinational time use dataset continues to be updated and is available for registered users.<sup>2</sup>

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<sup>2</sup> *Multinational Time Use Study, Versions World 5.5.3, 5.80 and 6.0 (released September 2010). Created by Jonathan Gershuny and Kimberly Fisher, with Evrim Altintas, Alyssa Borkosky, Anita Bortnik, Donna Dosman, Cara Fedick, Tyler Frederick, Anne H. Gauthier, Sally Jones, Jiweon Jun, Aaron Lai, Qianhan Lin, Tingting Lu, Fiona Lui, Leslie MacRae, Berenice Monna, José Ignacio Giménez Nadal, Monica Pauls, Cori Pawlak, Andrew Shipley, Cecilia Tinonin, Nuno Torres, Charlemaigne Victorino, and Oiching Yeung. Centre for Time Use Research, University of Oxford, United Kingdom.*

As described above, the time use diary used in this study was developed from the Omnibus Survey Short One Day Diary of Time Use from 2005, and designed to be comparable with the UK 2000/1 Time Use Survey. Data extracted from the UK 2000/1 time use survey section of the World 5.8 multinational data set will be compared to the comparison families' time use. The World 5.8 data set consists of two harmonised aggregate files, one for adult diarists aged 18 and over and a separate file for diarists younger than 18 (Fisher, Gershuny, & Gauthier 2011). The UK 2000/1 data set consists of 17,247 diaries.

#### **3.3.4 Validated Survey - PedsQL<sup>TM</sup> Family Impact Module Version 2.0**

The PedsQL<sup>TM</sup> Family Impact Module Version 2.0 (Varni et al. 2004) is one of a series of paediatric health related quality of life scales developed by Dr James Varni and his team. Some of these scales are to be completed by children and young people themselves and some on their behalf by parents. Studies relating to these quality of life scales have led to over 350 peer-reviewed journal publications since 2001 and have involved thousands of healthy children and children with a wide range of chronic health conditions (Limbers et al. 2011). The Family Impact Module was published in 2004 and the studies relating to this scale are more limited due to its more recent origin. It is designed to be completed by parents and to look at how concerns about their child's health condition impact on the parent's own health-related quality of life (HRQL) and on family functioning.

The studies that have been performed with the Family Impact Module have shown that the scales have good reliability and validity across a range of different populations, including children with complex health needs (Varni, Sherman, Burwinkle, Dickinson, & Dixon 2004) who were the original group studied, children with developmental delays (Hsieh et al. 2009), ADHD (Limbers, Repperger-Suhler, Boutton, Ransom, & Varni 2011), cancer (Scarpelli et al. 2008), sickle cell disease (Panepinto, Hoffman, & Pajewski 2009) and chronic pain (Jastrowski Mano et al. 2011). Only one of these studies looked at mothers and fathers separately (Jastrowski Mano, Anderson Khan, Ladwig, & Weisman 2011). The other studies had a single parent completing the scales, nearly always the mother. The study that did involve both parents (Jastrowski Mano, Anderson Khan, Ladwig, & Weisman 2011) found



that the mother reported significantly worse HRQL than fathers, but that parents did not differ on reports of Family Functioning.

Two of the studies had healthy comparison groups ((Limbers, Repperger-Suhler, Boutton, Ransom, & Varni 2011; Panepinto, Hoffman, & Pajewski 2009) with the other studies looking at differences between parents (Jastrowski Mano, Anderson Khan, Ladwig, & Weisman 2011), or between families with children with the same/similar health conditions but in different circumstances or degree of severity (Hsieh, Huang, Lin, Wu, & Lee 2009; Panepinto, Hoffman, & Pajewski 2009; Scarpelli, Paiva, Pordeus, Varni, Viegas, & Allison 2008).

A study in the UK, the MENDS trial (The use of MELatonin in children with Neuro-developmental Disorders and impaired Sleep; a randomised, double-blind, placebo-controlled, parallel study) used the PedsQL<sup>TM</sup> Family Impact Module to look at changes in parentally reported quality of life and family functioning following interventions to improve sleep. Parents of 178 children with a range of neurodevelopmental difficulties, including children with complex health needs and autism spectrum disorders, were involved. The results from this trial, which I was involved in, are not yet available (see Appleton & Gringras 2011 for an outline of the trial).

The PedsQL<sup>TM</sup> Family Impact Module Version 2.0 parent report is composed of 36 items across eight dimensions. These are Physical Functioning (6 items), Emotional Functioning (5 items), Social Functioning (4 items), Cognitive Functioning (5 items), Communication (3 items), Worry (5 items), Daily Activities (3 items) and Family Relationships (5 items). The items and scales were developed through focus groups, interviews and pretesting measurement protocols as well as the team's previous clinical and research experiences with children with chronic health conditions and their families (Varni, Sherman, Burwinkle, Dickinson, & Dixon 2004).

The scale has 5 Likert response options from 'never' (0) to 'almost always' (4). Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Therefore the higher the final score, the greater the estimated parent health-related quality of life, or the lower the impact on family life.

Three scores are obtained. These consist of ‘The Total Score’ which is the sum of all 36 items divided by the number of items answered, the ‘Parent HRQL Summary Score’ based on the sum of the first six dimensions divided by the number of items answered in those dimensions and the ‘Family Functioning Summary Score’ derived by the sum of the final two dimensions divided by the number of items answered in those two dimensions. If more than 50% of items are missing the scale scores should not be completed.

Following informed consent from parents to be involved in the study and the collection of basic demographic data, every parent was asked to independently complete the survey. The survey took approximately five minutes to complete. Although the PedsQL™ Family Impact Module was originally designed for parents with children with additional health needs, the survey was also given to comparison families to identify the level of concern parents in this group had about their preschool child without identified additional needs. Parents are often more concerned about their children’s health when they are young and this is also the time when the most decisions have to be made with regard to preventative health care measures such as consenting or declining to have the child immunised. Therefore the PedsQL™ Family Impact Module would provide some information about the impact these concerns had on parents with young children in order to help gain an understanding of the difference when families have a disabled preschool child.

### ***3.3.5 Semi-structured interviews***

Following the 7-day period of diary completion by a father-mother pair, the diaries were collected and underwent an initial broad analysis. This included looking for missing, conflicting or unclear data entries and identifying general patterns of parental activity, mood and family life to guide the subsequent semi-structured interviews. I attempted to see every participant to clarify the diary data, in a location of their choice. This was usually in the parents’ homes, but also occurred at the parent’s workplace and at the Child Development Centre. All parents in the ASD and TD groups who agreed to be seen (n=32) then continued into a semi-structured interview which was digitally recorded. These interviews were performed with each parent separately. In addition, one mother and one father from a comparison family was interviewed.

### 3.3.5.1 *Ethnographic interviewing*

*“Interviewing is a dynamic process fundamental to ethnography. It is part technique, part ethics, part theory, part method, part intuition, part collaboration, and part openness to deep vulnerability”*(Madison 2005, pg 35)

Ethnographic interviewing is considered different from some other styles of interviewing, such as survey interviewing, as it is undertaken when a relationship has already been established with the interviewee and there is already a degree of understanding of their circumstances (Atkinson, Coffey, Delamont, Lofland, & Lofland 2001; Madison 2005; O'Reilly 2009; Sherman Heyl 2001). There is an emphasis on rapport that enables interviewees to respond openly (Sherman Heyl 2001) and on a moral obligation to carefully use these confidences ethically with the *“direct well being of the Other as the first priority”* (Madison 2005, pg 85).

Some of the families who participated in this study I had already forged strong relationships with, as we had travelled together along the road of looking for a diagnosis, establishing medical and therapeutic care for their child and providing ongoing emotional and practical support for their family. For other families in the ASD and TD groups, although we knew about each other through the Child Development Centre I had not been personally involved in the care of their child. Within the context of this study, I had also met all the parents on at least two occasions prior to the interviews. The first occasion was to discuss the study, and if the parents had already had time to consider the information prior to the meeting, to proceed with consent, collecting demographic information and the completion of the PedsQL™ Family Impact Module. The second occasion was to collect the diaries. Additional meetings were also necessary with some parents depending on individual circumstances. Therefore, there had been the opportunity to establish a relationship and have some understanding of each parent's circumstances prior to the interviews.

### 3.3.5.2 *Constructing the Interview Guide*

Although not all interviewers use an interview guide, many find it helpful and it is particularly recommended for those new to the technique (Madison 2005). The construction of an interview guide enables reflection on the purpose and objectives of the interview and what areas are to be explored. It should be guided by knowledge of

the field, either through previous direct experience or a review of the literature or both (Madison 2005; O'Reilly 2009; Sherman Heyl 2001). Guided by my experience of working with children with disabilities and their families for more than a decade and my review of the literature, I formulated a broad outline of the topics to be explored. This guide was further added to in response to emerging themes from initial analysis. The final interview guide can be found in Appendix F.

One of the main purposes of the interviews was to interrogate the data from the time use diaries. Therefore the interviews initially explored parents' experiences of the diary and the ease and acceptability of the method for them. Parents were then prompted to discuss their perceptions about their time use, the typicality of the week recorded, and their feelings around different activities. In addition, key aspects of time use apparent from the diaries were highlighted and focused on.

The interviews then moved on to explore issues around the parent's perception of their parental role(s) and their partner's role(s) including their satisfaction with these and how these roles had been negotiated. In response to emerging themes from initial analysis, parents who did not spontaneously mention certain concepts were prompted to do so. Questions were also specifically asked in relation to sleep, leisure, level of support received from extended family, friends and services and to explore issues from the PedsQL™ Family Impact Module survey.

Although all the interviews were broadly approached in the same way for fathers and mothers, different techniques were used to facilitate rapport depending on the personality and experiences of the interviewee. While the interview guide was used, the conversation was allowed to flow in whatever direction the parent took it, with prompts provided at times to clarify certain points raised. By really letting the parent take control of the interview and allowing time for the parent to share and articulate thoughts that maybe distressing, I aimed to not only obtain deeper and richer insights, but also empower parents by providing an opportunity to share things in a way that they may have had limited opportunity to do previously. While being conscious of not deliberating causing emotional distress, I allowed myself to be 'vulnerable' (Madison 2005) by enabling parents to take control of the direction of the interview rather than keeping it safely constrained to what I considered to be safe topics. In this way I

hoped “to discover the interviewee’s own framework of meanings” (Britten 2006, pg14).

### 3.3.5.3 Subjectivity

The way the parent recounts, explains and interprets their experiences will include their own subjectivity (O’Reilly 2009). In addition, my perception and interpretation of the account will include my subjective influence. Rather than striving for an absolute truth, I have aimed for a co-construction of reality with the interviewee having an equal and often guiding role in the process and direction of the interview (Atkinson, Coffey, Delamont, Lofland, & Lofland 2001; O’Reilly 2009).

While it is sometimes assumed that “*subjects utterances*” are “*transparent passageways into experiences and selves*” (Mauthner & Doucet 2003, pg 423) I do not hold that view. Rather I believe there will be instances where what the parent says may appear to be a superficial standard response or a typically used familiar phrase, rather than reflecting their true feelings or opinions. This may particularly be the case if the true response could be considered socially unacceptable or reflect the parent in what they perceive to be a bad light. This again emphasises the importance of rapport to ensure that sufficient trust is achieved to enable the parent to share genuine opinions. In addition, it is necessary to provide sufficient time for the interviewee’s responses and to enable the interview to progress to a point where later responses may reveal deeper and even contradictory views to the ones initially expressed. However, these different responses may also be due to the parent relating in different ways to the subject being discussed, depending on the role - parent, employee, spouse - they are considering at the time (Sherman Heyl 2001). Awareness of these issues has not only guided the conduct of the interviews but also their analyses. Critical analysis has included looking for deeper meanings, and exploring the different roles that parents’ play.

## 3.4 Sample

Three groups of families were studied:

1. Families with a preschool child with complex health needs, dependent on technology and experiencing developmental delay (TD);

2. Families with a healthy preschool child with an autism spectrum disorder (ASD); and
3. Families with a healthy preschool child without disabilities or high level additional needs (ND)

All families had a clear father-mother pair who were co-habiting and had one or more children. Families in groups one and two were identified through their involvement with the local Child Development Centre. Families from group three provided a local comparison group. Following consent from the parents in group one or two to be involved in the study, the relevant family health visitor was asked to suggest similar families to be a comparison family, using a checklist of matching criteria to guide them (Appendix G).

The following exclusion criteria applied:

- child protection concerns;
- child clearly had a very limited life expectancy;
- uncertain diagnosis of an autism spectrum disorder; and
- only one parent wanting to participate

The target number of families in each of groups one and two was ten. The plan was for each of these families to have a matched comparison family, resulting in twenty families in group three. These figures were based on anticipated numbers of children with complex health needs dependent on technology meeting the study criteria and consenting to being involved. All eligible parents with a child with complex health needs dependent on technology were approached within the study period, with the plan being that recruitment would finish when ten families were recruited or the study period had finished. As there were a larger number of eligible families with a child with an autism spectrum disorder, sampling was more purposive, seeking to involve a range of different families based on family composition, geographical location and total annual income.

Families were given a participant information sheet by their family health visitors. After having had the opportunity to read this, if they were interested in the study, they

were contacted to discuss the information further and if still interested, consent was obtained to participate. Appendix H contains the Participant Information Sheet, and the adapted Comparison Families Information Sheet including flow charts of the period of time participants would be involved in the study.

### **3.5 Ethical Issues**

Ethical and moral obligations are intrinsically entwined with critical ethnography (Madison 2005; Thomas 1993). The motivation to perform a critical ethnographic study is to make a difference and to improve the quality of life of the group studied. However, even if the aim of the study is to make a positive difference it is essential to carefully to consider the participants in the study at every stage of it, and to ensure that no harm is done inadvertently. This includes obtaining informed consent, not creating a study that is overly burdensome and taking care in how participants are represented. This consideration of how ‘others’ are represented needs to include being respectful, responsible, honest and not sensationalising (Madison 2005; Thomas 1993).

It is also important to consider issues of status and positions of power. I am conscious that being a researcher and a doctor places me in a potential position of power. However, as a woman, entering into the parents’ territory, seeking to learn from the parents, who are the experts and the holders of knowledge, hopefully enabled me to negate some of potential power imbalances. In addition, I was aware that my role as a Consultant Community Paediatrician based at the Child Development Centre where many of the potential study families received services, may make some families feel obligated to be involved in the study. Therefore, to ensure that families felt able to decline involvement, the first approach was made by the family Health Visitor who provided the information sheets. Only if the parents expressed interest in the study, did the health visitor request permission for me to make contact. It was also repeatedly emphasised that whatever the parents decided would not influence their or their child’s subsequent clinical care.

When discussing the study with families, I made it clear the distinction between my clinical work and the research project. There was no advertising of my research at the Child Development Centre and it was not discussed with team members which

families were involved. I did not bring up issues about my research when seeing the families for clinical matters and if clinical issues were brought up during an interview or other contact for research purposes, I arranged a suitable time when these could be addressed separately.

### **3.5.1 Ethical review**

Full ethical review and approval were obtained. The study was approved by the University of Central Lancashire Faculty Research Degrees Sub-committee, the Local Research Ethics Committee, and the local Trust's Research and Development Department.

### **3.5.2 Data management**

Careful consideration has been given to issues of confidentiality, data protection and data storage. Identifying data were only be seen by myself and were securely locked in a cabinet at the Child Development Centre. Data were anonymised, including using numbers to identify and link data, changing participants' and their friends' and families' names, referring to professionals by their role rather than name, and omitting identifying place names or family characteristics. Further details about these measures are documented in the Participant Information Sheet in Appendix H. Consent forms can be found in Appendix I.

## **3.6 Data Analysis**

Data from the time use diaries and PedsQL survey were analysed using the SPSS statistical analysis software. Descriptive statistics were used to explore relationships between work and childcare activities, the amount of time couples spend together and as a family, opportunities for sleep and leisure activities, and time within and outside the home. Data from the comparison families were compared to the data from the parents in the ASD and TD groups. For normally distributed data, independent sample t-tests were performed. All tests were two-tailed with the significance level set at 5%. For data which were not normally distributed appropriate non parametric tests were chosen. In some instances, independent sample t-tests were used but equal variances were not assumed, with a corresponding reduction in the degrees of freedom and increase in the P-value. To ensure that this is apparent in the text, the full independent samples t-tests result are given: for example,  $t(11.32) = -5.53, P < 0.001$ . The non-

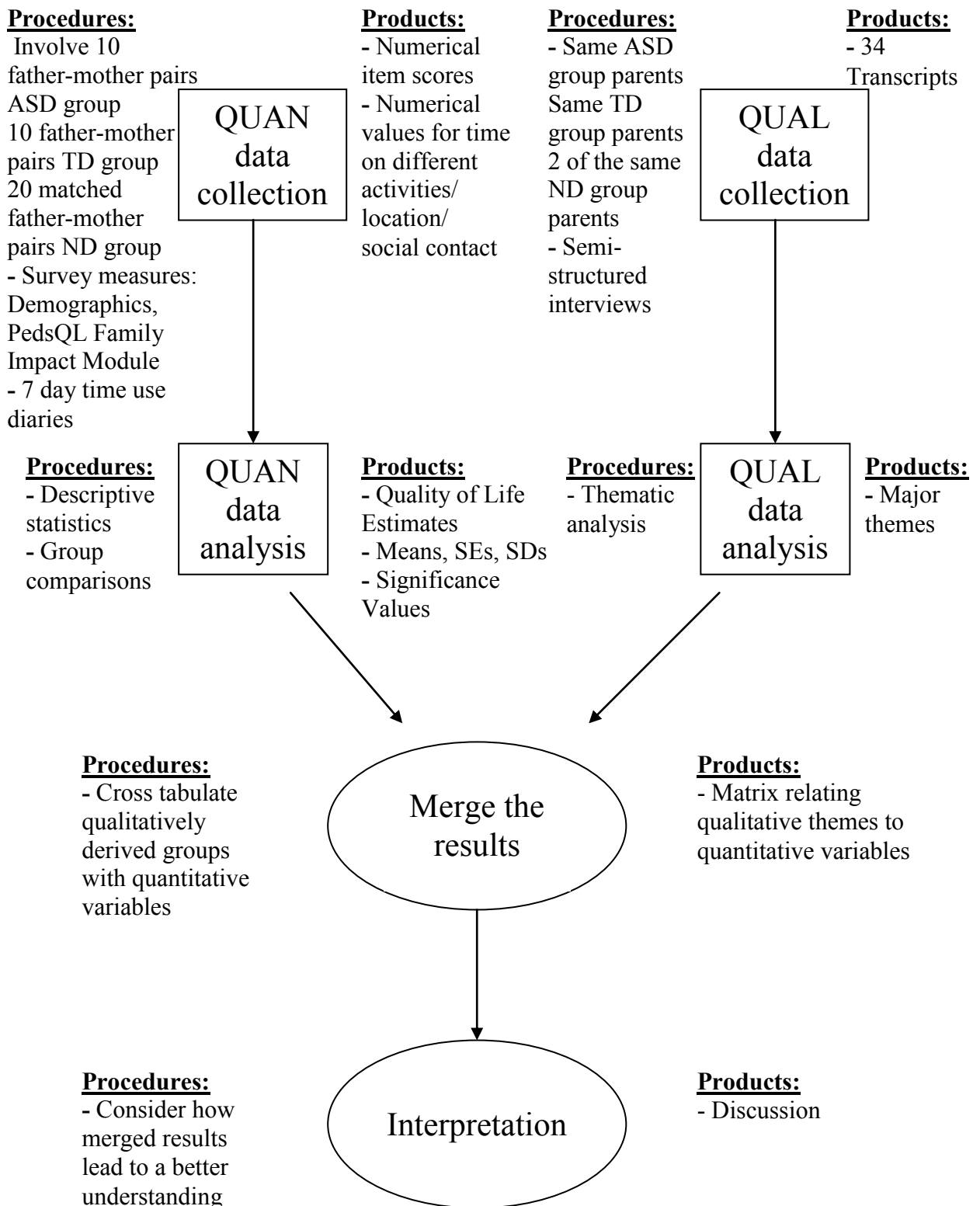


integer degrees of freedom in the brackets indicates that equal variances were not assumed. Data from the sample families were also compared to historical data on time use of spouse-pairs in the UK using comparison based on means and estimated standard errors.

The qualitative data from the semi-structured interviews were carefully transcribed and then subjected to detailed manual coding using Atlas-ti software to facilitate the process. Using thematic analysis techniques the codes were then organised into groups, and from these groups themes emerged. Detailed analytical coding and interpretation, supported through the inclusion of existing theoretical work on masculinities, fathering and gender were performed, as well as the incorporation of theoretical work on trust which emerged as an important unifying theme. As previously highlighted, the data and interpretation were subjected to critical reflection, to consider how my own ideologies and values may have influenced the study and the social implications of the findings (Madison 2005; Thomas 1993). Consideration of the language used by the parents during interviews, and whether their responses truly reflected their beliefs or not revealed deeper meanings from the data and, as Thomas (1993) states when referring to discourse analysis, care was taken with the language used to present the findings. Finally, triangulation of the data from the diaries, the interviews and the spouse records along with using a constant comparative approach to the identified themes provide reliability to the rich contextualised data.

### **3.7 Summary**

In summary, this project makes use of the diary: diary-interview method to critically interrogate the lives of parents of young children with disabilities. The time use diaries provide the method for observation while the surveys and interviews draw out the perceptions and views of the parents. Triangulation of the data from the diaries, the interviews and the spouse records along with using a constant comparative approach to the identified themes provide reliability to the rich contextualised data. The inclusion of matched comparison families increases the validity for quantitative analysis purposes in view of the small sample size, and the availability of large comparable time use data sets for UK father-mother pairs has enabled further statistical analysis to be performed. Figure 3.2 summarises the study design.



**Figure 3.2 Study Design<sup>3</sup>**

<sup>3</sup> Based on Figure 4.3 on page 118 in Designing and Conducting Mixed Methods Research by Creswell and Plano Clark (2011) including using the recommended notation system: QUAN = Quantitative and QUAL = Qualitative, capitalisation to indicate equal importance of both methods and the four letter shorthand version of each word to indicate the equal stature of the two methods

## CHAPTER 4 TIME QUANTITIES AND QUALITY OF LIFE

### Findings from the Time Use Diaries and PedsQL Family Impact Module

*“It was good to see what you do do. It’s like his injections, even though you think it’s a five minute job, but it was because you had to record these things you realise that it’s not always a five minute job at all. Because getting it ready obviously and then, how Travis is when you’re doing it and then he’s crying after and then you do feel bad and guilty. (...) Because we was recording everything there was a lot more things that you took on board rather than just going through each day, ‘cause you just seem to be on auto pilot all the time don’t you” Naomi (TD)*

#### 4.1 Introduction

The focus of this chapter is on the time use data from parents with a preschool child both with and without additional needs. Three groups are considered; parents with a child with complex health needs dependent on technology (TD group), parents with a child with a diagnosis of an autism spectrum disorder (ASD group) and parents with a child with no identified disability (ND group). The demographic information concerning these families is initially described alongside the demographic information relating to the selected UK participants from the Multinational Time Use (MTUS) Data Set. An explanation of how this comparison data set was achieved from the MTUS data is given in section 4.3.

The aim of the time use diaries was to provide insight into the daily lives of parents with young children with disabilities and to gain an understanding of the differences in these experiences compared to parents without a disabled child. Although an area of focus was intended to be child care, analysis of the diaries resulted in ambiguity at times as to which parent, or other adult present, was taking responsibility for this. In addition, due to the very young age of the children in the study, hours spent in childcare were high for families with and without disabled children, making differentiation based on hours of childcare alone less discriminating. However analyses of the qualitative data from the interviews, presented in the next chapter, identified clear differences as to the nature and intensity of the activities associated with childcare.

Consideration of intensity led to reflection on how this could be captured from the information recorded in the time use diaries. One way to consider intensity is to

measure the amount of breaks that are available for re-charging both mentally and physically. These breaks correspond to periods of uninterrupted rest, sleep or leisure. Therefore, this information was specifically extracted from the diaries and analysed.

Initial analysis of the qualitative data from the interviews highlighted emerging themes. Some of these related to aspects of time use evident from the diaries such as lack of sleep and reduced opportunities for social contact, and again provided insights as to further information that could be extracted and looked at in more detail from the quantitative data. As the data analysis of both the quantitative and qualitative data continued in an alternating or spiralling manner (Mendlinger & Cwikel 2008), both types of data were able to inform and explain each other as well as suggesting further analyses to be performed. The integration of the different types of data in this mixed methods study has produced new knowledge regarding parents' lives with a disabled child. This new knowledge includes greater understanding of previously identified concepts such as the increased burden of care, and revealed new concepts derived from parents' own interpretations of their time use decisions, both from a maternal and paternal view point.

Analyses of both types of data therefore led to certain aspects of parental time use being selected for detailed analysis. With regard to the activity data, sleep, work, (including work related travel) and travel activity are presented. Data on location, that is at home or elsewhere, and social contact including in relation to location are also described. Finally, intensity is considered, with time spent on quality leisure, including uninterrupted periods of quality leisure and the duration of uninterrupted sleep, as well as the frequency of sleep interruptions, presented. Comparisons of these data to national data sets are made where possible.

Following the presentation of the time use data analyses, the last section of the chapter concerns the results from the PedsQL<sup>TM</sup> Family Impact Module Version 2. The Total Score, Parent Health Related Quality of Life Score and the Family Functioning Score are provided for fathers and mothers in the different groups followed by the results from the individual sections. These are again provided for fathers and mothers in the different groups.

## **4.2 Demographic Information**

Over an eighteen month period all eligible parents in the study setting with a child with complex health needs dependent on technology (TD) were approached to be involved in the study. Six families were ineligible due to either their child being terminally ill, child protection concerns, only a single parent, or parents who were not co-resident. Of the nine families who were eligible, eight agreed to participate in the study and one family declined. The family who declined were interested in being involved but due to the father's health problems did not feel it was the right time.

Twelve families with a child with a diagnosis of autism (ASD) were approached over the same time period. Three declined to be involved. Reasons given were that the parents were too busy in one case, and in the other two families the mothers were interested but one father was not interested in research and the other was concerned about sharing personal information. At least three further families were ineligible due to having single parents. Additional eligible parents were not approached as they had very similar characteristics to some of the families already participating in the ASD group.

Recruiting comparison parents with a preschool child with no identified disability (ND) was much more difficult than initially anticipated. Comparison families were identified from the case loads of the family health visitors of the practices to which a recruited family with a child with autism or technology dependence belonged. Initial matching was rarely perfect and many of these families declined. It was not possible to be sure how many families the health visitors had approached before a family agreed but at least 12 families declined to be involved. While the parents of children in the ASD and TD groups could see the potential benefit of the study there was much less to attract a family where there were no concerns about their child or experience of individuals with disabilities. The information leaflet for comparison parents was re-written taking this aspect into consideration leading to some improvement in recruitment. However, comparison families could still not be matched as closely as planned, and original planned numbers were not achieved.

The sample demographics are shown in Table 4.1, including the demographics of the MTUS/UK sample. How this sample was achieved will be discussed in more detail in

the next section. Statistical tests for significant differences between the groups were performed on the ASD, TD and ND groups. For the purposes of this study, the child with additional needs within the TD and ASD groups is referred to as the 'study child'. The matched child in ND group is also identified in this manner.

No significant differences were detected between the groups for the mean ages of the parents. There was a significant difference between the groups in the mean age of the study child ( $P < 0.005$ ) due to the study children in the TD group on average being younger than those in the ASD group. The average age of the children in the national sample was also younger than the other groups. The age of the study child being younger in the TD group was due to the fact that concerns about the study child usually occurred within the first few months of life and nearly always by the child's first birthday in the TD group. While parents may have had some concerns about their child within the first year of life in the ASD group, this was not universal and in general the diagnosis was established between the ages of two and three years of age. Allowing time for parents to come to terms with the diagnosis before being approached for the study meant that the youngest child in the ASD group was two years and ten months of age (2.83 years), compared to the youngest child in the TD group being 16 months of age (1.33 years).

The majority of parents were married with one unmarried couple in each of the ASD and TD groups and two unmarried couples in the ND group. Although marriage still conventionally suggests increased stability in a relationship as compared to being unmarried, many couples have a period of living together before marriage. Therefore the duration of living together rather than the duration of marriage was recorded. This information was not available for the MTUS/UK sample. There was a significant difference between the groups in the mean time lived together ( $P < 0.002$ ) and this was primarily due to a difference between the TD and ND groups ( $P < 0.005$ ).

There was no significant difference in the number of children living at home between the three groups and families had between one and four children living at home. The MTUS/UK sample had between one and six children living at home, but with very small numbers of families having five or six children.

**Table 4.1 Sample Demographics**

	Autistic Spectrum Disorder (ASD)	Technology Dependent (TD)	No Disability (ND)	National Sample (MTUS/UK)
Number of families:	9	8	11	200
Parental age (years):				
Father mean (SD)	36.44 (1.69)	33.25 (2.31)	37.55 (1.45)	35.62 (6.84)
Range	30 to 40	22 to 42	28 to 47	20 to 56
Mother mean (SD)	33.00 (1.32)	34.38 (2.31)	35.64 (1.28)	32.60 (5.76)
Range	25 to 39	26 to 44	29 to 42	21 to 54
Cohabited (years):				
Mean (SD)	9.67 (0.99)	7.66 (1.29)	11.77 (0.68)	
Range	4 to 19	0.75 to 17.5	6 to 16	
Study Child Age (years):				
Mean (SD)	3.63 (0.15)	2.74 (0.25)	3.42 (0.21)	2.58 (1.01)
Range	2.83 to 4.50	1.33 to 4.00	2.00 to 4.75	1 to 4
Study Child Gender				
Boys : Girls	5 : 4	4 : 4	4 : 7	
No. of children living at home:				
Mean (SD)	2.22 (1.06)	1.88 (0.81)	2.00 (0.87)	1.98 (0.89)
Frequency (%)	1 22.2	37.5	27.3	33.5
	2 55.6	37.5	54.5	41.5
	3 0.0	25.0	9.1	20.5
	4 22.2	0.0	9.1	3.0
	5 0.0	0.0	0.0	1.0
	6 0.0	0.0	0.0	0.5
No. of cars per household:				
Mean (SD)	1.33 (0.69)	1.38 (0.72)	1.82 (0.40)	1.35 (0.64)
Frequency (%)	0 11.1	12.5	0.0	9.0
	1 44.4	37.5	18.2	47.0
	2+ 44.4	50.0	81.8	44.0
Gross annual family income:				
Frequency (%)				
<£20,000	22.2	37.5	18.2	
£20,000 -£40,000	66.7	25.0	18.2	
>£40,000	11.1	37.5	63.6	
Family income bands:				
Frequency (%)				
Lowest 25%				14
Middle 50%				56
Highest 25%				18 <sup>Ω</sup>

<sup>Ω</sup> 12% missing

Ninety one percent of participants were car drivers, meaning five parents were unable to drive a car, three fathers and two mothers. All of the ND group parents were car drivers. One father in the TD group was in the process of learning to drive and was having driving lessons. Four parents in the ASD group, two fathers and two mothers, who included one father-mother pair, were unable to drive a car.

Only one father-mother pair did not have a car, the pair where neither parent was able to drive. If the family did own a car they were asked whether they had one car or two or more cars. This was to establish whether both parents had access to a vehicle at the same time or needed to share the same car. There was a significant difference in the number of cars across the households with parents in the ND group owning significantly more cars ( $P < 0.05$ ).

Families came from a mixture of rural, suburban and inner city areas. The annual gross median family incomes varied for these areas from less than £24,000 in the least affluent inner city ward to more than £43,000 in the most affluent rural location according to statistics available from the local county council (Lancashire County Council 2011). Median gross household income across the three districts in which parents in this study lived was £32,000 for 2008, slightly less than the UK average of £35,000. Participating parents were asked to indicate whether their total annual income, including any benefits fell into one of three bands, <£20,000, £20–40,000 or >£40,000. This provides an indication as to whether gross annual family income fell within, above or below the median for the three districts.

The geographical area where the study was conducted had a predominantly White population with 2001 census data indicating 98.6% of the population as White. This was reflected in the participants of the study of whom 98.2% were White.

Due to the small sample size and rarity of some of the children's conditions, detailed information about each family's composition and the precise nature of individual children's additional needs will not be provided as this could lead to individuals being identified. All of the study children in the ASD group had a firm diagnosis of autism/autism spectrum disorder, a statement of special educational needs and were receiving specialist multiagency support. They did not have any significant on going



additional medical needs. The study children in the TD group had a range of diagnoses including chromosome abnormalities, cerebral palsy, hearing and visual problems, genetic syndromes and complex medical needs. They were all receiving specialist multiagency support and either had in place a statement of special educational needs or subsequently received one. The range of technology and medical needs are summarised in Table 4.2. Most of the children had more than one of the needs listed and several had many needs.

**Table 4.2 Additional Medical and Technology Needs**

<b>Additional Need</b>	<b>Number of children (n= 8)</b>
Tracheostomy	2
Home Ventilation	1
Daily Suction	4
Gastrostomy fed	6
Feeding pump	6
Daily Nebulisers	3
Prosthetics	2
Daily injections / blood tests	2
Porta Cath	1
Epilepsy	5
Daily need for multiple medications	7
Need for multiple surgical procedures	4
Need for specific housing adaptations	6

### **4.3 Time Use Data**

The data from the time use diaries were entered into SPSS version 18 for statistical analysis. Tests of normality were performed due to the small numbers and were satisfactory. All 56 participants completed at least one diary day, with 52 participants completing all seven diary days. One father in the TD group only completed one diary day which had some missing data entries. As it was not possible to go through the diary day with the father who withdrew from the study, this diary day was excluded from subsequent analysis other than for the analysis of the combined couple's data regarding sleep and work.

One mother in the TD group, the partner of the father who only completed one diary day, and one father in the ASD group each completed four diary days. One mother in the ASD group, the partner of the father who completed four diary days, completed two diary days. Weekly averages were performed only on the 52 data sets where data

are available for all seven days with the exception of combined couple data for sleep and work analysis. Week day averages used the data from 55 diary data sets for work (neither mother with incomplete diaries were in paid employment) and sleep, and 54 diary data sets for the other variables. Weekend averages used data from 52 diary data sets.

#### **4.3.1 *Multinational time use data***

The UK 2000/1 data set consists of 17,247 diaries. Criteria were used to identify diaries from individuals comparable to the parents in this study. Initially diaries were selected where the youngest child living at home was in the 0-4 age group to correspond to the ages of the study children who were, with the exception of one foster family, always the youngest child. Then diaries were removed from the selection that had been completed in August or December since these holiday periods had been avoided in this study. Finally diaries were removed that were categorised as 'bad diaries' as per the MTUS User Guide (Fisher, Gershuny, & Gauthier 2011). This left 1,537 diary days.

In the UK 2000/1 survey each participant was asked to complete one week day and one weekend day. Couple pairs were identified who had completed the same two days, resulting in 660 father-mother pairs. An SPSS database was created for each day of the week and the corresponding diary days for each couple entered, resulting in the following total number of diary days for each day of the week: Monday 122; Tuesday 144; Wednesday 138; Thursday 102; Friday 142; Saturday 328; Sunday 328. As Thursday had the least number of diary days, couples were included who had both completed the Thursday even if they had not both completed the weekend day. This increased the number of Thursday diary days to 118.

Frequency data of the age of the children then showed a large percentage of children either '0' or '1' with fewer children in the older age groups. In this study, only one family had a baby a few weeks old (not the study child) and none of the study children were aged less than one year, and only two aged between one and two years. Therefore, families were removed who had a child in the '0' age group leaving the following number of diary days: Monday 100; Tuesday 100; Wednesday 92; Thursday 94; Friday 108; Saturday 256; Sunday 232. Following this further couples

with an age ‘1’ child were removed from each day using well defined criteria. These were any missing data on income or employment status, any household with seven or more occupants (none of households in this study were larger than six), most of the families with a total family income in the highest 25% income bracket and/or with just one child, to leave 80 diary days on each week day, 212 diary days on Saturday and 186 diary days on Sunday. The paired diary days removed from the week corresponded to the same pairs removed at the weekend. This meant that there were a total of 400 diary days available for the week (Monday to Friday) and 398 diary days for the weekend (Saturday and Sunday) as one Thursday pair had no corresponding weekend day. However the age distribution was still skewed to the younger age group in the MTUS/UK 2000/1 data (Table 4.3).

**Table 4.3 Age distribution of ‘study child’ compared to extracted national data**

	Age 1	Age 2	Age 3	Age 4
This study	7.2%	25%	25%	42.8%
MTUS/UK Average for week	17%	32.5%	26.5%	24%
MTUS/UK Average for weekend	17.5%	32.5%	26%	24%

#### **4.3.2 Sleep**

Sleep fulfils a biological need and national data sets indicate that averages of sleep do not vary largely between countries (Gershuny 2000). Recent (1998 - 2005) weekly sleep times for the UK suggest an average weekly sleep amount of 58.8 hours, which equates to nearly eight and a half hours a day (Robinson & Michelson 2010). However, men in general have slightly less sleep than women, and parents with young children have less sleep than other groups. Sleep does vary from day to day, particularly in relation to working patterns and most individuals have more sleep over the weekend than during the week (Bin 2011; Robinson & Michelson 2010).

The families in the TD and ASD groups showed different patterns of sleep disturbance when measured by total minutes of sleep achieved. Fathers in the ASD group had the least amount of average sleep while mothers in the ASD and TD groups had very similar amounts of average sleep. Mothers and fathers in the ND group both had greater amounts of average sleep than the parents in the TD and ASD groups, and mothers and fathers in the MTUS/UK group had slightly more sleep than the ND group parents (Table 4.4). Although this did not reach significance when either parent

was looked at individually, the combined total amount of sleep that couples achieved was significantly less in the ASD group than that recorded by the ND group,  $t(18) = -3.31$ ,  $P < 0.005$ .

**Table 4.4 Average hours of sleep per day**

	ASD	TD	ND	MTUS/UK
Number of Parents				
Fathers	9	7	11	200
Mothers	9	8	11	200
Daily Mean (SE)				
Complete Week				
Fathers	6.96 (0.51)	8.06 (0.39)	8.02 (0.20)	8.20 (0.10)
Mothers	8.04 (0.26)	8.03 (0.35)	8.39 (0.12)	8.41 (0.09)
Daily Mean (SE)				
Weekdays				
Fathers	6.89 (0.56)	7.83 (0.41)	7.74 (0.28)	7.93 (0.10)
Mothers	7.88 (0.22)	8.00 (0.52)	8.21 (0.15)	8.21 (0.09)
Daily Mean (SE)				
Weekends				
Fathers	7.14 (0.55)	8.65 (0.41)	8.73 (0.24)	8.88 (0.12)
Mothers	8.42 (0.52)	8.09 (0.58)	8.84 (0.25)	8.92 (0.12)
Number of Couples				
Mean (SE)	9	8	11	200
P value	7.49 (0.18)	8.03 (0.21)	8.20 (0.13)	8.30
	< 0.005	= 0.467		

Comparing week days to weekend sleep patterns all parents except the mothers in the TD group were able to sleep more at the weekends than during the week. Mothers in the TD group recorded virtually the same average amount of time throughout the whole week. Despite having on average 45 minutes less sleep at the weekend than mothers in the ND group this did not reach statistical significance ( $t(16) = -1.35$ ,  $P < 0.2$ ) due to the small sample size, though this difference is likely to be of significance in daily life.

Fathers in the ASD group had relatively less sleep during the week than the fathers in the other groups but when tested against the fathers in the ND group this was not statistically significant. The same pattern was seen at the weekend with ASD fathers having on average one hour and 35 minutes less sleep than ND group fathers and this was significant ( $t(17) = -2.93$ ,  $P < 0.01$ ).

### **4.3.3 Work and travel**

The majority of fathers in the study and in the MTUS/UK data set were in paid employment (Table 4.5). All the fathers in the ND group worked, while one father in the ASD group and one father in the TD group were not in paid employment. In contrast, mothers' employment was more variable.

Analysis of the data revealed that fathers in the TD group worked the longest average hours per week at an average 6.33 hours per day, compared to 5.30 hours and 5.98 hours for fathers in the ASD and ND groups respectively. However, as many of the study participants did not differentiate between work and work travel the data presented in more detail consist of these two variables combined. For many participants travel was an integral part of their employment and as this time was committed to paid employment for all the participants, the total of work time and travel associated with work (work travel) was an appropriate variable to compare between groups (Table 4.5). Fathers in the TD group still worked the longest average hours a day at 6.90 hours though the difference with the ND group fathers was less than looking at work hours alone.

As all the fathers in the ND group and all but one of the ND group mothers were in paid employment their hours of work are somewhat inflated compared to the TD and ASD groups. The MTUS/UK data which includes participants with a range of employment patterns therefore provides a helpful additional comparison. No significant difference was detected between the weekly average number of hours per day that the ASD group fathers or mothers spent in work and work travel, compared to the ND group. This was also the case for fathers in the TD group but as would be expected there was a highly significant difference between mothers in the TD group and the ND group ( $t(11.32) = -5.53, P < 0.001$ ).

Participants in all of the groups worked more hours on average during the week than at the weekend. Fathers in the ASD group worked more hours than fathers in other groups at the weekend but the difference was not significant.

**Table 4.5 Work and travel**

	ASD	TD	ND	MTUS/UK
Paid employment rates, frequency (%)				
Fathers				
Full-time	88.9	87.5	100.0	84.2
Part-time	0.0	0.0	0.0	3.8
No paid work	11.1	12.5	0.0	7.5
Missing	0.0	0.0	0.0	4.5
Mothers				
Full-time	44.4	0.0	45.4	18.7
Part-time	11.1	25.0	45.4	37.9
No paid work	44.4	75.0	9.2	40.4
Missing	0.0	0.0	0.0	3.0
Number of Parents				
Fathers	9	7	11	200
Mothers	9	8	11	200
Average hours of paid work + work travel per day				
Daily Mean (SE)				
Complete Week				
Fathers	5.78 (0.72)	6.90 (1.22)	6.78 (0.78)	6.23 (0.26)
Mothers	2.43 (0.97)	0.28 (0.19)	4.41 (0.72)	2.94 (0.24)
Daily Mean (SE)				
Weekdays				
Fathers	6.85 (1.02)	8.53 (1.45)	8.96 (1.04)	7.94 (0.29)
Mothers	3.22 (1.33)	0.32 (0.24)	6.00 (1.07)	3.70 (0.28)
Daily Mean (SE)				
Weekends				
Fathers	3.11 (1.34)	2.84 (1.26)	1.32 (0.66)	1.96 (0.26)
Mothers	0.46 (0.46)	0.19 (0.19)	0.44 (0.33)	1.06 (0.19)
Couples Average hours work + work travel per day				
Mean (SE)	4.10 (0.74)	3.56 (0.58)	5.59 (0.63)	4.59
P value	= 0.14	< 0.05		
Average hours of non-work related travel per day				
Daily Mean (SE)				
Complete Week				
Fathers	0.50 (0.13)	0.55 (0.12)	0.66 (0.15)	
Mothers	0.99 (0.20)	1.45 (0.18)	1.02 (0.10)	
Daily Mean (SE)				
Weekdays				
Fathers	0.51 (0.18)	0.47 (0.12)	0.52 (0.18)	
Mothers	1.04 (0.26)	1.70 (0.23)	1.00 (0.16)	
Daily Mean (SE)				
Weekends				
Fathers	0.48 (0.24)	0.75 (0.20)	1.01 (0.26)	
Mothers	0.86 (0.23)	0.84 (0.27)	1.07 (0.20)	

Comparing couple averages there was no significant difference between father-mother pairs in the ASD or ND groups but the father-mother pairs in the TD group worked in paid employment for significantly less average hours a day than the ND group father-mother pairs ( $t(17) = -2.27, P < 0.05$ ). Therefore, although fathers in the TD group worked the longest hours this did not totally compensate for their partners reduced paid employment hours.

Travel to escort children to and from school, nursery, or other activities as well as travel for appointments, shopping, and leisure activities were also recorded. Mothers in the TD group spent the most time on this activity and the difference when tested against the time spent by mothers in the ND group was significant ( $t(16) = 2.32, P < 0.05$ ). This data was not readily available from the MTUS/UK 2000/1 data sets.

The same pattern was seen for weekdays and again the differences between the time spent on non-work related travel was significantly different between mothers in the TD and ND groups ( $t(16) = 2.53, P < 0.05$ ). No significant differences were noted at the weekends. When father-mother pairs were analysed for the week no significant differences between the groups were detected.

#### **4.3.4 Location**

Activities undertaken at home and in locations outside of the home are often different. For instance some activities such as swimming require special facilities that the majority of families do not have available at home. Other activities such as eating which are regularly performed at home have a different quality when performed elsewhere.

Families with a child with technology needs may find it difficult to access activities outside the home due to the amount of equipment that needs to be available. Conversely families with a child on the autism spectrum often reported the child's enjoyment of outdoor spaces and having the freedom to run. Therefore, location was looked at specifically to explore differences in the amount of time parents spent at home or elsewhere. This is further explored in the next section with regard to social contact. While location data were available from the MTUS/UK 2000/1 data sets,

these were at the episode level rather than daily aggregates and so not readily available for comparison purposes.

Fathers in the ASD group spent the most time at home out of the fathers while mothers in the TD group had the most time at home compared to the mothers in the other groups (Table 4.6). This was a significant difference for the mothers in the TD group ( $t(12.09) = 4.00, P < 0.005$ ) when compared to the ND group mothers and approaching significance for the fathers in the ASD group ( $t(17) = 1.93, P = 0.071$ ) when compared to the ND group fathers. The same pattern was seen when just the weekdays were considered with  $t(12.49) = 4.04, P < 0.005$  and  $t(18) = 1.94, P = 0.069$ .

However at the weekend, there was no significant difference in the amount of time spent at home between the fathers in the different groups. There was also no significant difference between the mothers in the TD group compared to the ND group mothers. At the weekends it was the mothers in the ASD group who spent the most amount of time at home, an average of just over 21 hours a day. This did not quite reach significance ( $t(17) = 2.03, P = 0.058$ ) when compared to the ND group mothers. Analysis of the combined father-mother pair averages for time at home for the whole week did not reveal any significant differences between the groups.

It was noted that a large proportion of the time that the participants were not at home was spent in paid employment or work related travel. Therefore, to compare the amount of time spent on activities not defined as work or work related travel, the time spent elsewhere with the totals for work and work related travel removed, are described. This does not relate to all paid employment hours as many participants undertook some paid employment at home.

Mothers in the TD group spent the most hours a week 'elsewhere' not at work or in work related travel. As only one mother in the TD group worked outside the home, very little time was removed due to work related activity to obtain this variable for the mothers in the TD group. However, there was no statistically significant difference detected between the weekly average for the mothers in the TD and ND groups ( $t(16)$



= 1.83,  $P = 0.086$ ). There was also no statistically significant difference noted between the weekly average for mothers in the ASD and ND groups.

**Table 4.6 Location**

	ASD	TD	ND
Average hours at home per day			
Daily Mean (SE) Complete Week	n = 8	n = 7	n = 11
Fathers	16.92 (0.78)	15.25 (1.09)	14.69 (0.81)
Mothers	18.66 (0.94)	19.78 (0.20)	17.18 (0.62)
Daily Mean (SE) Weekdays			
	n = 9F, 8M	n = 7F, 8M	n = 11
Fathers	16.03 (0.85)	14.30 (1.25)	13.33 (1.05)
Mothers	17.71 (1.45)	19.79 (0.29)	16.36 (0.80)
Daily Mean (SE) Weekends			
	n = 8	n = 7	n = 11
Fathers	18.92 (1.28)	17.63 (0.78)	18.08 (0.75)
Mothers	21.03 (0.82)	19.97 (0.80)	19.22 (0.48)
Average hours at home for couples per day			
Mean (SE)	n = 8 17.79 (0.83)	n = 7 17.52 (0.55)	n = 11 15.94 (0.62)
Average hours spent elsewhere per day (work + work travel removed)			
Daily Mean (SE) Complete Week	n = 8	n = 7	n = 11
Fathers	1.50 (0.34)	1.94 (0.25)	3.52 (0.62)
Mothers	2.62 (0.44)	4.00 (0.24)	3.10 (0.36)
Daily Mean (SE) Weekdays			
	n = 9F, 8M	n = 7F, 8M	n = 11
Fathers	1.46 (0.52)	1.26 (0.30)	3.07 (0.87)
Mothers	2.67 (0.57)	4.03 (0.28)	2.55 (0.54)
Daily Mean (SE) Weekends			
	n = 8	n = 7	n = 11
Fathers	1.60(0.45)	3.64 (0.81)	4.67 (0.42)
Mothers	2.49 (0.48)	3.95 (0.75)	4.47 (0.40)
Couples Average hours elsewhere per day (work + work travel removed)			
Mean (SE)	n = 8 2.06 (0.22)	n = 7 2.97 (0.21)	n = 11 3.32 (0.43)
P value	< 0.02	= 0.48	

Fathers in the TD and ASD groups spent less time outside the home on non-work activities than fathers in the ND group during the week. The differences were significant with  $t(12.94) = -2.36$ ,  $P < 0.05$  for the fathers in the TD group, and  $t(14.94) = -2.85$ ,  $P < 0.02$  for fathers in the ASD group compared to fathers in the ND group.

When just weekdays were considered, the difference between mothers in the TD group and ND group mothers reached significance ( $t(14.36) = 2.41$ ,  $P < 0.05$ ) but no

significant differences were detected for the other groups. At weekends, both parents in the ASD group spent less time than the ND group parents outside the home on non-work activities with the results highly significant for fathers ( $t(17) = -4.87$ ,  $P < 0.0001$ ) and significant for mothers ( $t(17) = -3.18$ ,  $P < 0.01$ ). No significant differences were noted between mothers or fathers in the TD and ND groups.

Analysis of the father-mother pairs' weekly averages showed couples in the ASD group spend less time a week 'elsewhere' in non-work related activities and this difference was significant when tested against couples in the ND group ( $t(14.49) = -2.63$ ,  $p < 0.02$ ).

#### **4.3.5 Social contact**

Participants were asked to record who they were with throughout the 24 hour period. Options given were: with partner; with study child; with other children; alone. More than one box could be marked if the participant was for instance with their partner, the study child and other children. Alone was defined as not being with a member of the immediate nuclear family as opposed to not being with anyone at all.

The MTUS/UK data does include information about social contact. The majority of this is still only available at the episode level and not as aggregate summaries and therefore not readily available for comparison purposes. Total amount of time spent with partner for the 24 hour period is available in the aggregate data set, though not subdivided into time alone with partner or other variables. This total amount of time spent with partner is used for comparison.

##### *4.3.5.1 Total time spent with partner*

Although it might be anticipated that the amount of time spent 'with partner' would be identical for both partners in a father-mother pair, this is rarely the case as there is some degree of interpretation of the 'being with' and diaries cannot be considered to be 100% accurate. Therefore data for mothers and fathers are presented separately (Table 4.7).

**Table 4.7 Social contact**

	ASD	TD	ND	MTUS/UK	MTUS/UK + SLEEP
Average hours with partner per day					
Daily Mean (SE) Complete Week					
Fathers	13.15 (1.00)	12.47 (1.01)	12.94 (1.16)	5.26 (0.08)	13.46
Mothers	12.44 (0.67)	12.80 (1.10)	12.71 (1.20)	5.96 (0.04)	14.16
Daily Mean (SE) Weekdays					
Fathers	12.48 (1.00)	11.26 (1.04)	12.13 (1.52)	4.20 (0.11)	12.13
Mothers	12.31 (0.92)	11.81 (1.03)	11.59 (1.47)	4.98 (0.04)	12.91
Daily Mean (SE) Weekends					
Fathers	16.50 (1.81)	18.11 (1.19)	20.28 (1.57)	7.90 (0.03)	16.78
Mothers	15.22 (1.70)	18.42 (1.20)	20.79 (1.61)	8.40 (0.03)	17.28
Average hours with study child per day					
Daily Mean (SE) Complete Week					
Fathers	1.69 (0.58)	1.28 (0.29)	0.68 (0.2)		
Mothers	2.48 (0.77)	6.73 (1.04)	2.62 (0.49)		
Daily Mean (SE) Weekdays					
Fathers	1.98 (0.62)	1.16 (0.34)	0.67 (0.17)		
Mothers	2.46 (0.67)	7.44 (0.98)	2.72 (0.41)		
Daily Mean (SE) Weekends					
Fathers	1.44 (0.69)	1.59 (0.34)	0.72 (0.31)		
Mothers	2.56 (1.29)	4.45 (1.15)	2.37 (1.08)		
Average hours with partner, study child + other children per day					
Daily Mean (SE) Complete Week					
Fathers	4.66 (0.73)	6.17 (2.11)	4.61 (0.65)		
Mothers	4.76 (0.63)	6.70 (2.28)	4.16 (0.54)		
Average hours alone per day					
Daily Mean (SE) Complete Week					
Fathers	8.54 (0.63)	9.92 (1.20)	9.73 (1.23)		
Mothers	6.62 (1.89)	3.26 (0.86)	6.79 (0.97)		
Daily Mean (SE) Weekdays					
Fathers	9.55 (0.61)	11.42 (1.25)	11.60 (1.44)		
Mothers	7.52 (1.52)	3.38 (0.99)	8.55 (1.26)		
Daily Mean (SE) Weekends					
Fathers	5.96 (1.60)	6.16 (1.25)	5.06 (1.15)		
Mothers	4.35 (1.06)	2.07 (0.59)	2.34 (0.68)		

Parents in all the study groups spent a similar average amount of time per day with their partner when all days are considered, with parents in the ND group spending the most time together (Figure 4.1). During weekdays, fathers and mothers in the ASD group spent slightly more time together than parents in the other groups, but the difference was not significant. At the weekends the comparison father-mother pairs

spent the most time together with the parents in the ASD group spending the least, but again this difference was not significant.

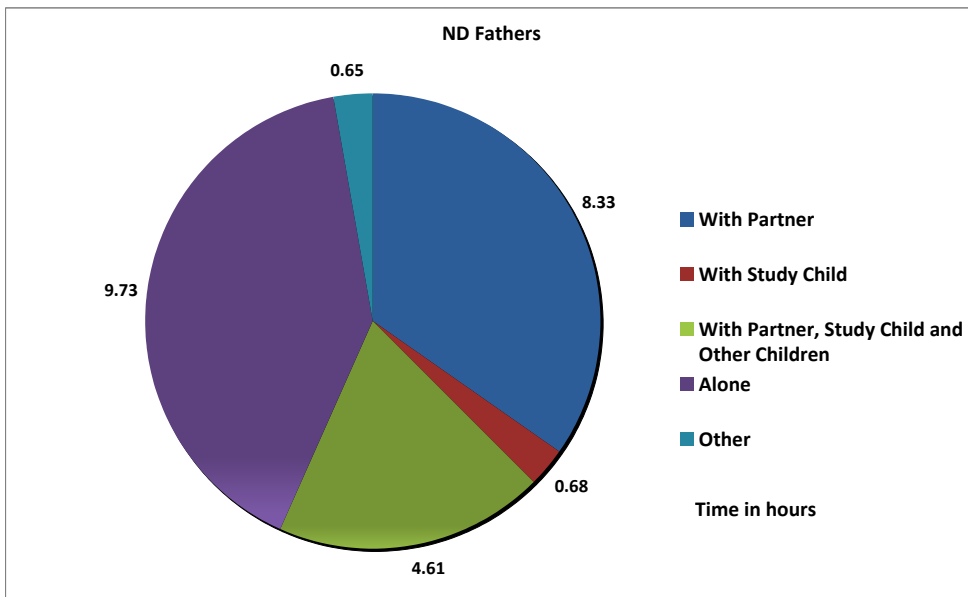
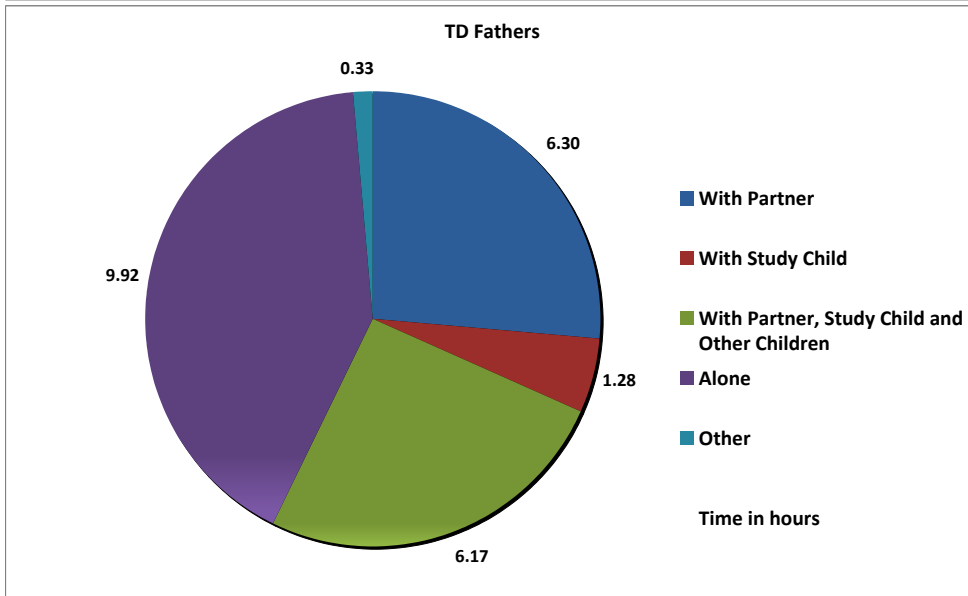
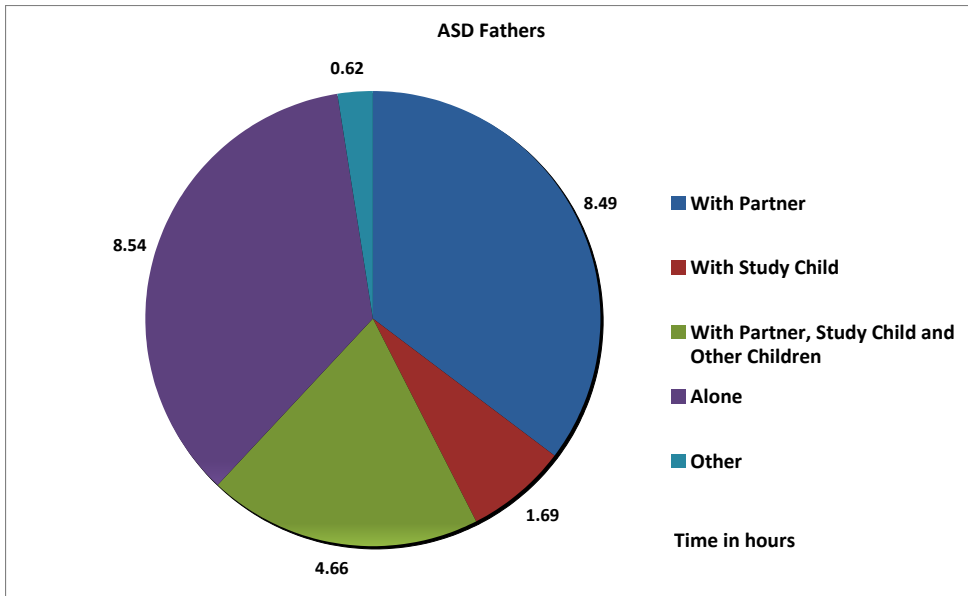
The MTUS/UK data provided very different averages for the time partners spent together and the reasons for this were not immediately clear. However, looking at the episode level data it appeared that social contact was not recorded for periods of sleep. While not all partners sleep together and if they do, not necessarily for the full period of sleep, if average sleep times for the MTUS/UK fathers (who sleep less than mothers) from Table 4.4 are added to the total time with partner averages, the results are very comparable to the findings from this study.

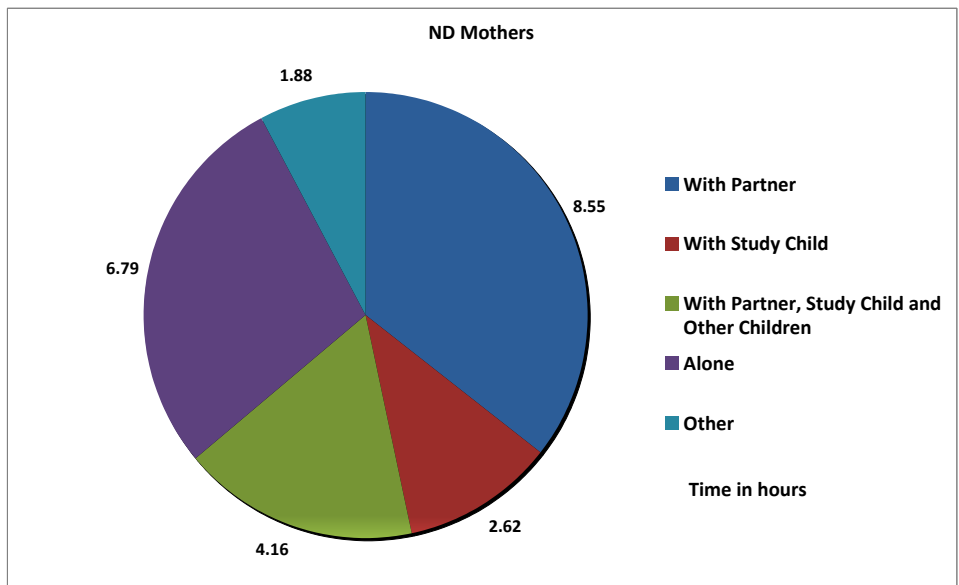
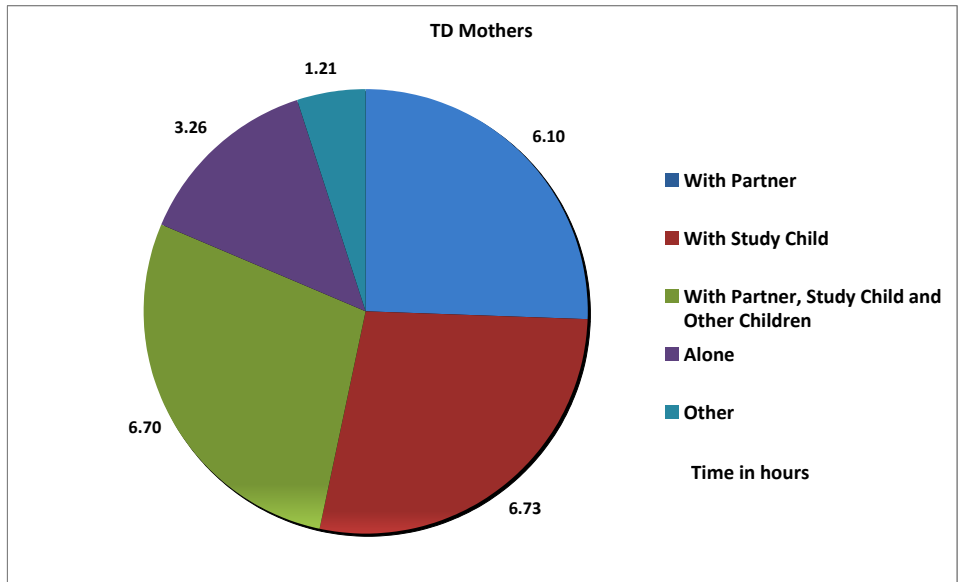
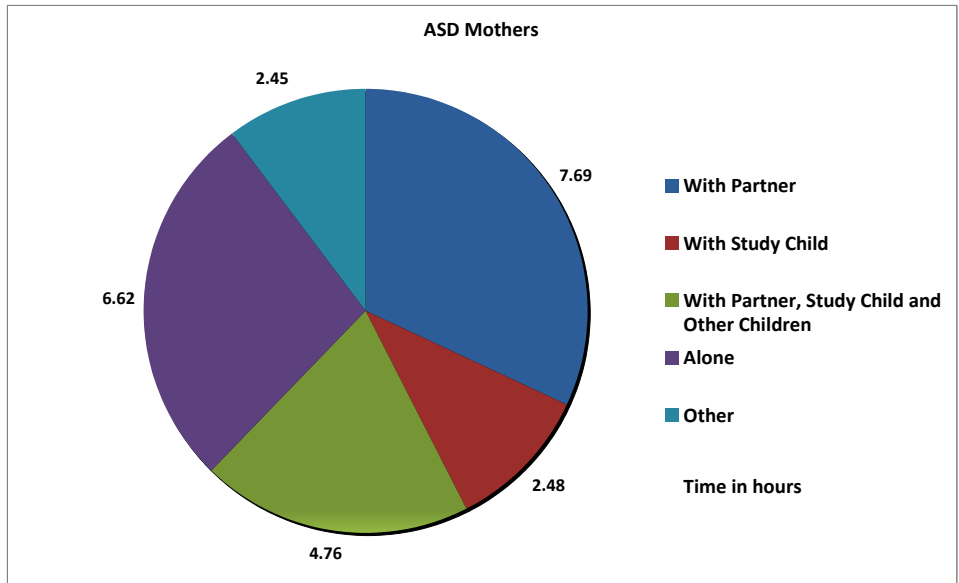
#### *4.3.5.2 Time spent with study child only*

Time spent just with the study child varied considerably between groups and between parents. The average amount of time per day spent with the study child differed by an hour between fathers in the ASD and ND groups but this did not reach statistical significance. Mothers in the TD group spent more than four hours a day just with their study child compared to mothers in the ND group and this was significant ( $t(16) = 4.03, P < 0.002$ ). Looking at the week days only, the same pattern is seen and again the difference between means for the fathers in the ASD and ND groups did not reach statistical significance ( $t(9.25) = 2.03, P = 0.072$ ) and the difference in means for the mothers in the TD and ND groups did ( $t(9.46) = 4.46, P < 0.002$ ). At the weekends, both fathers and mothers in the TD group spent more time alone with the study child than their counterparts but this was not statistically significant.

#### *4.3.5.3 Time spent with partner, study child and other children*

Families spent a similar average amount of time together a day. Parents in the TD group spent the most time together. Parents in the ASD group spent more time together as a family during the week than parents in the ND group, but less time together at the weekends. No significant differences were noted.





**Figure 4.1 Social Contact**

#### 4.3.5.4 *Time spent alone*

It could be anticipated that due to the amount of time that mothers in the TD group spent just with the study child that they would have less time alone than the other parents and this was the case. Mothers in the TD group spent on average 3.26 hours alone compared to the 6.79 hours that the mothers in the ND group spent alone and this difference was significant ( $t(16) = -2.51, P < 0.05$ ).

This difference was more pronounced during week days with mothers in the TD group spending 3.38 hours alone and the mothers in the ND group spending 8.55 hours alone ( $t(17) = -3.03, P < 0.01$ ). At the weekends time spent alone by all parents was more similar and although mothers in the TD group still spent the least time alone no statistical difference was detected.

#### 4.3.5.5 *Time spent with other children (not study child or partner)*

Some families only had one child. Seven father-mother pairs in ASD group, five in the TD group and eight in the ND group had other children. While fathers in the TD group appeared to be spending more time with their other children during the week, and mothers in the ASD group to be spending more time with their other children at the weekends the numbers are small and no significant differences were detected between groups (Table 4.8). This was also the case when couple averages were explored. Time spent with other children accounts for the 'other' section in the pie charts in Figure 4.1.

#### 4.3.5.6 *Time spent with children (study child and other children) but not partner*

This variable was also only explored with regard to families with more than one child. Being the sole responsible parent for the study child and other children at the same time occurred more frequently with mothers than fathers. No statistically significant differences were detected between fathers in the different groups or mothers in the different groups. While both mothers and fathers in the TD group spent less time in sole charge of their children than the parents in the other groups, this did not reach statistical significance when analysed at the father-mother pair level and compared to father-mother pairs in the ND group ( $t(11) = -1.94, p = 0.078$ ). Consideration of these results suggest that parents with a TD child have periods where they split their parenting responsibilities, with one parent looking after the study child and the other

parent, the other children. This may be due to the level of care the study child requires but may also be to try and achieve some quality time with the other children by allowing the parents to focus on their needs and participate in different activities than are possible with the study child present.

**Table 4.8 Social contact in families with more than one child**

	ASD	TD	ND
Number of Families	7	5	8
Average hours with other children only per day			
Daily Mean (SE) Complete Week			
Fathers	0.15 (0.08)	0.44 (0.17)	0.23 (0.09)
Mothers	0.79 (0.21)	0.62 (0.31)	0.39 (0.14)
Daily Mean (SE) Weekdays			
Fathers	0.10 (0.07)	0.56 (0.23)	0.17 (0.11)
Mothers	0.73 (0.16)	0.63 (0.33)	0.43 (0.15)
Daily Mean (SE) Weekends			
Fathers	0.27 (0.25)	0.13 (0.09)	0.39 (0.26)
Mothers	0.94 (0.56)	0.19 (0.19)	0.28 (0.14)
Average hours with study child + other children without partner present per day			
Daily Mean (SE) Complete Week			
Fathers	0.69 (0.22)	0.13 (0.07)	0.67 (0.24)
Mothers	2.48 (0.56)	1.49 (0.59)	2.19 (0.36)

#### **4.3.6 Social contact by location**

Social contact was also explored in relation to location, looking at who the parent spent their time with when not at home.

##### *4.3.6.1 Time with partner while 'elsewhere'*

For parents with preschool children to spend time alone together away from home means that someone else needs to be responsible for looking after their young child/ren. Such childcare may have to be paid for and therefore many parents with young children spend their available time together at home. If the childcare demands are high and constant, this may mean that it is not possible to have quality time together and therefore time away from the home may become a priority, but equally may be more difficult to achieve as appropriate childcare may be difficult to obtain. The weekly average amount of time that parents spent elsewhere together a day, as



shown in Table 4.9, was nearly identical between the different groups, ranging from nine to 12 minutes.

#### 4.3.6.2 *Time spent with partner, study child and children while 'elsewhere'*

Parents in the comparison group spent more time going out together as a family compared to the parents in the ASD and TD groups. The daily averages over the complete week for fathers and mothers in the ASD group were significantly different to the fathers and mothers in the ND group, with  $t(17) = -2.78$ ,  $P < 0.02$  and  $t(17) = -2.42$ ,  $P < 0.05$  respectively. This was also the case for the mothers in the TD group compared to the ND group mothers with  $t(16) = -2.54$ ,  $P < 0.05$ , and significance was almost reached for fathers in the TD group compared to ND group fathers with  $t(16) = -2.12$ ,  $P = 0.050$ . Significant differences were also detected when father-mother pairs were analysed. While weekday daily averages were not significantly different between parents in the different groups, weekend daily averages were all significantly different.

#### 4.3.6.3 *Time spent with child/ren (study child and/or other children) but not partner while 'elsewhere'*

This variable is slightly different to the variables presented in the previous tables, where contact with the study child and other children were explored separately. In this variable time spent with any child away from home with only one parent present was explored. Mothers in the TD group spent significantly more time away from home with the study child and/or other children than the ND group mothers during the week ( $t(16) = 3.74$ ,  $P < 0.005$ ). This was also the pattern during weekdays ( $t(17) = 3.51$ ,  $P < 0.005$ ) but not at the weekend and was partly due to attendance at appointments. Fathers in the ND group spent more time with the study child and/or their other children without their partner present at the weekend and this reached significance in comparison to the fathers in the TD group ( $t(10) = -2.82$ ,  $P < 0.05$ ) and approached significance in comparison to the fathers in the ASD group ( $t(14.11) = -2.10$ ,  $P = 0.054$ ).

#### 4.3.6.4 *Time spent 'elsewhere' alone on non-work activities*

As already discussed above, the majority of time spent elsewhere is committed to work or work related travel. Therefore, this variable only looks at time spent

**Table 4.9 Social contact by location**

	ASD	TD	ND
Average hours elsewhere with partner per day			
Daily Mean (SE) Complete Week			
Fathers	0.19 (0.13)	0.16 (0.08)	0.15 (0.09)
Mothers	0.17 (0.09)	0.19 (0.09)	0.20 (0.10)
Average hours elsewhere with partner, study child + children per day			
Daily Mean (SE) Complete Week			
Fathers	0.42 (0.16)	0.59 (0.17)	1.38 (0.27)
Mothers	0.53 (0.16)	0.44 (0.16)	1.30 (0.25)
Daily Mean (SE) Weekdays			
Fathers	0.23 (0.15)	0.26 (0.17)	0.81 (0.32)
Mothers	0.34 (0.17)	0.12 (0.11)	0.71 (0.29)
Daily Mean (SE) Weekends			
Fathers	0.83 (0.49)	1.43 (0.39)	2.79 (0.43)
Mothers	1.00 (0.50)	1.25 (0.48)	2.79 (0.44)
Average hours elsewhere with study child and/or other children without partner per day			
Daily Mean (SE) Complete Week			
Fathers	0.22 (0.08)	0.26 (0.15)	0.41 (0.09)
Mothers	1.26 (0.41)	2.59 (0.36)	1.21 (0.18)
Daily Mean (SE) Weekdays			
Fathers	0.27 (0.10)	0.36 (0.21)	0.35 (0.11)
Mothers	1.31 (0.40)	2.91 (0.35)	1.35 (0.28)
Daily Mean (SE) Weekends			
Fathers	0.09 (0.09)	0.00 (0.00)	0.55 (0.19)
Mothers	1.16 (0.51)	1.79 (0.56)	0.86 (0.30)
Average hours elsewhere alone on non-work activities per day			
Daily Mean (SE) Complete Week			
Fathers	0.66 (0.26)	0.93 (0.21)	1.63 (0.57)
Mothers	0.64 (0.18)	0.78 (0.18)	0.46 (0.14)
Daily Mean (SE) Weekdays			
Fathers	0.67 (0.26)	0.64 (0.22)	1.85 (0.77)
Mothers	0.77 (0.23)	0.99 (0.23)	0.44 (0.13)
Daily Mean (SE) Weekends			
Fathers	0.62 (0.34)	1.66 (0.60)	1.09 (0.34)
Mothers	0.33 (0.16)	0.23 (0.13)	0.51 (0.33)

‘elsewhere’ alone on non-work related activities. While some of this time will be spent on essential activities such as shopping, much of this time also relates to leisure activities. Leisure activities are considered in more detail under intensity.

Fathers in the ND group spent the most time alone ‘elsewhere’ in non-work related activities during the week but no significant differences were detected between any of the groups. Weekday daily averages revealed a significant difference between mothers in the TD and ND groups with mothers in the TD group spending more time alone ‘elsewhere’ in non-work activities ( $t(16) = 2.22, P < 0.05$ ). Fathers in the ND group still spent the most time alone ‘elsewhere’ in non-work activities though no significant difference was noted in comparison to the other fathers. No significant differences were noted at the weekend or when father-mother pairs’ weekly averages were analysed.

#### **4.3.7 Intensity**

The level of adult care required for children usually changes with age from a constant supervision and attention, to more monitoring of activities and availability at certain times. For preschool children, at least one adult needs to take responsibility for supervision of the preschool child at all times though the degree of attention and necessity for physical proximity will vary with the personality and abilities of the child and to an extent, that of the adult. Therefore, when considering intensity of care and the opportunities for ‘down time’ and ‘recharging’, any time that a parent is responsible for a very young child could be considered care and not leisure, even if the activity engaged in is typically regarded as leisure, such as sport or a visit to the zoo. Diary activities were analysed in this manner. As there is no guidance in the published literature about minimum periods of time that are required for physical and mental ‘recharging’ a pragmatic decision was made to only consider episodes that lasted more than 30 minutes (Table 4.10).

Sleep is also important for recharging and while totals of sleep have already been considered, this section concerns the number of recorded interruptions of sleep and the longest period of uninterrupted sleep achieved. However, not all interruptions will have been recorded in the diaries as some parents had the child in their room, or even in bed with them, and so may have experienced multiple minor disturbances that were not documented.

The number of interruptions that parents experienced was similar during weekdays and at the weekend. Mothers in all of the groups experienced more interruptions than

**Table 4.10 Proxy measures for intensity**

		ASD	TD	ND
Average number of sleep interruptions per night				
Daily Mean (SE) Complete Week				
	Fathers	0.30 (0.13)	0.43 (0.32)	0.05 (0.03)
	Mothers	0.77 (0.19)	1.34 (0.37)	0.22 (0.11)
Daily Mean (SE) Weekdays				
	Fathers	0.30 (0.15)	0.43 (0.27)	0.07 (0.04)
	Mothers	0.72 (0.21)	1.31 (0.37)	0.27 (0.14)
Daily Mean (SE) Weekends				
	Fathers	0.31 (0.16)	0.43 (0.43)	0.00 (0.00)
	Mothers	0.88 (0.23)	1.43 (0.47)	0.09 (0.06)
Average longest period of uninterrupted sleep (hours)				
Daily Mean (SE) Complete Week				
	Fathers	6.44 (0.45)	6.87 (0.54)	7.61 (0.27)
	Mothers	6.55 (0.54)	5.51 (0.60)	7.81 (0.32)
Daily Mean (SE) Weekdays				
	Fathers	6.25 (0.50)	6.72 (0.47)	7.48 (0.23)
	Mothers	6.48 (0.56)	5.26 (0.43)	7.45 (0.39)
Daily Mean (SE) Weekends				
	Fathers	6.91 (0.56)	7.25 (0.80)	7.93 (0.44)
	Mothers	6.74 (0.66)	6.13 (1.25)	8.69 (0.26)
Average longest period of uninterrupted leisure > 30 mins when not responsible for study child (hours)				
Daily Mean (SE) Complete Week				
	Fathers	0.25 (0.12)	0.82 (0.10)	1.00 (0.23)
	Mothers	0.15 (0.05)	0.67 (0.26)	0.30 (0.10)
Daily Mean (SE) Weekdays				
	Fathers	0.31 (0.13)	0.51 (0.11)	0.90 (0.29)
	Mothers	0.18 (0.06)	0.68 (0.27)	0.25 (0.13)
Daily Mean (SE) Weekends				
	Fathers	0.12 (0.08)	1.59 (0.47)	1.24 (0.25)
	Mothers	0.08 (0.08)	0.66 (0.32)	0.42 (0.26)
Average uninterrupted leisure > 30 mins when not responsible for a study child (hours)				
Daily Mean (SE) Complete Week				
	Fathers	0.31 (0.16)	0.91(0.12)	1.01 (0.24)
	Mothers	0.18 (0.07)	0.73 (0.28)	0.31 (0.10)
Daily Mean (SE) Weekdays				
	Fathers	0.39 (0.20)	0.58 (0.13)	0.92 (0.30)
	Mothers	0.22 (0.10)	0.76 (0.30)	0.26 (0.14)
Daily Mean (SE) Weekends				
	Fathers	0.12 (0.08)	1.73 (0.53)	1.24 (0.25)
	Mothers	0.08 (0.08)	0.66 (0.32)	0.42 (0.26)

fathers did. Looking at the average number of sleep interruptions throughout the whole week, mothers in the ASD and TD groups experienced significantly more interruptions in their sleep than mothers in the ND group with  $t(17) = 2.60$ ,  $P < 0.02$

for mothers in the ASD group and  $t(7.12) = 2.88$ ,  $P < 0.05$  for mothers in the TD group. Although fathers in the ASD and TD groups experienced more sleep interruptions than fathers in the ND group these differences did not reach significance. When father-mother pairs were compared, parents in the ASD group had significantly more interruptions than parents in the ND group ( $t(17) = 3.52$ ,  $P < 0.005$ ) but the difference in sleep interruptions did not quite reach significance ( $t(6.53) = 2.39$ ,  $P = 0.051$ ) for parents in the TD group.

When the average of the longest period of uninterrupted sleep experienced by parents each day is considered, mothers in the TD group had the shortest periods of uninterrupted sleep. Taking the average daily amount for the week as a whole, mothers in the TD group had a significantly shorter period of uninterrupted sleep than mothers in the ND group ( $t(16) = -3.69$ ,  $P < 0.005$ ). There was an almost significant difference between mothers in the ASD and ND groups ( $t(17) = -2.11$ ,  $P = 0.050$ ) and a significant difference between fathers in the ASD and ND groups ( $t(17) = -2.36$ ,  $P < 0.05$ ). Significant differences were also noted when father-mother pairs in the ASD and TD groups were compared with the ND group parents. Parents in the ASD group  $t(17) = -3.10$ ,  $P < 0.01$  and parents in the TD group  $t(16) = -2.92$ ,  $P < 0.02$ .

Moving on from sleep to look at leisure, the average longest period of uninterrupted leisure of greater than 30 minutes, when the parent was not in the presence of a young child for whom they had responsibility is shown in Table 4.10. As parents did not have any period of leisure meeting these definitions on many days of the week, the averages in some of the analyses come out as fewer than 30 minutes. Considering the week as a whole, fathers in the ASD group had less leisure time than fathers in the other groups and when compared to fathers in the ND group this was significant ( $t(14.42) = -2.92$ ,  $P < 0.02$ ). While no significant differences were noted during weekdays, at the weekends fathers in the ASD group had much less leisure time than the fathers in the other groups, and this was highly significant when compared to fathers in the ND group ( $t(12.03) = -4.21$ ,  $P < 0.002$ ). Although ASD mothers appeared to have less leisure time than ND group mothers this was not statistically significant. However, when father-mother pairs were analysed, parents in the ASD group experienced significantly less leisure than parents in the ND group ( $t(13.77) = -2.96$ ,  $P < 0.02$ ).

If the total amount of time spent in leisure for periods of at least 30 minutes were added together and then averaged to provide daily amounts, a similar pattern is seen as to that already described above. Fathers in the ASD group had less total leisure time than fathers in the other groups and when compared to ND group fathers this was significant ( $t(16.48) = -2.45, P < 0.05$ ). No significant differences were noted between groups during weekdays but at the weekends the difference between the ASD fathers and the other fathers was greater and this was highly significant when compared to fathers in the ND group ( $t(12.03) = -4.21, P < 0.002$ ). When father-mother pairs were looked at, parents in the ASD group had less total leisure time than parents in the ND group and this difference was statistically different ( $t(15.61) = -2.45, P < 0.05$ ).

#### **4.3.8 Summary of time use results**

Analysis of the time use diaries has revealed significant differences in the time use of parents with children with disabilities compared to parents of children without identified disabilities in a number of areas.

Fathers in the ASD group had the least amount of sleep on average, and had shorter periods of uninterrupted sleep and less leisure outside the home than fathers in the ND group. When father-mother pairs are considered, parents in the ASD group had less average total sleep, more interruptions in their sleep, shorter periods of uninterrupted sleep and less leisure outside the home than the ND group parents.

Again considering father-mother pairs, parents in the TD group worked significantly less hours in paid employment than parents in the ND group, despite fathers in the TD group working the longest hours of any of the groups. Mothers in the TD group spent the most time out of any of the groups, in non-work related travel and also spent the most time just with the study child and the least time alone. Mothers in the TD group had the shortest periods of uninterrupted sleep and were unable to catch up with sleep at the weekends. They experienced more sleep interruptions than mothers in the ND group and couples in the TD group had shorter periods of uninterrupted sleep than couples in the ND group.

Parents in the ND group spent more time going out together as a family than the parents in the TD and ASD groups. Where MTUS/UK couples data are available, there are similarities with the ND group data, and differences to the ASD and TD groups' data.

#### **4.4. PedsQL™ Family Impact Module Version 2.0 Survey Data**

The PedsQL™ Family Impact Module Version 2.0 Survey responses complete the quantitative data. All 56 parents completed the survey independently from their partners and there were no missing responses. Three combined scores are presented below in Table 4.11: Total Score (combined result from all questions); Parent Health Related Quality of Life Score (combined result from first six headings) and a Family Functioning Score (combined result from last two questions). Results from each of the sections individually are presented in Table 4.12 with the independent samples t-test results in Table 4.13.

Results were analysed using SPSS version 18. Some questions, particularly with regard to responses from the parents in the ND group, demonstrated a ceiling effect. This has been noted previously by Panepinto and colleagues (2009), but they also demonstrated that there were low floor effects and that the scale was reliable.

##### **4.4.1 Total Scores**

Fathers and mothers in the ASD and TD groups had very similar total scores which were significantly different from the total scores of the ND group parents. For mothers in the ASD group the results were  $t(18) = -6.34, P < 0.001$ , and for mothers in the TD group the results were  $t(17) = -6.10, P < 0.001$ . Analogous results for fathers in the ASD group were  $t(18) = -4.74, P < 0.001$  and for fathers in the TD group  $t(17) = -5.80, P < 0.001$ .

##### **4.4.2 Parent Health Related Quality of Life scores**

The impact of concerns about their child's health on their own well being was greater for parents in the ASD and TD groups and this difference was significant when tested against the fathers and mothers in the ND group. For mothers in the ASD group  $t(18) = -4.68, P < 0.001$ , and mothers in the TD group  $t(10.74) = -4.04, P < 0.005$ .

**Table 4.11 PedsQL combined scores**

		ASD	TD	ND
<u>Total Scores</u>				
Fathers	Mean (SE)	51.4 (5.1)	50.5 (3.5)	80.2 (3.6)
	Min, Median, Max	26.0, 47.2, 81.9	38.2, 51.0, 63.9	61.8, 84.7, 98.6
Mothers	Mean (SE)	41.8 (5.8)	41.1 (6.5)	82.5 (3.4)
	Min, Median, Max	18.8, 39.6, 70.1	14.6, 39.2, 66.0	62.5, 82.6, 98.6
<u>Parent HRQL Scores</u>				
Fathers	Mean (SE)	57.7 (5.1)	58.3 (4.0)	77.4 (5.4)
	Min, Median, Max	30.5, 56.2, 88.8	42.5, 61.9, 75	36.2, 81.2, 98.8
Mothers	Mean (SE)	42.9 (6.3)	41.9 (7.6)	76.7 (4.0)
	Min, Median, Max	16.2, 42.5, 76.2	10.0, 42.5, 71.2	55.0, 75.0, 97.5
<u>Family Functioning Scores</u>				
Fathers	Mean (SE)	40.6 (5.7)	47.6 (4.0)	85.2 (5.4)
	Min, Median, Max	18.8, 37.5, 71.8	28.1, 48.2, 59.4	46.9, 87.5, 100
Mothers	Mean (SE)	42.0 (7.8)	43.0 (5.3)	86.1 (5.4)
	Min, Median, Max	3.1, 46.9, 75.0	25.0, 40.6, 68.8	53.1, 93.8, 100

For fathers in the ASD group  $t(18) = -2.61$ ,  $P < 0.02$  and fathers in the TD group  $t(17) = -2.66$ ,  $P < 0.02$ . Mothers in general scored lower than fathers with this being more noticeable in the ASD and TD groups rather than the ND group. Of note was the wide range of scores in all the groups.

#### **4.4.3 Family Functioning scores**

Parents showed very close agreement with regard to the impact their child's health had on their family. Differences between parents in the ASD and TD groups tested against the ND group parents were again highly significant. For mothers in the ASD group  $t(18) = -4.77$ ,  $P < 0.000$ , and mothers in the TD group  $t(17) = -5.49$ ,  $P < 0.000$ . For fathers in the ASD group  $t(18) = -5.62$ ,  $P < 0.000$  and fathers in the TD group  $t(17) = -5.20$ ,  $P < 0.000$ .

#### **4.4.4 Individual section scores**

Parents produced a wide range of responses to the different questions, but the average results for each group showed close similarities between the ASD and TD groups and marked differences with the ND group. Mothers in the ASD group scored lower than



fathers in the ASD group in all responses other than family functioning. Mothers in the TD group scored lower than the fathers in the TD group other than in

**Table 4.12 PedsQL individual section scores**

		ASD	TD	ND
<u>Physical Functioning</u>				
Fathers				
	Mean (SE)	59.7 (4.8)	56.2 (5.4)	73.9 (5.6)
	Min, Median, Max	45.8, 58.3, 91.7	29.2, 62.5, 70.8	41.7, 75.0, 100
Mothers				
	Mean (SE)	44.0 (5.9)	38.6 (8.2)	74.2 (4.8)
	Min, Median, Max	25.0, 41.7, 70.7	4.2, 35.4, 66.7	54.2, 79.0, 100
<u>Emotional Functioning</u>				
Fathers				
	Mean (SE)	52.8 (5.1)	53.8 (4.8)	74.4 (5.9)
	Min, Median, Max	25.0, 55.0, 75.0	30.0, 55.0, 70.0	45.0, 75.0, 100
Mothers				
	Mean (SE)	39.4 (6.7)	40.6 (8.6)	75.9 (4.1)
	Min, Median, Max	0, 45.0, 60.0	5.0, 37.5, 80.0	50.0, 75.0, 100
<u>Social Functioning</u>				
Fathers				
	Mean (SE)	59.0 (8.8)	60.9 (5.6)	79.6 (7.2)
	Min, Median, Max	6.2, 62.5, 100	37.5, 59.4, 87.5	25.0, 87.5, 100
Mothers				
	Mean (SE)	40.3 (10.4)	39.1 (10.7)	84.7 (4.6)
	Min, Median, Max	0, 31.2, 100	0, 34.4, 87.5	56.2, 87.5, 100
<u>Cognitive Functioning</u>				
Fathers				
	Mean (SE)	59.1 (7.2)	63.1 (4.2)	82.7 (6.7)
	Min, Median, Max	35.0, 50.0, 100	50.0, 62.5, 80.0	30.0, 95.0, 100
Mothers				
	Mean (SE)	47.2 (7.8)	49.4 (9.4)	76.8 (4.8)
	Min, Median, Max	5.0, 50.0, 80.0	30.0, 35.0, 95.0	50.0, 75.0, 100
<u>Communication</u>				
Fathers				
	Mean (SE)	48.1 (7.2)	38.6 (7.9)	89.4 (3.9)
	Min, Median, Max	25.0, 41.7, 83.3	16.7, 33.3, 66.7	66.7, 91.7, 100
Mothers				
	Mean (SE)	43.5 (9.3)	45.8 (7.6)	94.7 (2.6)
	Min, Median, Max	8.3, 50.0, 83.3	25.0, 37.5, 83.3	75.0, 100, 100
<u>Worry</u>				
Fathers				
	Mean (SE)	45.6 (6.6)	30.6 (6.1)	87.7 (4.2)
	Min, Median, Max	20.0, 45.0, 75.0	0, 30.0, 55.0	60.0, 95.0, 100
Mothers				
	Mean (SE)	41.1 (6.4)	31.9 (7.8)	92.7 (2.1)
	Min, Median, Max	10.0, 40.0, 75.0	5.0, 27.5, 65.0	80.0, 90.0, 100

		ASD	TD	ND
<u>Daily activities</u>				
Fathers				
	Mean (SE)	29.6 (7.4)	37.5 (5.2)	84.0 (6.3)
	Min, Median, Max	0, 25.0, 66.7	8.3, 37.5, 58.3	41.7, 91.2, 100
Mothers				
	Mean (SE)	22.2 (6.1)	38.5 (7.9)	83.3 (7.4)
	Min, Median, Max	0, 16.7, 50.0	16.7, 25.0, 75.0	33.3, 100, 100
<u>Family Relationships</u>				
Fathers				
	Mean (SE)	47.2 (6.4)	53.8 (3.8)	85.9 (5.4)
	Min, Median, Max	20.0, 45.0, 85.0	40.0, 52.5, 70.0	45.0, 90.0, 100
Mothers				
	Mean (SE)	53.9 (9.4)	45.6 (5.0)	87.7 (4.6)
	Min, Median, Max	0, 60.0, 90.0	25.0, 42.5, 70.0	60.0, 95.0, 100

communication, worry and daily activities, although the scores for worry and daily activities were very similar. Mothers in the ND group scored higher than fathers in the ND group with the exception of the cognitive functioning and daily activities scores. Differences between parents in the ASD and TD groups tested against the parents in the ND group were significant in all sections, other than fathers in the ASD group with regard to physical functioning, and fathers in the ASD and TD groups with regard to social functioning (Table 4.13).

#### 4.5 Conclusion

Analyses of the time use data has revealed that there are significant differences in the ways parents with a disabled child spend their time as compared to a similar group of parents with children without disabilities. There are also possible differences in the ways parents with a child with complex health needs dependent on technology spend their time as compared to parents with a child on the autism spectrum and differences between mothers and fathers. Further insights into the reasons for these time use decisions are achieved by the analyses of the qualitative data which are presented in the next chapter.

While it is apparent that many parents of children with high level additional needs experience a related impact on their quality of life, this experience varies considerably between parents experiencing apparently similar challenges. Reasons for this are considered in the next chapter and explored in more detail in the following chapter.

**Table 4.13 Independent samples t-test results for the PedQL individual sections**

	ASD	TD
<u>Physical Functioning</u>		
Fathers	t (18) = -1.87, P = 0.078	t (17) = -2.19, P < 0.05
Mothers	t (18) = -4.04, P < 0.005	t (17) = -3.99, P < 0.005
<u>Emotional Functioning</u>		
Fathers	t (18) = -2.71, P < 0.05	t (17) = -2.58, P < 0.05
Mothers	t (18) = -4.79, P < 0.001	t (10.3) = -4.04, P < 0.005
<u>Social Functioning</u>		
Fathers	t (18) = -1.82, P = 0.085	t (17) = -1.92, P = 0.072
Mothers	t (11.04) = -3.90, P < 0.005	t (9.57) = -3.93, P < 0.005
<u>Cognitive Functioning</u>		
Fathers	t (18) = -2.40, P < 0.05	t (17) = -2.25, P < 0.05
Mothers	t (18) = -3.36, P < 0.005	t (10.61) = -2.61, P < 0.05
<u>Communication</u>		
Fathers	t (12.54) = -5.04, P < 0.001	t (10.43) = -5.79, P < 0.001
Mothers	t (9.24) = -5.31, P < 0.001	t (8.65) = -6.12, P < 0.001
<u>Worry</u>		
Fathers	t (18) = -5.61, P < 0.001	t (17) = -8.02, P < 0.001
Mothers	t (9.64) = -7.63, P < 0.001	t (7.99) = -7.55, P < 0.001
<u>Daily activities</u>		
Fathers	t (18) = -5.65, P < 0.001	t (17) = -5.38, P < 0.001
Mothers	t (18) = -6.21, P < 0.001	t (17) = -4.09, P < 0.002
<u>Family Relationships</u>		
Fathers	t (18) = -4.66, P < 0.001	t (18) = -4.52, P < 0.001
Mothers	t (11.70) = -3.22, P < 0.01	t (18) = -6.11, P < 0.001

## CHAPTER 5 PARENTS' REFLECTIONS AND INTEGRATION OF THE QUANTITATIVE AND QUALITATIVE DATA

*"I considered using the image of a jigsaw puzzle but that isn't right. The pieces don't fit together snugly. No life with Tom is more like a mosaic. Incidents. Memories. Fears. Celebrations. Successes. Pains. Questions. No one part shows it all but if the viewer takes a step back, a picture begins to emerge."*

Bill Dodds (1995) A Mosaic. In Meyer D.J (Ed) *Uncommon Fathers* (pg159)

### 5.1 Introduction

The data from the time use diaries and surveys presented in the previous chapter provide some insights into how families with a young child with a disability are spending their time and some suggestions of what daily life is like. This chapter further explores these issues using data from the 34 semi-structured interviews. The interviews were undertaken with all the fathers in the ASD and TD groups who fully completed their time use diaries (15 out of 17) and all of the mothers in these two groups, including the two mothers who did not fully complete their diaries. In addition, one father and one mother (from the same father-mother pair) from the comparison group were interviewed. All names have been changed, and professionals are referred to by their roles rather than names, with identifying place names also omitted in order to preserve anonymity. Due to the rarity of some of the children's diagnoses, and potentially identifying features of particular families' characteristics and ethnicity, specific details are not provided. Unless otherwise specified the use of the term parents in this chapter relates to the parents in this study with children with disabilities.

As described in the Methodology chapter, following careful transcription, the interviews were subjected to detailed manual coding using Atlas-ti software to facilitate the process. Using thematic analysis techniques the codes were then organised into groups, and from these groups themes emerged. The major themes were: 'feeling trapped at home'; 'twenty-four seven caring'; 'trying to achieve a balance'; 'discovering a whole new world'; and 'evolving roles.' While data from the interviews enabled issues from the time use diaries and surveys to be further explored and interpreted, parents' comments and interpretations of their own experiences led to further analysis of the time use diaries. This triangulation of the data from the diaries,

the interviews and the spouse records along with using a constant comparative approach to the identified themes provides reliability, richness and context to the data. The relationships between the different data sources are illustrated in Table 5.1.

Further in-depth consideration of the data findings, following merging of the different data sets, resulted in 'trust' emerging as an overarching theme providing a framework for understanding time use decisions and subjective interpretations of experiences and situations. While trust does not explain every aspect of the different sub-themes, it provides a foundation for subsequent analysis of the differing experiences of parents and a structure on which to consider possible strategies to improve these experiences. As trust being a unifying concept had not been anticipated prior to detailed data analyses, consideration of trust and further data analysis ensued. These findings are presented in the following chapter.

Prior to discussing the five main themes, an overview of the daily experiences and activities of the families with children with additional needs is presented, as this provides a context or background for the following themes. Direct quotes from the parents are used extensively as these powerfully express parents' reality but to prevent this chapter from being too extensive, quotes have been abbreviated. To indicate this the annotation (...) is used. In addition, repeated words and partial words, or phrases that are commonly used in conversational speech but do not provide further meaning are omitted.

## **5.2 Daily Lives**

Having a child with autism or complex health needs dependent on technology has an impact on many aspects of family life. Parents with a child with a disability frequently referred to family life being more restricted or stressful than prior to having their child with additional needs with 20 out of the 32 parents making some reference to this. Some activities that would be enjoyable for other family members were challenging for the child with additional needs either due to fragile health, large amounts of equipment or difficulty coping in new or busy environments.

**Table 5.1 Comparison of Qualitative and Quantitative Information**

		QUALITATIVE	QUANTITATIVE	
Unifying concept	Major Themes	Semi-structured Interviews	Time use Diaries	PedsQL Survey
Trust	Feeling trapped at home	Safety Support Planning and mental effort Society and environment Equipment Social contact The future	Time at home or elsewhere	Social functioning Worry Daily activities
	Twenty-four/seven caring	Sleep Feeling tired	Time asleep Longest period of uninterrupted sleep Number of sleep interruptions Quality leisure time	Physical functioning Emotional functioning
	Trying to achieve a balance	Work in order to meet financial responsibilities Appointments	Time at work and work travel	Parent HRQL Communication Cognitive functioning
	Discovering a whole new world	Different worlds Parents' changed by child Positive aspects Negative aspects Changed directions	No single time use correlate	Total Score
	Evolving Roles	Parental roles Mothers' roles Fathers' roles Partner support Acceptance of difference Mutual appreciation Communication	Time responsible for study child	Family relationships Family functioning

This meant that certain activities were not even attempted. As Stuart (ASD) put it

*“I suppose the autism does prevent you from doing some things I think if you're really honest about it. Because there are things that you would normally do with a three year old that you can't do with a three year old who has got autism. Because he just, he wouldn't sit and watch a film at the cinema as simple as that.”*

Other activities were arranged when they could be achieved such as when other people were not around as Emma (ASD) describes

*“If we want family time at the park, we can't go when all the other families are there, we have to go at eight o'clock in the morning when Ria's not in danger. When no-one else is on the swings that she can run into. So one of us is always watching her, while the other one's watching the other one...”*

Alternatively, activities were still participated in but required much more effort to achieve and sometimes left parents wondering if the effort had been worthwhile.

Parents in the TD group had to regularly undertake tasks not usually associated with parenthood. Some of these required specific training to be performed and sometimes this training had only been given to the mother, such as using a central venous access device or ventilator. Feelings about having to perform these tasks were mixed, particularly if they were associated with pain or discomfort for the child and often took up considerable parts of the day. Most parents in both groups also had additional therapy tasks they were expected to fit into their day. Some of these tasks were viewed positively particularly if direct benefits were easy to see as Sally (TD) felt with regards to doing physiotherapy *“I like to do that because I know we're getting somewhere with it”*. Other tasks such as incorporating the PECS (picture exchange communication system) cards into the day along with all the other things that had to be remembered and achieved while initially *“quite daunting”*, over time just became part of life with *“everything's in a book now, an easy file and we just take it with us everywhere we go”* (Marion (ASD)).

However some parents felt that these tasks affected their whole relationship with their child with parents of children on the autism spectrum more commonly referring to the pressures to perform a teaching role and parents of the children with technology needs highlighting the medical care demands. Emma (ASD) who had an older son Seth, and

then Ria with autism highlighted the different experiences in parenting her two children

*“It is being a teacher to her, because I never sat with Seth when he was her age for a couple of hours each day going mummy or just getting to say simple words, or doing the PECS (...) what I do with Ria I don't think's fun. Because I'm constantly trying to teach her to do something, whereas with Seth it would be, you get your trains out or you get your bean bags out (...) it is a teacher role rather than a fun mum role. You know it's not... it's not playing muddy monsters and things like that, it's a teaching role’*

Naomi (TD) on the other hand summed it up by saying *“I only wanted to be a mum I didn't really want to be a nurse and doing eyes and you know all that sort of thing”*.

Nevertheless many of the parents in both the TD and the ASD groups also highlighted the positive aspects to having a child with significant additional needs and the positive impact their child had had on them as a person as well as their family and were keen to ensure that I was aware that *“it really isn't doom and gloom, there's masses and masses of positivity to be had”* (Tessa (TD)).

Twenty-two out of the 32 parents of a child with additional needs and both comparison parents were surprised by some aspect of their time use as highlighted by completing the time use diaries. One of the issues highlighted was a greater appreciation of their partner's role. For example Stuart (ASD) was now more conscious of not just how much his wife Becky was doing but also how he used work as an excuse not to do more at home himself

*“Because I'm working and I get quite stressed with my work if the kids wake up in the night it does tend to be Becky most of the time who will go and see to them. And it does tend to be Becky that you know does most of the cooking and cleaning because I tend to use work as an excuse. Yeah and that did hit me a little bit actually when I started filling it in.”*

The diaries also highlighted the intensity of activities for many parents who had become acclimatised to the constant demands throughout the day and night

*“I didn't realise how constant it really was and I've sort of got used to the nights and I don't really take any notice of times any more and it all sort of rolls into one whereas it was making me realise again how much I do actually get up”*(Tessa (TD)).



Mothers in particular found the diaries drew to their attention their constant caring responsibilities as Sally (TD) reflected “*everything I do he’s with me (...) every single thing I do, he’s there*”. Many parents became more aware that their lives were completely taken up with their child with additional needs who “*tends to be the focus of everything even when she’s gone to bed*” (Patience (ASD)).

It should not to be overlooked that comparison families also experienced challenges with family life and getting everything done in a day but there were some notable differences. While only one of the comparison group mothers was interviewed, Michelle in common with all but one of the other comparison group mothers worked outside the home. Again like several of the other families in the comparison group she had close family nearby who frequently helped out with childcare. This meant that Michelle’s experience of completing the diaries was in contrast to most of the mothers in the ASD and TD groups but is likely to be similar to some of the other comparison group parents. Michelle found the diaries highlighted how much time she spent away from her children

*“it’s how I thought it was but it still surprised me because I just do things and don’t think about it and then after going through it realising how much time I hadn’t spent with the children over the last few weeks”*

This broad overview of the families’ daily lives has alluded to some of the themes which will now be explored in more detail.

### **5.3 Feeling Trapped at Home**

Many parents, predominantly but not exclusively mothers, referred to feelings of being ‘trapped at home’, ‘a prisoner in their own home’ or in ‘solitary confinement’. Data from the time use diaries, as presented in the previous chapter, reveals that fathers and mothers in the TD and ASD groups do spend more time at home than the comparison fathers and mothers and this was statistically significant for mothers in the TD group and approaching significance for the fathers in the ASD group. However it was not just absolute amounts of time at home that were associated with the feelings of being trapped. A number of other key issues were highlighted including concerns about their child’s safety, a lack of support, the planning and mental effort involved in leaving the house, the perceived stigma associated with

having a disabled child and the barriers presented by the physical environment, the physical challenge associated with the amount of equipment always required, a loss of previous social contacts and a perception of the situation not changing in the future.

Many of these issues were related to lack of trust. Trust in this context does not just refer to one relationship or one situation but rather to many relationships and many situations that parents with a disabled child engage in. Lack of trust in other people and incidences of broken trust were regular threads weaving both subtly and explicitly through parents' accounts of their lives.

### **5.3.1 Safety**

Parents had concerns about their child's safety while they were out or when they were in the care of other people. This restricted when or where they would go, or whether they would allow their child to participate in activities without their close proximity. This was usually due to parents not trusting other people to look after their child appropriately and many parents echoed Stuart's (ASD) view that "*nobody watches him, in my opinion, as well as I do*".

The fact that their child had very limited verbal abilities added to the concerns and lack of trust parents had in carers other than themselves. The parent's intimate knowledge of their child enabled them to tune into non verbal communication so that they were able to understand what their child wanted, pick up on when things were not quite right, enabling prompt medical intervention, and anticipate and avoid problems before they occurred.

For parents in the TD group, many of their child's technology needs required specific training to manage and therefore it was not safe to leave their child in the care of others unless they had had specific training which was rare. For one family who were supplied with a trained carer at times, the mother was still expected to be within the home while the carer was there in case an emergency situation arose that the trained carer was unable to deal with on her own.

Unfortunately parents had had experiences where their trust in other people to care for their child appropriately had not been fulfilled. These incidences of broken trust made

it much harder for parents to trust other people to care for their child again. For instance when the nursery teacher “*stood there with the door wide open and watched Sky just run straight past her, didn’t stop her*” only the fact that the nursery had a long path before reaching a busy main road meant that Sky was able to be caught before a serious accident was likely to have happened. Not surprisingly, Sky’s parents were unable to trust that Sky was safe at that nursery anymore and removed her from it, meaning she was at home in their care twenty four hours a day, seven days a week. However, not all parents were confident to manage their child safely on their own particularly if they had other young children to keep a watch on. For instance Becky (ASD) commented

*“I’m a bit wary of going out on my own, sort of outside on my own if you like with Corey because I could be distracted by April and he could be off so I won’t actually go out on my own with them both, other than places that are enclosed to be quite honest, you know, because I’d be frightened to death of something happening”*

Therefore, there was evidence that parent’s time use decisions were also affected by their trust in their own abilities to keep their child safe.

### **5.3.2 Support**

The amount of support available to families was also important as to whether they were happy with the amount of time they were spending at home and how they perceived the quality of the time at home. Trust was found to be a fundamental issue in how well services worked with families. Where parents felt that professionals had trusted their judgements and listened and acted on their concerns, they both felt more supported and also had increased trust in that service and those professionals.

Unfortunately, a frequently repeated experience by families was that support from services was not there when they needed it, or was not the type of support requested. This was most commonly the case with regard to support from Social Care Services. Parents also repeatedly expressed how hard it was to ask for support which made it all the more upsetting when it was refused. Parents were then made to feel inadequate that they had made the request for support.

Despite Tessa (TD) having been assessed by a social worker at a time when she “*was very depressed and hadn’t had a diagnosis (for child), had a very poorly mum, had*

*nowhere to live, sold our house, living with the in-laws*”, no offer of support was forthcoming. However, Tessa *“didn’t have it in me to chase them and I just kept trying to tumble on”* and was only able to chase things up when she started to feel better. This was in common with Sophie (TD) who was *“disappointed”* that it took so long to get help despite having *“hit rock bottom”* and that she had *“sort of come out the other side”* before receiving any help. Ironically both these mothers felt that it was only as they were coping better and had the strength to fight that support was finally provided.

Another common experience was for parents to be told that their child *“wasn’t that different from a normal 2 year old”* or that their child *“seems to be cared for”* and so they were not entitled to any help. Rather than services trusting that parents’ requests for help were based on genuine need, criteria were often rigid, concerned with child protection issues and seemed to be trying to find ways of why they did not need to be involved. This also led to parents doubting themselves and their trust in their own judgement *“thinking well is it me, you know do I need any help”* (Tessa (TD)). However, it was not only Social Care Services who were criticised for their lack of support. Many children did not appear to fulfil different services’ criteria for support, either being too complex such as being on a ventilator, too young, living in the wrong catchment area, or having needs that were neither classified as ‘health’ nor ‘social care’.

Not all parents’ experiences of support were negative and some parents felt the support they had received had been timely, excellent and met their needs very well. Others acknowledged that the delay in obtaining support had been their own lack of readiness to receive it and lack of trust in others to give it but when they had taken the plunge the support had been very valuable, while others were still at the stage where they were unwilling to accept support from others.

Parents described various stages in the acceptance of support from others. This was largely built on establishing trust. People who spent time getting to know the child, listening to parents’ views and adopting their ways of doing things were particularly likely to establish trust. This time element, as well as consistency of personnel, was also important in building up trust with service providers. In addition, people with

good communication skills, who kept parents informed about what was happening including requesting their help and opinions when required were valued, as Marion (ASD) describes “*But it’s just that personal touch and I think, you speak to somebody who does understand and it just brightens your day just a little bit*”. However, a further important element in accepting support was the child’s ability to trust others. Parents noted that their child responded in different ways with different people. Therefore, the child’s trust relationships influenced how easy or possible it was to involve other people in their care.

For most parents accepting support also involved coming to terms with their situation and the need for support. Trusting in others and relinquishing some of the control they had over their child and their family was very hard for many parents. In addition, the implications of some of the support providers, such as hospices, required time to adjust too. Some parents, particularly those with children with complex technology needs, felt that they were given enormous responsibility to deliver the care of their child but then were not trusted to make what they considered were simple decisions with regard to their child’s management or day to day living. This lack of trust between professionals and parents, had led to concerns by the professionals on occasion around child protection when what was needed was better communication, trust and understanding between all parties.

Support was not only available from services but also from the wider family, friends and neighbours. It was this type of support that seemed to make the most difference to whether parents felt trapped or not. All parents were asked as part of the general information about the family whether they received support from other family members, friends and neighbours. This type of support was more readily available to families with children without additional needs, but some of the families in the ASD and TD groups did receive extensive support from families and friends also. The proximity of the wider family and their health and attitudes affected the degree to which parents could rely on their family and trust in them for support. Family’s trust and confidence in parents’ abilities and decisions was very important in how supported parents felt. The wider family’s trust in service providers and society as a whole also had an influence on parents’ views.

However, some of the parents of children with additional needs found the support from other parents in a similar situation particularly valuable, and this was often emotional rather than practical support. This was particularly though not exclusively the case for mothers. While many parents found it difficult to go out of the home with their disabled child for the many reasons described in section 5.3.4, when with other parents in a similar situation Tessa (TD) describes “*we take them out because we are a team and we support each other*”. This also meant that events that would be regarded as potentially stigmatising were now normal for their group and “*if one has a fit or one needs to go on the pump you just don’t feel isolated you feel like everyone can stare because you have got back up*”.

### **5.3.3 Planning and mental effort**

Some parents felt trapped at home due to the amount of planning and mental effort required in order to go out and sometimes the predicted difficulties appeared overwhelming. This meant that “*sometimes it actually puts you off going anywhere, because you just think it’s too much hard work you know, it’s just easier to stay in*” (Sophie (TD)). Even though “*you’d love to be able to do more things but it is very difficult*” so that “*a lot of time you do get to the point where it takes you that long, you think is it worth it and you do something else instead*” (Tim (TD)).

While for parents with a technology dependent child much of the planning involved anticipating medical needs such as ensuring sufficient oxygen was available “*he had one tank on, I had one tank under the pram, two tanks in the car just in case something went wrong*” (Sally (TD)) and frequent interruptions to perform medical procedures such as suction, for parents with a child on the autism spectrum the mental planning was more in anticipation of their child’s behaviour and response to their environment. This meant that Emma’s (ASD) comment “*every time I leave the house (...) I mentally prepare myself for what’s going to happen*” was typical.

Some parents found the amount of planning and lack of spontaneity in their lives difficult. Patience (ASD) describes the restriction this places on family life and highlights again the challenges experienced in going out of the more controlled and familiar environment of the home, resulting in feelings of frustration and resignation

*“We can't do anything just off the cuff. We can't just make a decision and do it. It's got to be planned and organised and Pandora has got to be the first for how is she going to react to the situation. Is she going to be alright. I mean the amount of time we have gone places and had to come home because she's just traumatised by it. There's too much noise, too many people so it's just ... and then you get to the point where you think, well why bother. If we've just got to go all that way to come all the way back again and not do anything”*

The unpredictability of their child's medical or environmental needs meant that many parents felt unable to trust their child to cope in situations outside the home, or to trust themselves to cope with anticipated and unanticipated circumstances. This lack of trust in their child's ability to cope was not unfounded but usually based on previous negative experiences. Parents' trust in their child had many different facets and was coloured by previous experiences. For some, their trust in their child had already been undermined by the child not fulfilling prior expectations such as by being born too early, having a chromosome disorder or not following the expected developmental trajectory. For some parents there was the difficulty trusting their child to continue breathing, play safely or to be able to let their parents know if they needed help.

Therefore, the amount of additional effort required to try and achieve a successful outing were weighed up against the perceived benefits and additional risks, as well as considered against previous experiences. On occasions parents reached the conclusion that the benefits of going out did not outweigh the benefits of staying in.

#### **5.3.4 Society and the environment**

The attitudes and comments from strangers affected parents' willingness to go out into the world. Sometimes it was felt the strangers were just showing a natural curiosity or were trying to be friendly but in a clumsy or intrusive manner. Comments like “*what's wrong with your baby*”, “*isn't he small, he's like a little doll*” or “*why doesn't he speak*” were common but parents often found them “*shocking*” and unwelcome and expressed a lot of uncertainty as to the best way to deal with them. Other times people appeared more openly hostile, staring and rude particularly in response to children with autism saying things like “*in my day he'd have been in a borstal*” or “*shut up you noisy beggar*”. Understandably parents found these comments very hurtful and varied in their responses from trying to explain that their

child had additional needs, to being openly aggressive in return or most commonly trying to avoid such situations altogether. Such experiences reduced parents' trust of strangers and how strangers would respond to their family in the future as well as reducing their trust in society in general. Many of the parents expressed the view that their child was not wanted, valued or appreciated by society and Geoff (ASD) commented "*surely the last thing we want to do is hide from society but it's very difficult when society rejects you*".

Reactions from strangers also contributed to parents' worry about the future. Many parents commented that while their child was still very young they felt that strangers were possibly more tolerant, but as their child grew up their differences may become more marked and would lead to greater hostility and rejection from the general public. However, some parents found UK society much more accepting than other countries where they had lived and therefore held more optimistic, trusting and positive views about how society would respond to their family.

The environment outside of their own home was also often challenging for a variety of reasons in contrast to the home environment which parents had been able to adapt and modify to meet their child's needs. For instance Geoff (ASD) highlights some of the particular challenges when shopping "*there's not enough room (...) everything's brightly coloured they want to grab it (...) lights everywhere (...) it's all engineered against them*".

Changing facilities are generally only suitable for babies and Tessa (TD) described how her daughter is now "*too heavy*" and "*nearly pulled the one off the wall at McDonalds*" which makes going out "*really, really hard*". Even obtaining hot water to prepare feeds or flush a line was often difficult. This was the case if requested from cafes on the high street or cafes within hospitals and it was not unusual to be charged which Sally (TD) found infuriating as "*they charge you more than they do for a cup of tea*" making her feel "*you're ripping me off, and I've got no choice*". Therefore, many parents were unable to trust that the environment would be suitable to meet their child's needs or that society would be welcoming and accepting of all members of the family.



### **5.3.5 Equipment**

Children with complex needs dependent on technology often have large amounts of equipment that needs to be transported with them wherever they go. The equipment includes things such as feeding pumps, feed bags, oxygen cylinders, suction machines, ventilators, special seating systems, buggies/wheelchairs, spare feeding or breathing tubes, emergency bags, syringes, and changing bags. The transportation of all the equipment requires physical effort, planning and a car for anything other than very short trips, as public transport is not usually a realistic option. Therefore for families without a car or only one car going out was restricted. Even for those with a car it could be challenging and exhausting and there was also the issue of parking with sufficient space in a safe place to unload everything in close proximity to the desired destination. George (TD) described the typical situation when his wife took his daughter out

*“basically the car is jam packed. It’s a people carrier but there’s only 4 seats in it because she has all the rest of the room....(...) Ventilator, suction machines, chairs, feeding pumps, everything. Whatever she can cram in the car, has to be crammed in the car. Trachy bag, emergency bag, oxygen bottles there’s all sorts of stuff”*

There was the feeling that this was a recurring battle and indeed parents in both the TD and ASD groups used the phrases ‘*it’s a military manoeuvre*’ and ‘*a military operation*’ that conjured up this imagery. While the equipment was often different for the children with autism many still required a large number of different items to manage and anticipate the different situations that might be encountered out of the home. For instance particular foods were required as the children could or would not eat standard foods that would be easily available and many parents took snacks, favourite toys, items used for distraction, changing bags, specific drinking cups, special buggies and so on with them.

### **5.3.6 Social contact**

Another common finding with the parents who reported feelings consistent with being trapped at home was reduced social contact and there was evidence of this from the time use diaries. Only one of the mothers in the TD group worked outside the home and this was for one day, some weeks. Five out of nine of the mothers in the ASD group worked outside the home and 10 out of the 11 mothers in the comparison

group. All the fathers except one in each of the TD and ASD groups worked outside the home. The majority of all the parents had worked prior to having the child with additional needs.

Mothers in particular referred to feelings of “*isolation*” and losing contact with friends and for Fiona (TD) who had previously worked fulltime and had no family living nearby this was “*the biggest thing for me*”.

In addition concerns about how their child would behave with their friends restricted social contact with Serena (ASD) highlighting that she was unable to visit her friends as “*he will trash people’s houses*” and that even within her own home she was aware her friends were “*worried how Ben is, because he can be a force to reckon with*”.

### **5.3.7 The future**

Parents’ perception of whether their current situation was a temporary one, or one that was at least going to improve over time or not also affected parents’ feelings of being trapped. The thought that this demanding and exhausting period of their life “*doesn’t end*” was regarded as “*the hard part and that is the frightening part as well*” (Serena (ASD)) by parents. Parents who anticipated changes in the future, either due to the completion of a particular course of treatment or perceived improvements in their child’s condition over time were less likely to report feelings of being trapped.

### **5.4. Twenty-four/seven Caring**

Another notable difference highlighted by the time use diaries was the intensity of activities for parents’ with a child with additional needs, with reduced opportunities for ‘down time’ or to recharge either through leisure activities or sleep, particularly quality uninterrupted sleep. These issues were also frequently referred to in the interviews. The lack of opportunity to have mental as well as physical breaks had an impact on parents’ health and well-being and was noted to be a cause of friction and tension between partners. Parents had few people they could rely on to provide any opportunities for respite, partly due to the particular additional needs of their child and partly as parents did not trust other people to look after their child at all or for more than very brief periods. In particular, most parents found the concept of overnight care for their young, non verbal child unacceptable even though they were having

insufficient sleep due to their caring commitments. While most parents trusted each other to care for the disabled child appropriately, in some cases this was not the case, which contributed to these parents feeling a continual burden to be available twenty four hours a day, seven days a week to ensure optimised care.

While sleep and feeling tired are very similar concepts they are discussed separately as some parents felt that while their sleep was adequate they still frequently felt tired and other parents who had short amounts of sleep felt they were able to manage on this amount although acknowledging it may not be good for them. Therefore, sleep and feeling tired while closely related were not interchangeable. Finally in this section the concept of intensity, which incorporates the consideration of leisure opportunities as well as sleep as a way of mental and physical restoration, is discussed.

#### **5.4.1 Sleep**

Sleep was a huge issue for parents with nearly all parents of a child with additional needs reporting that they did not get enough sleep. For the three or four parents who did feel they had enough sleep, they still tended to feel tired for much of the time. Reasons for the lack of sleep for mothers were predominantly due to the child with additional needs. Some of these issues were practical ones, in that some form of physical intervention was required during the night. However, another element was trust with mothers unable to trust that their child would be safe overnight. This meant that it was harder for mothers to fall asleep and they often slept very lightly ready to respond to any need immediately. Some mothers described feeling as though they were ‘on call’. Although some fathers also reported these issues, long working hours and unsociable shifts also had an important impact on fathers’ sleep. Therefore it was not just the quantity but also the quality of parents’ sleep that was an issue. Many parents who had previously slept very soundly now found that even the slightest noise would arouse them. Some parents, particularly those with children with technology needs, had the child sleeping in the same bedroom as them. While this provided some comfort and reassurance that if they were needed they were instantly available, it also meant that they were frequently disturbed even when the child did not need direct attention. Parents reported being “*tuned into*” their child so that they never seemed to be deeply asleep and would be awake as soon as there was the suggestion that their child might need them.

Although some fathers in the TD group would get up at night at times, most of the care at night was provided by mothers. In some cases this was because the mother had the particular skills or training to deal with the situation while for other mothers this was a conscious effort to ensure that fathers were fit and safe for work and travel and fathers were aware of this. Sally (TD) shares

*“especially in the winter when he’s awake for all those hours in the night, then he gets up and it’s dark and he goes to work, driving down a motorway in the horrible weather, then he comes home and it’s dark and he’ll say, ‘when we go to bed, you better sleep through tonight you or I’m gonna do you in’ and this kind of thing, and I think, he’s only joking but I think really he must think, god I’m absolutely shattered I wish he’d just go to sleep type of thing”*

Parents tried different strategies to deal with the sleep disturbances such as sleeping in separate bedrooms but fathers were still often disturbed or found it difficult sleeping away from their partners. For one family, who had paid carers providing care for some nights, the other nights the mother would have to be up all night providing the care. She would then have to continue to provide all the care the following day as well. If for some reason a carer was unable to attend then the mother would have to do that night shift as well, and this happened not infrequently. Even when the paid carer was there they would sometimes require support or advice from the mother and so her sleep was still disturbed. Although this did not directly involve the father he was also disturbed as *“you obviously stay awake till I get told what’s going on, but there’s no point in me running down the stairs with her and everyone filling the room in”* (George (TD)).

In contrast three out of the nine fathers in the ASD group played an equal role looking after the child at night, with one of the fathers always looking after the child at night. This latter father had taken to sleeping in his child’s doorway *“my head up against the door”* so that if she woke in the night, which she frequently did, he would be woken before she left her room and either made a mess downstairs, placed herself in danger or tried to get out of the house. This father appeared to get very little unbroken sleep and described this lack of sleep as his least favourite activity in the week and the fact that it was *“day after day”* was *“like you’re in a concentration camp or something”* (Geoff (ASD)).

Five other parents also described the lack of sleep or getting up at night as being what they liked least about their week, two of them mothers in the TD group, one father from the TD group and two fathers from the ASD group.

#### **5.4.2 Feeling tired**

Not surprisingly many parents referred to feeling tired much or all of the time and not having the energy to participate in some activities even when the opportunity arose. The tiredness was not just associated with lack of sleep or poor quality of sleep but also the full on nature of the activities during the day with little opportunity to stop and rest or have a relief from the constant hyper-vigilance associated with caring for their child as will be described in more detail in the next section. The tiredness was not just physical but also mental. Many parents described the mental pressure of feeling that there was never the opportunity to truly have a break and to be able to let go of the constant responsibility of looking after the study child as there was no-one to trust to take over this responsibility fully.

Due to tiredness, often at times bordering on exhaustion, activities took much longer to achieve. Opportunities to get things done were grasped in child free moments such as before picking a child up from nursery or once the child was in bed although Garth (ASD) who worked shifts often starting in the middle of the night commented “*you know I'm drained by then, my body has started to shut down if you like. It's just tiredness I guess. But I do try to do as much as I can, when I can*”.

About a third of the parents said that if they had the chance to have a child free evening they would use it to catch up on sleep rather than going out. This was often the result of experience as Ronnie (TD) suggested “*you're not getting a rest and you're twice as worse the next day*”. Tom (ASD) almost with a touch of embarrassment described the typical course of a very rare child free evening

*“invariably when that does happen, and this is really sad, we don't go out, we actually tend to stay in and relax and probably just have something to eat [laughs], and this is the pitiful bit, nine o'clock let's go to bed, we can have an undisturbed night's sleep and you know, that's it”*

Tiredness also affected parents' moods with parents finding they were more irritable, short-tempered and less likely to get on with their partner or other family members

when they were tired. Tiredness also made the whole situation of having a child with additional needs more difficult to cope with and that it contributed to low moods, feeling “*an emotional wreck*” and unable to cope.

### **5.4.3 Intensity**

Intensity relates to the amount of activities that need to be achieved, often simultaneously, the lack of opportunity for a break or to be able to relax and encompasses mental as well as physical aspects. Although parents were not asked to comment on the intensity of their activities directly, intensity was assessed from the time use diaries by looking at the opportunities for uninterrupted leisure time, the number of recorded interruptions of sleep and the longest periods of uninterrupted sleep. As has been documented in the previous chapter, mothers in the TD group and fathers in the ASD groups appeared to have the fewest opportunities to recharge. Fathers and mothers in both the ASD and TD groups had less uninterrupted sleep than comparison parents and this was statistically significant for all but the fathers in the TD group. Fathers in the ASD group also had significantly less uninterrupted child free leisure time and less total child free leisure time than comparison fathers.

Parents frequently made references to the intensity of their lives in the interviews. Not only were there references to never having a break, never stopping, and the need to supervise and care for their child 24 hours a day, seven days a week, there was also the constant pressure to plan which Fiona (TD) felt was “*more tiring than anything else*”, and to anticipate and to make the most of opportunities. Rose (TD) commented “*I feel I’ve got to do so much with her so that when she is five or six I can say, well I’ve done everything*”.

The pressure to anticipate potential problems and intervene before they happened meant that some parents felt that they had to be constantly vigilant, sometimes even when they were not physically present with the feeling “*you don’t ever switch off*” (Tom (ASD)). For some children it was important to be close by at all times as things could happen so quickly. With children on the autism spectrum this was most often running off, climbing onto things or other potentially dangerous activities. Although some of the children with technology dependence also demonstrated this lack of awareness of danger and had the abilities to place themselves in similar situations,

more often the concern was with regard to becoming entangled in tubes, disconnected from important pieces of equipment or requiring immediate medical assistance in some way.

These concerns meant that many parents found it difficult to switch off and relax, even if they did have the opportunity to take a break. This was partly due to the fact that parents often did not completely trust the person looking after their child and also the frequent experience of being contacted to come home when the person caring for the child could not cope so that *“you’re always thinking, they could ring (...) you’ve always got to be semi prepared, so you can’t ever relax”* (George (TD)). Malcolm (ASD) had recognised the fragmented nature of his breaks from caring for his son commenting on spending time with his partner *“it’s not the time we get together, it’s sort of unbroken time together, time without having to come back to Nev, which is rare, you know, I think we’ve done twice this year without having to come back to Nev all the time.”*

However, some parents did find they were able to switch off and relax when they left their child in the care of others. This was most commonly in the care of their partner, but there were sometimes others who, over time had built up expertise and parents felt could be trusted to the extent that they were able to relax when the child was in their care. Again this was commonly a family member such as a grandparent or sister, but also occasionally a hospice, or a support worker at nursery.

While some couples felt they had enough time together at home, other couples felt even at home they did not spend any quality time together. What nearly all the parents agreed on was that they did not have enough opportunities to go out together as a couple.

With regard to time by themselves or opportunities to participate in leisure outside the home parents’ experiences were very different. Some parents prioritised having opportunities to participate in exercise each week and each parent had their protected time to do this. Other parents would have regular times to meet friends or family, or a weekly bingo night. However there was never any spontaneity to these events which

were always carefully arranged and negotiated in advance. Despite this some parents still felt guilty at this time for themselves. Two of the mothers felt that time for themselves was a waste of time and was better used achieving lots of the things they needed to get done and other parents felt that they just never had the opportunity for anytime to themselves.

Holidays are usually another time for people to relax and recharge. Although some families had found holidays enjoyable other families had not. Hilary (ASD)

*“we try to do holidays but it doesn’t really work, he doesn’t, Zac doesn’t feel happy I suppose in it being such a change and such a different thing to do. Like the whole point of being on holiday is just to go and do what you want, when you want and not having to think about things or but it’s no good really. We went to Tenerife and all he wanted to do was stay inside and watch CITV cos he knew what was coming on”*

Other families had hardly any holiday time available as they had had to use it to attend appointments, or to be available when the child was unwell.

### **5.5 Trying to Achieve a Balance**

It is generally estimated that it costs three times as much to bring up a child with a disability compared to average child rearing costs. In addition many families go from dual earner families to single earner families due to the additional care needs of their child and the difficulty in finding appropriate, affordable childcare. Therefore it was not unexpected that financial issues were frequently raised by parents during the interviews. Issues highlighted included the need to work to meet financial responsibilities but also the need to achieve a balance with child care responsibilities and family life. This had an influence on both fathers’ and mothers’ career choices and working patterns.

It was particularly noticeable that parents did not feel that they were able to go to work and trust that everything would be fine at home. Rather fathers ensured that their jobs allowed them to be accessible at short notice and stayed in very regular contact with their partners. Most mothers felt work was not a realistic option.



The impact of frequent appointments on work and time was also emphasised with the perception by some parents that service providers did not always consider the implications of appointments on the family as a whole. There appeared to be a lack of trust between service providers so that some services that could be provided locally were not trusted to be appropriate, with parents having to travel long distances, sometimes just to have a simple blood test performed on their child. There was also the suggestion that some service providers did not trust parents and many appointments were described as a “waste of time”.

### **5.5.1 Work in order to meet financial responsibilities**

Only one of the mothers in the TD group worked outside the home and this was for an occasional one day a week. Fathers in the TD group were all employed, with the exception of one father. Fathers in the TD group worked the longest number of hours out of all the fathers. While being conscious of this, fathers in the TD group felt it was important to provide financially for the family and to enable the mother to be at home to provide the optimum care for their child. Oscar (TD)

*“I’m ever conscious, particularly on a week like the week that we reviewed that I am away from Sam a lot, we know that’s the case and I think Fiona would like to go back to work at some point but at the moment we’ve both accepted that that’s not practical. (...) I’d like to have more time at home but on the other side (...) would probably mean that Fiona would have to have gone back to work by now and that would probably have affected Sam’s needs and development”*

Having a child with additional needs had an impact on fathers’ as well as mothers’ career choices. It was notable that fathers were unable to trust that things would proceed uneventfully at home and quite a number of the fathers were either self employed or ran their own businesses. In this way they had control over the hours they worked and could be available at short notice when required or provide support at particular times of day. However being available had financial implications because if work was not being done, money was not being earned. In addition, employees could not always be trusted to work well when unsupervised. Frank (TD) who runs his own business explained the impact of supporting with the school run that if he was not directly supervising his employees “*they’ll probably have a cup of tea when they get there (...) instead of getting stuck into doing work*” and “*leaving at half three as*

*soon as I'd gone out the gate at three o'clock to go and pick Ann up". Although the "extra 15, 20 minutes work out of them" at each end of the day might not seem much with "four, five men it mounts up" and the result was his business "really suffered".*

Fathers in both the ASD and TD groups tended to have jobs that were based locally and did not participate in business trips away from home for days at a time, in marked contrast to many of the fathers in the comparison group. This need to be based locally again affected and limited career choices including the need to maintain the support and important trust relationships that had been built up over time. Tim (TD)

*"I'm getting to the point now where I probably do need to start thinking well, you know, what's the next step, and to think outside of this area is difficult because it's not like, I'll take the kids out of school you know, Matt's care is so embedded in this area in terms of you know, his links with (...), it would be horrendous to have to move to somewhere else and set all that service care up again you know and build those relationships up again would be very, very difficult"*

Fathers in the ASD group were more likely to work unsociable shifts and worked more hours than the other fathers at weekends, although this difference was not statistically significant. The choice to work unsociable hours was sometimes to meet the needs of the family including providing the opportunity to share childcare and for the mother to work outside the home as well in some cases. In other families it was due to the higher wage that came with accepting the unsociable hours and for others it was that there were just not than many jobs available to choose from.

Mothers had quite ambivalent views about work. Some of the mothers welcomed the opportunity to spend time at home with their children and this had always been the plan. Most had planned to return to work sooner than they had been able to, but again for some mothers they were glad they had a reason why they needed to stay at home for longer, although aware of the financial pressures it placed on the family and the need for the father to work longer hours. However some mothers missed work and the social contact that it provided. They also felt they had lost some of their identity and feelings of self worth. While really wanting to work they felt they had no choice but to stay at home as there was no-one they could trust to provide the level of care and support their child needed. Standard child care providers were not set up to meet the

particular needs of their child or the financial implications were too great. If specialist support was provided it was for very short periods and often the unpredictability of their child's health care needs meant that they could not be trusted to be well enough to attend any provision regularly.

For the mothers who were working, views were again mixed. Some mothers resented the time taken away from their child and only worked for financial reasons. Others enjoyed their work. Many mothers, whether they enjoyed their job or not, expressed feelings of guilt about not directly caring for their child while they were at work.

### **5.5.2 Appointments**

Many parents highlighted the problems that frequent appointments presented for them. The need to attend appointments significantly contributed to the reason why many mothers did not work and presented challenges for the parents who did. Ronnie (TD) felt that attending appointments had contributed to him losing one job and was now reluctant to take time off to attend any appointments apart from those which he regarded as the most important as he did not trust his employers not to hold it against him

*“the job I was at before, when Travis was born (...) I had quite a lot of time off with Travis, because there was the emotional side of Travis and then there was like the not sleeping and just all the appointments we had. So my boss at the time, said take the time off if you need it not knowing that the company was going to end up having to go through redundancies. And then obviously one of the things they look for with redundancies is time off. So that's why they said (...) because you've had so much time off we have to let you go”*

There were also the financial implications of attending appointments in that for many parents if they were not working they were not earning, as previously mentioned. For some parents, employers allowed them to make up the time missed at other times, but this created its own pressures. However some parents had to use up their holiday allowance. Garth (ASD) regarded his employers as “*an absolute nightmare*” as “*there's no flexibility*” and everything has to be done “*officially*” with always having to book any time off as a days holiday. He felt that his employees did not value him or trust that his reasons for missing work to attend appointments were important. Garth in common with some of the other parents found it particularly hard to miss appointments as “*I want to be there for every appointment, I want to see what's going*

*on and face things, I want to talk to the doctors and the consultants and all that*". Although his wife ensured that he was kept informed with what had happened and he acknowledged *"the feedback is great and I know how it's going along"* he still felt strongly that there was a *"need to be more involved presence wise"*.

The costs imposed on families were not just with regard to the impact on paid employment. The time costs were also considerable and in addition there were travel costs with the feeling *"they must think my diesel cars run on fresh air"* (George (TD)). This was particularly the case if appointments were at a tertiary centre some 50 or 60 miles away. It would usually take the whole day in order to attend the appointment due to the travel time and waiting time and sometimes the appointment would only last a few minutes. Usually both parents, or one parent and a friend or other family member would need to attend due to the challenges of ensuring the child was safe during travel.

Parents viewed these appointments differently and this was often due to the level of trust in the relationship between the parents and the service providers and the level of trust that the appointment would make a difference. For some parents there was a sense of frustration and the feeling that too many appointments were *"a waste of time"* both for the parents, the child and the professionals involved. This was frequently due to people *"saying they're doing this and doing that and nothing ever gets done so"* or that no decisions would be made and so parents were *"not getting any further with it"*. However as Tim (TD) pointed out *"for every nine of those there's one where you do learn something new and you do make a bit of progress so you've got to take the rough with the smooth I think"*.

It also sometimes seemed as though professionals had not considered the implications of what they were asking of parents or the impact of the appointment on their lives. Parents felt that what was being done could have been done locally or co-ordinated with a different visit or that different service providers did not trust each other. Sally (TD) highlighted the frustration at having to see two different specialists at the tertiary centre in one week who *"run the same clinics, they're doing the same thing basically but you might have to go to see 'one' on Monday and then back to see 'the other' on*

*Wednesday and one will be sat on one floor and one will be sat on the other, that that's annoying”.*

Whilst the appointments at the tertiary centres would usually take the most time and effort individually, there were also numerous appointments to attend locally and many visits to the home. Time spent on non-work related travel was highest for mothers in the TD group on weekdays compared to other parents, at almost one and three quarter hours a day, and much of this was spent on travel for appointments. This was significantly different to mothers in the comparison group ( $P < 0.05$ ). Sophie (TD) describes a typical week

*“I usually have at least perhaps two or three a week - not just appointments, people coming here, social worker or you know portage things like that. (...) There was only two that week, so I would say there was more on average of three a week. I mean I've had three today so, well four including yourself”*

Various suggestions were made as to ways of making appointments easier to attend particularly for working parents. Evening and weekend appointments were ideas but often discarded as being no easier to attend than other times due to shift work or other commitments. Due to the very young age of the children involved it was also felt they would not be up to being seen in the evening, or if the child did not need to be present there would be childcare issues if both parents were going to attend the appointment. Weekends were often felt to be family times and some parents did not want this time intruded upon by appointments. Equally while some parents welcomed home visits others found the constant influx of people overwhelming and unwanted with Rachel (TD) clearly expressing her opinion *“school have offered me someone to come and I told them to get stuffed, I didn't want anyone else in the house”*.

## **5.6 Discovering a Whole New World**

Having a child with a disability opened up a different world for parents; a world that was unexpected and unlooked for but nevertheless provided opportunities, friendships and experiences previously unimagined. As parents began to trust the value of this new world, many were able to embrace the new situation. However, many also sought opportunities, even if just for a brief time to escape from this world and return to their previous world.

Parents recognised differences about their child that made them part of this new world but also recognised the changes that had happened to themselves, both positive and negative. Parents' future plans were also affected by the new perspectives they had acquired through having a child with a disability. This led to a change of direction for many and in particular mothers, with 70% of mothers with a disabled child now considering working with individuals with additional needs in the future.

### **5.6.1 Different worlds**

Parents, but particularly mothers spoke repeatedly about the “*whole new world*” and the “*different world*” which parents had not only “*never thought you would ever enter*” but also that “*people don't know about*”. Serena (ASD) likened it to the whole new world experienced by new parents and how “*you can't explain to somebody how it is going to be when they have a child, they don't know until they're there*”.

While this new world was recognised to be different this was not equated with bad. Over time parents learned to trust that this new world had value and indeed had some advantages over their more familiar world. Lots of positives were described and things that would have been previously overlooked or ignored were now appreciated more fully. Serena (ASD) explained

*“you see colours, especially with autism, I hear noises that I know that they'd hear, I see light that I think they would see bright and just generally you go around looking for things that you think will trigger them. So you become more aware of what is around you and what affects you and stuff like that. (...) I can see the way Ben will look at something like a spider's web and you look at it in real big detail and you see the things they see and you know the way they're fascinated by the grain on the floor, or something like that, which I wouldn't have necessarily known before.”*

Parents also noted how they had developed a whole new set of friends, parents who also had children with disabilities, people who normally they would not have associated with or become friends with due to diverse backgrounds and outlooks but the shared experience of parenting a disabled child brought them together and enabled a bond of trust to form. As Malcolm (ASD) described it

*“we socialise with people you know who are in a similar situation with their children, which I'd have never done before; they're not the sort of people I'd have normally sort of gravitated towards”*

This social contact with other parents was regarded as being “*SO important*” but some parents enjoyed maintaining their previous friendship group as “*they are really like my escape from my Matt world*” (Sophie (TD)). With these friends who “*of course will ask how Matt is*” Sophie did not “*even want to talk about it cause I just live in a different world now, since having Matt it's a totally new world and that's still my old one so it's like a little escape really if that makes sense*”.

For some of the parents who worked outside the home, they saw work as a way of escape. They therefore chose not to talk much about their home situation to their work colleagues in a similar way to Sophie not talking too much about Matt to her previous set of friends. Tim (TD) did not “*feel the need to discuss it*” and Patience (ASD) enjoyed the opportunity to “*just be Patience not Patience, Pandora's mum and Patience, Garth's wife, at work I am just me and nobody knows what happens when I get in my car and drive home*”.

However, other parents did not find work an escape but felt that it made the whole situation more difficult to cope with. This was often because of the tension they felt between working and being the carer for their child. Some mothers strongly felt that they should be at home full-time with their child even if they also recognised their desire or financial need to work. These mothers did not necessarily trust that they had made the best decisions for their child and family, or trust in their own value and importance. Therefore, there was a continual distress associated with the lack of trust in the acceptability of their situation. Marion (ASD)

*“I've got to find my way of dealing with it and you might say that I'm at work a lot and that I don't have to deal with it. But I think that makes me feel worse because I am at work and I'm not at home doing what I feel I should be doing. Which is being a mother to me children and looking after them all of the time.”*

### **5.6.2 Parents changed by child**

Parents noted a number of ways in which the experience of having a child with a disability had changed them and their lives. Some of these changes were due to becoming a parent and were experiences that many parents would relate to such as having “*so much fun*” with their child and having an “*immense sense of pride*” but others were more unique to their particular situation. Some parents mentioned

becoming more “*patient*”, recognising that they could “*give a lot more*”, wanting and having “*to grow up*” and having a purpose and “*something to live for*”.

Many parents mentioned that their priorities had changed and things that had seemed important previously now seemed of little consequence. This had led to Hilary (ASD) changing her job from working as a beauty therapist to working with children with special needs as “*I just wanted a bit more from life I suppose*”. She explained that a lot of her previous clients were “*ladies with a lot of money*” who talked about their problems which now in light of her own experience of having a child with disabilities “*just seem a bit trivial*”.

Although maternal depression is often attributed to having a child with a disability Rose (TD) found that “*having Eve for some strange reason has made me positive. I don't know why because that doesn't really make sense. It just has, I think I'm positive for her*”. This was despite having experienced postnatal depression after the birth of a previous healthy child.

Parents' interests and the way they spent their time also changed. Malcolm (ASD) was not certain “*whether it's Nev that's changed it or just natural progression of time*”. However on reflection he noted

*“I spend time going to the National Autistic Society courses and things like that. There's things like that I just wouldn't have done before, would never have considered, it just wouldn't have entered my head (...) I suppose really he has changed a lot about my life. I don't get three hours a day to go down the gym anymore, unfortunately (laughs)”*

None of the parents suggested that their experiences had led to them adopt a religious faith or reject one but several parents made reference to their trust in God or the importance of religious traditions in their lives. Two parents, one mother and one father but not from the same family, expressed a strong trust in God which influenced their activities, their interpretations of events and their expectations for the future. While having a disabled child had challenged them to consider why such things happen they had found that trusting in God had been a constant “*the only thing that's always been the same*” which “*does help me personally*” (Rose (TD)). This faith in God also helped Bryan (TD) accept the precarious nature of his child's life and the uncertainty about the future



*“I thought she’s God’s gift. At the end of the day, it is God that is going to decide. So sometimes you have to put your faith in God. If she’s going to live ... she’s going to live ... there’s nothing anybody can do. The doctors are only serving as mediators. They are only doing ... what is humanly possible here. Yes, but if God says, look I’m going to take her away ... she’s had enough ... there’s nothing we as parents can do to stop that”*

### **5.6.3 Positive aspects**

Parents were asked to think about what were the activities they most enjoyed doing in a week. As expected there were a range of responses including shopping, playing football with friends and sleep! However the majority of parents referred to activities with family members, generally fairly ordinary events like going for walks, watching TV or just playing together. Despite all the additional challenges many parents expressed enjoyment of their current life, particularly when their child was well or settled, with Patience (ASD) explaining *“I don’t think I want it to be different because if I wanted it to be different then that would be saying that I’m not happy and I am”*.

Some parents who appeared particularly content with their current life had a high level of trust that things were in place for their child with disabilities, confidence in their support networks and a high level of trust in their partner’s support and abilities. These high levels of trust gave parents a degree of release from the stresses and anxieties associated with the new world, enabling them to enjoy it.

Several parents described the experiences they had with their disabled child as being much more intense both from a positive and negative point of view. Doug (ASD) who has two boys, one with autism and one without tried to explain *“when he (child with autism) does things it’s ... the feeling that you can’t describe and you can’t beat, when he does something that he doesn’t normally do or if he makes you laugh”*. These same actions performed by their typically developing child were expected and therefore hardly noticed but when their child with autism performed them it was *“such a good thing.”*

### **5.6.4 Negative aspects**

Parents also expressed feelings of sadness about their current situation and how things might have been. These feelings were often precipitated by observing other families

with Garth (ASD) noting when *“I’m chatting to the mums and dads it just makes me kind of see the other side you know, what it could have been like”*. Seeing other children of a similar age to their child with additional needs often highlighted the differences between them which could be particularly upsetting for parents

*“I find it hard to be around children Eve’s age at the minute, I don’t know whether that’ll change (...) or that’s just something that I’ve got to come to terms with. But I do find it difficult to be round other children that are doing what they should be doing. I don’t find that easy at all”* (Rose (TD))

However sometimes these feelings of sadness or loss could occur at any time or for some parents persisted as an under current in their every day lives. Some parents although realising these hopes were unrealistic still longed for their child to change although, or perhaps even because, they *“love her so much”*. Emma (ASD)

*“I know one day she’s not going to wake up and I’m not that stupid, she’s going to wake up and suddenly speak as much as I would really like her or she’s just going to change. But I suppose deep down you do think, she’s plotting to save the world and she’s just storing it all up and one day she’s just going to turn around and say something to me, but I know that’s not going to happen”*

Well meaning comments by friends or family could be particularly distressing as well as the intrusive comments of strangers already mentioned earlier in the chapter. Comments like *“don’t know how you do it”* were considered the hardest thing by Rose (TD) who pointed out *“well you don’t really have a choice, you can’t send them back”*.

Platitudes offered by work colleagues such as *“oh, it could be worse”* angered Ronnie (TD) who had *“been so close to hitting them sometimes”*. This was particularly as they had healthy, typically developing children of their own with Ronnie feeling *“no it couldn’t be worse, it could be a lot f..g better”*.

Some mothers who had previously worked highlighted missing the time they used to spend on their own appearance and identity, and how all their effort now went on achieving the optimal support and services for their child. Having to fight for services rather than being able to trust that what the child and family needed would be provided was a continual source of stress and one of the most negative aspects of the new world.

Serena (ASD)

*“You know, there are things that I miss, I mean when I used to work I used to wear suits and I used to wear skirts and high heels and things like that, now I’m continually in jeans and t-shirts because it’s practical because I’m going to be going on the trampoline any time and I’m going to be climbing across something to go and get Ben, or he’s going to wipe stuff all over my hands, you know all over my jeans of whatever. It’s like my hair keeps getting shorter and shorter because it’s more and more practical. It’s like, oh I haven’t got time to straighten it, or I haven’t got time to do this, so it gets shorter and shorter, or Ben’s pulling it, or whatever. I’ve lost my identity I think, a lot (...) you’re lost in this world and you’re not quite sure what to do for the best, you just don’t know and you do, you lose a bit of yourself every time, that you’re trying to fight for something, you shouldn’t have to fight for these things”*

Society’s attitudes about disability which previously some parents had also embraced were challenged by having their own child with a disability and therefore parent’s attitudes had to be reconsidered in light of their new experiences. Doug (ASD)

*“It’s hard because you look at it as a negative and I think ... when I used to look at it, other people what had disabled children or thinking, everybody always looks at it as a negative. And its one of them you’ve got to come to terms with. It’s not a negative, he’s Taylor”*

As mentioned in the section about ‘feeling trapped at home’ many parents struggled coming to terms with accepting support from other people, using services such as a hospice or trusting anyone to look after their child. Parents “*felt terribly guilty*” but positive experiences helped establish these relationships so that “*when I knew that he was enjoying it I just thought well this is the way, it’s a nice thing to have, a back up if anything does happen*” (Naomi (TD)).

Accepting support also had its downside particularly when people were unreliable, or felt they knew better than parents. Sometimes people would just give 10 minutes notice about not coming and “*that makes you mad*”. Family, while meaning well, undermined parents’ trust in their own abilities by “*telling me I’m doing it wrong*” which made parents “*cross*” and think “*well you come and look after her then*”.

Being able to trust that someone was going to follow their routines and advice in looking after their child was particularly important in enabling parents to let someone

else look after their child. This could present particularly challenges with parents' own mothers who often thought that due to their experience with their own children they knew best. Sally (TD) was experiencing this around feeding her son who could only take small amounts orally and was mainly gastrostomy fed. Sally worried that despite her instructions her mother would attempt to give him more food orally, which would result in her son vomiting "*everywhere*". After this had happened on a number of occasions she had decided "*you can't just spend your time worrying, you've got to trust people with him*" and that if her mother was "*going to keep doing it, then I won't ask you to look after him again*".

The majority of the parents interviewed expressed high levels of worry, both about their present situation and also about the future for their children, but most particularly the future for their children with additional needs. These worries were often overwhelming, and at times interfered with all aspects of life. Parents had developed different coping strategies such as not thinking about the future or having '*a mission*' to focus on. This would mean that they could divert all their energies and worries onto this one aspect rather than allowing their mind to run wild over the many possibilities the future could hold.

### ***5.6.5 Changed directions***

Parents had adjusted many of their future plans since having children, and this was sometimes due to the associated issues of having a child with a disability. Future reproductive choices were also affected in some situations, with different parents both more likely and less likely to have further children following the birth of their child with additional needs.

Some parents felt their lives were currently on hold while they focused on completing various courses of treatment, established the correct support and looked forward to their child starting fulltime education. Many parents highlighted how all parents wanted the best for their children, and were willing to make sacrifices in order to achieve this.

However one of the most striking changes to future plans was with regard to mothers' future work aspirations. Twelve out of the 17 mothers were now considering working

at some point in the future with adults or more commonly, children with additional needs. This was a radical career change for most of them, with only one having had any experience of working with children before, let alone children with additional needs. This desire to work with individuals with disabilities was a reflection of the trust that they had in the value of their children with disabilities and a greater appreciation and understanding of the possibilities for individuals with disabilities in general. It was also an acknowledgement of the trust they had in their own abilities and the new skills and techniques that they had learned through looking after their child with disabilities. Their own experiences had not only opened their eyes to this new world and new opportunities, they had also provided the mothers with new skills and knowledge.

Naomi (TD) who had previous experience working with children felt she had gone as far as she could in her current job but *“with everything I have learnt, one from being a mother, but one then from being a mother of the child with all these needs that Travis’ got”* she now felt that *“I would like to go into looking after children with special needs, you know as a play worker or something”*. Becky (ASD), a manager, had *“swore blind I could never work with other people’s children”*. She and her husband were surprised at the change in her since she had been helping out her son’s preschool which he was not allowed to attend without her additional support. She discovered that not only did she *“like being with Corey”* at the preschool with all the other children, even though she recognised the many different challenges this brought, she also felt *“I do quite a good job with him”* giving her the interest and confidence to consider this line of work in the future.

A different mother felt it was important to be *“giving something back”* after the benefits she and her child had received from services and due to her belief that there was often *“not enough staff”*. Quite a few of the mothers felt that they would need to work on a voluntary basis as they could not trust being able to commit to paid employment even when their child was in full-time education due to the unpredictable nature of their child’s condition and did not want to feel under additional pressure or to be letting people down. Other mothers saw working with children with additional needs as a way of further increasing their own knowledge. Emma (ASD) for example felt she did her *“best but I don’t really know what I’m doing”* and by working with

children with special needs she could perhaps “*get an insight into helping her a bit later*”.

However, all of the mothers considering returning to work were clear that their job or future career would now come second to meeting the needs of their children. Many of the parents already working also shared this view.

### **5.7. Evolving Roles**

Parents organise their lives to fulfil their various different duties and obligations. The time use diaries indicate that in the families with a child with complex health needs dependent on technology, the mothers had the main ‘carer’ role for the child, while the fathers were the ‘breadwinners’. However in the families with a child with an autism spectrum disorder, the care-giving role was more equally shared between the parents. In three out of nine families the father could be considered the main carer and in over half the families, mothers contributed to the ‘breadwinning’.

The reasons why parents took on various different roles were explored with parents in the interviews, as well as their perceptions of what parental roles should be and the attributes of an ideal father or mother. While some parents did hold traditional views and had gender stereotypical ideas about what mothers or fathers should do, the majority felt that it was personality rather than gender that influenced what roles were adopted by different parents and how parents had responded to different situations. One of the crucial determinants of what each parent did, particularly in relation to looking after the child with additional needs was the level of trust between partners. Partners were also better able to support each other if they were able to accept the differences between them, appreciate their strengths and worked hard on their communication.

#### **5.7.1 Parental roles**

The majority of parents stated that were happy with the roles that they performed within their families. While often these roles were described as not “*something we discussed and said, it just happened*” they had required adjustment and adaptations to previous roles sometimes in order to “*literally survive day by day*”. Other families felt

there was “*not needed to talk with each other, we just know what to do*”. In one of the families where the father provided as much, if not more care than the mother this had come about due to an unexpected job opportunity occurring for the mother which was full-time and as her husband was at home during the day, he had encouraged her to apply.

However some parents did have prior expectations, particularly parents with more traditional views. Tom (ASD)

*“I’m old-fashioned so Emma and I have very distinct roles in the house. I... it is my job to be the breadwinner and look after everything and it’s Emma’s job to look after the house internally. So if anything needs doing, of a physical nature, whether it’s from changing a light bulb to emptying the bin, that’s down to me”*

A few parents felt that their roles were largely interchangeable and either parent could, and in some cases did, fulfil any role successfully. Jenny (ASD)

*“Malcolm and I definitely do the same things you know. Obviously I mean Malcolm’s doing I suppose a mother’s role all week long when I’m at work. I feel as if we’ve swapped roles but on the other hand he’s still working as well. He is just doing it at night time. So I mean one example, the other night, one night Nev wouldn’t go to sleep. When the clocks went back he refused to sleep and he just cried and I sat upstairs with him for two hours. And I ended up having to ring Malcolm because I was so upset because I couldn’t calm him down. So I had to ring him and he came in and he calmed straight down. So we are just support for each other really”*

Other parents saw their roles as being different and distinct but nevertheless equal, and that these complimentary roles enabled them to work together well as a team.

### **5.7.2 Mothers’ roles**

Although parent’s lives showed that many of them had embraced more liberal views with regard to parenting roles, when asked to consider an ideal mother or an ideal father, traditional views were often predominant. This may contribute to why many parents expressed guilt and other strong emotions with regards to aspects of their lives as there was a continual tension between everyday reality and necessity, and aspirational ideals. Therefore, there was the suggestion that parents’ did not trust that their parenting patterns were as good as those projected in the media or perhaps performed by their own parents.

Mothers not only tended to provide the majority of care but also appeared to spend more time mentally planning things with regard to their children than fathers did. This also happened in a practical sense in that while many fathers were happy to look after their children without the mother present, the mothers often felt they had had to prepare everything in advance for them such as ensuring lunch was prepared or medicines, nappies and equipment were all readily to hand. In this way mothers felt they still had the ultimate responsibility for the child even when the father was physically in charge. However, these mothers also trusted their partners completely with their child's safety and to look after them properly. Despite highlighting this additional burden and the desire for fathers to be more proactive, these same mothers also strongly appreciated the fact that their partners allowed them to take the lead with their children and respected and trusted their opinions and expertise. Tessa (TD)

*“he’s totally let me take the role, he doesn’t question me, if I come home and say ‘right, she now needs to have cranberry juice at night, she’s going to start because of her water infections’ he wouldn’t say ‘well hang on a minute, I’m not sure about giving it her at night’ or, he would never question me and he wouldn’t want to add his, ‘well I think you should do it like this’ because like I was saying, he knows I would have thought of the best possible way for Josie”*

Although three of the fathers in the ASD group provided most of the childcare for their children, in two out of the three of these families, the mothers still took the children to the majority of appointments. In one family the father would have really liked to attend the appointments but his employers made this very difficult and in addition he did not drive. In the other family, the father did bring the child to some appointments but had had some disagreements with a number of professionals. This meant that he sometimes felt his time was better spent achieving tasks that he could only do while he was not looking after his daughter, while his partner took her to the appointments.

Malcolm, who did take his son to all the appointments, with his wife only attending the occasional appointment with him, had a very similar outlook with regard to caring for his child and planning for his needs as did the mothers in the study. Therefore it may not be the fact that parents are either mothers or fathers but the amount of time and energy they devote into the caring role which affects their outlook and actions. In addition as they build up their expertise and familiarity with looking after their child it



becomes more important that things are done ‘their way’. It may also be that the more frequent contact with professionals affects the way that parents think and act with parents taking on some of the professionals’ expectations and more medicalised roles and attitudes. Malcolm (ASD)

*“I’m quite critical of anybody else who sort of takes in to, you know steps into my role and I’ll always pick fault with what they’re doing, so it’d just be fruitless trying, so I’d just kind of step back in any way. I’d always, you know I’m quite critical and I don’t sort of like things being done wrong or differently to my way of doing things, so, although sometimes it would be nice that somebody else would take some responsibility at times, I don’t think I’d ever let them anyway”*

### **5.7.3 Fathers’ roles**

Several parents highlighted the physical aspects of fathers and how they were able to either do, or do more easily some roles due to their greater physical strength compared to mothers. While many parents did feel that fathers had a traditional provider role to play the majority of parents felt that the most important thing was for a father “*to be there*” for his children. Spending time, being approachable and being actively involved with their children’s lives were common themes which Malcolm (ASD) contrasted to the “*hit and run sperm donors, a lot of supposed fathers that I know are*”. Susannah (TD) also picked up on ‘being there’ for the children being more defining of a father than the biological aspects with her view following previous unsuccessful relationships “*it doesn’t matter who makes the babies, it’s important who look after them*”. This emphasis on the father ‘being there’ implied the need for dependability or trustworthiness on the behalf of the father, as opposed to fathers who did not take their responsibilities seriously or did not remain involved with the family.

Several fathers saw their role as fathers included supporting their wife and looking after the whole family and not just with regard to their children. Mothers also valued being able to trust their partners and the support that fathers could provide. Susannah (TD)

*“It’s not you know some people say when you say support they think it’s money, no, it’s not the money, it’s emotional support, it’s about when he’s there when you need it, because the life at the moment is so difficult”*

The majority of the fathers were happy to share jobs around the home when they were at home, including all aspects of childcare. Fathers referred to the fact that they felt they were always available once they were home to do whatever was required, even if they did not do these activities without being asked. Nearly all the fathers also reported that they felt they were constantly available even when at work and would, and indeed had previously, leave work immediately to come home and help out if required. These fathers also tended to stay in very regular communication with their partners ringing home “*three or four times a day*” to check on how things were going, texting, e-mailing and staying “*in constant contact*”. Several mothers highlighted that they valued this staying in touch and being able to trust fathers to be available if they needed them, while being conscious of their partners’ work responsibilities.

#### **5.7.4 Parental support**

The families in this study were all two parent families living together and therefore their parenting experiences were influenced by the fact they had a partner to support them. This parental support was very evident in the majority of families and consisted of a number of different aspects including accepting that their partner handled situations differently than they did, appreciating the good qualities in their partner and prioritising communication with each other.

Parents had had very different experiences of family life. Some had come from broken homes or even experienced openly abusive and destructive relationships with their families of origin. Others had experienced warm, positive and nurturing relationships which were an ongoing source of support. Others still had experienced something in between. These previous experiences influenced their expectations of their current relationship with their partner and also affected how they wanted to be as a partner and as a parent.

The level of trust between different sets of parents was noted to vary. It was also noted to be an important influence on parents’ satisfaction with their relationship and their current situation.

#### *5.7.4.1 Acceptance of Difference*

Parents recognised and accepted that their partners did not necessarily follow the same path as they had when it came to coming to terms with the realisation that their child had a disability. Although sometimes parents attributed their partner's reaction to the fact that they were a man or a woman, more often it was again down to personality or experiences. Both mothers and fathers were described as being in denial, finding the issues harder to come to terms with, being more laid back or accepting or seeking to find out as much information as possible. While mothers more often seemed to want to talk about issues with other people, this was again not universal and in some cases it was the fathers who found it easier to talk than mothers.

Parents who attended appointments tended to be the ones less taken by surprise by diagnoses and less in denial about the nature and extent of their child's difficulties. They also tended to be the ones with a plan of action to maximise the child's potential rather than being happy in the here and now and accepting the child as they were. Again this is possibly due to the increased contact with professionals who emphasise the need for interventions, treatment and progress.

While some parents looked to their partner for emotional support and would only trust them with discussions on personal issues, others felt the need to shield their partner from some of their feelings and instead chose to talk to other family members or friends. Again this was the case with both mothers and fathers.

#### *5.7.4.2 Mutual Appreciation*

Fathers and mothers both spoke about how good a parent they felt their partner was. This mutual trust and respect helped parents ignore or live with some of the issues they disagreed with and gave them confidence that their child was receiving the best care and opportunities possible. It also meant that in a number of cases the trust parents had for each other and each other's abilities meant the only time the parent could relax and take a break was when their partner was looking after the child.

While parents recognised that the additional challenges of having a child with a disability can place a strain on a relationship, nearly all these couples felt that their relationships in general had been strengthened by the experience. Ronnie (TD)

*“I think it’s brought us... in... the long term it’s brought us closer together, but it has... there has been a lot of arguments because of it, because of our different views.”*

The importance of already having a strong relationship was highlighted and how if this was not the case it was understandable *“why it would have a detrimental affect on other couples”*. However despite the *“tensions”*, the *“bad patches because we’re down”*, the general feeling was *“if anything it’s brought us closer”*.

#### 5.7.4.3 Communication

Communication was seen to be vitally important and even more so since having a child with additional needs. Patience (ASD)

*“We’ve had to make sure it’s good because we have so many other stresses, we have to tell each other what the problem is. And if there is a problem then we’ve got to tell it how it is straightaway. Or else with everything else that goes on it just festers and gets worse”*

As already mentioned, many parents were in contact several times a day by phone, text or e-mail. Parents kept in contact this way to keep their partner up to date with how their child was doing, give immediate feedback from appointments, ask for an opinion on something or if their child had *“done something funny, or unusual, or cute”*. Oscar (TD) explained

*“for example the other day, he managed to climb onto the sofa the first time and was sat with his legs crossed watching the TV, so she sent me a photograph of that, and that’s great ‘cause it, it really sort of brightens the day as well if you’re having a boring day at work”*

The majority of parents discussed all issues together and reached a consensus with regards to plans of action, medical intervention, educational support or any other important issues. In many families the mothers took the lead in finding out what the different options available were. Although parents tended to feel they always reached an agreement and trusted that they always would, the general consensus in most families was that ultimately if an agreement could not be reached about a situation directly regarding the children, the mother would have the final say. Stuart (ASD)

*“It wouldn’t happen. No it wouldn’t, one of us would convince the other one way or other. We would never, I would never overrule Becky or visa versa (...) I don’t know if I had to say one way or another I’d say I would probably give into her where the kids are*

*concerned because she spends more time with them than I do she probably ... I don't know, mum knows best I suppose isn't it so. But I don't think we would get there, I don't think to be honest I don't"*

## **5.8 Trust**

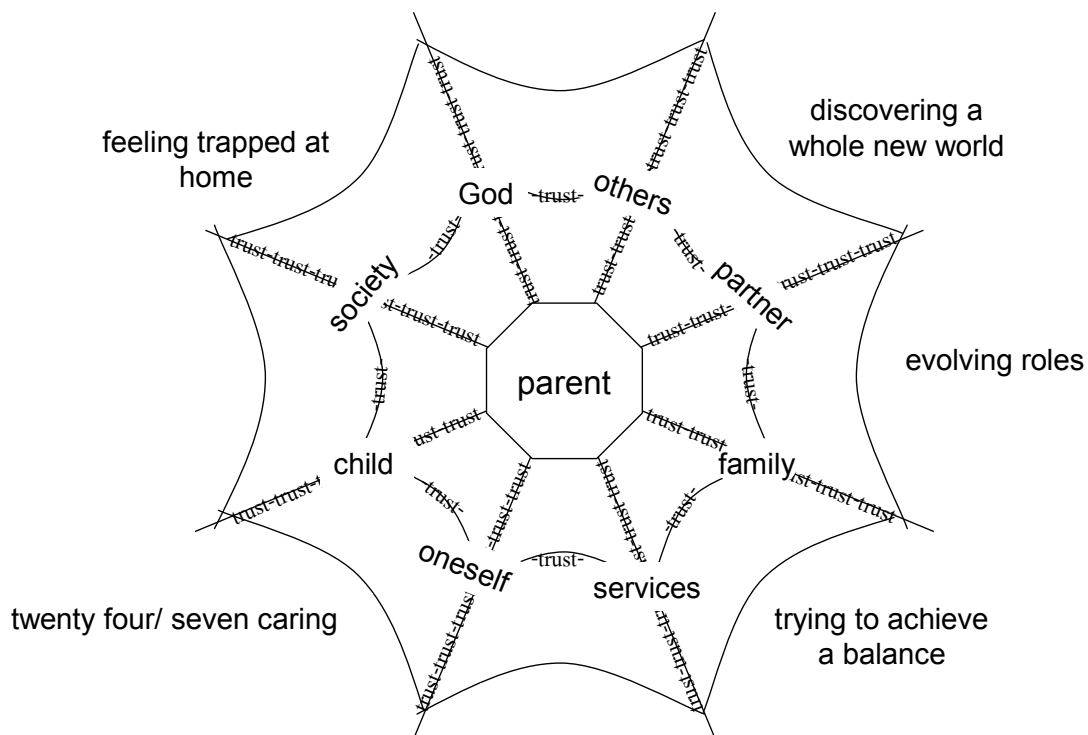
The importance of trust in the many different relationships that parents with a disabled preschool child engage in, has been shown in the previous sections to influence parents' interpretations of their life situations, influence their time use decisions and impact on their quality of life.

Trust implies a co-dependence and mutuality, the need to work together and the need to give and receive and was noted to be a pervading influence weaving both subtly and explicitly through parents' lives. Parents having found themselves in a 'new world' with so many circumstances being out of their control, and many associated risks and possible negative outcomes, were faced consciously or unconsciously with decisions about how they would cope. The strength of previous trust relationships formed the foundation for parents' approaches to adjusting family life to accommodate their child's disabilities. Their ongoing experiences both positive and negative further shaped existing trust relationships and forged new ones, some becoming stronger and more resilient over time and others remaining fragile or being broken.

Eight main trust relationships were identified involving parents and that impacted on their daily lives, interpretations of their experiences and their time use choices. These have already been discussed within the major themes and sub-themes and therefore are not discussed further individually here. These trust relationships were 'trust in oneself', 'trust in partner', 'trust in child', 'trust in family', 'trust in health services', 'trust in others', 'trust in society' and 'trust in God'.

Parents are part of a complex web of relationships. I conceptualise that threads of trust create a dynamic web that affects parent's daily lives. Some of these threads form strong bonds particularly if given time to develop and strengthen, while others are weak or fragile, and still others are broken and damaged. These relationships also do not occur in isolation, but are multiply interconnected by varying bonds of trust

between the different relationship groups, further impacting on parents' lives. For instance, the strength of their child's trust in other family members will affect how parents choose to spend their time and who they can trust to look after their child. In this way, it can be seen that different parents' different levels of trust in the different relationships described, provides meaning and explanation for parents' different experiences and ongoing time use decisions. These different experiences of their daily lives are captured by the five themes of 'feeling trapped at home', 'twenty four/ seven caring', 'trying to achieve a balance', 'discovering a whole new world' and 'evolving roles'. I have provided a visual representation of this dynamic web in Figure 5.1.



**Figure 5.1 Trust relationships create a dynamic web that affects parents' daily lives**

## **5.9 Summary**

In this chapter I have presented the qualitative findings from the 34 semi-structured interviews. Following a description of parents' daily lives five main themes have been discussed that encompass some of the differences having a child with either complex health care needs dependent on technology or an autism spectrum disorder makes to time use choices, parental experiences and family life. The thread running through these different themes, linking and helping to explain them, is trust. Trust is presented as integral to relationships and eight main trust relationships identified.

As mentioned at the beginning of this chapter, this was a finding driven by data analysis and not based on any prior concept or literature review. Therefore, it was necessary to review the literature concerning trust before further reflection and analysis of the data. A review of the relevant trust literature and the results of the further data analysis are presented in the next chapter.

## CHAPTER 6 TRUST

*“Trust is the glue of life. It's the most essential ingredient in effective communication. It's the foundational principle that holds all relationships”*  
*Stephen R. Covey*

### 6.1 Introduction

Trust is difficult to conceptualise and define. Nevertheless, it is helpful to try and achieve a degree of clarity around the concept in order to further interpret the role it plays in relationships, and the influence it has on individuals' time use decisions and quality of life. Therefore this chapter starts with an exploration of the definition of trust. The fundamental nature of trust in all relationships is highlighted as well as trust being an organic web which connects individuals, organisations and society with threads that require time to develop and strengthen into bonds and can be fragile and easily damaged. The quality and quantity of these threads have an impact on an individual's daily life and their ability to respond and cope with the many different challenges and pressures experienced. The quality and quantity of these bonds of trust also have an impact on society as a whole.

However, trust cannot be considered an ideal in every situation as it has the potential to be misplaced or unwise. Acknowledging this, suggestions are provided as to ways of increasing appropriate or reasonable trust. This includes the need to enable trust to increase and strengthen over time, particularly by stepwise building on positive trustworthy experiences.

In the previous chapter, eight main trust relationships were described which were 'trust in oneself', 'trust in partner', 'trust in child', 'trust in family', 'trust in health services', 'trust in others', 'trust in society' and 'trust in God'. As this study has focused on father-mother pairs, a greater understanding of the relationship between parents has been achieved, compared to the other relationships. A closer look at the different levels of trust in the relationship between fathers and mothers has resulted in a model of three different types of interparental trust relationships. These are referred to as dictatorship, democracy and coalition. These different trust relationship types are presented in this chapter and related to the findings documented in the previous



chapters with regard to parents' time use and quality of life. They are also discussed with regard to the relevant published literature.

## 6.2 Definition of Trust

Trust is both a process and an outcome (Johns 1996). Its definition can vary depending on whether the perspective is economic, sociological, political or philosophical. Even limiting the perspective, trust has a number of different properties and this makes it difficult to concisely define and conceptualise (Calnan & Rowe 2004; Misztal 1996; Mollering 2001). In this critical ethnographic study, trust is considered from a primarily sociological perspective and with regard to the role it plays in relationships. Therefore the definitions presented are concerned with this context.

The Oxford Dictionary includes in its definition of trust the following aspects:

- firm belief in the reliability, truth, or ability of someone or something
- the state of being responsible for someone or something
- a hope or expectation (Oxford Dictionaries 2010)

While this captures many of the qualities of trust some elements are still missing. Misztal's comprehensive text about trust in modern societies (Misztal 1996) includes an exploration of these missing elements. Misztal also suggests that social theories have tended to use the benefits trust provides in order to define trust

*“it (trust) is seen as essential for stable relationships, vital for the maintenance of cooperation, fundamental for any exchange and necessary for even the most routine of everyday interactions.”*  
(Misztal 1996, pg 12)

Misztal (1996) highlights that trust involves an element of risk because if something is known with certainty then trust is not required. Therefore while there is a similarity between trust and confidence, there is more of the element of risk associated with 'trust'. This makes trust a particularly important attribute when managing situations associated with risk. Increasingly individuals in modern society have moved away from living in situations where they have to manage danger to situations where they have to manage risk (Misztal 1996). This is especially pertinent in this study where parents continually have to weigh up risk factors associated with the care of their children, as parenting decisions are made more complex and associated with more risks when the child has a disability. While placing one's trust in something does not

remove the risk, it makes living with the risk more manageable, comfortable and acceptable.

Trust has both cognitive and affective components (Calnan & Rowe 2004), relating to the amount of knowledge on which a decision about whether to trust or not is made, and the 'gut feeling' or faith elements. It is also not an all or none phenomenon. It is possible to completely trust someone with regard to certain issues, such as perhaps letting them drive your car, while not trusting them with other things, such as your credit card (Lewicki, Tomlinson, & Gillespie 2006). Therefore, there can be varying levels of trust in the same relationship. Some authors refer to this as 'bandwidth' or breadth while the strength of the level of trust is referred to as depth (Lewicki, Tomlinson, & Gillespie 2006). This leads to the consideration that "when asked whether one trusts or distrusts another, the proper answer is not "yes" or "no" but "to do what?" (Lewicki, Tomlinson, & Gillespie 2006)

Mollering (2001) suggests that trust has three components 'expectation', 'interpretation' and 'suspension'. The first component, expectation, concerns the outcome of the process, with interpretation relating to the consideration of different options based on what information is available. Suspension is the component of trust that enables one to feel comfortable with living with the risk, "*the mechanism of bracketing the unknowable, thus making interpretative knowledge momentarily certain*" (Mollering 2001, pg 403). Interestingly, while I have analogised trust as being like the threads of a web, Mollering makes a similar comparison suggesting "*the concept of trust as a thread spun of weak inductive knowledge and faith*" (Mollering 2001, pg 407).

Another key feature of trust is the time element. There is always a period of time between placing one's trust in someone and the action involved in fulfilling that trust or otherwise. This time element is shortest in emergency situations such as those which occur following accidents, where individuals place 'immediate trust' in the professionals seeking to save their or their loved one's lives (Wilson, Morse, & Penrod 1998). However, trust is not a steady state but relates to circumstances and requires individuals to repeatedly evaluate different possible courses of action (Misztal 1996).

When considering trust it is also helpful to consider its opposite, distrust. Although trust is usually considered a good thing, blind, inappropriate or unreasonable trust is not. It is important to weigh up the risks involved in trusting someone or a particular course of action and then respond with a reasonable or proportionate level of trust. Trust and distrust can occur simultaneously and both perform important functions. In situations where trust has been damaged by past experiences it may be particularly appropriate to limit the amount of trust placed in that individual or situation or ensure additional precautions are in place to minimise the risk. Thus trust is given, but distrust remains. However, *“the result for the individual is an increased emotional and cognitive work-load and considerable anxiety”* (Misztal 1996, pg 173).

Thus trust can be seen to be multifaceted. Different aspects have been focused on in different studies and in different definitions. I have been unable to find a definition that fully resonates with my own conceptualisation of trust in relation to this study. Therefore, to try and capture the different elements of trust that I believe are key I conceptualise trust as being:

*“the conscious decision to place hope in the trustee (an individual or organisation or society) to do their best to ensure a good outcome consistent with the trustor’s expectations and the belief that this desired outcome is achievable”*

Thus having provided a definition of trust, the following section moves on to consider the influences different factors can have on the development of trust within relationships.

### **6.3 Types of Trust Relationships**

Different types of trust relationships have been described in the literature depending on a number of different factors. These include the social context, the balance of power within the relationship and the time frame over which trust has had the opportunity to develop. These factors will now be considered.

#### **6.3.1 Social context**

The expectations that an individual has from a relationship varies according to the nature of that relationship. For instance, the expectations from a relationship with a family member are very different to those from the relationship with for example, a

supermarket assistant or a doctor (Misztal 1996). These different relationships affect the types of trust created. Trust between individuals is usually referred to as personal trust or interpersonal trust (Johns 1996).

Trust can also occur at a more abstract level where the trust may be in someone or some organisation with which the individual has no direct or personal relationship. This type of trust is referred to as generalised, abstract (Misztal 1996) or institutional trust (Brownlie & Howson 2005). This is the trust that one has in society, or a government or a hospital. There have been concerns that levels of generalised trust have reduced over recent years in the UK as well as other countries. This can be seen in the increased concern or distrust of strangers particularly in relation to the safety of unsupervised children and the scepticism with which various government health recommendations are treated by the general public (Brownlie & Howson 2005). Despite this, cross-national surveys have continued to show high levels of general trust in fellow citizens in Western European countries with 88 to 90% of respondents from the UK agreeing that ‘people can be trusted’ in a 1982 survey (Misztal 1996).

An Ipos MORI poll in 2011 asked 1,026 people in the UK whether they trusted various different groups to tell them the truth and found that doctors were the most trusted group with 88% of the general public expecting them to tell the truth. This was higher than in 1983 when 82% had this expectation (Ipos MORI/ BMA 2011). Politicians were found to be the least trusted, with only 14% of the public expecting them to tell the truth, down from 18% in 1983. With regard to the ordinary man or woman on the street, 55% of the respondents expected these individuals to tell them the truth, almost the same as in 1983 when 57% did. Although trusting someone to tell the truth does not correspond exactly to generalised trust, these results do suggest that there may not have been a marked change in generalised trust levels since 1982.

In UK society there are clear expectations of how strangers interact with each other in public places. These social rituals enable strangers to feel comfortable sharing the same social space and are based on habit that leads to feelings of trust that individuals’ reactions and behaviour are going to be non intrusive and unthreatening. This “*civil inattention - that is the courtesy performed between two persons passing on the street*” (Misztal 1996, pg 114) is clearly violated by some people in relation to families with a disabled child, as has been highlighted in the qualitative findings in

section 5.3.4. This damages parents' trust in strangers, making it much harder for them to freely inhabit social spaces with their disabled child. It also can have an impact on the individual's basic trust in themselves and their ontological security (Giddens 1990).

In order to ensure that individuals with disabilities and their family members can have reasonable trust in the behaviour of strangers, and that they will be afforded 'civil inattention' there needs to be increased tolerance in society of individuals who are considered different for whatever reason, such as disability, race, religious affiliation or sexual orientation. This tolerance is likely to be achieved through education. However, tolerance should not be based on indifference, and therefore just allowing to be, but rather involve acceptance and an element of welcoming the difference

*“without broadening the notion of tolerance to include mutual understanding and trust, we will be unable to resolve our contemporary problems in such a way as to enhance social cooperation”* (Misztal 1996, pg 228)

### **6.3.2 Power relationships**

Unequal positions of power in a relationship affect the types of trust produced. Parents are in a position of power in relation to their children particularly when their children are infants, or while the children continue to be highly dependent on them. The trust that babies exhibit towards their parents is usually 'blind' and 'uncritical' (Misztal 1996, pg 160). However life experiences such as spending time on a special care baby unit can have an impact on this trust bond, both from the baby's and the parents' point of view, making the baby less trusting and equally the baby less trustable as they have not behaved in the expected way by being born healthy or at the right time.

Typically relationships between doctors and patients have been characterised by an unequal balance of power, with the doctor perceived as being in a position of power. This previously resulted in patients having 'blind' trust in their doctor and is often associated with patients not expecting to have an active role in any decision making process (Calnan & Rowe 2004). Due to a number of reasons 'blind' trust is no longer as prevalent, including the fact that patients themselves have become much more knowledgeable and can challenge the expertise of the doctor. In addition, doctors and other healthcare providers are themselves actively promoting trust relationships based

on 'informed' rather than 'blind' trust and a more equal sharing of power in decision making. This is achieved by "*sharing information, identifying areas of common ground and by emphasizing patient self-competence*" (Calnan & Rowe 2004, pg 10). The patient's awareness that the health care provider has trust in their own ability to manage their own condition, particularly in chronic disorders has also been noted to increase that patient's trust in the healthcare provider (Calnan & Rowe 2004). Dixon noted that strong partnerships between health care providers and the parents of acutely ill hospitalised children were achieved when "*each person's viewpoint was heard, respected and incorporated into the child's care*"(Dixon 1996, pg 119) again suggesting that the sharing of power promoted positive, trusting relationships. Johns suggests that trust is essential to patient empowerment and is of importance in improving patient care (Johns 1996).

Therefore, while unequal power relationships may promote certain successful trust relationships such as in infants, unequal power relationships present a challenge for successful collaborative relationships and generally hamper their development (Vangen & Huxham 2003). It is important that these power imbalances are not ignored but actively addressed and managed if collaboration is to be achieved. This is not likely to be a one off event but rather a cyclical process requiring re-addressing at regular intervals (Vangen & Huxham 2003). However, it is not necessarily an easy process for parents and the need to develop and sustain trusting relationships with staff was reported as a continual source of stress for mothers of children with chronic illnesses (Swallow & Jacoby 2001).

In addition, while informed trust may be preferable to blind trust, it brings with it its own pressures and stresses particularly when decisions are being made on behalf of another, as is the case for parents on behalf of their children. It can be challenging to remain informed or to appropriately evaluate all the information on offer, whether it be with regard to medical decisions (Brownlie & Howson 2005) or optimising their child's development (Misztal 1996). The increasing availability of expert opinions and conflicting sources of information can impact on parental confidence thus reducing the trust they place in themselves to make the best decisions for their child (Misztal 1996). Therefore Brownlie and Howson conclude

*“living in an information-sceptical age means a refocusing of priorities away from getting information out there, towards building relations of trust that make it easier for people to accept that information as reliable” (Brownlie & Howson 2005, pg 235).*

### **6.3.3 Temporal context**

Initial trust is ‘naïve’ (Thorne 1993; Thorne & Robinson 1988) and influenced by an individual’s natural tendency to trust (Misztal 1996) which is directly related to past experiences, particularly as a child (Giddens 1990), as well as intrinsic personality traits. An infant’s blind trust when appropriately rewarded and nurtured by their family enables that child to develop an inner security and to be more ready to form other trusting relationships. Each further positive experience, re-inforces the individual’s basic level of trust, providing resilience against the future challenges and stresses encountered in life. In the same way, damage to these early trust relationships can continue to have an impact and negative influence on all future trust relationships (Giddens 1990; Misztal 1996).

Other people’s experiences can influence initial trust, such as the opinions of family members or friends. Calnan and Rowe refer to this as ‘network trust’ (2004). Brownlie and Howson (2005) also refer to the importance of parents’ personal networks to increase or decrease trust in the safety of the MMR immunisation.

Once a relationship is entered into, levels of trust are influenced by direct experience: ‘experiential trust’ (Calnan & Rowe 2004). Depending on the experiences this trust is either strengthened or damaged. Thorne and Robinson (1988) refer to a ‘disenchantment’ phase, when the individual’s initial naïve trust has been challenged and broken. In many relationships between healthcare professionals and patients there are periods where things do not go optimally, affecting the levels of trust. Periods of distrust are characterised by *“dissatisfaction with care, frustration and fear”* (Thorne & Robinson 1988, pg 297). Following this there may be attempts to ‘reconstruct’ trust which can lead to a ‘guarded alliance’ where trust has been reconstructed on a more informed and realistic level enabling a co-operative partnership to be formed (Thorne & Robinson 1988). However, the ‘guarded alliance’ can vary depending on the levels of reconstructed trust and the individual’s confidence in their own or their family’s competence to manage their care. In some cases this leads to ‘hero worship’ where one healthcare professional is identified as the only one as being trustworthy, to

‘resignation’ where levels of trust in self and health care professionals are very low, to ‘consumerism’ where trust in one’s own competence is high but low with regard to professionals, or finally to ‘team playing’ where confidence in one’s own abilities and trust in the health care professionals are both high (Thorne 1993).

Lynn-McHale and Deatruck (2000) performed a concept analysis of trust between families and health care providers with the families having either an adult or child member who was ill. They found six characteristics of trust which included that trust was a process that evolved over time, as well as that it consisted of various levels and was based on mutual intention, reciprocity and expectations.

In looking at building trust between organisations, Vangen and Huxham (2003) again highlight the time commitment required. They recommend the ‘small-wins’ approach. In this a small task involving trust is initially attempted and when this is successful the increased trust produced allows further perhaps more ambitious tasks to be considered. This cyclical trust building process requires work to maintain and build and the authors suggest this includes managing issues such as trusted members leaving the collaboration or new members entering the group. At this time particular efforts need to be put into nurturing and sustaining trust and finding ways to ensure that power is shared (Vangen & Huxham 2003).

I believe this is an ideal model for parents working with a range of practitioners to meet the needs of their child and family. Trust needs to be built up gradually with ‘small-wins’. This requires people getting to know the child and family and requires consistency of people within the trust loop or particular efforts at times when new people are introduced or trusted members leave in order to maintain, consolidate and then continue to build trust. Parents in this study reported that too often there is the expectation for parents to place immediate trust in people they do not know. This often results in parents turning down offers of help as the leap of faith is too big for them to manage. Sadly, as has been highlighted, when parents do trust, sometimes practitioners fail to meet the parents’ expectations as they had not got to know the child well enough or fully identified parents’ expectations first, and actually could not fully meet the child’s needs in an acceptable manner. This broken trust can then be devastating and adversely influence all relationships in the future.



Wilson, Morse and Penrod (1998) describe the process of developing reciprocal trust in a care-giving relationship. The relationships being examined were between ventilator dependent children aged four to fifteen and their care providers on a summer camp. Four types of relationship were described and the amount of time that the caregiver-camper dyads had to develop their relationship was crucial to the types of relationship seen. These relationships progressed from the 'tentative' to 'familiar', to 'mutually protective' to finally a 'connected' relationship. However not all dyads progressed through all the relationship stages during the five day period of the camp with only those campers who had been to camp before and already knew their caregiver attaining the connected relationship. Similar to the small-steps approach described by Vangen and Huxham (2003), Wilson et al's model (1998) while occurring over a more compressed time frame, demonstrated that trust grew "*through repeated, numerous interactions over several days*".

Therefore, trust relationships can be seen to be influenced by a number of factors including the social context, the balance of power and the time element. While many trust relationships will be of importance in the daily lives of parents with a young child with disabilities, one of the fundamental relationships is between the parents themselves. There seems to be no reference in the literature to models or concepts of different levels of trust between parents. The maternal gatekeeping model discussed in Chapter 2 includes mothers' trust in their partners' competence in childcare and domestic activities as one of its elements. However, the other elements are not trust related and maternal gatekeeping does not encompass other trust issues between the parents. Since the relationship between parents is an interpersonal trust relationship, I have coined the phrase interparental trust relationship to refer to the trust relationship between parents. The following sections are based on further analysis of the data from this study incorporating a more in-depth understanding of the concept of trust.

#### **6.4 Interparental Trust Relationships**

In common with Lewicki et al (2006) and Lynn-McHale and Deakin (2000) who described varying levels of trust in complex relationships, I found that there were varying levels of trust between partners. Three particular aspects or areas where trust was needed or expected, were common to all the relationships. Levels of trust in

relation to these aspects, appeared pertinent to parents' satisfaction with family life, and influenced their behaviour and time use decisions. These trust aspects were:

Aspect 1 - that their partner would act in the best interest of the family and fulfil their particular roles and obligation;

Aspect 2 - that their partner would put their family's needs before their own; and

Aspect 3 - that their partner would care for the disabled child in a way that fulfilled their expectations

Based on levels of trust with regard to these different aspects, I have created a model of three types of interparental trust relationships; dictatorship, coalition and democracy. While I do not feel that these relationship types are unique to parents with a disabled child, and can also be seen in families with typically developing children, I believe the usefulness of the model lies in recognising what particular strengths and weaknesses each parental relationship type has, and therefore different possible strategies and approaches to use to provide support that is appropriate and enabling.

The size of the sample on which this model is based is small, and unfortunately all the missing time use and qualitative data are from parents who are in the dictatorship group. Therefore, these findings need to be treated with caution and require validation by subsequent studies to further develop the model or disprove its relevance.

#### **6.4.1 Dictatorship**

The dictatorship model is characterised by generally low levels of interparental trust in relation to the three aspects described. However, mothers and fathers expressed different patterns of trust. Mothers expressed variable levels of trust with regard to the first aspect (that their partner would act in the best interest of the family and fulfil their particular roles and obligations), low levels of trust with regard to the second (that their partner would put their family's needs before their own) and particularly low levels of trust in relation to the third aspect (that their partner would care for their disabled child in a way that fulfilled their expectations). In contrast, fathers appeared to have high levels of trust regarding this third aspect, variable levels of trust of the second and low levels of trust concerning the first aspect (Table 6.1). It is to be noted

that the expectations of what their partner's roles and obligations consisted of also varied between the different groups which will be discussed later.

I have used the term dictatorship to capture not only the low trust levels that I believe are present in dictatorships in general, but also the mode of decision making. The partners in the dictatorship group had an unequal say in the decisions relating to the child with disabilities. There was a sense that if one partner did not like the other partner's decisions they could learn to live with them or leave but either way they were non-negotiable.

The dictatorship group was the smallest group identified, with only three couples (7/8, 17/18, 41/42) demonstrating this type of interparental trust relationship. Two of the families had a technology dependent child, and one family a child with an autism spectrum disorder. While all the families had other older children, for one of the fathers, the child with a disability was their first child. Within the period of the study, two of the couples separated and the third was moving to a more democracy based relationship. This suggests that the dictatorship relationship could be the least stable of the three types described.

The suggestion that the dictatorship relationship type is the least stable, is supported by the finding that this was the smallest group in this study looking at families with two co-resident parents. A study looking at families with disabled children in general may well find evidence of this relationship type in a larger number of partnerships and possibly was the relationship type in some of the families ineligible for the study due to parental separation. Equally several of the families in the democracy relationship group discussed how their relationship had evolved from what was a more dictatorship model to the current democracy one and there was evidence of the third family in the dictatorship group moving through this process.

Unfortunately, for the purposes of drawing robust conclusions about this group, within this group were the two fathers who did not participate in the interviews, and the two couples who did not complete the full seven days of their time use diaries. This means that the quantitative data with regard to time use are limited and there is an unequal representation of parental views on family life with a maternal predominance. However, all participants did complete the PedsQL Family Impact

Module which reveals some interesting findings. The PedsQL results for the different groups, the levels of trust with regard to the three aspects described and five quantities of time use are compared in Table 6.1.

With regard to the PedsQL Family Impact Module, higher scores suggest less of an impact, or better functioning. It is apparent that there is a discrepancy between the mothers' and fathers' scores, with fathers appearing to be experiencing less of an impact than mothers particularly with regard to their social opportunities. In addition the impact on family functioning for both parents is greater than that with regard to the parent's health related quality of life (HRQL). The family functioning asked questions around family activities taking more time and effort, and about family relationships including decision making as a family, communication issues, and stress, tension and conflicts between family members.

**Table 6.1 Comparison between Interparental Trust Relationship Groups**

	Dictatorship	Coalition	Democracy
Number of families	3	5	9
Trust Aspect Levels Father (Mother)			
1	low (variable)	high (high)	high (high)
2	variable (low)	high (high)	high (high)
3	high (low)	variable (variable)	high (high)
Mean hours per day Father (Mother)			
Sleep	8.50 (6.75)	6.98 (8.01)	7.67 (8.23)
Leisure	0.93*(2.25*)	0.46 (0.26)	0.62 (0.34)
Caring for Study Child	1.39* (10.07*)	1.97 (4.31)	1.77 (6.25)
Home	14.36* (20.86*)	15.06 (17.01)	16.94 (20.21)
Time as family	1.54* (2.93*)	3.59 (3.70)	6.77 (7.06)
Mean PedsQL scores Father (Mother)			
Physical	56.9 (32.0)	56.7 (31.7)	59.2 (50.0)
Emotional	46.7 (38.3)	53.0 (25.0)	55.6 (48.9)
Social	68.8 (29.2)	56.3 (27.5)	59.0 (50.0)
Cognitive	61.7 (30.0)	50.0 (42.0)	63.0 (63.3)
Communication	38.9 (36.1)	40.0 (30.0)	47.2 (55.6)
Worry	30.0 (35.0)	43.0 (40.0)	38.9 (41.1)
Activities	16.7 (25.0)	31.7 (15.0)	39.8 (39.8)
Relationships	51.7 (30.0)	40.0 (44.0)	55.6 (60.0)
Total Score	48.1 (32.2)	48.5 (31.7)	53.3 (50.0)
Parent HRQL	57.9 (32.5)	55.7 (31.8)	59.2 (51.6)
Family Functioning	38.5 (28.1)	36.9 (22.1)	49.6 (52.4)

\* Based on a single result

The mothers in this group were all the main caregivers for the disabled child and none of the mothers were employed, while all of the fathers were in paid employment outside the home. I gained the impression that while all these families had other children the disabled child was the mother's main focus and centre of attention. Indeed two out of the three mothers spent no time during the week just with their other child/children without the disabled child present. It was also clear that mothers placed the needs of their disabled child before the needs of their partner and spoke about this quite openly. There was also the suggestion that to a certain extent mothers felt that they had to care for their husbands as well as their children and this added to their burden.

All the families in this group appeared to have adopted traditional parenting roles and had traditional gender role expectations. A study by Coltrane (1996) suggested that the age of the mother when the first child is born influences the likelihood of whether traditional or more egalitarian roles will be adopted, with mothers under the age of 27 at the birth of their first child being more likely to adopt traditional roles. Consistent with this, is the finding that delaying motherhood is associated with increased rates of maternal employment and higher levels of maternal education (Family and Parenting Institute 2009) and mothers who work more hours and have higher levels of education tend to have more egalitarian parenting practices (Gaunt 2008). The mothers in this group were 18, 20 and 26 when they had their first child.

Parents appeared to have different ways of coping with the additional needs of their disabled child and any diagnosis. Mothers were very 'hands on', taking control and actively finding ways of meeting their child's needs no matter what this involved. Fathers appeared more withdrawn, reluctant to discuss issues with their partner or others and had a low attendance at meetings or appointments about their child. For one father, the mother said that he would like to attend appointments but that work commitments made this difficult. For the father who was interviewed, it was a conscious decision as he found the meetings frustrating and 'a waste of time.' Whatever the reason this resulted in fathers being less informed about what was happening with their child and mothers felt that fathers had less understanding of the situation.

Interestingly in contrast to some of the literature on this subject parents did not report that they felt professionals treated each parent differently. However one of the mothers had noticed this differential behaviour from friends and family. She said that friends and family always spoke to her rather than her partner about how she was doing and how she was managing but never asked her partner how he was coping, which she thought was wrong. She also objected to the fact that people would say to her partner “*I don’t know how Rose does it*”, ignoring his contribution completely. Hobson and Noyes’ (2011) study of fathers of children with complex healthcare needs also noted that fathers experienced gender bias from family members, who demonstrated more sympathy and concern for mothers rather than fathers.

Therefore, while parents’ different reactions, coping styles and gender role stereotypes create the situation where mothers are performing all the care for the disabled child and making all the decisions, the increasing gap in knowledge and skills between parents, and friends and family’s traditional views on parenting, reinforces the situation. This unbalancing of the family’s subsystems leads to strain and tension in family relationships (One Plus One 2007; Seligman & Darling 2007).

All the parents interviewed in this group, three mothers and one father, talked about the strain that the high level needs of their disabled child had on the parent’s relationship. While it was acknowledged that there were or had been other problems in the relationship it was felt that these additional stresses and the lack of time and energy to concentrate on their own relationship was a cause of considerable tension.

The mothers’ low level of trust in their partners’ abilities to care for the disabled child in the way that met her expectations (aspect 3), also meant that care overnight was unequally shared with mothers performing either all or the vast majority of this. While there was strong evidence of maternal gatekeeping, or mothers maintaining their position of providing all the care and limiting the father’s involvement, there was also evidence that fathers contributed to this by not actively pursuing greater competence as has been suggested previously by Allen and Hawkins (1999). In contrast to this was the family who were moving to a more democratic relationship. Here the mother recognised that the reason her partner did not do more was because she stopped him, “*‘cause I’ve always stopped him, it’s my fault. I’m in charge and I’ll do it and he’s not good enough to do it. No-one’s good enough to look after her.*”

As this mother crumbled under the pressure of several years of providing all the care she began to realise that things could not continue in this way. To her surprise her husband, who hated going to hospitals and appointments, went to the Tertiary Centre to receive the required training and was now providing more support. However, it was still an ongoing process as she commented *“it’s me, I have to step back and think, no, he’s her dad and he’s got to do stuff. So I step back. And he’s quite capable to do it, but it was letting him.”*

Unfortunately, I do not have the views of two of the fathers with regard to whether they trusted their partners with the care of their child but their actions would suggest they did. The third father described very high levels of trust for his wife’s competence and abilities to look after their disabled child. However, what was less apparent was a trust that his wife would fulfil her roles and obligations towards him such as recognising and prioritising his needs and incorporating and responding to his opinions. As many fathers see their partners as their main source of support (MacDonald & Hastings 2010; McNeill 2004; Towers 2009) the mothers’ predominant focus on the disabled child, and lack of time and energy for them, may have affected these fathers’ abilities to cope and adjust (One Plus One 2007). Mothers’ tendency to obtain support from external sources (MacDonald & Hastings 2010) may have resulted in mothers feeling supported by the wider family or services, but depending on the nature of this support, may have had their current coping mechanisms reinforced rather than challenged.

In summary, the dictatorship relationship is potentially an unstable one, characterised by low levels of trust between parents resulting in unequal sharing of the care of the disabled child, unequal impact on parents as measured by the PedsQL Family Impact Module and strain and tension in family relationships. Due to the lack of time use data for four out of the six parents with the exception of sleep, comments can not really be made on time use decisions. However, in contrast to findings from other studies that fathers have less sleep than mothers (Gershuny 2000), mothers were noted to have less sleep than fathers. Parents were also noted to have a tendency to perform traditional roles and hold gender stereotypical views and ideals.

#### **6.4.2 Coalition**

In the coalition relationship levels of trust between the parents were again variable. However, this group was characterised by fluctuating levels of trust with regard to the third trust aspect, regarding their partner caring for the disabled child in a way that fulfilled their expectations. Both parents trusted their partners to act in the best interest of the family and fulfil their particular roles and obligations (aspect 1), and that they would put their family's needs before their own (aspect 2). However, parents expressed tensions and anxiety about how their partners cared for the disabled child in a different way to them, but they often tried to rationalise these concerns. For the parent more commonly being criticised, or being asked to do things differently, there were expressions of frustration and the suggestion that their partner was being overly particular about certain issues. The parent who made the criticisms felt that the other parent did not understand and anticipate the child's needs as well as they did. In four out of five cases this latter parent was the one who was present at the majority of appointments, such as therapy and Portage as well as medical appointments. They also tended to view their child's needs as greater than their partner's perception of them, and in more need of specific interventions to address them. This was perhaps due to their involvement with practitioners holding these views or perhaps these parents were motivated by their own views to prioritise attending the appointments.

Five couples demonstrated this type of relationship (13/14, 21/22, 33/34, 39/40, 49/50) and all the parents, mothers and fathers, had paid employment outside the home. However, there was marked ambivalence by many of the parents with regard to work and child care with a desire to spend more time with their disabled child but also frustration at the challenges of care at times.

Child care was the most equally shared in any of the groups and three of the fathers contributed large amounts of time to looking after the disabled child. Both parents regarded their child/children as being their main focus and while parents often had differing views on aspects of child care and ways of doing things, they were willing to make compromises and sacrifices in order to do what they perceived as the best for their children. However, in four out of the five couples it was usually the father who would yield if there was a difference of opinion regarding a decision about the disabled child. In the family where the father provided the most care, it was his



decision that was the final one. This father also demonstrated gatekeeping tendencies typically attributed to mothers.

Four out of the five families had a child with an autism spectrum disorder and four out of the five disabled children were boys. In three families, the child with additional needs was the only child and in the other two, the disabled child was the second child of two children. While for the majority of the families with a technology dependent child problems were apparent at birth, for the children with an autism spectrum disorder concerns tended to occur later. However, the family with a technology dependent child in this group, while aware of some problems at birth, became aware of additional problems over time which required further and more demanding intervention and support. Therefore, all these families had an initial period of fewer concerns which perhaps allowed fathers to play a more involved role before the additional challenges became apparent. Thus both parents had developed skills and familiarity in taking care of their child, and mothers had followed their planned course of returning to work.

Interestingly, it was only parents in this group who stated that it was often easier to manage the child with additional needs when their partner was not present and more challenging when they were all together. This was also reflected in parents' time use, with parents in the coalition group spending much less time together as a family during the week, just under two and a half hours as compared to the families in the democracy group who spent over six hours together on average a day. Times were more similar at the weekend with just under six and three quarter hours spent together at the weekend in the coalition group and just over seven and a half hours spent together in the democracy group on average per weekend day. This lack of time together as a family was also due to many of the couples leading largely desynchronised lives, often with one parent working antisocial shifts to facilitate child care arrangements, a pattern described by Lesnard as becoming increasingly common in dual earner families (2004).

In contrast to the parents in the dictatorship group, while parents acknowledged that concerns and disagreements about their disabled child had caused arguments and tensions in their relationship, the coalition parents felt that having a disabled child had brought them closer together. The PedsQL Family Impact Module again shows a

greater impact for mothers rather than fathers but the fathers' social opportunities are reduced in the coalition group compared to the dictatorship group as they are playing a more equal role with mothers. This is reflected in parents' time use with fathers on average only having 34 minutes a day during the week for leisure without child care responsibilities and 12 minutes at the weekend. Mothers had 18 minutes on average a day during the week and eight minutes a day at the weekend. In addition, views about shared decision making, conflict and tension between family members and communication, as looked at in the relationship section, suggests that mothers are happier with these issues in the coalition group than the dictatorship group, while fathers are somewhat less happy.

Fathers in the coalition group tended to have more egalitarian views on gender roles and saw it as their role to help with housework and childcare. The majority felt that the parenting roles were largely interchangeable and one father had actively wanted to be a full-time dad and 'house husband' soon after their child was born, but the mother had opposed this idea. One of the fathers did provide the majority of the child care during the day, though also worked at night.

In contrast, the mothers in the coalition group tended to hold traditional views, particularly about ideal mothers being at home and providing all the care. This led to feelings of guilt that they were not doing this for their own children and also frustrations that when they were with their children that they were not able to fulfil the mothering ideals they had. Four out of the five mothers also stated that rather than work being an escape it created more problems and pressures for them. The reasons for their employment included financial ones and to maintain or develop skills for the future when they envisaged working would be easier as their child would be in school fulltime. These four mothers were all under the age of 27 when their first child was born: 20, 22, 21 and 26 years. The fifth mother did enjoy her work and saw it as an escape from home life. She was 30 when she had her first child and therefore according to Coltrane (1996) more likely to have non-traditional views on parenting and gender roles.

The Canadian Father Involvement Research Alliance looked at fathers' and mothers' roles with children with special needs (McNeill et al. 2008). They describe a model where parents either show complementary roles, where each parent has specialist

skills in different areas or symmetrical roles where either parent can do any of the tasks. However, they found the reality was really a continuum with most parents showing elements of both complementarity and symmetry in their roles. This balance also was subject to change over time and in relation to different needs and circumstances. In relation to this model, the parents in the coalition group had symmetrical roles as either parent could do any of the tasks.

In summary, the coalition relationship is characterised by fluctuating or variable levels of trust with regard to the care of the disabled child but trust concerning the first two aspects is high. Both parents are very involved in looking after the child and are also involved in the breadwinning role. Different interpretations of the best way to parent leads to conflict and tension but there is a high commitment to the common aim of doing the best for their child which includes making the relationship work. Therefore, the additional challenges of having a disabled child have strengthened the couple's relationship and brought them closer together. Fathers have more egalitarian views with regards to parenting and household work and are not constrained to gender stereotypes. Mothers while practicing non-traditional roles hold traditional role ideals leading to some role strain and tension.

### **6.4.3 Democracy**

The democracy relationship is characterised by high levels of reciprocal trust between partners regarding all the three aspects previously described and a strong sense of the parents being a mutually supportive team. However, there was evidence from some of the parents who had a technology dependent child that there had been an earlier period of a more dictatorship type of trust relationship which had evolved over time into the democracy relationship.

There were nine couples in this group (1/2, 3/4, 5/6, 11/12, 25/26, 27/28, 29/30, 35/36, 43/44) with six families having a child dependent on technology and three families with a child with an autism spectrum disorder. Two families, both with technology dependent children had an only child, both boys. For three other fathers the disabled child was their first biological child although their partner had other children. None of the mothers had paid employment outside the home though one of the mothers was a foster carer and another mother worked for a few hours a week within the home. Seven of the fathers worked and two were unemployed. One of

these provided the majority of care for his daughter with autism particularly overnight, while the other was hoping for employment when the appropriate paper work came through.

The PedsQL Family Impact Module shows more equal scores across the domains for both parents, with mothers having higher scores in a number of areas. While most of the scores in each of the domains are higher than in the other groups, in particular the relationship domain and family functioning total show the highest scores of any of the groups, suggesting the least impact of their child's health needs on the family's quality of life. However, the needs of the children in this group were no less demanding and challenging than the needs of the children in the other groups.

In the seven families where the father was working the parents adopted traditional roles with the mothers providing the majority of the care and looking after the home and the fathers regarding being the provider as one of their key roles. In these families roles were specialised and complementary (McNeill, Beaton, Montgomery, & Nicholas 2008) and fathers viewed their participation in housework and looking after the children as supporting their wives. Couples adopted the manager/helper model (Coltrane 1996) with mothers arranging and directing father's activities in family work and fathers providing help with the family work, but not initiating or organising this. Although there was evidence of gatekeeping in most instances this was due to the specialisation of the roles, with mothers managing complex health care routines, or enrichment type activities with their children that the fathers were not fully familiar with. However, other than a few niggles at times, this was a situation that both parents had agreed to and wanted to continue. Importantly, mothers reported absolute trust in their partners when they were looking after their disabled child in their absence, even if they had had to prepare things beforehand. This meant that mothers were able to and actively encouraged by their partners, to participate in child free leisure activities outside the home. Fathers also had these opportunities particularly at the weekends.

The two families where the fathers were not working shared activities more equally and had more symmetrical roles. Both fathers engaged fully in housework and child care and who did what was negotiated on an almost daily basis with often both parents doing activities together. They also helped looked after the disabled child at

night with one of the fathers providing virtually all of this care while in the other family, the disabled child shared a bed with both parents and therefore both were involved in overnight care.

In the seven families where the father was working the mothers provided the majority of overnight care. In many families this was a conscious decision by mothers to protect their partners as they were aware of the long hours they worked. In others it was due to a perception that this was part of the mother's role. Both these reasons for mothers providing the majority of overnight care have been described previously in families with typically developing children (Venn et al. 2008). Nevertheless, due to the long hours of work by the fathers and the particularly low levels of sleep by the father looking after his child with autism in this study, fathers in the democracy group had on average 45 minutes less sleep than mothers a night during the week. At the weekend fathers had on average five minutes more sleep than their partners.

In contrast to the families in the dictatorship group, both mothers and fathers scheduled time to spend individually with their other children without their disabled child present. This comparison is not really possible with the coalition group as three out of the five families in that group only had a single child, though the two families with another child did refer to times when they prioritised spending time with their other child and there was some evidence of this from the diaries.

The majority of the fathers in the democracy group performed traditional roles and saw parents' roles as distinct. Some of the parents had discussed and negotiated roles before having children, while for others roles developed over time. In general fathers were happy with the balance of the roles between the parents and spoke highly of their partner's attributes as a mother. They were also confident in their own role as a father with regard to caring for their child with additional needs.

All the fathers related strongly to the provider role. This was also the case for the two fathers who were not currently working who both expressed feelings of inadequacy and failure for not providing financially for their families. This was despite both fathers participating fully in housework and childcare and one of the fathers being the main carer. This father felt that when he had done some work on the house or

decorating he had done something more worthwhile than his usual activities as the maintenance type jobs related more closely to his ideas of man's work.

Many of the fathers also saw it as their role to manage the finances and to protect their wives from any financial concerns. Despite sometimes having to manage stressful situations at work they again tended to avoid discussing these issues with their partners who they felt already had enough to worry about. However, they did seek emotional support from their partners and in most cases discussed issues about their disabled child fully with them, seeing no need for outside or additional support in this area.

All of the mothers had worked in paid employment outside the home before having children. Their views on parents' roles and gender roles were much more variable than the fathers. Two of the mothers had made the decision that they wanted to stay at home when they had children, at least till the child/children had started school. These mothers had traditional views on parenting and gender roles and were happy in their current roles even if parenting their child with additional needs was not quite what they had expected. They anticipated that they would go back to work at some point but this was not an immediate issue. These mothers were 27 and 29 when they had their first child and therefore would have perhaps been expected to hold more egalitarian views (Gaunt 2008; Family and Parenting Institute 2009; Coltrane 1996). Another mother who was 27 when she had her first child had gone back to work following her two previous children. She was enjoying the extra time she was having at home with her third child who had complex health needs dependent on technology. She also welcomed the additional time it meant she could be at home with the other children. Despite knowing that financially the family could do with her going back to work, she did not feel this was a realistic option and was not keen to pursue it anyway. Ultimately she knew she would have to return to work but had not set any particular target for this.

The two mothers whose partners were not working saw parenting roles as interchangeable. Their perceptions of an ideal father centred on emotional aspects, such as loving the children, providing stability for the family and emotional support for the mother rather than financial aspects. One of these mothers was keen to get back to work as she felt this was important for herself but as she was also pregnant

with her third child she accepted this would not be for some time. The other mother could not contemplate going back to work for the immediate future even though her daughter was soon to start fulltime school. However she thought she would like to possibly do some volunteer work to ‘give something back’. Previously she had been the main breadwinner in the family. These mothers were 18 and 20 when they had their first children.

Three other mothers had seen themselves as career women before having children. They were 28, 30 and 36 when they had their first child. For two of them not being able to work was causing them considerable distress, undermining their self esteem and confidence and leading to feelings of isolation and being trapped. Although on the one hand they felt it was of great importance to personally look after their child with additional needs and were devoted to this activity, there was also regret at not being able to pursue other options and some occasional resentments that their partners did not provide more help. The third mother had found having her child with autism had transformed her from being career-orientated to child-orientated. She now regretted having gone back to work when her first child was four months of age and felt guilty about what she had missed out on. While she still intended going back to work at some point, she now intended for this to be part-time and to play a secondary role to caring for her children. She was also, like many of the other mothers in the study now considering working with children with special needs.

Scott’s (2010) study of the emotional impact of mothers’ changed employment trajectories following the birth of their disabled child highlighted that “*overwhelming care demands, an inflexible labour market, woefully inadequate public supports for care and pressures derived from a cultural norm of ‘intensive mothering’*” (Scott 2010) presented barriers to mothers returning to work. For some mothers not being able to return to work caused considerable disappointment and distress and for others the conflict of trying to balance home and work demands was equally destructive.

The final mother in the democracy group was a foster mother. She had chosen this career as she enjoyed being at home and looking after children and this had not changed when one of the foster children, who had been fostered at birth had been found to have autism. She had traditional views of parents and gender roles and was

very happy with the support from her partner. She was aged 21 when she had her first child.

All the parents reported that their relationship had been made stronger and they had been drawn closer together by having a child with a disability. Two couples spoke of an initial period where their relationship had been under strain. The fathers talked about not really being aware of what was happening and the mothers described being completely immersed and overwhelmed in meeting the needs of their child. For one family in this situation, their child had been born extremely prematurely and had quite a prolonged period on the special care baby unit. For the other family, also with a child with complex health needs dependent on technology, the mother had picked up on her child's difficulties before her husband or indeed health care staff detected the child's regression. These couples appeared to have gone through an initial dictatorship type trust relationship. However, the fathers remained committed to the relationship and made adjustments to try and support their wives who gradually increased their trust in their husbands. The fathers' understanding and confidence in looking after their child's additional needs had also grown over this period. While parents had had different ways of coping and adjusting, and their relationship had suffered as a consequence, time and perseverance particularly working on communication issues, had led to increased levels of trust and a stronger relationship than before. In some ways this mirrors the small-wins approach advocated by Vangen and Huxham (2003).

In summary, the democracy relationship is a stable, mutually rewarding relationship characterised by high levels of reciprocal trust between partners. The partners see themselves as a team, who reach decisions together and support each other emotionally. This team can have a number of different configurations, with partners engaging in complementary or symmetrical roles, and maintaining traditional or more egalitarian views on ideal parenting and gender roles. This type of interparental trust relationship appears to minimise the negative impact of having a disabled child on the family with higher quality of life and family functioning scores, particularly for mothers, compared to the other groups. Families in this group also spend more time together than families in the other groups.



## **6.5 Conclusion**

Trust is an important aspect of relationships and contributes to feelings of security and well-being. Analyses of the qualitative and quantitative data from this study have resulted in trust being recognised as a unifying concept, providing a framework for understanding parents' different experiences of daily life with a young child with high level additional needs, and different patterns of activities and time use decisions.

Focusing on the relationship between parents, variations in the levels of trust in particular aspects of the interparental relationship, has led to the creation of an interparental trust relationship model. This model consists of three groups, the dictatorship, coalition and democracy groups. While it is acknowledged that the sample size is small and in particular the dictatorship model is affected by missing data, the model's usefulness lies in recognising what particular strengths and weaknesses each group has, and therefore possible strategies and approaches to use to provide support that is appropriate and enabling.

This chapter concludes the findings from this study. The next and final chapter discusses the importance of quality and quantity with regard to parents' time use and their trust relationships. Positive ways of supporting parents and families of children with disabilities are also considered with the chapter concluding with some recommendations.

## CHAPTER 7 QUALITY VERSUS QUANTITY

*“Rather, for all objects and experiences, there is a quantity that has optimum value. Above that quantity, the variable becomes toxic. To fall below that value is to be deprived.”*

Gregory Bateson

### 7.1 Introduction

Parents with young children experience multiple demands on their time and more time pressure due to these demands, as compared to other periods of the life course (Bittman & Wajcman 2000; Gershuny 2000). The data presented in the previous chapters have demonstrated that parents whose preschool child has high level complex needs, face additional demands and constraints upon their time use choices, compared to parents with typically developing children. If parents with a disabled preschool child are considered as a group or subculture, the findings suggest that they are disadvantaged in a number of ways compared to the dominant culture of parents with a typically developing child. These disadvantages include having less sleep, fewer leisure opportunities, increased intensity of mental and physical activities, less economic potential, reduced social contact, decreased levels of trust, and increased levels of worry and stress.

While strategies can be adopted by service providers to address these symptoms of disadvantage, the underlying problems and causes of the symptoms of disadvantage need to be addressed. Although superficially these problems and their cause may appear to be having a child with a disability, I have suggested that one of the main underlying problems that families’ experience is with regard to levels of trust, and this has been discussed in the previous chapter. Finding ways to positively address trust is likely to have a beneficial effect on all the other issues as well.

One of the strengths of this study is the combination of methods which has enabled both quantitative and qualitative aspects of phenomena to be explored and has resulted in some new and important findings. These include the empirical evidence that the quality and quantity of sleep and leisure time are reduced for parents with a disabled preschool child. This decreases opportunities for parents to ‘re-charge’ and hence can impact on the parents’ health and wellbeing. In addition, the level of trust

between mothers and fathers has been found to influence parental time use and to be an important determinant of parental quality of life.

These new contributions to knowledge concerning parental sleep and leisure and the influence of trust relationships on parents' time use, will be further expounded in this chapter. Strategies and approaches to positively address these issues will be proposed and include the need to strengthen parents' relationships and a need to reduce the way services and society can unintentionally promote unequal and less stable partnerships between parents. They also include the need to promote appropriate trust in other relationships in addition to the interparental relationship.

Findings from this study also support findings from previous studies and these will be discussed in the context of the relevant literature. The broad similarities with previously published work suggest that the families who participated in this study share many experiences with other families with disabled children documented previously. The results of the data from the comparison families and the MTUS/UK time use data suggest that generalisation of the findings can be considered. Finally, the chapter and this thesis conclude with recommendations arising from this study and suggestions for future research.

## **7.2 Sleep**

Sleep is vital to health and wellbeing. Lack of sleep has been linked to hypertension and other cardiovascular problems, lowered immunity, obesity, problems with memory and learning, mood disorders and increased rates of accidents (Harvard Health 2006). Sleep takes up about one third of our lives and therefore is of considerable importance when considering time use. It is also an activity that can be 'compressed' or reduced if required with individuals sacrificing sleep in order to achieve certain goals. When this is happening regularly it contributes to feelings of time pressure and "*when need time, cut back on sleep*" is one of the ten statements on the Time Crunch Scale devised by Robinson and Godbey (1997).

It is acknowledged that parents of very young children and particularly infants often have their sleep disturbed due to caring demands (Cooklin, Giallo, & Rose 2011). Time use studies of general populations find that parents with preschool children have

less sleep than other groups, and men in general have slightly less sleep than women (Gershuny 2000). Many studies on families with children with disabilities including autism and complex health needs, report that parents' sleep is compromised (Acton Shapiro 2003; Bennett 2009; Brotherton et al. 2007; Brotherton, Abbott, & Aggett 2007; Crowe 1993; Crowe & Florez 2006; Curran et al. 2001; Heaton et al. 2003b; Hobson & Noyes 2011; Rogers & Hogan 2003; Sawyer et al. 2010; Towers 2009; Towers & Swift 2006). However, only one of these studies has attempted to quantify these sleep differences.

The time use study that has looked at the sleep of parents of preschool children, only recorded mothers' sleep although all the families were co-resident two parent households. This study by Crowe (1993) of 45 mothers with children with moderate to severe disabilities, 45 mothers with children with Down syndrome and 45 mothers of typically developing children considered amounts of sleep and rest combined and did not demonstrate a significant difference between the groups. However, the children's ages were from six months to five years and potentially quite a number of the younger children in the typically developing group would still be unsettled or requiring care overnight. There are no studies that have focused on fathers' sleep in families with disabled children.

The findings in the previous chapters document that both fathers and mothers with preschool children with disabilities have less total sleep and more fragmented sleep, than parents with children without recognised disabilities. The following discussion will explore the quality and quantity of parental sleep as well as some of the reasons and implications of the deficit experienced by parents of children with disabilities.

### ***7.2.1 Night work***

Children with complex health needs dependent on technology often have health care regimes which include interventions overnight. In this study this included predictable events like overnight ventilation or gastrostomy feeds, as well as less predictable events such as the need for oropharyngeal suction. Some parents needed to stay awake for the whole, or for large portions of the night, in order to be able to respond to the different events and to ensure that their child was safe. In effect they were working a

night shift although unlike paid carers there was no prospect of a day off the following day.

For one family, a package of care had been agreed that meant that a nurse and a carer provided the overnight care for some of the nights of the week, while the mother provided the overnight care the other nights. Packages of care for families with children with high level needs are still very difficult to arrange, expensive to deliver, inadequately commissioned and vulnerable to frequent disruption (Glendinning et al. 2001; Kirk & Glendinning 2004; Noyes, Godfrey, & Beecham 2006). Not having adequate and reliable support not only takes a physical toll on parents it also takes a mental toll. For this family, the package of care frequently broke down resulting in changes of personnel and sometimes parents finding out at the last minute that no-one was turning up. The constant worry and anticipation of being let down and left to do additional night shifts, placed an enormous strain on the parents. The father shared

*“They give all these promises and they don’t keep them. One of them nurses have the night off, then Rachel has to do it and everyone thinks oh it’s OK, it’s alright, she’ll be alright. And the carer doesn’t turn up. Rings up 10 minutes before they are due on, that makes you mad”*

In addition, the frequent changes of personnel undermined the parents’ trust that their child would be appropriately looked after leading to hyper vigilance at times and an inability to leave their child in the new person’s care (Dixon 1996), or an inability to relax and sleep. Again, this same father said *“I’m probably still only like half asleep if you will. I can get up 2 or 3 times in the night without, and just sit there and have a fag and then go back to sleep”*. This lack of trust in other people to care for their child appropriately has also been noted by Carnevale et al (2006) with one mother concluding *“right now, I’m fearful whenever they offer me services, because they are always poisoned services”* (Carnevale et al. 2006, pg e56).

Families in this study whose children needed less constant overnight attention still experienced disturbed sleep. This was partly due to the physical tasks associated with the technology being used as has been noted by Brotherton et al (2007). Other reasons included the need to be instantly aware of any problems their child might be experiencing such as becoming tangled in tubing, choking on feeds or secretions, or

having an epileptic seizure. Other authors have also noted that sleep can be disturbed due to the alarms of the various devices (Heaton et al. 2003a).

For some parents night time was a time when uncontrollable thoughts and fears occurred which also impacted on their sleep. One mother in this study commented

*“most of the time I just wake up and I feel so scary or I have nightmares, lots of nightmares, I still have the odd one and sometimes I just wake up and I'm sweating because I'm scared. I don't know, something like somebody just get me, yeah and I can't breathe, I just think and think”.*

Night time has been described as the period most associated with intrusive and intense thoughts, perhaps due to relaxation of conscious control or perhaps due to the lack of activity and distraction at night (Cohen 1995). While some parents in this study experienced these intense fears and nightmares, they appeared to be more common for the parents' whose child had a life limiting or life threatening condition, as also reported by Cohen (1995).

While packages of care, including overnight care, are difficult to arrange for children with complex health needs dependent on technology there is at least some recognition by service providers and commissioners that these are required. However, it is clear from this study that it is not only the parents with children with complex health care needs that are performing a night shift in order to keep their child safe and respond to their needs overnight but also the parents of children with autism. Parents of children with autism often went to extraordinary lengths to achieve some peace of mind that they would be aware if their child needed them, in order to allow themselves to go to sleep. Despite this none of the families in this study with a child with autism received any respite care or any packages of support within the home. This may be another reason why the fathers of children with autism were more active in contributing to the overnight care albeit at a considerable cost to their own sleep requirements.

### ***7.2.2 Sociological aspects of sleep***

While there is a considerable body of literature on the physiological and health implications of sleep and sleep disorders there is now also a growing body of literature on the sociological aspects of sleep. Previously sleep was considered as a private event during which we were unaware and removed from society's normal

rules and expectations (Meadows et al. 2008b). More recently sleep has been recognised as “*both a shared human biological universal and a time of sociological interaction*” (Meadows 2005). Particularly for couples, sleep is a significant time and closely linked with their personal and intimate relationship (Venn et al. 2008). The importance of this aspect of sleep was clear from this study, where several parents mentioned their altered sleeping arrangements to accommodate the needs of their child with a disability, adversely affecting what they considered to be an important time with their partner. Different parents approached these challenges in different ways. For some parents, the importance and closeness of sleeping together meant that they continued to share a bed and for both to be disturbed, rather than choosing to sleep separately. For other parents, the decision was made to either sleep separately, or to have a variety of places where they could sleep depending on how the night went. However, this was considered to be going against what was ‘normal’. Meadows (2005) referred to the ‘negotiated night’ in situations where the sleeping arrangements were shared. Therefore, the needs and desires of both parents and sometimes children are ‘negotiated’ in order to determine the sleeping arrangements. In this study there was an additional ‘body’ to consider for some families in their night negotiations: the service providers.

Meadows (2005) described a theoretical framework for considering the embodiment of sleep. This consisting of four modes: ‘normative’, ‘pragmatic’, ‘experiential’ and ‘visceral’. The normative mode relates to what opinions and perceptions are associated with healthy sleep behaviour. This also encompasses societal expectations and therefore, for many couples in this study and also in Meadows work, normative behaviour includes sleeping together without anyone else present.

The ‘pragmatic’ element is closely associated with function. Therefore, sleep behaviour is affected by the need to fulfil certain roles. Both fathers and mothers in this study talked about the need to ensure that they caught up on sleep when they could and how they prioritised sleep over social activities in order to fulfil their roles and responsibilities. However, the pragmatic element acknowledges that an individual’s social roles can prevent sleep being prioritised, despite the need for sleep to perform their functional roles (Meadows 2005). Again, this aspect was noted in this study with mothers in particular consciously deciding to have less sleep and provide

more care at night than their partners, due to the need to ensure their partners achieved enough sleep to be able to travel safely and perform their work duties.

The 'experiential' mode relates to how tired or well rested an individual feels. Frequent feelings of tiredness and exhaustion by parents in this study resulted in less harmonious negotiations of responsibilities at times, both during the day and night and consequently stress and tension in relationships. For some parents this contributed to their feelings of going into 'survival' mode where things were done and decisions made in order to survive, rather than out of consideration for their partner's needs. This was particularly seen in the 'dictatorship' group where decisions about where the child slept were not always negotiated or agreed. However, this was also related to trust as previously highlighted.

The final mode described by Meadows (2005), the 'visceral' mode, relates to an individual's need for sleep. Different people have different basic physiological requirements for sleep, and also feel more energetic or engaged at different times depending on whether they are a 'morning' or 'night' person. Again the tensions this can place on the sleep habits of partners were evident in this study. One father, who started work very early, described the problems arising from his wife being a night person and him being a morning person. He would stay up as this was the only time they had together but felt so tired that he did not enjoy it and started to resent his wife for not adjusting some of her behaviours. Another mother described the problem she had with having quite a high requirement for sleep, so that she found the sleep loss associated with caring for her child with additional needs unbearable, while her husband appeared to be able to cope with it much better.

Therefore, the sociological aspects of sleep as well as the physiological aspects can be seen to be of importance to parents' of children with disabilities. An additional sociological aspect not yet considered in this discussion of sleep is gender, which will now be discussed.

### ***7.2.3 Gendered aspects of sleep***

Incorporated into traditional concepts about parental roles is who looks after children at night. This continues to have a strong influence on many families, with the mother



being expected to play the main role in looking after children in most families (Venn, Arber, Meadows, & Hislop 2008). In many instances this does not seem to be open to 'negotiation' Venn et al (2008) highlighting that mothers continue to provide the main caregiving role overnight for their children even when they have returned to paid employment, despite one of the main justifications given for mothers initially taking the 'night shift' being the fact that fathers but not mothers were in paid employment.

What is striking in this study is how involved in overnight care fathers of children with disabilities were in contrast with fathers of typically developing children. This was particularly pronounced for fathers with children on the autism spectrum, but fathers with children with complex health needs dependent on technology were also involved. This involvement encompassed both the physical aspects of caring and also the sentient activity of being acutely tuned into their child's needs and therefore being aware very quickly when their child might need them (Venn, Arber, Meadows, & Hislop 2008). Interestingly, in Venn et al's (2008) study of 25 heterosexual couples with children, only two couples reported that the father was actively involved in responding to young children's needs. One of these couples had a five year old son with degenerative kidney disease and shared night-time caring with his wife, and the other couple had twin boys with autism aged four and the father was the main night-time carer. It is also apparent from Brotherton et al's (2007) study of parental perspectives of gastrostomy feeding in children that some fathers were actively involved in caring for their children overnight.

However, gender has more of an influence on sleep than just traditional parenting roles. Not needing sleep or managing to function on a few hours of sleep can be regarded as an indication of masculinity (Meadows et al. 2008a) and there was evidence of this machismo from some of the fathers in this study. One father who was very involved in looking after his son with autism, went into quite a lot of detail about his exploits over the years in proving to his friends and family how little sleep he required and he very much equated this to other aspects of his masculinity such as his large size and considerable strength. While he recognised that not having sufficient sleep may have a negative impact on his health, this 'risk taking' behaviour was also linked into his idea of masculinity (Courtenay 2009).

Men's and women's thoughts about sleep have been shown to vary, with men regarding sleep more as an unwanted necessity that often interrupts other things they want to do, but women regarding sleep more as a pleasurable activity and of importance in itself (Meadows, Arber, Venn, & Hislop 2008a). An exception to this in Meadows et al's study (2008a) was a couple with children with unspecified special needs. Not unexpectedly, the wife agreed with the question that sleep was important. However, the father stated that he would not have agreed with the statement that sleep was important except that he had children with special needs which placed a greater demand on him, meaning that sleep was now important (Meadows, Arber, Venn, & Hislop 2008a). Both fathers and mothers in this study, regarded sleep as important and it was a frequent issue discussed in the interviews. Both fathers and mothers emphasised how hard it was to cope without sleep, with one father equating the lack of sleep to a form of torture. Lack of sleep as highlighted earlier is known to have health implications and this has been taken into consideration when producing health and safety rules with regard to employment, as are considered in the next section.

#### ***7.2.4 Worker's health and safety rights***

Due to the many demands on individuals' time, particularly those who are working and who also have children, sleep can be compromised or reduced during the week although the weekend offers an opportunity for compensatory rest (Bin 2011; Robinson & Michelson 2010). However, this opportunity for compensatory rest was less apparent in this study for fathers in the ASD group and virtually non-existent for mothers in the TD group.

Health and safety rules for workers in the UK and most other European countries state that workers should not have to work for more than 48 hours per week and are entitled to one day off each week (Citizens Advice Bureau 2011). The amount of time that the majority of mothers, particularly in the TD group put into caring for their child with complex health needs would more than equate to a full time job, but there was no opportunity for a day off a week or an alternative means for acquiring compensatory rest. This contravenes basic health and safety laws and should be considered when evaluating the need for appropriate respite services.

The lack of a 'day off' as well as insufficient sleep contributes to the poor health and increased stress levels that many parents of disabled children and other carers experience. A recent report highlighted that up to 40% of carers experience psychological distress or depression and that carers have an increased rate of physical health problems (The Princess Royal Trust for Carers & The Royal College of General Practitioners 2011). A lack of feeling of control over the situation or things changing in the future also contributes to the psychological distress and pressure (Dunn et al. 2011).

Zuzanek and Smale (1999) in their reflections on the collective rhythms of life highlight the importance of Sundays and the need to have a day which is recognised to be different from other days in order to help break time up into weeks instead of endless days. Again for some of the mothers in particular, in this study, the psychological toil associated with relentless caring may have been exacerbated by the sameness of the caring tasks to be performed day in and day out. Sleep and the lack of it, are also known to have a direct impact on mood and emotions which will now be considered.

### ***7.2.5 Impact on parenting and mood***

Many parents reported that all aspects of life were more difficult to cope with when they were tired. In addition, several parents commented it was often tiredness that led to friction and tensions in the relationship with their spouse. These findings have also been noted in the Contact a Family study looking at the relationships between parents with a disabled child (Acton Shapiro 2003). In the Contact a Family study, 72% of respondents had experienced tiredness/lack of sleep and the comments about the impact this had on daily life and on relationships were very similar to this study.

Looking at the same situation but from a different angle, a subsequent study also by Contact a Family asked parents 'What makes my family stronger?' (Bennett 2009). Thirty percent of respondents said that a good night's rest would make them stronger socially, while 34% stated that it would make them emotionally stronger. Despite this a large number of respondents (number not provided) indicated that short breaks were not applicable to them. The authors were surprised about this finding and uncertain as to its reason. The findings from this study, suggest that it may be due to parents not

considering that short breaks are an option for them, as they would not trust anyone else with the care of their child. Interestingly, the option with the highest response with regard to what would make families stronger emotionally in the Contact a Family Study (Bennett 2009), was having a supportive relationship with their partner, with 52% of respondents indicating this option.

In a study of mothers with physically disabled children in Canada, Tetreault et al (1994) found that 54% of mothers reported that 'sleep' used as a coping mechanism was always helpful. Although, further elaboration of what is meant by sleep as a coping mechanism is not provided in the article, it would appear to refer that either getting sufficient sleep or having the opportunity to catch up on sleep, enabled mothers to cope better with their situations.

Tiredness and fatigue while clearly related to sleep quality and quantity are also related to other psychological issues as has already been highlighted. Cooklin et al (2011) identified inadequate social support, poorer diet and ineffective coping styles such as self-blame and behaviour disengagement, as contributing to parental fatigue. Of concern, but to be expected, higher fatigue was also significantly associated with lower parental competence, greater parenting stress and more irritability in parent-child interactions. While Cooklin et al's (2011) study was not with parents of children with disabilities, there would be every reason to expect similar findings if such a study was to be performed.

### **7.2.6 Summary**

This study has demonstrated that the quality and quantity of parental sleep in families with a disabled preschool child are reduced when compared to similar families with a typically developing preschool child. This has a negative impact on parents' health and wellbeing and can have an influence on many different areas of life. While the nature of sleep clearly has important physiological and psychological implications, it also has sociological ones. Involving both parents in this study has facilitated the exploration of gender and other sociological issues. Although gender has an influence on parental roles during the night-time period, the presence of a disabled child affects this influence. Therefore, fathers play a much greater role in looking after their child at night if their child has a disability compared to their role with a child without any

recognised disability. An additional factor that can influence physical and psychological restoration and recharging is leisure, and this will be considered in the following section.

### **7.3 Leisure**

Leisure has become an area of increasing interest in time use, economic and sociological studies. This has resulted in debate about the nature of leisure and has led to the concept of leisure ‘quality’ (Sevilla-Sanz, Gimenez-Nadal, & Gershuny 2011). Therefore, quantity of leisure time is no longer the only important variable to consider when evaluating variations in leisure participation and opportunities and inequality between groups (Bittman & Wajcman 2000; Sevilla-Sanz, Gimenez-Nadal, & Gershuny 2011).

Leisure provides opportunities for mental and physical refreshment and recharging. Participation in active leisure has a positive impact on health helping to control weight, reduce the risk of cardiovascular disease, some cancers and type 2 diabetes, strengthen bones and muscles, and improve mental health and mood (Centers for Disease Control and Prevention 2011). Leisure also provides opportunities for social contact and usually involves doing an activity that the person wants to do, as opposed to being obligated to do. Therefore, leisure is often considered in relation to quality of life (Bittman & Wajcman 2000).

Data already presented in the previous chapters have indicated that the quantity and quality of leisure varies between parents with a disabled preschool child and the comparison parents. This was found to be the case for both mothers and fathers. The following section considers some of these differences in relation to leisure quality including the sociological aspects of leisure, and the impact of gender on leisure time.

#### **7.3.1. Leisure quality**

Sevilla-Sanz et al (2011) in their study of leisure in the US from 1965 to 2003 found that while absolute quantities of leisure time have increased over this period, the quality of leisure has actually decreased across all groups in society. Interestingly, these authors also showed that ‘highly educated’ individuals now have substantially less leisure time than ‘low educated’ individuals, in a reverse of previous trends.

However, the decrease in the amount of quality leisure time was noted to be much less for 'highly educated' individuals compared to 'low educated' individuals. Thus, individuals with more human capital are apparently prioritising quality over quantity with regard to their leisure.

Various features can be considered when assessing the quality of leisure. These include whether the leisure is 'pure' or 'uncontaminated' by other simultaneous activities, who else is 'co-present' which may increase or decrease leisure quality and the degree of 'fragmentation' (Bittman & Wajcman 2000; Sevilla-Sanz, Gimenez-Nadal, & Gershuny 2011). Alternatively asking individuals to classify their enjoyment of activities can lead to some understanding as to the subjective quality of the activity (Krueger 2007).

As has already been discussed in Chapter 4 in the section on 'intensity', this study considered whether the leisure was 'pure', who else was present and 'fragmentation' to judge leisure quality. Although time with children, and particularly time playing with children, can often be considered leisure and enjoyable, children's presence is associated with an element of responsibility on the behalf of the adult and also 'constraint' to the type of leisure that can be participated in (Bittman & Wajcman 2000). Therefore, when considering pure leisure in this study, both the lack of other simultaneous activities and the absence of children for whom the adult could be considered responsible, were used as definitional elements.

Previous research has indicated that parents with a disabled preschool child can become socially isolated (see for example Acton Shapiro 2003; Bennett 2009; Brotherton, Abbott, & Aggett 2007; Carnevale et al. 2006; MacDonald & Callery 2004; Smith 1986; Wang & Barnard 2008; Woodgate, Ateah, & Secco 2008; Yantzi, Rosenberg, & McKeever 2006). Leisure time with other adults is important in maintaining relationships, preventing feelings of isolation and contributes to the quality of leisure time (Bittman & Wajcman 2000; Pentland & McColl 1999; Sevilla-Sanz, Gimenez-Nadal, & Gershuny 2011). The time use diaries in this study only documented the co-presence of immediate family members. However, parents in the ASD and TD groups frequently spoke of the difficulty they had finding the time to

spend with friends and to a lesser extent, their extended family. This was particularly the case for time outside the home and without children present.

Only three of the families with a disabled preschool child were using formal respite opportunities. None of the families with a child on the autism spectrum had access to respite or had been offered this. Families who were accessing respite had not found it an easy service to accept but once it was established, found it very valuable. Reluctance to accept respite was often due to concerns about trusting other people to look after their child. It was also sometimes due to the fact that the offered respite was not what the parents wanted but no alternatives appeared to be available. This lack of availability of appropriate respite facilities has been highlighted previously (Acton Shapiro 2003; Bennett 2009; MacDonald & Callery 2004). MacDonald and Callery (2004) discovered that parents, nurses and social workers can have different ideas about respite. Social workers valued respite within the home and with the family present, while nurses and parents saw the value of the child having the opportunity to have respite out of the home without family members present. This enabled the family to spend their time in a greater variety of ways.

Fathers in the ASD group had significantly less quality leisure time than the comparison group fathers and this was predominantly the case at the weekend. When parents were considered as couples, couples in the ASD group had significantly less quality leisure time than the comparison group couples. This may at least partly be due to the lack of respite opportunities provided. The more equally shared child care arrangements in the ASD group couples also contributed to the reduction in the ASD group fathers' leisure time compared to the fathers in the ND group. However, it did not lead to an increase in the quality leisure time for mothers in the ASD group.

Barnett and Boyce (1995) in their time use study of 237 mothers and 134 fathers of a child with Down syndrome, and 216 mothers and 174 fathers of children without Down Syndrome, also found differences in the amount of time spent by parents on social activities and leisure. Mothers in two parent families with a child with Down Syndrome, spent less time on social and leisure activities, particularly active leisure than comparison mothers but it was not only mothers who were affected. Fathers in the group with a child with Down Syndrome, spent two hours fewer a week in social

activities than fathers in the comparison group. In addition, they spent about half an hour less per week participating in passive leisure but about half an hour more per week participating in active leisure. However, the children in Barnett and Boyce's study (1995) ranged from three to 17 years of age and the inclusion of school age children is likely to have an impact on parents' time use.

Although, quality leisure may be defined as leisure when an individual is not responsible for children, many families both in this study and previous studies wanted more opportunities to participate in leisure as a family (Acton Shapiro 2003; Bennett 2009). While parents described the difficulties in physically getting out the home, as has also been highlighted by Yantzi et al (2006), for many parents a considerable problem with going out was the attitude of society and the perceived stigma associated with their disabled child. This was the case both for parents of children with visually apparent physical disabilities and parents of physically healthy children on the autism spectrum. Twenty-five out of the 26 parents interviewed in a study about respite care (MacDonald & Callery 2004) commented that one of the benefits of respite was the opportunity for the family to be a 'normal' family when their child with a disability was not present. This included not having to deal with the unwanted attention from strangers as well as the freedom to engage in activities without large amounts of planning.

In common with Gray's (2002) study of parents of children with autism, many parents in both the TD and ASD groups experienced 'felt' and 'enacted' stigma. Felt stigma, corresponded to parents with a disabled child believing that they were considered different, due to their child's disabilities. It also related to feelings of being judged on their child rearing abilities or being made to feel embarrassed or not wanted in a situation. Enacted stigma related to the active avoidance of social contact by friends and family members, overtly hostile staring by strangers and rude comments. Therefore, stigma resulted in reduced social contact and family leisure opportunities due to parents' avoidance of situations which might potentially become embarrassing and challenging, and other peoples' avoidance of social contact with them. However, in contrast to Gray's (2002) study suggesting that mothers were more likely than fathers to experience enacted stigma, it appeared to be that either parent could experience enacted stigma in this study. However, how parents reacted to these



episodes differed. More mothers spoke of being upset about it while fathers tended to be more likely to feel angry about what had occurred, but to feel upset for their wife's distress.

Gender does not only influence parents' reactions to stigma but also potentially has an influence on leisure opportunities and the subjective experience of leisure. Bittman and Wajcman's (2000) study of leisure time and gender equity using time use data from ten countries including the UK, demonstrated that women's leisure was more fragmented than men's and consisted of less adult leisure time. These differences were most marked for parents with young children in comparison to adults without children. While absolute totals of leisure time between men and women were similar, the quality of leisure time for women was lower, suggesting a gender equity gap with regards to leisure.

This study has not focused on absolute totals of leisure time but has concentrated on quality leisure time. As shown in Chapter 4, across all the groups, men experienced more quality leisure time than women but this difference was most marked in the families with typically developing children. In these families, fathers were participating in quality leisure for an average of 42 minutes more per day than mothers. In the TD group, this difference was just less than 11 minutes and in the ASD group, just less than eight minutes. Again looking at Bittman and Wajcman's study (2000), the total leisure time spent by that parents with children younger than four years of age, without being responsible for children, was 6.62 hours per week for men and 4.00 hours for women. Although this is not exactly the same as the measures used in this study, it is very similar and allows some comparison. In this study, fathers in the ND group spent 7.07 hours per week in quality leisure and mothers spent 2.17 hours. Interestingly, mothers in the TD group had more quality leisure than mothers in the other groups, with 5.11 hours per week, but still less than the fathers who had 6.37 hours a week. However, fathers and mothers in the ASD group had the lowest totals of quality leisure time a week with fathers experiencing 2.17 hours and mothers 1.26 hours.

### **7.3.2. Summary**

Like sleep, leisure quality is reduced in families with a disabled preschool child when compared to families with typically developing young children. This is a concern as families with preschool children are already disadvantaged with regard to quality leisure when compared to parents with older children or adults without children. While a gender equity gap persists in parents' participation in quality leisure, this is reduced by the presence of a child with complex disabilities. Parents with a child on the autism spectrum appeared to be experiencing the fewest opportunities to participate in quality leisure.

In the following sections the ways of potentially addressing these shortfalls in sleep and leisure opportunities for parents with children with disabilities are considered, particularly in relation to building and strengthening their trust relationships.

### **7.4 Building and Strengthening the Web**

As discussed in Chapter 6, trust is a key component in all relationships. Parents are part of an organic, dynamic, complex web of relationships with trust forming the connecting threads (Figure 5.2). These relationships do not exist in isolation but are multiply connected by varying bonds of trust between different relationship groups. Chapter 5 discussed how the quality and quantity of these bonds of trust have an impact on parents' daily lives and Chapter 6 discussed how differences in levels of interparental trust had an influence on parents' time use and their quality of life.

The quality of the parents' relationship has been shown to be important in previous studies of families, including families with children with disabilities (Acton Shapiro 2003; Baxter & Smart 2010; Boyraz & Sayger 2011; Tetreault, Weiss-Lambrou, & Vezina 1994; Trute & Hiebert-Murphy 2002; Woodgate, Ateah, & Secco 2008). It has been shown to be important in predicting parenting stress and overall family adjustment in families with a disabled child, although Trute and Hiebert-Murphy (2002) suggest that the impact of the quality of the parents' relationship on the wellbeing of fathers, maybe less profound than it is for mothers. Nevertheless, fathers see their partners as their main source of support in the majority of families, with over 77% of fathers in the 'Recognising Fathers' national survey (Towers 2009) agreeing

with this statement and the majority of fathers in this study, also regarding their partners as their main source of support.

Boyraz and Sayger (2011) found that family cohesion and paternal self-efficacy played an important role in the psychological wellbeing of fathers of children with disabilities. Arguably what is described as 'self-efficacy' in Boyraz and Sayger's study (2011), could be equated with 'trust in oneself' in this study. However, the quality of the parents' relationship is not only of importance for the parents themselves but also for their children. A recent study in Australia of fathers with young children in couple relationships (Baxter & Smart 2010) found that marital quality was a consistent and important factor in explaining variations in fathering behaviours. There were found to be positive associations with the amount of time that fathers spent with their children, the amount of co-parenting that occurred and the use of more positive parenting styles. In addition, the quality of the marital relationship directly correlated with outcomes for their children. These child outcomes were both socioeconomic and learning.

Therefore, how parents cope and respond to the situation of having a child with disabilities depends on the quality of their couple relationship and therefore on interparental trust. Other coping strategies that parents employ also involve trust and these will be discussed in the following section. While the focus of this study up to this point has been on the interparental trust relationship, it is important when considering trust relationships in families with a disabled preschool child to also consider the family context. Rather than considering the parents' relationship or other relationships with a particular family member in isolation, the family needs to be considered as a 'system'. As Bronfenbrenner (1979) highlights the family 'system' also needs to be placed in the context of the community and wider society. To redress the balance on the consideration of trust relationships, relationships with others, such as health care providers will be discussed later in this chapter. This discussion includes ways to promote the quality of these trust relationships and a consideration of the quantity of strong trust relationships that are realistic or achievable.

#### ***7.4.1. Parents' coping strategies***

This study has highlighted that parents do not experience the additional challenges of having a child with complex disabilities in the same way, with trust in different relationships and particularly interparental trust influencing positive adjustment and coping. Trust is mentioned in the literature about parents coping with a child with disabilities or individuals coping with chronic or disabling conditions.

Tetreault et al (1994) suggested four different predictors for the degree of burden that mothers experienced when they had a physically disabled child. These were the amount of time the mother spent on caregiving, the secondary health problems of the child, the number of years the mother had been married and the mother's use of specific coping strategies. The first two predictors related largely to the level of complexity of the health needs of the child. The third issue was described as relating to marital stability and the quality of the parent's relationship, and therefore related to interparental trust. The fourth predictor highlighted that more positive coping strategies such as facing reality, changing expectations and asking for help decreased the perception of burden, while negative strategies such as hiding feelings and blaming self, increased the burden. Taking into consideration the findings from this study, the positive strategy of 'asking for help' would suggest the acceptance of the need to trust others. This would potentially include parents trusting others with the care of their child, rather than trying to manage everything themselves.

Two of the eight trust relationships discussed in Chapter 5 were 'trust in healthcare providers' and 'trust in God'. Trust in doctors and trust that treatment will work, as well as trust in God or spiritual support are considered positive coping strategies while distrust and pessimism are considered to be negative coping strategies (Abbott 2003; Dunn, Burbine, Bowers, & Tantleff-Dunn 2011).

There is a growing assumption that the use of positive or optimistic coping strategies can enhance quality of life and facilitate treatment adherence (Abbott 2003). While avoidance is generally considered a negative coping strategy and associated with poorer treatment adherence, there is some evidence to suggest that avoidance is better than active coping in uncontrollable situations and is a way of maintaining psychological health and a degree of normality (Abbott 2003; Cohen 1995). In this

study, some parents did appear to demonstrate some avoidance coping strategies that led to less engagement with health appointments and interventions. However, other parents used the avoidance of dwelling on the seriousness of their child's condition as a positive way of coping and being able to continue to function on a daily basis without becoming overwhelmed by the reality of their situation. This is an important strategy to recognise and differentiate from denial, as the way practitioners support parents will be very different in the two situations (Cohen 1995). Nevertheless, it is not without its negative aspects. Dunn et al (2011) found that this type of 'distancing' (as they described parents' avoidance of continually acknowledging the seriousness of their child's condition), corresponded to increased depression in parents of children with autism. Interestingly though, 'distancing' tended to be associated with less social isolation. The authors suggested that parents who were not able to use some 'distancing' placed a strain on their social relationships which lead to increased social isolation. Perhaps counter intuitively, no direct relationship was found between social support and isolation, suggesting that some of the parents felt isolated despite the presence of social support. Dunn et al (2011) found it was the type of coping strategies that were used, particularly escape and avoidance and failure to use positive reappraisal, that were associated with feelings of isolation and that negative coping styles were also a predictor of spousal problems.

What is clear from this study and has been noted in other studies, is that having a disabled child is not a dichotomous experience; many parents experience both positive and negative feelings and recognise both joy and hardship in their situation (Boyras & Sayger 2011; Carnevale, Alexander, Davis, Rennick, & Troini 2006; Towers & Swift 2006; Trute & Hiebert-Murphy 2002). However, it is the balance of these experiences and the parents' overall evaluation of them that correspond to parents' well-being and quality of life. Recognition of this has led Trute and Hiebert-Murphy (2002) to devise the "Family Impact of Childhood Disability Scale (FICD)". The FICD provides a parental appraisal of the impact of childhood disability on the family, with the total score providing a balance between the positive and negative aspects. The questions in the scale highlight some of the positive and negative experiences expressed by parents in this study and can be found in Appendix J.

Trute and Hiebert-Murphy (2002) found that the total score provided a significant predictor of future parenting stress of mothers and fathers even when controlling for other important variables such as marital adjustment and the level of disability of a child. Interestingly, while there was a correlation between mothers and fathers on the negative subscale scores there was no relationship between the positive subscale scores. What is particularly useful about this scale is that it is looking at the impact on the family system rather than the parental subsystem or the child's subsystem, although it is relying on the parent's appraisal of this impact. The importance for the family that they are viewed as a whole, as opposed to individual members in isolation, is discussed in the next section.

#### **7.4.2 Family systems perspective**

The family systems perspective as advocated by Seligman and Darling (1997; 2007) is derived from both the sociological and psychological literature. It *“views the child as part of a family system of interacting units and a social system of interacting families, individuals, and social institutions”* (Seligman & Darling 2007, pg 15). It also

*“rejects the view that linear relationships characterize family life and that the only important relationship is that between a mother and her child. Instead families are viewed as interactive, interdependent, and reactive”* (Seligman & Darling 2007, pg 17).

Not all families are the same but are made up of a variety of subsystems. These subsystems are dependent on whether the family is a traditional (in Western societies) two parent family with their biological children living with them, single parent families, families made up of different generations or 'blended' families with a number of different parent figures. The subsystems are also dependent on which point along the life cycle families are on. For instance, whether there are young children in the family or whether the children have grown up and are leaving home.

Most researchers refer to three main subsystems within families; the 'spousal', 'parental' and 'sibling' subsystems. A fourth the 'extended family' subsystem is also sometimes considered (Seligman & Darling 2007). What is fundamental to this systems perspective is that interfering with one subsystem has a high probability of having an impact on the other interrelated subsystems. Therefore, while it may be considered a positive intervention to promote and strengthen the relationship between

a mother and her child, this may in fact negatively impact on the relationship between the parents, the father's relationship with the child, sibling relationships or the mother's relationship with other children (Seligman & Darling 2007).

The family systems perspective incorporates the social ecological model (Bronfenbrenner 1979) and considers not only the subsystems within the family but also that the family is located within their community and within wider society. Therefore, changes and circumstances in these systems also have an impact on the family. Likewise the relationships formed with other families and service providers and the way these are influenced by political and economic events impacts the members of the family with a disabled child. According to Seligman and Darling (2007)

*“It simply is not sufficient to study only the child, the child and his or her mother, or the dynamics occurring within the family. It is becoming increasingly important to examine the family within the context of larger social, economic, and political realities” (Seligman & Darling 2007, pg 34).*

Although these are ideals that many service providers would agree with they are not necessarily easy to achieve. For instance, one of the problems in working in this way is that the majority of paediatricians and many other practitioners working with families have not had the training in parenting styles and assessing parenting support needs that facilitate family centred support (Kellett & Apps 2009). Rather the focus of training has been on the child only.

However, according to Robinson (1996) some families have an expectation that health care providers, such as nurses, will support family relationships when offering interventions for families with a member with a chronic health condition. She suggests

*“from the families’ perspectives, interventions that made a significant difference were primarily those that promoted and enhanced particular kinds of relationships: among family members and between the family and the nurse” (Robinson 1996).*

It is therefore of crucial importance to consider and incorporate the family systems perspective into interventions that promote trust relationships.

### ***7.4.3 Promoting trust relationships***

In Chapter 6 the importance of trust in the relationship between parents was explored and highlighted. However, when considering family systems theory and social ecological theory it is clear that other relationships are also important and impact directly on the wellbeing of the family. Some authors suggest that forming positive trust relationships makes it easier to form subsequent positive trust relationships (Misztal 1996; One Plus One 2007) and therefore parents who have high levels of trust with each other may also be more able to trust others.

This study has suggested that the trust relationship between some parents and their children with disabilities had been adversely affected by earlier life experiences. These included the child having been born prematurely, not fulfilling parents' expectations or behaving in unpredictable ways. Parents may need to be supported to build a reciprocal trusting relationship with their child. This can be promoted by building parent's confidence in the care they are providing and preventing the child from being overwhelmed by too many practitioners and interventions (Limbrick 2009). Parents and their child need time to develop and nurture their relationship which may have had a very shaky start or still be compromised by pain, sensory problems, the need for unpleasant procedures or a lack of intuitive understanding of social relationships.

It is also clear from this study that it is important to widen the circle of trust outside the nuclear family so that parents are not just depending on themselves or their partner to meet all their family's needs. Additional support is required to relieve the relentless twenty-four seven need for care and support of their child highlighted in Chapter 5, and to prevent parents from feeling trapped at home. Increasing the quality and quantity of bonds of trust would enable parents' a greater quantity of opportunities, to engage in more or higher quality social and economic activities.

Dempsey and Keen (2008) in their review of family-centred services for children with disabilities highlighted four beliefs that underpin this type of care. These included: the belief that it is the family and not the professional who remains the constant in the child's life; the family is in the best position to judge their needs, including those of their child; the child is best helped by helping the family and understanding the community in which that family lives; and that families should participate in



decisions about the provision of services, be shown respect, have their strengths affirmed and work in partnership and collaboration with service providers. These beliefs are all of importance in promoting positive trust relationships.

When considering ways of promoting positive trust relationships it is also important to consider what barriers prevent the formation, or lead to damage of, the threads of trust rather than strengthening them. From listening to the experiences of the families in this study there were three main barriers to trust in other personal relationships. The first one was a lack of reciprocity in the trust relationship. The second, was not allowing sufficient time to build trust and expecting parents to take unacceptable 'leaps of faith' and the third was experiences of when trust has been broken. Each of these will be discussed in turn.

#### *7.4.2.1 Lack of reciprocity in trust relationships*

There is a body of literature that relates to promoting positive trust relationships between users of health services and the healthcare providers. However, there appears to be a lack of articles that consider how to promote service providers' trust in the service users. Nevertheless, there is the recognition that people will find it easier to build trust in an individual who is demonstrating trust in them (Calnan & Rowe 2004) and that a key characteristic of trust between a family and health care provider is that it is reciprocal (Lynn-McHale & Deatruck 2000; Thorne & Robinson 1988; Wilson, Morse, & Penrod 1998). Despite this many service providers expect parents to trust them without investing trust in the parents.

In the majority of cases it should be assumed that parents are in the best position to decide the priorities for their families and to weigh up the risks and benefits of various courses of action (Dempsey & Keen 2008). Many parents in the TD group in this study were expected to manage complex health care regimes within the home environment. This presented a number of problems in the relationship between parents and practitioners. For instance one mother stated

*"It's like all this retraining and everything, I go mad, so why are you retraining me, I'm not on your pay. I don't have to do what a nurse does, I'm a mum. But then they'll say, you're not competent to make a medical decision. But I do them all day. It's daft and I think I'm going round in circles 'cause all I'm doing all day is deciding on the ventilator, oh oxygen up, you do it all day. But then when you do*

*something and they don't like it you're not... what do they call it.  
You are not medically competent to make a medical decision"*

Wang and Barnard (2004) noted similar issues in their review of technology-dependent children and their families, with parents finding it challenging that they had to defer and comply with advice from professionals who had not necessarily carefully considered the parents' views and opinions.

Some parents in this study had had experiences where decisions they had made had led to professionals raising child protection concerns. For instance, concerns that the child was being placed at risk by engaging in activities with their family outside the home, rather than remaining in the more controlled home environment. While sometimes these concerns may be valid, as Bob Dale states "*life is to be lived – risks and all*" (Meyer 1995, pg 3). It is not in a child's best interest to be so protected that they never experience any opportunities even if these opportunities are more risky than doing nothing. Parents' expertise and knowledge should be trusted and respected and also their requests for help considered carefully. However, other studies have also recognised that this is not always the case (Hobson & Noyes 2011; Kirk & Glendinning 2004; Kirk, Glendinning, & Callery 2005; Towers & Swift 2006; Wang & Barnard 2004) with perhaps fathers being less likely to be trusted than mothers due to professionals' gender discrimination and assumptions about caregiving roles and levels of parental expertise. However, practitioners' own prejudices and beliefs about parenting and gender roles should not influence the way they work with families. Practitioners should trust parents working out their own roles and support these different configurations. Fathers who take the lead role should be trusted and respected and equally mothers should not be made to feel that they are neglecting their essential role in these situations. Likewise, fathers should not be forced into roles that they and their partner do not want but which practitioners view as desirable (Featherstone 2009).

A recurring story from many of the parents in this study was how requests for additional support from social care were turned down because their child's needs were considered no different to other typically developing children of that age or because they were 'coping'. This suggests that there is a lack of trust and respect by practitioners of parents' evaluation of their situation and need for help. Brotherton et

al (Brotherton, Abbott, & Aggett 2007) also found that many of the unmet needs of parents of children with gastrostomies were not clinical needs but social needs. However, it should not be the case that services wait for parents to stop coping before they intervene. Mencap's 'Breaking Point' campaign highlighted that eight out of ten parents and carers of individuals with disabilities had reached breaking point due to not receiving the support they needed. Despite an increase in Government funding, many families with complex needs still do not receive any short break services, or receive fewer services than they received in 2008 (Mencap 2010).

An additional problem with the lack of reciprocity in the trust relationship between practitioners and parents is the time element. Practitioners often require time to assess the child and their family and to validate the information that parents have often already given them. This can be a source of frustration for parents but also presents a challenge for practitioners who have to consider "*whose knowledge counts – the parent's, the professional's or both?*" (Brotherson & Goldstein 1992). However, time is also important from the parent's perspective in order to enable trust to develop. One of the major problems parents in this study reported that prevented them from accepting help or trusting others was people not allowing sufficient time for trust to build.

#### *7.4.2.2 Not allowing sufficient time for trust to build*

As stated previously, a helpful model to follow is the 'small-wins' approach to building trust (Vangen & Huxham 2003). If services from inpatient hospital health care, to therapists, to nursery and educational providers were to follow this model, parents and practitioners would have the opportunity to build much stronger trust relationships. One of the reasons many parents in this study reported a strong appreciation for Portage intervention and Specialist Health Visitor support, may be due to the gradual, consistent building up of a trusting relationship over time. A supportive system by nurses which gradually builds trust overtime while recognising the need to support all the family's subsystems is PRIFAM and evaluations of this approach have been very positive (Pelchat 2010). However, too often parents appear to experience an all or nothing approach. Parents can wait for services for many months and then are expected to instantly accept and follow what ever interventions and advice are given by professionals who the family have just met.

Not allowing time for trust to build can present a particular challenge with regard to childcare, including respite services. In this study, some parents found that childcare providers were reluctant to allow parents to initially stay with their child to help them to settle in and build relationships. However, one family found the nursery would only accept their child with autism if the mother stayed with him the whole time. This meant that the mother did not get a break and she also felt that the child's nursery experience was affected by her presence. A different family had been impressed by the special school nursery sending one of the members of staff to the family home to get to know the child and his usual routine and ways of communicating, before he started any sessions. For many parents concerns about their child's reduced capacity to communicate was one of the most important worries regarding other people looking after their child appropriately and their child being able to let them know if anything happened to them while they were not in their parents' care. This meant that many of the parents in this study did not feel that childcare or respite services were acceptable options. While service providers may interpret this as parents not wanting any additional support, the reality is that the support is not appropriate to the parents and their child's needs as trust has not been established.

Mencap's report "Still waiting for a break" (2010) highlighted some of these issues. Many parents reported that they did not trust the staff offering the breaks. This was often due to the fact that parents did not have confidence that staff had developed sufficient knowledge of their child or competency in meeting their child's needs. There was also a problem with the length of time between breaks and different staff being assigned to their child. Yantzi et al (2006) noted that often personal care workers rather than nurses were assigned to provide respite for children with complex health care needs and therefore were unable to fully meet the needs of the child leading to an appropriate lack of trust and confidence in the carers by the parents. They also highlighted the problems with frequent changes in staff and how this not only led to trust problems with the parents, but also increased anxiety and lack of trust by the child.

The Disabled Children Access to Childcare (DCATCH) evaluation (Abbott et al. 2011) highlighted that the two main barriers to the delivery of DCATCH was parents lack of trust in the ability of childcare to meet their children's needs and the resistance

to inclusive working encountered in some mainstream settings and local authorities. When the childcare worked, this was because trust had been established in the support staff and the childcare was provided flexibly in an individualised and tailored way to meet the family's needs. One of the ways this trust was achieved was by allowing time to fully assess the child's and parents' needs and time to find the most suitable setting to meet those needs. Interestingly, the evaluation noted that staff appointed in a 'brokerage' role were key to the success of the project. Part of this role was building up a relationship with parents and through this trusting partnership arrangement, facilitating parents' trust of the provision offered. This model has been shown to be successful in other situations and one that can be readily replicated. For instance, Vangen and Huxham (2003) highlighted the need to use someone who is already trusted to introduce new participants in a trust relationship, to facilitate the development of trust with them. Similarly, Lynn-McHale and Deatrick (2000) found that an effective strategy to build trust was to use people who had already established a level of trust to introduce a new nurse to a family with a member with a chronic health condition.

It is not always appreciated how many practitioners parents have to try and build supportive relationships with and the strain and stress this itself can create (Swallow & Jacoby 2001). Dickinson et al comment

*“To obtain the best care for their child, families must weave and negotiate a unique network of relationships between the practitioners of different professions. Because of their central position in relation to all these relationships, the child and family are most likely to experience and see the complex and intricate patterns of the web” (Dickinson, Smythe, & Spence 2006)*

However, having a smaller number of practitioners, or even one 'keyworker' to have a close trusting relationship with, may enable parents to manage these other trust relationships more easily. If this relationship is maintained it may also help parents when almost inevitably some of their other trust relationships are damaged or broken.

#### 7.4.2.3 Experiences of trust being broken

Chapter 5 includes a description about a family's experience of their child escaping from nursery leading to broken trust relationships with the nursery staff. However, this was not the only incident leading to broken trust relationships that parents' in this

study experienced. Most of the parents were able to recount many instances from the apparently trivial to the life threatening where other people had not lived up to parents' expectations with regard to the care of their child resulting in damaged trust. Some parents accumulated a core of professionals, family members or friends who they trusted but for other parents these experiences meant that they would either trust no-one except themselves, or themselves and their partner. This placed an enormous pressure on them and heightened experiences of stress. In many of the instances the person who had betrayed the trust would have regarded the incident as fairly inconsequential or after a heartfelt apology would have not considered it again. However, for parents these episodes were of great significance as they seriously undermined their trust and had long term consequences.

There did not appear to be any direct relationship between the type of interparental trust relationship that parents experienced and their responses to broken trust. None of the parents described incidents where they felt their partner had really let them down regarding the care of their child, although parents in the dictatorship group in particular, did describe the measures they had taken to ensure that this possibility could not arise.

Factors noted to damage trust between parents and professionals that are documented in the literature, include the perception that professionals do not value their child's life (Carnevale, Alexander, Davis, Rennick, & Troini 2006), poor communication or the perceived withholding of information (Kirk & Glendinning 2004; Swallow & Jacoby 2001) a lack of trust by the professionals in the parents' knowledge of their child (Kirk, Glendinning, & Callery 2005) and the perceived allegiances of the healthcare professional (Brownlie & Howson 2005). In other words, whether the parents judged that the healthcare professional acted solely in the best interests of their child or had been following hospital or government policy. Dixon (1996) suggests that "*when parental frustration and anger are high, it is usually the result of a loss of trust, lack of control and barriers to participation in care and decision making*" (Dixon 1996, pg 129).

Fathers in this study and in previous research, related to the 'protector role' (McNeill 2004; Swallow et al. 2011) for their child and their family. This also meant that they

were willing to risk damaging their relationship with providers in order to achieve certain important aims. For instance, fathers were willing to be unpopular with the healthcare team or to cause conflict, if they felt that they needed to advocate for their child and saw this as part of their protector role. Again some of the fathers in this study, and in other studies (McNeill 2004; Swallow et al 2011), saw their relationship with their partner as part of a team, with each partner's responses to situations balancing or compensating for the other's actions. Therefore as McNeill suggests

*“Understanding this behaviour in the context of the couple relationship and the way partners co-construct their respective roles, rather than solely on an individual's characteristics (e.g., unreasonable, difficult, hostile, angry) might provide a helpful vantage point for clinicians”* (McNeill 2004, pg 542).

This again highlights the value of the family systems approach, in that fathers' responses while often different to mothers' were nevertheless related to them, and needed to be considered within that family context (McNeill 2004). When there is evidence of problems with trust, providers should seek not to label family members, withdraw from them or try to re-establish a passive trusting relationship usually associated with naïve trust, but to try and move forward to a more co-operative caring model associated with guarded alliance (Thorne & Robinson 1988).

Therefore, there is evidence that the *“preconditions to the development of trust include competence, respect, being trustworthy, being reliable, communication, knowing each other and negotiation”* (Lynn-McHale & Deatrck 2000, pg 228), and the absence of these conditions prevents trust formation or leads to mistrust or broken trust. However, one of the other main challenges that parents in this study reported in addition to trust in personal relationships, was trust in society.

#### **7.4.4 Promoting trust in society**

For many parents in this study, one of the main barriers they experienced in their lives was perceived or experienced stigma. This fear of people watching, judging or commenting on their child or their parenting meant that some families were reluctant to go outside their homes particularly if they were unaccompanied by another adult. This has already been discussed in relation to leisure quality (see section 7.3.1) and therefore will not be further discussed here. However, there is a need to increase the

public's awareness of disability and the impact of their actions on families. Tolerance needs to be actively promoted but this is not an instant process. While there are many problems in the UK, the family in this study who had lived in other countries outside the UK, found UK society to be very tolerant and welcoming compared to their experiences elsewhere.

#### **7.4.5 Summary**

Trust is a fundamental component of relationships which are the essence of family life. Strengthening the complex web of trust relationships that parents are part of by promoting strong trust bonds has the potential to help address and minimise many of the disadvantages parents with a disabled child experience. Some of the current practices by service providers and society have been highlighted as impacting on the development of the optimal quantity and quality of trust bonds. It can be considered the moral duty of service providers, the government and society to ensure that parents' trust in them is appropriate.

#### **7.5 Conclusion**

This critical ethnographic study has focused on the areas where the minority subgroup of parents with a disabled child are disadvantaged in comparison to the majority group of parents with typically developing children, in order to bring about positive change. The study has provided a unique contribution to knowledge in identifying that the quality and quantity of sleep and leisure time are reduced for parents with a disabled preschool child decreasing opportunities for parents to 're-charge' and potentially having long term negative impacts on the parents' health and wellbeing. However, it has also provided evidence that levels of trust within couple relationships in families with a disabled preschool child exert a strong influence on parental time use decisions and perception of their quality of life. Therefore, supporting trust relationships, particularly between parents has the potential to improve the quality and quantity of sleep and leisure time for parents with a preschool child with disabilities.

While it is apparent that different levels of trust can occur simultaneously within a relationship, the "*optimality*" of these levels of trust will depend on the nature of the particular trust relationship (Lewicki, Tomlinson, & Gillespie 2006). Nevertheless, in this study higher levels of trust within the interparental trust relationship appeared to



be associated with more positive evaluations of family relationships, and higher parental health related quality of life and family functioning for both parents.

Despite this focus on the negative impact of having a child with high level additional needs, this study has also shown that there are many positive aspects to having a child with a disability and it is important that these are not overlooked. However, parents' experiences did not solely lie on one end of the positive to negative spectrum but rather they simultaneously included joy and sadness, enrichment and distress (Carnevale, Alexander, Davis, Rennick, & Troini 2006), challenges and rewards. The balance of these experiences resulted in parents' overall evaluations of their situations.

Unfortunately, it is clear that many of the challenges and causes of distress for parents were the result of the relationships and interactions with healthcare and other service providers. It is important that these messages are heard and that interventions are provided that are supportive, enabling and take the family systems perspective into consideration. It also needs to be remembered that whatever a parent is asked or expected to do in order to meet the needs of their child or family, means that they will not be able to do something else, as there is only so much time available for anyone to use.

A strength of this study is that it has considered all these issues from both fathers' and mothers' perspectives. There is evidence that for many mothers and fathers, having a child with disabilities had created the opportunity to develop a much closer and more involved parenting role than they had previously enjoyed. There was also evidence of a range of successful and different couple relationships and parental roles that need to be recognised and respected by service providers. Fathers' and mothers' roles and experiences were noted to be subjected to reciprocal influence, with the couple's relationship having a key effect on the development of parents' identities and roles.

These study findings and conclusions have resulted in a number of recommendations which are presented after a consideration of the limitations of this study and suggestions for further research.

## **7.6 Limitations of the Study and Suggestions for Further Research**

There are a number of limitations to this study. The time use diaries while completed well by the majority of parents were time consuming to analyse and therefore not all aspects of time use have been fully explored within this thesis. However, this analysis can be undertaken in the future. In addition, while childcare had been an intended focus of the study, it was not always clear who was taking responsibility for this from the diaries which meant that this was not able to be considered in the way originally intended. Slight adjustments to the diary design could help clarify these issues in future studies. The use of technology, with hand held devices being used rather than paper diaries would potentially be as straightforward for parents to complete and would facilitate more rapid analyses of the data. This would be an interesting potential area for future research and hand held devices have already been used in some time use studies.

Although the use of seven day diaries was very effective, the total number of participants and therefore diary days was still small. The use of the national data sets helped compensate for this, but not all aspects of time use were able to be compared. The other major way that the power of the study was going to be increased was with the involvement of matched comparison families. However, this proved to be the most challenging aspect of the study with recruitment of appropriately matched comparison families impossible to achieve. Although families with a disabled child were recruited from across the whole socioeconomic spectrum, comparison families tended to predominantly be middle class families.

The small numbers of participants had an impact on the interpretation of the quantitative data results from the time use diaries and the PedsQL<sup>TM</sup> Family Impact Module. While some of the differences in time use between the groups did not reach statistical significance this was likely to be due to the sample size. Despite the lack of a statistical difference, the differences may well be of clinical significance. This was also the case with the quality of life data. A statistical difference was not found between the results for fathers in the ASD group and the ND group for the physical functioning scale despite a 14.2 point difference, or between fathers in either the ASD or TD groups when compared with the ND fathers with regards to social functioning,

despite a 20.6 and 18.6 points difference respectively. However, differences of this magnitude would strongly suggest clinical significance.

The small numbers of participants and missing data from four parents affected the robustness of the interparental trust relationship model, and in particular, the defining of the dictatorship group. Therefore, this typology of relationships must be considered as provisional. A key area for future research would be to explore the validity of this typology by involving a much larger group of parents. This would also enable the impact the interparental trust relationship has on other trust relationships, to be explored.

Although data were collected on parents' moods by the time use diaries, these data cannot be considered an accurate reflection of parents' moods. The cartoon faces provided on a laminated card with the diaries, were to provide a prompt for parents and to enable the easy inclusion of mood information by the insertion of a number into the diary, rather than a detailed description. However, it is acknowledged that the 15 cartoon faces did not provide a clear mood scale and no attempt at validating their reliability was performed. In addition, the mood section was entirely optional with the majority of parents only completing a small number of time slots with mood data a day. Nevertheless, the inclusion of information about mood was very useful in guiding the interviews and highlighted particular time use activities that needed to be explored further due to their association with a particular mood or emotion.

This study has provided valuable information on the daily lives of parents with pre-school children. It would also be interesting and potentially enlightening to perform this same study on the same families now that their children are older, or other families with school age children, to assess the impact on families when the children/young people are in full-time education.

Finally, a further area of potential research would be to have the children/young people complete the time use diaries themselves which may be facilitated by the use of modern technology.

## **7.7 Recommendations**

1. Professionals, practitioners, commissioners, politicians and society in general need to truly value individuals with disabilities and their parents who are disabled by association. There needs to be a move away from everything being judged on its economic value and potential to a broader appreciation of diversity and quality that may not be immediately obvious or consistent with previous opinions and evaluations.
2. Service providers and commissioners should carefully consider the multitude of ways highlighted by this study that fathers are actively supporting their families in actions not seen or limited by practitioners' and professionals' expectations. A greater understanding and respect for fathers and their roles will help guide supportive services.
3. Parents should be supported to strengthen their interparental trust relationship, and given information regarding the importance and advantages of both parents being actively involved and supporting each other, recognising that there are many different ways of achieving this.
4. Service providers need to build positive reciprocal trust relationships with family members, including parents and the child with additional needs, taking the family systems perspective into consideration. The formation of reciprocal trust relationships can be facilitated by strong trust relationships with a small number of individuals, who can then promote the development of further trust relationships as required. The 'small-wins' approach (Vangen & Huxham 2003) should be considered as a potential model and time be allowed within service contracts to build these relationships.
5. Additional opportunities for respite and short breaks for families that are acceptable, flexible and tailored to meet parents', the child's and the whole family's needs should be available to families with young children with complex disabilities. Support should be provided to build up parents' trust and confidence in service providers and to build up providers' knowledge and competence. Time and resources are required to achieve these requirements and to ensure consistency of staff. The many time pressures, lack of sleep and lack of leisure opportunities for parents, and the difficulties of doing activities as a family when compared to families of typically

developing children of the same age, need to be recognised and all the challenges not just attributed to the child's young age.

6. The respite needs of families of young children with autism spectrum disorders need to be acknowledged. Support again should be provided to build up parents' trust and confidence in service providers and to build up providers' knowledge and competence. Time and resources are required to achieve these requirements and to ensure consistency of staff. In addition, the many time pressures, lack of sleep and lack of leisure opportunities for parents, and the difficulties of doing activities as a family, recognised.

7. Many parents undergo extensive training in how to use equipment, moving and handling, nursing tasks, therapy activities, communication strategies, behavioural management and sensory regulation. Despite this they have no formal recognition of their skills and abilities, no financial reward and by learning these skills ensure that no-one else is as good as they are at managing their child's needs, adding to their burden. Furthermore, 71% of the mothers in this study were considering working with individuals with disabilities in the future. Therefore, parents should receive formal recognition for the training they undertake. This should be in two ways. Firstly, they should receive a higher level of benefits if they have been recommended or required to undergo particular training or a parent course in order to meet their child's needs. These higher benefits would both recognise the additional time and effort required to meet their child's needs but also the difficulty and expense associated with employing someone else to look after their child if and when required. Secondly, they should receive some form of certification that is recognised by employers or goes towards recognised qualifications such as an NVQ in order to facilitate parents' future employment prospects.

8. Sufficient priority needs to be given to sleep problems in children with disabilities, and their parents, including resources for services that aim to address these needs. A specialised sleep service should be available in every district and seen to be part of core service provision.

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## APPENDICES

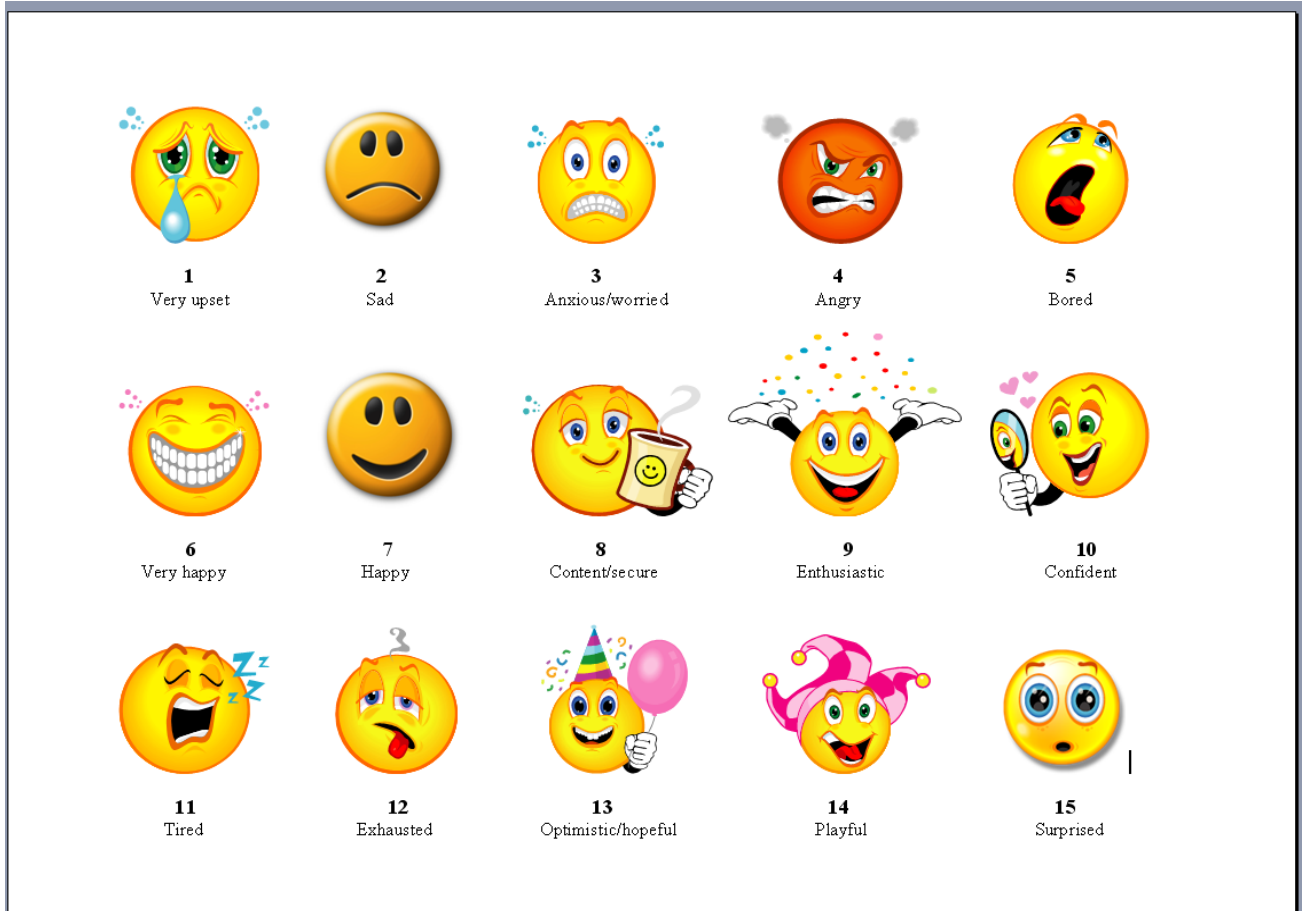
## Appendix A

### Omnibus Survey Short One Day Diary of Time Use from 2005

Activity groups	Activity codes and descriptions (Also see notes on right hand page)	Early morning			
		6am	7am	8am	9am
		30	30	30	30
Personal care	1 Sleeping 1	X-----X			
	2 Resting (doing nothing, 'time out') 2				
	3 Washing, dressing/undressing, etc 3	X-----X			
Eating, drinking	4 Eating or drinking/ having a meal (at home or away from home) 4	X X			
Housework and other household tasks	5 Preparing food and drinks, cooking, washing up 5	X			
	6 Cleaning, tidying house 6				
	7 Washing, ironing or mending clothes etc 7				
	8 Maintenance of house, DIY, gardening 8				
	9 Pet care (including walking the dog) 9				
Travel	10 Travelling 10	X-----X			
	10a How you travelled (enter letter - see right page) 10a	W W T T			
	10b Type of trip (enter letter - see right page) 10b	E P-----P			
Work for paid job	11 Work for job (include paid and unpaid overtime and work brought home. Exclude lunch and other breaks) 11	X-----X			
Education and courses	12 Formal education 12				
	13 Recreational courses and study 13				
Voluntary work	14 Voluntary work for or on behalf of an organisation, charity or sports club 14				
Caring for children and adults	15 Caring for/looking after and playing with own children 15	•-----•			
	16 Caring for/looking after other children 16				
	17 Helping or caring for adults who live with you 17				
	18 Helping or caring for other adults who don't live with you (not as voluntary or paid work) 18				
Shopping and appointments	19 Shopping (incl. internet shopping), banking (incl. internet banking), post-office, appointments with the doctor, dentist, hairdresser, plumber etc. 19				
Leisure	20 Watching TV and videos/DVDs, listening to radio or music 20				
	21 Reading 21	•-----•			
	22 Playing sports, exercising 22				
	23 Spending time with friends, family, neighbours at home or at their homes 23				
	24 Going out with friends, family, neighbours (e.g. to the pub, restaurant etc.) 24				
	25 Contact with friends and family by telephone, text, e-mail, instant message or letter 25				
	26 Visits to cinema, theatre, concerts, sporting events, museums, galleries, historical monuments, library etc. 26				
	27 Attending church, temple, mosque, synagogue, or other religious meetings, praying alone, attending political or other meetings 27				
	28 Hobbies and other leisure activities 28				
Computer and internet use	29 Using a computer or accessing the internet - Record what the computer is being used for above e.g. internet shopping or banking code 19, playing games code 28, e-mailing friends code 25 29				
Other	30 Other activities not listed (please write in below) 30				
LOCATION	31 Where were you? At Home (incl. the garden) or Elsewhere. Give for each activity. 31	H - - - - - H E - - - - - E			
		6am	7am	8am	9am
		30	30	30	30
		Early morning			

## Appendix B

### Mood Chart



## Appendix C

### Early Draft of Time Use Diary

Activity Groups	Activity codes and descriptions	6:00 AM	7:00 AM	8:00 AM	9:00 AM	10:00 AM	11:00 AM
	Who were you with ? Alone, with: Child, Partner, other Kids, Friends, Relations, Staff						
	Please indicate all that apply for each activity						
Personal Care	1 Sleeping	1					
	2 Resting (doing nothing, 'time out')	2					
	3 Washing dressing/undressing/personal care etc.	3					
Eating, drinking	4 Eating or drinking/having a meal	4					
Housework and other household tasks	5 Preparing food and drink, cooking, washing up	5					
	6 Cleaning, tidying house	6					
	7 Washing, ironing or mending clothes etc.	7					
	8a Maintenance of house, DIY, car maintenance	8a					
	8b Gardening	8b					
	9 Pet care (including walking the dog)	9					
Travel	10 Travel - Car, Public transport, Taxi, Bike, Walk	10					
Work for paid job	11 Work for job ( paid, unpaid overtime, work brought home). Exclude lunch and other breaks.	11					
Education and courses	12 Formal education	12					
	13 Recreational courses and study	13					
Voluntary work	14 Voluntary work for an organisation, charity or club	14					
Caring for children	15 Caring for/looking after and playing with own children	15					
	15a Feeding child	15a					
	15b Bathing, dressing, changing, cleaning child	15b					
	15c Specific care of child	15c					
	Description						
	15d Reading, playing with child	15d					
	15e Carrying out therapy programme	15e					
	Description						
Caring for adults	16 Caring for/looking after other children (not yours)	16					
	17 Helping or caring for adults that live with you	17					
Shopping and appointments	18 Helping/caring for adults who don't live with you	18					
	19a Shopping, banking, post-office, appointments with doctor, dentist, hairdresser, plumber etc.	19a					
	19b Appointments for child	19b					
	Description						
Leisure	20 Watching TV and videos/DVDs, listening to radio or music	20					
	21 Reading	21					
	22 Playing sports, exercising	22					
	23 Time with friends, family, at home or their homes	23					
	24 Going out e.g. to the pub, restaurant, café etc.	24					
	25 Contact with friends and family by text, telephone, e-mail	25					
	26 Visits to cinema, theatre, sporting events, library etc	26					
	27 Attending church, mosque etc or other religious meeting	27					
Computer	28 Hobbies and other leisure activities	28					
	29 Using a computer or accessing the internet-	29					
Other	30 Other activities not listed (please write in below)	30					
LOCATION	31 Where were you? At Home or Elsewhere.	31					
MOOD	32 How did you feel? Use face scale numbers to indicate Use as many as apply						
SPECIFIC CARE OF CHILD	15c Please tick each time you did something that took less than 5 minutes to perform e.g. give medication, move position, reward, restrain etc Please give an indication underneath or on postcard						

**Appendix D**

Pilot Questionnaire

1. How easy was it to complete the Time Use Diary?  
Please circle

Very easy                      Easy                      OK                      Difficult                      Very Difficult

2. How long did it take you to complete in total?  
Please circle

5 – 10                      10 – 20                      20 – 30                      30 – 60                      1-2                      more than 2  
minutes                      minutes                      minutes                      minutes                      hours                      hours

3. Do you think it would become easier to complete if you continued the diary for several days and became more familiar with it?  
Please circle

Much easier                      Easier                      No different                      Harder                      Much harder

4. Would you be willing to keep a diary like this for a week if you felt it was for a good reason?  
Please circle

No                      Maybe                      Don't know                      Probably                      Yes

5. Did you find the face chart easy to use?  
Please circle as many as apply

Couldn't match                      Didn't feel                      Easy to use                      Found                      Too much  
a face to my                      comfortable                                           amusing                      to complete  
feelings                      using                                                                as well

6. Any parts of the diary you found confusing or unclear?  
Please specify

.....  
.....  
.....  
.....  
.....  
.....

7. Any comments, suggestions, recommendations?  
Please continue overleaf if required

.....  
.....  
.....  
.....

Thank you

## Appendix E

### Final Version of Time Use Diary

Activity Groups	Activity codes and descriptions	12.00			13.00			14.00			15.00			16.00			17.00					
		00	15	30	45	00	15	30	45	00	15	30	45	00	15	30	45	00	15	30	45	
<b>WHO WERE</b>	Alone																					
<b>YOU WITH ?</b>	With partner																					
<b>Indicate all that apply</b>	With study child																					
	With other children of your own																					
Personal Care	Sleep																					
	Rest (doing nothing, 'time out')																					
	Wash/ dress/ undress/ personal care etc.																					
Eating, drinking	Eat/ drink/ have a meal																					
Housework and other household tasks	Prepare food/ drink/ cook/ wash up																					
	Clean/ tidy house																					
	Wash/ iron/ mend clothes																					
	Maintenance of house/ car/ DIY																					
	Gardening																					
	Pet care (including walking the dog)																					
	Own Car																					
TRAVEL	Public Transport																					
	Friend's car or taxi																					
	Walk/bicycle																					
Work for paid job	Work for job ( paid/ unpaid/ brought home)																					
	Lunch and other breaks at work																					
Education and courses	Formal education																					
	Recreational courses and study																					
Voluntary work	Voluntary work for organisation/ charity/ club																					
Caring for children	Care for/look after/supervise own children																					
	Play/ feed/ read to/ teach/ bathe own children																					
	Care for/look after/supervise children not your own																					
CARE FOR STUDY CHILD	Care for/look after/supervise study child																					
	Feed study child																					
	Bathe/ dress/ change/ clean study child																					
	Read/ play with/ teach study child																					
	Carry out therapy programme/ portage																					
	Description																					
	Specific care of study child (see also below)																					
Caring for adults	Helping or caring for adults that live with you																					
	Helping/caring for adults who don't live with you																					
Shopping	Shopping/ banking/ post-office																					
Appointments	Doctor/ dentist/ hairdresser																					
Appointments for study child	Description																					
Leisure	Watch TV/ videos/ DVDs/ listen to radio/ music																					
	Read																					
	Play sports, exercise																					
	With friends/ family, at home/ their home																					
	Pub, restaurant, café etc.																					
	Contact with friends/ family by text/ telephone/ e-mail																					
	Cinema, theatre, sporting events, library etc																					
	Religious activity at home or elsewhere																					
Computer	Using a computer or accessing the internet																					
Other	Other activities not listed																					
	Description																					
LOCATION	Home																					
	Elsewhere																					
MOOD	Write in the number next to the face most closely matching your mood. Use as many as apply.																					
SPECIFIC CARE OF STUDY CHILD	Tick each time you did something for the study child that took less than 5 minutes to perform e.g. give medication, move their position, keep safe etc																					
	Please give an indication underneath or on postcard.																					
<b>Activity Groups</b>	<b>Activity codes and descriptions</b>	<b>00</b>	<b>15</b>	<b>30</b>	<b>45</b>	<b>00</b>	<b>15</b>	<b>30</b>	<b>45</b>	<b>00</b>	<b>15</b>	<b>30</b>	<b>45</b>	<b>00</b>	<b>15</b>	<b>30</b>	<b>45</b>	<b>00</b>	<b>15</b>	<b>30</b>	<b>45</b>	



## **Appendix F**

### Interview Guide

#### Go through each day of time use diary

- query any incomplete data
- any difficult to read sections
- any comments/postcards

#### Start recording

#### General question re time use diary

- any problems
- how long did it take
- were they surprised over any aspect of their time use
- was it a typical week
- any particular issues they want to highlight
- did they enjoy it hate it
- favourite activity
- least favourite activity

Explore any aspects of time use that stand out

#### Perception of role

- with regard to their disabled (index) child
  - main carer
  - supporter
  - same as other children/different
  - want to do more/ want to do less
  - which part they did more/ which part they did less
  - why divide the responsibilities this way
  - how have parents worked out these roles

#### Sleep and Leisure

- enough/ disturbed/ 'on-call'
- any time to self
- guilt

#### Worry

- explore issues from PedsQL

#### Level of support

- family/ friends/ services

#### Additional topics added

- ideal father
- ideal mother
- their parenting experiences
- what gets in their way of being an 'ideal' parent
- able to do things as a family
- time with partner
- job – choices/prospects

## Appendix G

### Checklist for family health visitor for matching families

Please use the following to guide you when looking for a suitable comparison family from your caseload. It may not be possible to match all these criteria perfectly. It would be helpful if you could suggest two or three possible families. I will then check the details with you to see which family are the most suitable match. If they do not want to be involved in the study I will then ask you to contact the next most closely matching family.

Many thanks for your help with this study.

- Same sex preschool child with birthday in the same 6 month period as the index child i.e. September - February      March – August
- Comparison child same birth order position as index child
- Parental ages in the same decade (comparing fathers to fathers and mothers to mothers) i.e.  $\leq 20$  years  
21 – 30 years  
31 – 40 years  
41 – 50 years  
51 – 60 years  
 $\geq 60$  years
- Same parental work patterns for each parent i.e. full-time work  
part-time work  
not working outside the home
- Same approximate social class
- Same possession of car or not and same number of vehicles up to 2  
i.e. 0 car  
1 car  
2 or more cars

## Appendix H

### Participant Information Sheet

Study Title:

**A time use study of father-mother pairs of a young child with a disability**

Chief Investigator: Dr Megan Thomas

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please discuss it with your partner as you both need to be willing to be involved, to take part in the study. You may also want to talk to other people about the study.

This information sheet tells you about the purpose of this study and what you will be asked to do if you take part. It also gives you information about the conduct of the study. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

*What is the purpose of the study?*

The purpose of this study is to find out more about the daily experiences of parents with a preschool child with significant additional needs/disability. The study will be looking at three different groups of families. Families with a preschool child whose health needs mean that they require special equipment on a daily basis, such as a gastrostomy for feeding or a tracheotomy to help with breathing, will make up one group. Families with a preschool child with a definite diagnosis of autism or an autistic spectrum disorder that is not on the mild end of the spectrum, will make up a second group. A third group of families will be a comparison group. These families will have a child the same age and sex as one of the children in groups one or two, but this child will have no identified significant health or developmental needs.

*Why have I been invited?*

You have been invited because your family meet the criteria for one of the study groups described above. That is, you have a child with health needs requiring special equipment on a daily basis, or you have a child with a diagnosis of autism or you have a child who is the same age and sex as one of the families who has already agreed to be in the study.

*Do I have to take part?*

No, it is up to you to decide whether you take part or not. I will describe the study and go through this information sheet, which I will then give to you. If you agree to take part I will ask you to sign a consent form to show that you have agreed. You are free to change your mind and withdraw at any time without giving a reason. This will not affect the standard of care you or your child receives.

*What will happen if I take part?*

If you agree to take part you will be involved in the study for a period of 4-6 weeks. The whole study is going to take 3 to 4 years. I am planning to involve eighty parents in total.

If you are interested in being involved in the study the first step is that your family health visitor will inform me (Dr Megan Thomas). I will then contact you after a couple of days, to arrange a time for a home visit when you and your partner are both available. This home visit will take about 1 to 1 ½ hours. If you change your mind before I contact you, you can phone your family health visitor, who will let me know.

I will go through the study information with you again and answer any questions you may have. If you want to proceed, you will then be asked to both sign a consent form. Some basic information about your family will be collected such as the number of children you have, their ages, how many hours you work outside the home a week and so on. You will also be asked to complete two short surveys. The first one is the Measure of Processes of Care (MPOC-20)<sup>1</sup>. This takes about 5 minutes to complete and looks at how you have found services for your child have worked with you over the past year. The second one is the PedsQL™ 2.0 Family Impact Module and also takes about 5 minutes to complete. This looks at how your child's health or concerns about your child's health may affect you. Both you and your partner will be asked to complete these two surveys independently.

You will then be shown a time use diary and how to complete it. Both you and your partner will be asked to complete the diary for the same 7 day period. You will be asked to indicate what you were doing in each of the 15 minute slots throughout the whole 24 hour period for 7 consecutive days. This can be done by filling the diary in 2 – 4 times a day. Other people who have used this diary found it took between 10 and 20 minutes a day to complete and that it became easier to use as they became familiar with it. You will be asked to both start your diaries on a particular day and will be offered a home visit on that day to discuss any initial problems you may have had completing the diary. You will also be given a mobile phone number that you can phone at any time if you have a query about the diaries.

At the end of that week I will collect the diaries and check if there are any other questions you have about them. An appointment will be made for a further home visit in 1 – 2 weeks time when I will interview you and your partner separately. If you prefer 2 separate visits can be arranged. The first part of the interview will be to go over issues related to the information collected from the time use diaries. The next part of the interview will be to ask you to share some of your views about your experiences of looking after your child/children. Each interview will take about 1 ½ hours. With your permission the interview will be recorded on to a digital audio recorder. If you do not want the interview to be recorded then notes will be taken of what you say instead. After the interview you will have completed your involvement in the study.

Please see 'The Participant Involvement Flow Chart'.

*What are the possible disadvantages and risks of taking part?*

WI do not think there are any risks involved in taking part as you will not be asked to do anything other than complete the surveys, time use diary and interview described above. This will involve a time commitment from you which you may regard as an inconvenience or a disadvantage of taking part.

---

<sup>1</sup> Although MPOC data were collected these are not included in this thesis

*What are the possible benefits of taking part?*

I do not think there are any direct benefits for you from your taking part, but you may find the study interesting. You will also be contributing information which may help to provide better services for families with a disabled child in the future.

*What happens when the research study stops?*

Your involvement in the study does not have any affect on the services you and your child are receiving and nothing changes after you complete your part of the study. When the research study stops the results will be available to read and there will be a meeting held to feedback some of the conclusions. Participants in the study will be invited to that meeting.

*What will happen if I don't want to carry on with the study?*

You are able to stop being involved in the study at any point and do not have to give a reason. You will be asked whether I can continue to use any information you have already given. If you refuse permission for this information to be used it will be destroyed.

*What if something goes wrong?*

I do not believe that anything will go wrong with this study. However, if you wish to complain about something to do with this study then you should contact either me as the Chief Investigator: Dr Megan Thomas, (address removed) or my academic supervisor: Professor Bernie Carter, Dept. of Nursing, University of Central Lancashire, Preston, PR1 2HE or Dr Bernard Gibbon, Head of Department, Dept. of Nursing, University of Central Lancashire, Preston, PR1 2HE. The matter will be followed up via the University complaints procedure. The normal National Health Service complaints mechanisms will also be available to you.

*Will my taking part in this study be kept confidential?*

Yes. All information which is collected during the course of the research will be kept strictly confidential. I will be the only person who will know who the information relates to. Your name and address will be removed from all data before it is seen by anyone else and will never be used in any reports or publications. Quotations from interviews maybe used in publications or presentations but I will not use your name and it will not be able to be traced back to you.

The data will be stored for at least 10 years. The data collected from the time use studies may be used by other time use researchers but will not be able to be traced back to you.

*Why do you want to access my child's medical records?*

I will be the only person who will access your child's medical records. This will be to identify how the diagnosis of autism has been made if relevant, or more information about your child's health needs.

*Why do you want to inform my child's Consultant Paediatrician?*

I am a Consultant Community Paediatrician at (removed) Child Development Centre, and your child may be under my care. If not, as a courtesy I would like to let the

relevant Consultant, if your child has one, know that you are involved in this study. If any new, important information about your child's health is noted during the study, you will be asked whether this can be shared with your child's Consultant Paediatrician.

*What will happen to the results of the research study?*

This research will be submitted by me for the award of a PhD. It will also be submitted for publication in peer reviewed journals and may be presented at conferences locally, nationally and internationally. It will be used to guide and develop services for families with children with disabilities in the future.

*Who is organising and funding the research?*

I am organising this research with the support of a supervisory team from the Department of Nursing at the University of Central Lancashire. I do not receive any payment for doing this research but I have an allowance for expenses incurred during the research, from the University of Central Lancashire. You will not receive any payment for your participation in the study and it is not anticipated you will incur any expenses.

*Who has reviewed the study?*

The study has been reviewed by the University of Central Lancashire Faculty Research Degrees Sub-committee, the Local Research Ethics Committee, and the Blackpool Fylde and Wyre Research and Development Department.

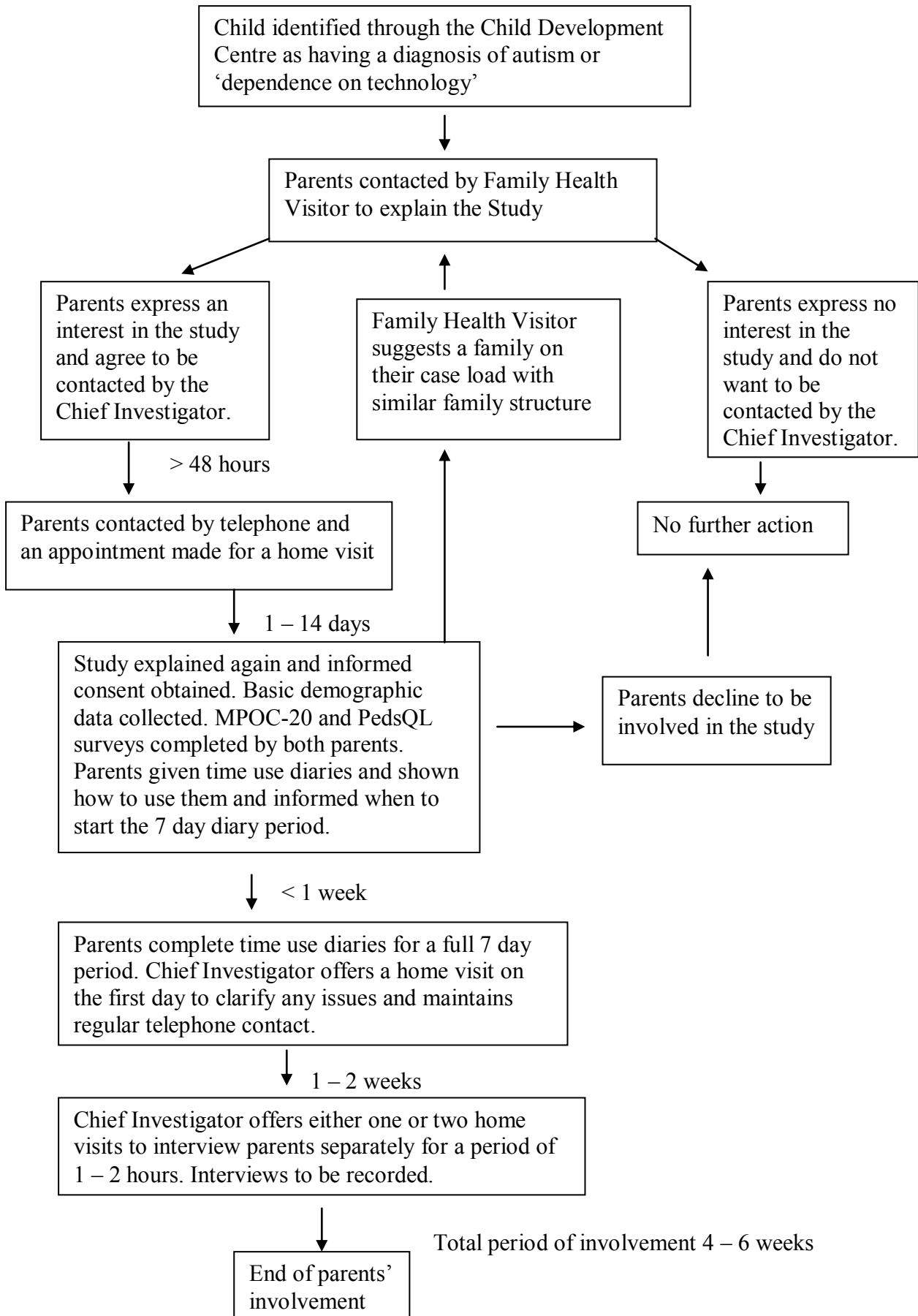
*Contact for further information?*

If you want further information about this study contact me. My contact details are:  
Dr Megan Thomas, (contact details removed)

Thank you very much for your time in reading this information leaflet.

Dr Megan Thomas  
Consultant Community Paediatrician

**Participant Involvement Flow Chart**  
 A time use study of father-mother pairs of a young child with a disability



## Comparison Families Information Sheet

Study Title: **A time use study of father-mother pairs of a young child with a disability**

Chief Investigator: Dr Megan Thomas

I am a Consultant Community Paediatrician and work at (removed) Child Development and Family Support Centre (removed). I have been a Consultant for more than 10 years working with children where there is a concern about their development and their families.

I would like to invite you to take part in a research study that I am doing. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please discuss it with your partner as you both need to be willing to be involved, to take part in the study. You may also want to talk to other people about the study.

This information sheet tells you about the purpose of this study and what you will be asked to do if you take part. It also gives you information about the way the study will be carried out. Take time to decide whether or not you wish to take part.

*What is the purpose of the study?*

The purpose of this study is to find out more about the daily experiences of parents with a preschool child with significant additional needs/disability. The study will be looking at three different groups of families:

1. Families with a preschool child who requires special equipment on a daily basis to meet their health needs
2. Families with a preschool child with a diagnosis of autism
3. Families with a child the same age and sex as one of the children in groups one or two, but with no identified significant health or developmental needs. These families are a comparison group.

I am planning on involving 40 families in total.

*Why have I been invited?*

You have been invited because your family fits into this third group. I asked the local family health visitor whether she knew of any families similar to one that has already agreed to take part from one of the other two groups. She thinks your family is similar and might be interested in taking part.

*Do I have to take part?*

No, it is up to you to decide whether you take part or not. Your family health visitor will give you this information sheet to read. If you are willing to hear more about the study please let your family health visitor know. I will then make an appointment to visit you and tell you more about the study. If you then agree to take part I will ask you to sign a consent form to show that you have agreed. You are free to change your mind and withdraw at any time without giving a reason. This would not affect any services you or your child receives.



*What would happen if I don't take part in the study?*

If you decide you do not want to take part in this study I would ask your health visitor to suggest another family. They may not be as close a match as your family so it would be helpful if you could consider carefully whether you are willing to take part. To find out the important differences about the way that families with a disabled child spend their time we need to compare them with families who are as similar as possible.

*Why do both my partner and I have to take part?*

Most studies looking at families only involve the mother or ask the mother about what the father does or thinks. I think that it is very important to involve both parents in my study because although one parent maybe more involved in directly looking after the children that doesn't mean the other parent's role, opinions and contributions are not important.

*What will happen if I do take part?*

The first step is that your family health visitor would inform me (Dr Megan Thomas). I would then contact you after a couple of days, to arrange a time for a home visit when you and your partner are both available. This can be in the evening or on a Saturday if this is more convenient for you. The home visit would take about 1 to 1 ½ hours. During this visit, I would go through the study information with you again and answer any questions you might have. If you decide to take part, both you and your partner would be asked to sign a consent form. You would also be asked to complete two short surveys regarding any concerns you may have about your child's health and how services such as your GP or nursery have worked with your family. Each survey takes about 5 minutes to complete.

You would then be shown a time use diary and how to complete it. Both you and your partner will be asked to complete the diary for the same 7 day period. You would be asked to indicate what you were doing in each of the 15 minute slots throughout the whole 24 hour period for 7 consecutive days. This can be done by filling the diary in 2 – 4 times a day. Other people who have used this diary found it took between 10 and 20 minutes a day to complete and that it became easier to use as they became familiar with it.

At the end of that week I would collect the diaries and check if there are any other questions you have about them. An appointment would be made for a further home visit about a week later when I would spend about 20 minutes going through the diaries with each of you separately to clarify any missing pieces of information or things I am not sure about. After that visit you would have completed your involvement in the study. Although the study will take around 3 to 4 years to complete you would only be involved for a period of about 2-3 weeks.

*Do I have to record what I am doing at work?*

If you work outside the home you only have to record that you are at work for those time periods. I do not need to know anything else about what you are doing.

*What will happen if I don't want to carry on with the study?*

You are able to stop being involved in the study at any point and do not have to give a reason. You would be asked whether I can continue to use any information you have

already given. If you refuse permission for this information to be used it would be destroyed.

*What are the possible disadvantages and risks of taking part?*

I do not think there are any risks involved in taking part as you will not be asked to do anything other than complete the surveys, time use diary and visits described above. This will involve a time commitment from you which you may regard as an inconvenience or a disadvantage of taking part.

*What are the possible benefits of taking part?*

I do not think there are any direct benefits for you from your taking part, but you may find the study interesting. You will also be contributing information which may help to provide better services in the future for families with a disabled child.

*What happens when the research study stops?*

Your involvement in the study does not have any affect on the services you and your child are receiving and nothing changes after you complete your part of the study. When the research study stops the results will be available to read and there will be a meeting held to feedback some of the conclusions. Participants in the study will be invited to that meeting but do not have to attend.

*What will happen to the results of the research study?*

This research will be submitted by me for the award of a PhD. It will also be submitted for publication in peer reviewed journals and may be presented at conferences locally, nationally and internationally. It will be used to guide and develop services for families with children with disabilities in the future.

*Will my taking part in this study be kept confidential?*

Yes. All information which is collected during the course of the research will be kept strictly confidential. I will be the only person who will know who the information relates to. Your name and address will be removed from all data before it is seen by anyone else and will never be used in any reports or publications. Quotations from interviews maybe used in publications or presentations but I will not use your name and it will not be able to be traced back to you. The data will be stored for at least 10 years. The data collected from the time use studies may be used by other time use researchers but will not be able to be traced back to you.

*Who is organising and funding the research?*

I am organising this research with the support of a supervisory team from the Department of Nursing at the University of Central Lancashire. I do not receive any payment for doing this research but I have an allowance for expenses incurred during the research, from the University of Central Lancashire. You will not receive any payment for your participation in the study and it is not anticipated you will incur any expenses.

*Who has reviewed the study?*

The study has been reviewed by the University of Central Lancashire Faculty Research Degrees Sub-committee, the Local NHS Research Ethics Committee, and the Blackpool Fylde and Wyre NHS Research and Development Department.

*What if something goes wrong?*

I do not believe that anything will go wrong with this study. However, if you wish to complain about something to do with this study then you should contact either me the chief investigator, Dr Megan Thomas,

or my academic supervisor:

Professor Bernie Carter, Dept. of Nursing, University of Central Lancashire, Preston, PR1 2HE

or Dr Bernard Gibbon, Head of Department, Dept. of Nursing, University of Central Lancashire, Preston, PR1 2HE

The matter would be followed up via the University complaints procedure. The normal National Health Service complaints mechanisms would also be available to you.

*Contact for further information?*

If you want further information about this study contact me.

My contact details are:

Dr Megan Thomas,  
removed

Telephone Number: removed

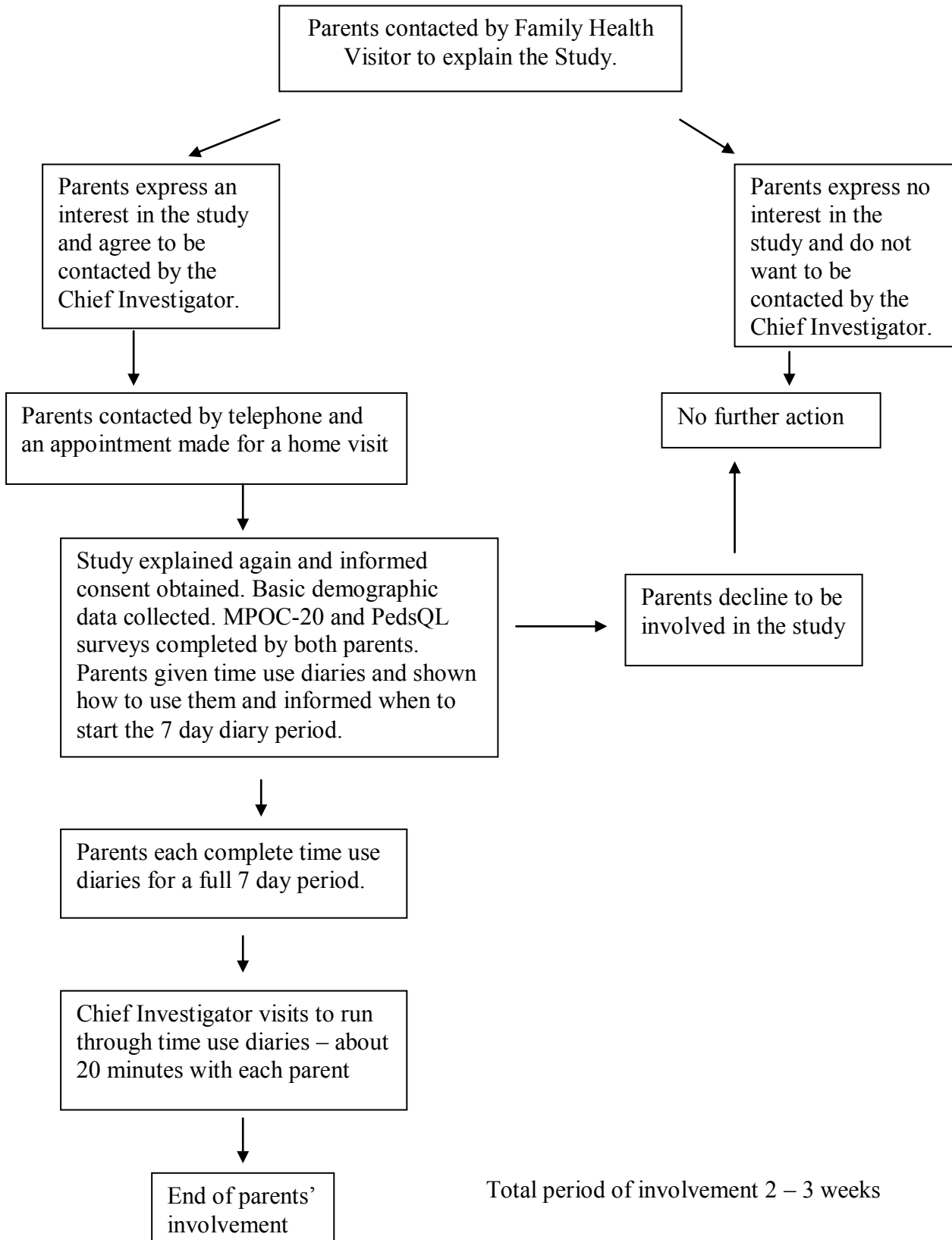
e-mail: removed

Thank you very much for your time in reading this information leaflet.

Dr Megan Thomas  
Consultant Community Paediatrician

## Comparison Family Flow Chart

A time use study of father-mother pairs of a young child with a disability



## Appendix I

### CONSENT FORM

STUDY TITLE:

**A time use study of father-mother pairs of a young child with a disability**

Name of Researcher: Dr Megan Thomas

Please initial box

1. I confirm that I have read and understood the information sheet dated 13/09/2007 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my or my child's medical care or legal rights being affected.
3. I understand that the final interview will be recorded (with my permission). I understand that quotations from my interview may be used in publications or presentations resulting from this study, but that they will not be able to be traced back to me.
4. I understand that relevant sections of my child's medical notes may be looked at by the researcher, Dr Megan Thomas, where it is relevant to my taking part in this research. I give permission for Dr Megan Thomas to access my child's records.
5. I understand that anonymised data collected during this study may be looked at by individuals from the University of Central Lancashire, from regulatory authorities or from the NHS Trust. I give permission for these individuals to have access to this data.
6. I understand that anonymised data from the time use diaries may be shared with other time use researchers. I give permission for these individuals to have access to this data.
7. I agree to my child's Consultant Paediatrician being informed of my participation in the study.
8. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person Taking Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed, 1 for participant; 1 for researcher file

## CONSENT FORM

STUDY TITLE:

**A time use study of father-mother pairs of a young child with a disability**

Name of Researcher: Dr Megan Thomas

Please initial box

1. I confirm that I have read and understood the information sheet dated 29/04/2008 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
  
3. I understand that anonymised data collected during this study may be looked at by individuals from the University of Central Lancashire, from regulatory authorities or from the NHS Trust. I give permission for these individuals to have access to this data.
  
4. I understand that anonymised data from the time use diaries may be shared with other time use researchers. I give permission for these individuals to have access to this data.
  
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person Taking Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed, 1 for participant; 1 for researcher file

## Appendix J

### Family Adjustment to Childhood Disability Scale (FICD)

Barry Trute and Diane Hiebert-Murphy

Journal of Pediatric Psychology 2002 Volume 27, Number 3 Pages 278 - 279

Scale Question: "In your view, what consequences have resulted from having a child with a disability in your family." Score each item in a four-point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree.

1. *There have been extraordinary time demands created in looking after the needs of the disabled child. (-)*
2. *There has been unwelcome disruption to "normal" family routines. (-)*
3. *The experience has brought us closer to God. (+)*
4. *It has led to additional financial costs. (-)*
5. *Having a disabled child has led to an improved relationship with spouse. (+)*
6. *It has led to limitations in social contacts outside the home. (-)*
7. *The experience has made us come to terms with what should be valued in life. (-)*
8. *Chronic stress in the family has been a consequence. (-)*
9. *We have had to postpone or cancel major holidays. (-)*
10. *It has led to a reduction in time parents could spend with their friends. (-)*
11. *The child's disability has led to positive personal development in mother and/or father. (+)*
12. *Because of the situation, parents have hesitated to phone friends and acquaintances. (-)*
13. *The situation has led to tension with spouse. (-)*
14. *Because of the circumstances of the child's disability, there has been a postponement of major purchases. (-)*
15. *Raising a disabled child has made life more meaningful for family members. (+)*

## **Appendix K**

### Published Journal Article

Time-use diaries are acceptable to parents with a disabled preschool child and are helpful in understanding families' daily lives

M. Thomas, A. Hunt, M. Hurley, S. Robertson and B. Carter



# Time-use diaries are acceptable to parents with a disabled preschool child and are helpful in understanding families' daily lives

M. Thomas,\* A. Hunt,† M. Hurley,‡ S. Robertson§ and B. Carter†

\*Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust, Blenheim House Child Development and Family Support Centre, Blackpool

†Families, Children and Life Transitions Group, Faculty of Health and Social Care, University of Central Lancashire

‡School of Public Health and Clinical Sciences, Faculty of Health and Social Care, University of Central Lancashire, Preston, and

§Centre for Men's Health, Leeds Metropolitan University, Leeds, UK

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## Abstract

**Background** In order to provide services for children with disabilities which are family focused, strengthening and enabling families in addition to meeting the child's identified needs, it is important to understand families' lives. This study investigates whether time-use diaries can provide an acceptable tool to explore the daily lives of parents with a disabled child.

**Methods** A precoded time-use diary divided into 15 min time slots was designed. Father–mother pairs with a preschool child with either autism (ASD) or technology dependence (TD) were asked to complete a 7-day diary independently, over the same time period. Each parent was then interviewed separately to ascertain their experiences of using the diary. Participants were identified through their involvement with a Child Development Centre.

**Results** Twenty-six parents (13 father–mother pairs) were invited to participate. Eighteen parents agreed to be involved; 16 completed the diaries and interviews. Three father–mother pairs in the ASD group and one father–mother pair in the TD group declined to be involved. One father–mother pair from the TD group withdrew from the study. Of the 18 parents who agreed to participate, 15 found the diaries acceptable and either easy or straightforward to complete. One parent with dyslexia and one who described himself as a non-reader completed the diaries successfully, finding the colour coding helpful. Parents spent between 10 and 60 min a day completing the diaries, with the median 20–30 min. The diaries provided information on the total amount of time spent on different activities and how much time parents spent together, with their other children, at home or elsewhere.

**Conclusion** The time-use diaries designed for this study were acceptable to the majority of parents and provided detailed information about their daily lives.

## Keywords

autism, child disability, complex care, fathers, parents, service provision

## Correspondence:

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E-mail: dr.thomas@bfwhospitals.nhs.uk

## Introduction

Historically paediatric early intervention services have been child centred. While initially this sounds appropriate, it often fails to take into account the family situation. Therapeutic inter-

vention is offered to meet the identified needs of the disabled child and the child's family are expected to arrange their lives to comply with the interventions and recommendations (Kirk & Glendinning 2004). Often multiple different interventions have to be carried out on a daily basis, ranging from positioning the

child, to alternative methods of communication, to complex medical procedures involving a variety of different technologies. In addition, the information and training for these procedures and equipment may only be given to one family member, usually the mother (Beresford 1994). This 'child centred' approach can inadvertently add to the pressures and difficulties that parents with a disabled preschool child experience (Hornby 1994). Therefore, there is now a move towards family-focused services that strengthen and enable families as well as meeting the child's identified needs (Department for Education and Skills & Department of Health 2003).

In order to guide family-focused service provision, it is important to understand the daily lives of parents with a disabled preschool child (Seligman & Darling 1997). Time-use diaries provide a tool to achieve this. By using a diary format, activities are placed in context and can be considered with regard to location, social contact and satisfaction. The time-use diary is a particularly relevant instrument for studying the lives of families, including families with a disabled child, as they not only give an account of the total amount of time spent on a particular activity, but also in what sequence activities occur, and an indication of what activities have been omitted or truncated in order to complete other activities. Looking at sequences of activities helps to clarify how lives are organized to achieve necessary objectives. In addition, because information about the respondents' satisfaction with the activities that they are participating in can be included, time-use diaries are increasingly used in studies attempting to assess quality of life.

Time-use research is rapidly expanding and it has diverse potential applications. Initially sociologists were leaders in the field but now researchers in anthropology, economics, environmental planning, market research and psychology are increasingly involved. Time-use studies have explored among other things societal changes, gender roles, employment patterns, leisure activities, the use of roads and services, economic systems, daily energy expenditure and exposure to environmental pollutants (Johnson 1990). However, time-use studies are currently underutilized in health research and knowledge about them by health care professionals is limited.

An example of this relates to the study of the time use of parents with disabled children. Only a very limited number of studies have been performed in these families in contrast to those of parents with non-disabled children. Studies that have been performed in relation to the time use of parents with disabled children have mainly though not exclusively been done by occupational therapists (Lucca & Settles 1981; Breslau 1983; Johnson & Deitz 1985; Barnett & Boyce 1995; Crowe *et al.* 2000; Tetreault *et al.* 2000; Crowe & Florez 2006; Gevir *et al.* 2006).

This is understandable as time use is an intrinsic part of an occupational therapist's role (Meyer 1922). However, the majority of these studies have only looked at the mother's time use.

One of the reasons that time-use studies are currently underutilized in health research is the concern that asking respondents to fill in activities over a 24-h period is unnecessarily burdensome for participants (Curran *et al.* 2001) and sufficient information can be obtained by only asking for information relating to parts of the day, for example, the amount of time spent feeding a child. However, this does not identify what impact spending more time on feeding has on family life, and as there are only 1440 min in a day, if more time is spent on one activity, less must be spent on something else. An indication of what activities are being 'sacrificed' can be obtained by collecting information about all activities and comparing these with the activities that parents with non-disabled children participate in. Therefore, collecting information on all activities can be considered the ideal. Nevertheless, it is important to establish whether this is realistic and acceptable for already very time-pressured parents managing the multiple demands of family life, work and care for their children, including meeting the additional needs of a disabled child. This paper describes the design of a time-use diary to record parental activities throughout a 24-h period, together with an assessment of its acceptability and ease of use when used by parents of a disabled preschool child over the course of a week. The findings in relation to parental time-use are not presented in this paper.

## Aims

The study aimed to:

- design a time-use diary to explore the daily lives of parents with a disabled preschool child;
- assess the acceptability of completing the time-use diary for a 7-day period for both fathers and mothers with a disabled preschool child.

## Methods

### Development of the time-use diary

The time-use diary was selected as a method to look at parental activities as other methods are more prone to error. For instance, Robinson (1999) showed that retrospective time-use interviews which required an individual to estimate how much time they had spent on particular activities, led to the total number of hours spent on activities during a week exceeding

the total number of the actual hours available. Even activities that might be anticipated to be accurately recalled, such as paid work, have been shown to be overestimated when compared with time diary records (Robinson & Bostrom 1994). The construction of a diary that encourages the participant to recall a sequence of events, with estimates at what time these events occurred, for example when they got out of bed, enables more accurate aggregate totals of time-use categories to be achieved (Gershuny 2000). The less time between recall and recording, the more accurate the data (Gershuny 2000).

A precoded diary was designed by the first author using the Omnibus Short One Day Diary 2005 (Lader *et al.* 2006) as an initial template. Consequently most of the data collected in this study can be compared with national historical data sets. A precoded diary format was selected in order to reduce the effort required by the participants to complete it, to reduce the effort required to analyse the collected data and to focus data collection on particular areas of interest, which for this study was family life. For example, when the participant was at work the only information they needed to complete was that they were at work but not what actual activities were being performed there. While precoded diaries require less effort on the part of the participant, if the codes are not sufficiently explicit participants can become frustrated trying to determine which code their activity falls under. This can lead to non-compliance or incomplete diaries which are then either very difficult to interpret or cannot be analysed at all. As the families being studied were all two-parent families with at least one preschool child, it was possible to tailor the codes to activities most likely to be engaged in.

The final version of the diary had four social contact codes (alone, with partner, with study child, with other children of your own), two location codes (home or elsewhere) and 45 activity codes. In addition, an optional mood section was included where a number could be entered, selected from a specifically designed face chart depicting 15 different moods such as happy, anxious, bored or tired. The diary was colour-coded to help rapidly identify different sections of activities and time slots, and printed on high quality A4 paper to help withstand some of the wear and tear of family life. Each side of A4 covered a 6-h time period. The presentation of each diary sheet was identical apart from the time of day. Thus four sides of A4 (two pages) made up each diary day and these were stapled together. Each participant was provided with a vinyl folder containing the diary sheets, a face chart, a laminated worked example with explanations, a sheet with further instructions on how to complete the diaries, postcards for additional comments and contact details of the first author.

Each diary day was divided into 96, 15-min time slots. Time periods in time-use diaries typically range from 5 min to half an hour. Again there is a trade off from the additional information achieved by having a short time period to the increased burden for respondents and higher likelihood of omissions in the data. Longer time periods are likely to miss certain short activities. Previous studies have compared fixed time slots with open time intervals. Some of these studies have found little difference between the two, while others suggest there maybe hidden problems, with the use of time slots and their size having more of an effect on certain activities than others (Harvey 1999, p. 22). However, when analysing the data, times are often amalgamated into 96 periods of the day to create a 'time-points file', that is one point for each 15 min of the day (Harvey 1999, p. 27). Therefore, taking all these different aspects into consideration, a 15-min fixed time slots diary was produced with the instruction that if an activity took longer than 5 min to perform it should be recorded in that time period. An additional section was added at the bottom of each diary page for important activities that took less than 5 min but were to do with specific care of the disabled preschool child, such as giving medicines or performing suction. The respondent was asked to place a tick in this area with a comment either in the diary margin or on a postcard as to what the activity was.

With large data sets looking at population trends, participants are often asked to complete a single diary day only. These single-day diaries are then pooled to enable meaningful analysis. In contrast, looking at smaller subpopulations or at particular issues necessitates a longer period of data collection to ensure that less frequent activities are not missed or over-represented (Gershuny 2000). In particular, it is clear that activities performed at the weekend are likely to differ from those performed during the week and therefore some studies have used one week day and one weekend day. However, the most common recommended period is 7 days, that is one week, as many aspects of life are scheduled over this time frame (Harvey *et al.* 2003). This is the case when studying parental childcare responsibilities, or time use of couples, when paired diaries (father–mother) of the same 7-day period provide the best data. In most families work, leisure and childcare activities tend to be organized on a weekly rather than a daily basis (Fisher 2010).

The diaries were initially piloted with four parents (a father–mother pair, a single mother and a father) for a single diary day. The single mother had an infant less than one year of age. The father–mother pair had four children, two of whom were preschool and the father had three children, one of whom was preschool. None of these children had identified additional needs or disabilities. The pilot confirmed the instructions for

**Table 1.** Participant demographics

Family number	Parents' ages male : female (years)	Child's age (months)	TD/ASD	Children living at home ( <i>n</i> = )	Parents in paid employment (yes/no)	Total family annual income (£'s)
1	44:32	36	ASD	4	Y : N	20 000–40 000
2	28:38	26	TD	3	Y : N	20 000–40 000
3	41:39	36	ASD	4	Y : Y	20 000–40 000
4	37:44	52	TD	2	Y : N	<20 000
5	39:35	42	TD	2	Y : N	>40 000
6	30:25	54	ASD	1	Y : Y	<20 000
7	22:30	16	TD	3	Y : N	<20 000
8	37:36	48	ASD	2	Y : Y	20 000–40 000
9	34:32	25	TD	1	Y : N	>40 000

ASD, autism spectrum disorders; TD, technology dependence.

the diaries were understandable and three out of the four parents felt the time taken to complete them reasonable. The fourth parent, the mother of four children, had completed the mood section for most of the time she was awake which had proved time consuming.

### Sampling

Convenience sampling was used with families identified through their involvement with the local Child Development Centre. Predefined inclusion criteria were: families with a clear co-habiting father–mother pair; a preschool child with a diagnosis of either autism (ASD) or complex health needs dependent on technology (TD); and in addition, the need for ongoing multiagency involvement. Exclusion criteria were: when there were child protection concerns or the child clearly had a very limited life expectancy. All families who met the study criteria over a 10-month period were invited to participate in the study.

### Sample characteristics

Twenty-six parents (13 father–mother pairs) were approached. Eighteen parents (nine father–mother pairs) agreed to take part while three father–mother pairs in the ASD group and one father–mother pair in the TD group declined. Of the 18 parents who agreed to participate, 16 completed the diaries and interviews. One father–mother pair in the TD group withdrew from the study. The father completed one diary day and declined to be interviewed, while the mother completed four diary days and was interviewed. The demographics of the families are shown in Table 1. Reasons for not wanting to participate are shown in Table 2.

### Ethical issues

Ethical and governance approval was obtained for the study from the local NHS research ethics committee, the university

**Table 2.** Reasons for not participating in study

Father–mother pair ASD	Father not interested in research
Father–mother pair ASD	Both parents felt they were too busy
Father–mother pair ASD	Father concerned about sharing personal information
Father–mother pair TD	Both parents interested but father unwell

ASD, autism spectrum disorders; TD, technology dependence.

ethics committee and the research and development department of the Hospital Trust and two local Primary Care Trusts. As the researcher works as a clinician at the Child Development Centre where the families were being sampled, the first approach for involvement in the study was made by the family health visitor to avoid the possibility of the families feeling coerced.

### Data collection

Data collection was carried out by the first author (M.T.). Parents were each asked to complete a specifically designed precoded time-use diary for 24 h a day for seven consecutive days. The researcher explained to parents how to complete the diaries and also left a worked example to refer to. Parents were asked to complete the time-use diary between two and four times each day to optimize recall without being overly burdensome. Father–mother pairs completed the diaries for the same 7 day period but completed the diaries independently. The researcher then collected the diaries and arranged a time to interview each parent separately to clarify any data omissions or conflicts and ascertain the parent's experience of using the diary. Each parent was asked specific questions (see Table 3), unless they had already spontaneously covered the information, and were also given the opportunity to discuss any other aspects of the diaries or their time use that was felt by the parent to be of interest or importance.

**Table 3.** Interview questions regarding diary completion

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Any problems completing the diary
How long did it take to complete each day
Any aspect of your time use surprise you
Was the week the diary was completed a typical week
If it wasn't a typical week what was different about it
Did you enjoy/hate/not mind/other completing the diary
Any changes you would suggest to improve the diary
Any other issues with regard to the diary or your use of time you would like to mention

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## Results

Eighteen parents agreed to participate in the study with 16 parents completing all seven diary days and the interview.

Fifteen parents found the time-use diaries acceptable. Acceptability included ease of completion and length of time taken each day to complete the diaries, which varied from 10 min to 1 h. See Fig. 1 for the length of time parents reported they spent completing the diaries each day. Women tended to take longer than men and were more likely to enjoy completing the diaries with five out of nine mothers stating that they had enjoyed the process. The mother who spent the longest time completing the diaries said

I did quite enjoy doing it actually. And as I said the day afterwards I was still in the mode and I still wanted to, you know I should be filling in my diary. I don't really know why I enjoyed doing it. Perhaps it was just something different for me because my routine is quite mundane and the same and so it was just something a bit different – but yeah I think I did quite enjoy doing it.

Most fathers found the diary 'just something that had to be done' but did not find it a problem and would be willing to do it again. Twelve parents found some aspect of their time-use surprising.

Three parents did not find the diaries acceptable. Two of these parents withdrew from the study. No feedback was received from the father but the mother stated that she found the diaries very difficult. However, she went on to say that she finds all paperwork difficult and therefore did not feel that any diary format would be acceptable. Despite this, the 4 days that she completed appeared to be done well. The final father described himself as a non-reader. He completed all 7 days and said he had no problems with the diaries after having some initial help familiarizing himself with the codes. His comment was

I've got better things to do than putting lines through silly bits of paper asking what I'm doing (laughs)

This father, and another father with dyslexia found the colour coding particularly helpful.

Nine parents found the diaries much easier to use after the first day or so and several commented that while they initially looked daunting they were actually straightforward to complete. Three parents found the fixed time slots presented some difficulties, such as when multiple short activities were completed within 15 min leading to uncertainty about what to enter on the diary. Three parents found the diaries and the spacing too small which made it difficult at times to calculate where an entry should go.

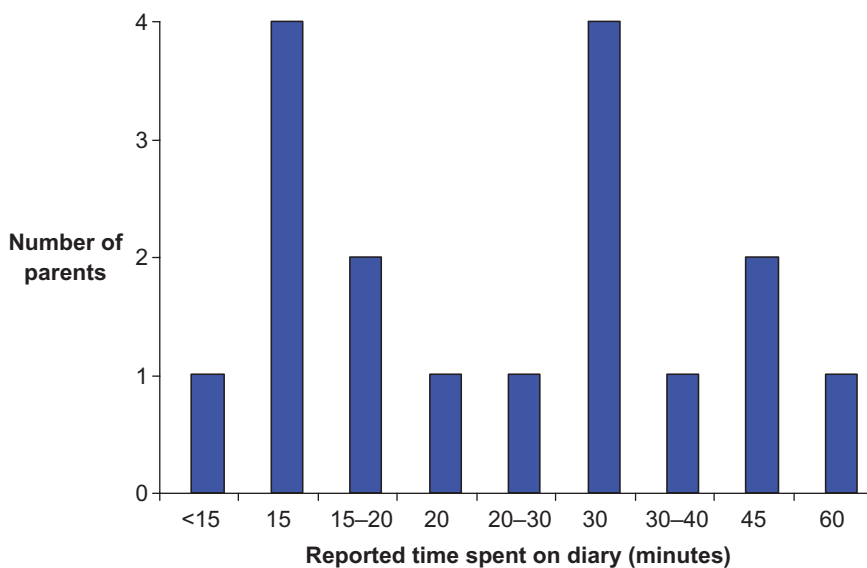
The diary included an optional mood section where a number could be entered, selected from a face chart depicting 15 different moods such as happy, anxious, bored or tired. One of the fathers felt that too many moods were offered while two mothers found that more moods were required.

While 16 parents completed the full 7 days, all diaries had some missing or conflicting entries. Going through the data with each parent was therefore crucial to ensure the data were complete and to clarify what parents had meant by certain entries. Parents who spent longer on the diaries generally had fewer errors. This data-checking process took between 10 and 20 min with each parent.

## Discussion

The time-use diary designed for this study was acceptable to the majority of parents both with regard to ease of use and length of time taken to complete. Of importance is that both fathers and mothers participated fully and the diary was equally acceptable for both sexes. As highlighted earlier most time-use studies have looked at the time use of mothers as they are recognized as most commonly being the main carer. However, this fails to consider the family as an interdependent unit and the reality that what happens to one member of the unit has an impact on other members. There is also an increasing recognition of the positive impact involvement of fathers has on subsequent outcomes for their children, leading to an increasing number of Government initiatives to involve fathers more (Lloyd *et al.* 2006; Barnes *et al.* 2009). Therefore, it is important to record fathers' as well as mothers' time use.

The few studies including fathers' time use in families with a disabled child have shown that fathers' time use is also affected. Barnett and Boyce (1995) found that fathers of children with Down Syndrome spent 4 h a week more on child care and 2 h a week less on social activities compared with fathers with typically developing children. The authors comment that although these changes are small relative to the estimated effects on



**Figure 1.** Minutes spent completing diary per day.

mothers' time use, the effects are large compared with the time men typically devote to child care and social activities. Smith (1986) in a study of Saturday time use of parents with a physically disabled child found an increase in total child-care time for both parents compared with parents in a nationwide sample. This was more marked for fathers however, who contributed 45.6% of their household's total child-care time in comparison with fathers in the nationwide sample who contributed 28.9%.

In contrast to some professionals' expectations, parents are often well motivated to complete time-use diaries especially where it relates to their children. Parents participating in this study viewed it positively that an interest was being shown in the reality of their lives and that the results may have an impact on the way services worked with them in the future. Some parents, particularly mothers, found reflecting on the way they spent their time interesting and used the opportunity to consider if there were some alternative ways of doing things.

The time-use diaries designed for this study enabled data to be collected on fathers' and mothers' daily activities over a 7-day period, whether these activities were performed alone or with another family member, and whether they were at home or elsewhere. These data can be compared with historical UK data sets, and further understanding gained about how parents' with a young disabled child have lives which are similar to and different from those of families with typically developing children. Because one of the identified aims of many families of children with disabilities is to live 'ordinary lives', this additional understanding may help guide services to work with families to make this aim a reality.

### Key messages

- Time-use diaries are a useful tool that could be used more widely in health and health services research.
- Fathers' as well as mothers' time use should be considered in family studies.
- The time-use diaries designed for this study were successfully completed for 24 h a day for a full week by the majority of parents.
- The time-use diaries in this study were acceptable to the majority of both fathers and mothers.

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